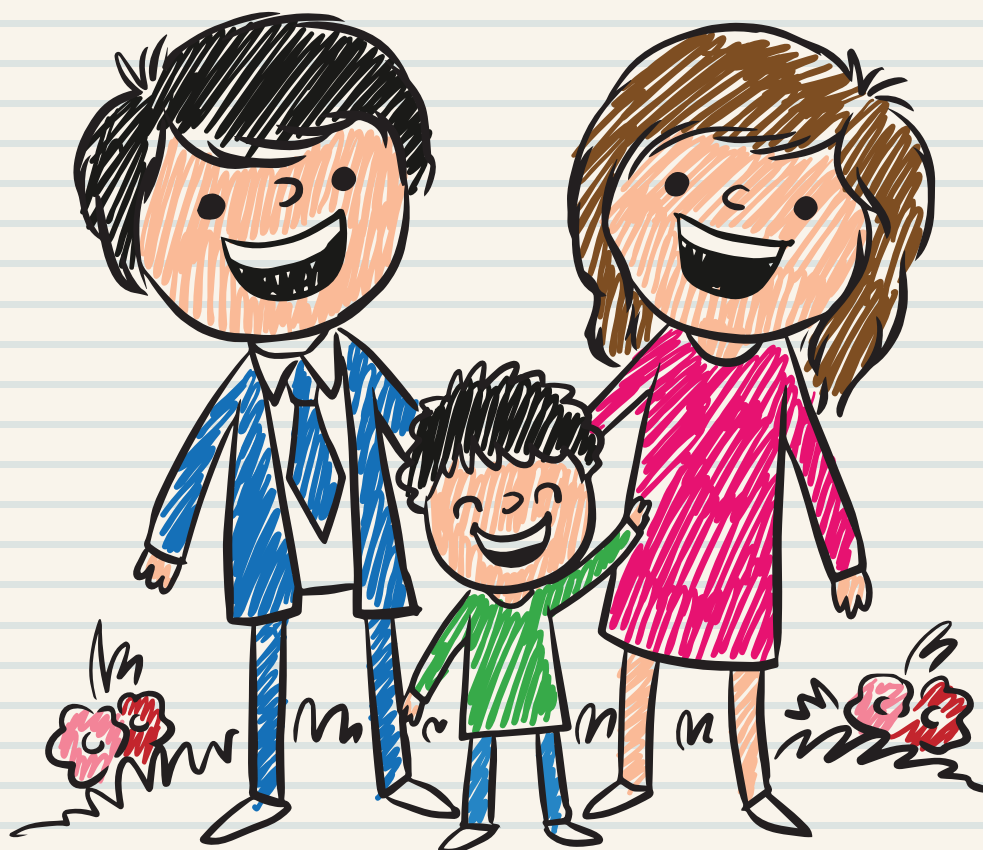


FAMILY SUPPORT & DEVELOPMENT



Newsletter | Spring 2017

捐助機構 Funded by:



香港賽馬會慈善信託基金
The Hong Kong Jockey Club Charities Trust
同心 同步 同進 RIDING HIGH TOGETHER

主辦院校 Host Institution:



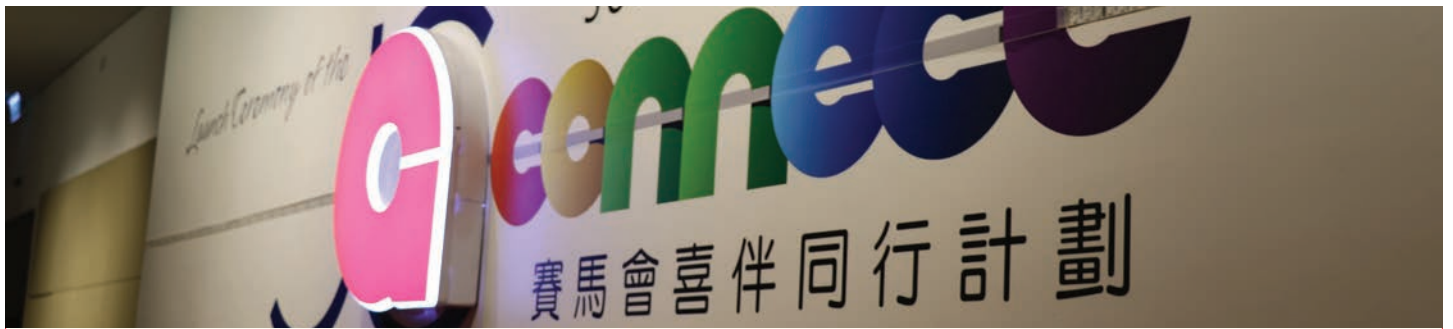
Faculty of
Social Sciences
The University of Hong Kong
香港大學社會科學學院



合作夥伴 Partners:



教育局
Education Bureau



"JC A-Connect: Jockey Club Autism Support Network" is a three-year, \$167 million programme funded by The Hong Kong Jockey Club Charities Trust. The project aims at addressing the needs of students on the Autism Spectrum Disorder (ASD) in Hong Kong mainstream primary and secondary schools and their families. The project which commenced in the 2015/16 academic year, is in collaboration with the Faculty of Social Sciences, The University of Hong Kong, the Education Bureau, Caritas-Hong Kong, Heep Hong Society, New Life Psychiatric Rehabilitation Association, SAHK, The Salvation Army and Tung Wah Group of Hospitals. The Programme comprises three main elements: School Support, Family Support, and Public Education as noted below.

SCHOOL SUPPORT



Enhances the capacity of mainstream schools and NGO professionals to support students with ASD via:

- school-based coaching programmes with professional support
- training activities
- development of resource package
- research support

FAMILY SUPPORT



Strengthens the skills and acceptance of families with members with ASD via:

- facilitation of knowledge acquisition
- development of localised evidence-based family support framework

PUBLIC EDUCATION



Promotes better public understanding and acceptance of autism to further establish an inclusive community via:

- public education activities
- international conference
- online platform
- publications
- media coverage

In the two academic years, the Programme has served over **4,000** students with ASD in over **405** primary and secondary schools, covering **50** percent of students with ASD studying in mainstream schools in Hong Kong. More than **11,000** parents have benefited from over **2,900** parent support and training sessions provided by **18** district-based centres in the first 18 months.

A-POWER

Family Support Framework

"I have to deal with all negative emotions generated by myself, my children, my family, and even the resentful looks from random strangers in the street."

The above quote was from a mother of a child with autism spectrum disorder (ASD) during a focus group interview. Research shows that parents of children with ASD often experience a higher level of parental stress than those of typically developing children (Lai et al., 2015; Hayes & Watson, 2013), and are more prone to symptoms of anxiety and depression (Mak & Kwok, 2010; Lai et al., 2015).

With the launch of the JC A-Connect project, the Family Support Team was able to reach out to parents who received services from three designated non-governmental collaborators. The team sought to tap parents' views on the strengths and limitations of existing family support services and asked for needed suggestions. Parents commented that the current services were useful in improving their parenting skills, managing their emotions and facilitating communication with other family members.

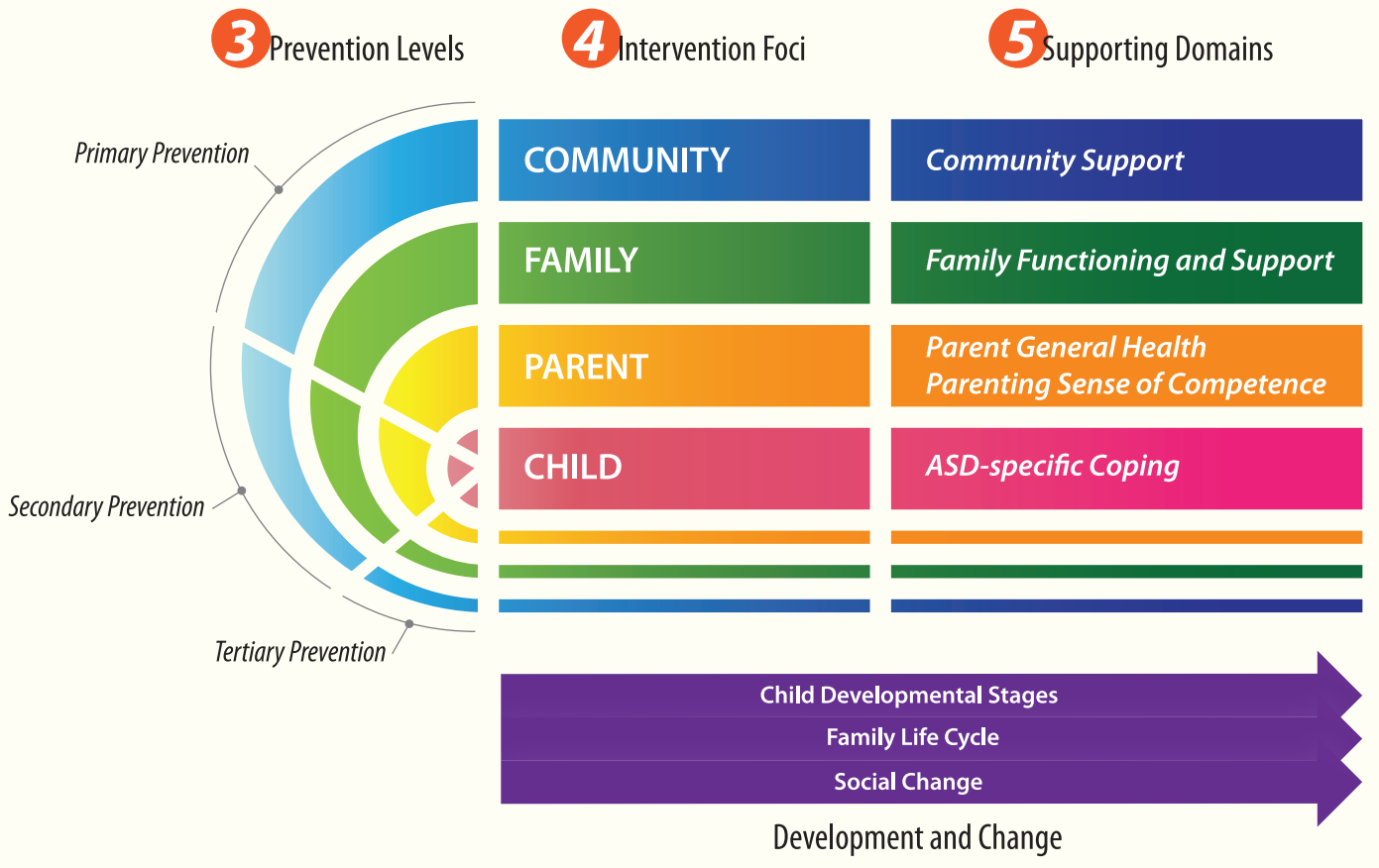
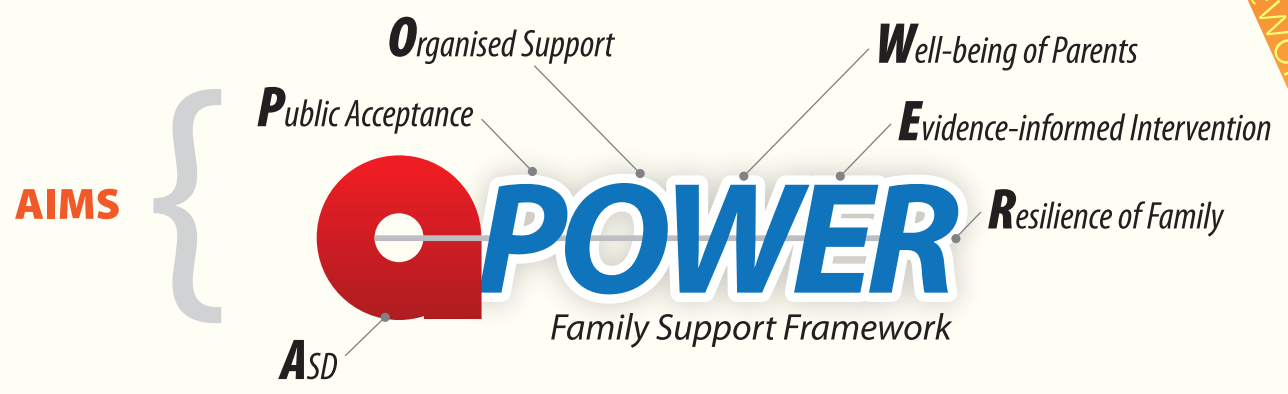
However, some parents said, "skills learnt from one-off programs are never enough to solve new troubles." There are still gaps in the services provided by different social service

organisations, therefore, parenting children with ASD remains challenging. It is especially challenging when the children progress from one development stage to another and face new settings and strangers. The division of caregiving responsibilities among family members and handling public responses are other common challenges.

A-POWER Family Support Framework

Stakeholders have stated that a guide-map for service and research review and development would be useful to help families with members along the ASD spectrum to seek out and receive proper and adequate social services. The team developed the "A-POWER" family support framework as this guide for the families. They developed this guide through a systematic literature review and by evaluating the existing services and interviews with parents and stakeholders. The framework aims to enhance parenting skills and alerts parents to take care of their health. It also asserts that quality support to families should be provided at the child, personal, family and community levels, and should cover at least five support domains as listed below:







ASD-specific coping: I need to understand my child

"The instructor told me that there was always a reason for my child's act."

"I didn't know about autism."

The top-priority need expressed by all parents is knowing about ASD and ways to help such children. With a basic understanding of their child's conditions, parents would be better able to develop corresponding coping strategies.



A parenting sense of competence: I need practical parenting skills

"Since I changed the way I interact with my child, I realise he has the potential to improve, and I'm more at ease."

Teaching effective parenting strategies is one of the most common forms to support parents of children with ASD. More efficient communication with their children will enhance how they manage verbal communication. In turn, this can create nurturing relationships between children and parents and improves management and development.



Parent general health: I need to take good care of myself

"I feel connected with the group members as we have experienced similar issues in our lives."

"I realise that I'm not alone."

Parents need to reclaim the right and space to take care of their health as parenting such children can be a life-long journey. Allowing themselves to take some leisure time, getting support from families with a similar situation, or enjoying support from services should all be useful ideas to help parents.



Family functioning and support: I need understanding and support from my family members

"My family members should not be held responsible for the problems, but we can face the problems together."

"If I'm not alright, my family will not be alright."

ASD not only affect parents, but it also poses a threat to the well-being of all family members. Therefore, comprehensive support should be provided to take care of the whole family.



Community support: I need other people to accept my child

"I'm sorry that my child's act may make you feel uncomfortable, but as a parent, I feel upset too."

Public awareness of ASD is still insufficient. Even some helping professionals do not know enough about ASD. Understanding and acceptance of the community is the only way to reduce parents' suffering from discrimination and pressure.

Taking care of children with ASD is a challenge. Through continuous training and sufficient family support, persons on the autism spectrum will have better chances to grow with potential in healthy families to benefit themselves and society.

References

- Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of autism and developmental disorders*, 43(3), 629-642.
- Lai, W. W., Goh, T. J., Oei, T. P., & Sung, M. (2015). Coping and well-being in parents of children with autism spectrum disorders (ASD). *Journal of autism and developmental disorders*, 45(8), 2582-2593.
- Mak, W. W., & Kwok, Y. T. (2010). Internalization of stigma for parents of children with autism spectrum disorder in Hong Kong. *Social Science & Medicine*, 70(12), 2045-2051.

When a child is diagnosed with Autism Spectrum Disorder, parents set the needs of the child to top priority, thereby, forgetting to take care of themselves. Parents embrace a humongous pressure when facing the child's behaviours due to the difficulties of social communication and restricted behavioural patterns. Although parents have knowledge and training techniques, many parents would say, "At that moment I got so angry, I just couldn't recall any techniques!" Under the influence of negative emotions, parents typically cannot apply the techniques of taking care of children with Special Educational Needs (SEN).

The Jockey Club Autism Support Network has been offering various talks, therapeutic and support groups, parent-child groups and family activities to parents and caretakers. These are to assist parents to manage emotions, lower parenting stress and nourish parent-child relationships. The team of social workers applied Cognitive Therapy in supporting parents to utilise skills to help on their personal emotional management.

Cognitive Therapy was developed by American Dr Aaron T. Beck M.D. The belief is that the emotions, behaviours and body reactions of an individual responding to an incident are primarily due to the individual's perception of the event. Through guided discovery, social workers assist the parents to find the thinking patterns behind negative emotions; parents' perspective and insights about the incident are evaluated through rhetorical questions. One parent shared the event of her child forgetting homework; she expressed that she immediately felt guilty when she saw the word "miss" and blamed herself for not checking the child's homework. With the help of the worker this parent eventually realised that it is her habit to put the responsibility on herself. In another instance, a father shared that he absolutely would not blame himself for the same incident, but he would feel angry because he believes that completing homework is the child's initial responsibility. In the end, the first parent learned



to ask herself, "Am I putting everything on my shoulder and blaming myself for others' responsibilities? And isn't letting my child face the consequence one of the growing lessons?" By doing so consequently, the influence of negative emotions has decreased.

The Family Support Team of JC A-Connect used a paired sample t-test and focus groups to evaluate the effectiveness of the therapeutic groups. After comparing the results of the pre and post questionnaires completed by participating parents, it was found that marital satisfaction, parental competence and social support showed notable differences statistically. Regarding the course's effectiveness, parents believed that understanding and managing emotions, communication among parents and the changing of the relationship with the children were the best gains. Some parents expressed that it was like getting lost in the maze of negative emotions, being led by the nose. After getting to know cognitive therapy, parents have learned to step back and reflect on the cause of the feelings. By understanding their thinking patterns, they have found concrete ways to help themselves escape from the negative emotional trap.

ASD-related Competence for Parents

Heep Hong Society



Heep Hong Society has long been the partners of parents. Being the life coaches, parents and main caregivers are equipped with ASD-related competence. From the beginning of the newly diagnosed ASD toddlers or children, the society aims at walking alongside the parents to go through the difficulties and support the needs of the families. By providing up-to-date information on training strategies and service support to the families, the parent supporting groups for the newly diagnosed ASD pre-schools children serves as the group support for parents to share useful information about current services.

To facilitate parents with localised and evidence-based parenting skills, the Society has been working hard in developing and delivering programmes in the organization and the community. The 'Happy Parenting' programme developed by Heep Hong Society in collaboration with The Hong Kong Polytechnic University and the University of Hong Kong, is the first evidence-based parenting programme tailored to the needs of local parents of children with special needs. Three more sessions have been added to the basic eight sessions as an enrichment programme to tackle specific needs.

Since its launch, the programme's parent course and coach course has been given the stamp of approval by parents and professionals for its effectiveness in enhancing parenting techniques and the parent-child relationship. The programme's research has been published in an authoritative international journal. Together with the Gold Award granted from the Consortium of Institutes on Family in the Asian Region, CIFA 2016, this Wofoo Asian Award for Advancing Family Well-Being has given the Society a shot in the arm for its efforts in parental support.



Challenges are brought up when children with ASD face changes and new tasks. To enrich the parents' knowledge about their children with ASD, developmental changes and transition needs are taught to the parents in the programmes P.1 adaptation and teenage children parent support groups. Tackling the core social and communication deficits of children with ASD, educational parent groups and workshops are designed and implemented from the perspective of Theory of Mind and social competence.

As we all may know, the parental stress of families with children with ASD is much higher than their typically developed counterparts. Self-care of the parents is one of the essential elements that make parenting more efficient and effective. In the present project, Heep Hong Society has made use of Expressive Art Therapy (EAT) as a means to help parents to relieve their stress. Through the enhancement of self-understanding and self-acceptance, these internal resources of the parents have been strengthened.

Holistic support for the whole family with children of ASD has been the prior goal of the JC A-Connect project. From the perspective of ASD-related competence to the concept of self-care, the Heep Hong Society has always been the partners of the parents who accompany their children with confidence and competence.





Social challenges for teenagers with High Functioning Autism

Deficits in social functioning are one of the significant features of autism spectrum disorder (ASD). As the social context becomes more complex and social expectations increase during the adolescent stage, teens with High Functioning Autism often experience various social difficulties in regular classroom settings (Locke, Ishijima, Kasari, & London, 2010). They may find it difficult to make friends and maintain friendships with peers. Some of them may also experience peer rejection, teasing and bullying in school.

PEERS®

The UCLA Semel Institute for Neuroscience and Human Behavior has developed an empirically supported social skills programme for youth with ASD: The Programme for the Education and Enrichment of Relational Skills (PEERS®). It is a parent-assisted program where the teen group and the parent group are run in parallel. While the teens are learning and rehearsing social skills, their parents are learning how to become a social coach and assist the teens generalising the skills learnt to daily context. The programme consists of 14 sessions and covers diverse topics such as conversational skills, choosing appropriate friends, use of humour, get-togethers, good sportsmanship and handling social rejection.

PEERS® utilises the principle of cognitive-behavioural therapy. On the one hand, the programme targets to foster the participants' social knowledge and social cognition through specific teaching methods, including presentation of concrete rules and steps of social behaviour, Socratic questioning, role play demonstrations and perspective taking questions (Laugeson & Park, 2014). On the other hand, the participants would have repeated opportunity to rehearse these skills through in-class behavioural rehearsal as well as a homework assignment. PEERS® trainers and the parents will provide performance feedback so as to help the participants to acquire more socially appropriate behaviours.





Localised PEERS® content for ASD teen in Hong Kong

With the support of The Hong Kong Jockey Club Charities Trust, SAHK is implementing PEERS® in Hong Kong since September 2015. The content, structure and format of the programme are largely maintained as the original model. However, a few modifications have been made to make PEERS® more culturally appropriate to the Hong Kong context. Firstly, culturally sensitive items such as types of extracurricular activities, the content of humour, the format of get-togethers have been altered based on a cultural survey done in the preparatory phase of the SAHK PEERS® programme. Secondly, to promote the parents' social coaching skills, role-play demonstration and coaching trials in parent group has been introduced. Lastly, as the learning style of Hong Kong students is mostly text-bound, a brief handout and homework worksheet are distributed to the teens after each session to facilitate their learning.

Preliminary result, parent and teen feedback

In our preliminary research result, teens that received PEERS® training showed significant improvement in social communication and social skills knowledge. They demonstrate a lower level of restricted interests and repetitive behaviours. They also show fewer conflict with friends during get-togethers and are less withdrawn.

Participating teens report that the programme covers most of the social topics that they are interested in. They find the sessions about conversation skills and handling social rejections match their social needs most. They enjoy the role-play demonstration from the PEERS® trainers and consider it an effective way to acquire perspective taking skills.

Participating parents report that some teens in Hong Kong might not be willing to disclose their social status or social rejections to their parents, yet PEERS® program provides a great platform for the parents and their teens to discuss these topics openly. They appreciate the homework assignments of the programme and find that the homework review in the parent group is useful in enhancing their social coaching skills. The parental involvement enables continuous intervention (even after 14 sessions) and helps to maintain the treatments effect.

In conclusion, the localised PEERS® is effective in improving the social functioning of teens with ASD in Hong Kong.

References

- Laugeson, E. A., & Park, M. N. (2014). Using a CBT approach to teach social skills to adolescents with autism spectrum disorder and other social challenges: the PEERS® method. *Journal of Rational-Emotive & Cognitive-Behavior Therapy*, 32(1), 84-97.
- Locke, J., Ishijima, E. H., Kasari, C., & London, N. (2010). Loneliness, friendship quality and the social networks of adolescents with high-functioning autism in an inclusive school setting. *Journal of Research in Special Educational Needs*, 10(2), 74-81.

Hong Kong ASD Conference

EVENT

Generous support from the general public is essential for the persons with Autism Spectrum Disorder (ASD) and their families to enjoy a happy life and further establish an inclusive society. JC A-Connect not only provides the support for students with ASD, their families and schools but also organises various public education programmes such as annual international conference to promote better understanding and increase public awareness of ASD.

Hong Kong ASD Conference 2016: Supporting Learning and Development, the first conference held in July 2016, brought together more than 900 different stakeholders to facilitate knowledge exchange. The 2-day conference and post-conference workshops invited the renowned ASD expert Dr. Brenda Smith Myles to deliver a keynote lecture on 'Optimizing Inclusive Education for Children with ASD: Factors and Benchmarks for Good Practice' and Dr. Florence Lee Mun-yau, Consultant Paediatrician, Department of Health, HKSAR to address a keynote speech on 'Public Services and Support for Children with ASD and Their Families'. Parallel symposia discussing different themes on school-based training were also held to encourage discussion and interdisciplinary collaboration.

The rising prevalence of autism has been observed around the globe. Apart from direct services to individuals with autism, greater emphasis has been placed on the support services to their families. The second Conference held on January 9, 2017 focused on 'Family Support and Development' to empower the professionals. The Conference 2017 aimed to promote efficient and evidence-informed support currently available to individuals with ASD and their families of the autism community and focused on its future development. The Conference invited distinguished overseas experts, scholars including Dr. Andy Shih from Autism Speaks, The United States, Dr. Sung Min from Institute of Mental Health, Singapore, Dr. Zou Xiaobing from Sun Yat-sen University, and local practitioners to share the international landscape of family support service development and the latest research findings, best practices and services to help families and caregivers of individuals with ASD in Chinese Communities. The 1-day conference received overwhelming responses with over 750 registrations. It can be seen that the cross-sector collaboration has attracted the public awareness on ASD for building an inclusive society.



PROFESSIONAL TRAINING 專業培訓



Professional Training Seminar 2015

睿智研討會 2015

August 6 & September 7, 2015

Workshops on Teacher Training 學校教職員培訓課程 單元二 第一節 《玩轉情緒「腦」朋友：情緒調控有妙法》

June 10, 24 & 28, 2016



Workshops on Teacher Training

學校教職員培訓課程 單元二 第二節

《「潛行空間」：透視社交上的潛規則》

December 9, 14 & 16, 2016



Professional Training Seminar 2016

睿智研討會 2016

August 22, 2016

PUBLIC EDUCATION 公眾教育



Launch Ceremony and Press Conference 啟動儀式及記者招待會

June 6, 2015

Creative Drawing Workshop 「樂聚共融」繪畫拼貼工作坊

July 24, 2015



Art Exhibition 香港自閉特色人士 繪畫比賽得獎作品展

July 7 - 30, 2015

Hong Kong ASD Conference 2016: Supporting Learning and Development 2016 香港自閉症研討會

July 8 - 9, 2016



Art Exhibition 2016 香港自閉特色人士繪畫及攝影 比賽得獎作品展 2016

July 14 - 20, 2016

Press Conference on A Comprehensive Study on Support Needs of Students with ASD in Mainstream Schools 自閉症學生支援需要研究結果發佈會

July 6, 2016



Talks to Secondary School Students 中學生講座

July 18, 2016



Hong Kong ASD Conference 2017: Family Support and Development 2017 香港自閉症研討會

January 9, 2017

Family Fun Day 喜伴共融同樂日

April 2, 2017

