

## **Study Protocol and Statistical Analysis Plan**

**Unique Protocol ID:** EA200329

**Brief Title:** Enhancing Mother-Child Ties and Psychosocial Wellness Through Arts Among Children With Intellectual Disability and Their Mothers

**Official Title:** Enhancing Mother-Child Ties and Psychosocial Wellness Through Arts: A Mixed Methods Study on Dyadic Expressive Arts-based Intervention for Children With Intellectual Disability and Their Mothers

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## **Enhancing Mother-Child Ties and Psychosocial Wellness through Arts: A Mixed Methods Study on Dyadic Expressive arts-based Intervention Group for Children with Intellectual Disability and their Mothers**

**Background:** Caregiving mothers of children with intellectual disability (ID) are vulnerable to caregiver stress and burnout. Children with ID may have difficulty in expressing emotions, thus imposes additional challenges for the parents to understand and interact with them. Existing intervention programs for families having children with ID focus on problem- and emotion-focused measures, while strategies focusing on improving parent-child relationships, mother-child communication and wellness of the dyads are limited. Expressive arts-based intervention (EXAT) can bypass verbal expression and cognition during interaction, and is also an engaging, enjoyable, and safe process of empowerment. Although evidence has supported the use of arts-based interventions for children with disabilities and for parents alone, there is a lack of evidence on multimodal dyadic EXAT on the mother-child interaction, their relationship and wellness.

**Objectives:** The present study aims to investigate the effectiveness of the dyadic EXAT group on psychosocial outcomes of children with ID and their caregiving mother. Primary outcomes include parent-child relationship, parenting stress, and caregiver burnout; secondary outcomes include mother's affect and quality of life; child's mood, emotional expression, behavioral and emotional problems.

**Method:** The present study adopts a mixed-methods design with quantitative, qualitative, and arts-based assessment methods. 154 Chinese parent-child dyads (77 dyads in each arm), composing of a child (6-12 years) with mild to moderate ID, and the caregiving mother, will be randomized into (i) a dyadic EXAT group or (ii) treatment-as-usual, waitlist control group. The dyads will be assessed on a questionnaire packet at baseline ( $T_0$ ), post-intervention ( $T_1$ ), 3-month post-intervention ( $T_2$ ), and 6-month post-intervention ( $T_3$ ). A random subsample of mothers ( $N=30$ ) will be invited to attend in-depth two in-depth interviews at  $T_1$  and  $T_3$  for understanding the experiences, perceived changes, and factors that are attributable to how the intervention achieves its intended goals. Data collected will be triangulated to provide an integrative evaluation to the effectiveness of the intervention.

**Significance:** This is a pioneer study exploring the benefits of dyadic EXAT on mother-child relationship of children with ID, and their psychosocial wellness. This rigorous scientific inquiry on the effectiveness of dyadic EXAT in this population can provide empirical support to EXAT as an evidence-based, relationship-focused intervention to help these families cope. Results of the study could establish EXAT as an evidence-based practice for these families and the potential to apply to other populations with children having developmental disorders, disabilities, or special education needs.

**Keywords:** Mother-child relationship, Psychosocial Well-being, Expressive Arts Therapy, Intellectual disability, Randomized controlled trial

## **Project Objectives (max. 800 words)**

### **Project Objectives**

The **primary objective** of the present study is to investigate the effectiveness of a dyadic Expressive arts-based intervention with reference to a waitlist control group on the caregiving mother on the following domains:

- (i) Parenting stress;
- (ii) Caregiver burnout, and;
- (iii) Parent-child relationship;

The **secondary objective** of the proposed study also aims to investigate the effectiveness of the dyadic Expressive arts-based intervention on other psychosocial wellness of the caregiving mothers and children:

- (iv) Mother's positive and negative affect
- (v) Children's mood (as indicated by a visual analogue);
- (vi) Emotional expressions (as indicated by arts-based assessment);
- (vii) Behavioral and emotional problems (as perceived by the teachers or social workers);
- (viii) Mother's quality of life;
- (ix) The participating parent's experiences in the intervention program (through qualitative inquiry), and;
- (x) The factors that may contribute to or affect the outcomes of the EXAT-based group intervention

## **Pathways to Impact Statement**

### The short-term potential beneficiaries

1. *Mothers of children with ID.* Mother caregivers of children with ID will have the chance to engage in an integrative, engaging, and enjoyable expressive-based caregiver support program that could improve caregiver stress, burnout as well as cultivate positive affectivity. They can also develop alternative ways to understand, communicate, and interact with their children, which may have long-term benefits also.
2. *Children with ID.* Children with ID will have the chance to participate in the dyadic EXAT, in which they can express themselves and communicate with their caregivers in a safe and enjoyable way through verbal and non-verbal channels. This may foster better psychosocial well-being, creativity, and relationship with their mother.
3. *Mother-child dyads.* Through engaging in art creation and appreciation, mothers will acquire a different perspective of their role as a caregiver of children with ID. During the collaborative and creative art-making process, mothers will have the opportunity to identify non-verbal communication cues and potential in their children despite intellectual impairments; these relational changes might help mothers view the caregiving experience in new lights, and instill hope and enhance their resilience. This would, in turn, facilitate adaptation to the caregiving demands in both the short and long runs.
4. *The caregiver community.* Improvements in holistic wellness of the caregivers would reduce the frequency of mental health and medical service utilization. This would save public health costs and relieve the heavy burden on existing healthcare services for families.

### The medium-to long- term potential beneficiaries

5. *Expressive arts-based intervention.* Results of the proposed study will contribute to the development of the use of expressive arts-based intervention as a care support modality for caregivers of children with ID or other children who have difficulties in cognition, communication and expression. This would bridge the existing research and service gaps in caregiver support services locally and globally. The study findings will inform us the underlying principles/factors that modulate the effectiveness of the program, channel existing knowledge gaps in arts-based intervention, lay the foundation for integrating expressive arts-based services into existing social service system, and reinstate the role expressive arts play in evidence-based, caregiver support services within the community.
6. *Researchers in psychology, social work, and related disciplines.* The study findings will broaden our understanding of how arts-based interventions establish the resilience and flourishing of caregivers of children with ID, as well as help foster the positive relationship with their children. Such knowledge advancement will open a new arena for conceptualizing and developing expressive arts-based interventions for caregivers and other populations that might potentially benefit from arts-based modalities.
7. *Mental health policymakers.* Findings from this study could indicate the development of appropriate support service for caregivers having children with ID or disabilities, as well as mental health services and care policies in the long run.
8. *Other populations with developmental disabilities.* Findings from this study could be generalized to other clinical populations of parents and their children with

developmental disorders or disabilities, or with cognitive, communicative and expressive problems.

Plan to increase the likelihood of achieving the identified benefits and reaching the identified beneficiaries

*Collaborative efforts of a multidisciplinary expert team.* Members of the multidisciplinary research team are experts in the practices and research in the areas of expressive arts-based intervention, intellectual disabilities, family-based intervention, and psychosocial interventions for chronic illness and community wellness. They showcase an established track record of research outcomes in terms of publications and local and overseas conference presentations in the field of social work, holistic healthcare, psychology, pediatric psychiatry, and expressive arts therapy. To ensure the identified impacts could be achieved and delivered to the said beneficiaries, the team will work collaboratively on execution, coordination, and implementation of the proposed project, ensure treatment fidelity, and accuracy in data collection and data analysis. The team will ensure this project achieving its expected impacts by collaborating with the network of long-time collaborators in the community serving people with ID and their family members. Hong Chi Association, one of the local, dedicated non-government organizations which serves over 7,000 people of all ages and all grades of ID, has already offered its support to this project.

*Protocolized treatment with fidelity and sensitivity.* The components of the proposed EXAT program have been developed and applied in various clinical populations, including adults and children with ID. The acceptability, efficacy, and feasibility of the program components have been tested by the research team [1-3]. The project team has carefully reviewed their experiences in the field and fine-tuned the content so that the program could be delivered in a dyadic format to serve both the children and mothers simultaneously and suit for local population [3]. The treatment protocol has been manualized to ensure fidelity. Extra care will be taken into consideration to ensure the safety and health condition of group participation. The dyadic group sessions will be conducted in face-to-face format due to the need for interactions. In case of pandemic within the community, larger venue will ensure adequate spacing and social distancing between the participating dyads as precautionary measures. We also plan to develop online format in the future based on this study; yet the dyadic intervention involves interactions among the mother, the child, and the therapist, it may need more time to develop and validate the virtual approach.

*Dissemination of knowledge.* This proposal will generate high quality research findings which will be disseminated in international conferences and academic publications in international peer review journals. Other forms of knowledge exchange initiatives will include public talks, seminars, and professional workshops to disseminate the research findings and practices insights with community collaborators and other stakeholders in the field. These events will be carefully integrated into the program plans of our collaborators so that the healthcare professionals, service users, and public could access these findings and their practical implications, and generate public momentum for potential policy changes in supporting caregivers of children with ID and other disabilities. The project will involve trainees of Expressive arts-based intervention and other healthcare professionals. This may help them develop their practical skills for serving this population or other populations in the community.

## **Background of Research**

Intellectual disability (ID) is a developmental disorder characterized by significant deficits in both intellectual and adaptive behaviors which result in restrictions in learning, communication, self-care, social skills, and adaptive skills [4]. It typically manifests in the developmental stage of childhood or adolescence. Intellectual disability is universally classified from mild, moderate, severe to profound range [5], based on standardized IQ assessments. In Hong Kong, the enrollment statistics for students with ID in 2019/2020 indicate a prevalence rate of 0.87% (approximately 7, 700 individuals) of the school age population [6]. Since children with ID may need assistance in almost all aspects of life, caregiving for children with ID can be overwhelming and taxing, and may cause disruptions to the social, occupational, and physical functioning of the caregivers' family [4], leading to caregiver stress and burden [7], and worsened overall quality of life [8].

### ***Psychosocial Needs of Family with Children having Intellectual Disability***

Caregiving for a child with intellectual disability (ID) is a lifelong commitment that affects members of the family. A recent tragedy of a caregiving mother who killed her own child having ID in Hong Kong raised the alarm of mental health issues of and support for family caregivers, in particular the mothers, who are more vulnerable to the negative impacts of caregiving than the fathers [9]. ***Caregiving stress/ burden*** is the negative perception of the caregiving experience; it is conceptualized as how an individual perceives and appraises events in relation to personal or other accessible resources [10]. ***Caregiving burnout*** is a multidimensional construct encompassing physical and psychosocial exhaustions experienced by the caregivers, which is a result of prolonged exposure to caregiving stress [11]. The primary source of caregiving stress of children with ID comes from the disrupted affective relationships among family members. Children with ID tend to have difficulty in expressing their thoughts and feelings verbally; thus increasing their likelihood to display emotions in form of maladaptive behaviors that aggravated social relationships and other psychosocial problems [1, 12]. Proper management and regulation of the relationships are thus critical for mitigating against caregiving stress and caregiver burnout [13].

Psychosocial interventions have been deployed to help families with child having ID, including parents' skills training, cognitive behavioural therapy, behavioural management programs for children with ID, or peer support services such as volunteering [13, 14]. While these programs offer supportive care to the caregivers, they are mostly problem- and emotional-focused [15], and were found to be inadequate in protecting against caregiver burnout resulted from interpersonal conflicts that are rooted in disrupted affective relationships among family members with high caregiving demands [16]. Contrarily, interventions that emphasize ***relationship-focused coping*** might be more culturally relevant in helping caregivers build resilience [15]. Relationship-focused coping focuses on behaviors that are instrumental in enhancing family relationships; and should also emphasize on the promotion of positive interactions of the parent and the child, as well as offering ways other than verbal or cognitive approach for promoting mutual understanding and communication within the dyad [13]. Furthermore, research also suggested that caregivers' well-being also has important implications to the quality of caregiving and the recipients' well-being with potential reciprocal effects [17]. Thus, there is an imminent need to support caregivers of children with ID to preserve both parties' well-being and prevent the occurrence of reciprocal suffering.

### ***Why Expressive arts-based intervention (EXAT)?***

Expressive arts-based intervention (EXAT) integrates psychotherapeutic skills with the use of the intrinsic expressive and healing power of arts, and seeks to engage the client holistically across the physical, cognitive, emotional, social, aesthetic, and transpersonal domains [18]. This approach uses different creative arts modalities (arts, dance/ movement, drama, music,

and other forms of arts expression) in an integrative way as a vehicle for establishing interpersonal connections (verbal or non-verbal), encouraging aesthetic appreciation (non-judgmental attitude), and cultivating mutual understanding and appreciation [18]. EXAT takes a “low-skill high-sensitivity approach”, as such the participants do not have to be proficient in any verbal or non-verbal communication skills, or arts ability; they would be facilitated to become sensitive to whatever they are experiencing so that they could engage creatively and meaningfully in different arts media, and find way of working with the situation that feels “just right” to them [18]. The use of different elements from EXAT has attracted much attention in community setting due to its safe, engaging, enjoyable process, and its non-pharmacological and strength-based orientation [19]. The use of arts also showed benefits in strengthening of the relationships within the family by promoting empathy, cultivating sensitivity to each other’s needs, modifying the habitual perception of the other family members, and establishing a more adaptive stance towards conflicts [20]. Moreover, a study on art facilitation with individuals who had developmental disabilities indicated improvements in communication and social relationship in the treatment group [12]. Music therapy was also found to benefit the parent-child relationship through the improvement of communication, the feeling of closeness and understanding [21, 22].

### ***Theoretical Basis of Dyadic EXAT in Improving Mother-Child Dyads Wellbeing***

Intervention strategies that help to facilitate and maintain relationship for children with ID and their caregiving mother, would help buffer against caregiver stress, prevent caregiving burden, and improve wellness of the caregiving dyads [2, 23]. However, the difficulty of children with ID in expressing their thoughts, needs, and emotions to their caregivers may impose additional hindrance in maintaining proper relationship. The use of arts can bypass the cognitive and verbal limitations [1, 24]. Multimodal EXAT may also help tap into different sensory channels for communication, expression, perception and interactions, and satisfy the different preferences of expressive channels that individuals or the dyad may have, while offering opportunities for them to explore new ways of knowing and interacting with each other [12, 18]. All these are shown to be important in building relationship, and strengthening attachment between the dyad [21, 23, 24]. In addition, given the reciprocal nature of interaction between the caregiver and the recipient, intervention that focuses on the caregiving dyads could be particularly beneficial. Evidence suggested that dyadic groups using different arts forms might help relieve caregiving stress through the followings:

*Improving Mother-Child Communication.* EXAT helps overcoming the barrier of the difficulties of children with ID in expressing their emotions and understanding of others’ emotions; thus, offering empowering and support to the parents [25], and strengthening the mother-child dyadic ties. In addition, communicating and expressing through arts are especially appropriate for local population as Chinese custom in which explicit displays of affection and emotion are generally considered inappropriate [26]. Evidence has shown the potential benefits of a dyadic expressive arts-based intervention on the mother, the child, as well as the mother-child relationship [2], and increasing prosocial behaviours of pre-school healthy children and positive affect of their caregivers [3].

*Acquiring New Ways of Relating.* The dyadic EXAT emphasizes the process of co-creation and exploration with arts; which encourages joint looking and shared sensory experiences between the mother and child. This will prompt the dyads to try out new strategies to communicate and relate to each other [2], facilitate better communication, and help secure their attachment [24]. Such exploration will also allow children more room to express or in charge of this new dynamic; open new ways for the mothers to understand, appreciate, and interact with their children [27]; benefit the relationship; enhance parental sensitivity; and facilitate the improvements of caregiving burden and well-being for the dyads [23].

*Soliciting Social Support Within and Between the Families.* Dyadic group intervention allows social support to synergistically emerge between the family dyads; whereas experiences of one family unit could provide the avenue for other families to model alternative communication patterns [26, 27]. When the group uses arts to share what they normally cannot verbalize, they open up possibilities for unexpected common themes for discussion and exploration [27]. The dyadic group format also allows the mother to connect more with the program, display attention, kindness, and appreciation of the child, rather than only learn practical skills for their children or resolve their own emotional issues [26].

Although evidence are accumulating on the use of arts-based elements to help families with children having disabilities to cope, existing evidence is plagued by: (i) small sample or not homogenous sample of children with ID; (ii) not having children in the intervention, (iii) no exploration on children's emotional expression and mood in outcomes; (vi) interventions with single art modality; (v) without post-intervention data collection time points. To address the above limitations and knowledge gaps, this study may generate rigorous multi-dimensional research evidence to support the use of dyadic EXAT which puts equal emphasis on the experiences and interaction of the mothers and children with ID. The study will bridge both the knowledge gap on the application of dyadic EXAT and service gap in supportive care for families with children having ID or other special needs (SEN) locally and internationally.

### **Work Done by the Team**

**Prof. Rainbow Ho (PI)** has rich experience in clinical practice and research in expressive arts-based intervention, including its cultural adaptation, and psycho-physiological outcomes [28]. She also has experiences in conducting mixed methods RCT on clinical populations including ID and the caregivers [1, 3, 29], and the use of arts-based assessment [2]. **Dr. Phyllis Wong** is an experienced researcher-practitioner in the field and has done a lot of works on investigating the quality of life and self-determination of people with disabilities, as well as in resilience of caregivers of people with intellectual disabilities [14, 30]. **Dr. Herman Lo** is an experienced researcher and practitioner in family-based interventions [3,5], parenting, caregiving, and children with special needs and developmental disabilities [29, 31]. **Dr. Adrian Wan's** research focuses on holistic wellness, mindfulness, expressive arts-based intervention, and social work practices in patients and caregiver supports [3, 32]. The team members has conducted important groundworks for the proposed project, which included applying EXAT for adults with ID, working with parents and children with or without special needs, family-based interventions, and other projects related to supporting individuals with disadvantages. These experiences will ensure proper implementation of the project and its high quality, as well as translation of the research findings to practical wisdom locally and internationally.

### **Research Plan and Methodology**

*Study Hypotheses.* The proposed study attempts to explore the following hypotheses:

1. The Dyadic Expressive arts-based intervention Group is more effective than the treatment-as-usual, wait-list control in improving parental stress, caregiver burnout, positive and negative affect, quality of life and parent-child relationship.
2. The Dyadic Expressive arts-based intervention Group is more effective than the treatment-as-usual, wait-list control in improving the behavioral and emotional difficulties, mood states, and expression of emotions of young children with ID.
3. Changes observed/ reported by participants in the dyadic expressive arts-based intervention group are sustainable at 3-month and 6-month post-intervention follow-up time points.

*Exploratory Questions.* The proposed study will also attempt to explore the followings:

4. To explore the relationships of the psychosocial variables and intervention effectiveness (e.g. meditation, moderation and other asosocaitions).



5. What are the participating mothers' experiences in the dyadic expressive arts-based intervention group?
6. The potential factors and conditions that may affect how and why the EXAT intervention works or does not work for the participating dyads; mothers' perception, acceptability, and real-life application of the non-verbal communication skills that they explored and practiced in the intervention.

### **Study Design and Methods of Data Collection**

Study Design. This proposed study adopts a RCT with *mixed methods design*. To address the research objectives, data collected will be triangulated and interpreted simultaneously to address the research questions. **Appendix A** depicts the CONSORT flow diagram of the present study. Outcome measures will be assessed on four time-points (T<sub>0</sub>: Pre-intervention at baseline; T<sub>1</sub>: Post-intervention; T<sub>2</sub>: 3-month post-intervention and; T<sub>3</sub>: 6-month post-intervention) to assess the immediate and sustained effects of the Dyadic EXAT Group on mother-child relationship and psychosocial wellness. Qualitative interviews will be conducted with a random subsample of 30 parents from the expressive arts intervention at T<sub>1</sub> and T<sub>3</sub> to collect fine-grained, information to explore their overall experience of participation in the intervention and how the experience has shaped their caregiver experience in terms of stress coping and establishing parent-child relationship. Results of the qualitative interviews will be used to enhance the interpretation and understanding of the quantitative findings [33].

Appendix B summarizes the conceptual framework of the proposed study.

Participants. Participants are mother-child dyads composing of a mother caregiver and a child who is aged 6 -12 years and fulfils the diagnostic criteria for *mild grade to moderate grade* ID (based on the age-relevant IQ test assessments administered by a qualified professional). In the judgment of health/school professional staff, the child is both physically and psychologically stable and be able to safely participate in the research procedures and intervention group. The dyads are able and willing to give consent for participation in the study (guardian's assent consent will be arranged for the participating children, while written consent will obtained from the adult mothers). Dyads are excluded if: (i) the child was diagnosed with attention deficit and hyperactivity disorder, (ii) the dyad is currently participating in any other behavioral or pharmacological trial, and/or (iii) either member of the dyads have other contraindications or severe comorbidities that may impair their full participation (e.g. severe physical disabilities).

Recruitment. The recruitment will be facilitated by our collaborative partners in the community (including SEN schools, and community-based units that serve families of children with ID), as well as referral from medical and mental health professionals working in the field of education, paediatric psychiatry, clinical psychology, and social work. The promotion materials will be hosted on the website/social media of the Department of Social Work and Social Administration and Centre on Behavioural Health of The University of Hong Kong. Screening for eligibility will be conducted by the researcher or referral professionals who have attended briefing sessions offered by the research team.

Sample Size: We expected a moderate effect size of 0.5 for the primary outcomes based on a local study [57]. Using power analysis software Gpower 3.1, assuming an attrition rate of 20%, a total sample size of 154 participants (i.e. 77 each arm) will provide 80% statistical power to detect an effect size of 0.5 in the 2-arm RCT with 4 measurement time points at 5% level of significance. For the qualitative data collection, a random subsample of 30 participating mothers will be invited to join individual, in-depth interviews at post-intervention (T<sub>1</sub>) and 6-month follow-up (T<sub>2</sub>). Based on various guidelines for mixed methods study design, a sample of 25 participants would suffice data saturation. If data saturation is not reached, more participants will be recruited into the study until no more new findings emerge [34].

Group Allocation. Eligible family dyads will be randomly assigned into one of the two study conditions on a 1:1 basis using a randomization table and a computer-assisted random number generator. The allocation list will be produced by an independent researcher and concealed from other researchers and participants until assignment.

(a) *The Dyadic Expressive Arts Group Therapy:* The 8-session intervention group (weekly session, 90 minutes each, with 3-4 dyads in 1 group) delivered will be by a registered Expressive Arts Therapist or an expressive arts therapy trainee, or a mental health professional trained in expressive arts intervention (under supervision). Each session consists of 5 basic processes in EXAT: check-in, warm-up, core art making, sharing, and closure [35]; and focuses on a specific theme related to parent-child relationship: communication, relationship, expression, empathy, interaction, love, gratitude, and connection. The program has been developed and adopted for people with ID and mothers of children having special needs and disabilities [1, 2, 36], and has been refined to integrate the cultural-relevant components (e.g. Chinese festivals, Chinese arts and music, etc.) and parent-child interaction skills and elements [2, 3]. The program has been used by the team in previous studies and community workshops [37-40]. **Appendix C** summarizes the structure of the program.

(b) *The Treatment-as-usual Waitlist Control Group:* The control group will continue with routine healthcare and social services and will be invited to participate in a similar intervention group program upon completion of the 8-month study period.

Treatment fidelity: Group facilitators participating in the intervention delivery will receive a training session covering the details of the protocol and safety precaution. Treatment fidelity will be assessed by the PI in the form of on-site or video-reviewing supervisions, preferably during the 3<sup>rd</sup> or 4<sup>th</sup> session on the condition that written consents are provided by the participants. The facilitators will receive off-site supervision provided by the PI. The assessment will be conducted using a pre-constructed observation checklist outlining the program pedagogy and the expected goals of the sessions.

Research ethics: Ethical approval will be obtained from the Institutional Review Board and Human Research Ethics Committee prior to data collection, and consent will be obtained from all recruited participants (the mothers, and children with ID) prior to assessment. The study will be registered in the ClinicalTrials.gov under the National Institutes of Health, and the HKU Clinical Trials Registry.

## **Measurements**

### *Mother's psychosocial outcomes and perceived parent-child relationship*

1. *Parenting stress.* The 36-item Parenting Stress Index (4th Ed, Short-form) (PSI/SF) [41] will be used to assess parenting stress of the mothers on 3 domains: (i) parental distress, (ii) parent-child dysfunctional interaction, and (iii) difficult child. The index reported an internal consistency of .92, and has been adopted in local studies of mothers with children having special education needs [42]. Higher scores indicate higher parenting stress.
2. *Caregiver burnout.* The 6-item client burnout subscale of the Copenhagen Burnout Inventory [43] will be used to measure the mothers' caregiving burnout. This scale has a central focus on fatigue and exhaustion which matches the definition of burnout; and this scale has been validated with good reliability in local context and has been used in a study on Chinese caregivers of individuals with ID [44]. The subscale used is rated on a 5-point Likert format ranging from 0 ("never/ to a very low degree") to 100 ("always/ to a very high degree"), with higher scores indicating higher levels of burnout.
3. *Parent-child relationship.* The subscales of *parent-child communication* (9 items) and *satisfaction with parenting* (10 items) from the Parent-Child Relationship Inventory (PCRI) will be used to measure the mother's perceived attitude towards parent-child relationship [45]. The items are rated on a 4-point Likert Scale from (1) strongly agree to (4) strongly

disagree; and negative items are reversed coded. Higher scores indicate positive perception of the specific dimensions of parenting perceived by the caregiving mother. The research team will undertake the authorized translation of the subscales.

4. *Positive and negative affect.* The 10-item International Positive and Negative Affectivity Schedule – Short Form [46] measures positive and negative affectivity of the mothers on a 5-point Likert format, ranging from 1 (“Never”) to 5 (“Always”). The scale yields positive affect and negative affect subscales. Higher scores in each subscale indicate more of that affective state for the respondent.
5. *Quality of life.* The 28-item WHO Quality of Life Scale, Brief version (WHOQOL-BREF) [47] addresses physical, psychological, social, and environmental quality of life. The Chinese version has been adopted in a study of caregiver burden of parents with children having ID scores denoting better quality of life in a specific domain.
6. *Psychological well-being.* The 5-item World Health Organization Five Well-Being Index (WHO-5) [48] measures the subjective psychological well-being on a Likert scale, ranging from 5 (“All of the time”) to 0 (“At no time”) in the past 2 weeks. Raw score is converted to a percentage scale to provide a score of 0 to 100. Higher scores reflect higher subjective well-being.

#### *Children’s psychosocial outcomes*

7. *Mood states.* The Ottawa Mood Scales are a series of Likert scales designed to help children express how they feel [49]. The scale is composed of 5 items which assess mood, anger, worry, stress and self-regulation. For self-regulation, there are faces depicting the corresponding emotional states and a thermometer icon represent the arousal state at the bottom. For mood, anger, worry and stress, there is a numerical scale with schematic faces showing the corresponding emotions. The tool has been validated to use in a Malaysian young adult sample [50]. The research team will undertake the translation of this scale.
8. *Emotional expression.* The Face Stimulus Assessment [51] is an arts-based projective assessment which is a viable means of extracting psychological information including emotional expressions for individuals with communication difficulties, including ID [52]. The assessment contains a series of three A4-size stimulus drawing templates: the first is a pre-drawn face, the second is a face outline, and the third is a blank sheet of paper. Participants will be asked to use the markers provided on the templates individually. The FSA will be administered in small groups and assessed through a quantitative and qualitative approach following guidelines from the FSA E-Packet and Rating Manual (2nd ed.) [51, 53]. The artworks will also be digitally scanned to analyze the pattern of color usage [1]. This assessment will be conducted by a trained Expressive Arts Therapist, a EXAT Trainee under supervision, or a trained research staff.
9. *Behavioral and emotional problems.* The 113-item Child Behavior Checklist (Teachers’ Report Form) measures behavioral and emotional behaviors related to child functioning and problem behaviors observed by the teachers/professionals [54]. The Chinese version is widely adopted in Hong Kong with established local norms [55]. School teachers or social workers of the participating children will be invited to fill in the checklist and indicate the degree or frequency of the behaviors described in the checklist on a scale of 0 (not true), 1 (somewhat or sometimes true), or 2 (very true or often true). The checklist yields three composite scores on externalizing, internalizing, and total behavioral problems, and eight syndromes of withdrawn, somatic complaints, anxious/depressed, thought problems, social problems, attention problems, delinquent behaviors, and aggressive behavior with higher scores indicating greater manifestations of the described behavior problems in the area [56].

### *Other variables*

10. *Demographics*: Participant profile including age, gender, education level, income, employment status, religiosity, marital status, and family composition will be recorded. Clinical information (time since onset/ diagnosis, medical treatment record, psychiatric history, comorbidity (physical disabilities, hypertension, diabetes mellitus, or other cognitive disturbance) and history of rehabilitation service utilization of the parents and children will be documented.

*In-depth Interviews*: 30 participating mothers will be invited to attend two individual, in-depth interviews at post-intervention (T<sub>1</sub>) and 6-month follow-up (T<sub>3</sub>) respectively. The first interview focuses on the immediate post-intervention changes perceived by the mothers upon program completion, while the second interview focuses on the sustainability of these changes at 6-month follow-up and explores additional changes that were observed between the follow-up windows. The interviews will be conducted by member of the research team (who are familiar with mixed-methods study design, in-depth interview), assisted by a research assistant, using an interview guide [57]. **Appendix D** shows the sample interview guide and its potential probes.

**Data Analysis**: Analyses of the outcomes will be performed according to standard intent-to-treat principle to address the effects of crossover and dropout. Missing data for the participants who drop out of the study at follow-up assessments will be handled using the full information maximum likelihood method. This method has been shown to produce unbiased estimates for clinical trials with missing data [58].

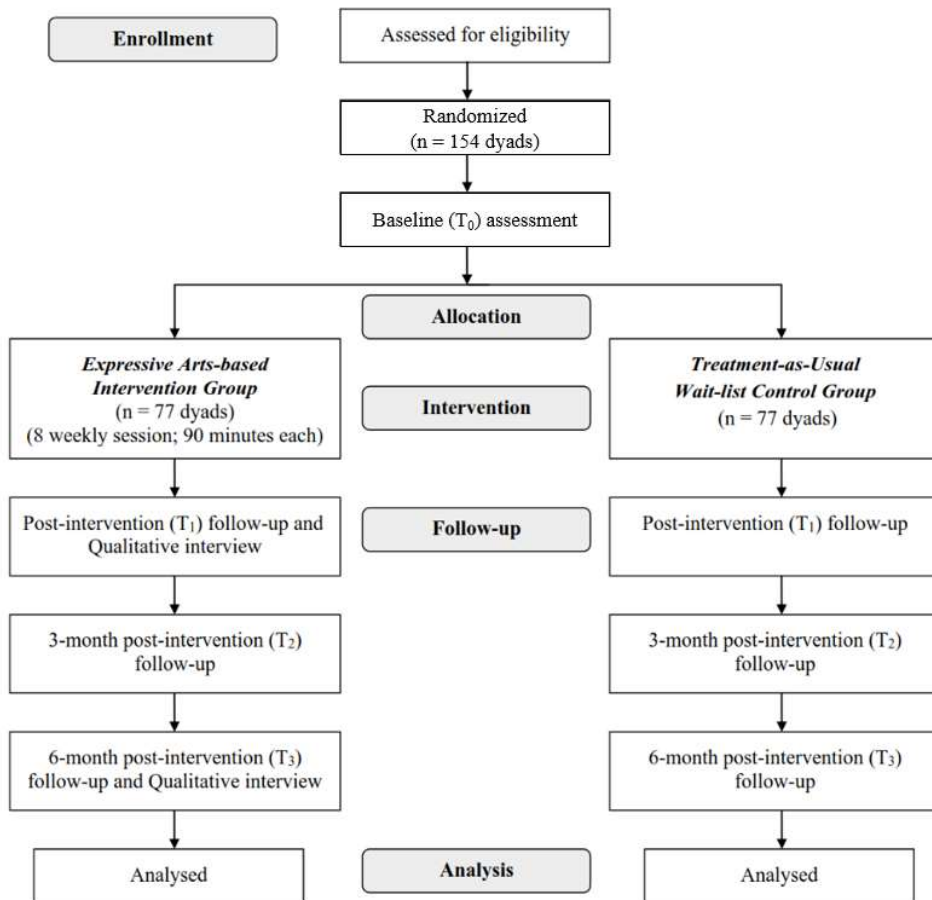
1. *Effectiveness of Dyadic EXAT group (Hypothesis 1 – 3)*. Descriptive statistics will be used to summarize the socio-demographic characteristics of the participants at all time points. Primary analysis of treatment outcomes will be conducted using mixed-effects regression models. Mixed-effects models analyze the repeated measurements between groups to obtain the time effect, group effect, and group\*time effect. The analysis will adopt the intention-to-treat principle to account for the missing data. Missing data for participants' dropout will be handled using full information maximum likelihood method [58]. Effect size of the intervention will be evaluated using Cohen d [59], with 0.2, 0.5, and 0.8 denoting cut-off of small, moderate, and large magnitudes. Demographic and clinical variables will be controlled in the analysis. All statistical tests will be two tailed and statistical significance will be set at 0.05 using Mplus 8.3.
2. *Process and Mechanism of Dyadic EXAT (Exploratory research question 4)*. Path analysis will be performed to examine the mediating role of parent-child relationship and parenting stress on the effect of EXAT on psychological distress and caregiver burnout. The path model will be built for the predictor variables at baseline (T<sub>0</sub>) on the dependent variables at T<sub>3</sub> via the mediators at post-intervention (T<sub>1</sub>) and 3-month follow-up (T<sub>2</sub>). Mediation effects will be assessed through the significance of the indirect effects from EXAT to psychological distress and caregiver burnout via the mediators. Given the likely non-normal distribution of the product terms of indirect path coefficients, confidence intervals of the indirect effects will be estimated using the bootstrapping approach [60].
3. *Individual experience of Dyadic EXAT (Exploratory research question 5-6)*. Qualitative data from the open-ended questionnaire packet will be converted into electronic text file for data analysis. The interviews will be audio-taped, and transcriptions will be produced by a research staff who have not been involved in the interventions. All data will be input, managed, and analysed using NVivo 12.0 or above. Analysis will be performed using inductive thematic analysis method. Transcripts will be coded, and themes will be identified by a research team member who is experienced in qualitative data analysis. Thematic analysis will be adopted to code the data; and the coded units will be put into

categories and subcategories, and recurrent themes and patterns will be explored. Audit trial will be conducted to ensure data credibility. The findings of the arts-based assessments and emerging themes will be reviewed for resonance with the quantitative data, and triangulated to assess the effectiveness of the intervention, and to identify the potential pathways for therapeutic group.

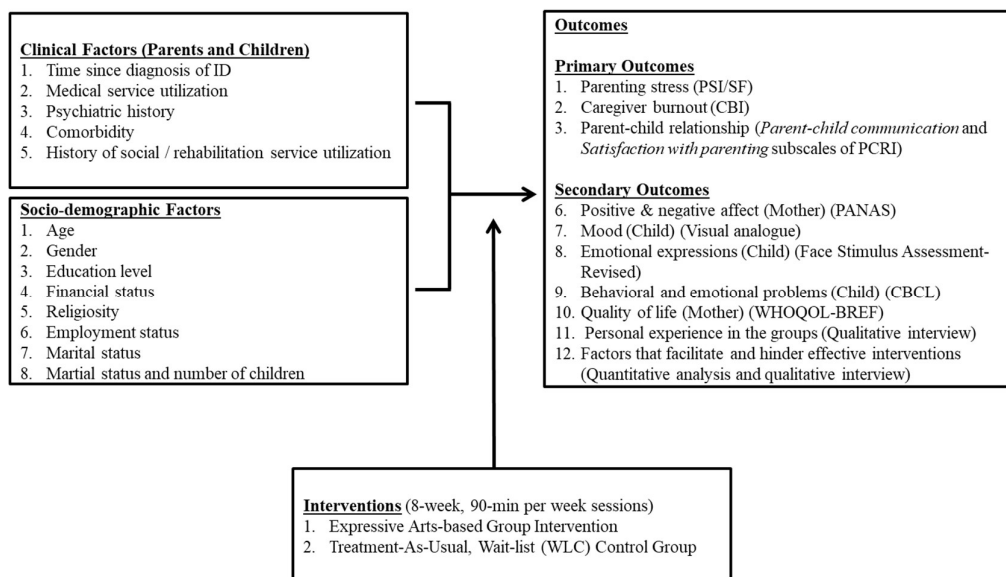
**Ghantt Chart** (Study Period: 3 years)

	2022				2023				2024			
	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4
Literature review and refinement of research protocol												
Preparation and Liaison with collaborators												
Recruitment, screening and randomization												
Baseline (T <sub>0</sub> ) assessment												
Expressive Arts-based Intervention Group (8 week)												
Post-intervention (T <sub>1</sub> ) follow-up and interview												
3-month post-intervention (T <sub>2</sub> ) follow-up												
6-month post-intervention (T <sub>3</sub> ) follow-up and interview												
Data cleaning and analysis												
Report writing												

## Appendix A: CONSORT diagram for the proposed study



## Appendix B: Conceptual Framework of the proposed study



## Appendix C: Sessions Outline & Structure of an EXAT Dyadic Group Session

### Themes of the Dyadic Expressive Arts-based Intervention Program

Session 1	Communication: interaction with or without words
Session 2	Relationship: happy moment and joyful relationship
Session 3	Expression: playfulness and de-stress expression
Session 4	Empathy: understanding and empathy through arts
Session 5	Interaction: creative interaction
Session 6	Care: love and concern
Session 7	Gratitude: appreciation and gratitude
Session 8	Connection: collaboration and connection

### A Typical Session (1.5 hour)

	Process	Purposes
<b>Greetings and check-in</b>	<ul style="list-style-type: none"> <li>Use verbal or non-verbal means i.e. gestures, voice, images etc. to greet and try to present how they are at the moment</li> <li>Briefly introduce the theme of the session verbally</li> <li>Offer a brief recap of previous session starting from the 2<sup>nd</sup> session</li> </ul>	<ul style="list-style-type: none"> <li>Transit from the real world to the therapeutic space.</li> <li>Establish rapport and relationship</li> <li>Have an idea of the focus of the session</li> <li>Build connection with previous session(s)</li> </ul>
<b>Warm Up</b>	<ul style="list-style-type: none"> <li>Use musical rhythm or simple movement sequence to interaction with each other within the dyad and the group</li> <li>Introduce the theme for art creation using music and movement</li> </ul>	<ul style="list-style-type: none"> <li>Warm-up physically and psychologically</li> <li>Prepare for the art creation and interactions</li> </ul>
<b>Arts creation and response</b>	<ul style="list-style-type: none"> <li>Use different art forms to create artworks together or individually, based on different themes of the session (see above)</li> <li>Share the artworks with each other and the group</li> <li>Appreciate and response to each other's artworks through verbal/nonverbal means</li> <li>Therapist will facilitate further sharing and discussion, and help participants to consolidate and summarize the experience/discovery from the process</li> </ul>	<ul style="list-style-type: none"> <li>Facilitate creative expression and interaction between mother and child, and also among the group members</li> <li>Foster mutual support and relationship in the group</li> <li>Share the experiences with and learn from other dyads in the group</li> <li>Consolidate the experiences and create articulation to foster positive mother-child relationship</li> </ul>
<b>Closure</b>	<ul style="list-style-type: none"> <li>Create a dyadic gesture or sound, with or without verbal language, to say thank you and goodbye to the group</li> </ul>	<ul style="list-style-type: none"> <li>Closing the session</li> <li>Transit to the real world</li> </ul>

## Appendix D: Interview Guide for Qualitative Interview

Questions	Potential probes
1. What was your experience like about the 8-week Dyadic Expressive Arts-based Group Intervention?	Acceptability of the program Satisfaction towards the program
2. What changes you have observed in <b>your relationship with the children</b> when compared with the times before you joined the program?	Mother-child relationship
3. What changes you have observed in <b>your caregiving experience</b> when compared with the times before you joined the program?	Perception of caregiver's role, caregiver stress, and caregiver burden
4. What changes you have observed in <b>your mood and general feelings</b> when compared with the times before you joined the program?	Mother's psychological wellness
5. What changes you have observed in <b>your child's behaviours</b> when compared with the times before you joined the program?	Children's emotional expressions, every day behavioural patterns
6. What are the <b>other changes</b> you have observed in you or in your child when compared with the times before you joined the program?	Family relationships with significant others; caregivers' own social/ occupational life
7. You have mentioned that you have observed changes in (i) your relationship with the children, (ii) caregiving experience, (iii) mood & general feelings, and (iv) your child's behaviours. <b>What are the possible reasons for these observed changes in these domains?</b> OR You have mentioned that there are no changes in (i) your relationship with the children, (ii) caregiving experience, (iii) mood & general feelings, and (iv) your child's behaviours. <b>What are the possible reasons for the lack of change in these areas?</b>	Underlying reasons, process, experiences that are attributable to the changes.
8. What kind of learning you can bring forward into your real-life situations, or in your caregiving experience?	How the mothers apply and generalize the learning from the classroom setting into real life situations.



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