An Exploratory Study on the Occurrence of Physical Health Problems in Psychiatric Outpatients with Intellectual Disabilities

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Objectives

Rates of health and medical issues are high among individuals with intellectual disabilities. Managing these conditions in addition to the pre-existing intellectual disability can be very difficult. It has been shown that side effects of certain medications prescribed to treat psychiatric disorders can also lead to complex health issues. Recent research has highlighted high rates of medical conditions in inpatients with dual diagnosis of intellectual disabilities and psychiatric disorders, but there has been limited research on health conditions of outpatients. The purpose of this poster is to describe the rates of health issues and preventative health monitoring among outpatients with dual diagnosis at the time of initial outpatient nursing assessment.

Methods

Information on physical health conditions of outpatients referred to the Dual Diagnosis Service at the Centre for Addiction and Mental Health is recorded on nursing assessment reports upon completion of detailed head to toe exams. A chart audit was conducted on 59 outpatient nursing assessments completed between 2009 and 2012. The clients were between the ages of 16 and 74 ($M = 33$) and the majority were male. The occurrence of metabolic, cardiovascular, respiratory, musculoskeletal, endocrine, neurological, dental, vision, and sexual health problems were investigated along with rates of completed recommended screenings and associated demographic information.

Results

Preliminary results indicate that outpatients with dual diagnosis have high rates of health concerns. Neurological, musculoskeletal, gastrointestinal, and dermatological conditions were the most common medical issues, each with a frequency greater than 50%. More than one third of the sample suffered from constipation and endocrine complications while auditory problems, obesity and urinary tract infections (UTI) each occurred in less than 30% of individuals. In terms of preventative monitoring, rates reported are far from guideline recommended care.

Conclusions

Findings of this study show that rates of medical issues in outpatients with intellectual disabilities and psychiatric disorders are high. Unfortunately, these patients do not always get the care they need for their physical health concerns because the focus tends to be on their psychiatric issues. By identifying and highlighting medical concerns and improving the rates of preventative monitoring, the quality of life of people with intellectual disabilities can be greatly improved.

Reliability of the York Measure of Quality of Intensive Behavioural Intervention

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Objectives

This poster focuses on the reliability of the York Measure of Quality of Intensive Behavioural Intervention (IBI). IBI is considered the treatment of choice for young children with autism, though outcomes are variable. Some of this variability may be related to treatment characteristics. Much research has focused on treatment intensity (e.g., 20–40 hours per week) and duration (one to three years), both of which are indicators of quantity of treatment, and occasionally on the model of supervision used in the program. However, the quality of this treatment has received much less attention, since it is rather difficult to measure due to the lack of an objective and reliable measurement method. The The York Measure of Quality of IBI (YMQI) is attempting to fill this gap. The YMQI was originally developed in our lab between 2004 and 2005, based on literature, training manuals, clinical experience, and surveys of parents and professionals. Revisions were made over time and good inter-rater reliability, internal consistency, and agreement with expert judgments were established. A self-guided training DVD was developed, which teaches how to use the YMQI and rate the 31 items (e.g., clarity of discriminative stimuli, speed of reinforcement, effectiveness of prompts) on a five-point scale based on two five-minute segments of videotaped IBI sessions. In a recent study, we found that undergraduate coders maintained high inter-rater agreement with no evidence of observer drift after training with the DVD and one in-person booster training session provided by the first author.

Methods

As part of a larger study, monthly videos of 39 participants engaged in IBI have been collected. A total of 411 videos have been coded by one of four raters, using the YMQI. Two coders have rated 83 videos (20%) in order to evaluate the inter-rater reliability. For this poster, we are focusing on the reliability of the measure. In particular, we will report on inter-rater reliability and scale reliability.

Results

In the results, we will present the inter-rater reliability for the total score, as well as the individual item scores, using percentage agreement and intra-class correlations, as well as the scale reliability, using coefficient alpha and the item-total correlations of all 31 items. Preliminary analyses indicate 88% agreement across items and videos, which is excellent for this complex coding scheme.

Conclusions

This poster will provide us with more current information on the reliability of this complex measure, based on a much larger sample than we have previously examined. This research will contribute to an area of autism intervention research that has not been explored in the literature due to the difficulty of measuring the quality of IBI. This study will examine whether different raters can assess the quality of IBI sessions reliably using the YMQI. We believe that assessing quality is as important as quantity, especially when such a significant amount of time and money is devoted to this intervention.

A Curriculum for Caring for People with Developmental Disabilities

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Objectives

Working with people with developmental disabilities offers an opportunity to foster compassionate, person-centred care among future healthcare providers. In 2008, with the launch of the Michael G. DeGroote School of Medicine's Niagara Regional Campus, an initiative began whereby medical students were provided with experiences to increase their capacity to provide competent and compassionate care to people with developmental disabilities. The program has included three phases over the course of the students' medical education. Nursing students have also been included with the added benefit of inter-professional learning.

Methods

There are three phases of training: (1) early exposure with an introduction to working with people with developmental disabilities, including an opportunity to meet patients and caregivers, (2) pre-clerkship clinical skills primer and interviewing experience, and (3) clerkship application in dual diagnosis clinics. As well, a video featuring people with developmental disabilities and their parents or caregivers discussing experiences with the healthcare profession is being produced to enhance and broaden the scope of the presentation to learners (first and second phases).

Results

Since 2008, student evaluations of the program, based on self-reports of comfort and competence with the population, as well as clinical preceptor observation have been reviewed and used to refine the program. Brock Center for Applied Disabilities Studies and McMaster University Department of Psychiatry and Behavioural Neurosciences are participating in further curriculum development and qualitative research. Medical and nursing students will be asked to complete a short questionnaire prior to and following each phase of the training with questions being related to comfort, competence and confidence in working with people with developmental disabilities.

Conclusions

This project has expanded to involve multiple collaborators within McMaster and Brock Universities, as well as the broader community of people affected by developmental disabilities (e.g., agencies, service recipients). A curriculum of caring for people with developmental disabilities has been developed and is being further evaluated and enhanced. The initiative complements other projects in Ontario and throughout Canada aimed at promoting excellence in competent and compassionate health care for people with developmental disabilities.

Sexuality in Autism Spectrum Disorders: Knowledge, Perceptions, and Experience

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Objectives

Many individuals with autism spectrum disorders (ASD) are interested in sex and engage in sexual behaviours. However, little is understood about sexual knowledge, perceptions, and experiences in ASD. Knowledge and self-perceptions are important factors in the development of safe sexual practices and healthy relationships for typical developing individuals. Parents and peers have been found to be particularly important sources of such knowledge. Given the specific areas of deficits found in people with ASD (particularly social relationships and social-cognitive processing), many may miss or misunderstand important sexual knowledge gaining opportunities and misinterpret sexual experiences. Thus individuals with ASD may be at risk for engaging in risky sexual exchanges and being victims of sexual violence. The current study aimed to understand the actual and perceived knowledge and sexual experiences of individuals with ASD and how it compares to that of typically developing individuals.

Methods

One-hundred individuals with high functioning ASD have been collected and matched by chronological age to 100 typical developing individuals. All participants are between 18 to 30 years of age, lived in North America, and were willing to participate in an online survey. Participants completed the Autism Spectrum Quotient, Sexualized Behaviour Scale, Revised Knowledge of Sexual Health, Sexual Experiences Survey, and researcher created questionnaires regarding sexual knowledge sources, perceived knowledge, sexual demographics, and sexual experiences and behaviours.

Results

Data collection and analysis is ongoing. The interaction between actual knowledge and self-perception of knowledge will be examined as it relates to risky sexual behaviours. The relationship between actual knowledge and where the participants obtained their knowledge (knowledge sources) will also be examined. It is hypothesized that young adults with ASD will report increased rates of sexual violence victimization than typically developing young adults, with females in both groups reporting increased rates and degrees of victimization than males.

Conclusions

The results of this study will provide an understanding of sexual health knowledge in the adult ASD population and how this relates to risky sexual behaviour. Results of this study may also have important implications in the development of sexual safety training and socio-sexual curriculum development.

A Provincial Study on Differences in Coping Strategies Used by Parents Seeking Services for Their Adult Children with Developmental Disabilities

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Objectives

Over time, parents of adults with developmental disabilities (DD) face increasing challenges related to health issues and declining strength which may affect their ability to support their family member's needs. One way for these parents to manage stress is to request support from Developmental Services Ontario (DSO), a new standardized application process for individuals with DD. Research has focused on service utilization in the USA and UK whereas less is known about the experiences of Canadian families. The current study aims to (1) examine how families requesting services through DSOs cope and (2) examine differences in families according to their scores on problem-focused and emotion-focused coping. Based on the literature, it is hypothesized that parents using primarily problem focused coping will report higher perceived support, mastery and psychological well-being. It is also hypothesized that parents using primarily emotion-focused coping will report lower perceived support, mastery and psychological well-being.

Methods

This study will use archival data collected from parents participating in the Multidimensional Assessment of Providers and Systems (MAPS) research project entitled "Parents Requesting Adult Developmental Services for their Children." Participants: Data collection is ongoing but a final sample of approximately 105 parents requesting services through a DSO organization for a family member with DD is expected. Individuals with DD will be aged 16 and above and living at home. Measures: Information about parents requesting services from DSO and their adult family members with DD will be obtained from standardized interviews and questionnaires, Parents will complete the Application for Developmental Supports and Services (ADSS) and the Supports Intensity Scale (SIS) which provide information about the parents (e.g., income) and their family member with DD (e.g., diagnosis). For purposes of this study, data collected at the initial interview and from the following questionnaires will be used: Family Support Scale: perceived informal and formal support; Brief COPE scale: problem and emotion focused coping; Mastery subscale of the Revised Caregiver Appraisal Scale: caregiver mastery, and the General Health Questionnaire-12: psychological well-being.

Results

Descriptive statistics for all measures will be reported. Two ANOVAs will be conducted to explore differences in child variables (i.e., age, diagnosis and behavioural support needs) and parent variables (i.e., perceptions of support, mastery and psychological well-being) according to parents' use of problem focused and emotion focused coping.

Conclusions

The results of this study will provide information regarding the impact of coping strategies on parents' perceived support, mastery and well-being. This information may be useful in developing supports for parents requesting services. Limitations and directions for future research will be discussed.

Transition from Elementary to High School for Students with Developmental Disabilities: Where Is the Research?

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Objectives

This report contains a critical review of literature on the transition from elementary to high school for students with developmental disabilities (DD). In recent years, the inclusion of people with DD has become an increasingly salient topic for policymakers, educational personnel, and to some extent North American society. High school may be more challenging than elementary school as: (1) students often move from a smaller to a larger school community which may be a less personal environment, (2) students transition from having one teacher to a rotary system, and (3) students are expected to meet more academic requirements. It has been shown that the transition into high school is an important time in the lives of typically developing students, but there is a notable gap in the literature on this transition for students with DD.

Methods

We originally set out to conduct a critical review of the literature on the transition into high school for students with DD however, due to the limited number of journal articles found, the objective changed to focus on directions for future research. The literature reviewed included sources related to: research on physical disabilities (e.g., Cerebral palsy), specific disabilities (e.g., Down syndrome, learning disabilities), and specific aspects of transition (e.g., Individualized Education Plans, the transition for typically developing students). Databases searched included: PSYCInfo, ERIC and Google Scholar.

Results

We found 49 related journal articles with the most frequently consulted journal being the *Early Childhood Education Journal*, followed by *Intervention in School and Clinic*, *The Career Development Quarterly*, *Early Childhood Research Quarterly* and the *Council for Exceptional Children* journal. Unfortunately, many of the studies that did explore the topic of transition were either descriptive (e.g., literature reviews), or had relatively small sample sizes (e.g., case studies). We found little to no evidence of a formal review process to ensure that transition planning is effective for the move into high school.

Conclusions

The vast majority of research focusing on students with DD has been conducted on the transitions into and out of school. The literature on the transition into high school is sparse and has focused on typically developing students or students with physical disabilities. Given the importance of successful transition for students' success in high school and in post-secondary environments, directions for future research are proposed to develop, implement and evaluate models of transition planning specifically for students with DD.

Grandparents Raising Grandchildren with Fetal Alcohol Spectrum Disorder: Unique Challenges and a "Second Chance"

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Objectives

Parenting a child with Fetal Alcohol Spectrum Disorder (FASD) often presents new and unique challenges for a family. For example, parents often express financial difficulties, barriers to obtaining support, and difficulties obtaining a diagnosis. Although every family experiences a unique set of challenges, these difficulties often result in increased levels of parenting stress. Additionally, increasing numbers of children are being raised in families led by grandparents. When a child's parents are not present due to financial, health, or other difficulties, grandparents will often assume a parental role. Current literature describes how increasing age and leaving the labour force presents grandparents with additional challenges while raising a second generation, but neglects to describe how past experience provides this population with unique advantages and parenting strategies. The current study will focus on the experience of grandparents who are raising grandchildren diagnosed with FASD and the specific challenges and stressors they face, but also the advantages that come with a "second chance" at raising children. This study is part of a larger project looking at families raising children with FASD in Ontario.

Methods

Data collection is ongoing, but at the present time, eight grandparents and great-grandparents and 51 non-grandparents completed various standardized questionnaires, such as the Parenting Stress Index: Short Form (PSI-SF) and the Questionnaire on Resources and Stress: Friedrich's Short Form (QRS-F). Guardians also participated in semi-structured interviews. A basic interpretive approach will be used to analyze the qualitative interviews to determine reoccurring themes as well as to provide further insight into the quantitative measures.

Results

Data analysis is ongoing. Preliminary analyses indicate that grandparents raising children with FASD may be experiencing increased levels of parenting stress when compared to caregivers of children with FASD who are not grandparents. During interviews, several grandparents discussed their own drinking during pregnancy and the suspicion that their own child may have FASD, thus having implications for the multi-generational effects of FASD. Further analysis of the qualitative interviews will potentially reveal what specific factors are contributing to the additional stress experienced by grandparents, but also what advantages grandparents may have when raising a second generation.

Conclusions

Increasing numbers of grandparents are becoming the guardians of children diagnosed with FASD. In some cases, there are multiple generations of FASD and thus grandparents are facing the combined challenges brought on by the kinship adoption process as well as raising a child with a developmental disability. However, grandparents may have an advantage when facing some of these challenges due to having previously raised children. By better understanding the specific parenting challenges grandparents face, supports and interventions can be specifically tailored to this population and be targeted to those in need.

Conducting Research with Individuals Who Have Intellectual Disabilities: Ethical and Practical Implications for Qualitative Research

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Objectives

Despite the acknowledgment that individuals with intellectual disabilities are the experts on their own experiences, these individuals have been largely omitted from the disability discourse. Research in the field of disability has typically been done *on* individuals with disabilities, rather than *with* them, disempowering this already vulnerable population and taking away their voice. Conducting research, particularly qualitative research, with individuals with disabilities is therefore essential, yet limited research has appeared to address the issues or concerns surrounding doing so. Research in the field has been predominantly quantitative in nature, giving little portrayal of the true lived experiences of individuals with disabilities. Of the qualitative research that has been conducted, researchers often recount that individuals with intellectual disabilities have been involved with research, but not in the analysis of it. This lack of involvement is surprising given that many authors have called for emancipatory and participatory research projects that emphasize the direct participation of individuals with disabilities in all stages of research, including development, implementation, and dissemination. Qualitative methodologies, such as Participatory Action Research (PAR), should be employed in order to challenge disempowerment and involve individuals with intellectual disabilities in the research process. However, ethical (e.g., obtaining informed consent and assessing capacity) and practical challenges (e.g., recruitment, data collection, analytic strategy, researcher interpretation) often interfere with researchers engaging in participatory research projects. This presentation provides a selective overview of the literature with regards to the challenges associated with conducting qualitative research with individuals with intellectual disabilities, addressing both the ethical and practical concerns with regards to this population.

Conclusions

Issues related to obtaining informed consent and assessing capacity will be addressed. In order for consent to be informed, participants must be able to grasp the information that is provided, as well as have an opportunity to ask questions, discuss, and consider whether they would like to participate. There is a misconception surrounding informed consent, whereby it is implied that problems regarding informed consent can be overcome if they are handled in a sensitive enough manner. Furthermore, because some individuals may be incapable of giving informed consent at a particular point in time, continually evaluating a person's capacity to participate in research is essential. An argument will be made for the importance of using Participatory Action Research as a methodology of choice for individuals with intellectual disabilities, and recommendations will be provided for how to address these issues with disability-specific populations.

"It's Like Being on a Bicycle, You Just Have to Keep Pedaling and Do the Best You Can": Adaptation in Families Raising Children with Fetal Alcohol Spectrum Disorder

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Objectives

Despite the wealth of literature on families of children with disabilities, limited research has been conducted on families raising children with Fetal Alcohol Spectrum Disorder (FASD). Current trends in family disability research have transitioned from deficit-based models of coping to those that bring to light strength-based aspects of family functioning, such as adaptation. Adaptation is realized when the family has accommodated to define and recognize the meaning ascribed to their situation and has developed competencies and capabilities to foster growth and development.

Methods

A mixed methods study was conducted with 67 adoptive, foster, and biological caregivers of children with FASD in Ontario, Canada. Employing a basic interpretive approach, informed by the Family Adjustment and Adaptation Response (FAAR) model, semi-structured, qualitative interviews were conducted. Participants also completed a number of quantitative questionnaires, including the Family Crisis Oriented Personal Scales (F-COPES) and the Family Resource Scale (FRS).

Results

Interpretative phenomenological analysis of the interviews revealed two main superordinate themes (Helpful Strategies and Support Systems), with several constituent sub-themes regarding what has helped families adapt to raising a child with FASD. Parents identified strategies they found helpful, including educating themselves about FASD, using routine, consistency, and repetition, taking things day to day, and picking their battles. Parents also emphasized the importance of doing what they have to when the unexpected occurs. Parents discussed their use of both formal and informal supports, such as significant others, family members, and friends as important sources of informal support. Participants also identified support groups, respite services, and important professionals who were supportive in a formal capacity. Interestingly, initial data analysis reveals no significant correlations between the F-COPES and the FRS; however, responses to individual items on each measure will be considered and discussed in their relation to the qualitative findings. For example, in response to the question *"Defining the family problem in a more positive way so that we do not become too discouraged"* on the F-COPES, 35 participants, or 55% of the sample, moderately or strongly agreed with the statement, indicating that many families attempt to reframe their situation in a more positive light. Overall, total F-COPES scores indicate that parents are coping moderately well, with percentile scores in the 55th percentile for females (M = 97.65, SD = 12.09) and in the 54th percentile for males (M = 94.50, SD = 13.45).

Conclusions

Understanding what families do in order to transform from a family in crisis to a family that is successfully adapting is important when implementing appropriate family supports. The lack of significant correlations between the F-COPES and FRS may suggest that a family's ability to cope or adapt may not be limited by the resources available to them.

Level of Parental Satisfaction with the Autism Spectrum Disorder Diagnostic Process: Implications for Early Diagnosis and Intervention

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Objectives

Parents often report that obtaining a diagnosis of autism spectrum disorder (ASD) can be frustrating for parents, often resulting in long delays in obtaining a diagnosis, multiple diagnoses given, and visits to a number of health professionals. A significant relationship has been found between the amount of time between parents' initial concerns for their child and the child's subsequent ASD diagnosis and level of parental satisfaction, with longer delays associated with less satisfaction. Long delays in obtaining a diagnosis and dissatisfaction with the diagnosis can be in part be attributed to the co-occurring mental health disorders that are often present with ASD. As such, it is essential to better understand the diagnostic process, parents' satisfaction with their child's diagnosis, and how comorbid mental health issues complicate the diagnostic process. This study aims to support previous research that indicates that the ASD diagnostic process must be improved in order to prevent delays in obtaining a diagnosis and increased access to services during crucial years of early development. The current study aims to examine parents' degree of satisfaction with their child's ASD diagnosis and investigate the diagnostic process, including the number of previous diagnoses received by the child and the amount of time between initial parental concerns. Additionally, this study will examine whether specific ASD diagnostic subgroups predict parental satisfaction with the diagnostic process.

Methods

A total of 132 parents completed a questionnaire related to their experiences in obtaining an ASD diagnosis. Questions included: "Are you comfortable that the current diagnosis captures your child's characteristics and issues?" and "Do you have any concerns about any additional psychological issues." The current sample is comprised of parents of children with various ASD diagnoses including autism, ASD, Asperger syndrome, pervasive developmental disability (PDD), and PDD-not otherwise specified (PDD-NOS).

Results

Frequency analyses, correlations, and regression analysis will be conducted to examine the present study objectives. It is expected that a shorter period of time between initial concerns and ASD diagnosis will result in greater parental satisfaction. Satisfaction is also expected to be negatively correlated with additional psychological concerns. Consistent with previous research, it is hypothesized that parents of children with AS will report less satisfaction with the diagnostic process than parents of children with other ASDs. How specific aspects of the current ASD diagnostic process may influence parental satisfaction with their child's diagnosis will be examined.

Conclusions

Understanding how satisfied parents are with obtaining a diagnosis will help to inform health professionals as to how to improve the diagnostic process. Furthermore, successful treatment of ASD requires reliable diagnosis and treatment of other co-morbid disorders, such as anxiety.

Where Are Persons with Intellectual Disabilities in Medical Research? A Review of the Literature

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Objectives

Persons with intellectual disabilities (ID) are exposed to the same medical interventions as everyone else. Yet, it is not clear if clinical trials evaluating the safety and effectiveness of medical procedures have included persons with ID. Given the unique health profiles of many persons with ID, it cannot be assumed that they will react the same to medical treatments as persons without ID. The purpose of this systematic review was twofold: (1) to examine the inclusion of persons with ID among included medical research trials, and (2) among studies that did not include persons with ID, to determine whether accommodations and/or study modifications could have been made to promote inclusion in medical research.

Methods

Three-hundred randomized control trials and clinic trials published between 2007 and 2011 in the top six high-impact medical journals (New England Journal of Medicine, The LANCET, Journal of the American Medical Association, Annals of Internal Medicine, Public Library of Science Medicine, and the British Medical Journal) were randomly selected.

Results

Only about eight (3%) of 300 randomly chosen studies included persons with ID. Over 90% of studies were designed in ways that would automatically exclude persons with ID from participating. However, a close examination of these studies revealed that the most persons with ID could have participated in at least 70% of the studies with simple accommodations and/or minor design modifications.

Conclusions

The findings highlight the exclusion of persons with ID in medical research. As such, considerations must be made in weighing the applicability of medical treatment effectiveness on persons with ID. Important research, clinical and rights implications of these findings on persons with ID and other vulnerable populations will be discussed.

Investigating Predictors of Depression in Individuals with Autism Spectrum Disorder: Caregiver Distress, Negative Life Events, and Diagnosis

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Objectives

Individuals with autism spectrum disorders (ASD) are reported to have elevated rates of mental health problems compared to their typically developing peers, with depression as one of the most common comorbid psychopathologies for youth with ASD. The Diathesis-Stress model of psychopathology proposes that multiple risk factors may be necessary to foster the development of a disorder, although researchers have yet to investigate the usefulness of this model in the study of individuals with ASD, in which the presentation of psychopathology can be very complex. The current investigation aims to examine the relationships among vulnerability (ASD diagnosis) and stressors (caregiver distress and negative life events (NLE)) as predictors of depression. In addition, the study aims to examine how levels of depression may vary depending on the child's ASD diagnosis.

Methods

As part of a larger study examining families of children with ASD, 145 caregivers completed an online survey. Caregivers (79% mothers) were 23 to 72 years of age ($M = 45.08$, $SD = 9.70$) and children with ASD (81% male) ranged in age from 6 to 49 ($M = 16.26$, $SD = 9.41$). Caregiver distress was measured with the Kessler six-item Psychological Distress Scale (K6), and NLE of the child were measured with an adapted version of the Life Events Checklist from the Psychiatric Assessment for Adults with Developmental Disabilities. In addition, caregivers completed a measure of demographic variables, and reported on their child's depressive symptoms using the Glasgow Depression Scale – Carer Supplement (GDS-CS).

Results

Analyses revealed significant differences in depressive symptoms for ASD diagnosis ($F_{(2, 111)} = 4.07$, $p < .05$), illustrating higher symptoms in individuals with Asperger syndrome compared to those with autism ($p < .05$) or PDD-NOS ($p < .01$). Regression analyses revealed that after controlling for child age and gender, NLE accounted for an additional 4% of the variance in child depression ($t_{(109)} = 2.52$, $p < .05$), and caregiver distress accounted for an additional 12% of the variance ($t_{(109)} = 4.19$, $p < .01$). The interaction between ASD diagnosis and NLE or caregiver distress did not significantly contribute to the model ($p > .05$).

Conclusions

The findings suggest that caregiver distress and NLE can significantly contribute to explaining depressive symptoms for individuals with ASD. Also, despite different levels of depression depending on ASD diagnosis, the diagnosis does not moderate the relationship between parent distress or NLE, and child depression. These associations were observed using caregiver report, and it is important to follow up with self-report to substantiate findings. Further research should also investigate the direction of the associations between caregiver and child, as they could be uni- or bi-directional. The present findings contribute to our knowledge of risk factors for depression by expanding our understanding of specific vulnerabilities for depression for individuals with ASD.

Common Elements of Successful Behavioural Treatments for Self-Injurious Behaviours in Children and Youth with Developmental Disabilities

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Objectives

Over the past 40 years there has been a lot of research into functionally-based Applied Behaviour Analysis (ABA) interventions for self-injurious behaviours (SIB) in individuals with developmental disabilities. While some interventions have been effective at reducing the frequency of SIB the specific components of successful behavioural treatments have not yet been identified and categorized by function. The purpose of this research was to (1) identify studies in which ABA interventions were shown to be successful at addressing SIB in individuals with developmental disabilities and (2) identify and categorize by function the most frequently used elements of these treatments.

Methods

A preliminary group of 73 articles were identified following the literature search. Inclusion criteria included: published from 1980 – present; treatment procedure targeted a reduction in SIB; authors' definition of SIB was consistent with the one being used; employed a single case time series design; employed an Experimental Functional Analysis; treatment was successful (i.e., Percentage of Non-overlapping Data points (PND) score at a minimum of 75% or through visual inspection); participants aged 18 years or younger; and participants had a diagnosed developmental disability. A total of 33 articles were discarded based on a review of the abstracts. The full content of the remaining 40 articles were then examined against the inclusion criteria, with inter-observer agreement (IOA) conducted on 25% of the articles at a rate of 97%. Fifteen articles with 30 participants in total were found to conform to the final inclusion criteria. Treatment interventions from these articles were categorized by the function of the problem behaviour and the different treatment elements (e.g., Functional Communication Training (FCT); Warning Stimulus; Non-contingent Reinforcement (NCR); Fading in Stimulus) were charted based on the frequency of implementation.

Results

The studies included a total of 30 (17 male and 13 female) participants. The average age of the participants was 9.3 years. Twenty seven out of the 30 participants were diagnosed with various levels of intellectual disability. Three participants had a diagnosis of autism. Additional demographic information such as socioeconomic status, family background or ethnic and racial background of the participants was not indicated in any of the studies in review. Sixty percent of the interventions (n = 18) employed more than one treatment element. When multiple treatments were utilized, all the elements were implemented concurrently. Forty percent of the interventions were implemented alone as a single treatment (n = 14). When a single treatment strategy was employed, Extinction (35%) and Functional Communication Training (35%) were reported with the highest frequency. The most frequently implemented treatment packages employed Extinction plus fading in instructions (33%) and Extinction plus Response Blocking (20%).

Conclusions

The study serves as a means of promoting evidenced based practice by identifying for clinicians the treatment options for SIB that have most often demonstrated success in research.

Assessment and Management of Pain in Children with Cognitive Impairments Who Are Nonverbal: A Survey of Support Workers' Attitudes, Beliefs and Opinions

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Objectives

Past research suggests that children who have cognitive impairments not only commonly experience everyday pain, but they are also frequently incapable of providing accurate self-reports of the pain they experience. This means that their pain is often assessed and managed by caregivers. Numerous factors may influence and contribute to pain opinions and management decisions made by different caregivers. Disability and pain-related beliefs could ultimately impact the level and type of care provided when pain is experienced by children with cognitive impairments who are nonverbal. The main objectives of this in-progress study regarding children who have cognitive impairments and are nonverbal include: (1) Compare existing disability and pain-related beliefs between active respite workers and undergraduate students presumed to have little to no experience with this population, and (2) Determine whether reported beliefs could affect care decisions made in relation to pain assessment and management of this population.

Methods

Participants will consist of (1) students from the University of Guelph's undergraduate research participant pool and (2) active support workers recruited from one or more organizations that provide respite care. Participants will be at least 18 years of age and will either have direct experience with the specified population, or little to no experience. It is estimated that there will be a minimum of 200 participants. In an online survey, participants will be asked a series of demographic questions, then respond to questions related to a series of situational vignettes. Three vignettes are adapted from a previous study, while the remaining have been created for this study. Pain source and whether or not the child communicates verbally will be manipulated in these vignettes; for each vignette, participants will answer questions related to intensity of pain and need for assistance. Participants will also respond to two previously validated inventories measuring attitudes towards individuals with disabilities and beliefs regarding pain experience in typically developing children versus children with cognitive impairments.

Results

Though similar research has been conducted with primary caregivers and health care professionals, beliefs of support workers in respite settings have not been assessed. Data collection for this survey project is to begin in March 2013. Using a series of independent samples *t*-tests, researchers expect to see differences in the questionnaire scores of support workers compared to those who have little to no experience with the target population. Repeated measures ANOVAs will investigate differences across vignettes within each participant group on ratings of pain severity and need for assistance. Correlational statistics will assess relationships between participant personal characteristics and vignette responses.

Conclusions

The poster will discuss the results, potential implications and limitations of the study. Future research may investigate whether the development of appropriate educational opportunities could provide respite workers with tools to become more confident and skilled in assessing and managing pain in this population.

Changes in Parent-Perceived Support, Coping, Mastery, and Well-Being Over Time

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Objectives

Research conducted with families of individuals with developmental disabilities (DD) has reported problems in the availability of services, and parent concerns over long wait times. However, very little research has examined the effects of waiting for services in general and to date, no information has been found pertaining to Canadian parents of adult children with DD specifically. The aim of this study is to investigate whether parents of adult children with DD who are waiting for services from Developmental Services Ontario (DSO) experience changes in their child's behaviour support needs, their perceived formal and informal family support, feelings of mastery, use of emotion and problem focused coping strategies, and psychological well-being over a period of six months.

Methods

The Double ABCX model of family adaptation will be employed as a framework to assess these changes over time. This study will use archival data collected from parents participating in the Multidimensional Assessment of Providers and Systems (MAPS) research project, "Parents Requesting Adult Developmental Services for their Children: a Provincial Study." Data collection is ongoing, but a final sample of approximately 105 parents requesting services through DSO for an adult child (aged 16 and above) with DD who is living at home is expected. Information about parents requesting services from DSO and their adult family members with DD will be obtained from standardized interviews and questionnaires on an initial occasion and then every three months for up to a year. Specifically, parents requesting services from DSO are required to complete The Application for Developmental Supports and Services (ADSS) and the Supports Intensity Scale (SIS) which collects demographic information about the parents and individuals with DD, and measures the support needs of the family. Additionally, for purposes of this study, data collected at an initial interview and six months later from the following scales will be used: Family Support Scale: perceived informal and formal support; Brief COPE scale: problem and emotion focused coping; Mastery subscale of the Revised Caregiver Appraisal Scale: caregiver mastery, and the General Health Questionnaire-12: psychological well-being.

Results

Descriptive statistics for all measures at both data collection points will be reported. In addition, a Repeated Measures ANOVA will be conducted to determine if parents report changes in perceived formal and informal support, feelings of mastery, use of emotion and problem focused coping, and well-being over a period of six months.

Conclusions

This study will provide important information regarding the impact of changes over time that may be helpful in developing appropriate supports for parents of adults with DD. Limitations and directions for future research will be discussed.

The Right to Self-Determination in Daily Living: Individual Lifestyle Planning in Services for Persons with Intellectual Disabilites

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Objectives

The main objective of our research was to determine if individual lifestyle planning was more effective than traditional planning in assisting individuals supported by community living in achieving their outcomes. An additional goal of our work was to examine whether there was greater improvement on some outcomes compared to others and if individual lifestyle planning lead to an increase in the exercise of personal rights.

Methods

We followed two groups of individuals through two years of outcomes planning (*n* = 29 per group). Each group was matched on a number of characteristics: General ability, age, outcomes present at time of first testing, and setting (group home vs. independent living). Group one received individual lifestyle planning in the first and second year, while group two received traditional lifestyle planning in year one and individual lifestyle planning in year two. Number of outcomes and supports present was measured for each individual at three time points – before year one, at the end of year one, and the end of year two.

Results

There were no significant differences between the two groups in the number of outcomes and supports present at the beginning of year one, however, group one who received the individual lifestyle planning showed an increase in outcomes and supports at the end of year one (e.g., satisfaction with services and choosing daily routine), while group two who received the traditional planning did not show an increase in outcomes and actually demonstrated a decline in supports at the end of year one. At the end of year two, both group one and two showed an increased in outcomes and supports as a result of the individual lifestyle planning. Results also indicate that individuals demonstrate improvement on some outcomes more than others.

Conclusions

Overall individualized lifestyle planning proved to be more effective in assisting individuals in achieving their outcomes and for putting supports in place. This research has important implications for practice as it informs care providers on the value of a person centered approach to planning and supports. In the future, researchers may want to target areas that have seen the least amount of progress such as "real participation in the community." In addition, researchers may want to look more deeply at the differences in individualized planning and traditional planning to determine which elements of individualized planning lead to the greatest improvement and success in the lives of the individuals receiving the planning.

A Closer Look at Fetal Alcohol Spectrum Disorder in the Sexual Offender Population

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Objectives

This study presents preliminary data that is part of a larger study focusing on Fetal Alcohol Spectrum Disorder (FASD) within the sexual offender (SO) population. As a result of the trauma caused to the central nervous system, individuals with FASD may experience primary disabilities including cognitive impairments, memory deficits, and attention difficulties as well as secondary disabilities, such as involvement with the criminal justice system (CJS), and social skill deficits that can be expressed through sexually inappropriate behaviour. It has been suggested that within 2008/2009 there were between 207 and 423 youth with FASD, and roughly 3,686 adults with FASD within Canada's CJS. However, the prevalence of FASD within the SO population is currently unknown; in a sample of 62 Canadians with FASD, 45% engaged in sexually inappropriate behaviour such as engaging in masturbation in an inappropriate place, or sexual intercourse with unwilling partners or children. All convicted SO's undergo assessment and treatment in order to decrease future sexual recidivism. While it has been stated that SO's often share similar characteristics and family histories, researchers have not determined whether those with FASD sexually offend for similar reasons as non-FASD SO's. This study looks at the similarities and differences between SO's with and without FASD.

Methods

SO's within the CJS with and without FASD will be assessed using the Vineland-II; the Minnesota Multiphasic Personality Inventory-2; the Wechsler Abbreviated Scale of Intelligence-II; the Multiphasic Sex Inventory; and the Socio-sexual Knowledge and Attitudes Assessment Tool-Revised. Participants will also part-take in a semi-structured interview in order to better understand the lived experience of individuals with and without FASD within the sexual offender population.

Results

Once data is collected, participants with and without FASD within the SO population will be compared on their adaptive living and social skills, measure of personality, cognitive ability, sexual deviancy, as well as knowledge regarding socio-sexual matters. It is hypothesized that individuals with FASD within the SO population will have less adaptive and social skills when compared to those without FASD within the SO population, that individuals with FASD will have lower cognitive ability, and lower sexual deviancy scores when compared to non-FASD SO's, and that those with FASD within the SO population will have lower levels of knowledge about sexual matters compared to those without FASD within the SO population.

Conclusions

SO's with FASD require specialized support and treatment that must be accommodated within the CJS. Understanding the similarities and differences of those with and without FASD within the SO population could provide insight into the adaptations needed within assessment and treatment practices for SO's with FASD.

Effectiveness of a Mindfullness Practice Program to Facilitate Psychological Well-Being of Parents of Teens and Adults with Intellectual and Developmental Disabilities

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Objectives

Being a parent of an individual with an Intellectual or a Developmental Disability (IDD) is associated with increased stress and poorer psychological well-being. Also, as family caregivers have the most responsibility in supporting individuals with IDD, it is essential that they are provided with appropriate supports and services. Recent research has identified the need for psychological support to empower these parents. Emerging evidence also suggests that mindfulness and acceptance based interventions produce better parent outcomes including improved caregiving for their child. Mindfulness meditation which cultivates a non-judgmental awareness anchored in the present moment is associated with psychological acceptance, which is essentially the ability to experience and face current difficulties without attempting to directly change them. This could be a helpful strategy for parents of individuals with IDD since it helps to remain calm during events associated with the child that cannot be resolved immediately. The current study was aimed at qualitatively evaluating the effectiveness of a mindfulness program as a service to enhance psychological well-being and promote positive parent outcomes.

Methods

Two groups of 10 parents each (mean age = 54.2 + 8.9 years; female = 95%) participated in a mindfulness program which consisted of four (spring 2012) and six (fall 2012) sessions, respectively. The weekly two-hour sessions offered experiential training, which involved meditation practices such as sitting meditation, walking meditation and gentle yoga as outlined in the Mindfulness Based Cognitive Therapy program (MBCT). At the conclusion of the program, parents completed a satisfaction questionnaire summarizing what they learned, what was most effective and whether they would recommend this group to other parents. Parents completed a measure of distress (DASS-7), which they also completed at the start of the group.

Results

All parents who completed the end of program evaluations (spring = 50%; fall = 70%) reported that they liked the group. In fact, all of them indicated their interest in participating in future programs and also said they would recommend the program to other parents. On average, parents attended three out of four sessions in spring and four out of six sessions in fall. Most parents appreciated the practicality of the mindfulness and stress-reduction exercises, content of the readings, audio recordings and the overall presentation as well as the opportunity to make connections with other parents that share similar problems. Only 12 parents completed the DASS-7 prior to and following intervention. Their scores were significantly lower at the end of the program, suggesting that the group may have helped to reduce their distress ($t_{(11)} = 2.83$, $p = 0.016$).

Conclusions

Our preliminary results indicate that a mindfulness based intervention could be helpful to parents interested in learning new strategies to cope with day to day stress associated with raising a child with IDD.

Romantic Relationship Understanding in Adolescents with Developmental Disabilities: Preliminary Findings

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Objectives

Adolescence is a time when many important social changes take place for typically developing teens, including one of the most salient of these changes: the emergence of romantic relationships. It remains unknown, however, whether adolescents with intellectual disabilities (IDs) have similar social experiences as typically developing youth. While it is evident that youths with a mild ID are more likely to have friendships and are sexually experienced, it remains unknown how adolescents with an ID understand romantic relationships. Filling in this important research gap would help in not only educating parents, practitioners, and policymakers, but to also effectively support youth with an ID in developing meaningful and healthy relationship. Thus, this study will examine dating and romantic relationship understanding, expectations, and experiences among adolescents with an ID. A strength of this study is that it will provide a voice to individuals that have often been neglected in this research area: adolescents.

Methods

The participants in this study are adolescents between the ages of 16 and 19 years with a mild ID residing within the Toronto Area. Eligible participants had sufficient verbal skills to express themselves during the interview and sufficient cognitive skills to participate (mild ID). Their cognitive skills were assessed with the WASI as a prescreening measure of their IQ. The caregiver was asked to complete some questionnaires. The parental standard measures used are as follows: The short form of Developmental Behaviour Checklist; The Teen Timetable; The Courting Behaviour Scale; Dating Questionnaire; and The Children's Social Behaviour Questionnaire. The semi-structured interview with the youth included some of the caregiver measures (Teen Timetable and Dating Questionnaire) for reliability purposes, as well as some open-ended questions and a questionnaire (Network of Relationships Inventory) which focused on the quality of their relationship with their parent(s), friends, and (if applicable) their romantic partner. All of the standardized measures have been found to have good validity and reliability and some have been normed with youth who have developmental disabilities.

Results

While this study is still in progress, preliminary results will be presented. Participants, in general, were found to recognize the difference between a "friend" and a "boy/girlfriend." Although they acknowledged that a friend and a boy/girlfriend have some similarities, such as "hanging out" and "have fun" with, they tended to describe a boy/girlfriend as someone who you would spend "all your time" with and "get married" to. Many of the participants reported having had a previous or a current boy/girlfriend. Those that have not had this romantic experience were very interested in having a boy/girlfriend, mainly for companionship reasons. More detailed findings will be presented.

Conclusions

Based on preliminary results, it appears that youth with ID are very much interested in having a serious romantic relationship which would provide them with the consistent companionship that they desire. These results provide new insight into the way youth with ID understand and experience romantic relationships. Understanding what these youth expect out of a romantic relationship will help practitioners understand how to best support these young people in this venture.

Enhancing Participation at School for Elementary School Students with Developmental Delays and Disabilities Through the Narratives of School-Based Allied Health Professionals

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Objectives

In Ontario, students with developmental delays and disabilities (DD) are being served in inclusive classrooms, though this does not guarantee the student's participation in classroom activities. School health support services, which include occupational therapy (OT), physical therapy (PT) and speech-language pathology (SLP) have been recognized as enabling inclusive education outcomes, though less is known on how allied health professionals (AHPs) – such as occupational therapists (OT), physical therapists (PT), and speech-language pathologists (SLP) support participation outcomes for students with DD. This study explored the perceptions of AHPs working in Ontario schools regarding their roles and responsibilities in supporting participation among these students.

Methods

Individual in-depth interviews with 15 school-based AHPs (11 OTs, 1 PT, 3 SLPs) were conducted. Participants were asked about their role, experiences working with others and vision for the future in supporting participation among students with DD. Appreciative inquiry was used to frame the interview questions so that emphasis was placed on the specific ways in which AHP's utilize their role and responsibilities to support participation. Interpretive description was used to frame the qualitative analysis of data.

Results

AHPs described the existence of two realities: how they felt school support services should be practiced, and how it is actually practiced. AHPs believed they should be able to go into a classroom and consult to the entire class, provide education to the teacher regarding curriculum modifications and ways to adapt activities in order to make them developmentally appropriate, but described a reality in which they provide services using a caseload model whereby they are only able to provide strategies to one specific student. AHPs also felt that ideally schools should have equipment readily available for use by students with DD instead of having to order supplies each time and wait for them to arrive. Despite significant challenges to the implementation of school health support services, participants identified (1) relational strategies and (2) specific supports. Relational strategies were revealed to be strategies AHPs use to communicate with educators (teachers, special education teachers, educational assistants), parents and other AHPs such as face-to-face communication and written notes. Specific supports AHPs used to teach other individuals activities in order to provide participation opportunities for the student included AHPs coaching, modeling, adapting environments and providing recommendations to support student growth and development.

Conclusions

Findings from this study contribute to improving the educational experiences of students with DD, as they are the beneficiaries of the approaches AHPs are implementing to facilitate their participation. Implications from this study suggest that AHPs view supporting educators with curriculum modifications as an important component in their role to supporting participation.

Social Inclusion of Children with Developmental Disabilities in School and Community Settings: Six Case Studies

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Objectives

Democratic values have been promoting the deinstitutionalization and inclusion of children with developmental disabilities increasingly in the past 40 years. This trend has been observed in both school and community settings in which individuals with DD are accommodated so they can participate and interact with typically developing peers. While most education and social policies promote this as a valuable goal, and some opportunities are available; it is unclear how successfully these children are actually included in terms of having positive interactions and meaningful friendships. The current study examines the social inclusion of six children in school and community settings. Live observations as well as parent, educator, community leader and child (when possible) perspectives are examined.

Methods

Great Outcomes for Kids Impacted by Severe Developmental Disabilities (GO4KIDDS) is an ongoing research project examining the health, well-being and social inclusion of children with severe DD. The six case studies are selected from the participant pool of the ongoing, broader social inclusion project. Participants were observed in school and in community settings (e.g., camp, swimming lessons) using live time-sampling coding for social interactions. Community leaders, parents and education workers were interviewed for their perspectives on each child's inclusion experience. The six cases include three boys and three girls with ages ranging from 8 to 13, three of whom have an identified ASD. Brief developmental testing for cognitive, language and adaptive skills was completed for each child. Intellectual abilities of the six children fell within the moderate to profound range. Selection for case study was based on participants' availability to be observed in more than one setting. Three of the six children were able to comment on their inclusion experience themselves in a semi-structured child interview.

Results

Initial review of the data suggests that these six children have opportunities to interact socially, sometimes with success and sometimes experiencing barriers. Themes that emerged from interviews suggest that professional training, family support and the availability of extra support staff help to facilitate successful inclusion. Strategies such as consistently structured activities and visual cues helped some of the children. Barriers to participation included aggressive behaviours, limited understanding of instructions and limited verbal abilities for some of the participants; and peers having a limited understanding of developmental disabilities. Live observation data revealed that, despite the availability of nearby peers or adults, limited interactions were observed. When interactions did take place, they were usually neutral in nature and more often with an adult rather than a peer.

Conclusions

The poster will provide additional, individual details on the observations and perceived inclusion experience, as well as adaptive abilities for each of the six children. Future research should continue to examine the discrepancies between perceived inclusion based on available opportunities, and the actual quality of inclusion experienced. It may also consider an examination of the perspectives of peers. Implications for education and social policies will be outlined.

Evaluating the Impact on Families of Two Autism Ontario Support Programs: March Break Funding and Summer Program Funding

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Objectives

Those raising children with autism spectrum disorders (ASDs) face unique challenges, with the severity of symptomatology varying within a wide range of behavioural, communication and social skill levels. Consequently, growing research indicates that parents of children with ASDs report higher levels of stress than parents of those with other developmental disabilities. Support programming such as respite service are often cited as major factors that aid to reduce parental stress; however, the financial burdens placed on families seeking such services can be overwhelming. Consequently, agencies such as Autism Ontario began to offer families the opportunity to apply for funding, which families can utilize towards supplemental programming for children with ASDs over the March and summer breaks. Given previous research indicating the benefits of such programming, it is necessary to assess these programs' effectiveness in reducing perceived stress by families and identify which support systems are most heavily utilized. The present study aims to examine the impact of funding for ASD support programming and its perceived effect on parental stress levels. Additionally, this study aims to understand how funding was utilized by families, what programs children participated in, what skills were obtained by children with ASDs, and most importantly how these factors relate to parents' reduction in stress.

Methods

An online survey was completed by 671 participants throughout Ontario. The survey obtained feedback related to basic demographic information, languages spoken by the families, years of Canadian residence, whether parents felt a reduction in stress, and how funding impacted their decision to enroll children in camps or seek respite help. Parents were also asked to describe the type of program their child participated in (e.g., mainstream day or residential camps, autism-specific camps) as well as the length of time spent in each program. Respondents were asked if observable improvements were made in areas such self-regulation, aggression, stereotypical behaviour, improved communication and social interaction.

Results

Support workers accounted for over 50% of funding expenditure with over 55% of those accessing summer programs using funding for programs lasting five to seven days. More importantly, 37% of respondents stated they would not have been able to take advantage of support programs without subsidization and almost 80% reporting a significant decline in stress. Lastly, results revealed a wide-spread improvement for ASD children in social skills and increased interaction with others.

Conclusions

The findings highlight that the funding provided through agencies, such as Autism Ontario, offer a critical financial opportunity to those families who would not otherwise be able to afford these support services. Findings indicate that supplemental programming benefits families as well children with ASD, shown by an improvement in skills and significant reduction in stress.

Profiles of Children with Autism at Different Ages and Intellectual Levels

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Objectives

Recent prevalence estimates for autism spectrum disorder (ASD) are approximately 1 in 88. Research and clinical experts suggest that a considerable amount of variability is present in symptom profiles of individuals with autism. While the proposed DSM-5 criteria defines autism in terms of two dimensions, factor analytic studies done on diagnostic measures such as the Childhood Autism Rating Scales (CARS) have found two-five factors with varying factor structures. About 70% individuals with autism also have an intellectual disability (ID). Thus part of the variability in autism symptom structure maybe be due to the developmental influence of age and intelligence quotient (IQ). Different factor structures in different age groups and IQ levels have also been found. All these issues interact to make it challenging for clinicians to diagnose an individual with autism, over and above ID, especially when low IQ accounts for a limited range of skills. However, there is very limited research that looks at how age and IQ intersect to influence the presentation of autism symptoms in individuals with autism and ID. The purpose of this study is to conduct a profile analysis of autism symptom profiles of individuals with autism and ID, at different age and ID levels.

Methods

For this study, data comes from three main sources in Ontario: an Autism lab at York University, TRE-ADD (a tertiary care centre for individuals with autism), and the participants from a previous CARS factor analysis study. The combined sample consists of 642 participants, 111 females and 530 males. Participants fall into one of 10 groups based on a matrix of two age groups (< 72 months and > 72 months) and five ID levels (IQ < 25; 25–39; 40–54; 55–69; > 70). Symptom levels were measured using CARS scores.

Results

The data from the three sources has been combined. An exploratory factor analysis of the data suggests that a three factor structure best fits this data. Detailed analysis is underway which involves profile analysis amongst the 10 groups of the three CARS factor scores: Autism/Social interaction, Language/Communication, and Sensory/Emotional Regulation. More specifically, the analysis will examine whether different groups score differently on the symptom and skills measures, whether the profiles are fairly flat or scattered in some groups versus others, and whether there are patterns that are significantly different across groups.

Conclusions

The presentation will elaborate on how the specific patterns of symptoms could be used to guide clinicians' decision making process when they assess younger and older individuals with varying levels of ID, especially those with severe and profound ID and autism.

Prevalence and Types of Significant Life Events Experienced by Adults with Asperger Syndrome

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Objectives

Significant life events experienced by individuals with developmental disabilities have been linked to and may result in psychiatric disorders. Considering their importance, little is known about the significant life events experienced by adults with Asperger syndrome (AS). The current study looks at the prevalence and the types of significant life experiences in the largest-available-to-date sample of adults with AS.

Methods

The Health Service use in Adults with Asperger study is a longitudinal study looking at planned and emergency health service use in adults with AS. The online survey was completed by 66 adults self-reporting a diagnosis of AS from across Ontario. The survey included a checklist of life events experienced over the previous two months, derived from the Psychiatric Assessment for Adults with Developmental Disabilities Checklist (PAS-ADD Checklist). Adults endorsed whether any of these activities had occurred in the past two months and could also list additional life events not captured within the list under “other.” Only the 51 participants that scored 26 or higher on the Autism Spectrum Quotient questionnaire and indicated a formal diagnosis of autism spectrum disorder/Asperger were included in this analysis (M Age = 34.9, SE = 1.62; 28 females, 23 males).

Results

The six most frequently reported life events in the two-month period were: unemployment (25.5%), financial problems (25.5%), mistreatment (harassment, teasing, discrimination: 21.6%), disruptions in interpersonal relations (problems with friends, break-ups, separation and divorce, and loss of or disruption in social circle: 19.6%), change in living arrangements (change in residence or roommates: 15.7%) and, finally, disruptions of routine related to work or school (15.7%). The majority of respondents (76.5%) had at least one significant life event in the last two months, with 58.8% having at least two and 41.2% having at least three. Individuals that reported being unemployed/seeking work also had higher levels of distress, $t_{(49)} = 2.57$, $p = .013$, as did individuals with financial problems, $t_{(49)} = 3.22$, $p = .002$. A significant relationship was found between the total number of life events and the reported distress levels ($r_{s(51)} = .501$, $p < .001$).

Conclusions

The findings suggest a high incidence of significant life events as experienced by adults with AS. Consistent with previous research, about 46.3% of the sample experienced one or more significant life event over 12 months. These results suggest that adults with AS may experience significant life events more frequently than adults with other types of developmental disabilities. Financial problems, unemployment, and overall negative life events were particularly related to higher levels of distress and are worthy of further attention.

Improving Accurary of Detection of Audio-Visual Intermodel Processing Differences in Autism Spectrum Disorders Using a Modified Preferential Looking Paradigm

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Objectives

Individuals with autism often have impairments with auditory-visual intermodal processing (IMP) (i.e., integrating information across auditory and visual modalities). A popular paradigm used to assess their IMP abilities involves presenting two side-by-side visual displays, with an auditory track matched to only one display, while measuring the child's preferential looking toward the synchronized screen. Preferential looking has been previously represented by 60% looking rates, even though chance looking patterns are 50% with two screens. We introduced a modification of this two-screen preferential looking paradigm (PLP) in a pilot study where we used a four-screen display. Better discriminability of looking patterns was found, since this methodology lowered chance looking probabilities to 25%, resulting in larger magnitudes of differences from chance. The present study further investigated the precision of the four-screen technique (with eye-tracking), using a larger autism spectrum disorder (ASD) sample size and including a typical development (TD) comparison group. Therefore, our objective for the present study was to assess the precision of the four-screen versus two-screen PLP. This was done in two stages. Firstly, the magnitude of effect (degree of difference from chance) on the two- and four-screen tasks for both ASD and TD groups was compared. Secondly, the differences in looking patterns between ASD and TD groups were investigated using the four-screen PLP and eye-tracking data with linguistic and non-linguistic stimuli, and these results were compared with previous differences on two-screen studies.

Methods

Twenty-three children with ASD and 23 TD children between the ages of 3 and 12 years were tested. The four-screen PLP involved displaying four identical videos which were each offset in time, with an auditory track synchronous to only one of the videos. Videos contained either linguistic (L, person telling a story) or non-linguistic (NL, hand playing a piano) stimuli. Preferential looking was assessed from differences in total time looking at each screen.

Results

Initial analyses indicate that the four-screen variant produces more discriminable magnitudes of effect compared to chance: approximately 40% greater looking time at the preferred video over chance, vs. the two-screen paradigm (approximately 10% greater than chance). Corrected for their relative chance levels (0.25 vs. 0.50), this is an eight-fold increase in precision in the ability to detect preference, which represents a major advance in sensitivity for the paradigm. Two other results from previous two-screen studies were also preserved: First, both groups showed similar proportions of preferential looking to synchronous non-linguistic videos. Second, we replicated the finding of an apparent speech-specific deficit in intermodal processing (IMP). Further analyses are ongoing.

Conclusions

These findings demonstrate the greatly increased sensitivity associated with a four-screen over a two-screen paradigm in detecting audio-visual integration differences in ASD and TD children. Often subtle differences occur, and the ability to detect them will enable a clearer understanding of variables contributing to the language impairments in ASDs. The corroboration of our previous findings of an apparent speech-specific IMP difficulty in ASDs lends additional confidence to the paradigm.

Antipsychotic Medication Use in Adolescents and Adults with Autism Spectrum Disorders

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Objectives

The goal of this study was to explore profiles and predictors of antipsychotic medication use in adolescents and adults with autism spectrum disorders (ASD).

Methods

As part of an online survey examining health service utilization patterns among individuals with ASD, 379 parents completed information on current medication use in addition to providing information on child demographic, clinical, and service use measures. In this sample, individuals with ASD (78% male) ranged from 12 to 39 years of age with a mean age of 18 years.

Results

Analyses revealed that 28% of adolescents and adults with ASD were taking antipsychotic drugs, and that 32% of these individuals had a comorbid medical condition. Rates of antipsychotic drug use differed between diagnostic subtypes with lower rates observed in those with Asperger syndrome relative to those with autism or pervasive developmental disability not otherwise specified (PDD-NOS). Very few individuals prescribed antipsychotic drugs had a psychotic disorder. More common diagnoses included anxiety disorders, followed by mood or behaviour disorders (e.g., attention deficit hyperactivity disorder, oppositional defiant disorder). Risk behaviours such as aggression, self-injury, and history of trouble with the law, were each more likely in those prescribed antipsychotics than those not prescribed these medications. The majority of individuals prescribed antipsychotic drugs (72%) were taking at least one other psychotropic medication concurrently. In terms of current service use, the majority of individuals prescribed antipsychotic medications had received some form of mental health (MH) treatment in the past two months, and one in five families were also receiving family therapy.

Conclusions

Teens and adults with ASD prescribed antipsychotic drugs reported significant behavioural and mental health issues. Their profiles were complex, with both psychiatric and medical issues being common. These individuals were typically prescribed multiple medications and were receiving multiple clinical services. Future research should explore what triggers antipsychotic drug prescription, as well as the long-term implications of medication use. By understanding the profiles and predictors of antipsychotic use we can attempt to better support the needs of these individuals and their caregivers.

A Further Examination of the DSM-5 Criteria for Autism Spectrum Disorder in Practice

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Objectives

The proposed DSM-5 criteria for autism spectrum disorder (ASD) will include individuals currently diagnosed with autistic disorder (AD), Asperger disorder, childhood disintegrative disorder, and pervasive developmental disability not otherwise specified (PDD-NOS). Instead of the previous 12 symptoms in the triad of impairments (social, communication, repetitive behaviour), the criteria are now reduced to 7 items in a dyad: social-communication and repetitive behaviour/ interests. Several recent studies imply that the new criteria for ASD could inadvertently exclude children currently on the spectrum, particularly those with PDD-NOS and AD, although others found the DSM-5 to perform well. In a previous file review study of 131 children, aged 2 to 13 years, previously diagnosed with AD or PDD-NOS, we found 62% met DSM-5 criteria, including 82% with AD but only 18% with PDD-NOS. Furthermore, children who met DSM-5 criteria had significantly greater autism severity and significantly lower cognitive and adaptive behaviour scores. The purpose of the present study was twofold. First, we set out to see whether these findings would be replicated in a different sample of older individuals and, second, we explored the inter-rater agreement of DSM-5 compared to the DSM-IV approach.

Methods

Retrospective file review data were examined for 22 individuals (21 males), aged 5 to 19 years, previously diagnosed with either AD (*n* = 16) or PDD-NOS (*n* = 6) using DSM-IV criteria by one of two experienced psychologists (DF or AP). One psychologist (AP) rated all 22 files, using the DSM-5 checklist developed for the previous study, rating each of the seven DSM-5 criteria as either met or not met. The group that met and did not meet DSM-5 criteria were compared on cognitive, adaptive, and autism severity measures. A subset of 10 files were rated by both psychologists (AP and DF) using both DSM-IV and DSM-5 criteria.

Results

Only 55% of the sample met the DSM-5 criteria for ASD, which included 69% of the children with AD and only one (20%) of the children with PDD-NOS. The subgroup who did meet DSM-5 criteria had significantly greater autism severity on the Childhood Autism Rating Scale, lower verbal, nonverbal, and full scale IQ, and lower adaptive behaviour scores on all domains of the Vineland. Reliability results showed comparable percentage agreement for individual criteria in both systems but higher agreement for overall diagnosis in DSM-5 (100% vs. 80%).

Conclusions

Although the sample used in this study was different (i.e., older, more severe), the results were consistent with those of the previous study and add to the body of literature suggesting that the DSM-5 may have low sensitivity in identifying higher functioning individuals. The inter-rater agreement results are likely as a result of the constrained scoring algorithm in DSM-5 versus DSM-IV (there are fewer combinations of symptoms leading to a diagnosis in DSM-5), which implies that diagnostic reliability may be overstated for DSM-5. Both of these findings have major implications for both research and clinical practice.

Mental Health Services Needed and Received by Youth with Severe Intellectual and Developmental Disabilities

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Objectives

It is widely recognized that children and youth with intellectual and developmental disabilities (IDD), including autism, have a higher prevalence of problem behaviours (e.g., aggression, self-injurious behaviour) and mental health difficulties (e.g., anxiety, depression) relative to peers without IDD. Although these children may require services from mental health related professionals, such as psychiatrists, psychologists, behaviour therapists, or social workers, clinical experience suggests that service accessibility and appropriateness is often lacking in this population. There is very little research in general, and even less in Canada, documenting these issues. Thus, the aim of the present study is to report data on mental health service needs and receipt in this group, examined in relation to a wide range of contextual factors.

Methods

This study is derived from GO4KIDDS (Great Outcomes for Kids Impacted by Severe Developmental Disabilities, www.go4kidds.ca), a CIHR-funded Emerging Team Grant studying the health, well-being, and social inclusion of children and youth with severe and multiple IDD. Data are reported here about 148 children and youth aged 3 to 19 (69% boys). Survey data were provided by 148 parents (mostly mothers) who were asked whether their child needed and received any of four mental health or allied health professional services: psychiatrist, psychologist, behaviour therapist, and social worker. Service need and receipt were examined in relation to several child characteristics, parent variables, and demographic factors.

Results

Of the four professions, psychiatry was noted to be least required, at approximately one third of the sample (34%). Psychology, behaviour therapy and social work were all needed in approximately two thirds of the sample. Most children who needed psychiatry and psychology received the services (90% and 89%, respectively). This level of receipt was somewhat lower for behaviour therapy (77%) and social work (83%). Overall, one quarter of children did not receive at least one service that they were noted to need. Mental health service need was positively correlated with several child variables, including the level of child maladaptive behaviour ($r = .45$, $p < .001$). At a contextual level, service need was positively related to parent mental health problems ($r = .31$, $p < .001$), parent stress ($r = .31$, $p < .001$), stressful life events ($r = .28$, $p = .005$) and negatively correlated with parent empowerment ($r = -.22$, $p = .008$) and family quality of life ($r = -.28$, $p = .001$). It was not related to child or parent age or child sex, or to socio-economic status. Further analyses will examine the profiles of children with unmet service needs.

Conclusions

Results will be compared to other samples in the literature and limitations of the study will be noted, together with suggestions for future research. Recommendations for practice and clinical implications will be discussed.

Effectiveness of Self-Instructional Mediator Training in Applied Behaviour Analysis

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Objectives

Interventions using applied behaviour analysis (ABA) to increase skill development in children with autism spectrum disorders (ASD) are widely used. Individuals who work with this population are an important group to target for ABA education. This study evaluated the efficacy of a self-directed program in increasing parent and student ABA knowledge and skills, self-efficacy, and new skill development in children with ASD.

Methods

Several modules of *Simple Steps* (www.simplestepsautism.com), a self-instructional ABA training package, was given to three parents of children with ASD and three university students. Eight children with ASD also participated. Participants were measured using a multiple baseline across participants and/or skills design.

Results

After training, ABA knowledge scores and self-efficacy showed variable improvement as did children's appropriate behaviours. Preliminary evidence was provided that *Simple Steps* may improve some areas of ABA knowledge for use with children with ASD by parents and students.

Conclusions

Because results were variable, further research should evaluate the training program in its entirety to determine whether or not *Simple Steps*, as a whole, can increase consumer ABA knowledge and skills. If *Simple Steps* is found to be effective in increasing consumer ABA knowledge and skills, this would be an affordable and accessible training program for parents of children with ASD and students who work with children with ASD.

Transition from Intensive Behavioural Intervention Programs to the School System: The Experiences of the Transition Team

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Objectives

The transition from Intensive Behavioural Interventions (IBI) to the education system can be challenging; however moving to an inclusive setting is a significant opportunity for students with autism spectrum disorder (ASD). Students with ASD may experience challenges in a classroom setting due to the nature of their disorder but there seems to be a consensus that they should still have access to public education with the appropriate services and supports. Furthermore, this transition produces challenges for the public school system, Autism Intervention Programs (AIP), and parents and/or guardians. Therefore, the transition from IBI to school must be carefully planned to ensure an individualized and successful transition. The purpose of the present study was to examine the views and perceptions of those actively involved in the transition of students with ASD from IBI to public school in Northern Ontario.

Methods

Participants were recruited through the North Region AIP. Eligibility criteria included any member of the transition team (e.g., IBI staff, school staff, and parents/guardians) of one particular child with autism, within the last six months of complete transition. Using a mixed-methods case-study approach, the members of multiple transition teams were asked to complete two questionnaires, The Transition Beliefs Inventory and the Transition Practices Questionnaire, to assess their actual transition experiences, as well as to gain an understanding of their beliefs regarding what are important contributors to the transition process and what is an ideal transition process. Additional open-ended questions were added to the Transition Practices Questionnaire to allow for qualitative assessment of their perspective.

Results

This study is part of an ongoing Master's research-based thesis. Data collection is in progress and results will be available for this presentation.

Conclusions

The present study will provide a picture of how the transition process is occurring in North Region of Ontario, according to the perspective of those who are directly involved. As the perspective of the whole transition team is sought, it is the intent to gain both a professional and service model point of view, as well as a personal and fundamental point of view of the transition process. Ultimately, the results of this study could be used to inform continuous improvement of service and practices.

Family Support and Perceived Burden in Parents of Individuals with Developmental Disabilities

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Objectives

To explore experiences of burden in parents applying for developmental services for their adult son or daughter with developmental disabilities (DD). The moderating effects of family support on the relationship between burden and impact of behavioural problems will be examined. Global, informal, and formal appraisals of support will be examined.

Methods

Two hundred and eleven parents of adult children (Mean Age = 23.2; *SD* = 7.4) with DD participated in this study. All parents were seeking adult developmental services for their child, and all children were living at home at the time of the study. Information was gathered through written and telephone surveys. Measures included demographics, the Family Support Scale for measuring perception of support, the Burden subscale of the Revised Caregiver Appraisal Scale, and an item asking parents to rate the impact of the adult child's behavioural support needs on the parent's ability to support him/her.

Results

Over half (56.5%) of parents reported high levels of burden (a score of 27 or more). Pearson product moment correlations indicated parental burden was positively related with impact of behavioural problems, $r_{(205)} = .373$, $p < .001$, and negatively related with perception of overall support $r_{(205)} = -.28$, $p < .001$ and informal support, $r_{(205)} = -.33$, $p < .001$, but not formal support. An initial hierarchical regression was calculated to examine how impact of behavioural problems (the stressor) and overall support (the moderator) would predict caregiver burden. After controlling for parent age and income, both impact of behavioural problems and overall support were significant predictors ($b = 2.97$, $t_{(182)} = 4.98$, $p < .001$ and $b = -2.62$, $t_{(182)} = -4.16$, $p < .001$, respectively), in an overall model that accounted for 18.4% of adjusted variance. However, the interaction term between impact of behavioural problems and overall perception of support was not significant. A similar hierarchical regression was then calculated with separate formal and informal support scores. In this model, impact of behavioural problems and informal support were significant predictors of burden ($b = 2.50$, $t_{(182)} = 4.25$, $p < .001$ and $b = -3.61$, $t_{(182)} = -5.75$, $p < .001$, respectively) and formal support was not significant. The overall model accounted for 24.0% of adjusted variance but the informal support moderator interaction term was not significant.

Conclusions

While impact of behavioural problems and overall perception of support predict parental burden, overall perception of support does not act as a moderator. Further, it appears perception of informal support predicts burden while perception of formal support does not. Support received from family, friends and neighbors is clearly a key resource for families with a son or daughter with DD.

Augmentative and Alternative Communication Use in Canadian Children with Developmental Disabilities

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Objectives

GO4KIDDS (Great Outcomes for Kids Impacted by Severe Developmental Disabilities) is a research project that focuses on the health, well-being and social inclusion of children (aged 6–18) with intellectual and developmental disabilities (IDD) and/or autism. Because of difficulties with speech, some children with IDD and autism are taught to use various forms of Augmentative and Alternative Communication (AAC), which are methods/technology used to supplement or replace spoken communication. Both psychologists and speech-language pathologists (SLP) are often involved with these children. This poster will be based on an investigation of AAC use and speech and language pathology services (SLP) within a sample of children who have IDD with or without autism.

Methods

Data has been collected through the GO4KIDDS online survey. Currently, survey data have been collected for 150 parents of children with IDD. At the time of the conference we expect to have $n = 200$. Questions from the larger survey will be used to investigate parent report of SLP service needs, use and satisfaction; the types of AAC systems most commonly used; and the levels of communication reached. These variables will be compared in children with autism to children with IDD only.

Results

Preliminary results based on $n = 150$; indicated that 97% of parents report a need for SLP services, 91% receive SLP services, however only 50% report being satisfied. In terms of AAC use, 37% of the sample used AAC, with 70% of systems low-tech (e.g., yes/no switches, picture exchange communication system). As well, 58% used their systems for little meaningful communication. AAC users had significantly lower expressive communication than non-AAC users ($\chi^2 = 24.6, p < .001$). When the sample was divided into two groups based on diagnosis, the autism group accounted for this difference. Children in the autism group had much lower levels of communication with AAC, while the group of children with IDD showed more varied levels of communication.

Conclusions

We expect that our results will shed light on how AAC systems are currently being used among children with IDD in Canada, the state of AAC health care services, and special considerations needed to implement services properly in populations of children who have IDD with and without autism.

The Relationship Between Social Competence and Bullying Victimization Experiences in Children and Adolescents with Autism Spectrum Disorder and Typical Development

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Objectives

There is an emerging body of research that demonstrates that individuals with an autism spectrum disorder (ASD) are at an elevated risk of experiencing bullying victimization relative to their typically developing (TD) peers. Many of these studies have included a measure of social exclusion, ostracism, or number of friendships, all of which have been linked to rates of victimization within the ASD population. Social skills difficulties are central characteristics of ASD, yet few studies to date have examined the association between specific social skills deficits and bullying involvement in those with ASD. This study aims to: (1) compare rates of several types of bullying victimization (physical, verbal, social, and cyber) across ASD and typically developing samples; (2) compare parent and child reports of bullying involvement; (3) examine social skills, as measured by the Social Skills Improvement System (SSIS), in those with ASD and TD; and (4) explore the relationship between social skills and bullying involvement in these two groups.

Methods

The current sample includes 22 children with ASD (6–16 years; 50% with Asperger syndrome), and 20 age- and IQ-matched TD children. Additional data collection is ongoing. Frequency of bullying involvement in the past month was measured using the Promoting Relationships and Eliminating Violence Network Assessment Tool-Parent and Child Versions. The SSIS was completed by parents as an estimate of social skills across several domains.

Results

Bullying involvement was significantly associated with group (ASD versus TD), χ^2 (1) = 8.64, $p = .003$. As expected, parents of children with ASD reported more frequent physical, verbal, and social victimization (30–45%) than the TD comparison group (5–15%). A modest relationship between parent and child ratings is predicted. It is predicted that frequency analyses and independent *t*-tests will reveal significant differences in SSIS scores between groups. It is hypothesized that social skills scores will be correlated with bullying involvement across both groups.

Conclusions

These results to date are consistent with the existing literature that demonstrates that individuals with ASD are at an increased risk of bullying victimization, both physical and social-relational. This study aims to explore the overlap in parental and individual perspectives of the circumstances surrounding bullying involvement in order to better understand what measures can be taken to foster safer environments for youths. Findings may be especially useful in educating teachers and parents with regards to creating and maintaining home and classroom atmospheres that reduce or eliminate bullying and promote positive peer relationships, such that all children are encouraged to work and play together with healthy and accepting interactions.

Parent Factors Predicting Outcomes of Children in Intensive Behavioural Intervention

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Objectives

The aim of this study is to examine the relationship between multiple parent factors in a sample of parents whose children are participating in Ontario's publicly funded Intensive Behavioural Intervention (IBI) program for children with autism. IBI is the treatment of choice for children with autism, however the outcomes of the children in the program are highly variable. This variability may be due to many different factors. Recent studies have examined factors related to the child (such as age and IQ) and intervention (such as model of supervision), however the parent component remains largely unexamined. There is minimal literature suggesting that high parent stress may be associated with less positive child outcomes, but many other parent factors have never been examined in this context. This poster will look at the relationship between ranges of parent factors, for example stress, self-efficacy, and demographic factors, such as, employment and immigrant status and children's outcomes after one year of IBI.

Methods

The sample consists of the parents of approximately 30 children in IBI. This data comes from a larger waitlist controlled study of Ontario's IBI program. Data were collected through interviews and questionnaires from the parents, and standardized assessments of the children at entry to IBI and after one year in the program. Parent factors being examined include: demographics (socio-economic status, family constellation, immigrant and employment status); stress (PSI-SF Parent Distress domain) and coping (F-COPES) at start of IBI: and parent involvement, measured after one year of IBI (involvement in child's IBI program, self-efficacy). Outcome variables include children's cognitive and adaptive scores at the one-year assessment.

Results

Data analyses are underway. Data will be represented as correlations of parent factors (e.g., stress, self-efficacy and demographics) with children's level of functioning after one year of IBI. Regressions will explore multiple predictors simultaneously, controlling for children's age and test scores at entry, to see whether parent factors account for significant variance in children's outcomes.

Conclusions

The results of this poster will provide an initial picture of the relationship between several parent and child factors in a sample of children in Ontario's IBI program. This preliminary information will help to elucidate the relationship between parent and child factors, and will assist with the formulation of hypotheses for the further examination of parent factors that are related to child characteristics important for IBI outcomes. We expect the results will lead to clinical implications in terms of how to better support parents in such a way as to maximize children's outcomes.

A Balanced Approach: The Development of an Adapted Physical Exercise Program for Individuals with an Intellectual Disability

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Objectives

Although there are numerous resources available regarding physical activity and strength exercises for the general population, when working with people who have an intellectual disability (ID) these activities must be adapted to meet their specific needs and potential mobility challenges. Unfortunately, these adapted exercises and activities are not well documented or understood by the general population, which limits opportunities and implementation into exercise programs. The main purpose of this research project was to safely integrate individuals with an ID into a whole body resistance training program within a local community fitness facility. A secondary goal was to develop an adapted physical activity manual for participants, other individuals with ID and support staff. Lastly, general health measures related to strength, flexibility and cardiovascular fitness were monitored throughout the program.

Methods

Twenty participants (13 males, 7 females, 36 ± 12 years of age) diagnosed with an ID were recruited in cooperation with Community Living Essex County. Some participants also had a dual diagnosis including but not limited to: Cerebral palsy, Down syndrome, autism and Asperger syndrome. A physical assessment was conducted for each participant in order to gain a better understanding of their physical activity history, specific health needs and to develop personal goals. Participants completed two workout sessions a week, lasting 1 hour and 20 minutes in duration, for 12 weeks. The workout sessions included a warm-up, group activity (sport, game), whole body resistance training exercises, cardiovascular fitness activity, flexibility training and a cool-down. The participants had baseline and post-program measures of weight, resting heart rate and blood pressure, grip strength, sit and reach (flexibility) and the Rockport one mile walking test (cardiovascular fitness).

Results

The exercise intervention was very successful at: (1) training the participants how to safely use exercise equipment and participate in a formal exercise program, (2) comfortably integrating the participants into a community fitness center with other users, and (3) developing an adapted physical activity manual. Furthermore, when the general health measures were averaged across all participants, small positive changes were observed for all parameters with the cardiovascular fitness showing the greatest improvement.

Conclusions

By the end of the program, the participants were comfortable completing their resistance training exercises within the community fitness facility with minimal supervision. The participants were excited to learn new exercises, health tips and become involved in games with other participants, as well as their trainers. In conclusion, the exercise program demonstrated the ability to get the participants started on a healthier lifestyle and provided the skills to continue exercising in the future.

Validity and Reliability of the GO4KIDDS Brief Measure of Adaptive and Maladaptive Behaviour

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Objectives

Individuals with developmental disabilities (DD) are characterized by limitations in cognitive ability as well as adaptive behaviour, which may include difficulties in self-care, communication and social skills. In addition, compared to typically developing children, those with DD tend to display more behaviour problems. Therefore, it is important to effectively measure the level of adaptive and maladaptive functioning of children with DD. One prominent and widely used measure is the Scales of Independent Behaviour-Revised (SIB-R). However, this measure, even in its short form, takes a long time to complete and cannot be incorporated in a brief survey. The purpose of this study was to investigate the reliability and the validity of the GO4KIDDS Brief Measure of Adaptive and Maladaptive Behaviour.

Methods

The Great Outcomes for Kids Impacted by Severe Developmental Disabilities (GO4KIDDS) is a CIHR-funded project, which explores the health, well-being, and social inclusion of school-aged children with mild to severe DD. Currently, 198 parents of children, ranging from 3 to 19 years, have completed the GO4KIDDS Basic and Extended surveys. The GO4KIDDS team developed a Brief Measure of Adaptive and Maladaptive Behaviour found in the Basic Survey. The adaptive scale includes 6 questions applying to three domains: daily living, communication and social skills. The maladaptive scale includes 4 questions regarding self-injurious behaviour, stereotyped behaviours, aggressive/destructive behaviours, and mental health issues. The items from the GO4KIDDS brief measure were tested for internal consistency and criterion validity in relation to the SIB-R Short Form, which was included in the GO4KIDDS Extended Survey.

Results

Reliability, in the form of internal consistency was high for the adaptive scale of the brief measure ($\alpha = .87$) and lower for the maladaptive items ($\alpha = .64$). Inter-item correlation was highest amongst eating, toileting and dressing ($r = .66$ to $.72$). In terms of validity, the adaptive scale (total of the 6 items) was highly correlated with the SIB-R Raw Scores and W-Scores, $r = .73$ to $.79$, $p < .001$. The sum of the maladaptive items was negatively correlated with the SIB-R general maladaptive index ($r = -.63$, $p < .001$).

Conclusions

Results indicate that the adaptive scale of the GO4KIDDS Brief Measure has good reliability and validity. The maladaptive scale has moderate reliability and moderate validity. Therefore, the developed measure could be useful for survey research where brief measures are needed. Further research is needed to investigate the use of the measure for quantifying adaptive and maladaptive functioning.

An Exploration of the GO4KIDDS Brief Self-Report Measure of Social Support

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Objectives

Parents of children with developmental disabilities (DD) may receive social support from various sources, such as extended family, friends, neighbours, religious groups, and the child's grandparents. Social support is an important factor in mental health and well-being in caregivers of children with DD and has been shown to be related to lower parental stress and positive gains (e.g., personal growth, closer family relations). Although social support is often associated with positive outcomes, parents sometimes view their social networks as a burden and source of stress. The Family Support Scale is a commonly used measure of social support. However, it does not allow participants to indicate that their social network made parenting more difficult. The current measure attempts to bridge this gap. This study will explore three different coding schemes for a brief measure of social support, developed by the Great Outcomes for Kids Impacted by Severe Developmental Disabilities (GO4KIDDS) team.

Methods

GO4KIDDS is an ongoing research project examining the health, well-being and social inclusion of children with severe DD. Data collection is ongoing. Thus far, 189 parents of children 5 to 19 years of age have completed the GO4KIDDS Extended survey online or on paper, which included the GO4KIDDS Brief Self-Report Measure of Social Support. The measure includes questions on whether seven sources of social support (e.g., parents, extended family, friends, neighbours) are nearby, how often they see these sources of support on a scale from 1 ("Almost never") to 5 ("Every day"), and how helpful the supports are on a scale from 1 ("Make it more difficult") to 5 ("Extremely helpful, I depend on them").

Results

Analysis is currently underway. Descriptive statistics for all variables will be reported. As an exploratory study into the use of this measure, we will compare three different coding schemes. The first scheme is a sum of the frequency and helpfulness scores for each support source. The second scheme is a product score, where helpfulness is recoded so it ranges from -2 ("Make it more difficult") to +3 ("Extremely helpful, I depend on them"), and the recoded helpfulness score is multiplied by the frequency score for each source. The third scheme arranges all the combinations of helpfulness and frequency ratings into an ordinal scale and assigns a "Total Social Support Score" from 1 ("Lowest Social Support") to 25 ("Highest Social Support"). Internal consistencies and inter-correlations will be calculated and distributions examined.

Conclusions

The results of this study will provide valuable information about the use of this self-report measure to quantify social support for parents of children with DD. Further research is needed to determine the reliability and validity of the developed measure.

Family Quality of Life: Measurement and Validity

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Objectives

Family quality of life (FQOL) is an umbrella construct that aims to capture the different aspects of family life and the level of functioning within those areas. Interest in FQOL emerged as disability services began to become more focused on families. The FQOL construct continues to be explored and there is some debate as to what it really means and how it should be measured. There is much need for further research to support the validity of FQOL measures. Traditionally, caregivers of children with developmental disabilities (DD) have been the focus of research for a number of years and there are many elements that have been examined, such as social support, stress, coping, and self-efficacy. It is important to establish that FQOL as a whole is unique from these individual elements or perhaps incorporates them all. The purpose of the current study was to compare portions of a published FQOL measure in relation to independent measures, to establish convergent and divergent validity of the published FQOL measure. It was hypothesized that portions from one measure will be strongly correlated with conceptually similar portions of the other measure, while unrelated constructs will not exhibit this pattern. This type of convergent and divergent validity analysis may aid in the distinction between FQOL and other variables such as self-efficacy, social support, stress, and coping. To further explore this, we also examined the way in which these variables contribute to a Global FQOL score derived from one of the measures. It was hypothesized that the contribution of the predictors would provide support for the FQOL measure's ability to incorporate a broad variety of factors but to be "greater than the sum of the parts."

Methods

GO4KIDDS is a Canadian team project exploring the health, well-being, and social inclusion of school aged children with severe DD and that of their parents. The sample for this study includes 30 ethnically and socioeconomically diverse caregivers of children aged 6 to 17 with a diagnosis of DD. Most of the children have additional diagnoses, including autism spectrum disorders, Down syndrome, and Cerebral palsy. These parents were interviewed using the Family Quality of Life Survey-2006 (FQOLS-2006) and completed the GO4KIDDS Basic and Extended Surveys ("GO4KIDDS Surveys") as part of one of the GO4KIDDS projects, the Family Quality of Life Study.

Results

There were no significant relationships between child variables and the Global FQOL score. Most of the domains on the FQOLS-2006 were significantly correlated with conceptually similar constructs on the GO4KIDDS Surveys. As expected, most of the correlations between FQOLS-2006 domains and conceptually different constructs on the GO4KIDDS Surveys were not significant. Finally, a hierarchical regression analysis showed that mental health accounted for the most variance of the Global FQOL score.

Conclusions

The results of this study provide modest support for the convergent and divergent validity of the FQOLS-2006. The Global FQOL score, however, was not accounted for by the combination of the constructs that we tested. The score we used as a global FQOL score, as well as the constructs that we selected, may not be a sufficient representation of the FQOL construct.

Defining Crisis in Mothers of Children with Autism Spectrum Disorders

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Objectives

Caring for a child with autism spectrum disorder (ASD) is a strenuous task for parents as periods of distress, coupled with the family's difficulty adjusting may lead to a crisis. Parents of children diagnosed with ASD often report higher levels of depression, anxiety, and mental health–related issues compared to parents of children without ASD. Despite the role crisis plays in the lives of these families, there is a limited amount of research in crisis and developmental disabilities. The current study investigated the subjective experience of crisis in mothers of children diagnosed with ASD, and examines the underlying themes present in their definition of crisis.

Methods

The study involved 155 mothers, 26–71 years of age whose children were diagnosed with autism (49%), Asperger syndrome (28%), pervasive developmental disorder not otherwise specified (PDD-NOS) (20%), and other (3%). A thematic analysis was conducted on a large, online Canadian survey of these parents of individuals with developmental disability to determine the dominant themes in their experience of crisis.

Results

Although some elements in the responses were similar to previous models of crisis, emerging themes were not fully represented by either of these models independently.

Conclusions

Consistent with previous research, the results suggest that crisis is characterized by factors influencing four major areas: (1) demands, (2) internal capabilities, (3) external resources, and (4) subjective appraisal. Understanding crisis in the family is important to mental health practice since it can serve as a guide for finding appropriate interventions for at-risk families. Establishing a more accurate definition of crisis may also lead to more uniform understanding between health care providers, and serve as a guideline for asking the right questions when working with families in crisis. The limitations of the study include its reliance on self-reported data, and the variability in the amount of data across respondents. The poster will elaborate on the results of the qualitative analysis and discuss the relationship between the four major themes.