

Acceptance and Commitment Training for Family Caregivers of People with Neurodevelopmental Disabilities: Protocol for a Collaborative Implementation Study

Kenneth Fung, Yona Lunskey, Kendra Thomson, Lee Steel, Soumya Mishra, Jodie Siu, Nicole Bobbette, Jonathan Weiss, Melanie Penner, Ullanda Niel, Dorothee Chopamba, Sheila Phillips, Johanna LAke

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Table of Contents

Original Manuscript..... 5
Supplementary Files..... 21
 Multimedia Appendixes 22
 Multimedia Appendix 0..... 22



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Abstract

Background: Family caregivers of individuals with neurodevelopmental disabilities (NDDs) experience high levels of stress, anxiety, and depression, yet few interventions are designed to improve their mental well-being. Additionally, most evidence-based interventions do not actively involve caregivers as peer facilitators.

Objective: To address this gap, we developed an Acceptance and Commitment Training (ACT) group intervention co-facilitated by trained caregivers and clinicians. This study evaluates the real-world implementation of this innovative, evidence-based ACT intervention aimed at enhancing caregiver mental health and resilience.

Methods: Guided by the RE-AIM implementation science framework, this study examines the intervention's reach, effectiveness, adoption, implementation, and maintenance. ACT workshops were delivered both virtually and in-person across 12 intervention sites in Canada. Caregivers participated in pre-, post-, and 3-month follow-up assessments measuring stress, resilience, and self-compassion using validated instruments (DASS-21, PSI-4 SF, BFDS, MSMR-I, SCS-SF), alongside ACT process measures (CFQ, VLQ, AAQ-II). Implementation fidelity was assessed through checklists, feedback forms, and reflective memos. Additionally, focus groups with caregiver facilitators, clinician facilitators, workshop participants, and organizational leaders provided qualitative insights into the implementation process and the caregiver-clinician co-facilitation model.

Results: The ACT intervention has reached (n=195) caregivers of individuals with NDDs. A total of two focus groups have been conducted, including 5 caregivers, 13 facilitators, and 5 organizational leaders. Preliminary qualitative feedback suggests that participants experienced meaningful benefits from the intervention, while facilitators and agencies expressed enthusiasm for its impact, despite implementation challenges. Quantitative and qualitative data analysis is underway.

Conclusions: Preliminary feedback indicates that this ACT intervention is a promising approach to enhancing the mental well-being and resilience of caregivers of individuals with NDDs. The RE-AIM framework has been instrumental in systematically capturing process data and documenting the balance between fidelity and adaptation. Further analysis will refine implementation strategies and support the broader scalability of the intervention to diverse community settings Clinical Trial: NA

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Original Manuscript

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Abstract

Background

Family caregivers of individuals with neurodevelopmental disabilities (NDDs) experience high levels of stress, anxiety, and depression, yet few interventions are designed to improve their mental well-being. Additionally, most evidence-based interventions do not actively involve caregivers as peer facilitators. To address this gap, we developed an Acceptance and Commitment Training (ACT) group intervention co-facilitated by trained caregivers and clinicians. This study evaluates the real-world implementation of this innovative, evidence-based ACT intervention aimed at enhancing caregiver mental health and resilience.

Methods

Guided by the RE-AIM implementation science framework, this study examines the intervention's reach, effectiveness, adoption, implementation, and maintenance. ACT workshops were delivered both virtually and in-person across 12 intervention sites in Canada. Caregivers participated in pre-, post-, and 3-month follow-up assessments measuring stress, resilience, and self-compassion using validated instruments (DASS-21, PSI-4 SF, BFDS, MSMR-I, SCS-SF), alongside ACT process measures (CFQ, VLQ, AAQ-II). Implementation fidelity was assessed through checklists, feedback forms, and reflective memos. Additionally, focus groups with caregiver facilitators, clinician facilitators, workshop participants, and organizational leaders provided qualitative insights into the implementation process and the caregiver-clinician co-facilitation model.

Results

The ACT intervention has reached (n=195) caregivers of individuals with NDDs. A total of two focus groups have been conducted, including 5 caregivers, 13 facilitators, and 5 organizational leaders. Preliminary qualitative feedback suggests that participants experienced meaningful benefits from the intervention, while facilitators and agencies expressed enthusiasm for its impact, despite implementation challenges. Quantitative and qualitative data analysis is underway.

Conclusion

Preliminary feedback indicates that this ACT intervention is a promising approach to enhancing the mental well-being and resilience of caregivers of individuals with NDDs. The RE-AIM framework has been instrumental in systematically capturing process data and documenting the balance between fidelity and adaptation. Further analysis will refine implementation strategies and support the broader scalability of the intervention to diverse community settings.

Keywords: Acceptance and Commitment Training, caregivers, NDD, peer facilitation, implementation science, adaptation, equity

Introduction

Family caregivers (hereinafter referred to as caregivers) of individuals with neurodevelopmental disabilities (NDDs) report higher levels of stress, anxiety, and depression than other caregivers [1-3]. The COVID-19 pandemic has exacerbated this, as caregivers have had to suddenly navigate the loss of structure, support, and routine for their loved ones with NDDs [4]. Furthermore, few mental health interventions are available to caregivers of individuals with NDDs, and of those that do exist, many are restricted by specific age or disability of the individual being cared for, or are available only in certain regions where there is more extensive expertise [5,6]. Finding ways to build community capacity to support the mental health of caregivers of individuals with NDDs is critical during the pandemic and beyond, and to do this effectively requires close collaboration between caregivers and clinicians [7].

Caregiver interventions help support the caregiver and, by extension, the entire family, including the child with a disability. While caregivers may benefit from individual support, they can experience additional benefits with caregiver group interventions, addressing feelings of isolation and providing opportunities for personal growth, connection, and mutual learning [8,9]. Traditionally, evidence-based interventions for caregivers, including mindfulness and acceptance-based therapies, are delivered solely by trained clinicians [10,11]. However, there is growing evidence that family caregivers can also play a vital role as peer co-facilitators in enhancing the success of these evidence-based interventions [12].

To support parents of children with autism, early evidence demonstrated the beneficial use of Acceptance and Commitment Training (ACT), a mindfulness-based intervention [13], as well as a study demonstrating the engagement of mothers as peer mentors in delivering a mindfulness-based intervention [14]. Based on our previous work employing ACT in non-clinical populations to promote well-being and address issues related to stigmatizing attitudes, we have adapted a two-day in-person group-based ACT intervention for caregivers of children with autism to increase their resilience in the face of stressors, co-delivered by caregivers and clinicians together [15,16].

Early efficacy research demonstrated that our in-person ACT intervention was effective in reducing stress, depression, physical health concerns, and social isolation in mothers of autistic children and youth [17]. Additionally, the intervention helped these caregivers detach from their distressing thoughts and act in ways that were more consistent with their values [15]. In a follow-up randomized controlled trial, caregivers of autistic individuals who participated in the workshop showed significant improvements in symptoms of depression and family distress relative to a waitlist control group, as well as significant treatment group improvements in stress, psychological acceptance, and cognitive fusion, which were not found for the waitlist group [18]. Workshop respondents reported that a key element to the success of the workshops was the caregiver-clinician partnership. We have also begun to explore the use of our intervention for caregivers of other NDDs [19], such as individuals with fetal alcohol spectrum disorder (FASD) [20]. With the onset of the pandemic, we adapted our in-person group intervention into a virtual group intervention. In addition to meeting social distancing restrictions during the pandemic, we aim to address access barriers such as lack of childcare, distance from services, and transportation costs.

Research Objectives

The aim of this study is to evaluate the implementation of our ACT intervention designed to enhance the mental health and resilience of caregivers of individuals with NDDs, co-delivered by caregiver-

clinician facilitation teams. Our research objectives and questions are:

1. *Evaluate the implementation of a caregiver and clinician-partnered ACT intervention delivered in communities across Canada to support the mental health and resilience of caregivers of individuals with NDDs.*

a. Is it feasible to recruit caregiver participants across study sites, and what proportion of participants complete the intervention?

b. Does the intervention lead to enhanced mental health and resilience in participants, and is this change maintained at follow-up?

c. What demographic, clinical, and organizational variables predict or moderate change, for example, whether the intervention is delivered to a mixed or homogeneous disability caregiver group, delivered in-person or virtually, or to caregivers of children or young adults?

d. How is the intervention perceived by various stakeholders, including participants, clinician facilitators, caregiver facilitators, and organizational leaders?

e. What adaptations become necessary as the intervention is implemented in various real-world settings?

f. What is the long-term sustainability of the intervention program in terms of its resource use, time, and potential for wide-scale adoption?

2. *Evaluate the unique collaboration between caregivers and clinicians co-delivering the intervention.*

a. What are the facilitators and barriers to successful caregiver-clinician collaborations with regards to facilitator training and intervention delivery?

b. What is the value of this collaboration from various stakeholders' perspectives, including participants, clinician facilitators, caregiver facilitators, organizational leaders, and the research team?

Methods

Implementation Science Framework: RE-AIM

The study was guided by the Reach, Effectiveness/Efficacy, Adoption, Implementation, and Maintenance (RE-AIM) implementation science framework [21], providing an overarching structure to examine the processes and outcomes of the real-world implementation of evidence-based health interventions in five areas: reach, efficacy, adoption, implementation, and maintenance. *Reach* is a measure of participation at the individual level, such as the number or characteristics of program participants. *Effectiveness* includes an assessment of positive and negative outcomes of the program. *Adoption* examines the uptake at the organizational level. *Implementation* examines the degree to which the program is conducted as intended in various real-world settings. *Maintenance* evaluates the extent to which the program impact is enduring at individual and organizational levels. We will also use the Practice Profile Planning Tool [22] to guide our identification of the essential components of our intervention model, including practice variation.

Intervention Description

Our intervention is a group intervention based on Acceptance and Commitment Training (ACT), which aims to increase psychological flexibility through training in six core processes: defusion (relating to thoughts as merely thoughts), acceptance (willingness to experience thoughts and feelings rather than avoiding them), contact with the present moment (being in touch with the here and now rather than being stuck in the past or worrying about the future), self-as-context (being in contact with a transcendent sense of self rather than being stuck with self-labels), values (clarifying what gives life value and meaning), and committed action (persisting in value-guided actions). The intervention consists of experiential exercises, mindfulness practices, and small and large group reflective sharing [23].

Groups are guided by trained co-facilitators, including at least one clinician with experience in the NDD community and at least one family caregiver of an individual with an NDD. Each group can accommodate 12–15 participants. For in-person delivery, the workshop is delivered over two consecutive sessions, an evening session (3 hours) and a full-day session (8 hours), followed by a final evening session (3 hours) one month later (see Table 1). For virtual delivery, the workshop is conducted over four consecutive weekly 2-hour sessions, with a fifth 2-hour session occurring one month later.

[Insert Table 1 here]

Methods

Project Description

The proposed project was conducted in three overlapping phases.

Phase I: Preparation and Contextualization

In this initial phase, research ethics and institutional approvals were obtained. Community partner organizations and family advisors were engaged to refine the implementation process. Site-specific discussions helped identify local needs and preferences, including in-person versus virtual delivery and whether to offer mixed or homogeneous caregiver groups (e.g., caregivers of individuals with autism, FASD, Down syndrome, or spina bifida). A core implementation protocol and fidelity checklist were developed to evaluate adherence and document adaptations. Each site completed a Health Equity Impact Assessment (HEIA) [24] to identify access barriers. Facilitator teams—composed of experienced caregivers and clinicians—were trained and supported based on the specific needs of each site.

Phase II: Implementation

From 2022 to 2024, we partnered with community agencies to deliver up to two ACT workshops per agency, with each workshop targeting 10–15 caregiver participants. These were conducted in two waves (6–9 months apart) to allow learnings from the first wave to inform the second and ensure adequate recruitment time.

Experienced peer facilitator leaders provided virtual coaching to local facilitation teams. After each ACT session, facilitators completed fidelity checklists and field notes describing how well exercises worked and any ad hoc adaptations. Post-workshop, facilitators wrote reflective memos [25]

detailing their experiences in delivering the intervention, the support they received, and reflections on caregiver-clinician collaboration. Family leaders also submitted reflective memos about their coaching experiences.

To evaluate effectiveness, caregiver participants completed electronic surveys at three timepoints: pre-intervention (T1), post-intervention (T2), and 3-month follow-up (T3). The survey included demographic, outcome, and ACT process measures.

1. Demographic Measures:

- Parent age, ethnicity, education, family composition
- Negative life events (e.g., family illness, job loss)
- Child's NDD diagnosis, time since diagnosis, age, and living situation

2. Outcome Measures:

- *Depression, Anxiety and Stress Scale (DASS-21)*: 21-item measure of depression, anxiety, and stress [26]
- *Parenting Stress Index, 4th Edition (PSI-4)*: 11 items from Health & Isolation subscales to assess stress specific to parenting [27]
- *Brief Family Distress Scale (BFDS)*: Single-item 10-point scale for family distress [28]
- *Multi-System Model of Resilience Inventory (MSMR-I)*: 27-item scale assessing internal, external, and mediating resilience factors [29]
- *Self-Compassion Scale—Short Form (SCS-SF)*: 12-item measure of self-compassion [30]

3. ACT Process Measures:

- *Cognitive Fusion Questionnaire (CFQ)*: 7-item scale assessing cognitive fusion, the degree to which individuals become entangled with their thoughts [31]
- *Valued Living Questionnaire (VLQ)*: 10-item two-part tool evaluating value importance and alignment [32]
- *Acceptance and Action Questionnaire II (AAQ-II)*: 7-item scale measuring psychological flexibility, the main target of ACT [33]

Following completion of the intervention, workshop participants were asked survey questions that measured how satisfied they were with the ACT program. Questions addressed the workshop content (how easy it was to understand, how relevant it was to their family, how interesting it was, whether it contained new information), how much the workshop addressed goals important to them, whether it provided skills that could be used in everyday life, the perceived value of having caregivers and clinicians co-lead the workshop, and how much the participants felt supported and valued throughout the workshop. Responses were provided on a five-point Likert-type scale, ranging from Strongly

Disagree (1) to Strongly Agree (5).

In addition, we conducted focus groups with caregivers, facilitators, and organizational leaders to explore perceptions of the intervention and caregiver-clinician collaboration.

Phase III: Data Analysis and Knowledge Translation

In this final phase, we are analyzing quantitative and qualitative data. We have hosted two virtual forums for our facilitation teams to share their experiences in the study. Lessons learned, particularly technical ACT-related facilitation tips, have been compiled into an implementation toolkit based on shared insights from facilitators and coaches. When we complete the analysis of study outcomes and implementation data, we will publish and disseminate findings to inform future intervention development and policy recommendations.

Project Evaluation Plan

The project is evaluated using a mixed-methods design to address the two primary research questions.

1. Evaluation of ACT Intervention Implementation Using RE-AIM

[Insert Table 2 here]

2. Evaluation of Caregiver–Clinician Collaboration

[Insert Table 3 here]

Statistical Analysis

Quantitative Analysis

To evaluate changes over time in outcome and process measures, we will use *mixed-effects modeling*, which accounts for repeated measures within individuals and variation across study sites. This approach also allows examination of potential predictors and moderators (e.g., type of delivery modality, group composition, demographic variables). We will conduct subgroup analyses stratified by gender identity, age, racial/ethnic identity, and living situation. We will explore how these factors relate to baseline characteristics and intervention response. Additionally, we will examine how gender interacts with other sociodemographic factors to influence caregiver mental health outcomes, using both quantitative and qualitative data. Missing data will be handled according to an *intention-to-treat (ITT)* principle, with *multiple imputation* conducted using SPSS. All demographic variables, baseline outcome scores, and variables in the analysis model will be used as predictors during imputation.

Qualitative Analysis

All qualitative data (focus groups, reflective memos, survey open-ended responses, meeting notes) will be analyzed using *thematic analysis* [34], following an inductive, six-step process: 1. Familiarization with the data, 2. Generating initial codes, 3. Searching for themes, 4. Reviewing themes, 5. Defining and naming themes, and 6. Producing the report. This approach allows for reduction of large qualitative datasets into meaningful themes while maintaining interpretive

flexibility.

Mixed Methods Integration

Findings from both quantitative and qualitative analyses will be triangulated to provide a comprehensive understanding of the implementation and outcomes of the ACT intervention and caregiver–clinician collaboration. This includes a *Sex and Gender-Based Analysis Plus (SGBA+)* lens to enhance the relevance of findings for diverse caregiver populations.

Results

At present, data collection has been completed and analysis is underway based on the protocol outlined above. Our ACT intervention reached a total of $n=195$ caregivers of individuals with NDDs. Two focus groups were conducted, comprising 5 caregivers, 13 facilitators, and 5 organizational leaders.

Preliminary feedback from qualitative satisfaction surveys indicated that many participants reported benefits from the intervention, and both facilitators and agencies reported enthusiasm about its benefits. We are currently conducting formal qualitative analysis of focus group transcripts, reflective memos, and survey comments. Quantitative outcome data will be analyzed from the pre-, post-, and 3-month follow-up surveys. These analyses will identify sociodemographic and process variables that moderate or mediate outcomes, helping to clarify mechanisms contributing to improvements in psychological flexibility and resilience.

Evaluation of implementation processes using the RE-AIM framework will further illuminate factors related to feasibility, acceptability, fidelity, adaptations, and resource utilization. These insights will help guide broader adoption of the ACT intervention model across community settings.

Discussion

This study evaluates the real-world implementation of a caregiver–clinician co-facilitated ACT intervention across community agencies in Canada. It addresses an important gap in caregiver mental health support—one that has become more urgent during the COVID-19 pandemic.

By using the RE-AIM framework and a mixed-methods approach, this study contributes evidence on both the effectiveness and the implementation processes of ACT-based interventions for caregivers of individuals with NDDs. In particular, it explores new models of co-facilitation that empower caregivers as leaders in intervention delivery, potentially increasing engagement, relevance, and sustainability.

Through the course of implementation, several noteworthy insights and challenges emerged. The inclusion of the Health Equity Impact Assessment (HEIA) during Phase I was a valuable exercise in identifying equity and access barriers. However, limitations in resources at participating sites restricted the ability to address all barriers identified—such as language accessibility for Francophone communities. This highlights the importance of implementation science in surfacing real-world challenges, while also pointing to the need for ongoing resource allocation and policy development to ensure equitable access.

Engaging caregivers as co-facilitators introduced important policy and logistical questions—such as appropriate compensation, training requirements, and support needs—that were addressed

collaboratively with our community partners. This model of partnership-based facilitation is still relatively new in caregiver mental health interventions and requires thoughtful infrastructure to support its success.

Our findings will not only inform future iterations of the ACT intervention, but also guide best practices in scaling caregiver mental health programs, especially in virtual and hybrid formats. Understanding factors that facilitate or hinder implementation—including caregiver involvement—will be critical to ensuring the long-term sustainability and equitable reach of such interventions.

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Conflict of Interest

The authors have none to disclose

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Table 1. Overview of ACT Content Across Delivery Modalities

	5-session virtual intervention 2 hours per session)	3-session in-person intervention half-day (3 hr); full-day (8 hr); half-day (3 hr)
Session 1	Overview of ACT (e.g., overview of the hexaflex and hand gestures) and contact with the present moment exercises (e.g., meditation with object)	Overview of ACT (e.g., overview of the hexaflex and hand gestures), introduction to mindfulness (e.g., leaves on a stream)
Session 2	Acceptance exercises (e.g., leaves on a stream, keeping the count)	Acceptance exercises (e.g., sweet spot); defusion exercises (e.g, paired sharing, chair sculpture); values exercises (e.g., values wordlist, 100th birthday); and committed action exercises (e.g., bull's eye, bus driver)
Session 3	Defusion exercises (e.g., elephant in the room, our song)	Self-as context exercises (e.g., LE'GO) and review of ACT model (e.g., matrix)
Session 4	Values exercises (e.g., values wordlist, 100th birthday) and committed action exercises (e.g., bull's eye, fireside chat)	
Session 5	Self-as-context exercises (e.g., who I am) and review of ACT model (e.g., matrix)	

*see Fung et al., 2021 for more detail on intervention content

Table 2. Implementation Process Evaluation

<i>RE-AIM Dimensions</i>	<i>Evaluation Indicators</i>
Reach	● # expressing interest; # recruited; # completers, % of completers / agency client volume / estimated eligible populations ● Sociodemographic and other participant characteristics (e.g., type of NDD) comparisons: participants vs. agency clients profile; participants vs dropouts ● Cross-site comparisons
Effectiveness	● Pre vs. post comparisons: ○ Outcome measures ○ Process measures ● Analysis of moderators on outcome measures ● Mediation analysis of process measures on outcomes ● Estimated cost ranges for staff, materials, and other items necessary to run the workshops ● Perceived benefits from cross-site focus groups
Adoption	● Perceived feasibility, acceptability, and fit from focus groups ● Expressed interest to conduct intervention based on our intervention model by participating and/or other agencies at the internal and external virtual forums
Implementation	● Fidelity checklists ● Adaptations based on site needs ● Post-workshop reflections completed by facilitators and coaches
Maintenance	● Pre vs. post vs. follow-up survey data ● Tracking of agencies implementing regular programming based on our model

Table 3. Caregiver-Clinician Collaboration Evaluation

	<i>Evaluation Indicators</i>
• Barriers & to successful collaborations in terms of training and intervention delivery • Stakeholder perspectives on value of the collaboration	• Post-workshop reflections completed by facilitators and family leader coaches • Reflections from quarterly team updates • Perceived benefits from cross-site homogeneous and mixed focus groups (e.g., caregiver facilitators, clinician facilitators, workshop participants, organizational leaders) • Collaboration item on the workshop participant feedback form • Internal stakeholder forum • Response to KT products and external KTE event

Supplementary Files

Multimedia Appendixes

This includes reporting document, which includes the response to reviewer comments, as well as the first round of grant review comments for the initial LOI application.

URL: <http://asset.jmir.pub/assets/96caf9079876ea732e34c4be86ff7126.pdf>