CHILD-BRIGHT PROJECT 3.2

BRIGHT COACHING: A DEVELOPMENTAL COACH SYSTEM TO EMPOWER FAMILIES OF PRESCHOOLERS WITH SUSPECTED DEVELOPMENTAL DELAYS

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PATIENT REPRESENTATIVES

- *Costello, Carrie*; Winnipeg Parent
- *Drover, Sarah*; Vancouver Parent
- *Edes, Judy*; Montreal Parent (bilingual)
- *Evans, Rachel*; Winnipeg Parent
- *Geller, Alana*; Montreal Parent
- *Outhouse, Felecia;* Halifax Parent
- *Prupas, Aren*; Montreal Parent
- *Spurway, Amy*; Halifax Parent
- *Young, Amanda;* Vancouver Parent

PROJECT RESEARCH QUESTION

A novel, technology-supported developmental coach service delivery model will be developed and tested. Importantly, the model will be responsive to the knowledge needs of families and service needs of children at high risk for new disabilities. Resulting service delivery models will empower families, will be effective, efficient and scalable across metro, urban and rural settings nationally, and will be associated with cost-savings to the system and patient/family benefits to health and well-being.

Research question: To evaluate the feasibility and the effectiveness (changes in parent health, developmental service utilization and cost-effectiveness) of a self-management intervention (including health coach, online education tools and support network), when compared to usual care in service delivery practices, for parents of preschool children with elevated risk of BDD prior to school entry.

PROJECT DESCRIPTION

RATIONALE

Children with, or at elevated risk for, brain-based developmental disabilities (BDD) experience chronic lifelong functional consequences with new challenges emerging at each stage of development. In the preschool years (3-6 years), needs arise from vulnerabilities linked to critical and newly emerging cognitive, speech, motor, behavioural and social skills [1, 2]. For families, this can be a stressful period as they witness their child's differences and await assistance to organize services and coordinate care, and must consider the best options in preparation for school entry. Nationally and internationally, service delivery models during this critical period are not standardized [3], and differ within and across provinces and across patient conditions, leading to long wait times, service gaps and duplications [4, 5].

Recently, a focus on care coordination (e.g. care planning, navigating healthcare system) has emerged in the literature for those with chronic disease [6]. At the same time, science has emerged demonstrating how patient education programs that promote self-management for those with specific chronic conditions have positive effects on health behaviours, improved health status, and decreased health care costs [7]. Health coaching research to date has, for the most part, focussed on improving motivation and adherence to health behaviours and to support lifestyle change in order to prevent the negative course of a disease [8]. Health coaching is tailored to the patients' knowledge needs, and can be delivered through many means – one to one or via telephone or technology [9].

The preschool years are a time of stress for families as their preschool child awaits assessment, or even as they receive services for brain-based disorders. Similarly, the system and society struggle to meet needs of families in a timely and appropriate manner in the face of escalating costs. Given these struggles, there is need to examine whether a health-coach style of intervention coupled with parent education delivered through an online platform can be effective in empowering families, by delivering information, providing social (parent to parent) supports, and decreasing demand on health and developmental services. This innovation provides a significant service re-design in a system at critical point of transition.

AIMS AND HYPOTHESES

Primary Hypotheses:

(1) A standardized approach to "developmental coaching" (i.e. coach + online education tools + peer support network) is *feasible* in the real-life context and *acceptable* to mothers and fathers and can be delivered across multiple inter-provincial sites that recruit patients from urban/suburban/rural settings.

(2) A standardized approach to "developmental coaching" enhances *parental health* (parents' empowerment and sense of competence, quality of life, and minimizes parenting stress), *family health care experience* (care coordination experience and process of care) at similar *health care cost* (economic analysis), when compared to usual care.

Secondary Hypotheses:

(3) Given the differences that exist in caregiver burden, Fathers will contact the coach and use the online platform less frequently then mothers. *(sex/gender hypothesis)*

(4) Parents will use the online platform most frequently during the expansion of referral ties and contacts in the early phase of transition.

(5) During the course of coaching, families' networks will move from more professional, health services support to more community, educational and peer support.

RESEARCH METHODS

The developmental coach model proposes a partnership with families in the redesign of care that fosters knowledge exchange and a supportive learning environment. The coach will provide knowledge about child development, support to foster parent empowerment and guidance on navigation of the health care system. Web-based tools on healthy development and a peer support network using an online platform (Igloo - see below) complement the coach's role. Participants will be randomized to either our BRIGHT systems model which includes usual care, or usual care alone, and tracked over time. The selected target population represents a group vulnerable to poor access to care and misuse (both overuse and underuse) of specialized developmental services in the preschool years, prior to school entry. This group provide a unique opportunity to understand how to best optimize child and family well-being.

Trial design:

This is a prospective, two-arm pragmatic randomized controlled trial (RCT) comparing a developmental coaching and e-health services intervention plus usual care to the control state in which children and their families receive usual care over an 12-month time frame. The target population for this novel service delivery model is preschoolers at high risk for or suspected of having developmental delays, that are beginning to manifest impairments in developmental domains (e.g. motor, cognitive, speech, social and/or behavioural). In the first year, a technology-supported health coach service delivery model will be developed in conjunction with families. A feasibility/acceptability pilot study will be conducted to ensure that the intervention can be done in the real life context across 4 provinces. Fidelity of the coach will be verified by the master trainers (AM and MO). After modifications to enhance feasibility, the RCT will follow.

Participants:

Eligible children and their families will be recruited to include preschool children 1.5-4.5 years (18 to 54 months) at the age of enrolment, who are not expected to enter school/kindergarten within 6 months of enrolment. Children will be living in four diverse parts of Canada to ensure national representation and future scalability: British Columbia, Manitoba, Nova Scotia, Quebec. Participants' postal codes will be analyzed to ensure representation: rural/remote, small urban and large urban/metro representation with purposeful sampling as required. From the patient population perspective, two different groups that are likely to manifest new global developmental delays at this stage will be recruited. They are at high risk for brain-based developmental delays, however some will have no delay and others will have mild, moderate or severe delays.

Children at risk who are not yet receiving developmental services: Primary care provider and/or parental concerns regarding their child's developmental progress become apparent in the preschool years.

Inconsistent use of screening tools and variation in triage and assessment methods often result in delayed detection and long wait lists for services. Children will be those waiting for their first formal appointment for diagnosis and assessment for “developmental delay”, from a public health facility, a child developmental centre and/or a dedicated hospital clinic. These children represent a group who are not currently receiving developmental services. These children may be found to have no delay, a delay in one domain (e.g. specific language impairment) or global delays, which can be mild to severe. This will be a consecutive sample on the wait list and who are between 1.5-4.5 years of age.

For this trial, children/families will be excluded if they: (1) are non-English speaking (and non-French speaking in sites where services are available in French); (2) are unwilling or unable to meet with the study team for intermittent assessments; (3) do not have access on a routine basis to the internet through a desktop or mobile device. We will recruit 350 subjects, 175 for both intervention and control arms.

<u>Study procedures: Intervention and control</u>

Recruitment will begin with family contact. Each site manages their own recruitment process and protocol. Please see our *Recruitment Protocol* in Montreal (Appendix). Families will be contacted via the centre to which they were referred for developmental diagnosis and assessment. A member of the clinical team will ask if they are interested to learn more about the BRIGHT Coaching study. If interested, the families’ contact information will be shared with the local research assistant (RA) overseeing the trial. The RA will speak to a parent by phone and follow up with an introductory letter by mail and/or email explaining the procedures of the study, together with the consent form. After 1 to 10 days, the RA will call the family to determine interest in participating and answer any questions. If interested in participating, parent can either 1) sign the consent form and scan by email to the RA, 2) send the consent form to the RA by mail/ hand it to them in person, 3) agree to a verbal consent process and verbal consent will be given to the RA over the phone (in accordance with the Tri-Council Policy Statement on verbal consent).Once consent is signed, participants will conduct baseline assessments including documentation of their care and social networks, and be randomized using a computer-generated algorithm; randomization will be stratified by site. The allocation ratio for intervention or control will be 1:1 for each site.

The developmental coaching intervention will be developed in year 1. A coaching consensus workshop took place in Vancouver for August 20, 2016, and focussed on the “key ingredients” for a coach model. This workshop will be followed by team meetings (with relevant stakeholders) in order to develop a standardized manual to include definition of roles and functions and ‘active ingredients’ to successful coaching. A standardized approach to coaching will be developed guided by the participation of families (our parent advisory group) and using the best evidence. The responsibilities of the coach are expected to include: i) helping families identify areas of developmental concerns (e.g. using the checklist of developmental milestones published by Centre of Disease Control & Prevention) , ii) proactive health promotion and guidance with respect to developmental stimulation and skills training to optimize development, iii) parent education about child development consistent with the child’s current strengths and challenges and the parents’ areas of greatest concern, iv) parent support, v) provision of general information regarding the general developmental services that might be of benefit to the child (e.g. seeing an audiologist or neurologist). The coach at each site will have skills in family support, and expertise in child development; but will not be a registered health professional (for real-life generalizability and cost). The coach will possess skills such as motivational interviewing techniques, individual and collaborative goal-setting and shared decision-making. There will be a minimum frequency defined as one telephone contact

2-4 times per month for 45-60 min for each session, and the duration of contact will be 12 months. Instructions for specific coaching situations will be created based on the assumptions that (1) parents have similar self-management skills and needs, (2) parents can develop skills in supporting their child's development and accessing services, (3) confident, knowledgeable parents will support their children in accessing services that are appropriate and utilize fewer health/social resources if they are more supported in determining the direction to which they should go.

The intervention will be provided in a flexible manner, as determined by the parents' needs, circumstances and preferences and the child's developmental condition. Mothers and fathers will both be encouraged to interact with the coach and seek advice and support. The coach will be reachable at least every second day (minimum 4-6 hours per day, 3 days per week); however, calls with families will vary from a minimum of every 4 weeks (ideally every 2 weeks) and will be scheduled at a time convenient for the parent with evening appointments available until 8 pm at least one night per week. Calls will be audiotaped and reviewed by the study team to ensure program quality and reviewed by peer-coaches for self-review and program quality improvement on an iterative basis. Coaches will receive manuals and specific training activities including small group discussions, experiential learning and sharing of best practices among coaches in the trial. A registered health professional (i.e. experienced social worker and family counsellor with expertise in family/ young child counselling) has been hired as a "Coach Lead" to provide training, mentoring and oversight of coach activities.

In addition to the coach, specific evidence-based *educational web content* will be sourced and curated by the project team and relevant stakeholders (conducted in the first year as part of intervention development). Input and feedback from the parent advisory group will further refine and inform the program content. The content will be linked to an online care coordination platform - the *Igloo platform* - which puts each family at the centre of each network (family, friends, health professionals), and then allows each family network to link with other family networks in the intervention arm of the study. This will enable families the opportunity to find and store resources, create connections with the coach, health providers and other families, thereby creating a network of individuals to support them formally and informally. Peer support (among parents in the intervention arm) will be a critical part of this service delivery strategy, enabling parents to share strategies This password-protected website will include credible links to sites based on the family-based needs assessment described above.

For those in the intervention arm, the coach will call within one week of enrolment to provide an overview of the BRIGHT program's goals and content, to enquire about the child's current developmental status. Specific goals with respect to the parents' involvement the BRIGHT Program, reflecting their desired needs, services will be set for the first nine month interval, the first of two.

Control intervention: Children randomized to the control group will receive usual care. They will be contacted at recruitment for baseline information and will be assessed at 8 and 12 months later using the outcome measures outlined below. Upon completion of the study, they will be provided with a one-time interaction with the coach who will provide general guidance regarding their child's development as well as providing them with access to the password-protected site containing the educational web-content and Igloo support platform that they can access.

A pilot study (2 participants per site for a total of 8 participants) will first be conducted to test feasibility of the procedures in the real world setting across the four sites and any challenges will be discussed by the team to find ways to ensure feasibility over a three month period. Parents will be interviewed about the acceptability of the recruitment, the coaching, the educational tools and support network using the Igloo platform. Any challenges will be minimized prior to launching the RCT.

Baseline, ongoing and final data collection and outcome measures:

For all participants, the following attributes will be measured at recruitment to *characterize* the sample: i) child's sex/gender and age, ii) postal code and parents' education (SES, urban/rural), iii) child's developmental and independence score using the Vineland [11] (phone interview), iv) family context (Parenting Stress Index [12], v) developmental services used. Finally, at baseline, families will be contacted by phone and asked a three question screening survey to assess their "readiness" to benefit from the coaching intervention:(1) do you feel that you have been provided with sufficient information about your child's health and development? (no = 1 point); (2) are there things that you would like to change about how your child Is accessing support or services in support of their development? (yes = 1 point); (3) Can you given an example of how you or health providers could help YOU change things for the better with respect to your child's development? (yes = 1 point). In addition, at baseline, care and social support networks will be documented in both arms of the study.

Because this is a pragmatic trial that is meant to be generalized to the real-world context, blinding is not appropriate or possible. In addition, the outcome measures to be used are primarily self-report in nature, again replicating what would be cost-effective and patient oriented in the real-world setting. Outcome measures will be measured at baseline, 8 months post-entry and 12 months post-entry.

The initial primary outcome (Hypothesis 1) relates to the assessment of feasibility and initial acceptability of the protocol implementation. Protocol feasibility will be evaluated with respect to ability to recruit and implement a standardized approach to coaching and use of the platform across the four diverse sites. The feasibility and acceptability of the intervention will be evaluated by: percent of successful virtual visits with the coach (defined as the ability to connect with family at home via telephone or e-health tool); participants' utilization of Igloo-based online education; parental (mother AND father, if both involved, or other caregiver, as appropriate) satisfaction surveys; and, feedback from the coaches.

Once past the feasibility stage, outcomes will be measured at 8 months and 12 months after recruitment. The primary outcome of interest in the RCT is the *parents' ability to self-manage and promote their child's development*. Thus, the primary outcome measure is the Family Empowerment Scale, which focuses on empowerment at the family (managing the day to day), services (working with system to receive adequate services) and community (finding or advocating for needed supports, policies, agencies) levels [13]. Its psychometric properties are acceptable. A second measure will be the Parents' Sense of Competence Scale which measures satisfaction (anxiety, motivation, frustration) and efficacy (capability, problem-solving) with parental roles [14].

Secondary measures of intervention efficacy apply the Triple Aim Framework and will include:

1. Parental well-being: SF-36 [15] (quality of life) and the Parenting Stress Index [12] (parent stress level).

2. Family health care experience: Measure of Process of Care [16] (the extent to which care is family-centred)

3. Health care costs/ service utilization patterns: the Resource Utilization Questionnaire (adapted from Drs. Ungar and Zwicker) uses standardized metrics for the evaluation of costs (health care and out-of-pocket), consequences and benefits from the patient, provider and health system perspectives.

4. Care and social networks: Care and social networks will be tracked using Igloo analytics. This will include tracking during the transition from preschool to school-aged services and the identification of professional and community supports.

5. Engagement of mothers and fathers with BRIGHT program: Analysis of electronic contact data from Igloo platform by mothers and fathers (gender).

Exploratory measures will include:

Child's functional abilities and independence: Vineland – daily living skills, socialization, etc .. Importantly, in the spring of 2017, an online "needs assessment" survey was conducted with Canadian families to influence the content of the coach intervention and to determine the outcomes of greatest interest to families and administrators.

Additional Qualitative study regarding acceptability of the BRIGHT program: At study completion, to better appreciate the patients/families' experience with the BRIGHT model, we will conduct exit interviews on those in the intervention group. Key ingredients to the intervention (what they most appreciated/valued) and the factors that influenced (positively and negatively) the success of the intervention will be probed. The responses will be coded using qualitative analysis software and analysis will be conducted to determine major themes. In addition, exit interviews with the coaches will similarly be completed to determine the feasibility of the intervention from their perspective.

Data collection and management:

Each of the four sites will have a part-time RA, with a Study Coordinator at the Montreal site. The Coordinator will organize regular teleconferences with the RAs to trouble shoot any challenges in recruitment or data collection, and will ensure standardization of procedures. There will be a data sharing agreement signed by the four sites, with a common REDCap database for all to use for data entry. The password-protected database will have personal information de-identified and a separate list will be kept of participants (child, parents) names, birth date of the child, and address/email. The Study Coordinator will have oversight of the database and ensure that there are no missing values.

Timeline:

Year 1: Develop coach manual and training; develop online educational tools and customize Igloo platform. *Year 2*: Pilot study; finalize methods and measures; begin recruitment. *Year 3*: Complete recruitment; 8 month outcome evaluation for early participants. *Year 4*: Complete 12 month intervention and outcomes. *Year 5*: statistical analyses; qualitative interview analysis; manuscript preparation; KT plan to include policy brief.

Statistical analyses:

Descriptive statistics will be used to characterize our sample in the experimental and control arms. The primary analysis is to ascertain benefit of the BRIGHT system (Coach + online education tools + online peer support) compared to usual care (control) will be between group (intervention vs control) comparison of primary and secondary outcomes using t tests (two-sided, p<.05). Statistical comparisons will be made at 8- and 12- months post enrolment, to determine if group differences manifest early and if they continue to improve or stabilize. This will be important in determining whether the BRIGHT system is necessary over a prolonged period (8 vs 12 months) to achieve its goals. Principles of intent-to-treat analysis will be applied. Repeated measures with mixed model analysis will be used to assess effect of group category and province with intervention at two time points. Within the intervention group, predictors of change scores between baseline and outcomes (dependent variable) will be tested to determine which children/families are more likely to be responsive to the BRIGHT system. Multivariate linear regressions will be conducted with independent variables, to include: parent readiness score, sociodemographic factors, child's functioning (Vineland), province, and engagement in the Igloo platform. The structural properties of the network (Igloo) will be analysed using UCINET [17]. Network analysis related to patterns of use of the online platform will be correlated with the outcome measures of interest in this study.

Sample size:
We will recruit 392 participants; we project a sample size of 352 based on: i) two-sided test of the null hypothesis at $\alpha=.05$, ii) $\beta=.80$, iii) 10% attrition; iv) difference of 0.3 SD.

Studies as of yet have not identified a minimal clinically important difference (MCID) for our primary outcome measure (the Family Empowerment Scale) that could be used to estimate sample size calculation. In the absence of a "clinimetric" MCID, a distribution-based methods approach is commonly applied that proposes a fraction of the pooled Standard Deviation (i.e. utilize effect size estimates). In this case, the difference of 0.3 standard deviation can be used to detect modest effects that may be clinically significant; or 0.5 SD for moderate to large effects [18, 19].

We aim to recruit a sample of 350 participants (randomized to either intervention or control group) across the four sites. This will be approximately 100 from British Columbia, 100 from Quebec, 75 from Manitoba and 75 from Nova Scotia. In order to be able to detect modest effects that may be clinically important (0.3 SD), this would require recruitment of a sample of 392, accounting for 10% attrition, for a sample of 352. Furthermore, this larger sample size would enable us to account for cluster randomization. We expect that all participants are independent, whether or not they live in any of the provinces. Nonetheless, it is conceivable that the association within provinces is slightly stronger (weak ICC=0.100) than the association between participants across provinces, due to environmental context (i.e. different health care and social service systems). A sample size of 346 (recruit 384, 10% attrition) would allow us to account for cluster randomization. We will apply a linear mixed model to account for the possible effect of province on the benefits of treatment on empowerment and parent competency.

PLANS FOR KNOWLEDGE TRANSLATION

The results of this study will be relevant to families, health service administrators, policy makers and providers.

Families: Families will be important consumers of the results of this study. In order to determine how best to communicate the results to them, a focus group of families will be brought together. They will guide strategy and tactics with respect to the study results. The content for this knowledge translation will be particularly focussed on the benefits and challenges from the perspective of families. With respect to tactics, it is anticipated that family councils, childhood-disability focussed organizations, the media, family-guided web-based materials and providers will be modalities undertaken to reach families. This plan will be modified subsequent to the focus group with families after the conclusion of the study.

Policy-makers and health/social service administrators*:* This audience will be a critical audience given the wait-lists and waiting times for developmental services that parents experience. The content for this audience will focus on the nature of the intervention, the key ingredients that showed success, the cost-utility analysis. With respect to tactics, a policy dialogue will be hosted in year 5 and policy options for implementation will be constructed. A policy paper with associated briefing notes (generic), which can be tailored to each province and their relevant ministries, will be created.

Providers: Providers will be interested in these results. The focus with respect to content for this audience is on the effectiveness of the intervention and its relation to "usual care". Tactics will include peer-reviewed articles and presentation at local, provincial, and national meetings will be undertaken.

PLANS FOR TRAINING

The British Columbia and Quebec recruitment sites have funding to support a doctoral or postdoctoral trainee throughout the duration of the project. The trainees will have the opportunity to expand their knowledge and expertise in health services research, network analyses, family engagement and pragmatic randomized trials. In addition, the trainees will be expected to participate in CHILD-BRIGHT's patient-oriented training program.

The investigators of our 'BRIGHT Coaching system' study will be working collaboratively with investigators from other projects (theme 3 projects, Strongest Families in theme 2) that are applying a coach model to develop a manual. This handbook will describe health coach frameworks and key ingredients of success (from the literature), and define the coach's roles and responsibilities and provide case examples to further clarify this service delivery approach. Our team will work with the other teams to develop training modules on the coach model, for the benefit of particular stakeholder groups that would be interested in learning more about this model of care. These modules will be tailored to the user (i.e. parents, clinicians, policymakers and health administrators) to promote greater understanding of the benefits and challenges. There will be an interactive component to enable stakeholders across groups to discuss the potential applications of a coach model to support children with disabilities and their families across key transition points of care.

IMPLICATIONS FOR CHILD AND FAMILY WELL BEING - PRACTICE AND POLICY

The preschool years between 3 and 6 years of age are a time of great developmental change and a time of great concern for parents who see differences in their child's development. Coordination of services, for those children receiving them can be challenging and confusing. Waiting for services for those not yet receiving them can lead to frustration and fear. From a policy and health/social system administrator perspective, despite large investments, waiting lists often exist.

At the conclusion of this study, should the hypotheses be proven to be correct, the following impact will be seen for the following groups:

- *Families:* This study will produce an evidence-based mechanism to support families during times of uncertainty. It will be effective across developmental severity levels making it very generalizable. It will enable families in feeling supported, will enhance family empowerment, will support enhanced family well-being. With guidance regarding services, it is expected that there will be reduced travel time and time off work for families, thereby reducing costs to families.
- *Policy makers and health administrators*: The results and KT products will provide mechanisms to facilitate discussion regarding how the program is delivered regionally. It is anticipated that the program and its key ingredients could be delivered through multiple means, allowing governments to tailor its use to reflect their provincial, regional and local nuances.
- *Service Delivery/Developmental Programs:* The draw on services across provinces will be reduced as families receive information that prevents them from being in the incorrect queue for services and assists them in coordinating their own services as has been done with other self-management programs in adults with chronic disease. Rural and remote service delivery will be enhanced through this care, which can be delivered from a distance.

TABLE 1. MILESTONES, DELIVERABLES

Major Project Activities/ Milestones	Year 1 (M)ilestones	Year 2 (M)ilestones	Year 3 (M)ilestones/ (D)eliverable	Year 4 (M)ilestones/ (D)eliverable	Year 5 (M)ilestones/ (D)eliverable
Clinical study protocol and ethics review	(D) Protocol finalized with family input (D) Ethics approves finalized protocol across sites				
Clinical procedures – Coaching intervention	(M) Families actively engaged in development of coaching intervention (M) Coaching procedures co-developed across relevant CHILD-BRIGHT projects (D)Coaching procedure finalized and manualized	(M) Coaching intervention pilot study for feasibility (D) Revised coaching manual post- pilot	(M) Coaching intervention being utilized	(M) Coaching intervention used and ceased with end of study period	(D) Coaching intervention results analyzed and presented
Recruitment	(M) Recruitment strategy plan for each site	(M) Recruitment strategy piloted	(M) Recruitment strategy used (D) Recruitment completed		
Educational tools	(M) Families and health providers collaborate to confirm foci for educational tools (D) Educational tools for e-health platform curated	(M) Educational tools on online education platform piloted in pilot study (M) Revisions to educational tools made based on pilot	(M) Online education tools used in intervention	(M) Online education tools used and use ceased at end of study period	(D) Evaluation of value of tools completed
Igloo online platform	(M) Families and health providers engaged with	(M) Customized platform trialed among parent	(M) Platform utilized by study sample		(D) Evaluation of value of

	customizing platform	advisory group, and potentially in pilot (D) Igloo platform finalized			platform completed
Data collection, measures and analysis	(M) Finalize tools and measures to be used with family engagement	(M) Baseline measures piloted	(M) Baseline and 8-month measures (child, family, network) collected	(M) 12-month measures collected and (D) completed (M) Plan network analysis	(M) Qualitative interviews completed (D) Analysis of all data in relation to hypotheses (D) Network analysis completed
Knowledge translation				(M) Scale up work with families regarding KT (M) Plan interactions with policy makers regarding KT (M) Project plan regarding clinicians and KT	(D) Carry out KT plan with families (D) Hold KT forum and complete policy briefs for policy makers (D) Complete clinician documents (D) Manuscripts complete

Anticipated Outcomes:	• **Parents** will be more empowered and knowledgeable, and make more informed decisions about their child's care and development • **Services** accessed will be appropriate based on the child's and family's needs and developmental services will be more cost-effective • **Providers** will feel confident that their clients are receiving appropriate services and supports based on client needs
Anticipated Impacts:	A more responsive health care system that meets the developmental needs of children and the health and knowledge needs of parents. The electronic platform (Igloo) will be tested with respect to its utility as an information and support network, for consideration for other chronic diseases of childhood.

	Research trainees will be well prepared to pursue future child health research with a strong inclusion of families and their support networks.

TABLE 2. SUMMARY OF MAIN PREDICTOR AND OUTCOME MEASURES

VARIABLES	**MEASURE**
PRIMARY PREDICTOR	
Intervention versus control group	Randomization to one group
Other Key Variables	
Child's age	Age at recruitment in months to one decimal place
Child's sex	Male/female
Parental involvement in the intervention	Mother vs father; # of uses of Igloo platform (areas: coach, online education tools, peer support)
Socioeconomic factors	Parents' education level, postal code
Readiness for health coach model	Readiness for coaching questionnaire (3-points)

OUTCOMES	
PRIMARY	
Empowerment (ability to manage and take charge) at the family, services and community levels	Family Empowerment Scale
Parental satisfaction and efficacy with competency	Parents Sense of Competence Scale
SECONDARY	
Family stress level	Parenting Stress Index
Parental well-being (quality of life)	SF-36
Family-centered care provided by coach to include educational benefits	Measure of Process of Care

Health service utilization and costs	Resource Utilization Questionnaire (adapted from Ungar and Zwicker)
Profile Form	Surveys on background of participant & family structure
Demographic Form	Survey on family socioeconomic status and education level
Child's functional abilities	Vineland
Survey on parent/caregiver mental health	Parenting Morale Index

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