RESEARCH PROTOCOL

Children and Teens in Charge of their Health: A feasibility study of solution-focused coaching to foster healthy lifestyles in children and young people with physical disabilities

Principal Investigator:

- **Amy McPherson**, PhD, CPsychol. Scientist, Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital, Toronto. Assistant Professor, University of Toronto, ON.

Co-Investigators:

- **Elaine Biddiss**, PhD, PEng, Scientist, Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital, Toronto. Assistant Professor, Institute of Biomaterials & Biomedical Engineering, University of Toronto, ON.

- **Paige Terrien Church**, MD. Physician Lead, Holland Bloorview Kids Rehabilitation Hospital, Spina Bifida/Spinal Cord Injury Program. Assistant Professor, Paediatrics, University of Toronto, ON.

- **Gillian Alison King**, PhD. Senior Scientist, Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital, Toronto. Professor, University of Toronto. ON.

- **Désirée B. Maltais**, PhD, PT. Associate Professor, Department of Rehabilitation, Université Laval, Quebec City, QC. Researcher, Centre for Interdisciplinary Research in Rehabilitation and Social Integration, Quebec City, QC

- **Chantal Mérette**, PhD, pht. Researcher, Center for Interdisciplinary Research in Rehabilitation and Social Integration, QC. Professor, Laval University, Quebec City, QC.

- **Hélène Moffet**, PhD, PT. Researcher, Center for Interdisciplinary Research in Rehabilitation Faculty of Medicine, Quebec City, QC. Professor, Department of Rehabilitation, Université Laval, Quebec City, QC.

- **Fiona J. Moola**, MSc., PhD. Scientist, Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital. Assistant Professor, Dalla Lana School of Public Health, University of Toronto

- **Heidi Schwellnus**, PhD, Collaborative Practice Leader, Holland Bloorview Kids Rehabilitation Hospital, Toronto. Status Lecturer, University of Toronto, ON.

Collaborators:

- **Patricia J. Baldwin**, B.Sc.(OT), MTS. Certified Solution-Focused Coach, Independent Consultant, London, ON.

- **Lorry Chen**, B.Sc., RD. Clinical Dietitian, Holland Bloorview Kids Rehabilitation Hospital, Toronto.

- **Janke F. de Groot**, P.T, PhD. Associate professor Research Group Lifestyle and Health, HU University of Applied Sciences, Utrecht, the Netherlands. Program leader Quality and Organization of Care, Netherlands Institute for Healthcare Services (NIVEL), Utrecht, the Netherlands.

- **Sarah Keenan**, MPH, CSFC. Life Skills Coach and Transitions Strategy Team Lead: Solution-Focused Coaching, Holland Bloorview Kids Rehabilitation Hospital. Clinical Team Investigator, Bloorview Research Institute

Children and Teens in Charge of their Health: A feasibility study of solution-focused coaching to foster healthy lifestyles in children and young people with physical disabilities.

OVERVIEW

This three year study explores the feasibility and acceptability of conducting a full randomized controlled trial (RCT) of a promising coaching intervention for improving and sustaining physical activity (PA) and healthy dietary habits in children* with physical disabilities (CWPD). Thirty children will spend 12 months in the study. All will receive usual care and basic printed information about healthy lifestyles. In addition, 15 will receive a coaching intervention for the first six months. Pre-defined success criteria will assess the feasibility of trial processes. Acceptability of trial participation and impact of coaching will be explored qualitatively. Health indicators and psychosocial outcomes will be assessed four times, at the start of the trial, immediately post-intervention and at three and six months post-intervention.

RESEARCH PROBLEM

The World Health Organization's Global Strategy on Diet, Physical Activity and Health Promotion highlights that PA and dietary habits are central to disease prevention and lifelong health [1]. Canadian children have increased health risks as their activity levels are drastically lower than recommendations [2] and ~26% are classified as overweight or obese [3, 4]. The situation is even more critical for children with disabilities; 4.2% of Canadian children have disabilities and this number is rising [5, 6]. Due to complex and intersecting factors, CWPD are more sedentary [7-9], have lower PA rates [9, 10] and poorer quality diets [8-10] than their non-disabled peers. It is therefore both unsurprising and concerning that CWPD are 2-3 times more likely to be classified as overweight or obese than those without disabilities [11]. Annual health care costs of obesity related to disability are estimated at $44 billion in the US [12], supporting the need to start health promotion activities early in life. Despite the serious proximal and distal consequences of this health profile, we lack robust evidence on effective strategies

* Refers to children and young people between the ages of 10 - 18 years inclusive

to foster and sustain health habits for CWPD. Our team's research over the past 5+ years has provided three key learnings: i) CWPD have far fewer opportunities to engage in health promotion programs than their typically developing peers [13, 14]; ii) Although prescriptive exercise/dietary interventions can be efficacious, they are unsustainable due to the extensive resources required [15, 16]; and iii) CWPD often need support to identify health promoting activities that are engaging and grounded in their abilities and daily life [17]. Our review of 34 health promotion intervention studies for CWPD [18] showed:

- 82% of the programs required professional supervision (on average **35 sessions over 12 weeks**)
- 94% used prescriptive intervention strategies (i.e. not tailored to the individual's circumstances)
- 90% of interventions focused on one specific health behaviour (i.e. PA or diet, but not both)
- Only 28% used a control group
- **No** article reported on how positive health outcomes might feasibly be supported long-term

A new intervention paradigm that produces sustainable results without undue burden (on families or services) is therefore urgently required to address the health promotion needs of CWPD. Interventions must empower individuals to make lifestyle changes that are personally meaningful in order to promote motivation and encourage sustainable changes [19, 20]. Critically, interventions must also consider the child's circumstances (individual, environmental, familial) to ensure that health habits can be integrated into everyday life and thereby have a long-lasting impact [21, 22]. And, researchers must rigorously evaluate such interventions to provide evidence-based recommendations on improving the short- and long-term health of this under-served population [23, 24].

We propose that a strengths-based coaching approach may meet all of these requirements. In coaching, clients are guided to identify their goals, develop strategies to meet them and monitor their performance [25, 26]. In particular, Solution-Focused Coaching in Pediatric Rehabilitation (SFC-Peds) has been recommended as a coaching model for children with disabilities, for its strong theoretical basis

and ability to be customized to children and families' resources, environmental settings, child age and developmental stage [27]. Taking a strengths-based approach (such as SFC-Peds) is a departure from usual rehabilitation research and practice, which has largely been problem-focused (i.e. what a child can't do). This can lead to feelings of ineptitude, learned helplessness, poor self-concept and low self-efficacy [27]. Instead, a strengths-based approach can result in hope, motivation and action [28]. Strengths-based approaches are also much briefer than most existing interventions, and behaviour change is less costly using strengths-based approaches than problem-based approaches [29].

However, given that we will be the first to use SFC-Peds to promote healthy habits with CWPD, a feasibility and acceptability study is essential. Evidence of feasibility is a critical prerequisite for a RCT [30], especially for complex interventions that have multiple interacting components and/or target multiple behaviours (such as SFC-Peds) [30, 31]. Feasibility studies rigorously examine the *processes* (e.g. recruitment and retention), *resources* (e.g. personnel, time required to complete measures), *management* (e.g. coordination of research personnel, quality of data entry) and *science* (e.g. appropriate methodology and outcomes) of the intended RCT [32, 33]. It is also critical to evaluate the acceptability of interventions for the target population (e.g. satisfaction with duration, intensity, level of interest, perceived impact) [34], as well as those allocated to the control arm (e.g. acceptability of not receiving coaching, perceived burden of assessments) [35-37]. Examining all of these issues before the efficacy trial begins increases the likelihood of success [30, 38]. Feasibility studies such as the one we are proposing help ensure that resources are invested in efficacy trials likely to generate clinically meaningful results [38] and therefore have maximum impact on health care knowledge and outcomes.

KNOWLEDGE TO DATE

The health promotion needs of CWPD are considerable and unmet. Health habits must start early [39-41], as adult habits often begin in childhood [42]. This is particularly pertinent for CWPD,

because they often experience a range of physical, social and psychological restrictions leading to sub-optimal health habits [8-10]. Fatigue, pain, incontinence, lack of professional support, and inaccessible fitness/recreational facilities have all been cited as PA barriers [43-46]. Low PA can lead to mobility and functional restrictions, osteoporosis, depression, social isolation and reduced overall health and well-being [24, 47]. The current obesogenic environment provides easy access to energy-dense food for all children, but CWPD report eating less fresh produce, more 'fast food', more high-fat food and more chocolate than their non-disabled peers [8-10]. Environmental settings significantly influence daily health habits in children [21, 48]; this is salient for CWPD, who spend more time at home [49, 50] and have fewer opportunities to participate in sports and recreational activities than their nondisabled peers [49, 51, 52]. Parents of CWPD experience high stress [53, 54] and reduced incomes [55], which may also affect their child's engagement in health promotion activities [49, 56]. Conversely, we know that health habits have substantial positive benefits for children with physical disabilities; for example, young people with spina bifida (SB) and cerebral palsy (CP), Canada's most prevalent non-progressive childhood physical disabilities [57], demonstrate higher fitness levels, muscle strength, and social inclusion when engaged in active lifestyles [58-60]. Despite this, PA and diet interventions are rarely tailored to CWPD [61-63]. Given the increasing number of Canadian CWPD [6], robust evidence is needed regarding intervention strategies to improve and sustain positive health habits in CWPD.

Coaching is a theoretically-based intervention for changing behaviour. Coaches use real-world situations to promote positive, long-term behaviour change. The primary aim of coaching is to enhance *self-determination*, that is, the feelings of choice and control over one's life [64]. Self-determination theory (SDT) posits that there are 3 basic psychological needs essential for behaviour change [65]: i) *Autonomy*, the opportunity to make meaningful choices [66]; ii) *Competence*, also termed 'self-efficacy' [27], an individual's innate sense of belief in their ability to be successful at a particular activity [67];

and iii) *Relatedness*, feelings of support and acceptance that provide affirmation [68]. The resulting *intrinsic motivation* is a powerful mechanism to foster sustained behaviour change through genuine interest, satisfaction and engagement [65]. It is operationalized in coaching through co-constructing goals with children around new habits, supporting clients to identify realistic strategies for goal attainment and facilitating client reflection/monitoring of goal progression [25, 26, 69].

There is evidence of coaching efficacy for health promotion. Coaching has been used to improve and sustain a range of health habits in typically developing children [19] and adults with physical disabilities [70]. For example, telephone coaching of children and their parents led to dietary improvements and increased fitness [71]. Reduced Body Mass Index (BMI) was also reported in children with obesity after group coaching [72]. Adults with physical disabilities reported fewer exercise barriers and improved eating habits following telephone coaching [70]. Coaching in CWPD also show promising and sustainable behavioural change e.g. improvements in mobility-related behaviours in children with CP were sustained 6 months after a coaching intervention [73].

Solution-focused coaching is a promising approach to promote health habits in CWPD. There are a number of reasons why SFC-Peds is promising for promoting healthy habits in CWPD. First, SFC-Peds is based upon solution-focused brief therapy, which has strong evidence of behaviour change [74-76] and requires considerably fewer resources than those used in more traditional interventions [27]. Second, SFC-Peds is the only coaching model using all eight of the evidence-based coaching features shown to promote positive behaviour change [77]. These features map onto the 3 psychological needs described by SDT: a) *autonomy:* through the use of strategic questions to help children identify personally meaningful goals and develop practical solutions to move toward a vision of their "preferred future"; b) *Competence:* through empowering children to assume ownership over their goals and develop robust self-regulatory behaviours; and c) *relatedness*: through the use of active listening,

empathy and affirmative language [27, 69, 78, 79]. The resulting *intrinsic motivation* is associated with positive health behaviour changes [18]. Third, strategies used in SFC-Peds are tailored to the child's age, developmental stage, abilities and environmental settings, so that the same coaching *processes* can be used with a heterogeneous sample [27]. Finally**,** early pilot work by our team showed that children with physical disabilities (5 children with Duchenne muscular dystrophy) were able to engage with SFC-Peds and attained at least 1 PA or dietary goal after 12 weeks [80, 81]. The feasibility and acceptability of conducting a full RCT with a 12 month commitment remains unknown, however.

SIGNIFICANCE AND IMPACT OF THE RESEARCH

Physical, environmental and psychosocial restrictions mean that CWPD are adopting worrying PA and dietary habits. Despite this, we currently have limited evidence to inform interventions that may enhance lifelong health in CWPD. We suggest that a paradigm shift is needed, one that moves beyond traditional prescriptive programs to a strengths-based approach where intervention strategies enable new health habits to be integrated seamlessly into children and families' everyday lifestyles for long-term sustainability. Research such as our proposed study will ensure that this potentially transformative approach is rigorously examined and used in an evidence-based manner. As little is known about effective and acceptable behaviour change interventions for CWPD, this study's findings will make significant contributions to the field: i) Greater understanding of ecologically valid interventions that have the potential to enhance the long term health of CWPD; ii) Insight into how two different rehabilitation populations respond to SFC-Peds; and iii) Data on the responsiveness of outcome measures to a SFC-Peds intervention. These insights will enable us to design acceptable, feasible and rigorous interventions that will result in robust data for informing both research and clinical practice.

Children and Teens in Charge of their Health: A feasibility study of solution-focused coaching to foster healthy lifestyles in children and young people with physical disabilities.

OBJECTIVES & RESEARCH QUESTION

Primary objective: To evaluate the feasibility (study design, methods, processes) and acceptability (family/child/clinician satisfaction, perceived usefulness) of conducting a RCT of a novel, brief, coaching intervention (SFC-Peds) for improving and sustaining PA and dietary habits in CWPD.

Secondary objective: To determine the responsiveness of selected outcome measures to SFC-Peds coaching over 12 months.

Principal research question: *"Is an efficacy trial to evaluate a six month SFC-Peds intervention to improve PA and dietary habits feasible to implement and acceptable to CWPD and families?"*

APPROACHES AND METHODS

Design: We will use a pilot RCT design [82] with two groups: One group (n=15) will work with a coach trained in SFC-Peds eight times over six months. The other group, the control group (n=15), will receive only standard printed materials at the start of the study. These materials will also be available to the SFC-Peds group to control for bias on study measures. The control group will allow us to control for information, maturation, repeated testing and attrition over the 12 month study [83]. All participants will receive standard care from existing clinicians who will not be delivering the SFC-Peds study intervention. The *feasibility* of trial processes, management, and resources will be assessed quantitatively. The *acceptability* of trial participation and coaching processes will be explored qualitatively. Qualitative enquiry lends insight into potential mechanisms of change and barriers to implementation and is therefore highly recommended when evaluating complex interventions [34].

Sample: Thirty children aged 10–18 inclusive and their parents who live within approximately two hours of Holland Bloorview Kids Rehabilitation Hospital (Toronto, ON) up to Thames Valley Children's Centre (TVCC) (London, ON) will participate. The sites serve diverse socio-cultural communities.

Children and Teens in Charge of their Health: A feasibility study of solution-focused coaching to foster healthy lifestyles in children and young people with physical disabilities.

Child inclusion criteria:

i) Between the age of 10 – 18 years inclusive

ii) Diagnosis of SB or CP

iii) Has physical capability to execute independent body movement with or without device

iv) Cognitively able and willing to set PA or dietary goals

v) Can communicate in English and respond to questions requiring some reflection and insight

vi) Home internet connection

vii) Lives within 2 hours driving distance from Toronto up to London, Ontario OR willing to travel to either HB or TVCC for first in-person coaching session if randomized into coaching group

Child exclusion criteria:

i) Surgery in past 6 months or upcoming 12 months that may impact PA or dietary intake (e.g. orthopedic surgery or neurosurgery)

ii) Medical condition severely restricting diet

iii) Underweight (less than fifth percentile)

iv) Receiving specialist dietetic services

Parent inclusion criteria:

i) Primary caregiver to a study participant

viii) Can communicate in English and respond to questions requiring some reflection and insight

Sample size

Feasibility studies do not assess intervention efficacy and therefore do not require formal sample size calculations [33, 85]. The sample size (n=30) was set as a minimum needed to assess the key feasibility issues, as per feasibility best practices [86]. Fifteen SFC-Peds participants will suffice to show

a tendency (p<0.10) within the intervention group of behavioural change assessed by Goal Attainment Scaling (GAS; see 'Outcomes'), equal to an effect size of 0.55 with a power of 0.80. The responsiveness of the secondary outcome measures will be compared with goal scores for evidence of concordance, e.g. a tendency of correlation between behavioural change and the Arc's Self-Determination Scale. *Post hoc* estimates of variance will be key for the full trial's design as they will inform the power calculations of the eventual RCT [85]. The sample size will allow us to assess recruitment success and show whether testing procedures, coaching goals and follow-up sessions are consistent across groups, mobility levels and sites. This sample size will also provide sufficient data for the qualitative work we are proposing to explore acceptability [87, 88].

Recruitment

We will recruit 15 children with SB and 15 children with CP (a total of 30 participants) and their parents from Holland Bloorview and TVCC.

Recruitment at Holland Bloorview

Children will be recruited from the Child Development Program at Holland Bloorview. Specifically we will solicit participation from clients in the Spina Bifida Service, LIFEspan Program, Hypertonia Clinic and through physiotherapists (PT's) and occupational therapists (OT's) in the Neuromotor Program. Following Research Ethics Board (REB) approval, a designated clinical member from the Spina Bifida Service, LIFEspan Program, Hypertonia Clinic as well as all PT's and OT's in the Neuromotor Program will identify eligible clients who meet study inclusion criteria and will provide study flyers and information letters. Clinicians may request the RC on site to speak directly to interested families about the study in further detail. Clients will be encouraged to review the information letter and discuss the study with their family members if they wish. The RC may obtain consent on this day if the family is ready. Otherwise, the RC will obtain permission from the family for a follow-up phone call to

confirm interest and schedule an appointment time to obtain written informed consent. Families may contact the RC for more information at any time.

In addition, flyers for the study will be posted on the Bloorview Research Institute's "Participate in Research" page and around approved areas of the hospital for any potential participants to self-refer to the study (see Appendix 1). They may call the number provided on the flyer where the RC will explain the study in greater detail and confirm that they are eligible for the study. On May 1st, 2018, we will begin to use centralized recruitment system at the Bloorview Research Institute.

Recruitment at Thames Valley Children's Centre

A research contact who is a designated staff member at the TVCC will introduce the study to clients seen in the SB and CP service. They will then obtain permission from families for the Holland Bloorview RC to contact the family to discuss the study. The TVCC research contact will share the family's contact information with the RC who will then contact the interested family and describe the study in more detail and confirm their eligibility to participate.

If recruitment is insufficient using these channels, the Spina Bifida and Hydrocephalus Association of Ontario (SBHAO) will distribute information letters to all families on their distribution list meeting the age and diagnosis criteria. Families who are interested in the study can contact the RC for more information and to confirm eligibility for the study.

Informed Consent

After a telephone or in-person conversation to confirm eligibility and interest (see Appendix 2 for script), a convenient time and date will be arranged for the RC to meet with clients and parents at their nearest assessment site (Holland Bloorview or TVCC) to complete informed consent followed by the first assessment session.

At this session, the RC will clarify any concerns, and answer any questions clients or parents might have and will judge the child's capacity to provide informed consent, guided by a structured tool (see Appendix 3). If the RC judges the child to have answered questions about the study with reasonable understanding, the child will sign the Informed Consent Form (ICF) (see Appendix 4). Otherwise, a parent will sign the ICF and the child will provide their assent (see Appendix 5). For parents who are willing to participate in the interviews and parent measures the parent will sign the ICF for their own participation in the study. The RC obtaining informed assent from prospective participants (children) will familiarize the potential participant about assent by explaining what free, informed consent is and how research is different from clinical care. The RC will have an open and age appropriate discussion with each child to assess readiness for assent. The RC may consult the parent to identify accommodations to assist in decisions to participate. The assent and consent forms will be provided prior to this discussion in order for families to review them on their own. While meeting with the client and parent, the RC will clarify any concerns, and answer any questions clients or parents might have. During this process, the highly experienced RC will observe and listen for any verbal and nonverbal indications of dissent. Furthermore, the RC will ensure ongoing informed assent by reconfirming agreement to participate throughout the study. At the end of the study, the family will receive a study summary letter at the end of the study. The local REB fully endorses these processes.

Randomization

Once participants have provided written informed consent and completed all baseline measures, they will be randomized into the study. The PLAN procedure of SAS/STAT software will create a random sequence to test randomization. Randomization block size will not be known to research staff to ensure blinding. Group allocation occurs after baseline assessment, stratified by diagnosis and recruitment site.

Standard care

All participants will receive standard care throughout. This may vary with the child's age, diagnosis, functional level and co-morbidities. Our previous work shows that advice related to PA/diet is rarely given with standard care [89]. However, to document any potential co-interventions, all interactions between study participants and their service providers will be recorded on a standard form see Appendix 6). The study will thus identify any differences in standard care between groups and across sites, and will inform recruitment, stratification and data analysis in the full RCT. We will identify if any service providers have SFC-Peds training. Coaches will not be part of participants' standard care.

Control information

After randomization, all participants will be given basic printed information relating to PA and healthy diets based upon Health Canada's *Eat Well and Be Active Toolkit* (www.health.gc.ca/eatwell-beactive), which has been reviewed for suitability by expert team members (*Church, Chen, Maltais*). This ensures that all children have exposure to information on healthy habits, thereby meeting our ethical imperative and ensuring a scientifically rigorous control group. It also helps to control for bias of responses on outcome measures (see Appendix 7 for booklet).

Intervention training

Coaches will be clinicians with physiotherapy, kinesiology, therapeutic recreation, dietetics or similar training who have already been trained in SFC-Peds. They will undertake a half day of training from expert team members, including Canadian PA and diet guidelines [90, 91], and their application to children with SB and CP (*Church, Maltais, Chen*).

Intervention implementation

Children randomized into the SFC-Peds group (n=15) and their parents will be allocated a coach for eight 60-min SFC-Peds sessions over six months. A six month intervention is supported by meta-analyses of health promotion studies for typically developing children [92] and adults [93]. Time is allowed between sessions for children and parents to work on their goals [27, 70] (see Appendix 11 for coaching schedule).

Coaching will be guided by a framework developed by SFC-Peds clinicians at Holland Bloorview to integrate the Canadian Occupational Performance Measure (COM) and Goal Attainment Scaling (GAS) outcome measures into SFC-Peds (see Appendix 8 for framework). The **first coaching session** will take place in the family's home to establish rapport. Parents play an important supportive role in the coaching process, although the level and type of support they provide will be customized to the age and abilities of their child. SFC-Peds is ideal for establishing 'common ground' between children and parents so that they are working towards goals that they both deem important, maximizing the chances of sustainability. To enhance child self-determination, the coach will first support the child to identify their 'preferred future,' i.e. the 'big picture' the participant wants to work towards in the context of health habits. Then, the child, parent and coach will co-create actionable goals to help children to work towards it. Focusing upon goals that are personally meaningful to the child fosters autonomy [94]. The coach and parents will then support the child to identify realistic, real-world goal attainment strategies using their own strengths and resources, supporting the development of competence. The use of active listening, empathy and attentive body language creates a trusting relationship, and promotes a sense of relatedness [95]. Parental involvement in the coaching sessions will ensure that goals and goal-attainment strategies are realistic for the child, his/her environmental settings and the family. For example, if the parent cannot transport a child to an organized activity to meet their physical activity goal, then a different strategy would be co-created that is appropriate for the

child's circumstances and available support systems (e.g. use of an active video game). This flexibility and customizability is a key strength of SFC-Peds. The coach will help parents to identify their own resources and action steps for supporting their child's goals, appropriate for their age, developmental stage and abilities. Children will each set at least one PA or one dietary goal. See Appendix 9 for examples of the coaching and goal setting process (supported by their parents). If this happens, the time taken to achieve goals will be recorded and used to inform future coaching protocols.

To reduce family burden and enhance adherence [43], the **remaining coaching sessions** will be held remotely usingZoom an online meeting tool used by Holland Bloorview requiring children only to have internet access. It enables coaches and families to have secure, face-to-face contact without onerous and expensive travel.. Remote coaching has previously demonstrated feasibility in typically developing children [71, 80]. 90% of Canadians have Internet access with 70% accessing the Internet daily [96]. Any instances of internet access being a barrier to study participation will be noted and will inform our assessment of study feasibility.

At **every coaching session,** coaches will employ SFC-Peds best practices and ask key questions that: Elicit any changes since previous sessions (e.g. *What's better? What worked?*); Amplify successes (e.g. *How did you figure that out?*); Reinforce key learnings (e.g. *What have you learned as a result of that success?)*; and Review the child's action plan (e.g. *With your new skills, what's next?*) [97]. After each coaching session, coaches will complete a standardized fidelity measure (see Appendix 10) to ensure **intervention consistency** (the Solution-Focused Fidelity Instrument, internal consistency of 0.83 [98]), which will be reviewed weekly by the team's coaching experts, and feedback provided. Coaches will randomly record 2–3 sessions each for review by the coaching team members and have ongoing supervisory sessions. Participant engagement will be measured using the Pediatric Rehabilitation

Intervention Measure of Engagement – Service Provider (PRIME-SP) (see Appendix 11) and will be assessed by the coaches after each coaching session [126].

STUDY OUTCOMES AND PROCEDURES

Study Procedures

After enrollment into the study, participants will complete the following assessments at the time points outlined below (see Appendix 12 for assessment schedule). Children in the SFC-Peds group will receive the eight 60 minute coaching sessions between Time 1 and Time 2.

Assessment Timings

To assess participant retention, the feasibility study will use four assessment points over 12 months as in the planned efficacy trial: **Time 1 Baseline** (immediately preceding randomization); **Time 2** (immediately post-intervention or 6 months post-baseline for control group +/- 2 weeks); **Time 3** (three months post-intervention or 9 months post-baseline for control group +/- 2 weeks); **Time 4** (6 months post-intervention or 12 months post-baseline for control group +/-4 weeks).

Study Assessments

PRIMARY OBJECTIVE: *To evaluate the feasibility and acceptability of conducting a RCT of a novel, brief, coaching intervention (SFC-Peds) for improving and sustaining PA and dietary habits in CWPD.*

Trial feasibility will be assessed using the following pre-identified criteria (as recommended [82]):

Recruitment	2–3 participants/month recruited over 12 months (for target sample size n=30)	≥ 10% recruitment response rate achieved (min. feasible RCT response rate [99])
Attrition	85% participants successfully complete study (i.e. complete T1 & T4 evaluations)	75% participants complete all assessments (i.e. protocol adherence)
Adherence	Successful completers participate in ≥75%	75% of the participants complete

	meetings with coach	evaluations in ≤2 hrs (to assess burden)
Stratification	Intervention/control groups similar for age and gender	Intervention/control groups comparable on diagnosis and functional mobility
Fidelity	High intervention fidelity (>8/10 on the Solution-Focused Fidelity Instrument [98])	Challenges/ease of remote coaching (coach, child, family report)

Trial <u>acceptability</u> will be explored qualitatively:

<u>Semi-Structured Survey</u>

Time 1: All child participants (*n*=30) and parents (*n*=30) will complete a semi-structured survey exploring expectations, motivations and views on health habits upon entering the study (see Appendix 13 for Baseline Interview Survey).

<u>Qualitative Interview Time 2 (SFC-Peds group only)</u>

Time 2: SFC-Peds participants (*n*=15) and their parents (*n*=15) will be interviewed (separately where possible) by a qualitative interviewer to explore: i) Satisfaction with coaching sessions (e.g. relationship with coach, experiences of virtual coaching; whether they would recommend it to others); ii) Coaching experiences (e.g. new opportunities, challenges experienced); iii) Perceived optimal coaching dose; iv) Role of SFC-Peds in children's and family's health habits (if any); v) Role/extent/experiences of parent involvement in supporting coaching goals and activities (see Appendix 14 for Time 2 interview guide).

<u>Photovoice (SFC-Peds group only)</u>

SFC-Peds participants will be given a digital camera (or they may use their cellphone, depending upon preference), and asked to take 1–2 naturalistic photos per month between Times 2 and 4, to provide insights into their lifestyles post-coaching (termed 'Photovoice' [100]). Photovoice uses

photographic images taken by participants to help researchers understand what is meaningful for them [101-105]. Data produced through this method enables participants to reflect their lived experiences and enhance our understanding of the acceptability and perceived impact of coaching. Children will be given guidelines on the types of photos they could potentially take (see Appendix 15). They will be reminded twice a month using their preferred method of contact (phone, email, or text message).

Time 3: No acceptability data collected.

Qualitative Interview Time 4 (SFC-Peds group only)

Time 4 (SFC-Peds group): Children and their parents in the SFC-Peds group will undertake separate in-depth interviews facilitated by a qualitative interviewer to explore their experiences after coaching completion, perceived impact of intervention, barriers/facilitators to maintaining PA and dietary habits, and any unmet needs (see Appendix 16 for interview guide). Children will be asked to select 6-8 of their photographs taken since Time 2 to share with the interviewer. This will help remind children of their lifestyles in the previous six months, and enable them to speak in more depth about their feelings and experiences [106]. Each child will first be asked to explain why he/she took the photo, its meaning, what it shows of his/her coaching experience and the time since it ended.

Survey Time 4 (Control group only)

Time 4 (Control group): Children in the control group (n=15) will complete a Time 4 survey (see Appendix 17) regarding what they liked most/least about the study, any changes in health habits in the previous 12 months, acceptability of not getting the intervention, and tolerance of assessment protocols [30].

Qualitative Interview (Coaches only)

Time 4 (Coaches): Coaches will be interviewed to explore their experiences of delivering the intervention, e.g. challenges/facilitators, optimal coaching doses, use of technology (see Appendix 18).

SECONDARY OBJECTIVE: *To determine the responsiveness of outcome measures to SFC-Peds coaching over 12 months.*

The following measures (excluding gender and date of birth) will be administered at Times 1, 2, 3, and 4 for all participants (approximately 1.5 hours duration). Issue identification and goal attainment measures are administered to SFC-Peds participants only with the first assessment conducted during the first coaching session. Measures have been selected based upon evidence of their responsiveness to change and psychometric properties in previous health promotion interventions [18]. Parent and child report questionnaires may be completed at home or online if the family prefers.

Participant characteristics

DEMOGRAPHICS: Gender, date of birth, ethnicity, diagnoses, medications, current sports involvement (see Appendix 19 for demographics form). Questions from the International Study of Childhood Obesity, Lifestyle and the Environment survey (see Appendix 20) about the child's environment (e.g. accessibility of play areas) will also be collected [107].

FUNCTIONAL MOBILITY: The six-minute walk test for walkers [108] and the six-minute push test for non-walkers [109] (see Appendix 21).

Primary outcome measure

ISSUE IDENTIFICATION AND GOAL ATTAINMENT (CHILD REPORT):

Within-group change will be assessed using the Canadian Occupational Performance Measure (COPM) (see Appendix 22), which identifies the person-centred goal performance issues to improve, and assesses changes in occupational performance and satisfaction. Participant goal attainment will be assessed using Goal Attainment Scaling (GAS) (see Appendix 23), by defining five levels of goal attainment, thus ensuring that all attainment levels are mutually exclusive and measurable. This is an

objective measure of behaviour change [110]. To minimize bias, GAS and COPM re-assessment will be conducted by a coach who has not worked with the child.

Secondary outcomes measures:

Between group change will be examined using the following measures:

BEHAVIOURAL ASSESSMENTS (CHILD REPORT):

Physical activity: The Habitual Activity Estimation Scale [111] (see Appendix 24) estimates time spent inactive, somewhat inactive, somewhat active, and very active, and shows good correlation with moderate to vigorous PA measured by accelerometry in our population (p=0.02) [112, 113].

Diet: The Dietary Screener Questionnaire (see Appendix 25) assesses dietary intake over the past 30 days and is validated against 24 hour multiple recall [114].

PSYCHOSOCIAL ASSESSMENTS (CHILD REPORT):

Self-determination: The *Arc's Self-Determination Scale* (see Appendix 26) has excellent reliability/validity with children with disabilities [64] and will assess self-determination to provide insight into potential mechanisms of behaviour change.

Self-efficacy: The *PA Self-efficacy Scale* (see Appendix 27) assesses confidence in the ability to be physically active when faced with challenges [115], with good internal consistency (α=.54- .71) and test-retest reliability (ICC= .61-.82). High self-efficacy scores are significantly associated with greater moderate-vigorous physical activity [116]. *Self-efficacy for healthy eating* (see Appendix 28) assesses participants' feelings of competence for making healthy food choices in: social, emotional, and typical situations [117]. Higher scores are associated with healthy food intake ($\beta = .33$, $p < .01$), test-retest reliability (ICC= .80) [118].

BODY COMPOSITION (CHILD ASSESSMENT):

Weight, height/length, waist circumference, and skinfold thickness (see Appendix 29 for record form) will be assessed, using standard guidelines [119].

Weight: Participants will be weighed minimally clothed (e.g. t-shirt, light shorts) without shoes to the nearest 100 grams using a chair scale.

Height: Those able to stand will be measured to the closest millimeter with a portable stadiometer or length measuring board. For those with severe contractures, careful segmental measurement will be conducted of the child's length in supine. Arm span and ulna length will also be measured as they offer useful proxies for length in children with lower extremity deformities [127, 128].

Body Mass Index (BMI): BMI will be calculated using both height and length as kilograms per meter squared (kg/m^2) and classified using Centres for Disease Control and Prevention cut-offs (85^{th}–95^{th} centile=overweight, above 95^{th} percentile=obese) [120].

***Waist circumference*:** Waist circumference (WC) has been shown to correlate well with fat mass as measured by dual-energy X-ray absorptiometry (DXA) [129-132] and has been specifically recommended for assessing body fat of children with SB [133] WC will be measured using a flexible tape measure at the narrowest level between the lower costal border and the iliac crest, over light clothing. Children with WC $\geq 90^{th}$ percentile have shown to be at higher risk of cardiovascular indicators [134, 135]. The RA will confirm lesion level using medical records and note any bulky masses, liposuction incision marks or spinal curvature.

Skinfold thickness: Skinfold thickness (SFT) is strongly associated with cardiovascular risk factors in children [136]. Tricep and subscapular skinfold thickness will be assessed, as per best practice [137] using Lange callipers (Cambridge Scientific Industries). Subscapular SFT in particular has

previously demonstrated excellent test-retest reliability when conducted by skilled practitioners [127, 133]. The Slaughter equation will be used to assess body fat [138].

HOME AND ENVIRONMENT ASSESSMENT (PARENT REPORT):

The Family Eating and Activity Habits Questionnaire (see Appendix 30) is a 32-item parent-report assessment to assess the health behaviours of family members as well as the nature of the home environment [121]. It has high internal consistency (0.76-0.87) and test-retest reliability (0.75-0.89). These data will provide context for the children's behavioural outcomes, and allow us to examine the impact of the coaching on the family over time, which will also be examined in qualitative interviews with parents and children.

Post-Study

Following completion of the study, both child and their parent will be thanked and provided with a $20 gift card for each visit ($25 for the final visit) as a token of appreciation. Participants will also be offered volunteer hours. Families will be reimbursed for their parking expenses. Additionally, all participants who have completed all of the assessments will be entered into a prize draw for a gift card of $150 at the end of the study. Participants and their parents will be asked if they wish to receive a summary of the research once the study is completed.

DATA ANALYSES

Sample characteristics will be summarized using descriptive statistics. Inferential statistics are not used in feasibility studies [82].

PRIMARY OBJECTIVE: Feasibility will be assessed using descriptive statistics using our ***a priori* success criteria** [82]. We will explore any sample/group differences between completers (complete Time 1 and Time 4 measures) and non-completers. We will also determine if there are sample and

outcome variable differences between sites, disabilities and functional mobility, which will guide our target sample for the efficacy study.

Surveys completed by participants at Time 1 (all participants) and Time 4 (control group only) will be analyzed with descriptive statistics and thematic analysis [122]. Verbatim transcripts from **in-depth interviews** with the SFC-Peds group at Times 2 and 4 will undergo interpretative thematic analysis [123] informed by the phenomenological research tradition to identify acceptability of the intervention (e.g. satisfaction with coaching, perceived impact). Team members will independently code transcripts with a flexible, inductive coding system consistent with research objectives. Similar codes will be grouped, from which a consolidated list of master themes will be created that show patterns in participant experiences, supported by data. Characteristics (e.g. child age, gender, diagnosis and functional mobility) will be considered to understand the context of the participants' experiences. The research team will play a key role in data synthesis/interpretation. Code-recode, peer examination and team discussions will help establish trustworthiness.

Data from the **Photovoice** portion of the Time 4 in-depth interview will be read multiple times to embed the research team in the stories of the participants. The research team will code each transcript by noting words, phrases, or data segments that occur commonly in participant's narratives. Next, the research team will group these commonly occurring data segments into categories. At the next stage of analysis, the research team will perform this coding activity on each transcript. Subsequently, the research team will search accords the entire group of transcripts to develop commonly occurring categories and themes across the data set. The derived themes will be refined carefully. Dr. Moola will supervise the coding activity. The themes will be written into a thematic overview of how children with SP and CP see the body, health and physical activity from their own situated life worlds.

SECONDARY OBJECTIVE: Measure responsiveness will be established by pre-post intervention differences using effect sizes (Cohen's *d*) and confidence intervals both within and between groups. It is well accepted to examine mean score changes for clinically significant differences pre and post intervention without calculating statistical significance (e.g. a score change of at least 2 points on the COPM is considered clinically significant [38]). We will therefore be able to assess the potential value of SFC-Peds over receiving printed materials only by examining goal scores over time. Our secondary outcomes will be compared with objective behaviour change (goal attainment) for concordance (e.g. whether successful goal attainment corresponds with increased self-determination). We will examine differences in outcome measures by disability, functional mobility, gender and age.

CHALLENGES

Our intervention (SFC-Peds) is largely virtual to reduce burden and enhance adherence [43]. All participants will receive gift cards for completing assessments to reduce attrition; this is a key feasibility outcome, especially in the control group. To reduce possible biases, participants will not meet during the study and coaches will not be involved in standard care. Standardized training (by 3 certified coaches) will be provided. Assessors will be asked which group they think participants are in; blinding success is indicated by accuracies at or below chance level. If adaptations are needed for the RCT, 'A process for Decision making after Pilot and feasibility Trials' (ADePT) [124] will be followed.

KNOWLEDGE TRANSLATION (KT)

A KT planning template [40] will ensure our findings have maximum reach yet are appropriate for feasibility study outcomes. The plan capitalizes on close collaboration of knowledge users and researchers within our investigative team. Integrated KT is promoted throughout the project by the involvement of clinical, family and knowledge user stakeholders, to ensure that the outputs meet the needs of the end users [125]. Holland Bloorview Research Family Engagement Committee members

have reviewed the proposal. Clinicians are team members, as are 2 parents of children with CP and SB and a young man with CP (see letters of support). End of grant KT will be: i) a refined proposal for a full RCT submitted to CIHR for consideration; ii) dissemination of study findings using traditional knowledge diffusion strategies: i.e. conference presentations and publications; iii) communications to lay forums with summaries, stories and infographics. The latter will be facilitated through our knowledge users and partners: Variety Village (a well-established Toronto organization offering resources for active, healthy lifestyles for all abilities), Spina Bifida and Hydrocephalus Association of Ontario, and Childhood Cerebral Palsy Discovery Network (CP-NET). They all have regular events (in addition to print and online platforms) where we can discuss strengths-based PA and dietary strategies that have been deemed useful in the study with parents and young people. We will keep a log to track all KT activities (e.g. presentations given, # attendees, paper requests, # infographic downloads). These activities will inform integrated KT for the future RCT. See letters of support from all partners.

EXPERTISE, EXPERIENCE AND RESOURCES

McPherson: health promotion expert in paediatric disability, has overall study responsibility. *Maltais*: physiotherapist, expert in health-related fitness in pediatric disabilities. *King:* social scientist, has written about the use of SDT, coaching and child health outcome measurement. *Schwellnus*: occupational therapist, has conducted seminal work using SFC-Peds to promote life-skills in children with CP. *Keenan:* life-skills coach, has extensive expertise applying SFC-Peds in clinical settings and is a trainer for GAS. *Moffet:* expert in RCT methodology, will ensure concordance with rigorous standards. *Mérette:* biostatistician, responsible for randomization procedures, database development, quantitative data analyses. *Biddiss:* biomedical engineer, expertise in rehabilitation telemedicine and PA in CWPD. *Church:* developmental pediatrician, will train coaches on the medical needs of CWPD. *Moola:* expert in the philosophy/application of qualitative methodologies (esp. Photovoice) in childhood

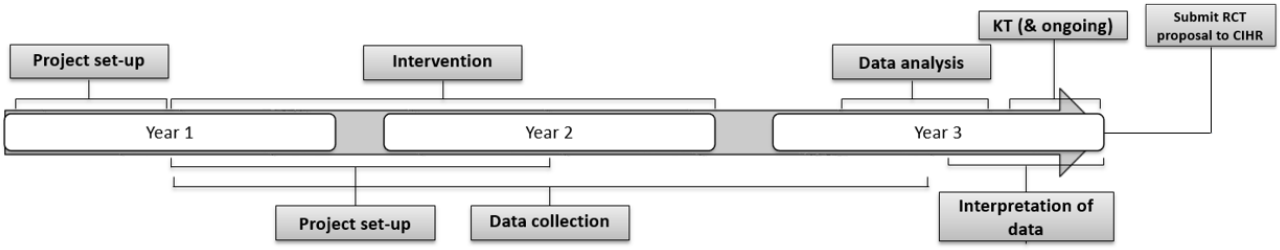
chronic illnesses. *de Groot* (PA interventions for CWPD) and *Chen* (nutritional needs of CWPD).

Baldwin: developed SFC-Peds, will provide intensive SFC-Peds training and monthly supervision.

Allison: Director, Access and Awareness at Variety Village, will play a Knowledge User role.

The core experts required for running the study are located in Toronto. The other team members will provide expertise at specific points of the study (e.g. *Merette* setting up the database). Technological strategies (e.g. e-mail, Adobe Connect, googledocs) will ensure the engagement of team members throughout the study (e.g. discussions and decisions, interpretation of findings, KT activities). Research will be coordinated by Bloorview Research Institute (BRI), situated within Canada's largest pediatric rehabilitation hospital, Holland Bloorview Kids Rehabilitation Hospital, known internationally for its leadership in childhood disability. TVCC, the 2nd recruitment site, provides rehabilitation services to children and youth with physical, communication and developmental needs in Southwestern Ontario. The hospitals have a close relationship through the Ontario Association of Children's Rehabilitation Services (OACRS), which also offers extensive KT opportunities.

TIMELINE



REFERENCES

1. Bauman, A. and Craig, C., The place of physical activity in the WHO global strategy on diet and physical activity. *International Journal of Behavioural Nutrition and Physical Activity*, 2005. **24**: 2-10.
2. Colley, R., Garriguet, I., Craig, C., Clarke, J., and Tremblay, M., *Physical activity of canadian children and youth: Accelerometer results from 2007-2009 Canadian health measures survey*, 2011. 1-9.
3. Shields, M., *Overweight and obesity among children and youth*, 2006.
4. Healthy Kids Panel, *No time to wait: The healthy kids strategy*, Ministry of Health and Long Term Care: Ontario,2013: http://www.health.gov.on.ca/en/common/ministry/publications/reports/healthy_kids/healthy_kids.pdf
5. Statistics Canada, *A profile of disability in Canada, 2001.*, 2002, Statistics Canada: Ottawa.
6. Statistics Canada, *Participation and activity limitation survey 2006: Families of children with disabilities in Canada*, 2008: Ottawa.
7. Steele, C., Kalnins, I., Jutai, J., Stevens, E., Bortolussi, J., and Biggar, D., Lifestyle health behaviours of 11-16 year old youth with physical disabilities. *Health Education Quarterly*, 1996. **11**(2): 173-186.
8. Hogan, A., McLellan, L., and Bauman, A., Health promotion needs of young people with disabilities: A population study. *Disability and Rehabilitation*, 2000. **22**(8): 352-357.
9. Steele, C., Kalnins, I., Rossen, B., and Biggar, D., Age-related health risk behaviors of adolescents with physical disabilities. *Social and Preventive Medicine*, 2004. **49**: 132-141.

10. Steele, C., Biggar, D., Bortolussi, J., Jutai, J., Kalnins, I., and Stevens, E., Health promotion and youth with physical disabilies. *Rehabilitation Digest*, 1995. **25**(4): 13-24.

11. Neter, J.E., Schokker, D.F., de, J.E., Renders, C.M., Seidell, J.C., and Visscher, T.L., The prevalence of overweight and obesity and its determinants in children with and without disabilities. *Journal of Pediatrics*, 2011. **158**(5): 735-739.

12. Finkelstein, E., J, T., J, C., and W, D., Annual medical spending attributable to obesity: Payer- and service-specific estimates. *Health Affairs*, 2009. **28**(5): w822-831.

13. McPherson, A., Ball, G., Maltais, D., et al., A call to action: Setting the research agenda for addressing obesity and weight-related topics in children with physical disabilities. *Childhood Obesity*, 2016. **12**(1): 1-11.

14. Rimmer, J. and Rowland, J., Physical activity for youth with disabilities: A critical need in an underserved population. *Developmental Neurorehabilitation*, 2008. **11**(2): 141-148.

15. de Groot, J.F., Takken, T., van Brussel, M., et al., Randomized controlled study of home-based treadmill training for ambulatory children with spina bifida. *Neurorehabilitation and Neural repair*, 2011. **25**(7): 597-606.

16. Verschuren, O., Ketelaar, M., Gorter, J., Helders, P., Uiterwaal, C., and Takken, T., Exercise training program in children and adolescents with cerebral palsy: A randomized controlled trial. *Archives of Pediatrics & Adolescent Medicine*, 2007. **161**(11): 1075-1081.

17. McPherson, A. and Lindsay, S., How do children with disabilities view 'healthy living'? A descriptive pilot study. *Disability and Health Journal*, 2012. **5**(3): 201-209.

18. McPherson, A., Keith, R., and Swift, J., Obesity prevention for children with physical disabilities: A scoping review of physical activity and nutrition interventions. *Disability and Rehabilitation.*, 2013. **36**(19): 1573-1587.

19. Olsen, J. and Nesbitt, B., Health coaching to improve healthy lifestyle behaviors: An integrative review. *American Journal of Health Promotion*, 2010. **25**(1): e1-e12.

20. van Wely, L., Balemans, A., Becher, J., and Dallmeijer, A., The effectiveness of a physical activity stimulation programme for children with cerebral palsy on social participation, self-perception and quality of life: A randomised controlled trial. *Clinical Rehabilitation*, 2013. **Early online**(DOI:10.1177/0269215513500971).

21. Findholt, N., Michael, Y., Davis, M., and Brogoitti, V., Environmental influences on children's physical activity and diets in rural oregan: Results of a youth photovoice project. *Online Journal of Rural Nursing and Health Care*, 2010. **10**(2): 11-20.

22. McKinnon, R., Reedy, J., Handy, S., and Rodgers, A., Measuring the food and physical activity environments. *American Journal of Preventive Medicine*, 2009. **36**(4S): S81-S85.

23. Rimmer, J., Health promotion for people with disabilities: The emerging paradigm shift from disability prevention to prevention of secondary conditions. *Physical Therapy*, 1999. **79**(5): 495-502.

24. Rimmer, J., Rowland, J., and Yamaki, K., Obesity and secondary conditions in adolescents with disabilities: Addressing the needs of an underserved population. *Journal of Adolescent Health*, 2007. **41**: 224-229.

25. Graham, F., Rodger, S., and Ziviani, J., Effectiveness of occupational performance coaching in improving children's and mothers' performance and mothers' self-competence. *The American Journal of Occupational Therapy*, 2013. **67**(1): 10-18.

26. Passmore, J., Peterson, D., and Freire, T., *The psychology of mentoring and coaching*, in *The Wiley-Blackwell handbook of the psychology of coaching and mentoring*, J. Passmore, D. Peterson, and T. Freire, Editors. 2013, John Wiley & Sons, Ltd.

27. Baldwin, P., King, G., Evans, J., McDougall, S., Tucker, M., and Servais, M., Solution-focused coaching in pediatric rehabilitation: An integrated model for practice. *Physical & Occupational Therapy in Pediatrics*, 2013. **33**(4): 467-483.

28. McAllister, M., Doing practice differently: Solution focused nursing. *Journal of Advanced Nursing*, 2003. **41**(6): 528-535.

29. Grant, A.M., Making positive change: A randomized study comparing solution-focused vs. Problem-focused coaching questions. *Journal of Systemic Therapies*, 2012. **31**(2): 21-35.

30. Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., and Petticrew, M., *Developing and evaluating complex interventions: New guidance.*, 2010. 1-39.

31. Moore, G., Audrey, S., Barker, M., et al., Process evaluation in complex public health intervention studies: The need for guidance. *Journal of Epidemiological Community Health*, 2014. **68**: 101-102.

32. Thabane, L., Ma, J., Chu, R., et al., A tutorial on pilot studies: The what, why and how. *BMC Medical Research Methodology*, 2010. **10**: 1.

33. Lancaster, G.A., Dodd, S., and Williamson, P.R., Design and analysis of pilot studies: Recommendations for good practice. *Journal of Evaluation in Clinical Practice*, 2004. **10**(2): 307-312.

34. Campbell, M., Fitzpatrick, R., Haines, A., and Kinmonth, A., Framework for design and evaluation of complex interventions to improve health. *British Medical Journal*, 2000. **321**(7262): 694.

35. Clark, P. and Macarthur, J., Children with physical disability: Gaps in service provision, problems joining in. *Journal of Paediatrics and Child Health*, 2008. **44**: 455-458.

36. World Health Organization. Ottawa charter for health promotion. 1986.

37. Jinks, A., Cotton, A., and Rylance, R., Obesity interventions for people with a learning disability: An integrative literature review. *Journal of Advanced Nursing*, 2010. **67**(3): 460-471.

38. Leon, A., Davis, L., and Kraemer, H., The role and interpretation of pilot studies in clinical research. *Journal of Psychiatry Research*, 2011. **45**(5): 626-629.

39. Government of Canada, *The well-being of Canada's young children*, 2007. 1-62.

40. Stock, S., Charmaine, M., Evans, S., et al., Healthy buddies: A novel, peer-led health promotion program for the prevention of obesity and eating disorders in children in elementary school. *Pediatrics*, 2007. **120**(4): e1059-e1068.

41. Piko, B. and Bak, J., Children's perceptions of health and illness: Images and lay concepts in preadolescence. *Health Education Research*, 2006. **21**(5): 643-653.

42. Best, A., Stokols, D., Green, L., Leischow, S., Holmes, B., and Buchholz, K., An integrative framework for community partnering to translate theory into effective health promotion strategy. *American Journal of Health Promotion*, 2003. **18**(2): 168-176.

43. Buffart, L., Westendorp, T., Erasmus, M., Stam, R., Henk, J., and Roebroeck, M., Perceived barriers to and facilitators of physical activity in young adults with childhood-onset physical disabilities. *Journal of Rehabilitation Medicine*, 2009. **41**(11): 881-885.

44. Kang, M., Zhu, W., Ragan, B.G., and Frogley, M., Exercise barrier severity and perseverance of active youth with physical disabilities. *Rehabilitation Psychology*, 2007. **52**(2): 170-176.

45. Shimmell, L., Gorter, J., Jackson, D., Wright, M., and Galuppi, B., "It's the participation that motivates him": Physical activity experiences of youth with cerebral palsy and their parents. *Physical & Occupational Therapy in Pediatrics*, 2013. **33**(4): 405-420.

46. Fischer, N., Church, P., Lyons, J., and McPherson, A., A qualitative exploration of the experiences of children with spina bifida and their parents around incontinence and social participation. *Child: Care, Health and Development* 2015. **Early online**(23 May 2015).

47. Rimmer, J., The conspicuous absence of people with disabilities in public fitness and recreation facilities: Lack of interest or lack of access? *American Journal of Health Promotion*, 2005. **19**(327- 329).

48. Belon, A.P., Nieuwendyk, L.M., Vallianatos, H., and Nykiforuk, C.I.J., How community environment shapes physical activity: Perceptions revealed through the photovoice method. *Social Science & Medicine*, 2014. **116**: 10-21.

49. Shikako-Thomas, K., Majnemer, A., Law, M., and Lach, L., Determinants of participation in leisure activities in children and youth with cerebral palsy: Systematic review. *Physical & Occupational Therapy in Pediatrics*, 2008. **28**(2): 155-169.

50. King, G., Petrenchik, T., DeWit, D., McDougall, J., Hurley, P., and Law, M., Out-of-school time activity participation profiles of children with physical disabilities: A cluster analysis. *Child: Care, Health and Development*, 2010. **36**(5): 726-741.

51. Kodish, S., Kulinna, P., and Martin, J., Determinants of physical activity in an inclusive setting. *Adapted Physical Activity Quarterly*, 2006. **23**: 390-409.

52. Goodwin, D. and Watkinson, E., Inclusive physical education from the perspective of students with physical disabilities. *Adapted physical activity quarterly*, 2000. **17**(2): 144-160.

53. Hall, H.R., Neely-Barnes, S.L., Graff, J.C., Krcek, T.E., Roberts, R.J., and Hankins, J.S., Parental stress in families of children with a genetic disorder/disability and the resiliency model of family stress, adjustment, and adaptation. *Issues in Comprehensive Pediatric Nursing*, 2012. **35**(1): 24-44.

54. Raina, P., O'Donnell, M., Rosenbaum, P., et al., The health and well-being of caregivers of children with cerebral palsy. *Pediatrics*, 2005. **115**(6): e626-e636.

55. Parish, S. and Cloud, J., Financial well-being of young children with disabilities and their families. *Social Work*, 2006. **51**(3): 223-232.

56. Park, J., Turnbull, A., and Turnbull, H., Impacts of poverty on quality of life in families of children with disabilities. *Exceptional Children*, 2002. **68**(2): 151-170.

57. Centres for Disease and Control and Prevention. *National center on birth defects and developmental disabilities (ncbddd)*. http://www.cdc.gov/ncbddd/index.html (Accessed 12/2/16) 2016.

58. Buffart, L., van der Ploeg, H., Bauman, A., et al., Sports participation in adolescents and young adults with myelomeningocele and its role in total physical activity behavior and fitness. *Journal of Rehabilitation Medicine*, 2008. **40**(9): 702-708.

59. Dodd, K.J., Taylor, N.F., and Graham, H.K., A randomized clinical trial of strength training in young people with cerebral palsy. *Developmental Medicine & Child Neurology*, 2003. **45**(10): 652-657.

60. Murphy, N., Carbone, P., and The Council on Children with Disabilities, Promoting the participation of children with disabilities in sports, recreation and physical activities. *Pediatrics*, 2008. **121**: 1057-1061.

61. Rimmer, J. and Braddock, D. Health promotion for people with physical, cognitive and sensory disabilities: An emerging national priority. *The National Center on Physical Activity and Disability*, 2009.

62. Reinehr, T., Dobe, M., Winkel, K., Schaefer, A., and Hoffmann, D., Obesity in disabled children and adolescents: An overlooked group of patients. *Deutsches Ärzeblatt International*, 2010. **107**(15): 268-275.

63. Minnesota Department of Health, *Children with special health needs: Health promotion*, 2004: St. Paul, Minnesota. 1-4.

64. Wehmeyer, M., A functional model of self-determination: Describing development and implementing instruction. *Focus on Autism and Other Developmental Disabilities*, 1999. **14**(1): 53-62.

65. Abraham, C., Kelly, M., West, R., and Michie, S., The UK National Institute for Health and Clinical Excellence public health guidance on behaviour change: A brief introduction. *Psychology, Health and Medicine*, 2009. **14**(1): 1-8.

66. Grant, A., Autonomy support, relationship satisfaction and goal focus in the coach-coachee relationship: Which best predicts coaching success? *Coaching: An international Journal of Theory, Research and Practice*, 2014. **7**(1): 18-38.

67. Bandura, A., *Self-efficacy*, in *Encyclopedia of Human Behavior*, V. Ramachaudran, Editor. 1994, Academic Press: New York. p. 71-81.

68. Ryan, R. and Deci, E., Self-determination theory and the facilitation of intrinsic motivation, social development and well-being. *American Psychologist*, 2000. **55**(1): 68-78.

69. Spence, G. and Oades, L., Coaching with self-determination in mind: Using theory to advance evidence-based coaching practice. *International Journal of Evidence Based Coaching and Mentoring*, 2011. **9**(2): 37- 55.

70. Rimmer, J., Wang, E., Pellegrini, C., Lullo, C., and Gerber, B., Telehealth weight management intervention for adults with physical disabilities: A randomized controlled trial. *American Journal of Physical Medicine and Rehabilitation*, 2013. **92**: 1084-1094.

71. Paineau, D.L., Beaufils, F., Boulier, A., and et al., Family dietary coaching to improve nutritional intakes and body weight control: A randomized controlled trial. *Archives of Pediatrics & Adolescent Medicine*, 2008. **162**(1): 34-43.

72. Rice, J., Thombs, D., Leach, R., and Rehm, R., Successes and barriers for a youth weight-management program. *Clinical Pediatrics*, 2008. **47**(2): 143-147.

73. Bar-Haim, S., Harries, N., Nammourah, I., et al., Effectiveness of motor learning coaching in children with cerebral palsy: A randomized controlled trial. *Clinical Rehabilitation*, 2010. **24**(11): 1009-1020.

74. Zimmerman, T., Jacobsen, R., MacIntyre, M., and Watson, C., Solution-focused parenting groups: An empirical study. *Journal of Systemic Therapies*, 1996. **14**(4): 12-25.

75. Cockburn, J., Thomas, F., and Cockburn, O., Solution-focused therapy and psychosocial adjustment to orthopedic rehabilitation in a work hardening program. *Journal of Occupational Rehabilitation*, 1997. **7**(2): 97-106.

76. Lindforss, L. and Magnusson, D., Solution-focused therapy in prison. *Contemporary Family Therapy*, 1997. **19**(1): 89-103.

77. Schwellnus, H., King, G., and Thompson, L., Client-centred coaching in the paediatric health professions: A critical scoping review. *Disability and Rehabilitation*, 2015. **37**(15): 1305-1315.

78. Visser, C., Self-determination theory meets solution-focused change: Autonomy, competence and relatedness support in action. *InterAction- The Journal of Solution Focus in Organisations*, 2010. **2**(1): 7-26.

79. Passarelli, A., *The heart of helping: Psychological and physiological effects of contrasting coaching interventions* D. dissertation, Editor 2014, Sase Western Reserve University, Weatherhead School of Management: Ohio.

80. McPherson, A., McAdam, L., Schwellnus, H., et al., *A pilot study using solution-focused coaching for health promotion in children and young people with Duchenne muscular dystrophy*, in *20th International Congress of the World Muscle Society*2015: Brighton, UK.

81. McPherson, A., McAdam, L., Keenan, S., et al., A feasibility study using solution-focused coaching for health promotion in children and young people with Duchenne muscular dystrophy. *Developmental Neurorehabilitation*, Under review.

82. Shanyinde, M., Pickering, R., and Weatherall, M., Questions asked and answered in pilot and feasibility randomized controlled trials. *BMC Medical Research Methodology*, 2011. **11**: 117.

83. Campbell, D. and Stanley, J., *Experimental and quasi-experimental designs for research*. 2015: Ravenio Books.

84. Warburton, D., Jamnik, V., Bredin, S., and Gledhill, N., The physical activity readiness questionnaire for everyone (PAR-Q+) and electronic physical activity readiness medical examination (EPARMED-X+). *The Health & Fitness Journal of Canada*, 2011. **4**(2): 3-17.

85. Arain, M., Campbell, M., Cooper, C., and Lancaster, G., What is a pilot or feasibility study? A review of current practice and editorial policy. *BMC Medical Research Methodology*, 2010. **10**: 67.

86. Billingham, S., Whitehead, A., and Julious, S., An audit of sample sizes for pilot and feasibility trials being undertaken in the united kingdon registered in the united kingdom clinical research network database. *BMC Research Methodology*, 2013. **13**: 104.

87. Patton, M., *Qualitative analysis and interpretation*, in *Qualitative research & evaluation methods*, M. Patton, Editor. 2002, Sage Publications: Thousand Oaks, CA. p. 431-540.

88. Draper, A. and Swift, J., Qualitative research in nutrition and dietetics: Data collection issues. *Journal of Human Nutrition and Dietetics*, 2011. **24**(1): 3-12.

89. McPherson, A., Swift, J., Yung, E., Lyons, J., and Church, P., A retrospective medical record review of overweight and obesity in children with spina bifida. *Disability and Rehabilitation*, 2013. **35**(25): 2123-2131.

90. Health Canada, *Canada's Food Guide*, 2009, Health Canada: http://www.hc-sc.gc.ca/fn-an/food-guide-aliment/index-eng.php.

91. Canadian Society for Exercise Physiology. *Canadian physical activity guidelines*. 2012; Available from: http://files.participaction.com/physicalactivityguidelines/csepguidelinesqa_e.pdf.

92. Kamath, C.C., Vickers, K.S., Ehrlich, A., et al., Behavioral interventions to prevent childhood obesity: A systematic review and metaanalyses of randomized trials. *Journal of Clinical Endocrinology & Metabolism*, 2008. **93**(12): 4606-4615.

93. Fjeldsoe, B., Neuhaus, M., Winkler, E., and Easkin, E., Systematic review of maintenance of behavior change following PA and dietary interventions. *Health Psychology*, 2011. **30**(1): 99-109.

94. Grant, A., The solution-focused inventory: A tripartite taxonomy for teaching, measuring and conceptualising solution-focused approaches to coaching. *The Coaching Psychologist*, 2011. **7**(2): 98-106.

95. Spence, G. and Deci, E., *Self-determination theory within coaching contexts: Supporting motives and goals that promote optimal well-being*, in *Beyond goals: Effective strategies for coaching*

and mentoring, S. David, D. Clutterbuck, and D. Megginson, Editors. 2013, Gower Publishing Limited: Farnham: England. p. 85-108.

96. Poushter, J., *Smartphone ownership and internet usage continues to climb in emerging economies*, Pew Research Center: Global Attitudes & Trends, 2016.

97. Berg, I. and Szabo, P., *Brief Coaching for Lasting Solutions*. 2005, New York: WW Norton and Company, Inc.

98. Lehmann, P. and Patton, J., *The development of a solution-focused fidelity instrument: A pilot study.* , in *Solution-focused brief therapy: A handbook of evidence-based practice*, C. Franklin, et al., Editors. 2012, Oxford University Press, Inc.: New York.

99. Rothwell, P., Factors that can affect the external validity of randomised controlled trials. *PLoS Clinical Trials*, 2006. **1**(1): e9.

100. Wang, C., Yi, W., Tao, Z., and Carovano, K., Photovoice as participatory health promotion strategy. *Health Promotion International*, 1998. **13**: 75-86.

101. Baxter, P. and Jack, S., Qualitative case study methodology: Study design and implementation for novice researchers. *The Qualitative Report*, 2008. **13**(4): 544-559.

102. Croghan, R., Griffin, C., Hunter, J., and Phoenix, A., Young people's constructions of self: Notes on the use and analysis of the photo-elicitation methods. *International Journal of Social Research Methodology*, 2008. **11**(4): 345-356.

103. Clark-Ibáñez, M., *Gender and being "bad" inner-city students' photographs.*, in *Doing visual research with children and young people*, P. Thompson, Editor. 2011, Routledge: Abingdon, Oxon. p. 95-113.

104. Jorgenson, J. and Sullivan, T., Accessing children's perspectives through participatory photo interviews. *Forum: Qualitative Social Research*, 2010. **11**(1): Art. 8.

105. Darbyshire, P., MacDougall, C., and Schiller, W., Multiple methods in qualitative research with children: More insight or just more? *Qualitative Research*, 2005. **5**(4): 417-436.

106. Rose, G., *Visual methodologies: An introduction to the interpretation of visual materials*. 2001, London: Sage.

107. Katzmarzyk, P.T., Barreira, T.V., Broyles, S.T., et al., The international study of childhood obesity, lifestyle and the environment (ISCOLE): Design and methods. *BMC Public Health*, 2013. **13**(1): 1-13.

108. Enright, P.L., The six-minute walk test. *Respiratory Care*, 2003. **48**(8): 783-785.

109. Verschuren, O., Ketelaar, M., De Groot, J., Vila Nova, F., and Takken, T., Reproducibility of two functional field exercise tests for children with cerebral palsy who self-propel a manual wheelchair. *Developmental Medicine & Child Neurology*, 2013. **55**(2): 185-190.

110. Østensjo, S., ØIien, I., and Fallang, B., Goal-oriented rehabilitation of preschoolers with cerebral palsy-a multi-case study of combined use of the Canadian occupational performance measure (COPM) and the goal attainment scaling (GAS). *Developmental Neurorehabilitation*, 2008. **11**(4): 252-259.

111. Hay, J. and Cairney, J., Development of the habitual activity estimation scale for clinical research: A systematic approach. *Pediatric Exercise Science*, 2006. **18**: 193-202.

112. Dufour, S., Lansing, N., Bouyer, L., Moffet, H., Ferland, C., and Maltais, D., The physical activity-related perceptions of youth with cerebral palsy are associated with their physical activity performance and fitness. *Developmental Medicine and Child Neurology*, 2015. **57**(S5): 63-64.

113. Knibbe, T., Church, P., Lyons, J., et al. Health, nutrition, and lifestyle behaviours of children with spina bifida: A feasibility study. in *Bloorview Research Institute Annual Symposium*. 2013. Toronto.

114. National Cancer Institute Dietary screener in the NHANES 2009-10. 2010.

115. Brown, H., Hume, C., and ChinAPaw, M., Validity and reliability of instruments to assess potential mediators of children's physical activity: A systematic review. *Journal of Science and Medicine in Sport*, 2009. **12**(5): 539-548.

116. Saunders, R., Pate, R., Felton, G., et al., Development of questionnaires to measure psychosocial influences on children's physical activity. *Preventive Medicine*, 1997. **26**: 241-247.

117. Neumark-Sztainer, D., Wall, M., Perry, C., and Story, M., Correlates of fruit and vegetable intake among adolescents: Findings from project eat. *Preventive Medicine*, 2003. **37**(3): 198-208.

118. Fitzgerald, A., Heary, C., Kelly, C., Nixon, E., and Shevlin, M., Self-efficacy for healthy eating and peer support for unhealthy eating are associated with adolescents' food intake patterns. *Appetite*, 2013. **63**: 48-58.

119. National Center for Health Statistics, *National Health and Nutrition Examination Survey Anthropometry Manual.*, 2007-2008, U.S. Department of Health and Human Services, Centers for Disease Control and Prevention: Hyattsville, Mariland.

120. Ogden, C. and Carroll, M., *Prevalence of obesity among children and adolescents: United states, trends 1963-1965 through 2007-2008*, 2010.

121. Golan, M., Fifteen years of the family eating and activity habits questionnaire (FEAHQ): An update and review. *Pediatric Obesity*, 2013. **9**: 92-101.

122. Elo, S. and Kyngäs, H., The qualitative content analysis proces. *Journal of Advanced Nursing*, 2007. **62**(1): 107-115.

123. Fade, S. and Swift, J., Qualitative research in nutrition and dietetics: Data analysis issues. *Journal of Human Nutrition and Dietetics*, 2011. **24**(2): 106-114.

124. Bugge, C., Williams, B., Hagen, J., Glazener, C., Pringle, S., and Sinclair, L., A process for decision-making after pilot and feasibility trials (adept): Development following a feasibility study of a complex intervention for pelvic organ prolapse. *Trials*, 2013. **14**(1): 353.

125. Canadian Institutes of Health Research, *Guide to knowledge translation planning at CIHR: Integrated and end-of-grant approaches*, 2012: Ottawa.

126. King, G., Currie, M., & Petersen, P. (2014). Child and parent engagement in the mental health intervention process: A motivational framework. Child and Adolescent Mental Health, 19(1), 2-8. doi:10.1111/camh.12015

127. Shurtleff D, Walker W, Duguay S, Peterson D, Cardenas D. Obesity and Myelomeningocele: anthropometric measures. The Journal of Spinal Cord Medicine. 2010;33(4):410-149.

128 Gauld L, Kappers J, Carlin J, Robertson C. Height prediction from ulna length. Developmental Medicine & Child Neurology. 2004;46:475-80.

129 Goran M. Measurement issues related to studies of childhood obesity: assessment of body composition, body fat distribution, physical activity, and food intake. Pediatrics. 1998;101(505):518.

130. Liu L, Roberts R, Moyer-Mileur L, Samson-Fang L. Determination of body composition in children with cerebral palsy: bioelectrical impedance analysis and anthropometry vs dual-energy X-ray absorptiometry. Journal of the American dietetic Association. 2005;105:974-797.

131. Goran MI, Driscoll P, Johnson R, Nagy TR, Hunter G. Cross-calibration of body-composition techniques against dual-energy X- ray absorptiometry in young children. The American Journal of Clinical Nutrition. 1996;63(3):299-305.

132. Taylor R, Jones I, Williams S, Goulding A. Evaluation of waist circumference, waist-to-hip ratio, and the conicity index as screening tools for high trunk fat mass, as measured by dualenergy X-ray absorptiometry. American Journal of Clinical Nutrition. 2000;72:490-5.

133. Grogan C, Ekvall S. Body Composition of Children with Myelomeningocele, Determined by 40K, Urinary Creatinine and Anthropometric Measures. Journal of the American College of Nutrition. 1999;18(4):316-23.

134. McCarthy HD. Body fat measurements in children as predictors for the metabolic syndrome: focus on waist circumference. Proceedings of the Nutrition Society. 2006;65(04):385-92.

135. Katzmarzyk PT. Waist circumference percentiles for Canadian youth 11-18y of age. European Journal of Clinical Nutrition. 2004;58(7):1011-5.

136. Freedman DS, Katzmarzyk PT, Dietz WH, Srinivasan SR, Berenson GS. Relation of body mass index and skinfold thicknesses to cardiovascular disease risk factors in children: the Bogalusa Heart Study. The American Journal of Clinical Nutrition. 2009;90(1):210-6.

137. Reilly J, Wilson J, Durnin J. Determination of body composition from skinfold thickness: a validation study. Archives of Disease in Childhood. 1995;73:305-10.

138. Slaughter M, Lohman T, Boileau R. Skinfold equations for estimation of body fatness in children and youth. Human Biology. 2011;60:709-23.