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Cover Image: “Arctic Sunset” by Tristen Metcalf.

Tristen says “Thank you for your interest in my art. In my art all of the animals are happy and get along.”

Tristen Metcalf is an Independent Artist born in Muskoka. Community Living Huntsville features Tristen’s story at their Community Inclusion Tours twice a month. He had an art show at Muskoka Baptist Centre, in Port Sydney, Ontario, October 20, 2016 and is planning his next art show at Algonquin Theatre in Huntsville. Currently Tristen is creating charcoal art. He plans to pursue his art career and has a dream to establish a website.

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Effects of Enhanced Structure in an Aquatics Environment for Three Boys with Autism Spectrum Disorders: A Pilot Study

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autism spectrum disorder,
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behaviour,
aquatic environment,
physical activity

Abstract

The purpose of the pilot study was to examine the effects of pictographic activity schedule implementation within a structured aquatic environment for individuals diagnosed with autism spectrum disorder (ASD). Three boys (11 to 17 years) enrolled at a school for children with developmental disabilities served as participants. An interrupted time series design (A/B/A) was used to assess the effects of the pictographic activity schedules on inappropriate response time in the aquatic setting. The results indicated that activity schedules, when used during structured teaching, improved behaviour in children with ASD by means of reducing inappropriateness. Additionally, a generalized effect of the activity schedules was found during free play with decreased rates of inappropriate behaviour. The implications of these findings show the importance of visual activity schedules within all domains of education, including those involving physical activity as a means of reducing maladaptive behaviour.

According to the Centers for Disease Control (CDC), 1 out of every 68 children is diagnosed with an autism spectrum disorder (ASD) in North America (CDC, 2014). Moreover, current epidemiological data indicate that the prevalence rate for ASD is increasing on an annual basis (Kim et al., 2011). As such, research has focused on effective educational treatments aimed at minimizing the effects of the condition (Ryan, Hughes, Katsiyannis, McDaniel, & Sprinkle, 2011). One treatment method that has been proven effective is the Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) program (Mesibov & Shea, 2010; Mesibov, Shea, & Schopler, 2004; Schopler, Brehem, Kinsbourne, & Reichler, 1971; Schopler, Mesibov, & Hearsey, 1995). The TEACCH approach is recognized as one of the most popular educational program models available for individuals with ASD today (NasoudiGharehBolagh, Zahednezhad, & Vosoughillkhchi, 2013) with it being used worldwide in whole or part by between 30% and 60% of families, respectively (Green et al., 2006).

Central to TEACCH is a concept called "Structured Teaching" (ST). Based upon evidence and observation that individuals with ASD share a particular pattern of neurological characteristics (Mesibov & Shea, 2010), ST is the reorganization of visual information within the individual's environment with the objectives of focusing the attention of the learner and controlling the learning context. Within this approach utilizing the visual modality is important as individuals with ASD possess strengths with visual information-processing, yet experience organizational deficits and an inability to independently understand or control their behaviour (Mesibov, Schopler & Hearsey, 1994). Specifically, ST alters the visual information presented to the individual with ASD in four ways: (1) organization of the physical environment, (2) addition of predictability by sequencing activities through the use of visual schedules, (3) incorporation of work and activity systems for facilitation of independent functioning, and (4) inclusion of visually structured instruction, organization, and clarity that help make the tasks meaningful and understandable (Mesibov et al., 2004). With the addition of such alterations, a sense of independence for the student is fostered thus providing an effective setting for teaching and learning (Schopler et al., 1995).

Much of the research that has empirically demonstrated the effectiveness of the TEACCH program has done so using the program as a comprehensive intervention (NasoudiGharehBolagh et al., 2013; Ozonoff & Cathcart, 1998; Panerai, Ferrante, & Caputo, 1997; Panerai, Ferrante, & Zingale, 2002). Yet, given the breadth of the approach, individual components such as activity schedules and work systems have been explored as stand-alone treatment methods. MacDuff, Krantz, and McClannahan (1993) explored the use of activity schedules for children within a home-based environment. Positive outcomes included sustained engagement in tasks, generalizability of skills, and improvements to behaviour (i.e., increased independence and fewer aberrant behaviours). Since this early investigation, similar findings have been found in contexts such as the classroom (Bennett, Reichow, & Wolery, 2011; Bryan & Gast, 2000; Massey & Wheeler, 2000; O'Reilly, Sigafoos, Lancioni, Edrisinha, & Andrews, 2005; Pierce, Spriggs, Gast, & Luscre, 2013; Schmidt, Apler, Raschke, & Ryndak, 2000), community (Carson, Gast, & Ayers, 2008; Dettmer, Simpson, Myles, & Ganz, 2000), and in clinical training settings (Pierce & Schreibman, 1994). In addition to activity schedules, Hume and Odom (2007) examined the use of classroom work systems on the independent work and play skills of students with autism. These investigators discovered that with the implementation of structured work systems, the students displayed increases in on-task behaviour, number of tasks completed, and a reduction of behavioural assistance strategies (i.e., prompting). Further research has added to this list of positive benefits including increases in task speed and accuracy, improvements to overall behaviour, generalizability across settings, and increased student engagement (Bennett et al., 2011; Hume, Plavnick, & Odom, 2012). Such outcomes provide indication that both activity schedules and work system interventions can be considered as independent means to facilitating the learning experiences of individuals with ASD.

The TEACCH program has been recommended for use in special education classrooms for children with autism for a number of years (Mesibov et al., 2004; Mesibov, Schopler et al., 1994; Schopler et al., 1995). Yet despite the attention and success that structured teaching and the TEACCH methodology has received as a classroom intervention, recommendations for its use in physical activity settings have superseded empirical validation (Groft-Jones & Block, 2006; Houston-Wilson & Lieberman, 2003; O'Connor, French, & Henderson, 2000; Schultheis, Boswell, & Decker, 2000; Staples & Reid, 2010). This lack of evidence is surprising given the breadth of information which exists in relation to the impact of exercise and physical activity on the developmental domains affected by ASD (Lang et al., 2010; Sowa & Meulenbroek, 2012). Moreover, it is interesting given the supplemental value that the core elements encompassed within the approach hold in reference to establishing program guidelines for enhancing physical activity among individuals with ASD (Dawson & Rosanoff, 2009).

To date, only the work of Pan (2010) has explored the effect of adding structure to a physical activity setting. Here, the research explored the effects of using recognizable features of the TEACCH model to improve aquatic skills and social behaviours of 16 boys with ASD. Results from this study indicated that there is potential for the adjustment of structure to facilitate the development of skills and improve behaviours in children with ASD. However, despite these positive outcomes, there is still a lack of evidence to support the use of structural interventions such as TEACCH within the areas of physical education and activity.

The purpose of this exploratory investigation was to examine the effects of both enhanced structure and how pictographic activity schedules within an aquatics program for individuals with ASD would affect participants' engagement in Inappropriate Response Time (IRT). The aquatic setting is important to explore, as it tends to include increased potential for distraction and unpredictability, as well as includes a variety of multisensory components that can affect behaviour in those with ASD. To date, the use of an aquatic environment has demonstrated benefits for individuals with ASD ranging from improvements in fitness levels and enhanced skill development to increases in social functioning (Fragala-Pinkham, Haley, & O'Neil, 2011; Pan, 2010; Summers & Wallace, 2013; Yilmaz, Yanardag, Birkan, & Bumin, 2004). In using an aquatic environment, the current investigation would lend support and extend the findings of other research conducted in such a setting, as well as lead to future considerations for ASD intervention research.

It was hypothesized that the activity schedules would decrease IRT over the course of the Adapted Physical Education (APE) teacher's instructional session. Behaviour upon the removal of the intervention (i.e., patterns of maintenance) was also examined.

Materials and Methods

Participants

Participants included three boys, with primary diagnosis of autism, ranging in age from 11 to 16 years of age enrolled at a school for children with developmental disabilities in a large metropolitan city. Physical education teachers, who thought schedules might improve motor performance, referred the participants to the researcher who was working in the school as a teaching assistant. A collaborative team of professionals from the school was responsible for confirming the diagnosis of autism through: (1) Observation for behaviours consistent with the criteria specified by the *Diagnostic and Statistical Manual of Mental Disorders* (4th ed., text rev.; *DSM-IV-TR*; American Psychiatric Association, 2000); (2) Formal assessment with the Childhood Autism Rating Scale (CARS; Schopler, Reichler, & Rochen-Renner, 1988); and (3) Formal assessment with the Psychoeducational Profile Revised (PEP-R; Schopler Reichler, Bashford, Lansing, & Marcus, 1990). While all participants had received formal diagnoses of autism from the educational team, resources did not allow for independent confirmation for this study. All participants had histories of disruptive behaviours, all displayed high levels of stereotypical responses, and each exhibited deficiencies in language (See Table 1). The boys were reliant on ongoing supervision and prompting to complete activities, however all were familiar with the concept of schedules as they were used in their regular classrooms.

Setting and Materials

The study occurred in an aquatic training pool at a recreational facility where the participants had taken part in a weekly aquatics program in the three months prior to the study. All sessions included the three participants in addition to 10 to 12 other students from the school with various disabilities. For the purposes of exploration, the participants were separated from the remainder of the group working within a distinct section of the pool as to minimize distractions. Sessions were conducted with the assistance of the participant group's special education classroom teacher. Due to scheduling limitations, the entire set of observations took place over a 13-week period. Each week consisted of one swimming session lasting approximately 30 to 40 minutes; swimming sessions included warm-up activities lasting approximately 5–10 minutes, skill instruction lasting approximately 15–25 minutes, and free play to complete the session.

Intervention materials included three pictographic schedules that were used within the activity environment (i.e., the swimming pool setting) comprised of coloured pictures, placed in sequential order, on a plain sheet of coloured paper using Velcro. All pictures were taken from a computer program (Boardmaker, Version 5) used by the school to create regular classroom schedules. Of the three schedules, one was used simultaneously by all three participants, one was used individually by each

Table 1. Participant Behaviour Profiles

Participant	Behavioural Characteristics
Matt	Displays echolalia and uses noncontextual speech; aggressive; hyperactive; impulsive; high levels of anxiety; inattentive; noncompliant; stereotypical behaviours (i.e., repetitive touching of those around, hand/arm flapping, bouncing)
Alex	High levels of anxiety; socially isolated; noncompliance when not observed by authoritative figure; inappropriate laughter despite being non-verbal; aggressive; self-stimulation (i.e., tapping fingers on back of neck, pacing, tapping inanimate objects)
Jake	Limited span of attention; avoidance; socially withdrawn; inappropriate vocalizations; stereotypical behaviours (i.e., licking and rubbing fingers, pressing outside corner of eyes, facial tics, grabbing and clutching himself)

participant, and one was set up in the form of individual work systems. Each schedule ranged in size and included activities corresponding to the Adapted Physical Education (APE) teacher's lesson. A further description of each schedule is given below.

The first schedule was used simultaneously by all three participants. Included on this schedule were activities corresponding to the APE teacher's daily lesson occurring within the swimming pool. For example, pictures representing warm-up activities, relays, games, and free time were incorporated. This schedule consisted of picture symbols approximately 21.5 cm by 28 cm which were placed on a wall beside the pool where the participants initiated their activities. In addition, to reduce the obstacle of the teacher getting in and out of the pool, an identical hand-held schedule with pictures approximately 3.5 cm by 3.5 cm was integrated. The teachers and assistants aided the participants in following this schedule through the use of a prompt hierarchy (Watkinson & Wall, 1982), whereby more intrusive prompts (i.e., direct manipulation) are gradually faded and less intrusive prompts (i.e., gestural and verbal prompting) are utilized.

The second schedule was an extension of the warm-up activities noted on the larger schedule of all pool activities. Each participant had their own copy of this schedule. Included within the schedules was a Polaroid photograph of the participant and pictures depicting the number of activities to be completed. For example, the schedule consisted of three pictures depicting running across the pool, three pictures depicting swimming with the use of a pool noodle, and three pictures depicting swimming with the use of a flutterboard. All pictures were 3.5 cm by 3.5 cm, and the complete schedule was attached to an inverted V-shaped "Wet Floor" sign, which was approximately two feet tall, at the edge of the swimming pool. This schedule was identical for all three participants.

The third schedule was set up in the form of a work system for each of the three participants. Each participant had a different work system, as each reflected individual interests. For example, one participant enjoyed jumping into the water; another enjoyed diving underneath the surface; while yet another enjoyed swimming in the deep end of the pool. Therefore, the picture symbols were representations of these activities. Specifically, pictures of hockey pucks that the participants had to dive for, the action of swimming and the action of jumping off the side of the pool were used. Each picture was 3.5 cm by 3.5 cm, and five identical pictures made up the complete work system schedule. Individual work systems were placed away from the larger group (i.e., in the deep end of the pool), and used after the warm-up activities were completed.

Experimental Design

An interrupted time series design (A/B/A) (Creswell, 2012) was used to assess the effects of the structured activity schedules on inappropriate behaviour. An interrupted time series design consists of obtaining multiple measures prior to an intervention, administering an intervention, and then measuring outcomes on multiple occasions. This design allowed the researchers to determine if changes in behaviour were apparent after the implementation of an intervention, and if alterations could be maintained once said intervention was removed. Baseline sessions occurred in the first three weeks of the 13-week investigation, while intervention and maintenance sessions took place for eight and two weeks, respectively.

Procedures

All procedures were carried out under the approval of the Institutional Review Board at McGill University.

Pre-baseline. Participants entered into this study with some experience of schedule-use as they had previously used picture symbol schedules in their regular special education classrooms. According to the homeroom teacher, they were able to discriminate amongst tasks and comprehend when an activity was completed. However, due to the unfamiliarity of the pictures in the current study, students had to be re-taught discrimination tactics to ensure that they could distinguish between the picture symbols being used. After each picture symbol was correctly identified from a larger group of pictures with the help of the classroom teacher or assistant, prompting was faded in order to promote a greater sense of independence. Criteria for participant inclusion in the investigation were an understanding of the picture symbols. Once the individual had correctly identified each of the pictures without the intrusiveness of prompting, it was believed that an understanding had been developed, and each individual picture could be incorporated into a schedule. The participant group's special education teacher was responsible for ensuring the discrimination of all picture symbols being used, thus establishing a level of understanding, prior to the commencement of the investigation.

Baseline. In the baseline condition, a trained APE teacher from the participants' school delivered a daily aquatic lesson to the entire group, including the participants under investigation. At the beginning of each of the activities within the lesson, the teacher performed a single demonstration, accompanied by verbal instruction. With the assistance of the participants' regular special education teacher, the participants' engaged in each of the lesson's individual activities. Physical and verbal prompting was used to keep the participants' within the confines of the activity area, as well as on-task with respect to the APE teacher's lesson.

Intervention. All baseline procedures were used throughout the intervention condition in addition to the schedules. Each of the schedules was implemented in the same way. Once the child had completed the task denoted, he was guided to tear the picture from the board and place it in a plastic pouch located at the bottom of the schedule. The child was then instructed to return to the schedule in order to determine if any additional items were left. Once all the items had been removed, it was indicated to the child that the schedule was finished. Once the schedules were completed, the participants were instructed to wait. Wait times were minimal; nevertheless data were taken on the dependent variable during this time. Additional prompting, such as verbal instruction and gestures, were used if and when the participant had difficulties manipulating schedule items. Prompting was not used to assist the child in completing the activities themselves. It is important to note that the first schedule (used by all three participants simultaneously) was teacher-regulated with each participant taking turns in removing items and placing them into their appropriate finished location.

Maintenance. Over this condition, activity schedules were removed and all instruction returned to baseline levels.

Response Definitions and Measurement

Child behaviours. Structured teaching is designed to educate individuals with autism and circumvent problems with difficult student behaviours. Therefore, research that has empirically evaluated the impact of structured teaching has typically selected dependent variables such as on-task and on-schedule behaviours, and inappropriate behaviours including stereotypies (e.g., Bryan & Gast, 2000; MacDuff et al., 1993; Panerai, Ferrante, Caputo, & Impellizzeri, 1998; Schultheis et al., 2000). Within the current investigation, inappropriate behaviour was measured as a function of time. The variable of *inappropriate response time (IRT)* was defined as time that participant behaviour was considered: (a) inappropriate to the time and place they occurred in, (b) non-functional to the completion of the activity, (c) disruptive in nature causing the teacher to stop instruction or a peer to stop engagement in activity, or (d) harmful to the individual or anyone in the surrounding area. Examples of inappropriate behaviours include aggression, hyperactivity, self-injurious behaviour, and stereotypical mannerisms such as self-stimulation and inappropriate vocalization.

Measurement procedures. All sessions were recorded using two digital video cameras, and stored in a secure location at the researcher's academic institution. Data for the dependent variable of inappropriate response time were subsequently coded over the course of two distinct periods of the swimming session: during the APE teacher's delivery and instruction of the daily aquatic lesson, and during the free play portion of the swimming session. The time period of free play was chosen to determine if any potential effect would extend beyond the period of formal instruction. Data were coded using a modified version of Siedentop and colleague's (1982) ALT-PE systematic observation instrument where behaviours were scored in 6-second intervals. Interval recording of the 6-second duration was used, as opposed to the 12-seconds outlined by the instrument in order to minimize the possibility of several behaviours being observed in the same interval (van der Mars, 1989). The ALT-PE instrument has been proven reliable at the .90 (Derri, Emmanouilidou, Vassiliadou, Tzetis, & Kioumourtzoglou, 2008) and .92 (Temple & Walkley, 1999) levels, as well as been deemed valid as evidence has been provided by at least 11 studies where some measure of student's engaged time and learning via appropriateness have been correlated (Metzler, 1989).

Interobserver agreement. Interobserver agreement (IOA) on participant responding and the researcher's adherence to planned procedures was collected on 25% of all experimental sessions. Via the recorded aquatic program sessions, a trained observer conducted at least one reliability check in each of the experimental conditions. For event recording purposes, training consisted of the researcher explaining categorical definitions, methods of data collection, and procedures in detail to the trainee. Additionally, the researcher conducted a practice session alongside the trainee whereby both watched, scored, and compared recorded video data simultaneously. If disagreements occurred throughout the practice sessions, the video was paused and a discussion surrounding the disagreement ensued. The interval recording training took approximately three hours, at which time agreement reached acceptable levels (approximately 80%) and subsequent reliability estimates could be conducted. Such reliability estimates were calculated using the point-by-point method in which the number of agreements is divided by the number of agreements plus disagreements, and multiplied by 100. Over the 13-week study, agreement ranged from 80% to 97% on all timed intervals, with a mean agreement of 90%.

Results

Mean results for the percentage of IRT in which the participants engaged in over the course of the swimming session is found in Table 2.

Figure 1 reports the results for each of the three participants when being formally instructed

Table 2. Mean Percentages of Inappropriate Response Time (IRT) Across Instructional Phases

	IRT During Instruction			*IRT During Free Play*		
Participant	*Baseline*	*Intervention*	*Maintenance*	*Baseline*	*Intervention*	*Maintenance*
Matt	11.2	5.1	8.5	12.9	7.7	4.0
Alex	12.2	3.1	2.3	23.6	11.8	5.3
Jake	10.0	3.0	0.0	13.9	4.6	1.4

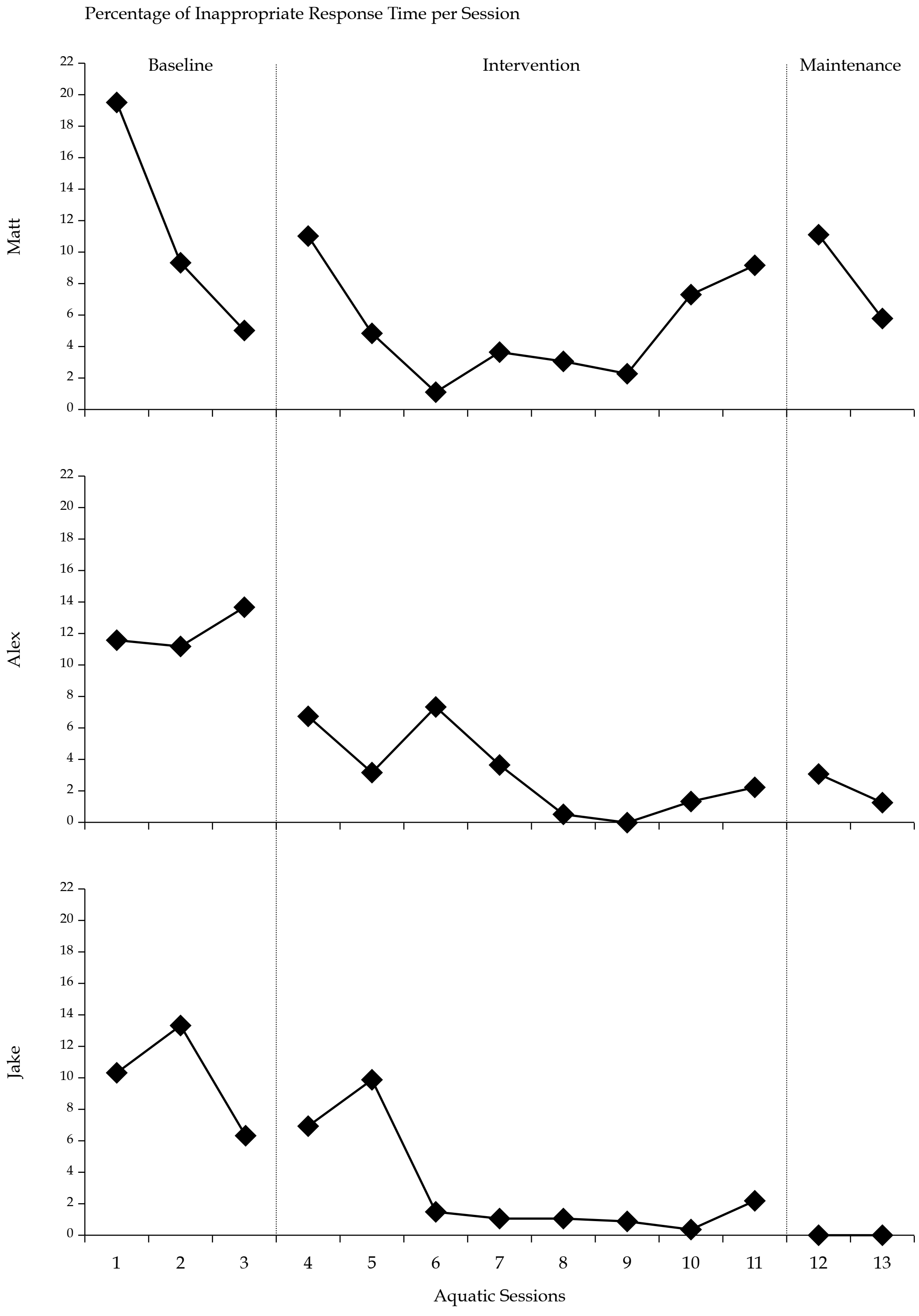

Figure 1. Percentage of Inappropriate Response Time (IRT) within instruction

by the APE teacher for all phases of the study. During baseline, the mean percentage for Matt, Alex, and Jake (pseudonyms) was 11.2%, 12.2%, and 10.0%, respectively. Over the duration of the intervention values dropped to 5.1% in Matt, 3.1% in Alex, and 3.0% in Jake. Finally over the maintenance condition, mean values remained below baseline levels, however varied amongst the three participants. Specifically, Matt engaged in inappropriate behaviour on a mean of 8.5% of intervals, Alex on a mean of 2.3% of intervals, and Jake showed no sign of inappropriate activity. As a whole, all three participants demonstrated a reduction in inappropriate behaviours through the use of activity schedules as the IRT variable fell below baseline levels over the course of the intervention sessions. Similar trends were observed when the intervention was removed.

Figure 2 shows percentages of IRT for all three participants over the period of free play (i.e., without formal instruction, not restricted in a specific area of the pool, and having opportunity to interact with the rest of the swimming class) for all phases of the study. During baseline, the IRT mean for Matt was 12.9%, while Alex displayed a mean of 23.6% and Jake a mean of 13.9%. Over the course of the intervention sessions, the use of picture symbol schedules produced reduced means of 7.7%, 11.8%, and 4.6% in Matt, Alex, and Jake, respectively. In maintenance, IRT was maintained and further reduced by all three participants as Matt displayed a mean of 4.0%, Alex of 5.3%, and Jake of 1.4%. Similar to the results of all intervals and those pertaining to instruction, these findings revealed improvements in IRT over the period of free play for all the participants.

Discussion

The purpose of this pilot study was to evaluate the effectiveness of using pictographic activity schedules on IRT of three adolescent boys with autism over a 13-week swimming program. The findings from this study lend support to previous research on activity schedule use in the educational environment for individuals with ASD (Bennett et al., 2011; Bryan & Gast, 2000; Hume & Odom, 2007; MacDuff et al., 1993; O'Reilly et al., 2005), and extend the recommendations and limited evidence of such intervention practices within aquatic physical activity settings (Pan, 2010; Yilmaz et al., 2004). Overall, the implementation of activity schedules positively influenced behaviour as the IRT variable was reduced. However, the extent of the influence varied between individuals as well as across the different time periods that were examined.

Within the formal instruction portion of the swimming session, two of the participants (Alex and Jake) demonstrated substantial reductions in inappropriate behaviour with the implementation of the activity schedule intervention, thus leading to minimal time spent engaged in inappropriate behaviours. The third participant (Matt) displayed more inconsistent behavioural patterns with initial reductions in IRT followed by an increase towards the end of the intervention sessions. It is unknown why the third participant demonstrated such variability with respect to behaviour as information was not recorded prior to and following the aquatics session. Moreover, resources did not allow for the confirmation of medications that may have also triggered variable responses over the course of the 13-week aquatics program. Nevertheless, the findings of improved behaviour for the first two participants are consistent with Yilmaz et al.'s (2004) study indicating stereotypical responses, such as spinning, rocking and echolalia, are reduced through active participation in aquatics programming for individuals with ASD.

A secondary aim of the research was to determine if the effects of improved behaviour would be transferred beyond the period of formal instruction. Similar to earlier trends, IRT was reduced and maintained below baseline levels in all three participants over the course of free play. This sense of generalization supports the findings of Bryan and Gast (2000) who discovered that students with ASD were able to generalize focus and appropriateness to novel activities not denoted by the picture activity schedules. In the case of the current investigation, the participants generalized their appropriate behaviour (i.e., reduced IRT) to the less novel activity of free play from the more structured component of the aquatic session, that being instruction.

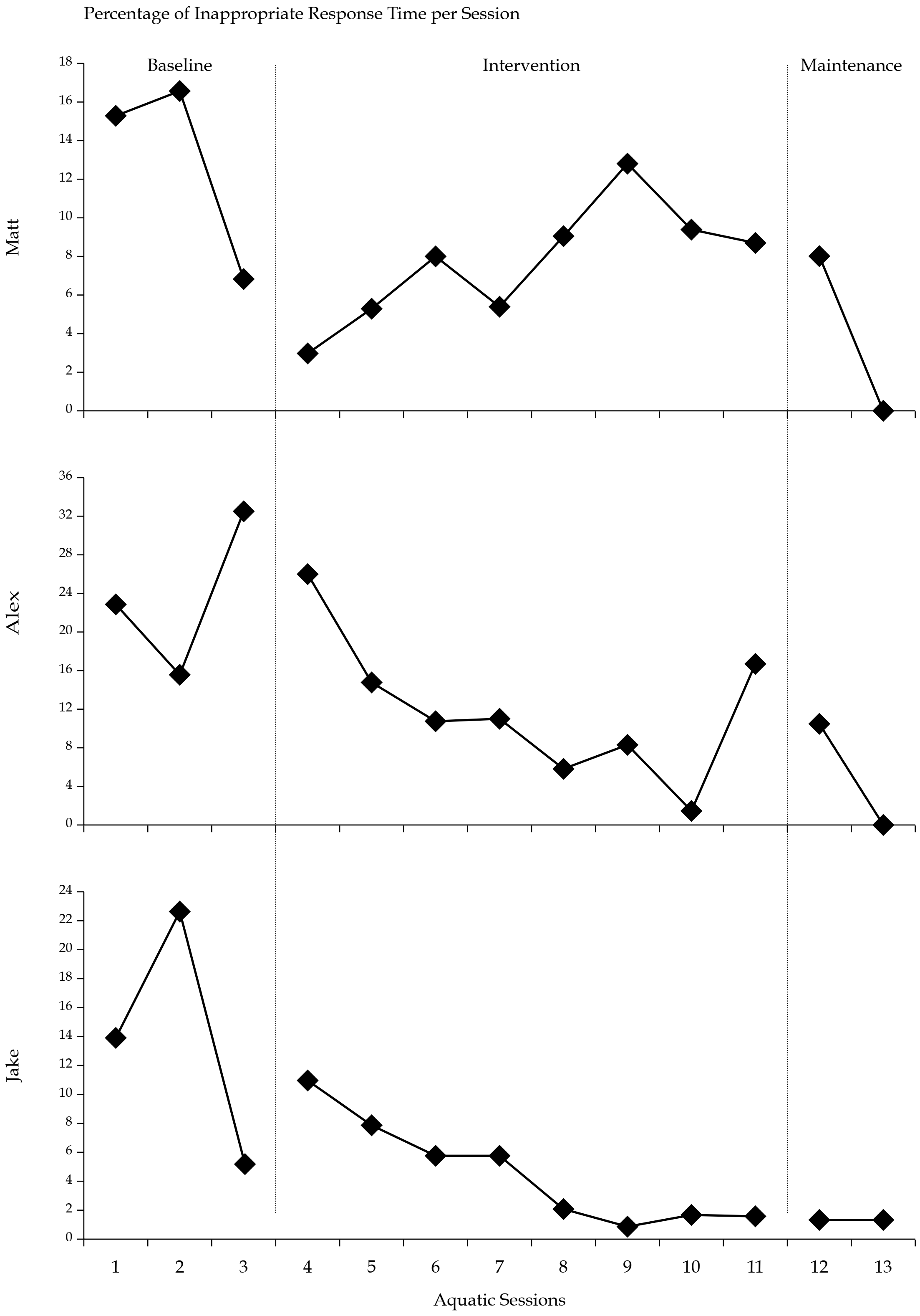

Figure 2. Percentage of Inappropriate Response Time (IRT) within free play

Finally, the current study examined how the activity schedules would affect behavioural patterns when removed. The results showed that maintenance effects for the dependent measure of IRT were inconsistent across all of the participants. Nevertheless, the findings are encouraging as the current investigation provides some support for the findings of Bryan and Gast (2000), who claimed the implementation of schedules allowed students to maintain high levels of on-task behaviour after schedules were removed.

Although the findings are positive with respect to the effect of activity schedules on behaviour, the limitations of the current investigation should be recognized. The first two limitations involve sample selection. Based on a convenience sample from an established aquatics program, each participant had already been exposed to the environment for a period of three months prior to the investigation. As such, a level of familiarity with the environment and the predictability of the APE teacher's lesson sequencing may have already been established masking the effects of the activity schedules. However, while a level of familiarity can be seen as a limitation, it is also important to consider that children, especially those with ASD, respond better in settings where the likelihood of events is predictable; if a more novel setting was selected for the intervention, it may not have been as successful. Secondly, this sample also represents one in which there was an established familiarity with schedule use. While discrimination tactics were used to familiarize the participants with the symbols, the result of the study may have been biased due to the additional practice that the participants had in using schedules within the special education classroom. These two limitations could have been minimized if a sample of participants, who were unfamiliar with the use of schedules, was selected from a larger population that had not been involved in the aquatics program three months prior to the commencement of the investigation.

The final limitation has to do with the experimental length. According to a meta-analysis performed by Virtues-Ortega, Julio, & Pastor-Barriuso (2013), studies examining a TEACCH-based intervention usually are conducted over an average of 19 weeks. In comparison, the current investigation is only examining an intervention of 8 weeks. While several studies have demonstrated positive effects over intervention lengths of shorter duration (i.e., Durham, 2000; Durnick, et al., 2000; Ozonoff & Cathcart, 1998), the length of the current study's intervention period must still be considered as a limitation. Despite the current investigation's encouraging results, a more substantial experimental length with additional sessions at all three treatment conditions, may have added to the value of the findings demonstrated in the current study. This would have provided more opportunity for the students to become accustomed to using the schedules in an environment outside their special education classroom, and the researcher to determine a more accurate account of the effects of activity schedule implementation.

In conclusion, this pilot study extends the present literature demonstrating that activity schedules can be used to elicit positive effects when used in physical activity settings for individuals with ASD. Future examinations with differing physical activities are warranted to verify if schedules are generalizable to activity environments with reduced predictability (i.e., physical education classrooms, inclusive community programs). Considerations should be given to the type and extent of their use, in addition to the time in which they are implemented. Through such structural considerations, physical activity programs advocating for the successful inclusion of individuals with ASD can provide optimal opportunities for activity participation, thus promoting healthy and active lifestyles inclusive of all individuals.

Key Messages From This Article

People with disabilities. Anyone can participate in physical activity; it is just a matter of finding the right way to structure the activity to suit one's needs.

Professionals. The use of activity schedules is an effective and easy-to-use means of support to enhance learning outcomes for individuals with ASD in an adapted physical activity setting.

Policymakers. Known intervention strategies used within general educational settings, and that can enhance the behaviour of individuals with ASD, should be encouraged as a means of promoting engagement in physical activity.

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La relation entre le trouble primaire du langage et la théorie de l'esprit : perspective

Résumé

La théorie de l'esprit (ToM), cette capacité à concevoir qu'autrui peut avoir des états mentaux différents des siens, est en étroite relation avec le langage. Pourtant, la ToM chez les enfants avec un trouble primaire du langage (TPL) a été peu exploré. Les premières études sur le sujet semblaient dire que les enfants présentant ce trouble réussissaient bien les tâches de ToM. Or, des études plus récentes soulèvent la possibilité que cette clientèle accuse plutôt un retard dans le développement de leur ToM. L'étude de la ToM chez les enfants avec un TPL pose certains défis méthodologiques qui doivent être considérés afin de clarifier la nature de ce lien et conséquemment son impact sur le fonctionnement de l'enfant au quotidien. Cet article propose une réflexion critique sur ces défis à partir d'une synthèse des principaux travaux portant sur la ToM auprès de la clientèle présentant un TPL.

Perspective on the Relationship Between Primary Language Disorder and Theory of Mind

Abstract

Theory of mind (ToM), which is the ability to conceive that others' mental states may differ from one's own, is closely related in close relation to language. Yet, ToM in children with primary language disorder (PLD) has not been extensively studied. Initial research on the subject seemed to conclude that these children performed well at ToM tasks. However, recent studies have shown that children with PLD may have delays in developing ToM. Studying ToM in children with PLD raises some methodological questions that must be considered in order to better understand the relation between ToM and language and how this relation impacts child daily functioning. The goal of our study is to reflect critically on these methodological questions by looking at our review of the main research on ToM in children with PLD.

La théorie de l'esprit (ToM) et les capacités langagières d'un d'individu sont fortement corrélées (Milligan, Astington, & Dack, 2007). Il serait donc attendu qu'une clientèle, aux prises avec des difficultés importantes sur le plan langagier, présente une perturbation de la ToM. À ce jour, peu de chercheurs se sont intéressés à cette clientèle et particulièrement chez l'enfant (Farrar et al., 2009; Gillott, Furniss, & Walter, 2004). Or, les jeunes présentant un trouble primaire du langage (TPL) s'avèrent intéressants pour comprendre le lien entre langage et ToM puisque la difficulté primaire de leur trouble porte sur le langage, contrairement aux autres troubles pour lesquelles les difficultés langagières sont davantage secondaires (surdité, autisme, déficience intellectuelle, etc.). Cet article tentera donc de faire une mise au point sur les recherches effectuées à ce jour concernant la ToM chez la clientèle présentant un TPL. Notons que cet article ne se veut pas une recension exhaustive des écrits sur les thèmes abordés. Son objectif est plutôt de mettre en contexte les thèmes afin de susciter une réflexion critique sur les conduites à tenir en termes de recherche et d'intervention.

Le trouble du langage

La terminologie entourant le trouble du langage, particulièrement dans sa composante orale, varie à travers le temps et les écoles de pensée. On retrouve dans la littérature des termes tels que audimudité (Ajuriaguerra, Borel-Maisonny, Diatkine, Narlian & Stambak, 1958), aphasie congénitale (Benton, 1964), trouble développemental du langage (Bishop & Rosenbloom, 1987), dysphasie développementale (Rapin & Allen, 1983), trouble spécifique du langage oral (Leonard, 1998). Peu importe son appellation, ce syndrome d'origine neurologique est présent dès la petite enfance et interfère avec la trajectoire développementale de l'enfant. Dans un souci de synthèse des connaissances et d'intégration, notamment avec les autres diagnostics neurodéveloppementaux du DSM-5 (American Psychiatric Association, 2013), l'Ordre des orthophonistes et audiologistes du Québec (OOAQ, 2014) a proposé récemment une terminologie considérant le langage en interaction avec les autres domaines cognitifs. Ainsi, le trouble du langage se caractériserait par une difficulté marquée dans l'apprentissage et l'utilisation du langage, par des déficits en compréhension et/ou en expression et dans différentes composantes du langage ainsi que par des déficits persistants et variables dans le temps avec un impact fonctionnel. Lorsque le trouble du langage se situe dans un développement global relativement harmonieux, on parlerait de TPL. Lorsque le trouble se présente à l'intérieur d'un profil neurodéveloppemental plus large tel que, par exemple, le trouble du spectre de l'autisme (TSA) ou le retard mental, on parlerait plutôt de trouble du langage secondaire (OOAQ, 2014). La question du diagnostic et de la terminologie en langage oral continue à susciter des questionnements et à alimenter les travaux.

Puisqu'il ne s'agit pas toujours des mêmes composantes langagières qui sont perturbées d'une personne à l'autre, et que ces composantes sont affectées à différents niveaux de sévérité, il est possible d'observer un large éventail de déficits langagiers, tant sur le plan réceptif qu'expressif. Les enfants avec un TPL peuvent présenter des difficultés tant sur le plan de la morphosyntaxe (Macchi & Schelstraete, 2012; Royle & Stine, 2013; Thordardottir & Namazi, 2007), du lexique et de la sémantique (Bragard & Schelstraete, 2006; Pizzioli & Schelstraete, 2011), que du discours et de la pragmatique (Collette & Schelstraete, 2012; de Weck, 2004).

Plus spécifiquement sur le plan réceptif, les difficultés d'une personne se traduisent par une compréhension restreinte du message verbal, notamment la compréhension de concepts plus abstraits (ex. : temps, quantité, espace), de certains morphèmes grammaticaux (ex. : temps de verbe, pronom clitique), de mots « questions » (ex. : quand, comment), de consignes plus longues et plus complexes, de même que la compréhension du langage plus complexe (ex. : ironie, inférences, humour, gestion de l'implicite). Les messages peuvent donc être difficiles à saisir pour certaines personnes ayant un trouble primaire du langage, ce qui peut l'amener à fournir des réponses erronées ou hors sujet (George, 2010).

Sur le plan expressif, le TPL peut affecter la production et l'élaboration du discours, de même que les règles de régie de l'échange. Il peut se manifester, entre autres, par un discours tangentiel, des difficultés à organiser ses idées en séquence, à initier un sujet de conversation, à maintenir le fil conducteur, à s'ajuster à l'interlocuteur et au contexte de communication, de même que par la présence d'un délai avant de fournir une réponse verbale. L'enfant peut également présenter une difficulté à exprimer ses besoins, ses émotions, ses opinions et ses pensées En plus des difficultés sur les plans pragmatiques et des habiletés discursives, d'autres difficultés expressives peuvent faire partie du profil des jeunes ayant un trouble primaire du langage, telles que des difficultés d'accès lexical, un vocabulaire restreint, et des difficultés morphosyntaxiques.

Le profil communicatif des personnes ayant un TPL varient considérablement d'un individu à l'autre en regard des composantes du langage affectées mais aussi de l'âge de l'individu et de la présence de comorbidités influençant ainsi le degré de sévérité (Leclercq & Leroy, 2012). Puisque chacune des composantes langagières suit son propre rythme de développement, la sévérité du trouble peut se transformer au fil du développement de l'individu. Finalement, des comorbidités, telles que la dyslexie, la dysorthographie, la dyscalculie, la dyspraxie, ainsi que des déficits attentionnels, mnésiques, d'abstraction, de la pensée verbale, des fonctions exécutives, de la notion temporelle, des fonctions visuospatiales et de la motricité fine et/ou globale, peuvent coexister avec ce trouble (Cohen, 1997; Lussier & Flessas, 2009) et engendrer des troubles de fonctionnement significatifs dans la vie quotidienne.

Par ailleurs, les capacités langagières joueraient un rôle important dans l'application de la ToM (Colle, Baron-Cohen, & Hill, 2007; Miller, 2001, 2004, 2006; Milligan et al., 2007; Nader-Grosbois & Thirion-Marissiaux, 2011). Avant de s'attarder à la relation qui existe entre ces deux concepts, il est donc pertinent de bien comprendre ce qu'est la ToM et la façon dont elle se profile chez la population normale.

Théorie de l'esprit

À ce jour, la ToM est définie comme la capacité d'attribuer des états mentaux [désirs, intentions, émotions, croyances (vraies et fausses), savoir, perceptions…] à soi et aux autres et à utiliser ces états mentaux pour inférer, expliquer et prédire ses propres comportements et ceux des autres (Astington & Jenkins, 1999; Baron-Cohen, 2001; Flavell, 1999; Miller, 2001, 2006; Milligan et al., 2007; Nader-Grosbois & Thirion-Marissiaux, 2011; Wellman, Cross, & Watson, 2001). Il ne s'agit donc pas seulement de comprendre que les autres ont des états mentaux, mais également que ce sont leurs états mentaux qui sont à l'origine de leurs comportements plutôt que les faits propres à une situation. La ToM serait primordiale pour notre équilibre psychologique et nos capacités de communication et d'adaptation sociale (Bakchine & Slachevsky, 2008; Carter, Aldridge, Page, & Parker, 2010). L'enfant, au fil de son développement, acquiert les habiletés cognitives nécessaires pour parvenir à atteindre une ToM dans toute sa complexité.

Développement normal de la théorie de l'esprit

L'attention conjointe préverbale, les habiletés à faire semblant, l'empathie et le style d'attachement sont considérés comme des précurseurs à l'acquisition de la ToM plutôt que des habiletés propres à la ToM (Nader-Grosbois & Thirion-Marissiaux, 2011). À cet égard, un enfant qui détient ces habiletés ne démontre pas nécessairement qu'il a les capacités de comprendre et de prédire le comportement d'autrui. Il a toutefois acquis les bases pour y parvenir.

Au cours des quatre premières années de sa vie, l'enfant acquiert différentes habiletés simples renvoyant à une ToM. La compréhension de l'intentionnalité, la reconnaissance qu'autrui peut avoir des désirs différents des siens et la compréhension de mots faisant référence aux états mentaux (penser, savoir, croire, etc.) en font partie (Bakchine & Slachevsky, 2008; Miller, 2006; Nader-Grosbois & Thirion-Marissiaux, 2011). Vers 4 ans, l'enfant parviendrait à saisir qu'une croyance est une représentation alors qu'avant, il percevait que c'était une copie de la réalité. En fait, il parvenait difficilement à se décentrer de ses propres croyances. Il projetait ses propres désirs sur autrui, percevant que tous avaient les mêmes croyances et les mêmes désirs que lui. L'enfant parviendrait alors, entre 4 et 6 ans, à réussir les tâches de distinction entre l'apparence et la réalité de même que les tâches de fausses croyances les plus simples (de premier ordre – élaborer et comprendre qu'autrui peut penser différemment de soi). Ainsi, il comprend que non seulement les gens ont des états mentaux, mais que ces derniers ne représentent pas nécessairement la réalité. L'enfant démontre ainsi qu'il est capable de se détacher de sa perception immédiate de l'environnement.

Bien que les bases de la ToM semblent généralement acquises vers ces âges, d'autres aspects se développeraient ultérieurement. Par exemple, la fausse croyance de deuxième ordre (élaborer et comprendre qu'autrui est aussi capable de comprendre qu'un autre peut penser différemment de lui) serait davantage comprise à partir de 6 ans et la compréhension de l'humour complexe et de l'ironie le serait vers 8 ans (Baron-Cohen, 2001; Miller, 2004, 2006; Nader-Grosbois & Thirion-Marissiaux, 2011; Richard, Degenne, Leduc-Destribats, & Adrien, 2006; Wellman et al., 2001; Wimmer & Perner, 1983). Viendrait ensuite le volet expressif de la ToM, où l'individu est capable d'expliquer verbalement le comportement des gens par leurs croyances et leurs savoirs et à expliciter qu'une croyance peut être fausse (Veneziano & Hudelot, 2009). Selon Bakchine et Slachevsky (2008), l'enfant atteindrait la dernière étape du développement de la ToM entre 9 et 11 ans, lorsque la complexité des interprétations se situe à un niveau beaucoup plus subtil. Par exemple, lorsqu'un enfant parvient à résoudre des problèmes de « faux pas », il est capable de reconnaître qu'un individu a tenu des propos qu'il n'aurait pas dû tenir, sans pour autant s'en rendre compte. Pour expliquer le « faux pas », les auteurs proposent l'exemple d'une femme qui reçoit, de son amie, un saladier en cadeau de mariage et qui, des années plus tard, casse devant cette amie le saladier en question par mégarde tout en banalisant son geste puisque, de toute façon, elle l'avait toujours trouvé affreux. Pour comprendre cet exemple, il faut être capable de se représenter l'état mental de la personne qui a réalisé le « faux pas » sans le savoir et celui de la personne victime du « faux pas » qui va se sentir blessée. En somme, l'acquisition d'une ToM se ferait sur un continuum développemental hiérarchique, le jeune enfant démontrant qu'il a acquis les bases de la ToM vers 4 ans pour ensuite y greffer des habiletés plus complexes au fil de son développement.

En général, les tâches le plus souvent administrées pour évaluer la ToM portent sur la fausse croyance liée à un changement de lieu (par exemple, la tâche de Sally et Anne (Wimmer & Perner, 1983) ou à un contenu insolite (par exemple, des crayons dans une boîte de Smarties), la distinction entre l'apparence et la réalité (*appearance-reality*; par exemple, une éponge qui ressemble à une roche) et les fausses croyances de deuxième ordre (par exemple, la tâche de Mary et John de Baron-Cohen, 1989) (Astington & Jenkins, 1999; Deak, Ray, & Brenneman, 2003; Hale & Tager-Flusberg, 2003; Miller, 2006; Nader-Grosbois & Thirion-Marissiaux, 2011).

Selon Nader-Grosbois et Thirion-Marissiaux (2011), quatre grands secteurs viendraient influencer le développement de la ToM : cognitif, langagier, socio-affectif et adaptatif, ainsi que la cognition sociale. Dans le cadre de ce texte, l'accent sera mis sur les capacités langagières et communicatives, sphères particulièrement touchées chez les jeunes présentant un TPL.

Théorie de l'esprit et trouble du langage

Si le TPL commence à intéresser les chercheurs en cognition, ce n'est pas nécessairement dans un but premier de mieux comprendre la ToM chez les jeunes dysphasiques, mais plutôt de tenter de clarifier la nature du lien existant entre langage et ToM (Farrant, Fletcher, & Maybery, 2006; Farrar, Fletcher, & Maybery, 2009; Miller, 2004, 2006). Bien que les auteurs s'accordent pour dire que le langage et la ToM sont fortement corrélés (Milligan et al., 2007), plusieurs hypothèses sont encore débattues pour expliquer la nature de cette relation (Astington & Jenkins,1999; de Villiers & de Villiers, 2000; Milligan et al., 2007). Étudier la clientèle présentant un trouble du langage serait donc une avenue intéressante pour explorer cette relation, mais également pour mieux comprendre l'impact qu'une atteinte langagière pourrait avoir sur le développement de la ToM. Dans cette section il sera donc question d'une mise au point des connaissances actuelles portant sur la ToM des jeunes présentant un trouble du langage afin de mieux orienter les recherches futures à ce sujet. Le Tableau 1 propose une synthèse des principales études qui se sont penchées sur les liens entre le trouble du langage chez l'enfant, particulièrement le TPL et la TOM. (Voir l'annexe, Tableau 1, à la page 29.)

Lorsqu'il est question de déficits au niveau de la ToM, les cliniciens ont souvent tendance à les associer directement au trouble du spectre de l'autisme, alors que la clientèle présentant un TPL ne leur semble pas d'ambler présenter de particularités à ce niveau. À cet égard, les premières études portant sur la ToM et la clientèle présentant un TPL (Leslie & Frith, 1988; Perner, Frith, Leslie, & Leekam, 1989) sont souvent citées dans la littérature contemporaine comme ayant démontré que ces jeunes ne présentent aucune difficulté avec la ToM (Farrant et al., 2006; Holmes, 2001).

Nous avons fait l'analyse de ces premières études et il est possible de constater que l'objectif principal de leurs recherches consistait à démontrer que les enfants autistes présentent des retards significatifs dans le développement de la ToM (Leslie & Frith, 1988; Perner et al., 1989). Les enfants dysphasiques servaient de groupe comparatif afin de contrôler la variable langagière. Il n'y a toutefois présence d'aucun groupe contrôle constitué d'enfants sans difficulté langagière et les tâches administrées portent seulement sur les fausses croyances simples. Il est à noter que ce type de tâche est généralement réussi chez des enfants normaux de 4 à 6 ans. Dans les deux études, les enfants présentant un TPL réussissent les tâches, mais comme ils sont âgés en moyenne de 8 ans et 8 mois, il n'est pas possible de se prononcer sur la présence ou non d'un retard de la ToM chez cette clientèle. Dans les deux études, les chercheurs ne se prononcent pas sur le sujet et mentionnent simplement que les enfants avec un TPL sont capables de réussir les tâches de fausses croyances contrairement aux enfants autistes. Ils ne portent donc aucune conclusion hâtive quant à l'absence de retard chez les présentant un TPL.

Des recherches plus récentes ont pourtant démontré que les enfants avec un TPL présentent un retard dans le développement de leur ToM (Farrant et al., 2006; Holmes, 2001; Ziatas, Durkin, & Pratt, 1998). Pour leur part, Farrant et al. (2006) démontrent ces résultats après avoir comparé la performance d'enfants normaux sans difficulté langagière (n = 20; M = 61,2 mois; ÉT = 5,9 mois) à celle d'enfants avec un TPL (n = 20; M = 62,9 mois; ÉT = 3,2 mois) lors de 10 tâches différentes évaluant la ToM. Holmes (2001) a, quant à lui, obtenu des résultats similaires pour un échantillon d'enfants âgés de 4 à 7 ans qu'il a scindé en deux [4-5 ans (Contrôle : n = 24; M = 5 ans; ÉT = 5,68 mois – TPL : n = 23; M = 5 ans 4 mois; ÉT = 5,3 mois) et 6-7 ans (Contrôle : n = 25; M = 7 ans; ÉT = 6,69 mois – TPL : n = 20; M = 7 ans 1 mois; ÉT = 7,8 mois)] afin de mesurer la ToM de premier ordre et de deuxième ordre. Quant à l'étude de Ziatas et al. (1998), les chercheurs ont d'abord comparé des jeunes avec TPL âgés en moyenne de 8 ans et 2 mois (n = 12; ÉT = 2,7 mois) avec des jeunes sans difficulté langagière ayant le même âge verbal qu'eux (n = 12; M = 5 ans 8 mois; ÉT = 1,9 mois) ainsi que des jeunes avec TPL (n = 12; M = 6 ans 11 mois; ÉT = 2,2 mois) et des jeunes sans difficulté langagière ayant le même âge chronologique qu'eux (n = 12; M = 6 ans 5 mois; ÉT = 2 mois). Les résultats démontrent que les enfants présentant un TPL parviennent à réussir les tâches de ToM à un niveau équivalent à celui des jeunes normaux qui ont le même âge verbal qu'eux, donc chronologiquement plus jeunes (n = 12; M = 5 ans 8 mois; ÉT = 1,9 mois). Ainsi, bien que les jeunes avec TPL soient capables de réussir des tâches de ToM, ils n'y parviendraient pas à un niveau équivalent aux jeunes de leur âge chronologique. Ces résultats sont toutefois à interpréter avec prudence puisque l'étude s'intéressait principalement à démontrer le retard de la ToM des enfants autistes et non celui des enfants présentant un TPL.

De son côté, Miller (2004) a démontré que les enfants sans difficultés langagières âgés de moins de 4 ans réussissaient des tâches de fausses croyances lorsque la complexité langagière était diminuée, alors qu'ils n'y parviennent généralement pas à cet âge. Dans une autre étude, les résultats de Miller (2001) mettent en évidence que la performance des jeunes avec TPL (n = 10; M = 5 ans 6 mois, allant de 4 ans 5 mois à 7 ans 1 mois) est équivalente à celle des jeunes de leur âge chronologique (n = 10; M = 5 ans 6 mois, allant de 4 ans 6 mois à 7 ans 2 mois) lorsque la tâche utilise des termes tels que « montrer » et « regarder » alors que, lorsque les termes utilisés sont « penser » et « prétendre », leur performance est équivalente à celle des enfants plus jeunes (n = 9; M = 3 ans 9 mois) qui ont des habiletés langagières équivalentes. Dans cette étude, les jeunes avec TPL démontrent donc qu'ils sont plus matures que les plus jeunes au niveau de leur capacité à réussir des tâches portant sur la ToM, mais seulement lorsque les habiletés langagières requises ne sont pas trop complexes pour eux. Ces résultats questionnent la validité des outils d'évaluation de la ToM. Comme les méthodes d'évaluation actuelles de la ToM nécessitent des habiletés langagières complexes pour performer adéquatement (Miller, 2004; van Buijsen, Hendriks, Ketelaars, & Verhoeven, 2011), il est à se demander à quel point les tâches de ToM mesurent réellement cette variable indépendamment du niveau d’habiletés langagières du jeune évalué.

Par ailleurs, les études chez les enfants sourds présentées dans l’étude longitudinale d’Astington et Jenkins (1999) démontrent que, malgré une intelligence non-verbale et des habiletés sociales dans les normes, ces enfants échouent fréquemment les tâches de fausses croyances adaptées à leur mode de communication (Gale, de Villiers, de Villiers, & Pyers, 1996; Peterson & Siegal, 1995). Ces résultats viennent renforcer l’idée que le développement du langage jouerait un rôle dans le développement de la ToM étant donné que les enfants sourds présenteraient des particularités dans leur développement langagier.

En somme, l’ensemble de ces résultats, bien que peu nombreux, soulèvent la pertinence de s’intéresser à la relation entre le langage et la ToM pour mieux comprendre ce retard observé au niveau de la ToM chez la clientèle présentant un TPL et ainsi mieux cerner les avenues à explorer chez cette clientèle et les facteurs pouvant influencer la présence ou non d’un retard de la ToM (ex : niveau d’intensité de l’atteinte langagière, composantes langagières atteintes, atteinte réceptive vs. expressive).

Théorie de l’esprit et langage

Afin d’éclaircir cette relation en ToM et langage, Milligan et al. (2007) ont réalisé une méta-analyse portant sur les tâches de fausses croyances qui regroupe 104 études pour un échantillon total de 8 891 jeunes participants. Ces enfants parlaient tous anglais, présentaient un développement langagier et un développement de leur capacité à comprendre les fausses croyances qui s’avéraient normal et étaient âgés de moins de 7 ans. Les études, pour être incluses, devaient avoir administré au minimum une tâche de fausse croyance de premier ordre. Les résultats de la méta-analyse démontrent qu’il existe bel et bien une relation significative entre le développement du langage et de la compréhension des fausses croyances, et ce, indépendamment de l’âge de l’enfant. À cet égard, les habiletés langagières expliqueraient 18% de la variance liée à la performance aux tâches de fausses croyances. En contrôlant la variance liée à l’âge, puisque l’enfant améliore ses habiletés de compréhension des fausses croyances en vieillissant, les habiletés langagières continuent d’expliquer 10% de la variance.

Milligan et al. (2007) soulèvent une importante variabilité de la variance d’une étude à l’autre, le langage expliquant de 0 à 40% de la variance liée à la performance aux tâches de la ToM lorsque l’effet de l’âge est contrôlé et de 0 à 77% lorsque cet effet n’est pas contrôlé. Ces résultats concernant la variance ont amené les chercheurs à se questionner sur les facteurs qui pourraient expliquer cette variabilité. Des analyses statistiques ont permis de démontrer que cela n’était pas dû aux caractéristiques démographiques des participants, ni aux caractéristiques des études telles que la date de parution, la taille de l’échantillon, le nombre de tâches de fausses croyances administrées, etc. Les auteurs se sont donc intéressés aux trois aspects suivants : le type de tâches de fausses croyances administrées, les composantes langagières impliquées et la direction de la relation entre le langage et la ToM.

Type de tâches administrées

D’abord, concernant le type de tâches de fausses croyances, la performance à chaque tâche prise séparément a pu être corrélée avec les habiletés langagières (Milligan et al., 2007). Toutefois, bien que les tâches diffèreraient, entre autres, au niveau de la complexité langagière et de la présence ou non de compléments de phrases, des comparaisons pairées *a posteriori* n’ont fait ressortir aucune différence significative entre les différents types de tâches. Cela signifie que la complexité langagière de la tâche et la présence ou non de compléments de phrases dans la tâche n’influenceraient pas significativement la performance des enfants. Quand on parle de compléments de phrases, c’est majoritairement dans les phrases impliquant les verbes d’états mentaux (penser, savoir, croire, deviner, se rappeler, oublier, espérer, souhaiter, etc.) (Miller, 2001). Par exemple, dans la phrase [Jean pense que [ses souliers sont dans sa chambre]$_c$]$_m$ alors qu’en réalité, ils sont dans le portique, il y a la matrice principale (m) et le complément de phrase (c) imbriqué dans la phrase. La matrice principale peut donc être vraie sans pour autant que le complément de phrase le soit. À cet égard, même si les souliers de Jean ne sont pas dans sa chambre (ils sont dans le portique), il est vrai de dire que ce dernier pense tout de même qu'ils le sont. Cette structure de phrase est souvent utilisée dans les tâches de fausse croyance. Finalement, la méta-analyse a seulement inclus des études avec des tâches verbales. Il serait intéressant, afin de valider cette avenue, de voir si les résultats demeurent les mêmes avec des tâches non-verbales.

Composantes langagières impliquées

Concernant les différentes composantes langagières, les résultats de la méta-analyse démontrent que chaque composante évaluée (langage général sémantique, syntaxe, vocabulaire réceptif, mémoire pour les compléments de phrases) est significativement liée à la compréhension des fausses croyances (Milligan et al., 2007). Plus spécifiquement, le vocabulaire réceptif expliquerait 12% de la variance, la sémantique 23%, le langage général 27%, la syntaxe 29% et la mémoire pour les compléments de phrases 44%. Par contre, comme un faible nombre d'études se retrouve dans les analyses pour chacune des composantes langagières, des comparaisons pairées *a posteriori* ont été réalisées et seuls le vocabulaire réceptif et le langage général ressortent significativement. Les auteurs expliquent ces résultats par le niveau de « pureté » des outils d'évaluation. En effet, dans une tâche de vocabulaire réceptif, seule la compréhension du vocabulaire est nécessaire pour résoudre la tâche. Toutefois, dans les tâches servant à mesurer les autres composantes langagières, bien qu'une habileté y soit principalement ciblée, leur réussite dépend aussi d'autres habiletés. Par exemple, une tâche syntaxique ne dépend pas seulement de la syntaxe, mais également de la sémantique puisque l'enfant doit d'abord comprendre les mots de la phrase (sémantique) pour parvenir à démontrer sa compréhension de la syntaxe dans la tâche (Milligan et al., 2007; Farrar et al., 2009).

Direction de la relation

Finalement, concernant la direction de la relation entre le langage et la ToM, les résultats de la méta-analyse démontrent que la performance d'un jeune lors d'une tâche langagière à un âge donné permet de prédire sa performance à un âge plus avancé lors d'une tâche de la ToM et inversement, ce qui amène les chercheurs à argumenter en faveur d'une relation bidirectionnelle (Milligan et al., 2007). Par contre, il est à noter qu'une différence significative a pu être observée au niveau de l'ampleur de l'effet directionnel, en ce sens que les résultats soutenant que la ToM dépend du langage sont davantage significatifs que ceux soutenant que le langage dépend de la ToM. Le langage viendrait donc jouer un rôle dans le développement de la ToM en procurant à l'enfant les ressources dont il a besoin pour bien se représenter et communiquer sa compréhension de la fausse croyance. Milligan et al. (2007) font toutefois ressortir le contre-argument de Slade et Ruffman (2005) qui émettent qu'un résultat statistiquement significatif peut ne pas l'être cliniquement et aller à l'encontre de fondements théoriques.

La méta-analyse de Milligan et al. (2007) est une avancée dans le domaine de la ToM et du langage, mais elle nous laisse encore avec des interrogations, entre autres parce qu'elle s'intéresse seulement au développement normal du langage et qu'elle ne tient pas compte des troubles langagiers. À cet égard, deux études se sont intéressées à l'apport du langage dans l'évaluation de la ToM avec, pour échantillon, des jeunes présentant un TPL. D'abord, de Villiers, Burns et Pearson (2003) ont démontré, avec un échantillon de 297 enfants présentant un TPL âgés entre 4 et 9 ans, que la compréhension du complément de phrases était le facteur qui permettait le mieux de prédire le degré de performance aux tâches de ToM. Quant à eux, Farrar et al. (2009) ont évalué 34 enfants avec TPL âgés entre 42 et 65 mois au niveau des composantes langagières suivantes : langage grammatical général, vocabulaire réceptif, morphosyntaxe et mémoire pour les compléments. Leurs résultats indiquent que toutes les mesures langagières sont corrélées à la performance aux tâches de ToM. Des analyses de régression ont toutefois permis de constater que seuls le langage général et le vocabulaire réceptif apportaient une contribution unique à la ToM. De plus, en contrôlant le langage grammatical général, la mémoire pour les compléments de phrase n'est plus significativement corrélée avec la ToM. Dans ces deux études, l'âge des participants pourrait être un facteur explicatif de la différence des résultats obtenus, l'étude de Farrar et al. (2009) incluant des enfants âgés de 4-5 ans et l'étude de Villiers et al. (2003), de 4 à 9 ans. Par contre, la recherche en est encore qu'à ses débuts sur le sujet et cette hypothèse basée sur l'âge pourrait ne pas être la seule hypothèse explicative. Afin de mieux orienter les recherches futures, une synthèse critique est nécessaire.

Synthèse critique

Bien que cet article ait démontré certaines avancées au sujet de la ToM chez les jeunes présentant un TPL, beaucoup de travail reste encore à faire. Cette section dressera un portrait critique de la situation afin de mieux orienter les recherches ultérieures sur le sujet.

D'abord, une première critique s'adresse au nombre restreint d'études portant sur le sujet. Parmi ces dernières, très peu présentent un vaste échantillon. Or, dans le cas spécifique du TPL, la grandeur de l'échantillon est importante puisque ce diagnostic renvoie à une multitude de portraits possibles. Bien que tous les jeunes présentent un TPL, cela ne signifie pas pour autant que les mêmes composantes langagières soient atteintes et qu'elles le soient avec la même sévérité. De plus, dans une même composante, les atteintes peuvent être variées. À cet égard, si on prend deux jeunes dont la compréhension est atteinte à un niveau de sévérité équivalent, cela ne signifie pas pour autant qu'ils comprendront les choses de la même façon ou qu'ils commettront les mêmes erreurs, et ce, malgré le fait qu'ils partagent le même diagnostic. Dans cette optique, lors du recrutement d'un échantillon de jeunes avec un TPL, il serait important d'investiguer plus loin que le simple diagnostic et de tenir compte au moins des composantes langagières affectées, des particularités propres à chaque composante et du niveau de sévérité. Ces notions sont d'autant plus importantes dans la mesure où les résultats de la méta-analyse de Wellman et al. (2001) démontrent que chaque composante langagière est reliée de près ou de loin à la ToM.

L'évolution de l'enfant présentant un TPL serait également un facteur intéressant à étudier en lien avec la ToM. Il est connu que certaines composantes langagières sont plus souvent atteintes que d'autres en bas âge et que le profil langagier d'un individu avec un TPL varie au cours de son développement. À cet égard, la sévérité peut se modifier ainsi que les composantes atteintes, l'exigence des compétences langagières augmentant en complexité au cours du développement de l'individu. Par exemple, la pensée critique est davantage sollicitée à l'adolescence qu'en jeune enfance. Il en va de même pour la ToM. Les études sur le sujet démontrent que les jeunes présentant un TPL seraient capables d'une ToM parvenus à un certain âge. Mais jusqu'où sont-ils capables de se rendre en termes de complexité? Car jusqu'à présent, les études ont principalement porté sur la fausse croyance de premier ordre et sur la distinction entre l'apparence et la réalité. Qu'en est-il de la fausse croyance de deuxième ordre? De la compréhension de l'humour complexe et de l'ironie? Et de la résolution de « faux pas »? Il est reconnu que les jeunes avec un TPL comprennent souvent ce qui leur est dit verbalement à un premier degré et qu'ils saisissent difficilement ce qui est implicite, et ce, peu importe leur âge (Kamhi & Clark, 2013). Or, la technique du faux pas, entre autres, nécessite de comprendre ce qui est implicite et subtil dans une situation.

L'évaluation d'habiletés complexes de la ToM chez les jeunes présentant un TPL soulève également un questionnement quant à la validité des tâches utilisées. Si ceux-ci échouent la tâche, serait-ce vraiment dû à une difficulté liée à la ToM? Brièvement, pour réussir une tâche de ToM, il faut d'abord être en mesure de comprendre la complexité langagière de la tâche. À cet égard, Miller (2001, 2004) souligne l'apport significatif du langage, démontrant que les jeunes présentant un TPL seraient capables de réussir des tâches de ToM à un niveau équivalent aux jeunes de leur âge chronologique en situation d'évaluation lorsque la complexité langagière est contrôlée. Par ailleurs, pour réussir, il faut également être capable de se concentrer sur la tâche, de se remémorer tous les éléments fournis (mémoire de travail), et d'inhiber ses propres connaissances d'une situation pour se représenter adéquatement la réalité d'autrui (contrôle de l'inhibition/absence d'impulsivité). Par exemple, dans une tâche de changement de lieu, la mémoire de travail de l'enfant est sollicitée puisqu'il doit parvenir à mémoriser tous les éléments (avant, pendant et après le changement) pour répondre adéquatement à la tâche. Sa capacité d'inhibition cognitive l'est également. En ce sens, il doit être capable d'inhiber la saillance que constitue la réalité. De ce fait, si les fonctions exécutives sont corrélées à la performance aux tâches de fausses croyances (Dennis, Agostino, Roncadin, & Levin, 2009; Duval et al. 2011; Müller, Liebermann-Finestone, Carpendale, Hammond, & Bibok, 2012; Nader-Grosbois & Thirion-Marissiaux, 2011) et que les enfants avec un TPL présentent souvent des difficultés au niveau exécutif (Deneault & Ricard, 2011; Ellemberg, 2012), il n'y aurait donc pas uniquement le langage qui pourrait influencer leur niveau de performance à ces tâches. De là, l'importance des instruments de mesure. Comme le langage et la ToM sont étroitement reliés, il importe de s'assurer que l'outil utilisé mesure correctement le concept de ToM indépendamment des difficultés langagières ou exécutives du sujet. Mais est-ce possible de mesurer la ToM sans faire appel au langage, puisqu'on sait maintenant que ces deux concepts sont fortement corrélés ? Quelles répercussions cette corrélation génère-t-elle chez le jeune présentant un TPL?

Plus globalement, le texte soulève la question à savoir si la ToM, d'un point de vue théorique, constitue un construit unidimensionnel ou, au contraire, s'il s'agit d'un construit pluridimensionnel, et ce, sans égard à la clientèle étudiée. Si la question se pose sur le plan théorique, elle se pose également en regard des outils qui sont utilisés pour mesurer la ToM. La question demeure entière : la ToM est-elle un construit unitaire qui se développe et qui se complexifie avec l'âge? S'agit-il plutôt, à l'image, par exemple, des fonctions exécutives, de sous-composantes ayant leur propre essence et profil de développement? Cette dernière façon de concevoir la ToM pourrait aider à mieux comprendre les résultats parfois contradictoires, ou du moins différents, que l'on observe d'une étude à l'autre. Le présent texte questionne ainsi les généralisations que l'on peut tirer des différentes études et souligne la nécessité de poursuivre la recherche dans ce domaine.

Somme toute, la recherche portant sur la ToM chez la clientèle présentant un TPL mérite d'être poussée davantage, que ce soit en tenant compte du développement de la ToM chez cette clientèle en regard de l'âge, des composantes langagières atteintes et du niveau de sévérité de l'atteinte, car malgré un même diagnostic, les profils qui s'en dégagent sont tous différents les uns des autres. Il serait également important de diversifier les recherches quant aux compétences liées à la ToM. En effet, la majorité des recherches ont porté sur les fausses croyances de premier ordre et la distinction entre l'apparence et la réalité. De plus, aucune étude ne semble avoir été réalisée sur la compréhension de l'ironie, la technique des faux pas, les fausses croyances de deuxième ordre, et d'autres encore. Qu'en est-il du lien entre ToM et langage? Jusqu'à quel point une atteinte aux habiletés langagières peut nuire à l'acquisition d'une ToM? Tous ces éléments constituent plusieurs avenues possibles et méritent une attention particulière lors des recherches ultérieures sur le sujet.

Malgré tout, nonobstant l'issue des travaux futurs, une préoccupation clinique demeure. Dans une situation quotidienne impliquant la ToM, les jeunes présentant un TPL vont continuer de présenter des difficultés, sans que la cause première de ces difficultés en soit nécessairement une liée à la ToM. Les praticiens devront donc être sensibles au contenu verbal par lequel la ToM va s'exprimer puisque, chez les enfants avec un TPL, c'est cette composante qui semble plus sévèrement atteinte, et qui, au final, crée des répercussions significatives dans leur quotidien.

Messages clés de cet article

Parents d'enfants présentant un trouble primaire du langage. La capacité à attribuer et à communiquer des états mentaux à autrui comme à soi-même, ainsi qu'à comprendre ses propres comportements et ceux des autres, sont parties intégrantes de la ToM et reposent en grande partie sur les facultés langagières de l'enfant. La ToM serait primordiale pour préserver l'équilibre psychologique et les capacités d'adaptation sociale de l'enfant tout au long de sa vie. Une meilleure compréhension du développement de cette capacité chez les enfants avec un TPL permettra aux parents un accompagnement plus ajusté aux besoins de l'enfant.

Professionnels. La qualité et l'efficacité des interactions avec autrui est fortement teinté de la façon dont l'individu parvient à se représenter l'autre et à aller au delà des apparences. Bien que l'apport significatif du langage ait été reconnu pour la réussite des tâches de ToM, d'autres habiletés sont également sollicitées telles que les fonctions exécutives. L'équipe d'intervenants doit donc s'assurer d'une évaluation complète de cette capacité et des habiletés qui la sous-tendent afin de fixer des objectifs d'intervention réalistes et susceptibles d'améliorer significativement le fonctionnement du jeune au quotidien.

Décideurs. L'importance de considérer les familles des enfants présentant un trouble neurodéveloppemental à travers l'offre de services en santé et services sociaux est maintenant reconnue. Une meilleure connaissance des caractéristiques influençant le comportement de l'enfant à travers ses relations permettra non seulement d'améliorer l'efficacité des interventions directes auprès de l'enfant mais aussi d'enrichir les contenus des interventions proposées notamment celles de type éducative aux parents que cela soit dans un contexte d'intervention individuelle ou de groupe.

Key Messages From This Article

Parents of children with primary language impairment. The ability to attribute and communicate mental states to others as well as to oneself, and to understand one's own behaviours and those of others, are integral parts of the ToM and rely heavily on the language abilities of the child. The ToM may be essential to preserve the psychological balance and social adaptability of the child throughout life. A better understanding of the development of ToM in children with primary language impairment will allow parents to be more responsive to the needs of the child.

Professionals. The quality and effectiveness of interactions with others is strongly affected by the way in which an individual manages to represent another and to go beyond appearances. Although the significant contribution of language has been recognized for the success of ToM's tasks, other skills are also needed such as executive functions. The team of professionals must therefore ensure a thorough assessment of this capacity and of the underlying skills, in order to set realistic intervention objectives that can significantly improve the functioning of the child on a daily basis.

Policymakers. The importance of considering the families of children with neurodevelopmental disorder through an offer of health and social services is now recognized. A better understanding of the characteristics influencing child behaviour through relationships will not only improve the effectiveness of direct interventions with the child, but will also enrich the content of proposed interventions, especially those of an educational nature for parents which might be provided individually or in groups.

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Appendix

Tableau 1. Synthèse des études portant sur le trouble primaire du langage et la théorie de l’esprit

Études	*n*	*Participants (n)*	*Age M (mois)*	*Tâches*	*Résultats*
Colle, Baron-Cohen & Hill (2007)	42	TPL[1] (15)	99	*ToM*[3]	TPL > TSA (p = 0,001)
		TSA[2] (12)	97	- Changement de lieu sans utilisation du langage	TPL = Contrôles (p = 0,143)
		Contrôles (15)*	54		
		*âge mental contrôlé			
de Villiers et al. (2003)	297	TPL	78	*Langage*	Corrélations entre tests de langage et ToM (r)
			48–108	- DELV[4] :	
				• Communication du rôle et compréhension des actes	Communication du rôle et compréhension des actes : 0,17 (p < 0,01)
				• Compréhension des compléments de phrase	Compréhension des compléments de phrase : 0,18 (p < 0,01)
				• Morphosyntaxe	Morphosyntaxe : 0,16 (p < 0,01)
				• Répétition de non-mots	La compréhension des compléments de phrases a une contribution unique et significative à la ToM.
				ToM	
				- Changement de lieu	
Farrant, Fletcher & Maybery (2006)	40	TPL (20)	62,9	*ToM*	TPL < Contrôles (p < 0,001)
		Contrôles (20)	61,2	- Attribution des désirs	
				- Attribution des croyances	
				- Contenu insolite	
				- Attribution des savoirs	

Tableau 1. Synthèse des études portant sur le trouble primaire du langage et la théorie de l'esprit (a continué)

Études	*n*	*Participants (n)*	*Age M (mois)*	*Tâches*	*Résultats*
Farrar et al. (2009)	34	TPL	56,1	*Langage* - SPELT-III[5]: Grammaire et langage (oral) - Morphosyntaxe (oral) : ex. : utilisation du morphème approprié dans une réponse à une question posée. - Mémoire des structures complémentaires de phrase - PPVT-III[6] : vocabulaire réceptif *ToM* : - Contenu insolite - Changement de lieu - Distinction entre apparence et réalité	Corrélations entre tests de langage et ToM (r) : SPELT- III: 0, 55 ($p < 0,001$) Morphosyntaxe : 0, 48 ($p < 0,05$) Structure complémentaire : 0, 51 ($p < 0,05$) PPVT-III : 0,52 ($p < 0,05$) Le langage général (SPELT-III) et le vocabulaire réceptif (PPVT-III) ont respectivement une contribution unique et significative à la ToM.
Holmes (2001)	92	Groupe 1 (4 à 6 ans)		*Langage*	Tâches de langage
		TPL (23)	64	- WPPSI-R[7] (4 à 6 ans) : Information	Groupe 1 : TPS < Contrôles ($p < 0,001$)
		Contrôles (24)	60	- WISC-III[8] (7 ans+) : Information	Groupe 2 : TPL < Contrôles ($p < 0,001$)
		Groupe 2 (7 ans +)	85	- CELF-P[9] (4 ans à 6 ans) : Concepts	Tâches ToM 1er ordre
		TPL (20)	84	- CELF-III : (7 ans +) : Concepts et Exécution de directives orales	Groupe 1 : TPL < Contrôles ($p < 0,001$)
		Contrôles (25)		*ToM*	Groupe 2 : TPL < Contrôles ($p < 0,001$)
				- Changement de lieu (1er et 2e ordre)	Tâches ToM 2e ordre
				- Contenu insolite (1er ordre)	Groupe 1 : TPL < Contrôles ($p < 0,001$)
				- Sarcasme (1er et 2e ordre)	Groupe 2 : TPL < Contrôles ($p < 0,001$)
				- Non-verbale : prêter une intention appropriée à une séquence d'images	Tâche ToM non-verbale
					Groupe 1 : TPL < Contrôles ($p < 0,001$)
					Groupe 2 : TPL < Contrôles ($p < 0,001$)
Leslie & Firth (1988)	30	TPL (12)	81	*ToM*	TPL > TSA ($p < 0,001$)
		TSA (18)	84	- Attribution des savoirs	
				- Changement de lieu	

Tableau 1. Synthèse des études portant sur le trouble primaire du langage et la théorie de l'esprit (a continué)

Études	*n*	*Participants (n)*	*Age M (mois)*	*Tâches*	*Résultats*
Miller (2001)	29	TPL (10) Contrôles 1 même âge chronologique que TPL (10) Contrôles 2 même âge verbal que TPL (9)	66 66 45	*ToM* - Changement de lieu avec le terme « penser » - Changement de lieu avec le terme « regarder » - Changement de lieu avec le terme « montrer » - Changement de lieu avec le terme « prétendre »	Tâche « Penser » TPL < Contrôles 1 (p < 0,01) Tâche « Prétendre » : TPL < Contrôles 1 (p < 0,02) Tâche « Regarder » TPL > Contrôles 2 (p < 0,05) Tâche « Montrer » TPL > Contrôles 2 (p < 0,02)
Miller (2004)	45	TPL (15) Contrôles 1 même âge chronologique (15) Contrôles 2 même âge verbal (15)	59 60 44	*ToM* - Changement de lieu avec le terme « penser » - Changement de lieu avec le terme « montrer » - Changement de lieu avec le terme « prétendre » - Changement de lieu sans utilisation du langage	Tâche « Penser » TPL = Contrôles 1 (p > 0,15) Tâche « Montrer » TPL = Contrôles 1 (p > 0,07) TPL > Contrôles 2 (p = 0,08) Tâche « Penser » TPL = Contrôles 2 (p > 0,12)
Perner et al. (1989)	38	TPL (12) TSA (26)	104 162	*ToM* - Contenu insolite	TPL > TSA (p < 0,001)
Ziatas, Durkin & Pratt (1998)	48	Groupe 1 : Même âge chronologique TPL (12) Contrôles (12) Groupe 2 : Même âge verbal TPL (12) Contrôles (12)	 83 77 98 68	*ToM* - Changement de lieu - Contenu insolite	Tâche changement de lieu Groupe 2 : TPL = Contrôles Tâche contenu insolite Groupe 2 : TPL = Contrôles

[1]*TPL : Trouble primaire du langage;* [2]*TSA : Trouble du spectre de l'autisme;* [3]*ToM : Theory of mind (Théorie de l'esprit);* [4]*Diagnostic Evaluation of Language Variation;* [5]*The Structured Photographic Expressive Language Test – Third Edition; 6 Peabody Picture Vocabulary Test – III ; 7Wechsler Preschool and Primary Scale of Intelligence – Revised ; 8Wechsler Intelligence Scale for Children- III; 9British Picture Vocabulary Scale*

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L'importance d'une évaluation intellectuelle des enfants présentant un trouble du spectre de l'autisme afin de bonifier leurs interventions

Résumé

Le présent article expose l'hétérogénéité des profils intellectuels que présentent les enfants ayant un trouble du spectre de l'autisme (TSA) et mentionne la pertinence de réaliser une évaluation cognitive ou développementale, et ce, particulièrement lorsque l'enfant effectue le passage vers la maternelle. Cette évaluation peut aider à cibler le type de classement scolaire, mais surtout à préciser les outils d'intervention complémentaires à l'enseignement. Quarante-trois protocoles d'évaluation d'enfants ayant un TSA ont été étudiés. Des forces et des faiblesses ont été notées et des outils d'intervention sont suggérés.

Relevance of Intellectual Assessments to Improve Intervention Planning for Children With Austism Spectrum Disorder

Abstract

This article discusses the diversity of intellectual profiles associated with autism spectrum disorder (ASD) and the relevance of performing a cognitive or developmental assessment. This issue appears even more important when a child with ASD is entering kindergarten. This evaluation can be beneficial as it can facilitate students' placement as well as identify teaching strategies tailored to their specific needs. Forty three assessment forms of children with ASD were examined. Strengths and weaknesses were noted and interventions tools are recommended.

Trouble du spectre de l'autisme

Le trouble du spectre de l'autisme (TSA) représente une pathologie neurodéveloppementale ayant un taux de prévalence élevé, soit un enfant sur 94 au Canada selon des données récentes (Ouellette-Kuntz, 2012). La dernière version du *Manuel diagnostique et statistique des troubles mentaux* (DSM-5, American Psychiatric Association [APA], 2015) caractérise ce trouble par une altération de deux sphères du développement, soit les habiletés de communication sociale ainsi que le caractère restreint, stéréotypé et répétitif des intérêts, des activités et/ou des comportements. Les symptômes observés dans ces deux sphères doivent se manifester en bas âge. À cet effet, Coo et ses collaborateurs (2012) indiquent dans leur étude menée dans cinq provinces canadiennes (Colombie-Britannique, Alberta, Ontario, Ile-du-Prince-Édouard et Terre-Neuve) et réalisée auprès de 2100 enfants ayant un TSA, que le diagnostic s'obtient généralement vers quatre ans. Les symptômes du trouble doivent également limiter de façon significative le fonctionnement global de l'enfant lors des activités quotidiennes (APA, 2015). Trois niveaux de sévérité s'ajoutent dans la nouvelle édition du DSM pour permettre de préciser le diagnostic relativement au niveau développemental et à l'âge chronologique de l'enfant (Lord & Bishop, 2010). Par ailleurs, le professionnel émettant le diagnostic de TSA doit maintenant se prononcer sur l'absence ou la présence d'une déficience intellectuelle (DI) ou toute autre condition médicale associée (APA, 2015).

Habiletés de communication sociale. Tous les symptômes de la sphère de la communication sociale doivent être présents, soit une difficulté à développer et à maintenir des relations sociales selon le niveau de développement de l'enfant, une altération des comportements de communication non verbale dans un contexte social et un déficit dans la réciprocité socioémotionnelle. Ces comportements peuvent s'exprimer de diverses façons, par exemple par un discours répétitif dénué de sens ou sans intention de communication (Barbaro & Dissanayake, 2012), par un échange social déficitaire lors de jeux symboliques, par une difficulté à s'ajuster au contexte et à son environnement, par l'utilisation de gestes effectués sans but de partage ou de demande d'aide jusqu'à l'absence de gestes descriptifs, conventionnels et/ou instrumentaux (Barbaro & Dissanayake, 2012), par un contact visuel peu fréquent, voire même absent, ou par une faible compréhension des expressions d'autrui (Rogers & Dawson, 2010).

Caractère restreint, stéréotypé et répétitif des intérêts, des activités et des comportements. Concernant le caractère restreint, stéréotypé et répétitifs des intérêts, des activités et des comportements, deux symptômes ou plus doivent être présents dans les comportements quotidiens de l'enfant pour pouvoir se questionner sur la présence d'un TSA. Ces derniers peuvent être observés, par un discours ou des mouvements répétitifs ou stéréotypés, par une adhérence inflexible aux routines, par des patrons verbaux ou non verbaux ritualisés, par une résistance au changement et par une rigidité de la pensée. De plus, certains enfants ont des jeux symboliques absents ou altérés ne correspondant pas à leur âge chronologique (Wing, Gould, & Gillberg, 2011) ou ces derniers orientent leur intérêt vers un objet ou une catégorie d'objet, souvent lors d'activités répétitives. Ces activités répétitives concernent aussi le corps, telles que des balancements corporels, des postures atypiques ou des mouvements des mains et des bras. Un nouveau critère ajouté dans le DSM-5 constitue la présence d'une hypo- ou d'une hyper-réactivité aux stimulations sensorielles de l'environnement (What is the best estimate of the prevalence of Autism Spectrum Disorder in Canada?, 2013).

Il importe de mentionner que les déficits sur le plan de la communication sociale et la présence de patrons de comportements, d'activités et d'intérêts restreints, stéréotypés et répétitifs peuvent porter entrave au bon développement de l'enfant, et ce, dans plusieurs sphères. Ainsi, les habiletés cognitives, langagières et motrices peuvent être limitées, ce qui peut générer des effets importants sur la capacité de l'enfant à s'adapter et à accomplir indépendamment des tâches de la vie quotidienne.

Niveaux de sévérité. En lien avec ce qui précède, les caractéristiques diagnostiques du trouble se présentent de manière diverse. Les profils développementaux distincts teintent également la manifestation du trouble. Trois niveaux de sévérité s'ajoutent dans la nouvelle édition du DSM pour qualifier le soutien associé aux besoins des enfants ayant un TSA afin qu'ils puissent fonctionner dans les divers milieux qu'ils fréquentent.

Ainsi, le niveau un (le niveau léger) identifie les enfants ayant un TSA qui « requièrent du soutien ». Sans ce soutien, des déficits sur le plan de la communication sociale amènent des difficultés notables, telles que des lacunes à initier des interactions sociales ou à émettre des réponses typiques si un autre enfant tente d'interagir avec lui. En effet, l'enfant est en mesure d'utiliser des phrases complètes et d'engager la communication, mais la conversation se voit souvent comme étant unidirectionnelle, ainsi ses efforts pour créer des liens d'amitié sont souvent voués à l'échec. Sur le plan des comportements restreints et stéréotypés, l'inflexibilité des comportements amène des interférences significatives quant au fonctionnement, et ce, dans un ou plusieurs contextes tels que le milieu familial, de garde ou scolaire et brime, par le fait même, le développement de l'autonomie.

Le niveau deux (le niveau moyen) mentionne que les enfants « requièrent un soutien substantiel » pour être fonctionnels. Ces enfants ont des déficits sur le plan de leurs habiletés verbales et non verbales. Leurs initiatives sociales sont limitées et leurs réponses sociales sont réduites ou anormales. À titre d'exemple, un enfant pourra répondre que par quelques mots à la question d'un pair ou d'un adulte. Il initiera peu la conversation si ce n'est que pour satisfaire ses besoins ou obtenir de l'information en lien avec ses intérêts spéciaux et limités. Une inflexibilité du comportement est présente ainsi que des difficultés à s'adapter aux changements.

Le niveau trois (le niveau sévère) correspond à un besoin de « soutien très substantiel » afin que l'enfant ayant un TSA puisse fonctionner au quotidien. Ainsi, un enfant peut être non verbal ou encore communiquer avec des mots isolés qui n'ont pas toujours la signification juste. Les habiletés sociales de ces enfants sont très limitées, associés à cela, les enfants montrent une inflexibilité sur le plan de leurs comportements et présentent des difficultés extrêmes à s'adapter lors des changements. Leurs comportements restreints et stéréotypés interfèrent de façon marquée dans toutes les sphères de leur vie. Le Tableau 1 décrit l'intensité des symptômes qui définissent les niveaux de soutien par domaines observés.

Fonctionnement intellectuel

Afin de cibler le niveau de sévérité de l'enfant en regard des deux sphères de symptômes centraux, il est essentiel que le professionnel effectue une évaluation globale des besoins de l'enfant. Une évaluation adéquate des capacités intellectuelles s'avère essentielle pour finaliser la démarche d'évaluation diagnostique et pour statuer sur l'absence ou la présence d'une DI (APA, 2015; Collège des médecins du Québec [CMQ] et Ordre des psychologues du Québec [OPQ], 2012). Une recension réalisée par Fombonne (2003) rapporte que 70 % des personnes ayant un TSA présente aussi une déficience intellectuelle. Toutefois, deux autres études indiquent un taux avoisinant 55 % (Baird et al., 2006; Charman et al., 2011), alors que des données plus récentes du *Centres for Disease Control and Prevention* (CDC) (2008; 2010) estime la prévalence de DI comorbide à l'autisme à 30 %.

De plus, il est recommandé de procéder à une réévaluation au cours de la période développementale, puisque le QI des enfants ayant un TSA peut fluctuer (APA, 2015). Au-delà du diagnostic de DI, cette évaluation apporte des indices importants sur la façon dont l'enfant apprend et se comporte et elle permet la mise en place d'interventions adaptées au potentiel de l'enfant (Courchesne, Nader, Girard, Bouchard, Danis, & Soulières, 2016). La description du profil cognitif et des observations comportementales issues de l'évaluation contribue à une meilleure compréhension de l'enfant et a pour conséquence des interventions mieux adaptées à son fonctionnement et un classement scolaire adéquat. De plus, les résultats servent à l'élaboration de recommandations bénéfiques pour l'ensemble des intervenants travaillant auprès de cet enfant ainsi qu'aux fins du classement scolaire.

Toutefois, l'évaluation du fonctionnement intellectuel d'un enfant peut être complexe en raison de l'absence de langage, de problèmes de communication ou de la présence de comportements problématiques inhérents à son trouble. Un enfant peut donc avoir de la difficulté à comprendre ce qui est attendu de lui ou il peut refuser de se soumettre aux exigences. Ainsi, le choix de l'instrument approprié pour l'évaluation est très important, car celui-ci devra considérer les caractéristiques de l'enfant et répondre à ses besoins de soutien afin d'optimiser sa performance.

Outils d'évaluation

De nombreux outils psychométriques sont utilisés en milieu clinique pour préciser dans un premier temps, le fonctionnement cognitif de l'enfant puis, pour préciser les principales forces et faiblesses de celui-ci. Alors que certaines épreuves standardisées sont administrées à la population générale, d'autres sont employées spécifiquement auprès de populations ayant des besoins particuliers.

Échelle d'intelligence de Wechsler pour la période préscolaire et primaire (*Weschler Preschool and Primary Scale of Intelligence* [WPPSI]). Dans le cadre de l'évaluation des compétences intellectuelles d'un enfant présentant un TSA de niveau léger, l'Échelle d'intelligence de Wechsler *pour la* période préscolaire et primaire *(WPPSI)* qui mesure les habiletés cognitives des enfants âgés de plus de deux ans devrait être priorisée. L'outil permet de fournir

Tableau 1. Niveaux de sévérité du trouble du spectre de l'autisme

Niveau de sévérité du TSA	*Communication sociale*	*Comportements restreints, répétitifs*
Niveau 1 Requiert un soutien	Sans aide, les déficits de la communication sociale sont source d'un retentissement fonctionnel observable. Difficulté à initier les relations sociales et exemples manifestes de réponses atypiques ou inefficaces en réponse aux initiatives sociales émanant d'autrui. Peut sembler avoir peu d'intérêt pour les interactions sociales	Le manque de flexibilité du comportement a un retentissement significatif sur le fonctionnement dans un ou plusieurs contextes. Difficulté à passer d'une activité à l'autre. Des problèmes d'organisation ou de planification gênent le développement de l'autonomie.
Niveau 2 Requiert un soutien substantiel	Déficits marqués des compétences de communication verbale et non verbale; retentissement social apparent en dépit des aides apportées; capacité limitée à initier des relations et réponse réduite ou anormale aux initiatives sociales émanant d'autrui.	Le manque de flexibilité du comportement, la difficulté à tolérer le changement ou d'autres comportements restreints/répétitifs fréquents sont assez fréquents pour être évidents pour l'observateur non averti et retentir sur le fonctionnement dans une variété de contextes. Détresse importante/difficulté à faire varier l'objet de l'attention ou de l'action
Niveau 3 Requiert un soutien **très substantiel**	Déficits graves des compétences de communication verbale et non verbale responsables d'un retentissement sévère sur le fonctionnement; limitation très sévère de la capacité d'initier des relations et réponse minime aux initiatives sociales émanant d'autrui.	Comportement inflexible, difficulté extrême à faire face au changement, ou autres comportements restreints ou répétitifs interférant de façon marquée avec le fonctionnement dans l'ensemble des domaines. Détresse importante/ difficulté à faire varier l'objet de l'attention ou de l'action.

Version francophone du DSM-5 (2016)

un QI afin de situer l'enfant par rapport aux enfants du même âge. Il précise également les forces et les faiblesses en lien avec les habiletés verbales et non verbales, la vitesse de traitement de l'information et l'acquisition générale du langage (Weschler, 2002).

Leiter International Performance Scale-R. La version révisée du *Leiter International Performance Scale* est une évaluation cognitive permettant de fournir un QI non verbal pour les personnes âgées de deux à 21 ans. Il mesure les compétences des enfants ayant des habiletés langagières limitées, autant sur le plan de l'expression que de la compréhension (Roid & Miller, 2002). Cet outil mesure le raisonnement, la visualisation et l'organisation visuospatiale et est à considérer dans l'évaluation cognitive d'un enfant présentant un TSA ayant un niveau de sévérité moyen ou sévère.

Profil psychoéducatif, version revisée (PEP-R). Le *Profil psychoéducatif* n'est pas un outil évaluant le fonctionnement cognitif. Il est créé pour mesurer les sphères de développement et les comportements de l'enfant présentant un TSA âgé de six mois à sept ans ayant une atteinte importante sur le plan cognitif. Les sphères évaluées sont (a) l'imitation, (b) la perception, (c) la motricité fine, (d) la motricité globale, (e) la coordination oculo-manuelle, (f) la performance cognitive et (g) la cognition verbale (Schopler, Reichler, Bashford, Lansing, & Marcus, 1990).

Profils cognitifs

Le profil obtenu lors d'une évaluation cognitive permet de faire ressortir des forces et des faiblesses généralement inhérentes au TSA. Ainsi, Dawson (1996) démontre que les enfants présentant ce trouble peuvent préconiser une approche séquentielle du traitement de l'information, faisant en sorte qu'ils éprouvent davantage de difficulté avec les tâches d'abstraction verbale et non verbale. Cela fait en sorte qu'ils peuvent montrer de la difficulté à utiliser des stratégies pour faciliter l'encodage des informations complexes, par exemple, par la création de regroupements sémantiques, et qu'ils ont du mal à effectuer des liens entre deux items, tel que perçu lors des sous-tests *Similitudes*, *Concepts en images* et *Raisonnement de mots* du WPPSI. Au contraire, la répétition de l'apprentissage leur permet de mieux performer (Crockett, Fleming, Doepke, & Stevens, 2007).

Sur le plan attentionnel, il est remarqué que les enfants présentant un TSA ont plus de difficulté à désengager leur attention d'un stimulus, affectant ainsi leur score aux tâches sollicitant leur attention sélective et divisée (Kenworthy et al., 2005). Les déficits les plus fréquemment observés chez cette clientèle sont en lien avec les fonctions exécutives, plus précisément avec la planification, l'organisation et la flexibilité cognitive, ce qui peut s'expliquer en partie par leur rigidité (Kenworthy et al., 2005) et ainsi avoir un impact important sur leur autonomie quotidienne. À ce tableau clinique parsemé de faiblesses, il ressort que les tâches d'organisation visuospatiale et visuoconstructive sont mieux réussies par cette clientèle (Nader, Jelenic, & Soulières, 2015), ce qui peut être perçu lors des sous-tests *Blocs* du *WPPSI* ou *Form Completion* du *Leiter-R*.

Objectifs

Dans un premier temps, l'étude vise à décrire les forces et les faiblesses pouvant émerger d'une évaluation cognitive ou développementale réalisée auprès d'enfants présentant un TSA s'apprêtant à débuter leur scolarisation. Dans un deuxième temps, cette étude a pour but d'outiller les intervenants du milieu scolaire en leur proposant des interventions répondant aux besoins spécifiques et favorisant les apprentissages et le fonctionnement de leurs élèves.

Méthode

Les données de cette étude rétrospective sont issues d'évaluations effectuées par une psychologue exerçant en clinique privée. Le motif de consultation était de procéder à une évaluation du fonctionnement cognitif afin de planifier la transition vers le milieu scolaire.

Les protocoles d'évaluation ciblés sont ceux d'enfants d'âge préscolaire présentant un TSA sans trouble associé connu au moment de l'évaluation. Les protocoles d'évaluation de 43 enfants présentant un TSA (35 garçons et huit filles, $M_{\text{âge}}$ = 57,41 mois, ÉT = 10,04, Tranche d'âge : 27–71 mois) ont été examinés, soit 14 protocoles de la troisième version de *l'Échelle d'intelligence de Wechsler pour la période préscolaire et scolaire* (Wechsler, 2002) d'enfants présentant un diagnostic de TSA léger, 16 protocoles de la version révisée du *Leiter International Performance Scale* (Roid & Miller, 2002) d'enfants ayant un diagnostic de TSA moyen et 13 protocoles de la version révisée *du Profil psychoéducatif* (Schopler et al., 1990) d'enfants ayant un TSA de niveau sévère. Ces trois outils d'évaluation, qui figurent parmi ceux étant les plus souvent utilisés en clinique pour mesurer le fonctionnement cognitif ou développemental, ont été administrés en fonction de l'âge chronologique de l'enfant, de son niveau langagier et selon le jugement clinique de la professionnelle en évaluation.

Les scores des sous-tests de chaque évaluation ont été compilés. La moyenne des scores d'équivalence, les écarts-types et l'étendue des scores ont été calculés. La moyenne obtenue pour chacun des instruments révèle deux sphères montrant des forces et deux sphères présentant des faiblesses. Des activités sont suggérées pour permettre la généralisation des acquis perçus ou pour développer les domaines déficitaires afin de faciliter la transition et d'outiller les intervenants du milieu scolaire.

Résultats

Forces et faiblesses

La section ci-dessous présente deux forces et deux faiblesses relevées à la suite du calcul de la moyenne des scores d'équivalence pour chacun des outils standardisés utilisés auprès des enfants de l'étude.

Échelle d'intelligence de Wechsler pour la période préscolaire et primaire, troisième édition (WPPSI-III)

La moyenne des scores d'équivalence aux sous-tests du WPPSI-III révèle deux forces, soit une au sous-test *Blocs*, où l'enfant doit reproduire des modèles à l'aide de cubes de couleurs, et une au sous-test *Concepts en images*, où l'enfant doit pointer deux ou trois dessins en fonction de leur catégorie. Deux faiblesses sont observées; une au sous-test *Connaissances* qui évalue le niveau d'information et le bagage culturel de l'enfant et une au sous-test *Vocabulaire*, où l'enfant doit définir le mot lu à voix haute par l'évaluatrice. Le Tableau 2 rapporte les scores moyens, les écarts-types et l'étendue des scores obtenus.

Leiter International Performance Scale-R

La moyenne des scores d'équivalence aux sous-tests du *Leiter-R* permet de décrire le profil des enfants évalués en identifiant les sous-tests les mieux et les moins bien réussis. Les résultats révèlent ainsi des forces au sous-test *Associations* et au sous-test *Assemblage de formes* et des faiblesses aux sous-tests *Ordre séquentiel* et *Répétitions de patrons.* Le Tableau 3 mentionne les scores moyens, les écarts-types et l'étendue des scores observés.

Tableau 2. Les scores moyens, les écarts-types et l'étendue des scores obtenus aux sous-tests du WPPSI-III

	Moyenne des scores d'équivalence	*Écarts-types*	*Étendue des scores*
Connaissances	7,08	4,72	3–16
Vocabulaire	6,27	2,90	4–13
Vocabulaire réceptif	8,31	3,81	4–16
Identification d'images	9,54	3,47	5–19
Blocs	11,00	5,04	4–17
Matrices	9,86	6,26	2–17
Concepts en images	11,33	7,55	5–19
Images à compléter	8,13	4,40	2–16
Assemblage d'objets	9,75	3,77	4–17

Tableau 3. Les scores moyens, les écarts-types et l'étendue des scores obtenus aux sous-tests du Leiter-R

Sous-tests	*Moyenne des scores d'équivalence*	*Écarts-types*	*Étendue des scores*
Repérage figure-fond	8,75	3,78	4–15
Assemblage de formes	10,31	3,18	3–17
Associations	12,13	2,66	6–16
Ordre séquentiel	7,82	3,06	1–12
Répétitions de patrons	7,88	4,26	2–16
Images en contexte	9,33	5,25	1–19
Classification	8,66	3,66	2–14

Profil psychoéducatif (PEP-R)

La moyenne des scores d'équivalence obtenus aux sous-tests du *PEP-R* permet de comparer et de souligner les forces ainsi que les faiblesses des enfants à cette évaluation. Des forces aux sous-tests *Perception* et *Motricité globale* et des faiblesses aux sous-tests *Performance cognitive* et *Cognition verbale* sont observées. Le Tableau 4 rapporte les scores moyens, les écarts-types et l'étendue des scores obtenus aux sous-tests.

Recommandations

Les résultats obtenus aux trois outils d'évaluation standardisés ont permis de cibler les habiletés les plus développées et celles à promouvoir dans cet échantillon. La présente section vise à proposer des interventions, sous forme de jeux pouvant être réalisées auprès des enfants présentant un TSA afin de permettre le développement et l'amélioration de diverses habiletés.

Tableau 4. Les scores moyens, les écarts-types et l'étendue des scores obtenus aux sous-tests du PEP-3

Sous-tests	*Moyenne des scores d'équivalence*	*Écarts-types*	*Étendue des scores*
Imitation	7,27	4,15	1–14
Perception	11	2,32	5–13
Motricité fine	9,13	2,20	5–13
Motricité globale	12,87	3,80	7–18
Coordination oculo-manuelle	6,73	2,61	3–11
Performance cognitive	6,53	5,66	1–18
Cognition verbale	3,67	4,32	0–14

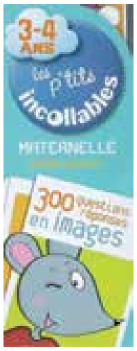
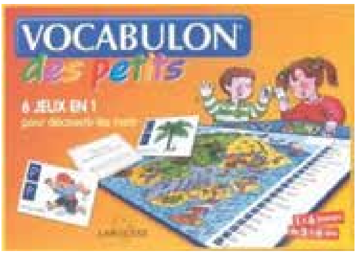
Tableau 5. Les activités suggérées pour généraliser les compétences liées aux modèles de blocs

Briques et fiches Éditions : LEGO®	Atelier Triolo Éditions : Breault & Bouthillier	Camelot Jr. Éditions : Smart Game
		
L'enfant doit, à l'aide de pièces de plastique, copier la forme illustrée sur une image.	À l'aide de ce jeu, l'enfant reproduit des modèles à l'aide de chevilles de différentes couleurs et de formes.	En suivant les indications illustrées dans un livret, l'enfant reproduit des modèles de châteaux et de ponts à l'aide de pièces de bois.

Tableau 6. Les activités suggérées pour généraliser les compétences liées aux concepts en images

Au royaume des catégories Éditions : Breault & Bouthillier	Bloc Complète l'image Éditions : Melissa & Doug	KiouKoi Jeu de tri-Les animaux Éditions : Breault & Bouthillier
		
L'enfant doit réunir le plus de familles de catégories à l'aide des images.	Bloc de 48 pages de papier à dessin comportant un début d'illustration. L'enfant doit compléter le dessin avec un objet d'une même catégorie.	L'enfant doit associer les images qui vont ensemble, tels que la perruche avec le goéland et le papillon

Tableau 7. Les activités suggérées pour pallier les difficultés en lien avec les connaissances générales.

Les Incollables Éditions: Play Bac	Mont à mots mini Éditions: Ludik Québec	Vocabulon des petits Éditions: Larousse
		
Des questions de connaissances générales sont posées à l'enfant et celui-ci doit y répondre à l'aide d'images.	Des devinettes sont posées à l'enfant. Si celui-ci répond correctement, il avance d'une case pour se rendre au sommet du mont.	Des devinettes sont posées à l'enfant et celui-ci doit y répondre en s'aidant des items d'une illustration.

Organisation visuoconstructive

Cette compétence peut être généralisée avec des jeux de construction tels que les « Ateliers Triolo », « Camelot Jr. » ou encore des modèles de « LEGO® ». Le Tableau 5 illustre ces jeux et rapporte une brève description de ceux-ci.

Habiletés de conceptualisation

Les jeux « Au royaume des catégories », « Bloc Complète l'image » et « Who's Hiding? » sont suggérés afin de favoriser la généralisation des habiletés de conceptualisation. Le Tableau 6 rapporte ces jeux ainsi qu'une description de ceux-ci.

Tableau 8. Les activités suggérées pour pallier les difficultés en lien avec le vocabulaire

Bingo des devinettes Éditions: Passe-Temps	Fais-moi une devinette Éditions: Placote	Tekitoua Éditions: Janod
		
L'enfant décrit les images qu'il voit afin que l'adulte puisse la repérer sur sa fiche de Bingo.	Ce jeu aide les enfants à formuler une devinette à l'aide de 5 dés-indices.	L'enfant doit poser des questions pour découvrir l'animal de son adversaire.

Tableau 9. Les activités suggérées pour généraliser les compétences liées aux associations

La fête des animaux Éditions : Breault & Bouthillier	Éducartes les métiers Éditions : Nathan	Puzzle Duo Éditions : Djeco
		
L'enfant lance le dé des animaux et le dé des couleurs et doit associer le bon animal avec la bonne couleur.	L'enfant associe ici un objet correspondant au métier, tel que la perceuse avec le menuisier.	L'enfant associe les animaux à leur habitat.

Connaissances

Pour pallier les faiblesses observées aux sous-tests des connaissances générales, les jeux suivants sont recommandés : « Les Incollables », « Mont à mots mini » et « Vocabulon des petits ». Ces derniers sont présentés au Tableau 7.

Vocabulaire

Pour aider l'enfant à définir et à expliquer les mots de son environnement, les jeux tels que le « Bingo des devinettes », « Devine à quoi je pense » et « Devine Tête » sont recommandés et présentés au Tableau 8.

Associations

Afin de généraliser la compétence liée aux associations, les jeux « La fête des animaux », « Associons les métiers » et « La soupe aux lettres » sont suggérés. Le Tableau 9 rapporte ces jeux ainsi que les indications pour y jouer.

Assemblage de formes

Ainsi pour bonifier et renforcer les acquis à l'assemblage de formes, différents jeux sont proposés. Le Tableau 10 comprend les jeux « Magnetico », « Formes » et « Architek » ainsi que leurs descriptions.

Tableau 10. Les activités suggérées pour généraliser les compétences liées aux formes à assembler

Genii Creation Éditions: Breault & Bouthillier	Coffret Géoformes Éditions: Breault & Bouthillier	Architek Éditions: Chenelière
		
L’enfant doit assembler des pièces pour faire différents modèles d’animaux.	L’enfant assemble des formes sur un canevas ayant des indices visuels.	L’enfant assemble des pièces sur des canevas ayant ou non des indices visuels.

Tableau 11. Les activités suggérées pour pallier les difficultés à placer en ordre

Bata-Waf Éditions : Djeco	Puzzle petits et grands Éditions : Djecoo	Atelier Séquences-Photos Éditions : Breault & Bouthillier
		
L’enfant place en ordre de grandeur les chiens illustrés.	L’enfant doit associer en fonction de l’image et la taille.	L’enfant place les images pour en faire une histoire logique.

Ordre séquentiel

Pour aider l’enfant à mettre en ordre divers éléments, les jeux « Bata-Waf », « Puzzle Logique-Taille » et l’« Atelier Séquences-photos » sont proposés et expliqués au Tableau 11.

Logique

Afin de pallier les difficultés à produire des suites logiques, il est suggéré de se procurer le « Coffret de pêche », le jeu « Ritmo » ou les « Brochettes de perles ». Le Tableau 12 illustre ces jeux et explique comment y jouer.

Perception visuelle

Les activités évaluées pour la sphère de la perception, concerne la réussite lors de casse-tête à encastrement, d’assemblage de pièces de puzzle et l’association d’objet à leur image. Les jeux « Magnetic’s », « Little Association » et « Tactilo Loto ferme » sont recommandés afin de généraliser cette habileté. Le Tableau 13 rapporte ces jeux ainsi que les indications pour y jouer.

Motricité globale

Pour bonifier les acquis sur le plan de la motricité globale, différents jeux sont proposés. Le Tableau 14 comprend un jeu de quilles, d’anneaux à lancer et un jeu de croquet.

Tableau 12. Les activités suggérées pour pallier les difficultés à faire des suites logiques

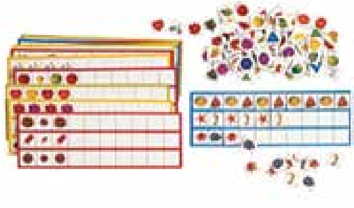
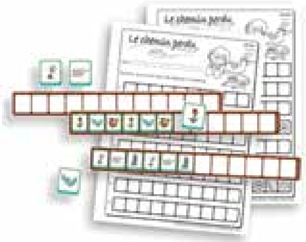
Coffret de pêche Éditions : Breault & Bouthillier	Ritmo Éditions : Brault & Bouthillier	Le chemin perdu Éditions : Passe-Temps
		
L'enfant place des objets selon une suite logique.	L'enfant poursuit la suite logique déjà indiquée à l'aide d'images.	L'enfant place des images selon un ordre pré-établi. Il peut également les dessiner.

Tableau 13. Les activités suggérées pour généraliser les compétences liées à la perception

Magnetic's Éditions : Djeco	Little Association Éditions : Djeco	Tactilo Loto ferme Éditions : Djeco
		
L'enfant doit placer des pièces pour reproduire des personnages.	L'enfant doit associer des objets à leur image puis des objets à leur contexte.	L'enfant doit associer des objets à leur image et selon leur catégorie.

Tableau 14. Les activités suggérées pour généraliser les compétences sur le plan de la motricité globale

Jeu de quilles en mousse Éditions : Brault & Bouthillier	Lancer d'anneaux en mousse Éditions : Brault & Bouthillier	Jeu de croquet Éditions : Louna
		
L'enfant doit rouler la balle vers les quilles pour les faire tomber.	L'enfant doit lancer les anneaux pour les faire accrocher aux piquets.	L'enfant doit faire passer la balle sous l'animal à l'aide d'un bâton.

Tableau 15. Les activités suggérées pour bonifier le vocabulaire réceptif et expressif

Boîte d'objets Éditions : Funny Home	Lotto Photo Éditions : Diset	Dé des premiers mots Éditions : Placote
		
L'enfant doit identifier et nommer les objets de la boîte.	L'enfant doit identifier et nommer les objets familiers.	L'enfant doit identifier et nommer les images insérer dans les pochettes du dé.

Performance cognitive

Pour pallier les difficultés concernant la performance cognitive, soit le langage réceptif et la cognition verbale, ainsi que le langage expressif, des objets et des cartes éclairs sont suggérés pour développer la compréhension et l'identification des mots. Le Tableau 15 illustre ces jeux et explique comment aider l'enfant à bonifier son vocabulaire.

Discussion

Le présent article décrit les forces et les faiblesses émergeant d'évaluations effectuées auprès d'enfants présentant un TSA préalablement à leur entrée scolaire. Les forces présentées peuvent servir de levier afin de promouvoir le développement des sphères déficitaires de l'enfant. À la lumière de ces résultats, des activités pouvant être réalisées en classe sont proposées pour bonifier l'enseignement et les modalités permettant aux enfants présentant un TSA, peu importe le niveau de sévérité, de plus facilement apprendre et de généraliser les acquis.

Les résultats obtenus aux sous-tests *Blocs* du *WPPSI-III* et *Form Completion* du *Leiter-R* confirment les propos de chercheurs indiquant une force sur le plan des habiletés d'organisation visuospatiale et visuoconstructive ainsi qu'un intérêt pour la copie de modèles (Mottron, Soulières, Ménard, & Dawson, 2005). Bien que certains auteurs (Gastgeb, Strauss, & Minshew, 2006) suggèrent que le sous-test *Concepts en images* du *WPPSI-III* puisse constituer un défi pour cette clientèle en raison des difficultés de conceptualisation généralement observées chez les enfants ayant un TSA, les scores se révèlent plutôt élevés chez les participants de l'étude. Cette divergence peut en partie être expliquée par le jeune âge de ces derniers et, par conséquent, la mesure d'items dont le niveau de difficulté est plus faible. La tâche *d'Associations* du *Leiter-R* constitue une force pour les enfants de l'étude. Plusieurs raisons peuvent contribuer à ce résultat. D'abord, elle sollicite les habiletés visuospatiales, elle ne requiert pas d'habiletés langagières et elle présente une propriété renforçante (Preissler, 2008). Ensuite, les écrits scientifiques révèlent que les enfants présentant un TSA vont généralement échouer la tâche demandant un assemblage de formes, puisque ces derniers ont des difficultés à visualiser les contenus abstraits (Van der Smagt, Van Engeland, & Kemner, 2007). Les scores obtenus vont donc à l'encontre de cette affirmation. En regard du sous-test *Ordre Séquentiel* du *Leiter-R*, certains auteurs indiquent que les enfants ayant un TSA présentent des difficultés avec les séquences temporelles, rendant cette tâche particulièrement difficile pour eux. Il est rapporté toutefois qu'un entraînement leur permettrait d'acquérir cette habileté (Gordon & Stark, 2007).

Les faibles résultats au sous-test *R*épétition de patrons révèlent la complexité pour les enfants ayant un TSA à construire un tout cohérent permettant de prévoir la suite (Gordon & Stark, 2007; Van der Smagt et al., 2007). Finalement, la bonne performance au sous-test *Perception* du *PEP-R* expose les habiletés du domaine visuel comme étant une facilité pour les enfants présentant un TSA (Dakin & Frith, 2005).

Conclusion

L'évaluation, cognitive ou développementale, est une étape importante dans la démarche d'évaluation diagnostique d'un enfant présentant un TSA. Elle permet d'obtenir une meilleure connaissance de ce dernier, en plus de planifier les services les plus appropriés pour répondre à ses besoins. Bien que les capacités intellectuelles peuvent prédire les comportements adaptatifs d'une personne (CMQ et OPQ, 2012), l'évaluation cognitive à elle seule ne suffit pas pour statuer sur la présence ou l'absence d'une DI. Les comportements adaptatifs devront également être examinés afin de conclure adéquatement (APA, 2015). Lorsqu'un enfant est prêt pour l'entrée à la maternelle, l'évaluation de son fonctionnement intellectuel devient un facteur déterminant de son classement scolaire. Il peut être orienté vers une classe ordinaire, une classe spécialisée ou une école spéciale. Quelle que soit la décision rendue, l'évaluation psychologique permet aux intervenants du milieu scolaire de faciliter la transition de l'enfant. Les informations contenues dans les rapports d'évaluation sont riches et gagnent à être partagées, surtout en ce qui a trait aux forces et aux difficultés que présente l'élève. Compte tenu du caractère confidentiel de ces informations, une synthèse du rapport d'évaluation psychologique doit être accessible aux intervenants scolaires afin que l'essentiel puisse être connu et que l'enseignement puisse être adapté aux forces et aux faiblesses de l'enfant. Une meilleure connaissance du profil de l'élève permettrait de cibler des objectifs plus pertinents et d'élaborer un plan d'intervention mieux adapté à ses besoins. Une étroite collaboration entre tous les intervenants du milieu scolaire est aussi souhaitable afin d'assurer une meilleure transmission de renseignements au profit du développement des élèves présentant un TSA. Cet article démontre bien la pertinence de procéder à une évaluation cognitive ou développementale, selon le degré de sévérité du trouble, des enfants entrant à la maternelle. En fait, l'évaluation s'avère pertinente non seulement lors de cette transition, mais également lors des autres transitions, notamment pour le passage du primaire au secondaire.

Les résultats et les conclusions de cette étude doivent être interprétés en tenant compte de ses limites. D'abord, la petite taille de l'échantillon ne permet pas de représenter l'ensemble des enfants ayant TSA, ou encore, de généraliser les résultats. De plus, il s'agit d'un échantillon de convenance, ce qui signifie qu'aucun pairage selon des critères d'âge ou de sexe n'a été réalisé. Il importe également de mentionner que les outils utilisés au moment des évaluations ne correspondent pas aux versions révisées actuellement employées dans les milieux cliniques. Toutefois, l'originalité de cette étude réside dans le fait qu'elle propose des interventions concrètes aux personnes exerçant auprès des enfants ayant un TSA en milieu scolaire tout en révélant les forces et les faiblesses de ces élèves sur le plan cognitif.

Messages clés de cet article

Professionnels. Cet article précise l'importance d'évaluer le potentiel intellectuel et du développement des enfants présentant un TSA afin de les diriger vers des interventions appropriées et de leur offrir un classement scolaire adéquat et répondant à leurs besoins.

Gestionnaires. La discussion de cet article stipule l'importance d'offrir des interventions appropriées aux besoins de chaque élève afin de s'assurer une transition et une intégration scolaire optimale.

Key Messages From This Article

Professionals. This paper discusses the relevance of performing intellectual and development assessments of children with ASD in order to guide them towards adapted interventions and to determine appropriate school placement that will meet their needs.

Decision makers. This paper shows the importance of offering interventions that are tailored to each individual's profile to ensure seamless transitions and school integration.

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A Knowledge Brokering Process for Challenging Behaviours in Special Education

Abstract

Previous research describes evidence-based ways to reduce challenging behaviours displayed by individuals with intellectual/developmental disabilities (IDD). These findings may not be put into practice because they are rarely delivered in user-friendly ways. Effective knowledge translation and exchange (KTE) may bridge this know-do gap; however, the literature tells us little about KTE processes as applied in special education. Here, we describe the KTE implementation process of our knowledge brokering team for a school that serves students with IDD. Researchers and teachers were highly satisfied with the process and deliverables. Challenges in the process and implications for future KTE research are described.

People with intellectual/developmental disabilities (IDD) have significant difficulty carrying out tasks of daily living (National Coalition on Dual Diagnosis, 2011). Approximately 3% of the world's population has been diagnosed with some form of IDD (World Health Organization, 2001), with 10–15% of these persons engaging in challenging behaviours (e.g., Emerson et al., 2001; Lowe et al., 2007). Challenging behaviours (e.g., physical and verbal aggression and self-injurious behaviour) are associated with poor educational, social, mental, and physical health outcomes (Nehring, 2005). These behaviours occur across a variety of classroom activities (Chiang, 2008) and present significant problems for students with IDD and their teachers and peers. When special education teachers and educational assistants are not trained with the knowledge and the skills for managing challenging behaviours effectively, they may experience significant work-related stress (Male, 2003; Male & May, 1997a, 1997b) and job dissatisfaction causing some to leave the profession (Ingersoll, 2001).

Although the research literature describes many evidence-based approaches that special education teachers and educational assistants can use to manage or reduce the frequency and severity of challenging behaviours displayed by individuals with IDD (Montgomery et al., 2014), these findings are often not put into practice nor are they used to inform decision-making (Logan & Graham, 1998; McGlynn et al., 2003). This may be because the information may not be delivered in user-friendly ways (Montgomery et al., 2014). Thus, there is a gap between what we know and what we do – an unfortunate situation because evidence-based information linked to policy and practice has the greatest potential to bring forth positive outcomes (LaRocca, Yost, Dobbins, Ciliska, & Butt, 2012).

Organized efforts to close the *know-do gap* (Lomas, 2007) are given various names such as research implementation, knowledge translation, knowledge exchange, knowledge mobilization, knowledge utilization, and knowledge translation and exchange (KTE) (McKibbon et al., 2010; Tetroe et al., 2008). Here, we use the term KTE – defined as a dynamic process involving the synthesis, exchange, and ethically sound application of knowledge between researchers and knowledge users (i.e., individuals who use the information generated through research to inform their decisions, including educators, practitioners, administrators, policy makers, and other researchers) (Canadian Institutes of Health Research [CIHR], 2013). Various KTE models are successful in health and health services research (CIHR, 2013; Straus, Tetroe, & Graham, 2011), yet “it has rarely been acknowledged or systematically studied as a formal process in the [IDD] literature” (Ouellette-Kuntz et al., 2010, p. 278). Research that has described this process (Blewett, 2007; Canavan, Gillen, & Shaw, 2009; Ouellette-Kuntz et al., 2010) has focused on the importance of translating knowledge to improve the *health* of children and adults with IDD. However, KTE implementation as it applies to special education teachers and educational assistants working with individuals with IDD displaying challenging behaviours appears to be absent from the literature.

To begin the process of addressing the gaps in KTE research in the education of individuals with IDD, we held three community workshops (Martin, Shooshtari, Temple, & Yu, 2010). These workshops involved 64 stakeholders (i.e., administrators, parents, policymakers, service providers, and researchers) involved in the health and education of individuals with IDD. We introduced a conceptual framework for KTE and asked various stakeholder groups to rate their ability or their organizations’ ability to acquire, assess, adapt, and apply research findings. Stakeholders then discussed facilitating and impeding factors for KTE from their own experiences. Although the majority of stakeholders valued research highly and recognized its importance in shaping practices and policies, they indicated that inadequate time, incentives, and resources for locating and applying research findings hampered KTE efforts. Physical access to research information (e.g., locating peer-reviewed journal articles) and comprehension (e.g., understanding the terminology and scientific merit of research studies) were also identified as major barriers (see also Barwick et al., 2008; Bowen, Martens, & The Need to Know Team, 2005).

One approach to overcoming KTE barriers is to identify an individual or group who specializes in knowledge brokering. A knowledge broker receives knowledge requests and facilitates the formation of researcher and knowledge-user teams consisting of individuals with various skills and resources. These skills include access to relevant findings and ability to judge their quality, clear communication skills, and an understanding of the organizational context and knowledge needs (Lomas, 2007). The findings are then delivered to the knowledge users in useful forms. For example, Duncan and colleagues (2008) assisted individuals working at a hospital to create and share personal learning projects, and to access research relevant to those projects. The knowledge brokers searched academic literature and consulted with experts, and disseminated practical guidelines to hospital staff through suitable venues. Over 100 personal learning projects were facilitated; importantly, one-third of projects led to changes in practice, relationships, or policies. Hence, knowledge brokering is a promising method for improving research use in health care settings (CHSRF, 2003). More research is needed, however, to evaluate the benefits of knowledge brokering to special education teachers and understand how to implement it most effectively (CHSRF, 2003; Straus et al., 2011).

Thus, our objectives were to implement *and* evaluate the knowledge-brokering role within special education; specifically at a school for students with autism spectrum disorders (ASD) and/or IDD because they were concerned about training and retaining staff. Through this process, our knowledge brokering team received and vetted requests from knowledge users and assembled working groups to conduct systematic reviews to address specific requests for information concerning the management of challenging behaviours exhibited by students with IDD. Working groups then prepared and disseminated evidence-based practice recommendations to knowledge users to promote uptake. In this report, we describe the implementation and evaluation of this KTE process and the use of the translated knowledge.

Method

Based on the Knowledge-to-Action framework (CIHR, 2003), we developed a logic model (see Figure 1) to guide our KTE activities. We also created a timeline for completion of various stages of the project (see Figure 2a). The activities described in this report occurred over approximately three years (June 2010–September 2013).

Participants and Setting

The Knowledge Brokering Team. KTE implementation was managed by a Knowledge Brokering Team, comprising six researchers and clinician-scientists (from disciplines such as behavioural and school psychology, community health sciences, and knowledge translation) with expertise in IDD, and two knowledge users (i.e., special education teachers employed at St.Amant School, Winnipeg, Manitoba, Canada). On three separate occasions, letters of invitation to attend information sessions and to serve on the knowledge brokering team and/or the working groups were mailed to parents and other family members of the students attending St.Amant School. Despite these recruitment efforts, parents or other family members did not participate as members of the knowledge brokering team nor the working groups.

Working groups. Four working groups, each consisting of two or three researchers from the knowledge brokering team (one served as chair), one knowledge user (i.e., special education teacher), and several research trainees, were formed. Trainees were graduate students from the University of Manitoba enrolled in or who had completed graduate level courses in applied behaviour analysis, community health sciences, IDD, school psychology, and research methods. For the present project, trainees received training specific to conducting systematic literature reviews and the KTE process. Members served on multiple working groups. Membership of the

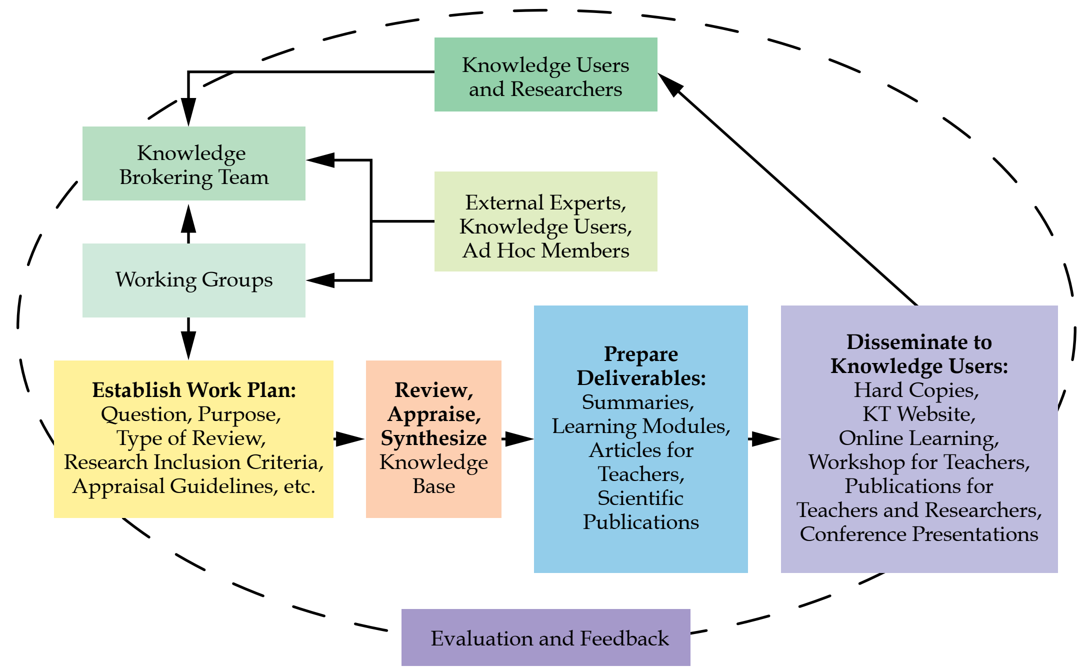

Figure 1. *Logic model of the Knowledge Translation and Exchange (KTE) process includes four components: (1) Establishing a Work Plan; (2) Reviewing, Appraising, and Synthesizing the Knowledge Base; (3) Preparing Deliverables; and (4) Disseminating to Knowledge Users. These components are part of a dynamical system involving not only feed-forward steps, but also feedback loops. Although feedback at every stage in the process adds time and effort to the process, the products are more likely to result in greater satisfaction in the knowledge tools/products.*

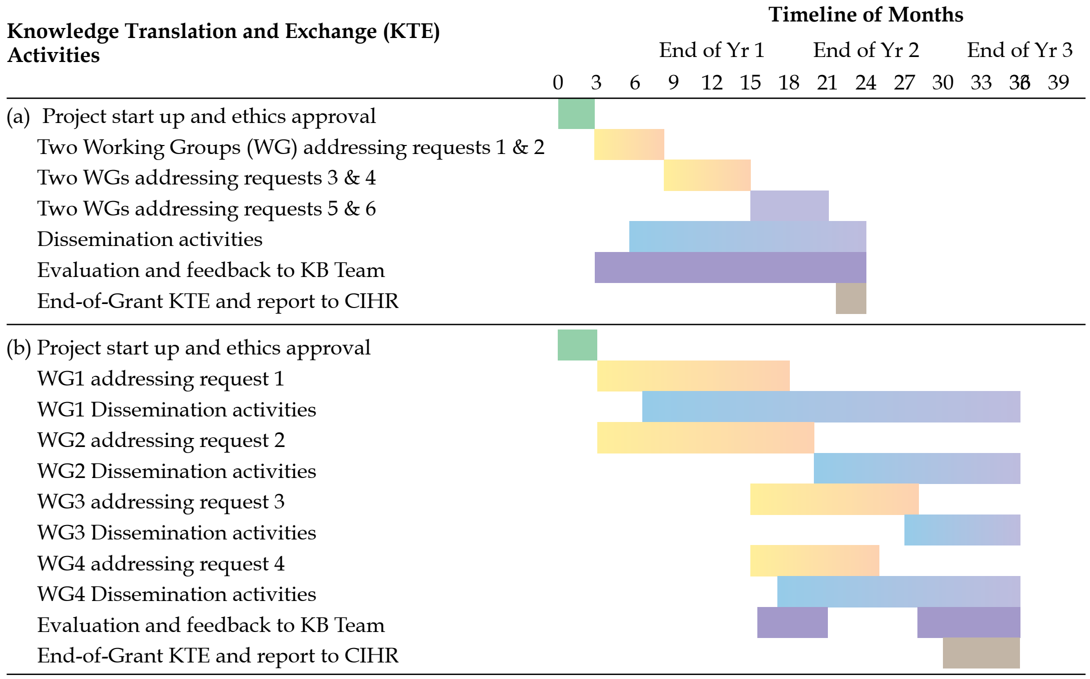

Figure 2. (a) Proposed and (b) actual timelines of the Knowledge Translation and Exchange (KTE) process

working groups remained relatively consistent over the course of the project with exception of the research trainees who were involved for varying durations (i.e., 6-month to 1-year terms that were renewable). The members of a fifth working group (authors of the present report) consisting of two researchers and two trainees were assembled to evaluate the KTE process and resulting deliverables.

Knowledge users. Knowledge users consisted of teachers and educational assistants employed at St.Amant School. St.Amant School provides individualized educational opportunities to persons with IDD aged 4–21 years. At the time of the study, the school employed 7 special education teachers, 30 teacher's assistants, 2 specialists, a recreation facilitator, and a music therapist, served 53 school age students, and provided a literacy program for 16 adult students. St.Amant teachers are a part of an interdisciplinary team including clinicians and caregivers and they implement individualized teaching plans for their students and supervise instructional assistants assigned to their classes. The majority of students have complex needs and many display challenging behaviours (e.g., physical and verbal aggression towards others and property destruction, and self-injury). St.Amant School has a team devoted to addressing challenging behaviours.

The University of Manitoba Research Ethics Board and the St.Amant Research Access Committee approved this study.

Procedures

The knowledge brokering team solicited and received information requests from knowledge users, refined and prioritized the requests (see *Knowledge inquiry and establishing work plans*, below), facilitated the formation of working groups to address requests, and supported working groups as they completed their tasks. Working groups developed work plans, reviewed and synthesized the literature relevant to the request, and prepared and disseminated user-friendly knowledge tools/products/deliverables. In addition to serving on the knowledge brokering team and/or working groups, school staff identified knowledge needs, and provided information regarding their satisfaction with the KTE process and deliverables that were developed.

Each working group chair supervised the completion of specific tasks and met with group members twice monthly to set objectives, review progress, and troubleshoot. Working group chairs reported progress of their activities at monthly knowledge brokering team meetings. Each group documented details of their progress in meeting minutes and work-plans saved in a secure online file-sharing repository. Each working group's specific knowledge requests and problem-solving processes drove KTE activities; thus we expected that the specific tasks and relative time contributed by each group would be variable. Work plans specified the type of review that would be written, established parameters (i.e., inclusion/exclusion criteria) for the review, appraisal systems, deliverables and dissemination activities, timelines, responsibilities, and the resources needed to complete specific tasks. Using the working groups' dated meeting minutes and work-plans, Working Group 5 (WG5) constructed chronological descriptions of the progress of each working group over a 3-year period, and compared them to the initial projections.

Knowledge inquiry and establishing work plans. Identifying knowledge needs was an iterative and multi-method process. An initial written survey of school staff identified approximately six inquiry topics using an open-ended question. This step was followed by a second written survey of the same group, the results of which revised and increased the list to eight candidate topics. Two knowledge brokering team members (themselves school staff) then held a series of three meetings with the school staff to discuss and prioritize the topics. From these meetings, draft versions of knowledge requests 1 through 4 emerged (see Table 1).

The requests received additional refinement after the working groups conducted preliminary literature reviews and began to see how the available findings related to each specific request. To clarify the terms and concepts used in the request, the knowledge brokering team presented school staff with a multiple-choice questionnaire. Items in the questionnaire presented a range of possible meanings for aspects of each request; school staff responses thereby helped the working groups to ensure that they would obtain relevant information. Knowledge brokering team members assembled and chaired working groups 1 and 2 (WG1 and WG2) (Year 1) and working groups 3 and 4 (WG3 and WG4) (Year 2). The original goal to address six requests over three 6-month periods was not met (see Figure 2). The four requests addressed during this project are summarized in Table 1.

Evaluation

We evaluated the knowledge brokering teams and the working groups' satisfaction with KTE implementation at the end of Year 1 and Year 2. In Year 3, we assessed knowledge user satisfaction with the KTE process. Satisfaction with the deliverables was measured upon completion and dissemination of deliverables. Evaluation measures and results are described in detail below.

Results

Knowledge Synthesis

We systematically reviewed existing research findings related to each knowledge request presented in Table 1. Working groups submitted reviews to scientific journals for peer review (Montgomery et al., 2014; Stoesz et al., 2016; Virues-Ortega et al., 2014). Synthesis is an important step that allows knowledge translators to identify and understand the main message delivered to knowledge users (see Grimshaw, Eccles, Lavis, Hill, & Squires, 2012). As can be seen in Figure 2b, the actual time required to address four requests in the *Establish a work plan* and *Review, appraise and synthesize* components of the project (see Figure 1) took longer than proposed. Longer timelines may reflect a lack of clear direction and/or communication between some working groups (see *Process Satisfaction*, below).

Deliverables and Dissemination

Following completion of the reviews, each working group prepared plans for dissemination and developed over 40 user-friendly deliverables, including: (a) non-technical summaries of synthesis papers (i.e., one-page briefings) to allow rapid scanning by teachers and non-researchers; (b) non-technical poster presentations for teacher and parent conferences;

Table 1. Knowledge Requests by Knowledge Users That Were Addressed by Four Working Groups

Knowledge Request	*Working Group (leaders)*	*Remarks*	*Knowledge Tools/Products/ Deliverables*
1. What intervention strategies are the most effective to prevent and manage challenging behaviours of students with severe and/or profound developmental disabilities?	WG1	Knowledge users (i.e., special education teachers) wanted to learn about the recent evidence regarding interventions for challenging behaviours among students with ASD and/or IDD enrolled in formal preschool programs and K–12 schools. Although there are reviews of challenging behaviour interventions in school settings, there are no syntheses of findings specific to individuals with ASD and/or IDD enrolled in formal preschool programs or K–12 schools. Given this, this group evaluated the effectiveness of interventions for challenging behaviours using established quality assessment and intervention effectiveness criteria (Montgomery et al., 2014).	(1) Table of preliminary findings; (2) Booklet outlining procedures for reducing/managing challenging behaviours in the classroom; (3) Online article written by a knowledge user describing her experience on a knowledge translation team; (4) Posters presented at professional meetings; and (5) Workshops presented at professional development days for special education teachers.
2. What are the common medications received by students with special needs, and how do they typically affect behaviour?	WG2	Because knowledge users felt they were not sufficiently informed of the medication effects on the behaviour of their students, they indicated that they wanted to learn more about the effects of medication typically prescribed to individuals with developmental disabilities as they relate to classroom behaviour, academic behaviour, and behaviour management in a school setting.	Two-page and half-page versions of Fact Sheets for each of the following medications: Aripiprazole, Citalopram, Divalproex Sodium, Levetiracetam, Loxapine, Olanzapine, Risperidone, Venlafaxine, and Ziprasidone.
3. What are the effective strategies to train school staff members who routinely encounter challenging behaviour among students with developmental disabilities?	WG3	Knowledge users clarified that they required effective training programs (addressing knowledge, skills, and attitudes) that would allow them to learn more about preventing and managing challenging behaviours, and for reducing the impact that repeated exposure to challenging behaviours has on staff (e.g., stress) (Stoesz et al., 2016).	(1) Poster presented at professional meetings; (2) Workshops presented at professional development days for special education teachers; and (3) Online article for teachers summarizing the findings from the review article.

Table 1. Knowledge Requests by Knowledge Users That Were Addressed by Four Working Groups (continued)

4. How can we more easily identify enjoyable activities for students with profound disabilities?	WG4	Knowledge users were interested in learning about simple and time-efficient methods for assessing students' preferred leisure and educational activities that would engage them for longer durations. Knowledge users also indicated their desire to learn how to adapt these methods for students with minimal verbal and motor skills, sensory impairments, and challenging behaviours (Virues-Ortega et al., 2014).	(1) Decision tree; (2) Scripts of preference assessment protocols; and (3) Preference Assessment iOS App.

ASD = autism spectrum disorders, IDD = intellectual/developmental disabilities.

(c) fact sheets; (d) workshops for special education teachers; and (e) technology (i.e., iOS® preference assessment application). Below, we describe three sets of deliverables and the results from their evaluations.

Procedures for reducing challenging behaviours. To address knowledge request 1 (see Table 1), members of WG1 produced a booklet called *Practical Scripts for Decreasing Challenging Behaviors in Students with Autism or Developmental Disabilities* to provide evidence-based recommendations for reducing specific challenging behaviours (e.g., inappropriate vocalizations, physical or verbal aggression towards others, self-injurious behaviour). The booklet includes a glossary of terms and references for additional resources (available from the authors upon request as a PDF or hard-copy). Five knowledge users evaluated the booklet by completing a questionnaire comprised of nine 5-point Likert items with values ranging from 1 (*Strongly Disagree*) to 5 (*Strongly Agree*), and a tenth item requesting additional comments. Overall, knowledge users rated the booklet highly (*Median* = 4; *Mode* = 4; *Range* = 3–5). Two knowledge users provided additional comments, noting positive aspects of the booklet (i.e., well-organized, good use of colours and visuals), but were concerned that it might not be easy for some staff to use. See Table 2.

Medication fact sheets. In response to knowledge request 2 (see Table 1), WG2 produced medication fact sheets for ten drugs commonly prescribed to students with special needs. Full (two-page) and condensed (half-page) versions of the fact sheets were developed that briefly describe each drug, its side effects, when medical assistance should be sought, and ways to support the student taking the medication. These medication fact sheets are available for download (http://stamant.ca/learning-centre2/healthcare/medication-sheets/). Eight knowledge users evaluated the 10 full version fact sheets collectively and 9 knowledge users evaluated the 10 condensed versions collectively using the 10-item questionnaire described above.

Overall, knowledge users rated both versions of the fact sheets highly (*Median* = 4; *Mode* = 4; *Range* = 2–5, data combined for full and condensed versions). The highest rated-items corresponded with evaluations of the condensed versions of the fact sheets. The highest-rated items were those that indicated that the fact sheets were: (a) applicable to their work as teachers, (b) well-organized and user-friendly, (c) delivered in an appropriate format, and (d) provided information in a clear and understandable way. The full versions of the fact sheets had the lowest ratings, which indicated that teachers neither agreed nor disagreed with the statements: "The information provided will influence the service that I provide" (*Median* = 3; *Mode* = 3; *Range* = 2–5) and "The amount of information is appropriate" (*Median* = 3; *Mode* = 4; *Range* = 3–5). Two teachers indicated that the full versions contained too much information, and one teacher suggested including the brand names of medications and noted preference for the condensed versions. One knowledge user indicated preference for the condensed fact sheets, three respondents offered suggestions for improving the condensed versions, with two requesting inclusion of brand names. One respondent indicated that most of the medications were unfamiliar.

Workshop. Two members of WG3 (a researcher and a trainee) and a trained mindfulness practitioner prepared and delivered a workshop in response to knowledge request 3 (see Table 1). The workshop summarized the KTE project but focused primarily on teaching ways to cope with the stress associated with working with individuals with IDD who exhibit chal-

Table 2. Evaluation of Deliverables Resulting from a Knowledge Translation and Exchange (KTE) in Special Education of Students with Intellectual and Developmental Disabilities

		Booklet			*Medication Fact Sheets (full version, n = 8)*			*Medication Fact Sheets (condensed version, n = 9)*	
Survey Item	*Median*	*Mode*	*Range*	*Median*	*Mode*	*Range*	*Median*	*Mode*	*Range*
The product is well organized and user-friendly.	4	4	4–5	4	4	3–5	5	5	4–5
The information provided is clear and understandable (e.g., unnecessary jargon is avoided).	4	4	4–5	4	4	3–5	5	5	4–5
The product addresses the question that was asked.	4	4	4	4	4	3–5	4	4	3–5
The product is applicable to my work as a teacher.	4	4	3–4	4	4	4–5	5	5	4–5
The information provided is relevant to me.	4	4	3–4	4.5	5	2–5	4	5	2–5
The product is useful.	4	4	4–5	4	4	3–5	4	4	3–5
The amount of information is appropriate.	4	4	4–5	4	3	3–5	4	4	3–5
The information is presented in an appropriate format.	4	4	4	4	4	3–5	5	5	4–5
The information provided will influence the service that I provide.	3	3	3–4	3	3	2–5	4	4	2–5

lenging behaviours. Eleven teachers evaluated the workshop by responding to 10 Likert-type items (1 = *poor*, 2 = *fair*, 3 = *average*, 4 = *good*, 5 = *excellent*), one dichotomous (*yes/no*) question, and 5 open-ended questions. See Table 3.

Responses to each of five Likert-type items, relating to the value of the presentation, presenter expertise, clarity of objectives, participants' active involvement in the learning experience, and overall experience were high. Three Likert-type questions relating to learning experience and usefulness were rated moderately. The majority of participants (*n* = 10) indicated that they would recommend this workshop to others. In response to the open-ended questions, six respondents indicated that the workshop was beneficial; five suggested changes to the format or setting of the workshop; and six indicated that they would try the techniques they learned during the workshop.

KTE Implementation Logic Model

Our logic model of the KTE process (see Figure 1) corresponded closely to the actual KTE process. Despite this, the model could be improved slightly to reflect the fact that working groups modified their goals and tasks as required. Challenges that arose in subsequent components often meant that revisions to the original work plans were compulsory on several occasions, which often resulted in extended timelines. This was particularly evident in WG1 where members of the group originally planned to use a particular method for appraising the research to address their knowledge request; when this failed to meet the requirements of the research, they searched for and used a new appraisal method. The end products were vastly improved as a result; evidenced by the fact that knowledge users were generally pleased with the deliverables. Despite the extended duration of these project components and the project as a whole, the timeframe for the dissemination of activities was largely adhered to.

Satisfaction with the KTE Implementation

The knowledge brokering team's and working groups' satisfaction with the KTE process was evaluated twice (end of Year 1 and end of Year 2) using web-based KTE process satisfaction surveys developed by the knowledge brokering team specifically for this project. The surveys included Likert-type questions to evaluate satisfaction with communication, stakeholder representation, involvement, resources, and effectiveness (1 = *poorly rated* to 5 = *highly rated*). Respondents were asked to explain the reasoning for their responses to each Likert-type question. The surveys also included several open-ended questions designed to identify

Table 3. Evaluation of a Workshop Resulting from a Knowledge Translation and Exchange (KTE) in Special Education of Students with Intellectual and Developmental Disabilities

Survey Item	*Median*	*Mode*	*Range (min–max)*
Value of presentation in meeting your needs	4	4	2–4
Expertise of the presenter	4	4	3–5
Presentation techniques of the presenter	4	4	3–5
Your learning experience	3	3	3–5
Usefulness of handouts or other "take aways"	3	3	2–4
Clarity of objectives	4	4	2–5
Active involvement of participants in learning experience.	4	4	3–5
Timeliness of the material presented	4	4	4–5
Use of practical examples	4	4	3–5
Overall rating of session	4	4	3–5

team members' roles, skills, and assets within each group, challenges, what respondents learned, and how to improve the function of the knowledge brokering team and working groups. Members who served in multiple groups completed one survey for each group in which they were a member. Surveys sent to each member were identical, except that the Year 2 survey included the formation of WG3 and WG4. As there was little variability in the data, comparison between the two evaluation periods was unwarranted and the data were collapsed. Fifty-four surveys were completed.

Overall, team members were satisfied with the KTE process (*Median* = 4; *Mode* = 4; *Range* = 1–5; see Table 4). The highest-rated items were those related to member involvement, resources, and communication within the working groups. The lowest-rated items concerned stakeholder representation and communication between working groups.

Knowledge brokering team and working group members' explanations for their responses to each Likert-type question were coded according to textual content. Analysis of these responses identified several distinct themes that mirrored the ratings from the Likert-type items.

Member involvement. Out of 44 comments, 31 (70%) indicated sufficient opportunities for input were available and 9 (20%) comments indicated opportunities were limited or decreased over time. Those that indicated sufficient opportunities to provide input on decision making commonly attributed their rating to open and collaborative team discussions. Many responses about ratings of confidence in participating as a team member did not appear to be related to confidence in participating. For example, 15 of 37 comments (41%) described their participation and/or specific contributions and 13 (35%) described a positive work environment (e.g., supportive team).

Resources. Out of 47 comments, 37 (79%) indicated that the resources (e.g., research assistants, financial support, informational, technological) were more than adequate to execute each group's work plan.

Communication. Twenty-two of 46 comments (48%) indicated good communication between group members (e.g., "members were respectful toward each other"), whereas 16 comments (35%) noted communication difficulties (e.g., "At times ultimate goals, objectives, procedures, and deadlines were unclear").

Effectiveness. Out of 45 comments, 26 (58%) indicated that their group met the requirements of the *Terms of Reference* (see Table 5) and 15 (33%) referred to challenges (e.g., expectations, timelines). Out of 45 comments regarding the extent to which they contributed to their group's outcomes, 19 (42%) identified contributing to products, 10 (22%) identified contributing as a leader/coordinator, and 9 (20%) identified sharing ideas and information.

Stakeholder representation. Out of 63 comments, 34 (54%) spoke positively about teacher involvement, whereas 16 (25%) noted there was no involvement from parents. Eighteen of 50 comments (36%) indicated that parent representation was missing, 17 (34%) commented that representation was good, and 10 (20%) commented that more knowledge users were needed.

Responses to open-ended questions. As indicated above, the surveys included four open-ended questions (1) *Do you think that members of [your group] brought the appropriate skills and assets to the project? What skills or assets do you think were lacking? Please explain;* (2) *What can be done to improve the function of your group?;* (3) *From your perspective, what was the greatest challenge facing the project over the past year? What factors may have contributed most to this challenge?*; and (4) *What did you personally learn as part of this KT research project over the past year?*

Out of 54 comments, 40 (74%) indicated that team members did bring the appropriate skills and assets to the project, but 12 (22%) comments indicated skills were lacking. Of those 12 comments, 3 commented on a lack of direction and clear expectations, and 2 commented on a lack of organization. Fifteen (38%) of 40 comments about what could be done to improve group function surrounded team meetings (e.g., "more structured meeting agendas and more frequent meetings") and 7 (18%) surrounded communication between and within working groups, and with students.

Table 4. Satisfaction with the Knowledge Translation and Exchange Implementation: Knowledge Brokering Team and Working Group Ratings for Each Survey Question (N = 54)

Survey Question	*Median*	*Mode*	*Range (min–max)*
Member involvement			
To what extent have you had the opportunity to provide input on decision making throughout the process of research? (1 = *Very little* to 5 = *A great deal*)	5	5	1–5
At this point in the project, how confident are you in participating as a team member in KTE activities? (3 = *Not that confident* to 5 = *Very confident*)	5	5	3–5
Rate your satisfaction with equal opportunity to be heard as a member. (1 = *Very dissatisfied* to 5 = *Very satisfied*)	5	5	1–5
To what extent do you think you have contributed to your group's outcome? (1 = *Not at all* to 5 = *A lot*)	4	4	2–5
Resources (1 = *Poor* to 5 = *Very adequate*)			
In your opinion, how adequate were the resources to execute your group's research work plan?	5	5	1–5
Communication (1 = *Very dissatisfied* to 5 = *Very satisfied*)			
How satisfied are you with how members of your group communicated with each other?	4	4	2–5
How satisfied are you with the communication between your group and the knowledge brokering team?	4	4	3–5
How satisfied are you with the communication between your group and another working group?	3.5	5	1–5
Effectiveness			
Rate your group's overall performance in meeting its purpose and objectives as stated in the *Terms of Reference 1* [a] (1 = *Poor* to 5 = *Excellent*)	4	4	2–5
Knowledge brokering team's clear response and direction to the working groups (1 = *Very dissatisfied* to 5 = *Very satisfied*)	4	4	2–5
Frequency of meetings (1 = *Very dissatisfied* to 5 = *Very satisfied*)	4	5	2–5
Stakeholder representation			
In your opinion, how was the representation of different stakeholder groups? (1 = *Poor* to 5 = *Excellent*)	4	4	1–5
To what extent have you had the opportunity to solicit input from knowledge-users? (1 = *Very little* to 5 = A great deal)	3	3	1–5

[a] *Terms of Reference refer to two documents that state the responsibilities of the knowledge brokering team and each working group.*

Out of 58 comments, the most commonly identified challenges facing the project were adhering to timelines (23, 40%), communication (14, 24%), and completing tasks (6, 10%). Time management (6, 30%), leadership (4, 20%), communication (4, 20%), a demanding workload (3, 15%), and a lack of clear direction (3, 15%) were identified as factors contributing to failure to adhere to timelines. Factors contributing to communication challenges included leadership (2 comments), a demanding workload (1 comment), technology limitations (1 comment), a lack of clear direction (1 comment), and changes in working group membership (1 comment). Communication (2 comments), a broad research question (2 comments), and changes in membership (1 comment) were identified as factors that contributed to the challenge of completing tasks. Despite the challenges, respondents indicated that they learned a great deal from participating in the KTE process. Out of 73 comments, 17 (23%) indicated that they learned to work in a multi-disciplinary group, 11 (15%) learned the importance of understanding various perspectives and needs, and 8 (11%) indicated learning more about their group's research topic.

Knowledge Users' Satisfaction with KTE

In Year 3, a group of knowledge users evaluated the KTE process, with a particular emphasis on the knowledge-needs assessment stage. Teachers and educational assistants (*N* = 34) completed an 8-item paper-based satisfaction survey containing 7 Likert-type items, with possible responses ranging from 1 (*Strongly Disagree*) to 5 (*Strongly Agree*), and an eighth item soliciting free-form comments. For items 1–7, the median and mode were "3" (*Neither Agree or Disagree*) for most questions. The large proportion of "3" responses (94/219) may reflect a limitation of the survey as a "not applicable" option was not included. Based on this assumption, we analyzed responses by combining ratings of 1 and 2 and coding them as disagreeing with the statement and combining ratings of 4 and 5 and coding them as agreeing with the statement. Knowledge users were generally satisfied with the KTE process and indicated that the final questions identified were important and accurately reflected their needs. Five respondents wrote free-form comments, with three speaking to the importance of the project or of specific knowledge needs, and one indicating that KTE projects should continue at the school. See Table 5.

Discussion

Our research team implemented and evaluated a formal KTE process to address the knowledge needs of special education teachers working with students with IDD displaying challenging behaviours. Although KTE and the knowledge brokering role are not new ideas, to our knowledge, this is the first study to describe how the process unfolded in a special education setting. Overall, the knowledge brokering team was satisfied with the KTE process and knowledge users were generally satisfied with the knowledge needs assessment process and products that were developed. Below, we describe several challenges and successes in our KTE implementation process, implications of this research, and potential solutions for improving the KTE process.

Challenges and Successes in Process Implementation

Working group members noted a lack of clear direction and inadequate communication within and/or between groups, which may have contributed to problems adhering to project timelines and work plans. Whereas one group member stated that fewer meetings would suffice, several others indicated the need for more frequent meetings. The process of educating one another about discipline-based terminology and working toward the accomplishment of mutual goals required substantial time and effort. Communication issues are common among interdisciplinary research groups, and competing philosophies often exist among team members (Innvaer, Vist, Trommald, & Oxman, 2002; Lomas, 1997); however, a combination of disparate viewpoints or biases often encourages the emergence of new knowledge (Nonaka, 1994; Nonaka & Konno, 1998).

As noted above, adhering to proposed timelines was difficult for all working groups. Longer timelines may simply be a reflection of the pragmatic design of the project – that to be successful in a normal workplace, the KTE process needs to be applied flexibly (see Bhattacharyya et al., 2011). Flexibility was particularly important in this project because the membership of the working groups changed during its duration; although not atypical in

Table 5. Satisfaction with the Knowledge Translation and Exchange (KTE) Process: Results of the Knowledge Users' Survey (N = 34)

Survey Question	*Disagree* *n*	*Agree* *n*
The final questions identified by the needs identification process are important.	0	27(100%)
I generally understand the purpose and method of this research project.	3 (13%)	21 (88%)
The final questions identified by the needs identification process accurately reflect teachers' knowledge needs.	2 (11%)	16 (89%)
The process used to identify and prioritize teachers' knowledge needs was sensible.	4 (31%)	9 (69%)
Communication during the knowledge needs identification process was clear and timely.	4 (31%)	9 (69%)
The process used to identify and prioritize teachers' knowledge needs was transparent.	5 (42%)	7 (58%)
I have had adequate opportunities to provide input and influence decision-making regarding this project (e.g., through the teachers on the research team).	11 (61%)	7 (39%)

normal workplaces, this limitation may have affected the proposed timelines as knowledge and skills were lost when a team member left the project (see also Kislov, Wilson, & Boaden, 2016). Moreover, the proposed timelines may have been too ambitious and delays that are typical of KTE research may have been underestimated. Extended timelines may affect the relevance of the information provided to stakeholders because of an urgency to obtain the knowledge immediately leading stakeholders to seek the information outside of the project or the need for particular information becomes greater over time. Results of the process satisfaction survey identified time management, leadership, and communication as the factors most contributing to delays. The specific time management suggestions offered by team members held few surprises: clear task assignments, deadlines, and accountability were cited several times. The extent to which working groups missed their timeline goals may speak to how the importance of time management, leadership, and communication skills is magnified when working with the large, diverse teams involved in KTE projects.

Another significant challenge was the unsuccessful recruitment of parents or other family members, despite the efforts made by knowledge brokering team members. We received little indication from potential parent collaborators about why they did not get involved, although one parent admitted to a knowledge brokering team member that the prospect of attending meetings with a group of scientists was intimidating. We also recognize that parents of children with special needs face many additional time demands. Rather than ask parents to join a committee with monthly meetings, it may have been more realistic to invite a parent to assist with a specific task (e.g., to evaluate a proposal for a deliverable) and then to build on that relationship. Finally, greater efforts could have been made to communicate to parents and other family members regarding the benefits of participation in KTE research (Bowen et al., 2005). Such participation may have changed the overall goals and outcomes of the present project. Successful partnerships between researchers and knowledge users with a variety of expertise and experiences are more likely to carry on to future KTE projects when there are potential payoffs, particularly for those who have not had prior experience with research.

Our study had several methodological limitations that could be improved upon in future research. First, there has been no long-term follow-up or assessment of uptake. We do not know whether our teachers continued to use and appreciate the deliverables in the months and years after the final evaluations, nor the ultimate impact the use of the deliverables has had on students. Second, a consistent group of individuals did not complete evaluations because several individuals joined and then left the working groups throughout the project. This may have influenced evaluation outcomes, but it may also accurately reflect a typical knowledge brokering arrangement that serves a relatively large organization. Finally, all evaluation respondents were to some extent connected with or invested in the project, whether directly (as team members) or indirectly (e.g., as co-workers of team members). We believe that it was appropriate and necessary to address these users, but it may also have biased responses to an unknown degree. Follow-up interviews with respondents may have led to greater insight into these biases and its impact on the evaluation of the KTE implementation process. Future studies may wish to ask both the organization served and "outside" knowledge users to evaluate products and processes.

Despite the challenges described above, our efforts to recruit special education teachers to the knowledge brokering team and working groups were successful. The culture of both research and practice (i.e., special education) were well represented, which likely contributed to the success of the KTE project (see Kislov et al., 2016; Lomas, 2007). Working with knowledge users is an essential component of any KTE process (see Figure 1), and doing so in the present project enabled the working groups to prioritize requests appropriately and translate evidence-based knowledge into usable deliverables for other knowledge users. In particular, staff indicated that the booklet of procedures for managing challenging behaviours and the medication fact sheets are useful resources applicable to their work as educators. Supplemental resources (e.g., demonstrations, workshops for practicing) would substantially improve the *Practical Scripts for Decreasing Challenging Behaviours in Students with Autism or Developmental Disabilities* and potentially increase the uptake of the knowledge and skills that the booklet contains. Finally, the workshop designed to provide staff with ways to reduce workplace stress was rated positively and met the needs of the majority of its participants. Overall, the research team contributed deliverables relevant to the services school staff provides.

Impact of KTE and Next Steps

The long-term impact of the KTE process and our products on special education teachers and students with IDD remains unknown. Our primary goals were to develop, implement, and assess a replicable KTE process before undertaking uptake evaluations. Follow-up surveys and interviews will be necessary to assess the degree of implementation of new knowledge and any barriers perceived by school staff. Interestingly, in the health field, data regarding benefits to patients is often missing in knowledge translation studies (see Bizovi, Wears, & Lowe, 2002). To our knowledge, the benefits of KTE in the special education setting have also never been described in the literature. Thus, an important next step in KTE research involving special education is to determine the direct impact of translational activities on student outcomes, in terms of education and challenging behaviours in the classroom.

Conclusions

The results from the present study address a significant gap in the KTE literature. We demonstrated that researchers and special education teachers can collaborate to form an effective knowledge brokering team for product development. We contributed to the *science* of KTE by sharing what we learned about its implementation in a special education setting, and to the *practice* of KTE by preparing user-friendly deliverables. What remains unknown is whether this particular implementation of the process can be transferred to other settings (e.g., schools serving other populations, such as typically developing students). The field of IDD presents many opportunities to examine the applicability of our knowledge brokering process and, in so doing, to further promote evidence-based practice.

Key Messages From This Article

People with disabilities. We hope that this project will help people understand that your special education teachers and educational assistants need appropriate training so that you can receive the education that you deserve and that you feel safe at school.

Professionals. Special education teachers and educational assistants may feel significant stress and job dissatisfaction if they are not equipped with the skills needed to deal effectively with their students' challenging behaviours. We need to find ways to help educators gain these skills; not only would this benefit the educator, but may also influence student outcomes positively.

Policymakers. Researchers and special education teachers can collaborate to form an effective knowledge brokering team to bridge the gap between knowledge and practice.

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Effects of a Self-Instructional Manual, Computer-Aided Personalized System of Instruction, and Demonstration Videos on Declarative and Procedural Knowledge Acquisition of the Assessment of Basic Learning Abilities

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Assessment of Basic Learning Abilities (ABLA), self-instructional manual (SIM), computer-aided personalized system of instruction (CAPSI), demonstration videos, teaching university students

Abstract

We evaluated the effects of three training components to teaching 12 university students the Assessment of Basic Learning Abilities *(ABLA; an instrument that measures an individual's ability to learn some basic behavioural functions). The three components involved the students (a) studying the ABLA using a self-instructional manual (SIM), (b) working on the manual combined with passing unit tests delivered via a computer-aided personalized system of instruction (CAPSI) program, and (c) watching demonstration videos. A multiple baseline design across the two training conditions was used to evaluate the effects of the components. Eleven students after receiving CAPSI training, as opposed to only three students after receiving SIM alone training, scored 85% accuracy or higher on declarative knowledge performance. Watching demonstration videos about the ABLA after the SIM and CAPSI training increased procedural knowledge performance for 10 students. The present study is one of the first to compare training effects of three components on teaching a behavioural assessment. The practical implications of training procedures were discussed.*

Practitioners working with individuals with autism or related disorders frequently encounter difficulty in determining what tasks should be taught to whom. To facilitate teaching, they should know the individuals' learning abilities and design training tasks accordingly (Martin & Yu, 2000). The Assessment of Basic Learning Abilities (ABLA) test – originally known as the Auditory Visual Combined Discrimination test (Kerr, Meyerson, & Flora, 1977) – was developed to address this difficulty. It measures how rapidly a testee can learn to perform some tasks, which are thought to reflect most of the activities found in daily life. During the administration of the ABLA test, a tester uses standard prompting and reinforcement procedures to teach one simple imitation and five two-choice visual and auditory discrimination tasks to the testee (DeWiele & Martin, 1998; DeWiele, Martin, Martin, Yu, & Thomson, 2010). The six separate tasks are hierarchically ordered in difficulty and therefore are referred to as measuring an individual's functioning at six ABLA levels. Research during the past two decades indicates that ABLA is a robust and reliable instrument to match the learning abilities of individuals with various levels of developmental disabilities (Yu, Martin, & Williams, 1989; Martin & Yu, 2000; Martin, Thorsteinsson, Yu, Martin, & Vause, 2008; Viel et al., 2011).

Administering the ABLA test with high fidelity requires a high quality of training. Training practitioners the repertoire of concepts, principles, rules, and facts, and the repertoire of procedures of administering the test involves training in both declarative knowledge (knowing *that*) and establishment of proficiency in procedural knowledge (knowing *how*) of the ABLA (Sternberg, 1998). The most common training strategies for behavioural techniques, including the ABLA, consist of complex direct instruction, typically through trainers conveying knowledge, modeling, role-playing, and providing feedback (Roscoe & Fisher, 2008; Sarokoff & Sturmey, 2004). However, direct instruction is labour intensive and difficult to carry out within a stable teaching structure (e.g., a highly experienced trainer needs to reliably deliver the knowledge and procedures to different trainees). With an increasing trend in the prevalence of diagnosed autism (Matson & Kozlowski, 2011) and a high demand of qualified staff in this field (Test, Flowers, Hewitt, Solow, & Taylor, 2003), direct instruction is becoming more costly. An effective, alternative training approach is needed.

To fulfill the need, some researchers have been applying learning principles to develop self-instructional manuals (SIMs) of behavioural techniques to facilitate training declarative and procedural knowledge (e.g., discrete-trial teaching, Fazzio & Martin, 2011; ABLA, DeWiele & Martin, 1998; DeWiele et al., 2010). The salient features of the SIMs include the following: (a) selected study materials are presented in small portions; (b) each small portion is accompanied by study questions; and (c) SIM users are asked to proceed to each successive portion only after mastering the current one (by demonstrating 100% accuracy on answering the study questions of the current one). Recent studies regarding the evaluation of SIMs indicate that the manuals can be effective in promoting knowledge development and increasing implementation accuracy (Fazzio, Martin, Arnal, & Yu, 2009; Wightman, Boris, Thomson, Martin, Fazzio, & Yu, 2012).

DeWiele, Martin, and Garinger (2000) compared the effectiveness of a SIM for the ABLA test (DeWiele & Martin, 1998) with providing its original description (Kerr, Meyerson, & Flora, 1977), which was the best available information package at the time. In DeWiele et al.'s first experiment, 21 undergraduate psychology students were randomly assigned to learn either the SIM or the original description and then, prior to a formal administration test, provided with an opportunity to practice what they had learned with confederates playing the role of an individual with a developmental disability. The authors found that the participants who studied the SIM produced better performances in obtaining declarative knowledge than those who studied the original description, in terms of accurately completing a comprehension exam about the ABLA test, a speed exam to gauge speed and accuracy of responding to questions about conducting the test, and a classification exam to assess ability to clarify training tasks in accordance with hierarchical levels of the test. With respect to procedural knowledge acquisition, the participants who studied the SIM produced superior results over their counterparts in administrating the ABLA test with the confederates.

In a subsequent experiment, DeWiele et al. (2000) evaluated a revised SIM for the ABLA test in an environment in which the participants were direct-care service providers in a residential training facility and administered the test to assigned clients from the facility. The participants were asked to study the SIM and to attempt to achieve mastery (90% accuracy) on the comprehension, speed, and classification exams specified in the prior experiment. Failure to reach the criterion led to restudying the SIM and retaking the exams. The participants then were required to practice administering the ABLA test to each other, with one of them role-playing a client with a developmental disability. Results indicated that, compared to those who studied the original description in the preceding experiment, staff who were trained with the SIM achieved better results in administering the ABLA test to real clients in a shorter period of time. In addition, based on the judgments of experts (i.e., professionals in the field of developmental disabilities), important clinically significant differences favouring the use of the SIM on the length of study, practice time of participants, and results obtained on the exams were observed.

Since, along with studying the SIM and answering study questions, the participants were required to self-practice or to role-play with each other, the effectiveness of the manual would likely be diminished in an environment in which the participants' behaviours on self-evaluating of study questions and self-practicing are not monitored. In addition, the effectiveness of the SIM is the reliance on the assumption that the learners will adhere to the mastery-before-proceeding-to-the-next-unit contingency. These limitations may hamper dissemination of the SIM. Computer-aided personalized system of instruction (CAPSI) offers a practical solution.

CAPSI is conceptualized as a teaching-learning process that involves the use of Internet-connected computers in the mediation of student-instructor and student-student interactions and the evaluation of learning (Pear, Schnerch, Silva, Svenningsen, & Lambert, 2011). It has adopted some features of personalized system of instruction (PSI, developed by Keller, 1968: a mastery-based method of teaching based upon learning principles). Five defining features distinguish PSI from direct instruction or lecture-based training: (a) the instructional material is presented in a written form and is broken down into small units; (b) students must demonstrate mastery of a given unit by passing a test of that unit; (c) students learn through the units in sequence at their own pace; (d) proctors, either former students or current students who have passed early units, grade and provide feedback to students regarding unit test performance; and (e) instructors may use occasional lectures as the main means of motivating interest, rather than as the source of imparting knowledge.

Following the tenets of PSI, a CAPSI course focuses on small units of information (e.g., one section or chapter) on selected textual materials (e.g., textbooks or manuals). Students are instructed to download a unit of content with assigned study questions from CAPSI, study the unit thoroughly, and respond to a number of study questions (e.g., 10) randomly sampled by the system. Feedback on each question (i.e., each correct answer is followed by a praise statement, and each incorrect answer followed by a presentation of corrective information) is provided either by the system immediately or by a human being (i.e., an instructor, mentor, or peer-reviewer) within 24 hours in written form. The mastery criterion of each unit is pre-determined. Students who reach the criterion of a given unit are allowed to proceed to the next unit. By contrast, students who fail to meet the criterion are prohibited by the system from proceeding. They are required to restudy the unit and rewrite a new test for the unit until the mastery criterion is met. Previous studies have indicated that CAPSI is effective in teaching university courses (Springer & Pear, 2008), enhancing critical thinking (Svenningsen & Pear, 2011), and developing declarative or verbal and procedural knowledge about specific behavioural techniques (Zaragoza Scherman, 2015).

Since the content of the SIMs has been sequentially separated into small units or sections accompanied by study questions, it seems that the SIMs are suitable textual materials for training individuals using CAPSI. For instance, Hu, Pear, and Yu (2012) evaluated a training package to teach the ABLA to three university students. The package included a SIM for the ABLA (DeWiele & Martin, 1998), five mastery-based unit tests corresponding to five ABLA levels (the original level 5 was deleted from the 1998 manual because research has shown that it overlaps with level 6), and five demonstration videos (one video for each level, which was accessible after passing a test for that level). The training was delivered via CAPSI, in which, for each level, students had to sequentially read a unit from the SIM, write randomly sampled study questions on a mastery basis (i.e., answer at least nine out of 10 correctly), and watch a demonstration video after passing the test for that level. The study questions required short answers that were automatically marked by the system. Unsuccessful attempts led to restudying the unit and rewriting the test. The training procedure ended when the student passed the last unit test and watched the videos for the last ABLA level. Acquisition of declarative and procedural knowledge of the ABLA were evaluated in a multiple baseline design across students. Results showed that the training package, as a whole, consisting of the SIM combined with unit tests and videos delivered via CAPSI was effective in developing declarative knowledge and in teaching the students to conduct the ABLA to a simulated client role-playing an individual with autism.

In summary, previous training interventions using the ABLA SIM share similarities in that participants were asked to read the SIM and attempted to either achieve mastery on all study questions (DeWiele et al., 2000) or pass mastery-based unit tests with sampled questions delivered via CAPSI (Hu et al., 2012). In addition, supplementary training components, consisting of either practicing with someone role-playing a client or watching demonstration videos, were also included in the training. Thus, the intervention effects of using the SIM combined with only passing mastery-based unit tests delivered via CAPSI remains unclear. Moreover, the effect of studying the SIM, along with study questions, has never been compared with CAPSI training. Finally, the effect of watching videos as a supplementary component has not been studied.

The primary purpose of the present study was to compare the effects of a SIM and a SIM combined with passing mastery-based unit tests delivered via CAPSI on participants' acquisition of declarative and procedural knowledge. Another purpose of the study was to determine whether students would improve their procedural performance further by viewing demonstration videos (Catania, Almeida, Liu-Constant, & DiGennaro Reed, 2009). Considering that CAPSI is highly efficient with regard to the utilization of human resources and can be used to train SIM users online, it was expected that the results of this study would indicate that combining the SIM with CAPSI would be more effective than the SIM alone for teaching declarative and procedural knowledge about the ABLA. It was also expected that the use of videos would be highly effective in teaching procedural knowledge.

Method

Participants

Recruitment posters were posted on information bulletin boards in key buildings at our university. Twelve university students (six males and six females) participated in the study, which was approved by the Psychology/Sociology Research Ethics Board of our university. According to the participants' self-report, they had not previously read any content related to the ABLA, had not had experience working in any behavioural intervention program, had not previously used CAPSI, and had Internet access. They had very diverse academic backgrounds; half of them took psychology courses before the study; and two of them were graduate students enrolled in a Master's program. The demographic information is provided in Table 1. Each participant received a total of 65 Canadian dollars for participating.

Table 1. Participants' Demographic Information

ID	*Gender*	*Age Range*	*Highest Level of Education*	*University Majors*	*University Minors*
P1	Female	26–30	2nd year Master's	Family Social Sciences	N/A
P2	Male	16–20	3rd year undergraduate	Psychology	N/A
P3	Female	21–25	2nd year undergraduate	Psychology	N/A
P4	Male	16–20	3rd year undergraduate	Psychology	Spanish
P5	Male	26–30	2nd year Master's	City Planning	N/A
P6	Male	16–20	2nd year undergraduate	Microbiology	N/A
P7	Male	21–25	1st year undergraduate	Not decided yet	N/A
P8	Female	21–25	1st year undergraduate	Engineering	N/A
P9	Male	21–25	2nd year undergraduate	Engineering	N/A
P10	Female	36+	Postgraduate	Nursing	English/ Sociology
P11	Female	16–20	1st year undergraduate	Biochemistry	N/A
P12	Female	16–20	1st year undergraduate	Not decided yet	N/A

Note: N/A = Not Applicable.

Materials

The training materials consisted of the ABLA SIM (2^{nd} edition, DeWiele et al., 2010), the web-based CAPSI program, and demonstration videos. The CAPSI program in this study was only used to present unit tests and automatically mark answers on the unit tests.

The six levels of the ABLA SIM were combined into three sets with approximately equal length. Each set of contents to be taught included an introduction, which described basic concepts and general guidelines for using the ABLA, and two levels of the ABLA that were 3 levels apart (although the ABLA levels were presented in order of difficulty in the SIM from levels 1 to 6, there is no research evidence indicating any difference in difficulty for testers to learn to administer). The systematic selection of the contents tended to average any difference in difficulty in administering the ABLA across the three sets. Set A consisted of an introduction, the simple imitation task (Level 1), and the visual identity match-to-sample discrimination (Level 4); Set B consisted of an introduction, the position discrimination (Level 2), and the visual non-identity match-to-sample discrimination (Level 5); Set C consisted of an introduction, the visual discrimination (Level 3), and the auditory-visual combined discrimination (Level 6). The introduction section, which was taken from the SIM, was similar to all three sets of contents to provide general information and guidance for the two levels that were learned.

Materials for administrating the ABLA included two containers (viz., a yellow can and a red box) and five manipulanda (viz., a piece of foam, a cube, a cylinder, a purple piece of wood with the word "Can" carved on it, and a silver piece of wood with the word "BOX" carved on it). A video camera and a tripod were used to record testing sessions for retrospective scoring.

For each phase, a written test with 10 fill-in-the-blank questions was used to measure declarative knowledge acquisition about the ABLA. An application test involving conducting 12 trials was used to measure procedural knowledge acquisition, i.e., how accurately participants were able to implement the ABLA test on two pre-determined levels (i.e., Levels 1 and 4 in Set A, Levels 2 and 5 in Set B, or Levels 3 and 6 in Set C). For each trial, a 20- to 33-component checklist (the number of components varied at levels being tested), called the ABLA tester evaluation form (Martin, Martin, Yu, Thomson, & DeWiele, 2011), was used to evaluate accuracy with which participants implemented the ABLA test. An anonymous training feedback and evaluation survey consisting of 11 items was given to participants to measure their evaluations of the training components.

Setting

The training setting of the first three phases could be anywhere the participants chose (e.g., home). Therefore, their learning behaviours were not supervised. However, when participants were asked to use CAPSI, they were required to have a computer or hand-held device (e.g., BlackBerry, iPhone, iPad) connecting to the Internet. The training of the last phase occurred in a research room equipped with an Internet enabled computer at our university so that the participants could access demonstration videos. The written tests and application tests of each phase were conducted in a testing room at the university.

Independent Variables

The training conditions to be compared, consisting of either the SIM alone or the SIM plus CAPSI, constituted the independent variable. Both conditions involved the participant reading designated sets of contents from the SIM and responding to study questions corresponding to three units (i.e., a unit for an introduction section and two units for detailed information covering the two levels of the ABLA) of each set. Moreover, in the last phase of the experiment, the participants viewed videos demonstrating correct procedures and common mistakes made in the administration of six ABLA levels.

In the SIM condition, participants were required to study a designated set of contents from the SIM, answer study questions corresponding to three units, and check their responses against answer keys included in the set of contents. In the CAPSI condition, participants were required to study a set of contents and study questions included in the set, with the omission of the answer keys, and write three mastery-based unit tests delivered via CAPSI. Each mastery-based test consisted of 10 study questions, with the answers being marked automatically by the CAPSI program. The study questions for each unit of each set of contents were identical for both conditions; however, participants in the CAPSI condition were required to demonstrate mastery of 10 questions randomly sampled from the pool of questions for each unit. There were 46, 25, 18, 20, 17, 18, and 16 study questions for the introduction unit and units of Levels 1 to 6, respectively.

The total number of questions (i.e., study questions plus questions reserved for written tests) across all units was 190. Most of the study questions required one-word (e.g., *Following each correct response, you should provide* ***praise*** *to the student*), multiple-word (e.g., *The containers involved in the testing of Level 6, Auditory-Visual, are the* ***BOX*** *and the* ***Can***), and short-phrase (e.g., *The verbal prompt for Level 1 is "****where does it go****?"*) answers. A minority of the questions were of the true-false (e.g., *An incorrect response for Level 1 is defined as placement of the object anywhere other than in the container.* ***True/False***. The statement is True) and two-choice (e.g., *The position of the containers during the testing of Level 2, Position Discrimination, are* ***stable/alternate*** *from one trial to the next.* The word "stable" is the correct choice) types.

Dependent Variables and Data Collection

The dependent variables were (a) declarative knowledge of the ABLA; (b) accuracy of administering the ABLA levels to the first author playing the role of a client with autism; and (c) the participants' subjective evaluations of the training conditions and components. The first two variables were measured in all phases. The third was measured only at the end of the last phase.

Declarative knowledge of the ABLA was assessed by written tests (described previously – Materials and Setting sections), which were marked by a research assistant using a standardized answer key. The questions in the written tests did not overlap with the study questions during training. Procedural knowledge – that is, accuracy of conducting the ABLA levels – was evaluated by application tests (described previously – Materials and Setting sections), which were rated by the first author and the research assistant using the 20- to 33-component behavioural checklist. The research assistant was blind to the experimental condition each participant was in.

Research Design

A multiple-baseline design across two training conditions was used. Each participant was exposed to all three sets of contents, one set for each phase with three phases in total. Different orders of the sets were used to counterbalance any order effect across the participants. Considering that participants were to learn the entire SIM by studying all three sets (A, B, and C), there were six possible orders in which they could experience these sets: ABC, ACB, BAC, BCA, CAB, and CBA. Twelve participants were randomly assigned to two groups, six participants in each group, and each order was randomly assigned to one of the participants in each group. The SIM condition was always introduced first and thus served as baseline. Participants in Group 1 received training under the SIM condition once followed by training under the CAPSI condition twice, and participants in Group 2 received training under the SIM condition twice followed by training under the CAPSI condition once. Finally, in the fourth phase, participants from both groups watched demonstration videos. The methodology is illustrated in Table 2.

Procedure

Phase I: Training under the SIM condition. Participants were asked to read the assigned set of contents (see Table 2 for the specific set of contents being assigned to each participant), answer study questions corresponding to the three units of the set, and check their responses against answer keys that were provided. When they felt ready to be tested, participants were instructed to make an appointment with the first author to take a written test and to administer the two ABLA levels they studied. Based on the participants' self-report, the training process took a mean of 2 hours (range: 1.75 to 3 hours).

Table 2. Research Design

ID	*Phase I*	*Phase II*	*Phase III*	*Phase IV*
P1	SIM (Set A)	CAPSI (Set B)	CAPSI (Set C)	Videos (All levels)
P2	SIM (Set A)	CAPSI (Set C)	CAPSI (Set B)	Videos (All levels)
P3	SIM (Set B)	CAPSI (Set A)	CAPSI (Set C)	Videos (All levels)
P4	SIM (Set B)	CAPSI (Set C)	CAPSI (Set A)	Videos (All levels)
P5	SIM (Set C)	CAPSI (Set A)	CAPSI (Set B)	Videos (All levels)
P6	SIM (Set C)	CAPSI (Set B)	CAPSI (Set A)	Videos (All levels)
P7	SIM (Set A)	SIM (Set B)	CAPSI (Set C)	Videos (All levels)
P8	SIM (Set A)	SIM (Set C)	CAPSI (Set B)	Videos (All levels)
P9	SIM (Set B)	SIM (Set A)	CAPSI (Set C)	Videos (All levels)
P10	SIM (Set B)	SIM (Set C)	CAPSI (Set A)	Videos (All levels)
P11	SIM (Set C)	SIM (Set A)	CAPSI (Set B)	Videos (All levels)
P12	SIM (Set C)	SIM (Set B)	CAPSI (Set A)	Videos (All levels)

Note: Multiple baseline design across training conditions in which two groups of six participants move across conditions in a semi-staggered manner, and three sets of contents (A, B, and C) from the SIM counterbalance any order effect across participants.

Phase I: Post-training measurements. The post-training measurements, which consisted of a declarative knowledge and a procedural knowledge test, were conducted in a mean of 6.6 days (range: 2 to 8 days) after the commencement of training in Phase I. The written (declarative knowledge) test, including 10 fill-in-the-blank questions, had a 10-minute limit. The questions in the test were novel to the participants, but closely followed the format and difficulty of the study questions from the set of contents. The written tests were only on material from the relevant section of the SIM, not on the introduction that was included in each set. During the application (procedural knowledge) test, each participant was asked to conduct 12 trials of the ABLA on the two studied levels (6 trials for each level), which were administered in a hierarchical order, with a brief break (30 seconds) between levels. For example, when Set A (including ABLA levels 1 and 4) was being administered, the participants who studied the set were always required to finish implementing 6 trials of Level 1 before starting Level 4. Note that the application test of each set of contents included two sessions, with each ABLA level presented as a session (the lower level was presented first). Each participant was asked to let the experimenter know when he or she finished a trial and was going to move on to the next trial. The application test was completed in a mean of 8.5 minutes (range: 5.5 to 21 minutes). All sessions were videotaped for retrospective scoring. Participants did not receive any further training or feedback on their performance during and after the written and application test.

Phase II: Training under either the SIM or the CAPSI condition. Six participants remained in the SIM condition while the others commenced training under the CAPSI condition (as shown in Table 2). All participants started out studying a different set of contents from the SIM. The participants in the SIM condition received the training process described previously. The participants in the CAPSI condition were asked to read the assigned set of contents sequentially on a unit-by-unit basis and to access a unit test. For each set, three tests corresponded to the three units: an introduction, an ABLA level from 1 to

3, and another ABLA level from 4 to 6. To pass a unit, the participant was required to correctly respond to at least nine out of 10 fill-in-the-blank and single-choice questions within 15 minutes.

The CAPSI program automatically marked the test and immediately provided feedback to all questions. Each correct answer was followed by a praise statement (e.g., "good work") on the computer screen, and each incorrect answer was followed with a presentation of all acceptable answers. If a participant met the mastery criterion, he or she would be complimented (e.g., "congratulations") with a result of a "pass" and could proceed to the next unit. If a participant scored below 90% correct, the program would notify the participant that he or she was required to restudy the material and write another test on the unit no sooner than 15 minutes after the failed attempt. The training under the CAPSI condition for phase II ended after the participant successfully passed all three tests in that phase. The training process with the involvement of CAPSI took a mean of 2.5 hours (range: 2 to 3.5 hours).

Phase II: Post-training measurements. The post-training measurements were similar to Phase I measurements and were conducted in a mean of 7.3 days (range: 3 to 12 days) after the commencement of training in Phase II. The participants were asked to complete a declarative knowledge test with a novel set of 10 questions and to administer a procedural knowledge test with 12 trials on the two ABLA levels that they just studied. The two tests were delivered in the same manner as described above.

Phase III: Training under the SIM plus CAPSI condition. All participants studied the remaining set of contents specific to them and accessed the CAPSI program for testing as described above for Phase II. The training process in this phase took a mean of 2 hours (range: 1.5 to 3.5 hours).

Phase III: Post-training measurements. The post-training measurements were conducted in a mean of 6.3 days (range: 2 to 9 days) after the commencement of training in Phase III. Similar to the measurements in the Phases I and II, the participants were, again, asked to finish a written test on a novel set of questions and to conduct 12 trials on the two ABLA levels they studied.

Phase IV: Watching demonstration videos. After participants completed the post-training measurements in the previous phase, they were asked to make an appointment to meet the first author to watch six demonstration videos. The videos were stored in a laptop and were played by media player software installed on the computer. Six videos showed actors (psychology graduate students in the field of applied behaviour analysis) demonstrating the correct procedures and common errors for assessing the administration of the ABLA levels, one video per level. All videos took approximately 40 minutes to watch and played only once.

Phase IV: Post-video measurements. The post-video measurements were conducted in a mean of 3.8 days (range: 1 to 9 days) after the completion of the measurement in Phase III. Like the measurements conducted in the previous phases, a declarative knowledge and a procedural knowledge test were given. However, these measurements were cumulative: i.e., a novel set of 10 questions was used to test declarative knowledge covered by the entire SIM, and 12 trials selected from all six levels of the ABLA test (2 trials per level), without replacement, were used to test procedural knowledge. Data presentation of the application test differed from previous phases in that two sessions in this phase presented participants' performance on the ABLA levels being learned under the SIM and the CAPSI condition (the averaged data for the levels being studied under the SIM condition always presented first).

Interobserver Agreement and Procedural Integrity Checks

Interobserver agreement (IOA) on the videotaped sessions was assessed as follows: The research assistant randomly sampled and viewed a mean of 45% (range: 35% to 50%) of the sessions across all participants. The first author and research assistant independently recorded either the occurrence or nonoccurrence of the participant's specific behaviours on each trial of the sampled sessions on a component-by-component basis using the checklist described above. An agreement was defined as both raters jointly scoring a component on the checklist as correct, incorrect, or not applicable for the level being tested. A disagreement was defined as a discrepancy between the two raters in scoring a component on the checklist. IOA per participant was calculated by dividing the number of agreements by the number of agreements plus disagreements and multiplying by100% (Martin & Pear, 2011, p. 266). Mean and range agreements across 12 participants is reported in Table 3.

Table 3. Interobserver Agreement (IOA) Across Participants

ID	*Mean*	*Range*
P1	94%	85%–99%
P2	94%	89%–99%
P3	92%	88%–95%
P4	100%	
P5	100%	
P6	96%	89%–98%
P7	98%	96%–99%
P8	96%	94%–98%
P9	95%	89%–100%
P10	97%	92%–100%
P11	89%	75%*–96%
P12	86%	80%–96%

* *The low IOA occurred in Phase I in which the participant did not explicitly inform the experimenter the completion of each trial.*

For procedural integrity, when scoring the sessions the research assistant also recorded whether or not the first author's behaviours were performed in accordance with a script on a trial-by-trial basis. The script described the first author's planned (i.e., correct or incorrect) response on each trial of the application measurements. Its purpose was to ensure that all of participants encountered the same response across trials. The mean procedural integrity score was 95% (range: 83% to 100%) based on 65% randomly sampled sessions across all participants.

Results

Table 4 shows participants' mean declarative and procedural knowledge performance among three sets of the ABLA for the first three training phases. The mean difference of declarative knowledge among the three sets was not significant, $F(2, 33) = 0.68$, $p > .05$. The mean difference of procedural knowledge among the three sets also was not significant, $F(2, 33) = 0.12$, $p > .05$. One-way ANOVA post hoc multiple comparisons indicated no significant differences between the three sets of the declarative and procedural knowledge tests. Table 5 presents participants' mean procedural knowledge performance including the data of the last phase on all six ABLA levels. An ANOVA test did not indicate any significant difference on implementing the levels, $F(5, 66) = 0.25$, $p > .05$. These data suggest that although the levels presented in order of difficulty for testees, the difference in difficulty may not be experienced by the testers by sets and levels.

Figure 1 (on page 74) shows performance (% correct) on declarative knowledge and procedural knowledge tests across training conditions for each participant. Arrows for each participant indicate the highest performance on the two different tests. The 85% accuracy criterion is used in the present study to evaluate whether a participant has reached mastery of the ABLA.

Table 4. Mean Declarative and Procedural Knowledge Performance Among Three Sets of the ABLA for the First Three Training Phases

	Declarative Knowledge[a]		*Procedural Knowledge*[b]	
Test Contents	*M (%)*	*SD*	*M (%)*	*SD*
Set A (Levels 1 & 4)	68.4	30.9	57.8	29.7
Set B (Levels 2 & 5)	78.3	10	60.1	22.1
Set C (Levels 3 & 6)	77.5	22.6	63.1	27.4

Note: [a] *Multiple comparisons using Tamhane's T2 test (equal variances not assumed);* [b] *multiple comparisons using Fisher's LSD test (equal variance assumed).*

Table 5. Participants' Mean Procedural Knowledge Performance on Six ABLA Level

	ABLA Levels					
Statistics	*Level 1*	*Level 2*	*Level 3*	*Level 4*	*Level 5*	*Level 6*
M (%)	52.8	60	64.5	61.6	60.3	62
SD	29.6	24.9	29	30.2	21.4	26.7

Table 6. Mean Declarative Knowledge Performance (% Correct Answers) for Two Groups of Participants Across Phases

Groups	*Phase I* *SIM*		*Phase II* *CAPSI*		*Phase III* *CAPSI*		*Phase IV* *Demo Videos*	
	M (%)	SD	M (%)	SD	M (%)	SD	M (%)	SD
Group 1	55.2	28.7	80.3	18.7	89.2	11.9	78.4	15.4
	Phase I *SIM*		*Phase II* *SIM*		*Phase III* *CAPSI*		*Phase IV* *Demo Videos*	
Group 2	54.3	23.4	76.7	8.0	92.7	5.9	77.7	11.0

This criterion is chosen because of its clinical significance in practical settings (e.g., DeWiele et al., 2000). For the declarative knowledge test, all participants reached their highest performance in the CAPSI condition. Three of six participants (participants 1 to 6 who received CAPSI training twice) in Group 1 reached their highest performance immediately after completing the first CASPI training in Phase II. All six participants (participants 7 to 12 who received CAPSI training only once) in Group 2 reached their highest performance immediately after the CAPSI training in Phase III. Moreover, only one participant (participant 5) in Phase I and two participants (participants 7 and 9) in Phase II scored greater than 85% accuracy after the SIM training. Finally, watching demonstration videos did not improve participants' declarative knowledge performance.

For the procedural knowledge test, participants' performance was averaged in each session (as shown in Figure 1). Ten of 12 participants reached their maximum application performance after watching the videos in Phase IV. The remaining two participants (participants 1 and 5) reached their best performance (99% accuracy) after the completion CAPSI training in Phase II or III, limiting the room for further improvement. Moreover, no participant scored greater than 85% accuracy after the SIM training in Phase I. Comparing performance in Phase II in which participants were trained in one of the two training conditions, three of six participants (participants 1, 4, and 5) in the CAPSI condition in Group 1 scored greater than 85% accuracy while only one of six participant (participant 10) in the SIM condition in Group 2 met this criterion. When all participants were trained in the CAPSI condition in Phase III, only one more participant (participant 9) than those in Phase II achieved the specified criterion. Interestingly, even though all 12 participants were asked to administer all levels of the ABLA in Phase IV, eight of them scored greater than 85% accuracy after watching the videos. This was twice the number of participants in Phase II that scored greater than 85% accuracy.

Figure 2 (on page 75) presents the mean percentage of correct performance on declarative knowledge (top panel) and procedural knowledge (bottom panel) tests across training conditions for the two groups of participants. Mean declarative knowledge increased across the first three phases regardless of training conditions. Table 6 shows that mean declarative performance for the two groups was approximately

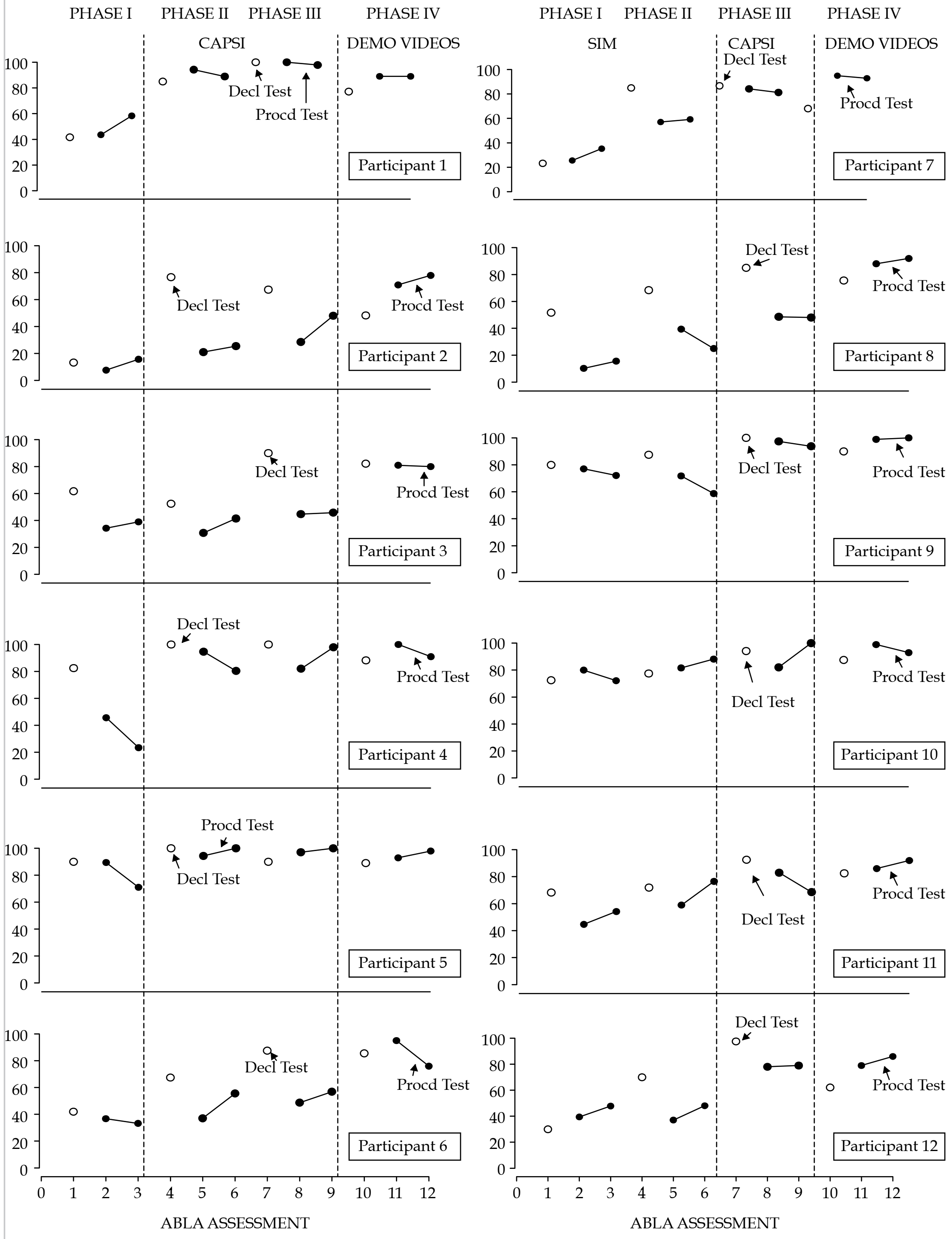
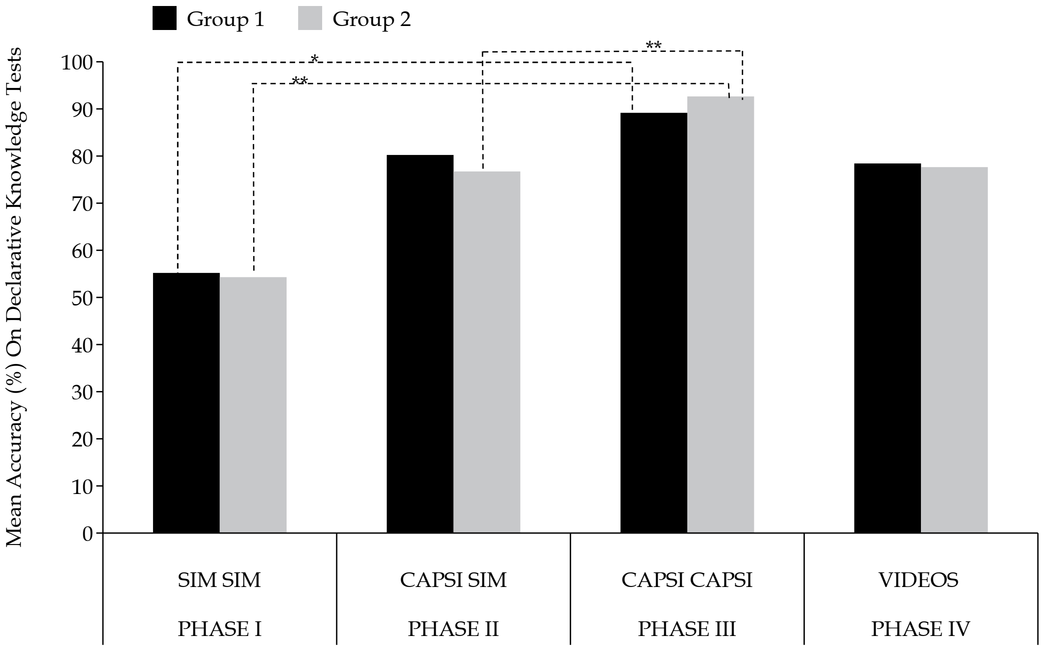


Figure 1. *Accuracy (% correct) on declarative knowledge and procedural knowledge tests across training conditions for each participant. Arrows for each participant indicate his or her highest performance on the two different tests.*



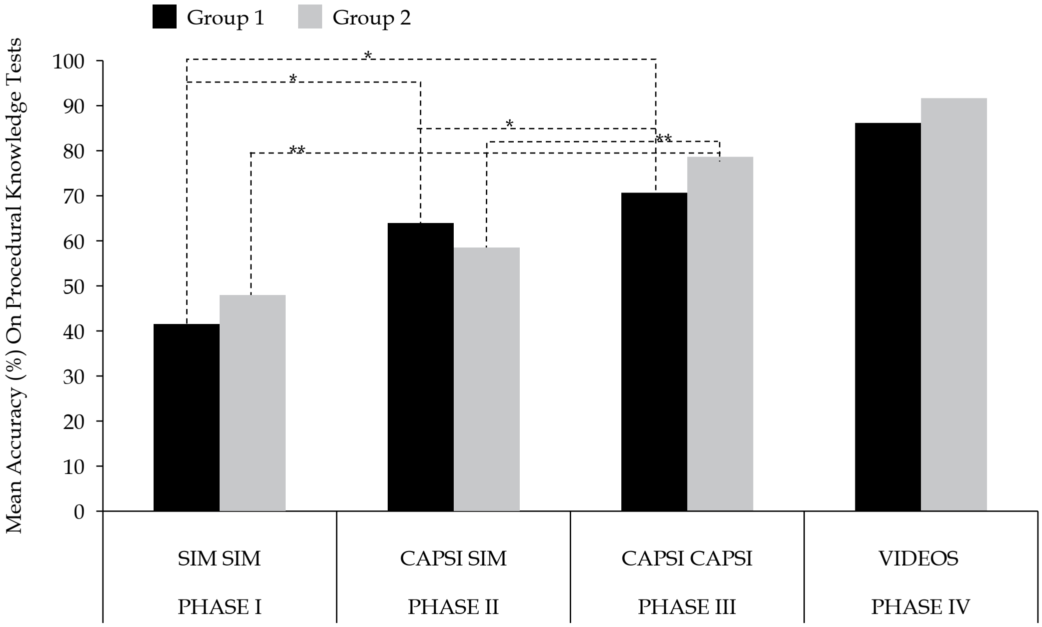


Figure 2. Mean accuracy (% correct) on declarative knowledge and procedural knowledge tests across training conditions for two groups of participants

*Note: * p < .05; ** p < .01*

equal after SIM training in Phase I, substantially increased in Phase II regardless of training conditions, then maximized after CAPSI training in Phase III, and slightly decreased after watching the videos in Phase IV. Although the between-group comparison in Phase II showed 3.6% difference in accuracy, the superiority over CAPSI training was not statistically significant: $t(10) = 0.43$, $p > .05$, two-tailed. However, within-group comparisons indicated that, compared to the 8.9% improvement ($t[5] = 1.12$, $p > .05$, two-tailed) for those in Group 1 who continuously received CAPSI training in Phase III, participants in Group 2 who just commenced the CAPSI training produced a significantly better outcome (16% improvement; $t[5] = 4.53$, $p < .01$, two-tailed).

Table 7 shows that mean procedural performance for the two groups also increased across phases regardless of training conditions. Group 2 started with higher performance than Group 1 after SIM training in Phase I. The two groups improved in procedural knowledge regardless of training conditions in Phase II. The performance continuously increased after CAPSI training in Phase III and reached its maximum after participants watched the videos in Phase IV. The between-group comparison in Phase II showed 5.5% difference in accuracy, but the advantage over CAPSI training was not statistically significant: $t(10) = 0.36$, $p > .05$, two-tailed. However, within-group comparisons indicated that, in contrast to the 10.6% improvement ($t[5] = 1.86$, $p > .05$, two-tailed) for those in Group 1 who remained in SIM training in Phase II, participants who switched to CAPSI training showed a significantly larger improvement (22.4%; $t[5] = 2.76$, $p < .05$, two-tailed). Similarly, participants in Group 2 improved significantly from Phases II to III when they finished CAPSI training (20.1% improvement; $t[5] = 4.09$, $p < .01$, two-tailed). Finally, both SIM and CAPSI training could not maximize procedural performance, which hence needs further training with the demonstration videos.

Pearson's correlation coefficient revealed that the two different tests were significantly and strongly correlated with each other, $r(48) = 0.66$, $p = .00$, two-tailed, suggesting that the participants, who had better performance on answering questions about the ABLA, were more likely to accurately administer the assessment, and vice versa.

Finally, on the training feedback and evaluation survey twice as many participants viewed the CAPSI training as being extremely helpful (six participants) as viewed the SIM training as being extremely helpful (three participants) with regard to the declarative knowledge tests. Three times as many participants perceived the videos as being extremely helpful (9 participants) as perceived either the SIM (three participants) or CAPSI training (three participants) as being extremely helpful with regard to the procedural knowledge test.

Discussion

Few studies have investigated the effectiveness of a training approach in teaching behavioural techniques to individuals under a completely unmonitored environment (Hu et al., 2012). To our knowledge, no studies have gone even further to compare the training effects of two self-instructional approaches on facilitating

Table 7. Mean Procedural Knowledge Performance (% Correct) for Two Groups of Participants Across Phases

	Phase I		*Phase II*		*Phase III*		*Phase IV*	
Groups	*SIM*		*CAPSI*		*CAPSI*		*Demo Videos*	
	M (%)	SD	M (%)	SD	M (%)	SD	M (%)	SD
Group 1	41.6	22.8	64	31.8	70.7	28.1	86.2	8.1
	Phase I		*Phase II*		*Phase III*		*Phase IV*	
	SIM		*SIM*		*CAPSI*		*Demo Videos*	
Group 2	47.9	24.7	58.5	18.8	78.7	16.6	91.7	6.1

declarative and procedural knowledge acquisition. Moreover, the effects of watching demonstration videos have received much recent attention and have been shown to be highly effective in teaching procedural knowledge (Catania et al., 2009). The present study compared two self-instructional approaches (i.e., SIM and CAPSI training conditions) on teaching the ABLA and also evaluated the effects of watching videos as supplemental training to the two approaches.

In this study, performance for each participant across phases on writing declarative knowledge tests suggests that: (a) studying the manual with all study questions can be effective, considering that three participants scored 85% accuracy or higher after SIM training; (b) CAPSI training (i.e., studying the manual and passing three mastery-unit tests) appears to be more beneficial as 11 participants scored 85% or higher after CAPSI training and as substantial improvements (15% or higher) occurred immediately after the first phase of CAPSI training for eight participants; (c) even though the helpfulness of the videos was reported, it seems that watching them provided a better model for procedural behaviour than for verbal behaviour; and (d) practice effects existed across the phases even though strong attempts were made to preclude them, indicating strong generalization across the teaching procedures at all ABLA levels. The between-group comparison in Phase II did not show significant difference favouring CAPSI training; however, the within-group comparison indicated that, compared to their performance after SIM training in Phase II, participants in Group 2 produced significant better outcome after CAPSI training. Taken altogether, the results may suggest the effectiveness of CAPSI on facilitating declarative knowledge acquisition.

Performance for each participant across phases on conducting procedural knowledge tests suggests that: (a) SIM training alone may produce suboptimal results as no participant achieved a high level of accuracy (85% or higher) in this condition; (b) although CAPSI training appeared to also show superiority on teaching administering the ABLA levels, participants' performance only reached a moderate level, suggesting the helpfulness of adding other training components (e.g., watching videos); (c) watching the demonstration videos further improved procedural performance to a high level, indicating the usefulness of adding the videos (thus extending the findings of Catania et al., 2009); and (d) practice effects appeared to have been present across the phases. Similar to participants' performance on the declarative knowledge tests, the between-group comparison did not differentiate procedural knowledge for the two groups of participants in Phase II; however, the within-group comparison suggests the superiority of CAPSI training. In addition, the results of the last phase indicate the usefulness of using the demonstration videos to teach administering the ABLA.

In summary, studying the SIM combined with passing unit tests delivered through CAPSI (CAPSI condition) appeared to be more effective than studying the SIM and study questions of the manual (SIM condition) in declarative knowledge acquisition. However, it appeared to be no more effective than the SIM condition in procedural knowledge acquisition, indicating the need of other training components. The addition of watching videos modeling correct procedures and presenting common errors in the administration of the ABLA did appear to be highly effective in teaching procedures for conducting the assessment. In addition, the declarative and procedural knowledge tests were complementary and tended to assess participants' abilities from different perspectives. However, keeping in mind that correlation does not necessarily imply causation, the strong positive correlation between the two tests suggests that, for professional development, the more effective a practitioner learns declarative knowledge about the ABLA, the more precise he or she would implement the assessment.

The results of this leave some questions to be answered in future studies. First, we do not know why some participants' performance continuously increased regardless of the training conditions. This may have been due to repeated exposure to similar material (e.g., introduction section from the SIM) across the first three phases for all participants. However, none of the tests contained materials from the introduction sections. Second, the between-group comparisons did not show significant differences. This may due to the limited sample size of each group. Third, the experiment did not include a generalization phase in which participants could apply learned skills to individuals whose basic learning abilities need to be assessed. Thus, we do not know whether the CAPSI training and demonstration videos would be effective for individuals working with real clients. Fourth, related to the first limitation, we do not know what the results would have been if the CAPSI condition rather than the SIM condition had served as the baseline. Finally, we do not know whether providing feedback after the tests would have improved accuracy on subsequent tests.

There are a number of possibilities for future research. First, in order to make a clear comparison, an independent groups design consisting of a SIM alone and a SIM plus CAPSI group might be needed. Or, as an alternative, a pre-test measure could be included in each phase to compare with the performance after training of that phase. Second, replications with other SIMs and with participants who might not be such efficient learners (as university students tend to be) would be beneficial. Third, research is needed to compare the effects of successfully passing three versus more mastery-based unit tests for each CAPSI training phase. Finally, participants in this study only viewed the videos once. Future research could evaluate the impact of the number of the videos viewed on the administration of the ABLA.

The findings of this study have implications for training individuals on behavioural techniques including the ABLA. SIMs combined with mastery-based unit tests and demonstration videos delivered via CAPSI could be an effective and low-cost training approach to teach both declarative knowledge and application of behavioural procedures. This comports with the findings of Hu et al. (2012) who used a training package involving CAPSI to facilitate teaching the ABLA. Because the participants both in this study and in the study by Hu et al. were trained in an unmonitored environment in which they studied at any location they chose and at their own pace and wrote unit tests online, a self-instructional approach involving the use of CAPSI would appear to be highly efficient. Because of the increasing demand for trained practitioners working with individuals with autism and related disorders, CAPSI with embedded demonstration videos holds promise to be an economical tool for conducting instruction and in maintaining a structure for staff training.

Key Messages From This Article

People with disabilities. You deserve to have your basic abilities accurately assessed by qualified assessors, using the assessment of basic learning abilities (ABLA). In addition, you deserve to have your abilities strengthened and extended with appropriate tasks based on the results of the assessment.

Professionals. Being able to provide the ABLA test with high fidelity to people with disabilities requires an effective and efficient training method.

Policymakers. The utilization of a computer-aided personalized system of instruction (CAPSI) program would be effective for training if a self-instructional manual and demonstration videos can be incorporated into the program.

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The Effects of Student Peer Review on the Efficacy of Computer-Aided System of Instruction to Teach Discrete Trials Teaching

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Keywords

peer-review, discrete-trials teaching, computer-aided personalized system of instruction, CAPSI, autism spectrum disorder

Abstract

Student peer-reviewing (SPR) contributes to their own learning and that of the students they are grading. More research is needed on the effects of SPR on the reviewer's knowledge and skills of behavioural instructional skills such as Discrete Trials Teaching (DTT). The present study evaluated the effects of adding SPR to an online teaching method, Computer-Aided Personalized System of Instruction (CAPSI). Following CAPSI in DTT, participants (N = 32) were randomly assigned to receive SPR or not. Both groups showed statistically significant increases in DTT knowledge and applied performances from baseline, with no between group differences. This study supports the use of computer-assisted self-instruction in teaching applied behaviour analysis knowledge and skills.

Autism spectrum disorder (ASD) is a neurodevelopmental disorder, characterized by repetitive and restrictive behaviours and impairment in social communication and social interactions (American Psychiatric Association, 2013). Given that prevalence rates of ASD are climbing at unprecedented rates in recent years (Ouellette-Kuntz et al., 2014; Zablotzky, Lindsey, Maenner, & Schieve, 2015), effective methods are needed to train professionals on empirically validated treatments for persons with ASD.

Several meta-analyses have indicated that the most researched and effective interventions to improve performance on standard measures such as adaptive behaviour, IQ, communication, socialization, and daily living skills in children with ASD is Early Intensive Behavioural Intervention (EIBI) (Makrygianni & Reed, 2010; Reichow, 2012; Reichow, Barton, Boyd, & Hume, 2014; Reichow & Wolery, 2009; Virués-Ortega, 2010). The effectiveness of EIBI programs relies on behaviour analytic principles and techniques (Lovaas, 1987). A major procedure in most EIBI programs is Discrete Trials Teaching (DTT). This is a structured instructional method that simplifies the teaching of foundational skills – for example, matching, pointing, and imitation (Sarokoff & Sturmey, 2004). DTT involves presenting many trials, each including an antecedent, a response, and a consequence (Fazzio & Martin, 2012). DTT on its own increased social-emotional functioning (e.g., social skills, adaptability), and adaptive behaviour development (e.g., daily living skills, communication) in children with developmental disabilities (Downs, Downs, Johansen, & Fossum, 2007).

Training staff to implement DTT with high levels of fidelity can require extensive training and direct supervision (Pollard, Higbee, Akers, & Broadhead, 2014). Alternative methods to teach DTT have been developed, including online training that can be as effective and may be more efficient than face-to-face training methods (Eldevik et al., 2013; Randell, Hall, Bizo, & Remington, 2006). One such online program, Computer-Aided Personalized System of Instruction (CAPSI) (Pear, Schnerch, Silva, Svenningsen, & Lambert, 2011) is based on Keller's (1968) Personalized System of Instruction (PSI). As in PSI, the core features of CAPSI are: (1) small portions of the course or training material are delivered at a time and according to each student´s progress in the course, (2) immediate and detailed feedback on the mastery of the study materials is provided throughout, and (3) students at more advanced levels have the opportunity to do peer reviewing (Pear et al., 2011). Preliminary studies have shown that CAPSI is effective in teaching DTT (Zaragoza Scherman et al., 2015) and other behavioural procedures (Hu, Pear, & Yu, 2012; Oliveira, Goyos, & Pear, 2013). These preliminary findings are extremely promising, but additional research with larger samples would be desirable.

Feedback provided by student peer reviewers can be as effective as that provided by faculty in producing performance improvement in a course (Batchelder et al., 2010; Martin, Pear, & Martin, 2002a, 2002b; Ten Cate, van de Vorst, & van den Broek, 2012; Tolsgaard et al., 2007). Furthermore, the experience of peer reviewing results in improved performance in the reviewers themselves (Cho & MacArthur, 2011; Ensergueix & Lafont, 2010; Springer & Pear, 2008). Two CAPSI studies incorporating peer reviewing found that (1) peer reviewers provide accurate feedback that improves subsequent student responses (Martin et al., 2002a & 2002b) and that (2) peer reviewers in CAPSI-taught courses demonstrated higher course progress rates when compared to non-peer-reviewers in that same course (Lambert, 2009). These studies suggest that peer-reviewing may be a strong component to incorporate in DTT training packages using CAPSI. The present study evaluated the effects of a simulated peer-reviewing component in CAPSI on providing DTT training to university students. A secondary purpose of the study is to extend previous research on using CAPSI to teach practical skills with a larger sample.

Materials and Methods

Participants and Setting

Forty-five potential participants were recruited from two university sites in Canada. From these participants, 32 participants (Site 1 = 17, Site 2 = 15, Dropouts = 13) completed the study. Participants were randomly assigned to either the Student Peer Review (SPR) condition ($n = 16$) or the No SPR (NSPR) condition ($n = 16$). Participants completed baseline, training, and post-training sessions in university research laboratories or in a private room at the treatment centre in Winnipeg, under the supervision of a trained research assistant (RA). Participants completed the training through WebCAPSI (http://www.capsiresearch.org/) for which a personal username and password were provided. Ethical approval was received from the Research Ethics Boards of both university sites.

A set of abbreviated instructions, a pen, materials appropriate to teach each one of the three tasks (see *teaching tasks and stimulus sets*), edibles, one datasheet for each task being taught, written knowledge assessments, a video camera, and a tripod were used in baseline and post-training.

Training was based on an 84-page self-instructional manual about how to teach DTT to children with developmental disabilities (Fazzio & Martin, 2012). The manual contains 12 chapters each of them accompanied by study questions covering the topic being described. Each chapter was associated with a unit assignment in WebCAPSI, except for chapters 11 and 12, which were merged together due to their limited length. Additional questions that were developed specifically for the purposes of this study were also used (see *supplemental questions*). The WebCAPSI system was accessed through a computer connected to the Internet.

Measures

Demographic questionnaire. This questionnaire asked 11 questions pertaining to the participant's age, gender, university courses taken, previous applied behaviour analysis (ABA) training and whether English was their first language. Table 1 summarizes the demographic information of the two groups.

Table 1. Characteristics of Participants

	Student Peer-Review Group	*Non-Student Peer-Review Group*
N	16	16
Females/males	10/6	12/4
Age range (years)	18 – 40	18–29
Mean years in university	3.6 (SD = 2.09)	2.7 (SD = 2.92)
English is first language	*N* = 10	*N* = 13
Participants with ABA course experience	*N* = 4	*N* = 5
Participants with ABA training	*N* = 1*	*N* = 4

*Note: * Represents intervention plan training*

Supplemental questions. In order to assess and teach higher-order thinking as originally defined by Bloom's Taxonomy (1956), and later modified by Crone-Todd, Pear, and Read (2000), additional questions called supplemental questions were developed and incorporated to the study questions in the manual (i.e., manual-original questions). Bloom's Taxonomy allows for classifying questions by their level of difficulty, which ranges from 1-6. The first three levels of Bloom's Taxonomy are characterized as "lower level." Level 1: *Knowledge,* involves recalling facts, terms, and basic concepts. Level 2: *Comprehension,* involves understanding the meaning of information. Level 3: *Application*, involves using knowledge in novel situations. The next three levels are characterized as "higher level." Level 4: *Analysis*, involves examining information and generating relations between pieces of information. Level 5: *Synthesis*, involves compiling information and proposing alternative solutions. Finally, Level 6: *Evaluation*, involves cogently arguing opinions and making judgments.

First, all manual-original questions were classified from levels 1-6. Chapters 1, 7, and 12 were then excluded because the content being described in those chapters was not sufficiently substantial for the development of higher-order questions (i.e., were either introductory or about the practical components of DTT procedures). Additional 1-6 level questions were then developed and divided into supplemental and reserved questions. The former set of questions was used as study questions along with the manual-original questions and inserted into the WebCAPSI system. The latter was used as part of the questions in the written knowledge assessments. The number of supplemental questions per chapter ranged from 6 to 22 questions covering all of the 6 levels. The question classification was done by two undergraduate students in psychology, one master's student, and one Ph.D. student who were carrying out research in applied behaviour analysis. The question development was done by the Ph.D. student and a postdoctoral fellow who was also carrying out research in applied behaviour analysis.

DTT knowledge assessment. To measure DTT knowledge, two versions – A and B of a written knowledge assessment – were delivered, one at baseline and one at post-training. Participants answered 10 short-answer comprehension questions covering the material in an 84-page self-instructional manual about how to teach DTT to children with developmental disabilities (Fazzio & Martin, 2012) plus the supplemental questions provided through handouts.

Assessment questions used in this study were assigned a difficulty level based on Bloom's Taxonomy (1956). A Ph.D. student and a postdoctoral fellow in ABA created the questions, while two undergraduate students in psychology, one master's student, and one Ph.D. student in ABA independently rated the questions according to their classification level. Interobserver agreement (IOA) checks were conducted for 25% of the questions and percent agreement was calculated by dividing the number of agreements by the number of agreements plus disagreements, and multiplying by 100. IOA on question levels averaged 94% (range = 88% to 100%). See Appendices A and B for the test questions (and their levels). IOA for the DTT knowledge assessment was conducted on 38% of the tests and was determined by comparing the marking of eight RAs on each assessment using an answer sheet. The RAs were arbitrarily divided in pairs and independently marked the tests. An agreement occurred when the two RAs in each pair scored the answer to a question the same (e.g., correct or incorrect), and a disagreement occurred when one RA said the answer was correct and the other RA said the answer was incorrect. IOA was calculated by dividing the number of agreements by the number of agreements plus disagreements, and expressing the result as a percentage. IOA on the DTT knowledge assessment across all pairs of RAs averaged 88% (range = 76% to 100%).

DTT performance assessment. The Discrete-Trials Teaching Evaluation Form (DTTEF) developed by Fazzio, Martin, Arnal, and Yu (2009) was used to score the DTT performance of each participant during baseline and post-training. The DTTEF contains 21 items to measure performance on how to: (a) prepare to conduct a teaching session defined by arranging teaching task, materials, reinforcer, and inviting the child to the table; (b) manage antecedents defined by checking task arrangements, securing child´s attention, and presenting instruction and prompt; (c) manage consequences and record data on standard trials; and (d) manage consequences and record data on error correction trials. A complete list of skills measured is available from the first author. The percentage of correct responses in the applied assessments was obtained by dividing the number of correct responses by the total number of components in the DTTEF. The DTT performance assessment was scored as the percentage of correct responses across three teaching tasks (matching, pointing, and imitation), with a RA role-playing an individual with ASD. This RA was given scripted cards that instructed them: (a) whether to attend to the participant, (b) what prompting level was required in order to respond to the participant, and (c) whether to respond correctly on each of the 12 trials. The scripts allowed the participant to experience different types of "learner" responses across the three tasks.

Stimulus sets for each teaching task were: (a) identity matching involving pictures of a cat, a house, and a tree; (b) pointing to pictures of a dog, balloons, and bananas upon hearing the spoken name of each picture; and (c) motor imitation (arms up, clap hands, and hands on lap). Each teaching task, if performed correctly, was carried out as follows. For the matching task, three cards were placed in a horizontal array on the table and a card identical to one of those cards along with the instruction *"Match"* was delivered. A correct response consisted of paring the sample to its correct comparison (i.e., the picture of a cat with the other picture of a cat). For the pointing task, three cards were placed in a horizontal array on the table and the spoken name of one of the pictures in the array was delivered. A correct response consisted of paring the sample to its correct comparison (i.e., the sound "cat" with the picture of a cat). For the imitation task, the model of the response to be emitted along with the instruction *"Do this"* was delivered. A correct response consisted of correctly imitating the action modeled. Most to least prompting (full physical guidance, light physical guidance, gestural, and no prompt) were used to encourage correct responding and were faded out across trials. Correct responses were followed by praise and edibles and incorrect responses were followed by an error correction procedure that included a 10-s pause with neutral facial expression, repetition of the trial, and prompt at the previous level to ensure correct responding. Correct responses on error correction trials were followed by praise. IOA checks were conducted on 29% of the test sessions across baseline and post-training sessions in both groups and were calculated by comparing the marking of eight RAs on each DTT task using the DTTEF. The RAs were arbitrarily divided in pairs and independently scored participants DTT applied performance. An agreement occurred when the two RAs in each pair scored an item in DTTEF the same (e.g., correct or incorrect), and a disagreement occurred when one RA scored the item as correct and the other RA scored as incorrect. IOA was calculated by dividing the number of agreements by the number of agreements plus disagreements, and expressing the result as a percentage. IOA for the performance assessment across all pairs of RAs averaged 88% (range = 58% to 98%).

Participant evaluation. This questionnaire, given immediately after the last training session, consisted of seven Likert-type questions measuring the subjective effectiveness of the intervention package received (SPR or NSPR). For example, the questions asked about whether the participants found the material easy and helpful in learning DTT, whether they felt prepared to use DTT with an actual child with ASD and whether they would complete future courses using CAPSI.

Procedure

Baseline. During the first session, all participants were asked to complete (a) a written DTT knowledge assessment, and (b) a role-played application of DTT assessment. The order of assessments was alternated across participants. Each participant was given 60 minutes to complete the 10-question knowledge assessment. The two versions of this assessment were randomly assigned across participants by alternation such that each version was used an equal number of times.

Before beginning the application assessment the participant was given 10 minutes to read one page of instructions about how to teach each of the three tasks (matching, imitation, and pointing). After reading the instructions, the participant was asked to teach each of the three tasks to the RA role-playing a child with ASD. For each task, the DTT application assessment continued until (a) 15 minutes elapsed, or (b) the participant taught 12 trials, or (c) the participant indicated that he wanted to stop. RAs did not give participants any feedback or respond to their questions. In total, each participant taught three tasks (12 trials each), with the order of the three tasks counterbalanced across participants and remained the same for baseline and post-training. All sessions were video recorded for later scoring. After completing all assessments in the baseline phase, each participant received a $10 honorarium regardless of their performance.

DTT CAPSI training for NSPR group. After baseline both the NSPR and SPR groups were provided with the DTT self-instructional manual. The NSPR participants were instructed to read the manual, stopping at the end of each chapter to write the corresponding three short-answer question mastery-based CAPSI unit assignment. Participants were given 60 minutes to write each assignment. The three question assignments were randomly generated by the WebCAPSI program from a pool ranging from 6 to 14 questions per chapter. A research assistant would immediately grade and give feedback to the participant via WebCAPSI. The mastery criterion for each unit assignment was 100%. In cases where mastery was not met, the participant studied the chapter again and rewrote the assignment until 100% was achieved. If a participant disagreed with the RA's grading they could submit an appeal. In total the NSPR group needed to pass 11 unit assignments.

DTT CAPSI training for SPR group. The participants in the SPR condition followed the same procedure as the NSPR group, but after each regular unit assignment, SPR participants were instructed to complete an additional assignment that required them to review answers to three study questions and provide feedback on the answers if errors were detected. The additional assignment was intended to simulate the process of peer-review. Participants in the SPR group did not receive information on the process that generated the SPR assignments. A guideline for determining the level of correctness of answers to those questions was developed (available from the first author). The overall number of correct, partially correct, and incorrect answers to the training questions were equal. When the SPR participants passed 11 unit assignments and completed 11 SPR assignments (whether they passed all 11 SPR assignments or not) they entered the post-training phase.

Post-training. The post-training procedure was identical to baseline, plus the participants completed the Participant Evaluation Questionnaire described above. After completing the post-training phase, each participant received an honorarium of $90 regardless of their performance.

Procedural integrity. All RAs video-recorded themselves carrying out the procedures during all sessions in each phase (i.e., providing participant with a brief study summary, baseline, and post-training). Procedural integrity was measured for 24% of the sessions across all phases and averaged 92.2% (range = 79.09% to 100%).

Results

A mixed-design ANOVA was used to compare the mean scores of the SPR and NSPR groups in baseline and post-training. Table 2 provides the means and standard deviations for scores on both the DTT knowledge and DTT performance assessments. All measures showed statistically significant main effects of time (baseline vs. post-training) on knowledge, $F[1, 30] = 146.6$, $p < .001$, and on performance, $F[1, 30] = 62.32$, $p < .001$. No assessment showed a statistically significant main effect of condition (SPR vs. NSPR) nor a significant interaction between time and condition. The mean number of minutes to complete a CAPSI Unit was 10.00 ($SD = 3.23$) and 10.48 ($SD = 5.55$) for SPR and NSPR groups, respectively. The average time SPR participants ($N = 16$) spent completing baseline, training, and post training phases in minutes was 82, 447, and 60, respectively. The average amount of time NSPR participants ($N = 16$) spent completing baseline, training, and post training phases in minutes was 115, 350, and 60, respectively.

Discussion

The results indicate that the self-instructional manual delivered through WebCAPSI is an effective method for teaching students DTT knowledge and applied performances. Supplemental training using simulated peer review did not yield greater improvement in the SPR group compared to the NSPR group. The latter finding is not consistent with other CAPSI studies that have found SPR to be beneficial in university courses (Lambert, 2009; Martin, Pear, & Martin, 2002). Unlike peer review in previous studies, our participants did not have a vested interest in the course (Lambert, 2009; Martin et al., 2002) or had a choice whether to do peer reviewing (Zaragoza Scherman et al., 2015).

The peer-review component did not produce differences between groups and this explains, to a large extent, why written-knowledge performance improvement was not observed during post-training. Therefore, it appears that the SPR training in this study was insufficient and it would not be expected to have an effect on DTT knowledge and performance. Future research should augment SPR training with more and varied training trials and add stronger reinforcement for correct responding. SPR training effects might also be enhanced by including participants who are more motivated and knowledgeable of ABA (e.g., EIBI trainees) rather than research volunteers, making peer reviewing an optional part of CAPSI, adding mastery criterion to the SPR training, offering real life opportunities for peer review and providing feedback on actual peer review performance. For instance, Zaragoza Scherman et al. (2015) found that peer-reviewing became more likely after it was made optional rather than mandatory in a DTT CAPSI-taught course. Also, Iwata, Furmedge, Sturrock, and Gill (2014) observed that experience in a course, as measured by the comparison between veteran and beginner students, accounted for peer-review effects.

Table 2. Mean Percentage on DTT Knowledge, DTT Performance (%) and SPR Video Assessments (Raw Numbers) in the SPR and NSPR Groups

Condition	*Mean Baseline (SD)*		*Mean Post-training (SD)*	
DTT Knowledge Assessment				
SPR	17.98%	(15.35)	51.25%	(15.17)
NSPR	19.12%	(15.35)	55.43%	(15.17)
DTT Performance Assessment				
SPR	41.18%	(10.91)	66.54%	(17.92)
NSPR	45.39%	(10.91)	73.72%	(17.92)

This study had several limitations including relatively small sample sizes. Also, the fact that the supplemental materials were provided in handouts may have limited the contact of the participants with the supplemental questions to a large extent, as information obtained through non-systematic observation revealed; in other words, we noticed that many participants would study questions in the manual only and not interact with the supplemental questions. Other limitations included lack of mastery criterion for SPR training, and lack of feedback and contingencies for SPR performance. Future research should investigate how feedback and progressing through the course contingent on mastery in each unit assignment affect SPR knowledge and applied performances. A final limitation was that the study consisted of a simulated training rather than an actual DTT staff training. The rationale for this was that the simulated peer-review was arranged in a particular way in order to be evaluated (e.g., was a requirement rather than optional, consisted of made up questions and were administered during supervised sessions); the simulated training was the way that the researchers found to maintain the experimental environment constant with respect to the remaining programmed variables.

In conclusion, this study furthers the research on using self-instructional online programs based on Keller's Personalized System of Instruction (Kinsner & Pear, 1998; Pear & Crone-Todd, 1999; Pear & Novak, 1996). Specifically, given the growing demand for ABA training, CAPSI can be used to teach ABA-based strategies such as DTT to a large number of individuals who need training.

Key Messages From This Article

People with disabilities. The extent with which you achieve success in your life is the extent with which we expect to be relevant to society.

Professionals. A career in this field requires not only the ability to teach but also the desire to learn.

Policymakers. Public policies measurement systems need to be constantly evaluated to ensure the quality of the data obtained and to assess the need for improvements.

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APPENDIX A
Written Test (Version A)

1. Define ABA. (level 1)
2. Describe the procedure and the result of the principle of positive reinforcement. (level 1)
3. Compare and contrast the use of social reinforcers and activity reinforcers, including what might be the advantages and/or disadvantages of each would be. (level 4)
4. What is a child required to do in a visual non-identity matching task? Give an example. (level 1)
5. Suppose that a teacher teaches a child to type a word by holding the student´s finger to press the keys. Knowing that there are other types of prompt (e.g., gestural, vocal, modelling, and environmental prompts), to what extent do you consider that the teacher chose the most appropriate type of prompt – physical prompt – for the above task? Justify your answer. (level 6)
6. What is the meaning of mastery criterion? Give an example. (Level 1)
7. What type of prompt was given on the first three trials, and did the child respond correctly or incorrectly on each trial? (level 3)

Trials	**Position of Pictures on Table**			**Picture to Give to Child**	**Standard Trials***		**Error Correction Trials***	
	Cat	**House**	**Tree**		**Correct**	**Error**	**Correct**	**Error**
1	**R**	**M**	**L**	**Cat**	**✓F**			
2	**L**	**R**	**M**	**House**	**✓F**			
3	**M**	**L**	**R**	**Tree**	**✓F**			
4	**R**	**M**	**L**	**House**	**✓P1**			
5	**L**	**R**	**M**	**Tree**	**✓P1**			
6	**M**	**L**	**R**	**Cat**	**✓P1**			
7	**R**	**M**	**L**	**Cat**		**XP2**	**✓P1**	
8	**L**	**R**	**M**	**Tree**	**✓P2**			
9	**M**	**L**	**R**	**Cat**	**✓P2**			
10	**R**	**M**	**L**	**House**	**?**			
11	**L**	**R**	**M**	**Cat**	**?**			
12	**M**	**L**	**R**	**House**	**?**			
13	**R**	**M**	**L**	**House**	**?**			
14	**L**	**R**	**M**	**Tree**	**?**			

8. How might you go about developing rapport with a child prior to a session? (level 2)
9. On a trial, a tutor claps her hands and says "Do this." Suppose that an error (e.g., waving hands) is in the process of occurring. What the tutor should do to block the error? (level 3)
10. Describe the response-cost punishment procedure. (level 1)

APPENDIX B
Written Test (Version B)

1. Who are behaviour analysts? (Level 1)
2. Define punisher and give an example. (Level 1)
3. Compare and contrast the use of social reinforcers and activity reinforcers, including the advantages and/or disadvantages of each. (level 4)
4. What is a child required to do in a visual non-identity matching task? Give an example. (level 1)
5. Describe how you would teach a child to recycle empty plastic water bottles using modeling prompts. (level 3)
6. What is the meaning of "mastery criterion?" Give an example. (level 1)
7. Suppose that a teacher opts to use DTT for educating a child with autism whereas another teacher opts to use a non-systematic method for teaching another child with autism. Assuming that both teachers have similar experience in teaching, and that both children have similar learning histories, which one of the teachers would likely be more successful in teaching the child in your opinion? Justify your answer. (level 6)
8. What is a standard DTT trial? (level 2)
9. On a trial, a tutor claps her hands and says "Do this." Suppose that an error (e.g., waving hands) starts to occur. What should the tutor do to block the error? (level 3)
10. Describe the response-cost punishment procedure. (level 1)

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Understanding Implementation of Frailty Measures Among Adults with Intellectual and Developmental Disabilities

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Abstract

As the general population ages, there has been greater interest in frailty measures to inform clinical practice and policy decisions. The population of adults with intellectual and developmental disabilities is also aging, and Canadian policymakers have expressed the need to monitor and treat their aging-related conditions as early as possible. Outside of Canada, two research teams in the field of intellectual and developmental disabilities have developed frailty measures, although neither frailty measure has yet been used to support policymaking. The purpose of this study is to understand the factors contributing to implementation of a frailty measure in populations of adults with intellectual and developmental disabilities. Key informants from each research team were interviewed about knowledge translation experiences. Interview questions were guided by the World Health Organization's Ageing and Health Knowledge Translation Framework, which is used to integrate evidence-based strategies and aging-related health policy, processes, and programmes. Transcripts were subsequently analyzed using the framework approach. Key findings included the following: To be implemented in practice, a frailty measure must be brief, relevant, and inform care decisions. The interviews revealed actions that should be taken prior to knowledge translation. These actions include ensuring that the frailty measures are valid and have a clear purpose, and collaborating with appropriate knowledge users. Linkages between frailty researchers and practitioners and policymakers are key to successful implementation of measures developed. Lessons from this study may be used to implement frailty measures in a Canadian population of older adults with intellectual and developmental disabilities.

As the number of Canadian older adults (65 years and older) reached nearly 5 million in 2011 (Statistics Canada, 2012), health care providers face an increase in both the number and types of health, economical, and social challenges (Lefebvre & Goomar, 2005). It is well-known that older adults are at risk of chronic conditions, mobility issues, dementia, and mental health problems (Taylor, 2014). Such concerns have led researchers to develop and use measures of frailty to better identify at-risk older individuals. Frailty is understood to be a multidimensional construct with physical, mental, physiological, social and environmental factors (Rodríguez-Manas et al., 2013). It is associated with increasing age and adverse outcomes (e.g., falls, decreased mobility, institutionalization, hospitalization, and death) (De Lepeleire, Iliffe, Mann, & Degryse, 2009; Rockwood, 2005).

On average, the population of adults with intellectual and developmental disabilities (IDD) experiences age-related co-morbidities and vulnerabilities prematurely. For this reason, individuals in this population are often viewed as "old" by age 50 years (Evenhuis, Hermans, Hilgenkamp, Bastiaanse, & Echteld, 2012; Ouellette-Kuntz, Martin, & McKenzie, 2015; Perkins & Moran, 2010; Schoufour, Mitnitski, Rockwood, Evenhuis, & Echteld, 2013), although this varies depending on IDD severity and diagnosis. Over a decade ago, the Government of Canada's National Advisory Council on Aging made the recommendation to: "regularly monitor [the health of adults with IDD] as early as 40 years of age in order to detect and treat changes in sensory and cognitive functioning and chronic health problems as early as possible" (Government of Canada National Advisory Council on Aging, 2004, p. 7). This acknowledgement is commendable but there is little evidence that the recommendation has led to systematic action. In a population with lifelong disability and frequent co-morbidities, it is a challenge to identify new vulnerabilities and functional declines (Evenhuis, Schoufour, & Echteld, 2013). As a result of increasing longevity (Bittles et al., 2002; Coppus, 2013; Patja, Iivanainen, Vesala, Oksanen, & Ruoppila, 2000) and growing numbers of older adults in general (Statistics Canada, 2011), the need to act on the Council's recommendation becomes all the more pressing.

Our recent scoping review revealed that only a few studies have specifically reported on frailty measures among populations with IDD (McKenzie, Martin, & Ouellette-Kuntz, 2016). Brehmer and Weber (2010) were the first to develop a frailty measure while considering the lifelong disability and early aging of this population: the Vienna Frailty Questionnaire for persons with Intellectual Disability (VFQ-ID), followed by the VFQ-ID-Revised (VFQ-ID-R) (Brehmer-Rinderer, Zeilinger, Radaljevic, & Weber, 2013). Three years later, Schoufour, Mitnitski, Rockwood, Evenhuis, and Echteld (2013), as part of the Healthy Ageing and Intellectual Disability (HA-ID) study, published a frailty index for individuals with IDD over 50 years of age. McKenzie, Ouellette-Kuntz, and Martin (2015) also developed a frailty index for home care users with IDD. See the recent scoping review by McKenzie, Martin, & Ouellette-Kuntz (2016), which compares and contrasts these measures. From these limited results, frailty appears to occur earlier in adults with IDD compared to those without IDD (McKenzie, Ouellette-Kuntz, & Martin, in press; Schoufour et al., 2013). Frailty is associated with the same outcomes afflicting the general population, including institutionalization (McKenzie, Ouellette-Kuntz, & Martin, 2016), disability (Schoufour et al., 2014), sarcopenia (Bastiaanse, Hilgenkamp, Echteld, & Evenhuis, 2012), higher medication use (Schoufour, Echteld, Bastiaanse, & Evenhuis, 2015) and mortality (Schoufour, Mitnitski, Rockwood, Evenhuis, & Echteld, 2015). While many measures of frailty exist in the general population, these measures may not be suitable to the population of adults with IDD given their life-long disability that can incorrectly appear as indicators of frailty (Evenhuis et al., 2013; McKenzie, Ouellette-Kuntz, & Martin, 2015a).

The existence of frailty measures allows for the possibility of acting on national recommendations to better monitor and detect early changes in functioning through implementation of frailty measures to improve care, inform policy and understanding of aging with IDD. Generally, however, it is difficult to find published literature on frailty assessments in practice, and there is no literature on such implementation for adults with IDD.

Before care providers and policymakers can use frailty tools, researchers must engage in knowledge translation to bridge the "know-do" gap (World Health Organization [WHO], 2006). In Canada, Graham and Tetroe's (2009) definition of KT has been widely adopted in health research: "a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system" (p. 46). The Canadian health care system increasingly acknowledges KT as an important function in the research process (Lavis, 2006); as such, knowledge users may be receptive to research-based frailty measures. This study aimed to understand the factors contributing to implementation, or lack thereof, of frailty measures in the field of IDD to inform future initiatives within Canada.

Materials and Methods

The study protocol was reviewed and approved by the Queen's University Health Sciences Research Ethics Board.

Recruitment and Participants

We contacted members of the two research teams who have published research on measures of frailty in populations with IDD. Two individuals from each team were interviewed (total N = 4).

Interviews

The development of the interview questions was guided by the World Health Organization's Ageing and Health Knowledge Translation Framework, which provides an approach to integrating evidence-based strategies and aging-related health policy, processes, and programmes (WHO, 2012). This framework has seven key elements:

(1) **Climate and context for research use.** The local context takes into consideration the characteristics, circumstances, and conditions of research and policy practices, with respect to aging and health.

(2) **Linkage and exchange efforts.** The linkage and exchange between researchers and knowledge users, policymakers, and stakeholders can enable informed policymaking and the transfer of research intro practice.

(3) **Creation of new knowledge.** Knowledge creation can influence evidence informed policymaking, if the research is timely, relevant and applicable.

(4) **Push efforts.** Activities by researchers and intermediate groups to push knowledge to the necessary groups in an appropriate format should be jargon-free and highlight actionable messages.

(5) **Facilitating pull efforts.** Efforts to facilitate a pull from knowledge users aim to make it easier for policymakers to acquire relevant research evidence.

(6) **Pull efforts.** Knowledge users embark on pull efforts when they value the use of research and recognize the presence of an information gap.

(7) **Evaluation of efforts to link research to action.** Evaluation is needed on the activities that support the linkage of research to better advise future knowledge translation events.

Interview questions (and probes) were designed to elicit information on participants' experiences implementing a measure of frailty and relationships with knowledge users. Additional information on participants' role in developing frailty measures was noted.

Participants from the same research program were interviewed together for approximately one hour. Interviews were audio-recorded to allow verbatim transcription for analysis.

Analysis

The interview was structured around pre-set research objectives (i.e., understand factors contributing to frailty measure implementation). Pope, Ziebland and Mays (2000) presented a deductive, framework approach to qualitative data analysis, which we applied in this study. The five steps of this approach involve:

(1) **Familiarization.** All authors immersed themselves in the data by reading the two transcripts to become aware of key ideas (referred to as "codes"). Each researcher suggested different ways of understanding and summarizing the findings.

(2) **Identifying a thematic framework.** The authors based coding on the seven core elements of the Ageing and Health Knowledge Translation Framework (WHO, 2012).

(3) **Coding.** The authors independently coded the transcripts according to the framework, and created new codes as needed. Next, the authors reviewed the codes together to reach agreement. Supporting quotes were identified.

(4) **Organizing the index.** The authors structured the codes into major themes.

(5) **Mapping and interpretation.** The researchers reviewed themes and explored the relationships between themes to explain the results.

The analysis adhered to the principles of naturalistic inquiry (Lincoln & Guba, 1985) to ensure dependability, credibility, and transferability.

Results

Selected quotes are included in Table 1 (on the following page) for each of the elements of the Ageing and Health Knowledge Translation Framework (WHO, 2012).

Context

In the Netherlands, only individuals with IDD with high support needs live in care settings, the remainder live in the community with family or in small group homes. Care is organized and provided regionally. No specific organization has a mandate dedicated to aging adults with IDD. Key informants viewed aging issues as the responsibility of all providers regardless of sector (e.g., health, social, disability).

In Austria, care providers vary from province to province, with a blend of non-governmental organizations, government, and private organizations in each of the nine jurisdictions. In Upper Austria, for example, support is determined based on the level of disability, which is identified using one measure. Individuals with IDD often age without extra medical care, as their allotted funds will not cover the cost of additional nursing support. Care plans are also sometimes based on outdated assessments.

Linkage and Exchange Efforts

In the Netherlands, there was no ongoing partnership between frailty researchers and policymakers. While care providers, such as non-profit organizations, may fund extensive research projects, there is no requirement for ongoing exchange of findings. For example, the organization that funded the multi-year HA-ID study required only a final summary report of results. Key informants viewed this partnership positively, and appreciated the freedom to conduct scientific research without intrusion by the funder.

One of the participants also noted the importance of improving the ability to link health data across jurisdictions and at the population-level, as well as permitting researchers to access that data. It was acknowledged that stronger partnerships with government were needed for this to happen. In Austria, more substantial research-stakeholder relationships and linkages appeared to exist. For example, one informant described a working group of service providers and researchers that developed a scale of support needs – though it was noted that this scale was not implemented into practice.

An instance in which the key informant herself played both the role of researcher and service provider, helped to bridge the gap and resulted in a more effective partnership. Here, the researcher worked with employees to develop a tool to understand aging within their clientele that could also objectively determine and prioritize areas for care improvement.

Knowledge Creation

Both groups of key informants spoke to the current use of frailty measures in practice. In the Netherlands, the frailty index has exclusively been used for research purposes. However, the need for a frailty measure that is relevant to practice was recognized by clinicians, who wanted something standardized, brief and easy-to-administer. While the frailty index developed by the HA-ID study team is relevant and timely, it is not likely applicable in its current state. Future work to develop and validate a shortened version is required for it to be used in practice.

In Austria, the frailty measure developed "in-house" by the researcher for the implementation within the organization, and so the focus to date has been on data collection and application to practice by the agency. This data could be useful for future work, for example, determining frailty outcomes and best practices.

Push Efforts

Knowledge was pushed by key informants from the Netherlands using a traditional, academic model, including conferences and published papers. Most of the papers were published in peer-reviewed journals targeting audiences interested in IDD, although some were also published in general aging journals (i.e., *Journal of the American Geriatrics Society*).

Table 1. Selected Quotes to Demonstrate the Ageing and Health Knowledge Translation Framework

KT Framework	*Netherlands*	*Austria*
Context	"We wanted to get an idea about how frail they were, and how they age, and can you compare that with the general population. Are they all frail, and are there any differences between these groups? And not immediately for clinical practice, maybe for information to get to know the population better." "This funding by the government … it's new, they have funding for people, not only aging, but for people with ID, to do research, to stimulate research. So they do care."	"There are different policies within the Lebenshilfe [community living] in Austria. Some are setting up in old people's house, others just want to integrate. They live over there, and they are supported over there, where they are getting older. But then when the medical system is getting higher, then sometimes they will change. Because in the disability services, they operate without nurses, it's a more social, education approach… If you need support for extra medical care, when you are getting older, then this rate they offer you will not cover the cost for more expensive nurse."
Linkage and Exchange Efforts	"…they select the best quality scientific study, but they don't interfere with the content. But you do have to report back…" "I've read studies in other countries where they extract data from general practitioners, but we cannot do that… I think it's technically possible that they're all connected to each other, but I'm not sure how. It's new. It's mostly for care reasons now."	"Employees were asking for a tool to follow up on aging to see which area of the daily living needs more attention- *really* needs- because some say the person is wobbly on the feet, and the other person says no, he can do it well…. My employees are annoyed when they have to fill in a questionnaire that has no point for their daily activities"
Knowledge Creation	"I think [the frailty index] could definitely it could be implemented, but it would have to be shorter. It is really long now and there are some extensive measurements in there. Blood measurements, and the block and block test …it takes a lot of time, and it would not be feasible to implement the full FI into practice. But you could shorten it and validate it again. And then, I think it could be used."	"But we're not a research institute, so we just collect on an individual basis…We do not have the resources to collect data. But it would be possible…You can do it on the individual level and it's very helpful, and on a health planning on the individual level, but we have group homes of six or seven people and they are currently 56 years old or 57, so we know in 10 years the health of the whole group will change, and we will certainly need a nurse for the whole group. So we can follow for all the persons with the [VFQ-ID-R] for health status and decide the time to reassess with the province and when to employ a nurse for the whole group. So you could use it on the higher level as well, in the service provider."

Table 1. Selected Quotes to Demonstrate the Ageing and Health Knowledge Translation Framework (continued)

KT Framework	*Netherlands*	*Austria*
Push Efforts	"I think, as a clinician… it would be very interesting to see if interventions can improve [health], and that's something clinicians are interested in."	"Sometimes there are links between service providers and researchers, but normal, lasting continuations with Lebenshilfe… very often the two systems are not linked in a continuous way. That is atypical what we have here."
Facilitating Pull Efforts	n/a	"There were subjective views… what is the situation for the person, really? …That's why I introduced [the scale]…The other reason is that employees were not sure when to call for a doctor and ask for a thorough health examination. The scale also helps to see OK, in the past 6 months, the person experienced five deteriorations in these areas, so now we should go see a doctor, and tell the doctor about this skill skills lost."
Pull Efforts	n/a	n/a
Evaluation Efforts	"The granters want to hear about [our initial report]. But it's not a real evaluation, because we did not implement anything."	n/a

However, as one of the key informants is a clinician, knowledge is likely pushed out informally as well (e.g., through discussion with individuals with IDD, families, and other staff).

In Austria, the relationship between the research team and the Lebenshilfe of Upper Austria (a community-based agency that provides residential, vocational, and other community-based programs, equivalent to a Community Living agency in Ontario) allowed the uptake of the frailty measure by employees. This research team also pushed knowledge through publication of papers on their measure (i.e., VFQ-ID-R).

Facilitating Pull Efforts

The VFQ-ID-R developers considered the preferences of on-the-ground staff members who provided daily care to individuals with IDD. Care providers did not see the benefit of administering lengthy interviews and questionnaires if they found it redundant without providing any benefit to the individuals for whom they provided care. They desired an objective measure that would reduce the confusion between staff members trying to determine the level of functioning of their clients. Employees were also unsure when to ask for medical attention from a doctor, and requested a formal indicator. As a result, and to meet these practical needs, the items in the VFQ-ID-R are multi-dimensional, encompass areas of functioning of interest to care providers, and emphasize changes in health status and functioning to signal the presence of deterioration and need for action.

Pull Efforts

None of the informants were aware of pull efforts by knowledge users. They remained focused on furthering their research using frailty measures, and less on exploring implementation opportunities.

Evaluation Efforts

None of the key informants had participated in formal evaluation efforts of activities aimed at implementing the measures in practice.

Discussion

The seven elements of the Ageing and Health Knowledge Translation Framework were addressed to varying degrees through the key informant interviews. Both teams were able to speak to the **context,** and explained the role of their respective social and health care systems in addressing aging in the population: neither had an organization specifically dedicated to aging individuals with IDD, and both had systems with a wide range of care setting options. In Austria, there were strong **linkage and exchange efforts**, which was largely due because one of the researchers was also a care provider, and was able to both develop a tool and implement it to improve care in her organization. In the Netherlands, research on frailty was primarily contained to the academic universe, although clinicians and care providers collaborated and were involved in data collection. Both groups were involved in **knowledge creation** – i.e., developing their unique frailty measures. The results were published in academic journals, which reflected their knowledge **push efforts**. However, these journals were primarily in the field of IDD. Publishing in journals that focus on geriatrics or aging in general, rather than on those focused on IDD, may help to increase interest in and knowledge about frailty among those with IDD. The team in Austria was able **to facilitate pull efforts**, by working with the organization to develop a frailty measure that was both scientifically rigorous and helpful to employees who could use it with their clients. Neither group of key informants clearly indicated **pull efforts** and **evaluation efforts.**

The interviews highlight two different approaches to developing a frailty measure, each appearing to have distinct purposes. Having been developed with care providers, the frailty questionnaire (VFQ-ID-R) is used in practice in Austria, whereas the frailty index, developed and validated within an academic environment in the Netherlands, is not. While research is ongoing in the Netherlands, it has ceased in Austria, largely due to limited resources available within the organization for academic endeavours.

These interviews revealed three important actions that should be taken prior to knowledge translation to facilitate uptake of frailty measures in practice and policy in the field of IDD. First, a clear purpose for the frailty measure must be articulated. The need for a clear purpose has previously been identified in frailty-related research as key to determining the approach to measurement (Cesari, Gambassi, van Kan, & Vellas, 2014). In Austria, the measure was developed with the purpose of being an objective indicator of decline in functioning that could inform future care activities (e.g., physician referral, medication monitoring). This specific purpose also aligns with goals of frailty tools in general: to understand frailty and its biology; to diagnose and care planning; to be an outcome measure; and to stratify risk (Rockwood, Theou, & Mitnitski, 2015). The HA-ID frailty index also aligns with these goals, and those related to understanding frailty and risk stratification in particular. To be used as a screening or diagnostic tool, modification of the HA-ID frailty measure is likely warranted.

The second action must be to establish the validity of the frailty measure. Four stages are documented for building a predictive measure in practice: development, validation, impact analysis, and implementation (Adams & Leveson, 2012). In research, the first two stages have plenty of evidence (Rockwood et al., 2015), and our key informants have published multiple articles on development and validation (for example, see Brehmer-Rinderer, Zeilinger, Radaljevic, & Weber, 2013 and Schoufour et al., 2013). However, the next stage should also be explored, and could take the shape of a cost-benefit analysis or an implementation feasibility trial (De Lepeleire et al., 2009).

Our last important action must be to facilitate explicit collaborations with knowledge users familiar with general practice and important outcomes. Both early and continued collaboration are required to ensure that the frailty measures developed are useful, relevant, and appropriate to individuals with IDD and the care providers who will use them. A close relationship can facilitate and support a relatively quick uptake of frailty measures into practice, as evidenced by the use of the VFQ-ID-R in Upper Austria.

These key findings highlight the difficulty experienced by researchers in many jurisdictions in moving research beyond academia. In Ontario (Canada), our research team has developed and maintained good linkages with knowledge users in both practice and policy over the course of the development of a frailty measure specific to adults with IDD since the project's inception. This appears slightly different from the approach taken by the other two teams, who focused on either the research outputs (i.e., the Netherlands) or practice implications (i.e., Austria). Beyond regular discussions with knowledge users to inform the research, the frailty measure developed by our team relies on clinical data obtained from an assessment used as part of regular clinical practice (McKenzie, Ouellette-Kuntz, & Martin, 2015a). Results can also be aggregated for use by policy and decision-makers. It is hoped that this embedded connection to both practice and policy, in addition to continued consideration of the purpose, development stages, and needs of knowledge users (who are also collaborators) will lead to easier implementation of the frailty measure for persons with IDD and facilitate its use in decision-making in Canada.

Key Messages From This Article

People with disabilities. Research shows that people with intellectual and developmental disabilities become frail earlier than people without disabilities. This is important for clinicians and policymakers to know. They must all work together to make sure that research gets used in real life.

Professionals. Brief and relevant frailty measures may be implemented in practice to better serve individuals aging with intellectual and developmental disabilities.

Policymakers. Linkages between researchers, policymakers and practitioners are vital to the development and implementation of measures to support aging care.

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HELP with Behaviours That Challenge

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Abstract

*When individuals with intellectual and developmental disabilities engage in behaviours that challenge, their potential for full community participation, integration and quality of life is greatly compromised. Embedded in the acronym HELP (***H***ealth,* ***E****nvironment & Supports,* ***L****ived Experience,* ***P****sychiatric Disorder), this article describes a biopsychosocial multi-perspective understanding of these behaviours. HELP is an approach that can be embraced comfortably by all stakeholders (including individuals with intellectual and developmental disabilities and their families), empowers problem solving and has implications for effective intervention.*

Behaviours that challenge (BTC), otherwise known as "challenging behaviours," (National Collaborating Centre for Mental Health [NCCMH], 2015) are observed in people with intellectual and developmental disabilities (IDD) (DSM-5; American Psychiatric Association, 2013). Epidemiological studies estimate that BTC are present in 5–15% of the population with IDD (NCCMH, 2015) and occur more frequently in those with greater severity of disability (Cooper, Smiley, Allan et al., 2009a; Cooper, Smiley, Jackson et al., 2009b). These behaviours may start early, have a relapsing and remitting course and can challenge services and care providers. As a consequence, individuals engaging in these behaviours are frequently the recipients of intrusive interventions including the over prescription of psychotropic medication, particularly antipsychotic medication, giving rise to serious side effects, increased medical morbidity and mortality (Alexander, Branford, & Devapriam, 2016; Sheehan et al., 2015). BTC lead to reduced quality of life both for individuals so engaged, and their care providers as well as frequently preventing full community integration.

Some BTC, while being a concern to care providers, are not apparently distressing to the individual (e.g., some repetitive behaviours, hoarding) and do not result in any harm to self, others or property destruction. These behaviours might more appropriately be referred to as antisocial (i.e., annoying, irritating and outside of the social norm; Bradley & Korossy, 2015). Whether to intervene in these antisocial behaviours should be given careful consideration because intervention may obstruct a vulnerable individual's right to self-expression.

BTC that result in harm to self, others, or destruction of the environment, can best be considered as communications of distress by individuals unable to communicate their distress in more conventional ways. This distress may arise as the consequence of body discomfort (e.g., medical condition), from situations in their environment (e.g., over-stimulating surroundings giving rise to hyperarousal and meltdowns), from the interaction between personal, emotional and environmental circumstances (e.g., a task is too difficult or sadness about loss of a care provider), or it may signal psychiatric disorder. There may be multiple factors compounding the distress and confounding simplistic approaches to these behaviours. Attempts to treat without appreciating underlying cause can escalate the distress and exacerbate the situation to crisis proportions.

Systematic consideration of the personal and biopsychosocial complexities that give rise to expressions of underlying distress is paramount (Banks et al., 2007; Banks, Bush, & Other Contributors, 2016; Koritsas & Iacono, 2015). A robust diagnostic formulation embracing multidimensional circumstances, creates opportunities for collaborative problem solving, accurate diagnoses and person centred solutions (Holland, 2015; Jahoda, Willner, Pert, & MacMahon, 2013).

BTC have historically been referred to as "challenging" or "problem" behaviours or "behaviour problems," the latter sometimes even morphing into "behaviour disorders." All four descriptors create the impression that these behaviours are primarily a characteristic of the individual and consequently the focus of intervention is on trying to change the individual. "BTC" on the other hand implies an interaction between the individual and his/her environment and begs the question who is challenging whom (NCCMH, 2015). BTC is favoured by the present authors because (a) these behaviours arise in the context of an individual with unique needs in an environment that may not be optimally understanding or supportive of these needs (Banks et al., 2007; Banks et al., 2016) and (b) evaluations of both the individual, their physical-social environment and supports, are required for effective intervention and successful outcomes.

This article describes an effective, efficient (Goh, 2013) and sequential approach for understanding BTC. The HELP framework described here (Figure 1), provides a meaningful, intuitive and straightforward way to organize assessment, formulation and interventions across multiple domains of complexity. Essentially a biopsychosocial approach, HELP is unique in paying special attention to the emotional lives and needs of people with IDD (their "lived experience") and the contribution of unmet emotional needs to BTC (Bradley, Hollins, Korossy & Levitas, in press).

Tools associated with this HELP approach are also available online through the Developmental Disabilities Primary Care Initiative at Surrey Place Centre (2011). A recently published chapter provides more details, clinical tips and references to online resources (Bradley & Korossy, 2015) such as a booklet for care providers (Bradley & Caldwell, 2016). The Curriculum of Caring Agenda (http://machealth.ca/programs/curriculum_of_caring) embraces the HELP approach and self-advocates with IDD have given their voice to HELP through a musical adaption (https://vimeo.com/125914430) (Boyd, 2016).

HELP Framework and Approach for Understanding BTC

The HELP framework considers the aetiologies of BTC within four main conceptual themes: (1) Health; (2) Environments, supports and expectations; (3) Lived experience and emotional well-being; and (4) Psychiatric disorder (Figure 1). In the HELP approach these four areas are explored in sequential order so that those circumstances most frequently contributing to BTC are identified and addressed before assuming that any unusual or problematic behaviour must be of psychiatric origin.

These four themes are considered separately below. Suggestions for clinical practice (☺), and clinical vignettes (☺☺) are inserted at the end of each theme.

Case vignettes are in Appendix 3.

Health

Medical conditions can give rise to BTC (Appendix 1). In this context, the BTC are signals, or put another way, communications from the individual of physical discomfort or pain they are experiencing (Appendix 2). Individuals with IDD vary in their capacity to communicate to others that they are experiencing physical discomfort or are in pain (Boardman, Bernal, & Hollins, 2014). Even those who use words may not spontaneously share their suffering with others unless specifically asked or prompted. However, care providers using effective communication strategies such as simple language, gestures and visuals (e.g., Books Beyond Words: Bradley & Hollins, 2013), enhance opportunities for individuals with IDD to alert care providers to their physical suffering; such detection paves the way for early intervention before pain-related behaviours escalate. For those individuals with limited or no language, care providers need to be attuned to small changes in facial expression or other body language that may signal that something is wrong (Caldwell, 2013; Leicestershire Partnership NHS Trust, 2013). Best practice guidelines in IDD recommend routine health screening (e.g., annual health checks) (Robertson, Hatton, Emerson, & Baines, 2014), and when BTC arise, review of physical status and examination (Sullivan et al., 2011).

Health – Helpful tips:

(1) Consider "head to toe" health when reviewing physical status (so as to cover all aspects of the body);

(2) identify the cause (aetiology) of the IDD (e.g., a syndrome) as different IDD aetiologies have increased prevalences of different health issues that need attention throughout the lifespan (e.g., thyroid and celiac disease in Down syndrome);

(3) screen for these syndromes/aetiological associated medical conditions;

(4) identify and document each individual's unique response to pain (e.g., such as may occur when exposed to a circumstance generally considered to be painful) and document in case notes for future reference.

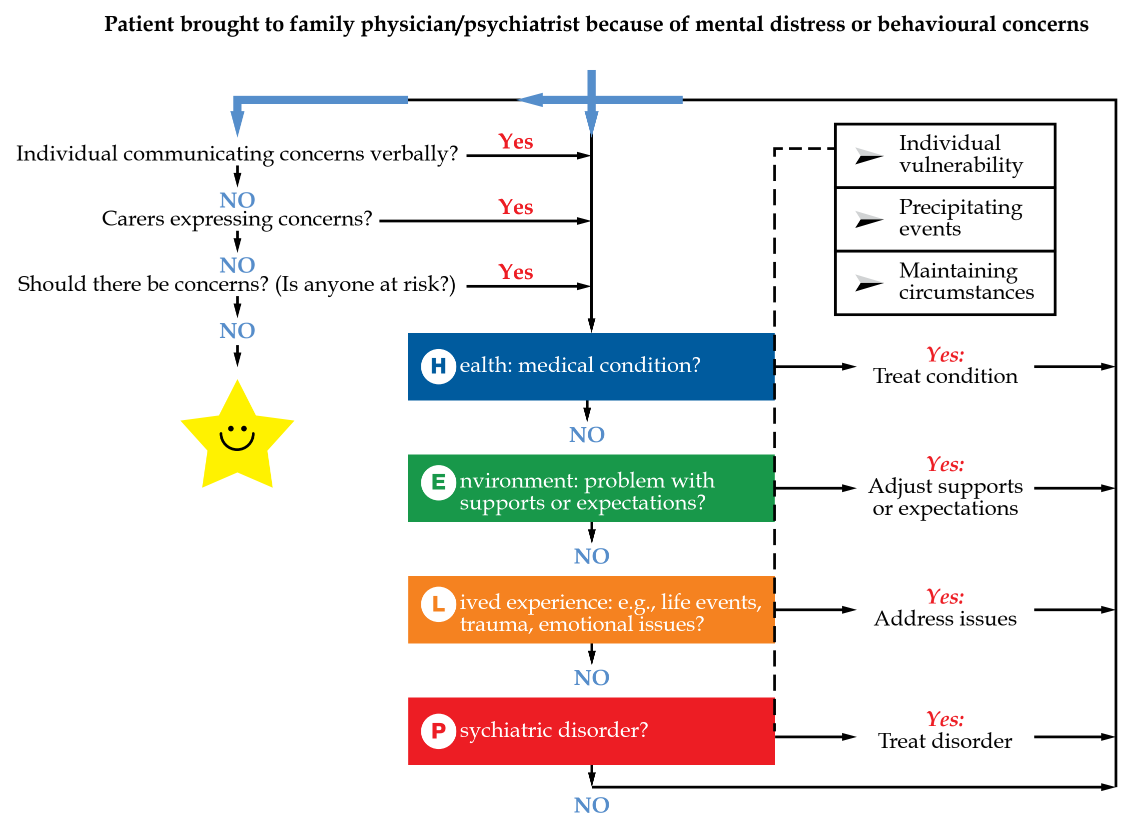

Figure 1. Understanding behaviours that challenge. A guide to assessment and treatment.

Reproduced from Bradley, E. & Korossy, M. (2015). Chapter 5: Behaviour problems. In M. Woodbury-Smith (Ed.), Clinical topics in disorders of intellectual development (pp. 72–112). London, UK: Royal College of Psychiatrists Publications. copyright© Elspeth Bradley, 2014.

☻☻ **Clinical vignettes:** Jane and Yvonne (see Appendix 3)

Environment, Supports and Expectations

Environment in this framework embraces family and social networks, as well as physical surroundings. Environment even includes the layout of places where people live, work and play and how they travel between these places (NCCMH, 2015). Supports and services can be broadly described as what is needed to enable full participation of all citizens in the communities in which they live (Ontario Ministry of Community and Social Services, 2016). For people with IDD, additional specific accommodations and adaptations may be needed to prevent secondary disabilities and handicap (World Health Organization, 1980) and to ensure opportunities for full inclusion.

Expectations can arise from within the individual or from care providers and systems of support. BTC may arise where there is mismatch between individual capacities, expectations, interests and preferences, supports available and care provider expectations. BTC arising from personal interest and preferences, while socially unacceptable, may not be distressing to the individual. On the other hand, mismatch between (a) the individual's unique developmental needs, skills, and capacities (b) supports and services provided or (c) care provider understanding and expectations, can result in some of the most severe BTC (e.g., screaming loudly, smearing faeces or aggression in response to a difficult request or to too many people being in close proximity).

As health workers, we tend to evaluate environments and supports from our own perspectives of what we find to be desirable and comfortable. However there are now numerous reports from people with IDD and especially from those with autism, alerting us to the reality that their sensory and perceptual experiences may be different and what is attractive to me may actually be quite "toxic" to another. In addition, the intensity of pleasure or discomfort may, for some, be related to the degree of control they have over the circumstance. For example, Temple Grandin, an adult with autism describes as a child: "When people hugged me, I stiffened and pulled away to avoid the all-engulfing tidal wave of stimulation. The stiffening up and flinching was like a wild animal pulling away" http://www.autism.com/advocacy_grandin. Yet Temple also describes herself as seeking deep pressure stimulation: "It was an approach-avoid situation." As a child she reports she "used to like to get under the sofa cushions and have my sister sit on them." As an older person she developed a "Squeeze Machine," a device to provide comforting pressure to large areas of the body (Grandin & Scariano, 1986, pp. 86-99). Attention to the uniqueness of each person with IDD (person-centred approach) and full partnership with that person in decisions that involve them, is critical to effective intervention for BTC (Beadle-Brown, Hutchinson, & Whelton, 2012; Mansell, Beadle-Brown, & Bigby, 2013).

Individual profile of needs. Individual developmental needs, skills and capacities can be identified through assessment of: cognitive and adaptive skills, emotional needs, attachment patterns, self-regulation capacities, communication, sensory sensitivities, motor skills and difficulties, and observed behaviour. Interprofessional participation that may be needed for comprehensive assessment (Daalemen, 2016; Kerr et al., 2014) is listed in Appendix 4. Ensuring a good match between individual developmental profiles and accommodations and supports needed, will prevent undue mental and emotional stress, mood dysregulation, anxiety and panic; the outside manifestations of these personal negative experiences can be BTC.

A functional behavioural assessment, usually conducted by a behaviour therapist, aims to determine what the outcome is for the individual when engaging in BTC – for example, does it result in getting needed attention ("attention-seeking"), or some other desirable outcome ("tangibles") or result in being able to exit a situation that is intolerable for them ("escape")? This assessment provides an *in vivo* evaluation of what is happening in the individual's actual environment during times when BTC are present and can identify triggers to occurrences of these behaviours. Identifying triggers offers opportunities for targeted interventions. Understanding the link between these triggers (stressors) and individual responses alerts care providers to individual needs that might otherwise be overlooked and if not attended to lead to more serious psychiatric disorder (Bradley, Hollins, Korossy & Levitas, in press)

Person-centred environments and supports. These can be considered at the Individual, Program, and Service system levels (Appendix 5) (Beadle-Brown et al., 2012; Mansell, Beadle-Brown, Whelton, Beckett, & Hutchinson, 2008; Mansell et al., 2013). Emotional distress arising from mismatches between individual needs and supports available can either be internalized (e.g., anxiety, mood dysregulation, adjustment problems) or externalized (e.g., BTC).

☺ **Environment, supports and expectations** – **Helpful tips**:

(1) Map out with individual and care providers a detailed "day in the life of" the individual from waking in the morning to going to bed at night to identify daily patterns, adaptive skills and needed supports;

(2) "Shadow" the individual for a half day to experience some aspects of their daily reality, circumstances they encounter and their responses to these (invaluable direct access to the individual's physical and social support environment and their unique responses to these).

☺☺ **Clinical vignettes**: John and Guthrie (see Appendix 3)

Lived Experience and Emotional Well-Being

Emotional distress may give rise to BTC. Many individuals with IDD have difficulty expressing in words their inner world and emotional experiences; and some may be completely unable to do so. Opportunities to share life's daily frustrations, as well as joys in work, recreational and social networks, with chosen like-minded peers are not so available in supported living circumstances. Because of these communication differences there may be mistaken assumptions that those with IDD do not have an emotional life and their feelings and concerns are consequently ignored or dismissed (Gilmore & Cuskelly, 2014; Hubert & Hollins, 2010; Sinason, 1992). However it is clear from self-advocate accounts (MacMahon et al., 2015) and from clinicians working therapeutically with individuals with disabilities, that mental well-being is experienced in the feelings of the body (as well as expressed in words) and is impacted profoundly by relationships, perception of self and empowerment in the outside world, irrespective of cognitive abilities. For those with IDD for whom these feelings and concerns about day to day circumstances and relationships have become intolerable, psychological therapies, including the range of talking therapies, with appropriate adaptations for communication styles, are of benefit (Beail et al., 2016; Campbell, Robertson, & Jahoda, 2014). Through body language such as breathing rhythms, motor patterns and non-word vocalizations, even individuals with no language can be observed to engage in meaningful reciprocal emotional responses to others and clearly experience emotional relief when the communicating partner takes the time to learn from them their unique non-verbal body language (Caldwell, 2013; Schuengel, Oosterman, & Sterkenburg, 2009; Sterkenburg, 2008). Validating painful emotional experiences, whether rooted in the present or the past, is a powerful therapeutic intervention for BTC arising from these distressing experiences (e.g., Eye Movement Desensitization Reprocessing (EMDR) treatment for trauma (Mevissen, Lievegoed, Seubert, & De Jongh, 2012); Intensive Interaction (Caldwell, 2013); and Individual Therapy for Attachment and Behaviour (ITAB) (Porges, 2003; Schuengel et al., 2009; Sterkenburg, 2008).

Daily stress. Managing stress in optimizing physical and mental well-being has become a most crucial part of 21st century living with its rapidity of change and the daily need to absorb an exponentially increasing amount of information. When the body is threatened with more than it can handle, it essentially "crashes" and moves from cognitive and communication strategies when solving problems into triggering a primal biological survival system – the autonomic nervous system (ANS) which offers, and prepares, the body for three immediate solutions: Fight (aggression), Flight (fleeing), Freeze (cessation of movement). These instinctive responses are experienced as emotion dysregulation (Dvir, Ford, Hill, & Frazier, 2014; Raju, Corrigan, Davidson & Johnson, 2012; Loos & Loos Miller, 2004; Porges, 2003; Porges, 2007). Some BTC (e.g., aggression to self and others, running, screaming and "noncompliance") are also signs of this triggering into ANS activity. The role of everyday stress, from the perspective of the individual with IDD, must be considered in any evaluation of BTC. Successful psychological and behavioural interventions and supports increase the capacity of the individual to tolerate negative emotions (in ASD positive emotions can also be difficult to manage) so as not to trigger into these distressing and disruptive states. (See Allen et al., 2015; Beail et al., 2016; Gore et al., 2013; Matson et al., 2011).

Vulnerability and lifetime stress. As a group, individuals with IDD live much more stressful lives than their same age peers. They experience greater exposure to negative life events and traumatic experiences (e.g., physical, sexual, emotional abuse, bullying, stigma, exclusion, hate crimes) (Llewellyn, Vaughan, & Emerson, 2015). Some IDD aetiologies may confer specific risk for such adversity and traumatic experiences (e.g., autism and sensory hypersensitivities). Individuals with IDD are at risk of developing insecure attachment patterns and consequent difficulties in affect regulation. (Schuengel et al., 2009; Schuengel, de Schipper, Sterkenburg, & Kef, 2013). They are also more vulnerable to the impact of stress in part because they use less effective coping strategies. Some mitigating circumstances such as confidants and social networks are less available. Social isolation is recognized, as are the need for supports in developing friendships, activities and relationships (Gilmore & Cuskelly, 2014). Some BTC (e.g., aggression), are associated with these past adversities and poor social supports and may be better understood in terms of post-traumatic stress conditions and associated characteristic symptoms of re-experiencing, avoidance and hyperarousal (Hubert & Hollins, 2010; Tomasulo & Razza, 2007).

Much can be done to promote resilience and reduce exposure to negative life events – at the (a) Individual, (b) Program and (c) Service system levels of support as well as (d) taking care to include perspectives from individuals with IDD. For example in (a) individual therapies successfully employed to enhance affect regulation include counselling, anger management, positive behaviour support, cognitive behavioural, dialectical, dynamic and trauma informed therapies and mindfulness practices (Beail et al., 2016; Mallinckrodt, 2000); in (b) "toxic" environments can be avoided by attention to unique individual needs such as sensory hypo- and hyper-sensitivities, structure and consistency in environments and skilled staff support; in (c) the impact of predictable psychosocial crises, such as those involving transitions (Levitas & Gilson, 2001) can be minimized or prevented with adequate planning and preparation; in (d) "Nothing about us without us" and "Being with rather than doing to" may be helpful reminders that disability confers a different experience and therefore different perspectives on daily existence; involving people with IDD in their care and in service development is necessary to understand and integrate these perspectives. Such efforts can be anticipated to reduce BTC.

☺ Lived experience – Helpful tips:

(1) Identify and document chronologically the individual's birth to old age life event experiences: identify traumas generally known to cause distress (e.g., loss and bereavement, abuse (physical, sexual, emotional, bullying, neglect), early separation) as well as those events that may be personally distressing to the individual with IDD but which may go unrecognized by care providers unless specifically looked for (e.g., transition transitions and sensory sensitivities in ASD, humiliation or shame associated with performance, teasing and exclusion)

(2) Identify specific vulnerabilities (e.g., ASD, attachment issues)

(3) Assist individuals develop resilience in response to stress (e.g., opportunities to learn coping strategies; affect management and de-escalation strategies; access to anger management training, as well as group and individual opportunities to explore emotional concerns)

(4) Consider, as required, staff training in: Attachment, Trauma, Developmental-focused support (e.g., Circle of Security http://circleofsecurity.net/for-parents/animations/) (Hoffman, Cooper, & Powell, 2016); Emotional regulation (Raju et al., 2012); Low arousal approaches (Woodcock & Page, 2010); ASD friendly environments (Bradley

& Caldwell, 2013); Intensive Interaction (Caldwell, 2013)

(5) Provide support for staff e.g., self care, mindfulness practices (Singh et al., 2009).

☺☺ **Case vignette:** Jack (see Appendix 3)

Psychiatric Disorder

People with IDD are often referred for psychiatric evaluation because of BTC. Psychiatric misdiagnosis are made by clinicians unacquainted with the lives of people with IDD and the many ways in which medical conditions, inappropriate environments, supports and expectations, and subsequent physical and emotional distress, can mimic psychiatric disorder (Bradley, Hollins Korossy & Levitas, in press). Additional complexities in understanding BTC arise when physical and mental health conditions and especially those that are cyclical or episodic (e.g., mood disorders, allergies, constipation) occur together; likewise several psychiatric disorders can co-exist (e.g., ADHD and mood disorder), other developmental disorders may be present (e.g., ASD) and life events may follow a predictable event pattern (e.g., anniversaries, holidays). Systematic psychiatric evaluation of these potential co-existing circumstances is crucial (Appendix 6).

Mood, anxiety, adjustment, trauma and stressor-related disorders are under-diagnosed in IDD (Fletcher, Loschen, Stavrakaki, & First, 2007) and psychotic-like presentations may be diagnosed as psychotic disorders (Emerson & Einfeld, 2011). Aggression is a symptom which has different causes in individuals with IDD (Bradley & Hollins, 2010, Table 18.2; Bradley & Lofchy, 2005, Table 1). Aggression (to self, others or the environment) is a common reason for Emergency Room visits by adults with IDD: in one study aggression represented greater than 40% of presentations, followed by suicidal behaviour or ideation at 26% (Lunsky et al., 2012; Tint & Lunsky, 2015). At these times antipsychotic medication may be initiated to manage risk in the acute situation. Unfortunately in the absence of subsequent review as to the underlying cause of these aggressive behaviours this medication is often continued despite being considered poor practice (Alexander et al., 2016). In Ontario 21.1% of adults with IDD are on antipsychotic medication in the absence of a psychiatric diagnosis (Lunsky, Klein-Geltink, & Yates, 2013). Conclusions from a UK primary care data base of 33,000 adults, six selected secondary care sites and second opinion Care Quality Commission-appointed doctors, related to 945 reports, provide robust evidence of widespread inappropriate use of psychotropic medication in people with IDD (Alexander et al., 2016); these findings have resulted in a "Call for Action" to improve this practice (NHS England, 2015; Sheehan et al., 2015).

When the above areas of concern (the H, E and L of HELP) are adequately assessed, psychotic presentations and aggression are often better understood in terms of mood dysregulation, anxiety, adjustment problems in response to acute and chronic stressors or trauma (Bilderbeck, Saunders, Price, & Goodwin, 2014; Bradley et al., in press; Marwaha, Broome, Bebbington, Kuipers, & Freeman, 2014). With appropriate intervention for these specific conditions the apparently "psychotic" symptoms and behaviours resolve (Dossetor, 2007; O'Dwyer, 2000; Van Schalkwyk, Peluso, Qayyum, McPartland, & Volkmar, 2015).

Hyperarousal (especially in ASD) triggered by "toxic" environments can also give rise to aggression – or running and freezing behaviours as part of the Autonomic Nervous System Fight-Flight-Freeze responses. Attending to this arousal and these toxic environments is usually therapeutic.

Sometimes BTC are truly a manifestation of psychiatric disorder or emotional distress so severe that it has triggered psychiatric illness. Careful evaluation is needed to differentiate between behaviours communicating severe mental distress associated with psychiatric disorder, from those underpinned by H, E and L issues (outlined above), as treatment is different. Several different parallel medical and psychological treatments may be required to target different aetiological circumstances (e.g., mood disorder requires ongoing treatment whereas allergies can be treated as these occur).

The mental state examination (MSE) is a clinical interview conducted by psychiatrists to understand presenting problems and diagnose psychiatric disorders (Levitas, Hurley & Pary, 2001). Patients without cognitive and communicative disabilities are usually able to share their inner thoughts, emotions, experiences ("symptoms") and observations by the examining psychiatrist (or described by others) of their behaviours ("signs") assist in determining whether these markers meet diagnostic criteria for psychiatric disorder(s). Respect, warmth and empathy usually enhance the dialogue between clinician and patient, optimize identification of important symptoms and signs, and increase psychiatric diagnostic accuracy. This standard MSE has to be adapted to the communicative, cognitive and emotional capacities of the patient with IDD (Boardman et al., 2014; Bradley & Lofchy, 2005; Deb, Matthews, Holt, & Bouras, 2001). Such adaptations include careful consideration as to where the interview is conducted (familiar place or unfamiliar clinic?), the length of the interview (as needed for patient comfort or according to a pre-determined outpatient standard?) and who might accompany the patient (who knows the patient best – e.g., family member, day staff, night staff?). It is always worth reflecting how the MSE may be experienced by the individual with IDD – from their perspective (Ng, Jarvinen, & Bellugi, 2014) and what their desired outcome of this meeting is. For example, questions the individual does not understand and particularly those with embedded meaning (e.g., the "do you hear voices") may be reminders to them of painful failure experiences at school and they reply "yes" to avoid exposing a lack of understanding. On the other hand the individual may reply "yes" because they want to please the doctor or they see this as a way to keep engaged with the empathic clinician who is helping.

It could be argued that focusing on the therapeutic rapport is the most important component of the MSE working with people with IDD; the need for any urgent specific information can usually be obtained from a care provider who knows them well. If therapeutic rapport is developed from the outset, there is opportunity in later meetings to develop more reliable strategies to determine whether crucial symptoms (from a diagnostic perspective) such as voices, are present, as well as a more accurate description of the nature of these voices. For individuals with severe communication disabilities (e.g., IDD and ASD) focusing on emotional engagement through non-verbal cues and body language is likely to be the only way the psychiatrist is going to gain accurate access to their current affective status; such access has substantial implications not only for diagnostic accuracy but also for determining what may be contributing to the behaviours of concern (see case # 6 Nada).

☻ Psychiatric disorder – Helpful tips:

(1) Review of Sections H., E., L., and implementation of needed interventions will diminish BTC unless these behaviours are associated with psychiatric disorder.

(2) Any remaining BTC can be reviewed: (a) to determine if these represent a significant change from baseline (usual) behaviours and (b) if changes meet criteria for diagnosable psychiatric disorder (Appendix 6).

(3) "Management" of BTC (actions taken to ensure immediate safety of everyone – these may involve sedating medication) is different from "treatment" of BTC (actions taken to eliminate or treat the underlying cause). Treatment with psychotropic medication is only indicated when psychiatric disorder has been diagnosed. Medication to manage BTC should be short term (while underlying cause and appropriate treatment is being sought).

(4) Review previous diagnoses – are they still valid after HELP review?

(5) Review psychotropic medications (Bradley, Behavioural and Mental Health Working Group, & Developmental Disabilities Primary Care Initiative Co-editors, 2011a), when and why prescribed, by whom, side effects, whether and how each medication has made a difference (if any) to behaviours for which they were prescribed (target behaviours) (Alexander et al., 2016).

(6) If medication is being tried for behaviours rather than for a psychiatric disorder, is the medication trial following robust practices (Bradley, Behavioural and Mental Health Working Group, & Developmental Disabilities Primary Care Initiative Co-editors, 2011b)

☻☻ **Case vignette:** Nada (see Appendix 3)

Discussion

The HELP approach with its catchy mnemonic, assists in robust evaluation of BTC, provides the basis for a comprehensive diagnostic evaluation and promotes multi perspective understanding, interventions and delivery of targeted treatments. HELP embraces a biopsychosocial and person- centered approach accepted as good practice in addressing these behaviours (NCCMH, 2015). The approach is unique in integrating the lived experience of people with IDD (the "L" of HELP) into the biopsychosocial perspective. HELP also addresses complexities that arise in BTC (e.g., the same behaviour, even in the same person, can have different causes; in contrast the same cause may give rise to different BTC; added to this the severity of the behaviour may not reflect the severity of the underlying cause). Caregivers, such as frontline staff, are often the first to observe emerging BTC and are in a key position to begin the process of problem solving surrounding their causal basis and their resolution. It is crucial to consider every behaviour that challenges, and each episode of occurrence, within a comprehensive framework that is meaningful to all stakeholders, including the individual with IDD, and one which stakeholders can readily implement.

Other ways in which HELP may be utilized with good outcomes include:

- Review of poor response to previous interventions and treatments
- Review of previous psychiatric diagnoses that have responded poorly to evidence-based practice for that disorder:
  - Is the psychiatric diagnosis accurate and the poor response to treatment because of unaddressed issues in the other domains (the H, E and L)?
  - When these other domains are addressed adequately do the symptoms and behaviours that gave rise to this diagnosis also remit?
- Medication reviews and management. For example a positive or negative response to a new medication or dose change may be due to other things going on in the person's life rather than attributable to the medication change.
- HELP provides "the scaffolding" to permit the implementation of medication good practice guidelines for adults with IDD (Bhaumik et al., 2015). Staff may be understandably fearful of changes in medications prescribed in the past for frightening and dangerous behaviours. With a collaborative multi perspective approach that identifies alternative, less intrusive intervention options, frontline staff are likely to be more willing to support reductions in these medications.

Systematically addressing, within a collaborative framework, medical, environmental, support, emotional and psychiatric issues that arise in the lives of people with IDD, will greatly improve their quality of life and diminish behaviours of concern. In this context, current practices of overuse of harmful psychotropic medication to manage BTC should become unnecessary (Alexander et al., 2016 p. 16).

Key Messages From This Article

People with disabilities. HELP is a way for all of us to understand when your behaviours are communicating distress and what can be done to help you feel better.

Professionals. HELP provides a biopsychosocial, multi perspective understanding of individuals with IDD who are engaging in BTC; this approach works to promote their health and well-being.

Policymakers. BTC prevent access by people with IDD to a range of health-promoting services available to the general population. HELP flags service system issues that may be contributing to these behaviours and illuminates opportunities for prevention.

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APPENDIX 1: Physical and Medical Conditions That May Cause Discomfort or Pain (Appendix 2) and May Be the Cause of, or Associated with, BTC

Consider discomfort/pain related to:

- Occasional common ailments (e.g., cough, colds, flu, headaches)
- Allergies (e.g., rash, itch)
- Sensory discomforts (e.g., new clothes, shoes)
- Otitis (ear infections); hearing impairment; sound hypersensitivity
- Visual problems (e.g., cataracts, light sensitivity)
- Mouth and teeth (e.g., cavity, abscess, gum disease, teeth grinding; drooling; swallowing problems)
- Gastrointestinal (e.g., dysphagia; GERD; H. pylori-related dyspepsia; gallstones; lower GI problems (Crohn's disease, ulcerative colitis, irritable bowel syndrome); constipation and hemorrhoids
- Menstrual cycle phases – dysmenorrhea/premenstrual syndrome; peri-menopause/menopause (may start earlier)
- Urinary tract infections; urinary incontinence
- Endocrine and autoimmune conditions (e.g., diabetes, thyroid)
- Musculoskeletal (e.g., related to physical condition such as cerebral palsy, spasticity, arthritis, fractures, myalgias, osteoporosis, degenerative disc disease)
- Neurological (e.g., epilepsy; headaches); acquired brain injury; dementia
- Dermatology (e.g., rashes, abrasions, infections, burns)
- Sleep problems (e.g., sleep apnea)
- Medication side effects, changes in medication
- Medical conditions associated with genetic syndromes (e.g., seizures and tuberous sclerosis)
- Syndrome-related BTC (e.g., self-injurious behaviours in Cornelia de Lange or Lesch-Nyhan syndromes)
- Respiratory (e.g., pneumonia, asthma, aspiration)
- Cardiovascular (e.g., congenital heart condition, vascular disease)
- Infectious (e.g., Tuberculosis (TB), Lyme disease, scabies, pin worms)
- Other (e.g., check family history for medical conditions and screen for these conditions)

APPENDIX 2: Pain and BTC

Pain may not be recognized if it presents atypically and is manifested as BTC; in people with IDD both verbal and non-verbal (gestures or body language) expression of pain may be compromised. Despite formidable difficulties in assessing pain in some people with IDD, there is no evidence that they suffer any less from a noxious experience; proposed "elevated thresholds" may be an artifact of extreme motor impairment (e.g., Rett syndrome). Pain may be a setting event for BTC resulting in greater frequency and intensity (Bradley & Korossy, 2015). There is evidence that pain may not be effectively recognized or managed (Beacroft & Dodd, 2011), that mistaken staff beliefs may be influencing care of residents who experience pain and that use of structured communication aids and additional training may be helpful (Beacroft & Dodd, 2011; Rose, 2011). Tools such as ***DisDat*** can guide care providers to systematically explore the possible cause of distress or pain (Regnard, Matthews, Gibson, & Learning Disability and Palliative Care Team at Northgate Hospital in Northumberland, UK, 2008)

APPENDIX 3: ☺☺ Case Vignettes Under Corresponding HELP Sections

Health

Jane: During adolescence, following a very stressful time transitioning from middle to high school, Jane started to engage in sudden episodes of frenzied agitation, hyperactivity and screaming, accompanied by pinching herself causing bruising. These behaviours were recognized as occasions of heightened intense anxiety triggered by too many people talking and too much activity going on around her. Systematically monitoring these behaviours, it was observed that Jane would trigger more easily when bothered by her seasonal allergies, monthly menses and occasions of constipation. Providing more proactive management of each of these medical conditions diminished these episodes.

Yvonne: A 30-year-old woman, registered blind with presymbolic language skills (no speech) engaged in serve head banging causing bruising and discolouration around her eyes. Thinking this cyclic behaviour might reflect mood disorder, her sleep wake hours were monitored over several months. Her sleep pattern was found to follow a phase shift pattern so that every 8 –10 weeks Yvonne would switch from sleeping mostly at night to sleeping mostly during the day. However in keeping with her group home routine she would be encouraged to get up during the day even when her inclination was to sleep; it was at these times the self-injury would occur. Melatonin was prescribed to regulate her sleep wake cycle and her self-injury stopped. Yvonne's visual impairment had prevented light activating those parts of the brain that regulate sleep (e.g., hypothalamus and pineal gland) (Lockley, Arendt, & Skene, 2007).

Environment, Supports and Expectations

John: An adult with presymbolic communication skills is observed to head bang when people become too noisy. When this occurs, care providers are reminded of John's autism, associated noise hypersensitivity and the necessity to ensure that others do not become too noisy or if this is not possible, assist John in removing himself. They are also working with John to encourage him to wear noise muting headphones; if these work for him he may be able to remain in the room with peers, despite the noise they are making.

Guthrie: 39 years. old, has mild ID and lives in a group home. He can engage in a two way conversation and describe his daily activities. He quickly gets anxious with certain events (e.g., disappointment that a prearranged meeting does not take place). Guthrie, who has fragile X syndrome, is of above average height and build. When upset, he appears frightening to those who do not know him. He has been picked up by the police on several occasions after being reported as displaying disruptive behaviour (shouting, threatening movements with sticks) in public places (e.g., after a friend did not show up).

Guthrie was assessed by the Multi-Discipline Team (MDT). Guthrie and care providers, working with the MDT Behaviour Therapist identified situations that caused him anxiety (fragile X syndrome is associated with anxiety). Changes in Guthrie as he escalated to full anxiety were identified. Staff taught him how to recognize these changes and agreed upon support strategies at each stage of his escalating behaviour (e.g., redirection, find a quiet place, count to ten). As staff became familiar with these behaviours and strategies, Guthrie learned to recognize his own feelings at these times and, with support, was soon able to initiate appropriate action (e.g., remove himself, rehearsed anxiety management strategies, relaxation exercises). Psychological and communication assessments indicated that Guthrie's strengths were in non-verbal understanding (e.g., visual) compared to verbal, even though he appeared to use words with great panache. Care providers were helped to recognize that in supporting Guthrie they needed to provide visual cues and check out his understanding in a sensitive way, even though he would insist he understood. A trial of beta blockers was prescribed to reduce his sympathetic (autonomic nervous system) drive and feelings of anxiety. Guthrie provided feedback through the use of visuals and staff monitoring target behaviours, to determine whether this medication reduced his reactivity to environmental triggers. The team supporting Guthrie liaised with the local community police unit to share ways to support Guthrie should he get into difficulties in the community. Ongoing staff training, especially when there were staff changes, was crucial to the maintenance of this support for Guthrie.

Lived Experience and Emotional Well-Being

Jack: A 32 year old gentleman with autism spectrum disorder and moderate IDD, reported hearing voices to his case worker. When seen in the ER he described hearing voices on and off over a long time. These voices he reported told him to hurt himself or others and although he had not acted upon this he was very concerned "I keep telling them to stop … and they follow me outside." As he spoke about his voices he became tearful, distressed and fearful, but denied they were currently present. He said the voices only occurred when at his work. He reported they started there several years previously after witnessing an altercation between two workers. Work was described as being stressful for Jack and staff said he would make up stories involving strange people and persisted in getting 1-1 staff attention. As a child Jack had witnessed violence between his parents, his father left and Jack was currently living with his mother and brother. On one occasion when Jack was describing his voices he suddenly interrupted with a memory of his brother collapsing in a restaurant. Jack started to relive distress that he was not allowed to go with his brother in the ambulance to the hospital.

Following medical, psychological, occupational therapy and psychiatric assessments it became clear that Jack's voices occurred when he was anxious and particularly when his anxiety was evoked by witnessing and hearing altercations between people around him and being confused as to whether he was the reason for their altercation. Essentially triggers in the present took him back to feelings he experienced as a child growing up in his family. The people he was speaking about to staff while at work, were identified as TV personalities and cartoon characters he had focused on to help him manage escalating anxiety in the work place especially when he was unable to garner the 1-1 support he desperately needed at these times. Jack was referred for trauma therapy and has responded well to affect regulation support with an EMDR-trained therapist and changes to his work environment to better accommodate his autism needs – clear expectations, consistency, quieter work space.

As with so many people with IDD what appears to be maladaptive and BTC are in fact their best attempts to manage with the resources they have available to them to deal with a present that has triggered unresolved issues from the past. Careful attention to the specifics of how individuals attempt to manage such past triggered distress may be key to assisting then with more adaptive strategies (e.g., Jack already had a repertoire of favourite cartoons and responded to staff working with him to select characters from these favourite movies to support better affect regulation).

Psychiatric Disorder

Nada: Care providers expressed concerns that Nada, a 54 year old adult with Down syndrome, had in recent months become more withdrawn. Usually a very talkative social person she was now saying little and no longer initiated any social interactions. She was having difficulties understanding verbal directions and showing less interest in usual activities. Care providers wondered if Nada was depressed; they also endorsed some items on a brief dementia screen. A visiting therapist observed Nada sitting alone at the lunch table (her peers had finished and left); she showed no response to peer or staff approaches and did not reply to their questions or requests. At times she made episodic repetitive deep inhalations and with subsequent exhalations made a sighing sound. The therapist engaged with Nada's noisy breathing in and out patterns using an Intensive Interaction approach (Caldwell, 2013). Within a few seconds Nada was looking directly at the therapist and engaging with her "in a conversation" of loud inhalations breaths and exhalation sighs. Within a few minutes Nada and the therapist had extended the conversation to involve their fingers, palms and arms. Nada began to initiate different movements and the therapist followed in the conversation. She smiled and laughed out loud; she was emotionally engaged with the therapist. Through this exchange the therapist determined that Nada was not demonstrating depressed mood. She was showing capacity to both initiate and sustain a conversation – a conversation in body language rather than using words.

It was subsequently found that Nada's hearing aids had been wrongly reassembled after her last checkup (which coincided with the changes in her behaviour); as a result Nada was not able to make out verbal communication. The therapist bypassed the need to use words and instead engaged with Nada in a body language conversation which Nada very much enjoyed and in which she fully participated.

APPENDIX 4: Examples of Interprofessional Participation Important for Assessment of BTC

(Lindsay & Hoghton, 2016; Bradley, Goody, & McMillan, 2009)

- Audiology
- Behaviour therapy
- Communication speech-language therapy
- Medical

- Family medicine
- Clinical genetics
- Pediatrics
- Neurology – Psychiatry

- Nursing
- Occupational therapy
- Other therapies – for example, music, drama, movement and dance, dietetics, counselling, pets
- Pharmacology
- Physiotherapy
- Psychology
- Service coordination and social work

APPENDIX 5: Elements of (a) Individual (b) Program (c) Service System Level Supports (d) Embracing the Perspectives of Clients, Families and Other Stakeholders

(a) Individual needs include attention to:

- The crucial role of communication. Finding ways that individuals, despite severity of disability, can communicate their needs whether through words or non-verbal means (Boardman et al., 2014) as well as feel emotionally connected, even in the absence of words (e.g., meaningful conversations with care providers using body language [Caldwell, 2013]). The General Medical Council, UK (General Medical Council, 2016) provides guidance on communicating with patients with IDD (includes videos on BTC)
- Physical environment e.g., appropriate adaptations for hearing, visual and motor impairments, attention to sensory hyper- and hypo-sensitivities, autism friendly; availability of a Snoezelen room; regular opportunities for exercise (Ogg-Groenendaal, Hermans, & Claessens, 2014) and physical activities
- Individualized programming with consistency of approach and coordination across environments (Banks et al., 2016)
- Psychological supports (Beail & Faculties for Intellectual Disabilities of the Royal College of Psychiatrists and the Division of Clinical Psychology, British Psychological Society, 2016)
- "Do no harm" approach to pharmacological interventions

(b) Program supports include awareness and understanding of:

- The importance of staff training about IDD, communication, disability-friendly environments and crises prevention (Bradley & Caldwell, 2013)
- The impact of positive and negative attitudes and emotions on client (and care provider) wellbeing
- Emerging practices (e.g., staff training in positive behaviour and low arousal approaches, acceptance based interventions, mindfulness practices)
- The difference between management of BTC and treatment of underlying causes of these BTC (see also page 108)

(c) Service system considerations:

- Many BTC can be prevented by a HELP approach with access to appropriate services for necessary assessments and interventions. BTC are more prevalent in services that are crises reactive i.e., no preventive planning and little access to specialized supports.
- Advocacy for the appropriate service(s) is an effective intervention for BTC
- Implementing the appropriate service(s) and addressing unmet needs, is effective treatment with good outcomes
- BTC may be a flag for service system failures. Identifying the latter offers opportunity to avoid inappropriate prescription of psychotropic medication in response to these behaviours

(d) Perspectives of clients, families and other stakeholders

- Inside-out and Outside-in perspectives (Bradley, Caldwell, & Korossy, 2015; Elbard, 2015)
- Perspectives from individuals with Down syndrome, their siblings and parents (Skotko, Levine, & Goldstein, 2011a; 2011b; 2011c).
- Curriculum of Caring (Boyd, 2015) "Voices of experience": Video clips of individuals with IDD, caregivers and health staff sharing their perspectives and wisdom.

APPENDIX 6: Determining Whether There is an Episode of Psychiatric Illness and Diagnosing Psychiatric Disorder

(1) Seek information from a care provider who knows the individual well currently and has known them in the past before the present behaviour concerns

(2) Elicit details about BTC such as when, where, frequency, antecedents, behaviours, consequences (Drummond, 2011).

(3) Identify when the individual's behaviour was last at their best – i.e., before the onset of behaviour concerns; find an "anchor" time (e.g., birthday, public holiday)

(4) Explore their daily pattern, skills and behaviours before this anchor time. Inquiry about the individual's daily life from getting up in the morning to going to bed at night will elicit important information about each individual's unique baseline against which to measure any change

(5) Compare symptoms and behaviours before concerns (4 above) with current concerns (2 above) and determine whether there has been a significant change (e.g., lasting at least one week, such as: loss of interest in play or work; self-care; social engagement, initiative, need for change in supervision or placement) (Bradley & Bolton, 2006). A significant change represents "an episode of illness."

(6) If there has been an episode of illness can this be subtyped? – (i.e., do the symptoms and behaviours meet criteria for a DSM or ICD mental health disorder?)

☹ **Note:** Even though it may not be possible to subtype the episode of illness (because of difficulty in getting an account of the patient's experience), this does not negate the presence of significant psychiatric disturbance (episode of illness) which has to be addressed

(7) Can an event be identified that may have triggered this episode of illness (e.g., loss, transition)?

(8) Are there other non-episodic symptoms and behaviours that meet DSM or ICD criteria (non-episodic disorder)? Identifying such "background" disorders is important to correctly interpret the origin of current behaviours (e.g., is concern about hyperactivity due to an increase in ADHD [background disorder] or due to an episode of mania [episodic disorder]).

(9) Several episodic and non-episodic psychiatric disorders may also co-exist. Determine which psychiatric disorders, if any, need to be the focus of immediate attention.

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Design of the Built Environment and the Integration of Wheelchair Users in the Kingdom of Saudi Arabia: Commentary and Exploratory Study

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Abstract

Many people in the Kingdom of Saudi Arabia (KSA) are living with disability and severe accessibility limitations, especially those with physical disability who constitute nearly 33.7% of the Kingdom's total disabled population. Disability policy in KSA has a history of half a century, beginning with the Royal Decree No. 1219 in 1956 and ending with the Disability Code in 2000. However, Legislation of Disability in 1987 and the Disability Code of 2000 were more dedicated to challenge the inaccessibility problem and provide disabled people with equal rights to their peers. The aim of this article is to address the question of: how far the disability policy of KSA has contributed to the creation of accessible built environments in which wheelchair users can experience their lives independently. To answer the question, a random sample of 13 public buildings from a list of 130 buildings in the yellow pages, and six different roads from the Central Business District of Riyadh city, were selected for field observation. The mandate of KSA's laws and the Americans with Disabilities Act Accessibility Guidelines were used as a yard stick to measure the accessibility compliance standards of the chosen sample. Quantitative analysis of the field observation data revealed that the accessibility compliance of the sample in Riyadh was extremely limited in the sense that only three buildings had an overall compliance of more than 50% while none of the roads had reached 50% overall accessibility compliance. The results of the observations revealed that the disability law has failed in guaranteeing the equal rights of accessibility by wheelchair users in society. As such, it is safe to conclude that even mandate of the law associated with political will tends to be ineffective and cannot be taken for granted for solving the environmental accessibility problem in KSA.

This article consists of two main sections. Part I provides background and commentary about disability laws and regulations in the Kingdom of Saudi Arabia (KSA) in relation to other countries, including barriers to accessibility faced by people with disabilities – especially wheelchair users. Part II describes an exploratory study to evaluate accessibility for wheelchair users in KSA to buildings and roads.

Part I: Background and Commentary

Disability and Barriers to Accessibility in the Kingdom of Saudi Arabia

According to the United Nations Development Program (UNDP, 2014), disability affects hundreds of millions of families in developing countries. According to this report:

- 10 % of the total world's population lives with a disability.

The same report estimated that:

- 80% of disabled children over the next 30 years will be living in the developing countries.

The national census of the KSA also indicates that:

- nearly 135,000 of the total Saudi population has some sort of disability of which one third (33.7%) of the total disabled population have physical disability (Al-Jadid, 2013; The Economic Bureau, 2000).

Theoretically, disabled people, including wheelchair users, should have access to a barrier-free environment including education, employment, social activities, etc. (Barnes, 1998; Shakespeare, 2010). However, in practice the accessibility in KSA is extremely poor or absent as architectural barriers in the built environment are still restricting, and even hindering full participation of wheelchair users to social life. The situation of inaccessible environment remains unchanged despite the enactment of legislation provision during the past 59 years (since Royal Decree No. 1219, dated 9/7/1956). Despite the existence of disability law (see the section called Accessibility in KSA for details), people with disability in KSA, especially wheelchair users, whose number is unknown in the Kingdom, are facing serious accessibility problems which are denying them their basic rights.

This situation has broadened the concept of accessibility to reach beyond physical accessibility and calls for social integration. Accessibility as such is not restricted to space but includes the shared societal atmosphere as well. It ensures physical mobility as well as personal integration towards inclusion in every sphere of the life of disabled persons.

The problem addressed in this article is founded on the fact that there is an acute restriction of accessibility to public roads and buildings by wheelchair users in KSA leading to their social exclusion. Such acute problems, in addition to the individual impairment, are caused by several societal, environmental and political factors such as ineffective implementation of disability policies which has resulted into more restriction for people with disabilities, especially wheelchair users.

Accessibility in Theory and Practice

The theoretical basis of disability legislation is to provide physical, environmental and social accessibility to enable persons with disabilities to move freely and use all the available services on an equal basis with other members of society (United Nations [UN], 2008). The removal of all barriers from the surroundings leading to an accessible environment constitutes the key component of disability law and regulations in all communities. Theoretically, disability law and regulations in KSA are also trying to help persons with disabilities to achieve independence and participate actively in society by giving them access to a barrier-free environment. However, in practice there has been no achievement in giving equal rights to disabled people or helping them to experience an independent life which has resulted in their further isolation. Even in the area of services delivery, the Japan International Cooperation Agency Planning and Evaluation Department (JICAPED) stated that: "provision of institutionalized services or institutionalization" is a form of "social segregation," rather than "social integration" of persons with disability" (JICAPED, 2002, p. 19).

Disability and Accessibility

The primary need for mobility is physical accessibility through effective legislation which in turn, can be a safe route to social inclusion. Disability has become an issue of humans seeking equal opportunity for all, and its combination with accessibility has recently been more in focus instead of being dealt with as a separate entity. In other words, disabled people are handicapped by barriers that impede their daily activities. The focus as such, is no longer on impairment and medical intervention; rather, disabled people should have access to a barrier-free environment for their daily life without limitation (Barnes, 1998).

However, a legislative framework that confers human and civil rights will not be effective for disabled people unless it also has entitlements to the "needs" in the context of social care and the nature of disabling environment

(Morris, 2004). If "needs" are not met then this can result in a denial of human and civil rights (Brisenden, 1989). The issue of inclusion versus exclusion can be argued within the context of accessibility for all areas of life, from early education at school through to employment (Barnes, Mercer, & Shakespeare, 1999). Gleeson, for example, states that despite the production of human rights legislation and its reassurance for creating accessible environment for all, "achieving the goals of human rights is still hampered by ineffective legislation and inaccessible design regardless of political concern" (Gleeson, 2001, p. 259).

Accessibility in the International Context

There are a number of countries that have initiated and implemented disability legislation with different levels of success. In the United Kingdom, for example, the Disability Discrimination Act (DDA) of 1995, gives several provisions for easy access to public places.

Similar attempts have been made for example, by the European Commission that views the social exclusion of people with disability as a multi-dimensional phenomenon which demands the understanding of several indicators of life quality (European Commission, 2000; 2006). Many of these countries applied the social model of disability as the basis for their disability legislation to curb the exclusion of disabled people (Nielsen & Nelson, 2005). This legislation recognizes the rights of disabled people and makes genuine efforts to eradicate discrimination (Finkelstein, 1993).

The Americans with Disabilities Act (ADA) of 1990, has many positive effects on the life of disabled American by prohibiting discrimination against disabled people. Disabled Americans however, continue to experience disproportionate high rates of unemployment (Cornell University, 2005; McClain, 2000). Similar findings are observed in the United Kingdom (Kumar, 1997) and other Middle East Arab Countries (Barghouti & Al-Dean, 1994). Like the failure of legislation in other countries, it seems that KSA's legislation has also failed in achieving its practical gains – either in employment or in social and civic participation.

However, since the enactment of the DDA in the United Kingdom and the ADA in the United States, there are a growing number of countries in the world including KSA, that were affected by the wave of ground-breaking domestic disability rights and disability legislation (Degener, 2005). This process reached its climax in December 2006 when the United Nations General Assembly decided to adopt the Convention on the Rights of Persons with Disabilities. The Convention stressed that people with disabilities have the same human rights as all other people. This convention was seen as a turning point for recognition of disabled people's rights (UN, 2008).

The legislation in Canada, Australia, New Zealand and Japan has also focused on anti-discrimination and the human rights approach. These countries have adopted even stronger legislation to achieve both recognition of full accessibility rights of disabled people and eradication of discrimination against them (Finkelstein, 1993). In Canada, The Accessibility for Ontarians with Disabilities Act of 2005, for example, aims to improve the process of identification, prevention and removal of the obstacles faced by people with disabilities (International Disability Network, 2005).

Accessibility in the Regional Context

The Middle East Arab countries including, United Arab Emirates, Yemen, Kuwait, Iraq, Qatar, Lebanon and KSA are different in political systems but similar in culture, religion and language. However, by visiting these countries, the researchers noticed that wheelchair users are facing similar problems of access to public places despite the existence of many laws and legislation that call for accessible environment for wheelchair users. A number of Arab countries' initiated legislation after the declaration of an "Arab Decade of Disabled People" in 2004 which was set for incorporating disability into the social and economic development of Arab states between 2004 and 2013 (UN, 2008).

The publication of "The Arab Human Development Report 2009" examined the deterioration of certain aspects of life in Arab countries, and their negative impact on disabled individuals. It was reported that the good initiative of the "Arab Decade of People with Disabilities" and the attempts to make it a regional framework was hindered by lack of urgency to reflect the social and human rights approach to disability (UNDP, 2009). In line with "Convention on the Rights of Persons with Disabilities" (CRPD) and its advocacy to co-operate with regional stakeholders, the League of Arab States has also initiated practical steps towards amending the Arab Decade of People with Disabilities to promote the general principles of the CRPD (Alazzeh, 2009). However, the benefit of disability legislation and government-sponsored programs vary significantly among countries in the region.

Accessibility in KSA

According to the United Nations, no part of the built environment should be designed in a manner that excludes certain groups of people on the basis of their disability. Disability policies in the KSA also claim to be focused on the rights of people with disability to access all services and live with dignity (JICAPE, 2002; Ministry of Health Care, 2010).

The medical approach to disability in KSA has been paramount and has played a pivotal role in a number of pieces of legislation for half a century, since the Royal Decree No. 1219/1956. Even the call of Nation Development Plans such as the Sixth (1995-2000) and the Seventh Development Plans (2001-2005) was for intensification and the follow-up of provision of only health care instead of focusing on the social inclusion of disabled people. For example, the 4th International Conference of Disability and Rehabilitation, which was held in Riyadh between October 19 and 21, 2014, proves that the focus of KSA's authorizes still was on medical rather than social model of disability. The authors of this article who attended the conference suggested the title for the future conference to be "Disability and Integration" in order to divert the focus and attention of the future participants of the conference toward social model of disability rather than just focusing on care and welfare.

However, the legislation in KSA received a boost from the International Year of Disabled Persons and the subsequent United Nations Decade of Disabled People leading to the provision of the Legislation of Disability (LD) passed in 1987 followed by the advanced Disability Code of 2000; both called for equal opportunities and assurance to disabled people for equal rights to their peers in society (Ministry of Health Care, 2010). The KSA's LD of 1987, for example, calls for "freedom of movement and safely" for disabled people. This principle also laid the ground for the provision of the Saudi Building Code (SBC) in 2007.

It is worth noting that the SBC is the only code that governs all buildings' activities in the country and was expected to revolutionize the environmental accessibility. However, it gave only a general subjective statement affirming that: "Buildings and facilities shall be designed and constructed to be accessible in accordance with this code requirements and the International Code Council (ICC) A117.1" without giving any measurement standards or achieving any noticeable effect on the ground. The code also reads:

> …minimum requirements to be considered in public and residential buildings as well as public facilities to enable easy and smooth access by the disabled. This code contains the general requirements of design of new buildings and the requirements to be satisfied in existing buildings and outside space to facilitate free access by the disabled. (SBC, 2007, Chapter 9, p. 4)

The provision no. 7/h/1402 (dated 21/01/1402, Islamic calendar; 18/11/1981, Gregorian calendar) states that:

> All departments are obliged to provide disabled people with all necessary services by observing the construction condition for accessibility when issuing construction permits….[These services will include internal and external] ramps, parking, paths, roads and routes, public facilities that exist at the public and private buildings such as doors, windows, lifts, pass ways and any other equipments. (Riyadh Municipality, 2007, p. 16)

There is however, little or no information about the success or failure of these policies except a report that 100,000 disabled people are unemployed and looking for an employment position (Trenwith, 2013**)**. This was the major drawback. However, this drawback is common in developing countries and not restricted to KSA.

Our argument is that the provision of law and regulation per se cannot be taken for granted to meet the need of people with disability without efficient implementation**.** Even if the law worked perfectly still there is a long way to achieve what was stated in the disability-related provision, policies and legislation in KSA. This might be due to the negative attitude (World Health Organization, 2006)**,** inadequacy of design, and ineffective implementation (Trenwith, 2013**)**. The law is more apparent on paper than in reality which constitutes the most inappropriate form of disability provision.

The outcome of many existing laws and regulations was poor which implies that accessibility cannot be achieved unless the societal concept of disability in KSA is changed and the suggested solutions be diverted away from the traditional individualistic (medical model) approaches towards those founded on the social model. The KSA's Legislation of Disability of 1987 as such, is the first law that diverted the attention from medical approach to what has been called a social model of disability. This model focuses on social solutions rather than individual solutions (Barnes, 1991; Barton & Oliver, 1997; Crow 1996; Lunt & Thornton, 1994; Oliver, 1990, 1996; Turmusani, 1999).

Nevertheless, the social model seems to be reflected in the KSA's inclusive education programme. The efforts for inclusive education has begun under "special education" or "mainstreaming" topics which reached an acceptable success in the enactment of the Provision Code for Persons with Disabilities in the Kingdom in the year 2000. This law ensures the rights of students with disabilities in all aspects of life, including a free appropriate public education. This programme for example, has been gradually moving away from segregated settings to a more inclusive environment (Al-Mousa, 2008a, 2008b; Kavale, 1979, 2002; Stout & Huston, 2007). Prior to the effects of the social model, there was a high rate of repetition, drop-out and leaving school with minimal education benefit among disabled children. The article nevertheless advocates that considering other methods such as the universal design and its techniques, can help lead to the "… necessary changes in the social relations of development and design processes" that disabled people aspire to (Imrie and Hall, 2001, p. 18).

Factors Affecting Accessibility

There is a combination of physical, environmental and social barriers that continue to exclude disabled people in general and wheelchair-users in particular from mainstream society. The key factors causing the exclusion of disabled people from the built environment as the literature suggests are: (a) the attitudinal barriers which frequently encountered by disabled people, especially wheelchair users, in all areas of their lives such as access to education, employment and public services (Zarb, 1995); (b) professionals' ideology and values influenced by societal negative attitude and who are involved in decision making, design and practices of construction processes (Hall & Imrie, 1999, p. 409); and (c) the role that architects and designers play during the process of design and development of the built environment –the key factor that discriminates between inhabitants (Giddens, 1993). These barriers continue to exclude wheelchair-users from mainstream society (Oliver, 1990). However, removing all barriers and obstacles, and achieving accessibility in all life aspects for all types of disabilities remains huge and pervasive.

Knowledge of Disability and its Impact on Accessibility

Knowledge is power, and inadequacy of knowledge on the side of designers and architects coupled with the negative attitude of society have a diverse effect in the creation of inaccessible built environment (Goldsmith, 1997; Hall & Imrie, 1999; Willis, 1990). Design experience in the United Kingdom, for example, indicates that a lack of knowledge about disabled people's needs by both tutors and students at architectural schools has resulted in more restricted accessibility (Goldsmith, 1997). Research findings in the United Kingdom's architectural schools reported by Holmes-Siedle (1997) show that more than fifty percent (56%), of the students of architecture were unable to address the needs of disabled people due to a limited or lack of their teachers' awareness. Similar findings were also reported by other studies carried out in Scotland (Imrie, 1999), Sweden (Fange, Iwarson, & Persson, 2002), and developing countries (Miles, 1995).

The Role of Professionals' Ideology in Accessibility

Many disability researchers believe that the oppression of disabled people in the built environment is caused by design impacted by social construction (Barnes, 1991; Giddens, 1993; Imrie, 1996, 1997). Much of the built environment designed traditionally, focuses on the majority of the able bodied sector of society with little or no consideration for the people with disability (Barnes et al., 1999; Holmes-Siedle, 1997; Russell, 1999).

A study by Hall and Imrie (1999) has also blamed the role and attitude of professionals towards disabled people and their spatial requirements. They point out that "architects are key actors or agents in the production of the built environment and their conceptions of different user groups are important … in contributing to the content of design processes" (p. 423).

Imrie (1996) further notes that designers and architects are part of the wider socio-cultural and political processes. As such the influence of their ideas in design practices is characterized by:

> ideological assertion of the aesthetic or prioritizing the idea of building form over use, the professionalization of architectural and other design practices, thus creating a new technical "expert" elite, and the rise of the corporate economy as the dominant clientele. (p. 76).

Inadequacy of Design

Designers, as mentioned above, tend to undermine their role and be misled by holding the assumption that they are "passive, as an instrument of the client, or elevated to a position of supreme control" (Imrie, 1996, p. 74). If this assumption remains unaltered, designers may have inevitable negative effects on the social oppression experienced by disabled people and their quest for accessibility and inclusion within main stream society (Weisman, 1992). The views and needs of end users should be paramount for designers in order to create an adequate and successful design in which all members of society, including disabled people, have equal accessibility to goods and services (Harker & Eason, 1984). Consulting end users in the decision making and during design process would help large numbers of the population to use the final product, which in turn would bring greater inclusion.

However, during the 1960s, attitudes towards designing the environment began to change. This was mainly attributed to Goldsmith (1997) whose way of designing for disabled people was instrumental. In his book "Designing for the Disabled," Goldsmith observed that:

"… buildings always have been, and always will be, geared to suit two-legged able-bodied people and not people rolling about in chairs on wheels" (Goldsmith, 1997, p. 16).

In KSA, despite the implementation of disability laws and establishing the Saudi Building Code which obliged designers and builders to ensure reasonable access for disabled people, people in wheelchairs, according to the co-author's self experience (as a wheelchair user), still encounter access problems in the KSA's built environment. To borrow from Imrie (2003), this lack of accessibility might be due to the inadequately designed environment caused by designers' shortfall in knowledge and a lack of understanding.

The Social Model of Disability

The social model of disability has undergone tremendous changes throughout the world in the last century (Barnes. 1991; Finkelstein, 1975; Oliver. 1990). The social model puts disability issues on the top agenda of human rights, seeking equal opportunity for all. According to the social model of disability, it is the social negative attitudes which create inaccessible built environments (Oliver, 2009). Unlike the medical model, the social model of disability focuses on the change of social attitude approach rather than individual rehabilitation solutions. The key assumption is that the social model approach will help in broadening the limited concept of physical "accessibility" to cover the social inclusion of disabled people. Accessibility therefore, is not restricted to space but rather includes the shared societal atmosphere as well.

Universal Design

The term "universal design" by Mace and colleagues describes the concept of designing all products and the built environment to be aesthetic and usable to the greatest extent possible by everyone, regardless of their age, ability, or status in life (Mace, Hardie, & Place, 1990). It was developed by a group of architects, product designers, engineers, and environmental design researchers (Christophersen, 2002) and is linked to a set of seven principles that offers guidance for designers to better combine features that meet the needs of as many users as possible. The seven principles are:

(1) "Equitable use;
(2) Flexibility in use
(3) Simple and intuitive use
(4) Perceptible information
(5) Tolerance for error
(6) Low physical effort, and
(7) Size and space for approach and use" (Calkins, Sanford, & Profitt, 2001, p. 7).

Applying the concepts of "universal design," "design for all" or "inclusive design," is a step forward towards removing the barriers imposed on built environment by the societal negative attitudes, as suggested by social mode and creating accessible built environment.

Design for all and inclusive design are terms and concepts used by different experts to explain their views of developing a sort of design in which the users are placed at the fulcrum of the design process rather than in the margin. The emphasis is "working with people rather than for them," allowing the users to "… have the ability to take control of their environments" (Hatch, 1984, p. 4). Inclusive design is, for example, challenging the technical, social and institutional relations of the design and building process, by prioritizing users' views, rather than being an "add on" to existing knowledge or a theoretical response to the needs of disabled people (Imrie & Hall, 2001).

Casserley and Ormerod (2003) consider environmental design as the legal driver for curbing discriminatory situations by removing barriers. They state that: "Inclusive design avoids institutional aesthetics, instead favouring simplicity, and elegant solutions that work for everyone equally" (Casserley & Ormerod, 2003, p. 153). The European Commission (1996) stated that: "to ensure equal chances of participation in social and economic activities, everyone of any age, with or without any disability, must be able to enter and use any part of the built environment as independently as possible" (European Commission, 1996, p. 7).

Disability and Inclusion in KSA

Having introduced the social model of disability and universal design, it is worth noting that these instrumental techniques are almost absent from the KSA's legislation as the disability law and regulations are mostly focused on the medical approach of disability which is offering very little scope for integrating of people with disability. The reported success (Al-Mousa, 2010) of the inclusive education programme in KSA indicates that utilizing the idea of education mainstreaming should also considered for integrating disabled people into mainstream society in KSA. In the other words, there will be a genuine change in the perception and attitude of general public towards disability if law and regulation be diverted from a caring perspective towards human rights and development perspective. However, the global movement towards a more inclusive society still requires dedicated efforts in the Arab region, including KSA. Nevertheless, there has been no genuine effort to apply the concept of inclusion for the society at large. Therefore, applying the concept of "universal design," or "design for all" and "inclusive design," is a step forward for creating an accessible built environment which will contribute to achieving the objectives of the social model of disability. In other words, KSA's new legislation should not focus only on care and welfare services such as community-based rehabilitation program, vocational training, sheltered workshop, and special education. Rather the integration and social inclusion of disabled people into mainstream society also must be targeted.

The Accessibility Compliance of Surveyed Roads and Buildings

Based on the accepted view that "physical manifestation is the agent of ideology," Part II of this paper focuses on the condition of physical accessibility to public roads and public buildings that are used by wheelchair users for their daily needs. According to Haywood et al. (1995), the extensive accessibility measures that required to be included for accessible buildings are toilets with changing facilities, wide entrance and inside opening doors, ramps, lifts, wide car parking bays, handrails on ramps, lever taps on wash basins, automatic doors and non-slip floors etc. The required data regarding accessibility and facilities in the public roads and buildings was intended to be collected based on the principles of KSA's laws and standards of the ADAAG.

The Aim of The Exploratory Study

The aim of this article is to investigate the KSA's disability law and its effectiveness, or otherwise, in creating an accessible built environment. For this reason and in line with the widely accepted view that "physical manifestation is the agent of the ideology," this article applied the method of field observation to assess the accessibility of public roads and buildings in the capital city of Riyadh. We therefore evaluated the accessibility of public roads and buildings in KSA to find out how far the disability policy based on Islamic principles (as claimed by the law) was successful in designing and creating an accessible built environment in which wheelchair users (the focus of this study) could physically be enabled to perform their daily duties independently and be socially integrated. To address this research question, we investigated the accessibility compliance of a random sample of public roads and buildings in Riyadh city in an exploratory study.

PART II: EXPLORATORY STUDY

Method

Riyadh city was chosen for investigating the accessibility compliance of public roads and buildings in relation to requirements of KSA's Legislation of Disability, the Saudi Building Code, and the international standards of the Americans with Disabilities Act (ADA) Accessibility Guidelines (ADAAG, 2010). The Access Board of the Americans with Disabilities Act (ADA) of 1990 developed the ADAAG in 1998 to assist with implementation of the ADA. Quantitative data were collected for a randomly selected sample of 13 public buildings from a list of 130 public buildings compiled from the yellow pages, as well as six different roads from the CBD in Riyadh city. The researchers did not have a chance to enter any building with accessibility measurement tools due to the strict security policy in Saudi Arabia. Furthermore, the researchers had no choice but to base their investigation on external observation of roads and buildings by taking pictures from locations that did not raise any concern. To record the internal condition of buildings, researchers just relied on eye scanning and taking notes. The internally and externally recorded data was then measured against the ADAAG standards and analyzed to find out the level of accessibility compliance of roads and buildings. The research process and field observation, therefore, were carried out under quite abnormal conditions due to the time limitation and security restriction that was not expected.

The percentage of compliance of roads and public buildings was calculated by dividing the number of available accessible facilities of each road or building by the total required number of such facilities multiplied by 100 (accessibility compliance = available/required x 100). For example, if 10 accessible parking spaces are required by the ADAAG standards for a particular place but only one space was available then the compliance percentage of parking in the given location is 10%. If the site lacked any accessible parking then the building in terms of accessible parking compliance was recorded as zero – or non-compliant. The same procedures were used to measure other areas of accessibility in terms of dropped curb and width or routes, paths and entrance doors.

However, due to the security limitation there was no permission to take picture or measure the facilities inside the public buildings, and even taking picture from outside of the premises and roads resulted in a one day detention in the local police station for one of the researchers. The main purpose was to examine to what extent, disability-related policies and regulations are implemented on the ground and what steps are being taken to facilitate the availability of services and accessibility to public sphere for persons with disabilities. The photos for this research were collected in September and October of 2014.

Results

The results of this study are summarized in Table 1. Typical examples of roads and buildings that present barriers to wheelchairs are given in Figures 1 to 13 (on the following pages).

Public and private buildings. The field observations show that:

- The majority of private and public buildings including those newly constructed in Riyadh city do not comply with the accessibility standards dictated by KSA's law, the Saudi Building Code, and the ADAAG.
- None of the observed buildings had a standard ramp or designated standard disabled parking.
- Despite the serious consideration of mainstreaming education by the KSA's government however, the findings show that in most cases, the condition of educational buildings including schools (Figure 1) and university (Figure 2) were not adapted to ease the mobility of students with impairment.
- The overall situation of physical accessibility at the workplace (Figures 3 and 4) is quite

Table 1: The Accessibility/Compliance of Observed Roads and Buildings (Percent)

Name of Roads and Buildings	*Year of Construction*	*Parking*	*Ramp*	*Lift*	*Entrance*	*Phone*	*Route*	*Toilet*	*Pedestrian Crossing*	*Dropped Curb*	*Average Percent Compliance*
Bank	2003	0	30	50	50	–	–	0	–	–	26
Housing complex	1998	0	0	40	70	0	30	0	–	–	20
Hospital	2009	10	60	50	40	0	30	0	–	–	20
Hotel	2007	60	70	80	70	0	40	45	–	–	52
Mosque	1971	30	10	–	50	0	40	0	–	–	21
Public park	2012	50	80	–	70	0	80	60	–	–	56
Post office	2002	10	50	–	60	0	40	0	–	–	26
Primary school	2000	0	0	–	60	0	0	0	–	–	10
Restaurant	1999	40	20	–	70	–	0	40	–	–	34
Secondary school	1993	0	0	0	60	0	40	30	–	–	19
Shop	1996	0	0	–	60	–	0	0	–	–	15
Shopping mall	2005	60	90	80	70	0	70	60	–	–	62
University	1999	0	40	50	70	70	60	40	–	–	47
Main road1	n/a	20	50	–	–	30	–	0	40	60	33
Main road2	n/a	10	30	–	–	20	–	0	40	40	21
Secondary road1	n/a	0	0	–	–	0	–	0	20	30	9
Secondary road2	n/a	0	0	–	–	0	–	0	10	20	5
Tertiary road1	n/a	0	0	–	–	0	–	50	0	0	8
Tertiary road2	n/a	50	40	–	–	0	–	30	0	0	20

Figure 1. Lack of ramp in a school

Figure 2. Lack of disabled parking in a university

Figure 3. Lack of ramp in a residential building

Figure 4. Lack of ramp in a workplace

similar to that of observed in the educational environment. In general, health, workplace, recreation and government buildings were found inaccessible by wheelchair users.

Accessibility to parking was so bad that in King Khalid Hospital, for example, there were only two substandard spaces designated for disabled parking which were occupied by non-disabled cars (pictures taken were deleted by the hospital security after detention). Similar condition found in other health centers (Figures 5 and 6). The parking spaces were also located far more than maximum standard of 50m away from the main building. Furthermore, even an access-

Figures 5 and 6. Cars, chain and traffic barriers block disabled parking lot at a hospital.

Figures 7, 8, and 9. Sidewalks blocked by planted or broken trees

Figures 10 and 11. Sidewalks blocked by parked cars putting people's life at risk.

Figures 12 and 13 : Main roads lacking any safe pedestrian crossing

ible parking with a disabled signpost could not guarantee the rights of disabled people to access as it might be occupied by non-disabled. This means that there are no sufficient parking spaces available for disabled people in KSA.

Based on the co-researcher's experience (as a wheelchair user) in a number of public buildings in KSA, parking areas could not be differentiated from walking paths as disabled parking lots were occupied by the non-disabled (Figure 5) or there was no sign or symbol of disability posted (Figure 6). In short, observation showed that the surveyed public roads and buildings even mosques were non-compliant with all the standards required by ADAAG or KSA's law and the Saudi Building Code which is based on The International Code Council. Building regulations seem to be either absent or ill defined with regard to accessibility for people with disabilities.

Public roads and sidewalks. The sidewalks and pedestrian crossings in the capital city were no better than its public building conditions. Most if not all the sidewalks of main and secondary roads were inaccessible and were blocked either by planted trees (Figures 7, 8, and 9) or parked cars – pushing people into the main roads and putting their life at risk of car accident. The width of the walkways in the newly constructed areas were too narrow to accommodate two pedestrians let alone a person with wheelchair, or blocked by parked cars (Figures 10 and 11). The main streets were too wide to be crossed safely by elderly and disabled people as they lacked any zebra crossing to help people cross the road without being hit by speeding cars (Figures 12 and 13). The outcomes of these hazardous roads was that the road fatal accidents in KSA (2.6%) was eight times more than that of the United States (0.313) in a period of six years (1971–1977). The number of people who died or were injured in this period were 564,762 – equivalent to 3.5% of the total population of KSA. According to Ansari et al. (2000) road accidents in KSA were mounting to one person killed and four injured every hour.

Discussion

A growing number of studies are investigating the compliance of legislation with accessibility to public roads and buildings in different localities. Most, if not all, of these studies indicate that there is no compliance between built environment accessibility and the disability legislations that call for making the environment accessible. The Disability Act in Zimbabwe, for instance, prohibits denial of disabled persons access to public premises, services and amenities. The act, nevertheless, does not enforce local authorities to act against architectural obstacles (Useh, Moyo, & Munyonga, 2001). This lack of enforcement has led to poor compliance of accessibility. A similar situation was observed in the United Arab

Emirates (Rivano-Fisher, 2004) where public buildings were still inaccessible, especially for wheelchair users.

Lack of law enforcement acted as a barrier that has negatively affected the accessibility of public buildings. For example, under article 10 of the 63rd Royal Decree of the Sultanate of Oman, it is mandatory for both government and private buildings to include facilities that make them accessible to people with disability. However, the design of many buildings makes it difficult – if not impossible – for wheelchair users to enter them (Christopher, 2012).

With the exception of western countries where the law and regulation regarding disability and accessibility are enforced effectively, there is no difference between developing countries when it comes to the built environment accessibility for wheelchair users. Examples above mentioned from developing countries imply that the legislations addressing accessibility are either ineffective or not enforced at all and, as suggested by the literature, this problem seems to be common among developing countries including KSA (Alazzeh, 2009; Al-Jadid, 2013; Rivono-Fisher 2004; Turmusani, 1999). Regardless of the economic status of these countries, the exclusion of wheelchair users from public buildings is multiple and complex, and yet is linked to the policies, practices, values and knowledge of professionals involved in design and construction processes (Hall & Imrie, 1999).

Although KSA's disability laws have been in place for long time, however, the struggles to deliver what was promised by the law tend to be unsuccessful. The King Salman Center for Disability Research (KSCDR) supported by King Salman is considered as the pioneering institution of disability research in KSA and its mission (as stated in their website) was "to improve the quality of life for the disabled through [their] research." The Center is attempting to enforce the application of universal design principles for creating accessible built environment for all in the kingdom (KSCDR, 2014). However, there has been no actual accessibility project implemented on the ground by this Center to provide wheelchair users with accessible parking even in its own main building. This condition in general is explained by Gleeson (2001) where he stated that despite the production of human rights legislation and its reassurance for creating inclusive environments for all people: "achieving the goals of human rights is still hampered by ineffective legislation and inaccessible design regardless of political concern" (Gleeson, 2001, p. 259).

In short, accessibility is a pre-requisite for integration of disabled people. As such no legislative process can endorse disabled peoples' request for a fully inclusive and accessible lifestyle unless designers and decision makers take into account the wider socio-cultural, socioeconomic, and socio-political context surrounding the built environment.

Conclusions

In this research, it is revealed that human culture has a profound influence on the construction of built environments and the lack of accessibility. Creating the built environment as such, is a key variable in enabling or disabling impaired people with regard to access to public space.

The social model of disability has also blamed human attitude and culture for having a profound influence on the construction of built environments. The lack of, or poor accessibility to, public roads and buildings as such have resulted from the societal negative attitudes, inadequacy of: either the design, law, regulation shortfall, or ineffective implementation. The research finding once again proves that the requirements by the law do not safeguard the accessibility and inclusion as intended.

The low compliance of roads and buildings indicate that the disability laws and regulations in KSA not only falls short of giving the right standards and required accessible environment but also reveals that authorities have failed to deliver what they promised due to ineffective implementation. Accessibility however, will not be achieved by developing law and regulations per se; rather, it must be associated with a change in the societal attitudes making designers and decision makers understand and accept the disabled person's culture and involve them in the design process.

In short, to achieve an accessible built environment, one would need to remove the imperfections, and to remove imperfections means correcting the underlying social forces which institutionalize the negative attitude towards disabled people. Although law enforcement is one way of addressing lack of accessibility to public roads and buildings, the priority should be making the general public aware of laws and regulations and of the great difficulties that people with physical disabilities and/or in wheel chairs continue to have with accessibility issues. Such activities are needed to change the culture and attitudes in society in order to lay the groundwork for easy acceptance of such laws. This would mean that dictating norms and regulations which have no cultural basis, inevitably, cannot be taken for granted to be effective. The clear message of this statement remind us of the old Arabic adage that says: "al-nefoos qablel-al-nesoos" – that is, a change of mind takes precedence over the provision of law.

In line with a social model that provides a method for arguing against societal exclusion, an inclusive method also emphasizes categorically that the end user is a central theme and should be an essential component within the design process. This process would promote inclusivity for all sectors of society regardless of age, race, gender or disability.

Key Messages From This Article

People with disabilities. The integration of people with disabilities into main stream society will require a genuine change in the perception and attitude of the general public towards disability. To achieve this target and provide the wheelchair users with full accessibility, the concept of disability and the suggested solutions in KSA should be diverted away from the traditional individualistic (medical model) approaches towards those founded on the social model. It is achievable by educating friends and family, and by advocating professionals and policymakers for changes that would help.

Professionals and policymakers. Professionals including decision makers (policymakers), architects and designers should also change their attitudes towards disabled people and the way they design to utilize inclusive methodologies. By doing so their decisions and design will inevitably affect the world differently and oppressive and discriminatory traits will begin to fade away with the assistance of the use of good design practice. They should consider the participation of end users (wheelchair users) during the design process.

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