

2023 RSIG Research Day Datablitz Presentations

Informing Quality Volunteer Experiences in an Adapted Physical Exercise Program for Individuals with Developmental Disability

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Purpose/Objective: Adults with developmental disabilities (DD) tend to engage in low levels of physical activity, which is associated with poor health and physical fitness. The Adapted Physical Exercise (APEX) Research Group has created an inclusive, community-based exercise program through one-on-one fitness training for individuals with DD. Pilot work with APEX volunteer fitness trainers demonstrated ameliorated misconceptions of people with DD, improving perceptions and understandings of their capabilities. The purpose of the current study was two-fold: (1) to explore the transformative impact of volunteer interaction with people with DD in a fitness setting, accompanied by a further emphasis on understanding its capacity to stimulate social change; and (2) to expand knowledge of factors associated with quality experiences for APEX volunteers.

Methodology: We recruited 10 student volunteer participants (18-25 years of age) based on their ability to provide a safe and welcoming environment for individuals with DD. Volunteer participants completed two semi-structured interviews, at the commencement and end of their three-month term. Questions explored their perceptions of APEX programming, along with their knowledge, attitudes, and behaviours relative to individuals with DD. In addition, volunteer participants completed brief audio diaries every two weeks answering questions pertaining to their experiences with the APEX program. Audio diaries were recorded immediately after a designated session; these data were captured at a time when phenomena were at the forefront of volunteer participants' minds and may not be as readily accessible in the context of an interview. Volunteer participants were asked to respond to a set of pre-determined prompts for these audio diaries, which were recorded on their phones and subsequently submitted to the research team.

Results: Our findings draw upon 20 interviews and 30 audio diaries. Emerging themes from volunteer participants suggested they had a positive experience both in the APEX program and with the adult with DD that they trained. The data analysis for this research project is still in progress.

Discussion/Conclusion: This study contributes to the fields of adapted physical exercise, disability, and sport for social change, which ultimately seeks to enhance the lives of individuals with DD through full inclusion in sport and physical activity. Investigating the perceptions of volunteer participants in the immediate social environment of individuals with DD is a novel

method of developing adapted exercise programming, and deepening understandings on social change toward inclusion.

Do “Evidence Based Practices” Translate to the Treatment of Mental Health Concerns in Individuals Labelled with Intellectual and Developmental Disabilities?

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Objectives: Evidence Based Practices (EBPs) are the use of the most current research to make clinical verdicts about an intervention best suited for a population and their needs. Many studies have evaluated the efficacy of EBPs for individuals with mental health needs, however very little literature has been dedicated to determining if such modalities deemed as ‘EBPs’ for the general population, also translate to be best practices for treating mental health concerns in individuals labelled with Intellectual and Developmental Disabilities (ILWIDD). This paper contains a vast review of the available research dedicated to the efficiency of EBPs, specific for the treatment of mental health concerns in ILWIDD. The objective of this review is to determine if interventions deemed to be evidence based for the general public, also translate to be effective and sound EBPs for the treatment of mental health concerns of ILWIDD.

Method: Over 60 studies pertaining to the efficacy of EBPs with ILWIDD experiencing mental health concerns were reviewed. Due to the limited amount of research available, all varieties of studies were included, such as RCTs and Case Studies. The EBP interventions that were included for the purposes of this discussion were: Cognitive Behavioural Therapy (CBT), Dialectical Behavioural Therapy (DBT), Acceptance and Commitment Therapy (ACT), Solution-Focused Therapy (SFT), Mindfulness, and Psychodynamic Therapy.

Results: Cognitive Behavioural Therapy is the most robustly examined therapeutic intervention in the literature for mental health concerns of ILWIDD. Although CBT shows promise as an effective intervention, there is evidence of harm in the qualitative literature. There is a need for further investigation for Dialectical Behavioural Therapy, which is in the preliminary stages, although the evidence does show promise. Acceptance and Commitment Therapy research also shows promise regarding effectiveness. The literature for the ACT model most considers the individual and inclusive methods. Mindfulness literature shows promise, if practice incorporates individual & strengths-based treatment. Solution-Focused Therapy research is in its infancy. Further RCT studies, larger sample sizes and more inclusive demographics are needed. Lastly, Psychodynamic therapy evidence is limited. There are no controlled studies, however the existing case studies and Qualitative research advances individual voices of ILWIDD.

Discussion / Conclusions: The review of the existing literature revealed that the evidence is sparse and further attention in this research area is needed. The research consistently presents gaps between evidence and the practical delivery of such interventions specific to the needs of ILWIDD. There is also limited use of self-reporting measures and tools that consider the stakeholder’s perspective of the effectiveness of the given treatment intervention. It is important that ILWIDD are not only actively included in research pertaining to EBP to treat mental health concerns but are also given the opportunity to take the lead in the development of such future research. Subsequently, further RCT studies are needed, with larger sample sizes and attention to diverse and inclusive demographics of ILWIDD. All therapeutic interventions

examined cannot be confidently determined as EBPs for the treatment of mental health concerns of ILWIDD.

Developing and Examining a Resource to Help Autistic Children and Their Caregivers Copy with Needle Procedures: A Research Proposal

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Background: Needle procedures like vaccines are critical to our health. Autistic children often fear needles and have difficulty undergoing needle procedures, in part due to their unique communication and sensory needs. My master's research interviewed caregivers of autistic children, and most emphasized the importance of preparing their child before the procedure. Many caregivers identified social stories as a potentially helpful resource. Similarly, several studies have mentioned social stories as potentially helpful resources or incorporated social stories into interventions to help autistic children cope with needle procedures. However, research has yet to explicitly examine the utility of a social story resource to help autistic children and their caregivers cope with needles. Furthermore, caregivers from my master's research, and other studies, have highlighted the importance of caregiver communication with healthcare providers before a needle procedure. While caregivers of autistic children would likely benefit from a resource to assist them with communicating and planning with healthcare providers before a needle procedure, such a resource has yet to be developed or examined.

Objective: *Study 1:* to identify and critically examine the content and format of publicly accessible social stories for needle procedures. *Study 2:* to co-develop a resource to help autistic children and their caregivers cope with needles, including a child-targeted social story and a parent-targeted guide for communicating and planning with healthcare providers. *Study 3:* to examine user satisfaction and initial effectiveness after autistic children and their caregivers use the resource.

Method: *Study 1:* An online environmental scan will locate publicly available social stories for needle procedures. A coding scheme will be developed to examine the content of social stories, such as the inclusion of evidence-based coping strategies. *Study 2:* An initial resource will be developed based on existing literature, my master's research, and the findings of study 1. Twenty autistic child-parent dyads will review the initial resource and participate in a semi-structured interview to provide feedback that will inform the final resource. No hypotheses will be developed for studies 1 and 2. *Study 3:* A pre-post study design will be utilized with 75 autistic children and –their parents who will use and evaluate the final resource. In a post questionnaire, parent-child dyads will report on outcomes including their satisfaction with and uptake of the resource. In a pre- and post- questionnaire, autistic children will report their fear level and perceived coping ability related to needle procedures and their parent will report their experiences with using the resource to communicate with healthcare providers. It is predicted that most child-parent dyads will report satisfaction and uptake of resource and that the autistic children will report less fear and greater coping ability after using the resource.

Results/Implications: This research is in the proposal stage, so no results are available. The first study will provide a compendium of available resources and outline gaps. The resource developed and used in Studies 2 and 3 has the potential to improve needle procedure experiences

for autistic children and their caregivers, including reducing autistic children's fear of needle procedures and facilitating communication between caregivers and healthcare providers.

Training in Trauma-informed Positive Behavioural Supports for Direct Support Professionals of Adults with Developmental Disabilities

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Objectives: Adults with a developmental disability (DD) who have high support needs and live in supported community settings are heavily reliant on direct support professionals to provide access to meaningful opportunities while respecting their autonomy. In Ontario, these direct support professionals may have a wide range of skills, educational backgrounds, and experiences, resulting in highly variable approaches to care and inconsistent implementation of support strategies. Government of Ontario regulations specify the need for person-centered supports including opportunities for autonomy and choice, but there is variation in the interpretation of these requirements and the specific training that agencies provide to their staff. Research regarding the outcomes of direct support staff training has focused on improving staff knowledge and/or skills, but few studies have also measured corresponding client outcomes as a result of staff training. The goal of this study is to respond to the unmet support needs of adults with DD and the lack of availability of training for direct support professionals through studying a new approach to training.

Method: Positive Behaviour Supports (PBS) includes evidence-based Applied Behavior Analysis strategies used to prevent or reduce problem behaviour by increasing autonomy and choice and teaching new skills to improve quality of life for people with DD. A trauma-informed approach to care (TIC) enables direct support professionals to design and deliver services that accommodate the vulnerabilities of trauma survivors, ultimately improving quality of life and reducing the frequency and severity of problem behaviours. Behavioural Skills Training (BST) is an evidence-based approach to staff training which employs instruction, modelling, rehearsal and feedback, and is competency-based. BST may be an effective approach in teaching skills consistent with PBS and TIC to direct support professionals to improve supports for adults with DD, promoting healing and improving their quality of life. This approach to training includes knowledge training on TIC and PBS, followed by behavioural skills training to teach direct support professionals specific PBS skills through a trauma-informed lens. Staff will be taught three skills in succession (present choices, present tasks, and provide assistance) within a multiple baseline across behaviours design. The study will include 25 direct support professionals from local partner agencies and the adults with DD who they support. The design will include four phases: 1) baseline; 2) BST with a colleague or confederate; 3) BST on the job with a resident; and 4) follow-up at two weeks and again one month later.

Discussion/Conclusions: Increased autonomy improves quality of life for people with DD. It is expected that client outcomes of autonomy, access to activities, problem behaviour frequency and severity, and mental health symptom severity will improve as a result of multi-component training of staff. Staff well-being and job satisfaction are also expected to increase with a greater understanding and skill set relating to best practices. If successful, we can improve staff's skills and the degree to which they provide non-intrusive support in a trauma-informed

and autonomous way. This research aims to give people with DD more opportunities for choice and enhanced supports that go beyond meeting basic human needs and towards meaningful improvements in quality of life.

An Open Learning Module: La communication pour une meilleur santé! Accès et qualité des soins pour les adultes autistes et ayant une déficience intellectuelle

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Objectives: There are few educational resources available in French to prepare future health professionals to work with people labelled with an intellectual or developmental disability. To fill this gap, a team of researchers from the University of Ottawa's School of Rehabilitation Sciences developed an open learning module in collaboration with people with a developmental disability, parents and health professionals. Funding was provided by the Office of the Provost and Vice-President, Academic Affairs. The module was created using the Pressbooks platform and will be available via eCampus Ontario. The purpose of this open learning resource is to introduce students in health sciences to a critical approach to developmental disability with a focus on communication in a clinical context. It is also to encourage students to anticipate communication with patients labelled with an intellectual or developmental disability and to reflect critically on respectful interaction.

Methods: The module contains two major components; 1) Context and key concepts related to intellectual disability from a critical perspective and, 2) Video-based scenarios and questions for reflection in a personal journal. Seven collaborators with a developmental disability, four parents and three health professionals took part in creating the video-based scenarios. Some were involved in preparing the scenarios, others in acting and adjusting the scenarios during production while others reviewed the videos postproduction and provided ideas for critical reflection.

Results: Three different scenarios depict encounters between an occupational therapist, a physiotherapist and a dietician with patients labelled as having an intellectual disability and their supporters. We produced two versions of the scenarios involving the physiotherapist and dietitian to demonstrate common errors and good practices. We then produced a third video involving an occupational therapist that contains errors and good practices. An annotated version of this same video was produced to allow students to compare their notes. Students are provided with a link to a reflection journal and prompted to identify errors, good practices and to suggest ways to improve.

Discussion/Conclusions: Important next steps to this project would be to evaluate the impact of the module with students in health sciences and to explore possibilities for in-person supported teaching by adults labelled with an intellectual disability in postsecondary French-language health science programs.