Study Protocol for a Randomized Controlled Trial Evaluating SSLD Parent Capacity Building Program for Parents of Children with Autism Spectrum Disorder

PRINCIPAL INVESTIGATORS

- Professor Cynthia Leung, Department of Applied Social Sciences, The Hong Kong Polytechnic University
- Professor Ka Tat Tsang, Factor-Inwentash Faculty of Social Work, University of Toronto

RATIONALE

Background

The intervention of children with Autism Spectrum Disorder (ASD) has long incorporated the utilisation of parent training programs and others to facilitate behavioral treatments (Koegal et al. 1982). A considerable body of empirical research shows training parents as co-therapists or parent education programs produced improved outcomes for children with ASD at follow-up assessment (Lovaas et al. 1973; Whittingham et al. 2009; Wetherby et al. 2014; Drew et al. 2002; Leung et al, 2016). Although the clinical effectiveness of these specific parenting training programs in treating children with ASD has been well documented, little research has been investigated on the experiences of children with ASD and their parents in a standard parenting programs that designed in vivo (real life) environments.

The Strategies and Skills Learning and Development (SSLD) System is an intervention system for bringing about change in human life, including our thinking, action, motivation, emotion, body, as well as our environment and it is also an action-oriented model for enabling clients in social work, health, mental health, and human services settings to address their needs and life goals. It is developed by Professor Ka Tat Tsang of the University of Toronto, and first named in 2005, based on over three decades of research and practice experience in social work, clinical psychology, and different areas of human services (Tsang, 2013). SSLD as a comprehensive model for practice in psychosocial service has been successfully applied in many domains, such as senior service (Tsang, 2017; Tsang & Ip, 2017; Chu et al. 2015), immigrants and refugees (Tsang & Li, 2017); settlement practice (Tsang et al. 2014); sexuality and intimacy (Tsang et al. 2014). SSLD Parent Capacity Building Program for Parents of Children with ASD designed to equip and empower parents is grounded in real life, involving people in the child's life world (parents, siblings, peers). From the SSLD perspective, the child with ASD is unable to process information effectively due to neurological impairment, especially complex and multi-modal interpersonal signals (biology and cognition). The autistic child’s inability to decipher and process information leads to feelings of being overwhelmed, perplexed, confused, and anxious (emotion). The child with ASD will adopt withdrawal or disengagement as strategies for avoiding negative emotional experience (motivation and behavior). While other children can gratify various needs through social interaction, children with ASD have to use other means such

as auto-stimulation, control and manipulating objects, maintaining rigid order/pattern (motivation, behavior, environment). Through SSLD systematic learning, the child does not only learn specific skills (e.g., eye contact, verbal requests) but also learns how to learn - imitation, observation learning, and symbolically mediated learning. Moreover, the child can master effective agentive, interpersonal and social strategies and skills. These will lead the child to need gratification, displacing the original symptoms (stereotypic repetitive behavior, withdrawal, isolation).

Aims

The SSLD Parent Capacity Building Program has the following fourfold emphases: 1) building a conceptual framework for parents to make sense of their child's behavior and experience, as well as their own reaction and coping; 2) mastering parenting skills for addressing the challenges presented by the child with the disorder; 3) developing a support system for the parents and their children so as to enhance effective coping with the challenges; 4) understanding the subjective sense of wellness and self-efficacy of both the parents and the children. Hence, the major objective of the evaluative study is to assess/investigate the clinical effectiveness/efficacy of SSLD Parent Capacity Building Program for Parents of Children with ASD. When considering the aims of this study, it is important to note that SSLD Parent Capacity Building is a parenting intervention and is not intended to be a substitute for child-focused interventions for children with ASD.

Hypotheses

The hypotheses of the present study are:

1) Participants the SSLD Parent Capacity Building Program would report lower parenting stress and higher parent sense of competence at post-intervention as the parents acquired positive parenting skills, compared with the control group.
2) Participants in SSLD Parent Capacity Building Program would report less frequent use of dysfunctional discipline strategies at post-intervention, compared with the control group.
3) Participants in the SSLD Parent Capacity Building Program would report lower child behavior problems at post-intervention, compared with the control group.
4) The aforementioned short term benefits would be maintained in the longer term (6 month follow-up).

METHODS

Setting

Seven centres from Hong Kong Christian Service will join the research program. Among the seven centres, five are Early Education and Training Centre (EETC), one is Special Child Care Centre (SCCC) and one is Child Development Centre (with EETC and SCCC integrated).

Participants

The key stakeholders to be involved in this randomized controlled intervention study include:

1) Parents/carers of Children with ASD under the program ;
2) Children from birth to 6 years (should be of (1) above and diagnosed with ASD (All cases are from Subsystem for Disabled Pre-schoolers, Central Referral System for Rehabilitation Services, Social Welfare Department of Hong Kong Special Administrative Region Government).

Study Design

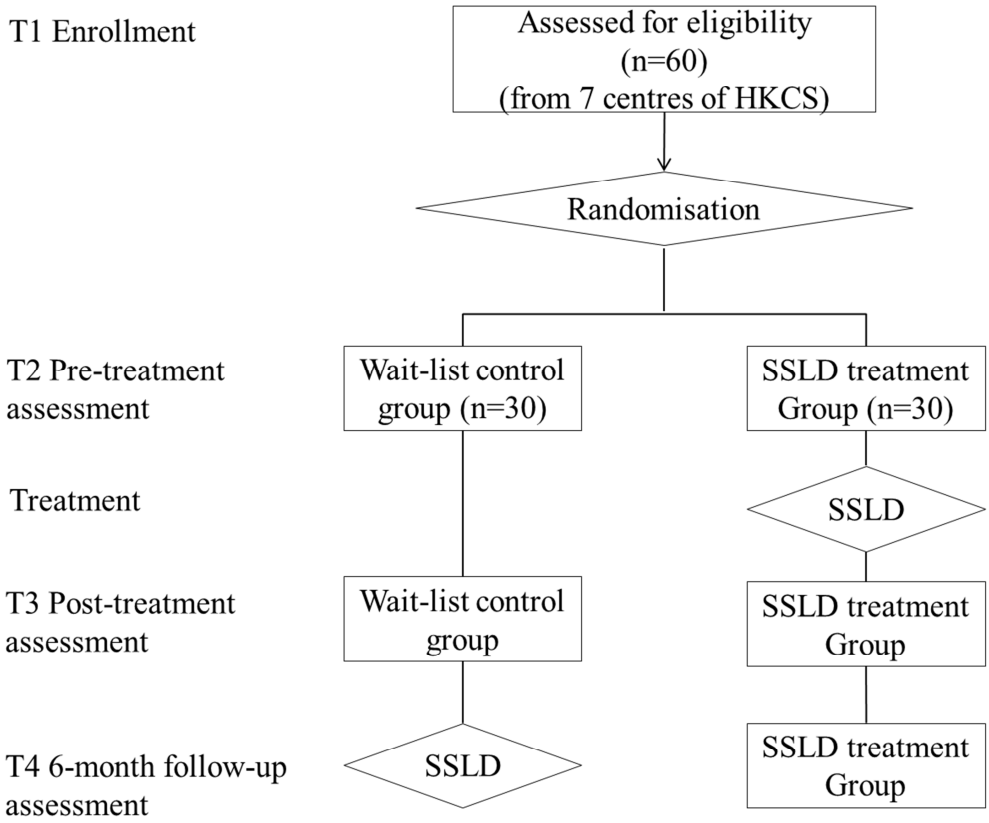
The study will use a randomised controlled trial design employing a mixed within-between-subjects design and a wait-list control group. Randomization will be achieved by drawing participant's names at random and allocating alternatively to the treatment and wait-list groups. Pre-treatment measures will be completed by both the treatment and the wait-list control groups before the treatment group received treatment. The treatment group only then will receive the SSLD Parent Capacity Building Program. After completion of the treatment, both treatment and wait-list control groups will complete post-treatment measures.

Following post-treatment assessment the wait-list control group will receive the SSLD Parent Capacity Building Program. The wait-list control group will receive the SSLD Parent Capacity Building Program before follow-up for ethical reasons. Follow-up will be conducted with the treatment group only 6 months after the treatment group completed the intervention. Follow-up consisted of assessing treatment maintenance within the treatment group. No parties will be blinded to group allocation.

Sampling

All eligible parent-child dyad will be included and abide by randomization to reduce to a minimum selective enrolment. Power analysis indicated that for a large effect it was necessary to recruit 26 participants per group (Cohen 1998). Thirty parents (relatives, primary caregiver/custodian) with their children will be allocated to wait-list control group and 30 parents (relatives, primary caregiver/custodian) with their children will be allocated to treatment group. Figure 1 outlines the anticipated participant flow.

Fig 1 Assessment and participant flowchart



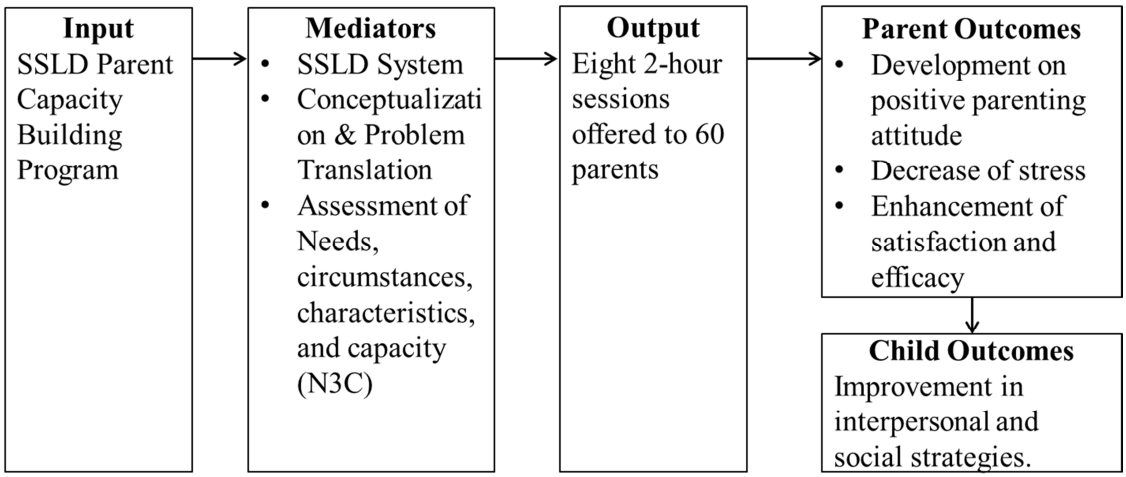
Intervention Programme

SSLD Parent Capacity Building Program: Parents/Caregivers in the treatment group will be provided with eight weekly sessions of training. Each session will last approximately two hours. The detailed agenda of each session are given in Table 2. This intervention programme has five key components: 1) Understanding children with ASD from an SSLD perspective; 2) Observing and making sense through assessment of needs, circumstances, characteristics, and capacity (N3C); 3) Engaging with the children in real life practice by applying the principles and methods learned; 4) Parents' personal development and self-care (e.g. parent support; respite; self-care, personal growth, and quality of life enhancement; specialized counseling programs if indicated). 5) Preparing the child for active learning and enhancing the child's learning and development of strategies and skills. Accordingly, the program logic is shown in Fig 2.

Table 2 SSLD Parent Capacity Building Program Outline

Session	Objectives	Content
1	• Individual pre-group session	• Individualized goal setting and learning and development plan for each parent-child dyad or group (when both parents are participating)
2	• Introduction to the Strategies and skills learning and development (SSLD) System and Conceptualization with Problem Translation • Understanding the relationship between child's problem and parents' need	• Problems understood in terms of unmet needs, as well as the circumstances, characteristics, and capacity (N3C) of the child
3	• Conceptualization (Problem Translation): • Understanding the parents' need	• Problems understood in terms of unmet needs, as well as the circumstances, characteristics, and capacity (N3C) of the parents
4 **5** **6**	• Learning respectful listening • Consolidation of strategies and skills learning • 1.5-2 hour real life practice • Learning strategies to increase positive behaviors: praise and rewards • Consolidation of strategies and skills learning • Learning communication skills and giving effective instructions (eye contact, distance and emotion) • Consolidation of strategies and skills learning • 1.5-2 hour real life practice	• Learning specific skills to bring about desired change through: a) actual hands-on practice learning with own child and/or other people's children; b) coaching by professional trainers; c) audio-visual recording and feedback; d) peer learning support, e) homework exercises and real-life learning;
7	• Personal development and self-care • Consolidation of strategies and skills learning	• Ongoing review and monitoring
8	• Closure: Synthesis of skills and strategies	• Skill integration and self-reflection sharing

Fig 2 SSLD Parent Capacity Building Program Logic



Assessment Measures

Parents and children will be administered the following validated Chinese measures and standardized tests before and after program completion.**Parent Outcome Measures**

Parenting Stress Index/Short Form (PSI/SF;Abidin, 1990)—this is a 36-item questionnaire on parenting stress, measured on a 5-point scale. It consists of three sub-scales, and a total could be calculated by adding up the scores of the three subscales. The three sub-scales were Parental Distress (PD), assessing the level of distress experienced by parents, Parent-Child Dysfunctional Interaction (PCDI), assessing parental perception of negative parent-child relationship; and Difficult Child (DC), measuring children's problem behavior. The Chinese version of the PSI/SF has been validated by Lam (1999), and the reliability (Cronbach's Alpha) of the 36 items was 0.89. There was no established cut-off score for Chinese population.

Parenting sense of competence (PSOC) (Johnston & Mash, 1989) The PSOC is a 16-item scale measuring parental satisfaction and efficacy and will be administered both as a pre- and post-intervention measure. Each item is measured on a 6-point Likert scale ranging from strongly agree (1) to strongly disagree (6). Higher scores indicate greater levels of competency.

Parenting Scale (PS) This is a 30-item measure of parenting style that separates dysfunctional parenting into three styles, laxness (permissive, inconsistent), over- reactivity (harsh, authoritarian, irritability and displays of anger) and verbosity (over reliance on talking) (Arnold et al. 1993). Parents respond on a 7-point Likert scale representing two extremes in a particular parental behaviour.

Parent–child interaction. A video coding procedure will be developed by the research team based on the SSLD Parent Capacity Building Program. The parent will be asked to interact with their children, applying the principles and methods learned. Standardised event sampling will be carried out recording the frequency of the following variables:

• Communication acts: verbal and non-verbal behaviours that have communicative intent or form part of a communication act.

• Asynchronous parental communication: responses aimed at redirecting, controlling or making demands on the child to respond.

• Synchronous parental communication: comments, statements, acknowledgments or social interaction, which maintained the child's responses.

• Semantic contingency: verbal responses related in meaning to the child's previous verbal or non-verbal topic.

• Shared attention: episodes in which the parent and child shared attentional focus.

Demographic information – at pre-intervention, parents will be requested to supply basic demographic information such as age, length of residence in Hong Kong, education attainment, occupation, income, social welfare status, family type and marital status. Information on children's general health status, such as birth complications will also be collected.

Child Outcome Measures

Hong Kong Comprehensive Assessment Scales for Preschool Children **(HKCAS-P) Social Cognition Scale** – validated for Hong Kong Chinese children aged 3 years 4 months to 6 years 3 months. It is individually administered to children and the user has to complete required training organized by Department of Health. It could distinguish between children of different age groups and children with developmental disability from children with typical development (Leung et al., 2011). There are 29 items on social relationships, understanding of social norms and rules, empathy and perspective taking ability and the Scale will be individually administered to children.

Pervasive Developmental Disorders Behavior Inventory **(PDDBI).** One of the most recently developed measures used in assessing social behaviors in individuals with autism is the PDDBI (Cohen & Sudhalter, 2005). The PDDBI is a behavior rating scale that was designed to assist in the assessment of children who have been diagnosed with or are suspected of having a Pervasive Developmental Disorder (PDD), such as autism. Completed by an individual's parent, the PDDBI assesses maladaptive and adaptive behaviors, the presence or absence of which are associated with PDDs. The PDDBI is different from previously used measures in that it was standardized with a sample of individuals with autism rather than with a typically developing group of individuals.

Physical risks connected with the proposed project: N/A

Psychological risks connected with the proposed project:

The questionnaires/scales used in the study have been used in other research with participants in Hong Kong or overseas and no adverse reactions have been reported. However, in the unlikely event that participants might feel distressed about particular questionnaire items,

EETC/SCCC centre staff can offer support on the spot. With participant consent, they can be offered follow-up services by the centres, or be referred to other support services as appropriate.

Social risks connected with the proposed project:

The social risk is minimal as all data will be kept confidential and only the investigators will have access to the data file. Only aggregate results will be reported. All data will be kept confidential and only the investigators will have access to the information.

Legal risks connected with the proposed project: NIL

Other risks connected with the proposed project: NIL

Confidentiality:

All information, including questionnaires and demographic information will be kept confidential. Only the investigators will have access to such data. Only group results will be reported and no individual names will be identified.

Informed consent:

A statement about the project will be provided to the participants and they will be requested to complete a consent form. It will be emphasized that participation is voluntary. The information statement and the consent forms are attached.

REFERENCES

1. Arnold, D. S., O'Leary, S. G., Wolff, L. S., & Acker, M. M. (1993).The Parenting Scale: A measure of dysfunctional parenting in discipline situations. Psychological Assessment, 5, 137–144.doi:10.1037/1040-3590.5.2.137.
2. Abidin, R. R. (1990). Parenting stress index/short form. Lutz, FL: Psychological Assessment Resources, Inc.
3. Cohen, I. L., & Sudhalter, V. (2005). The PDD behavior inventory. Lutz, FL: Psychological Assessment Resources Inc
4. Cohen, J. (1988). A power primer. Psychological Bulletin, 112(1),155–159. doi:10.1037/0033-2909.112.1.155.
5. Drew, A., Baird, G., Baron-Cohen, S., Cox, A., Slonims, V., Wheelwright, S., ... & Charman, T. (2002). A pilot randomised control trial of a parent training intervention for pre-school children with autism. *European child & adolescent psychiatry*, *11*(6), 266-272.
6. Johnston C, Mash EJ. A measure of parenting satisfaction and efficacy. Journal of Clinical Child Psychology. 1989;18(2):167–175.
7. Koegel, R. L., Schreibman, L., Britten, K. R., Burke, J. C., & O'Neill, R. E. (1982). A comparison of parent training to direct child treatment. *Educating and understanding autistic children*, 260-279.
8. Lam, D. (1999). Parenting stress and anger: the Hong Kong experience. Child and Family Social Work, 4, 337–346.
9. Lovaas, O. I., Koegel, R., Simmons, J. Q., & Long, J. S. (1973). Some generalization and follow‐up measures on autistic children in behavior therapy. *Journal of applied behavior analysis*, *6*(1), 131-165.
10. Leung, C., Chan, S., Lam, T., Yau, S., & Tsang, S. (2016). The effect of parent education program for preschool children with developmental disabilities: A randomized controlled trial. *Research in developmental disabilities*, *56*, 18-28.
11. Leung, C., Cheung, J., Lau, V. & Lam, C. (2011). Development of Preschool Developmental Assessment Scale (PDAS) on children's social development. *Research in Developmental Disabilities, 32,* 2511-2518.
12. Tsang, K. T. (2013). LEARNING TO CHANGE LIVES: THE STRATEGIES AND SKILLS LEARNING AND DEVELOPMENT APPROACH, University of Toronto Press
13. Whittingham, K., Sofronoff, K., Sheffield, J., & Sanders, M. R. (2009). Stepping Stones Triple P: an RCT of a parenting program with parents of a child diagnosed with an autism spectrum disorder. *Journal of abnormal child psychology*, *37*(4), 469.
14. Wetherby, A. M., Guthrie, W., Woods, J., Schatschneider, C., Holland, R. D., Morgan, L., & Lord, C. (2014). Parent-implemented social intervention for toddlers with autism: an RCT. *Pediatrics*, *134*(6), 1084-1093.
15. Tsang, A.K.T. (2017). *Play intervention for dementia: Practice manual*. Toronto: Centre for Learning and Change.
16. Tsang, A.K.T., & Ip, C.F.L. (2017). SSLD and senior service: A comprehensive model for practice. In B. Fong, A. Ng, & P. Yuen (Eds.), *Sustainable health and long-term care solutions for an aging population* (pp. 238-258). Hershey, PA: IGI Global.
17. Tsang, A.K.T.**,** & Li, B.Y. (2017). Building a practice system for working with immigrants and refugees: The SSLD approach. In M.C. Yan & U. Anucha (Eds.), *Working with*

immigrants and refugees: A handbook for social work and human services (pp. 67-86). Toronto: Oxford University Press.

18. Chu, M.L.S.C., Liu, K.Y., Ip, C.F., Leung, E., & Tsang, A.K.T. (2015). Transforming organizational culture using the SSLD system to address the taboo of sexuality and intimacy needs of seniors. *Journal of Contemporary Management*, *4*(4): 15-23.
19. Tsang, A.K.T., Kim, H., Kim, S., Peng, T., & Wu, J. (2014). *Handbook of Settlement Practice: The Strategies and Skills Learning and Development (SSLD) Approach.* Toronto: Factor-Inwentash Faculty of Social Work.
20. Tsang, A.K.T., with Chu, M., Liu, K.Y., Ip, L.C.F., & Mak, N.S. (2014). *Managing sexuality and intimacy issues among seniors: The SSLD approach.* Toronto: Yee Hong Centre for Geriatric Care.