



Preliminary Findings of the Jockey Club Autism Support Network (JC A-Connect) Project - Family Support Team

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Hong Kong ASD Conference 2016: Support Learning and Development

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香港大學社會科學學院

Rising ASD prevalence in the world, also in Hong Kong

- Prevalence of ASD in Hong Kong rising at a rate of 20% in mainstream schools from 2010
- More families demand for resources and support!!!

Family Support Team



Suet, Sandra, Ryan, Karine, Wylie, Paul, and Samantha

Aim and outline

Aim of this Presentation

- Report preliminary findings on the needs and support for families having individuals with ASD
- Report period: **September 2015 to June 2016**

Outline

1. Risks and needs of such families
2. Preliminary findings in the past 10 months
3. Observations
4. Way forward



Risks and needs of such families

Some reported Risks and needs of such families

1. Higher level of parenting stress

(Hastings, et al., 2005; Davis & Carter, 2008; Wang, et al., 2013)

2. Lower health-related quality of life

(Allik, et al., 2006; Lee, 2009; Khanna, 2011)

3. Higher rate of anxiety and depression

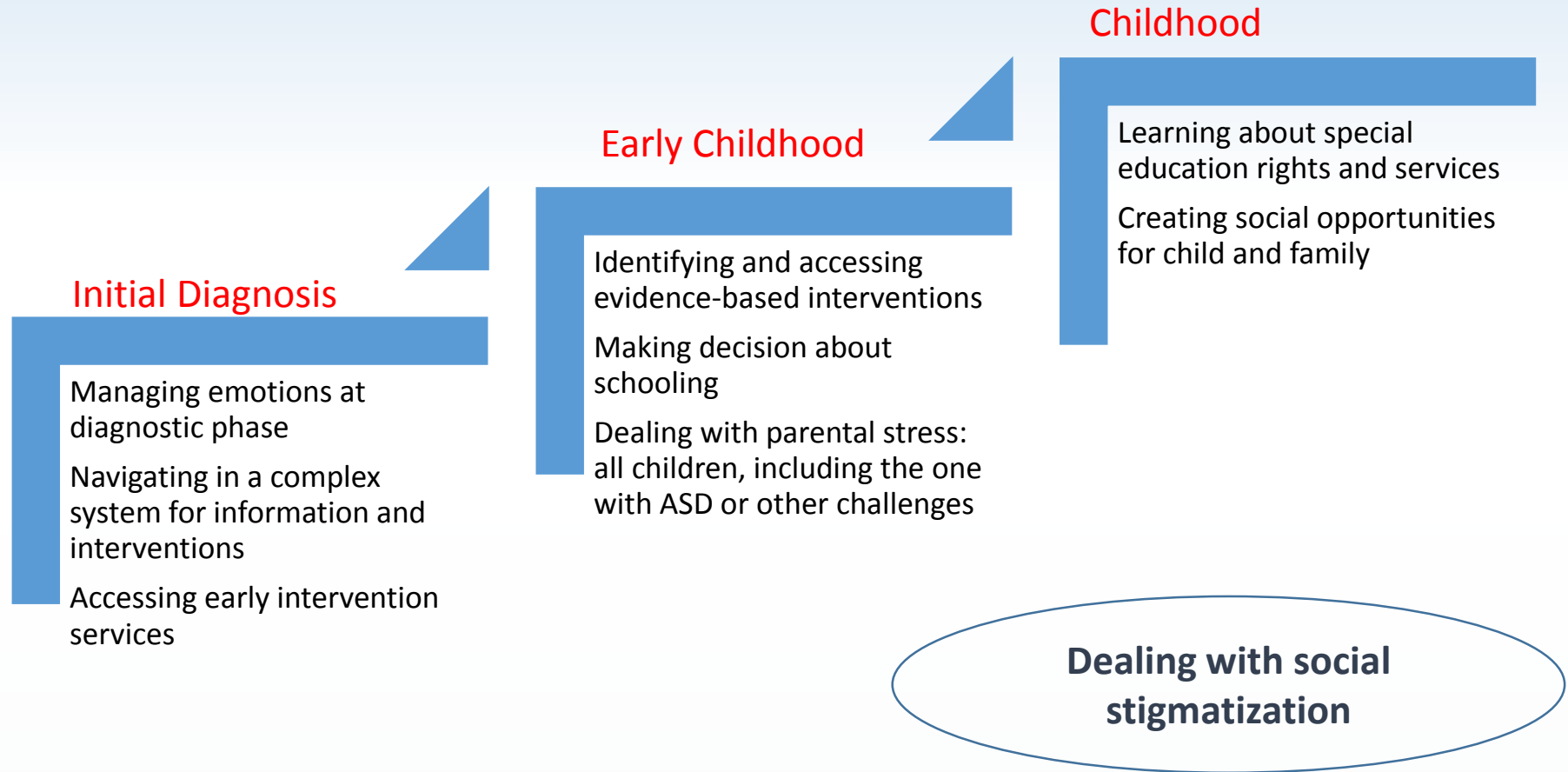
(Olsson & Hwang, 2001; Firat, et al., 2002; Davis & Carter, 2008)

4. Poorer self-perceived health

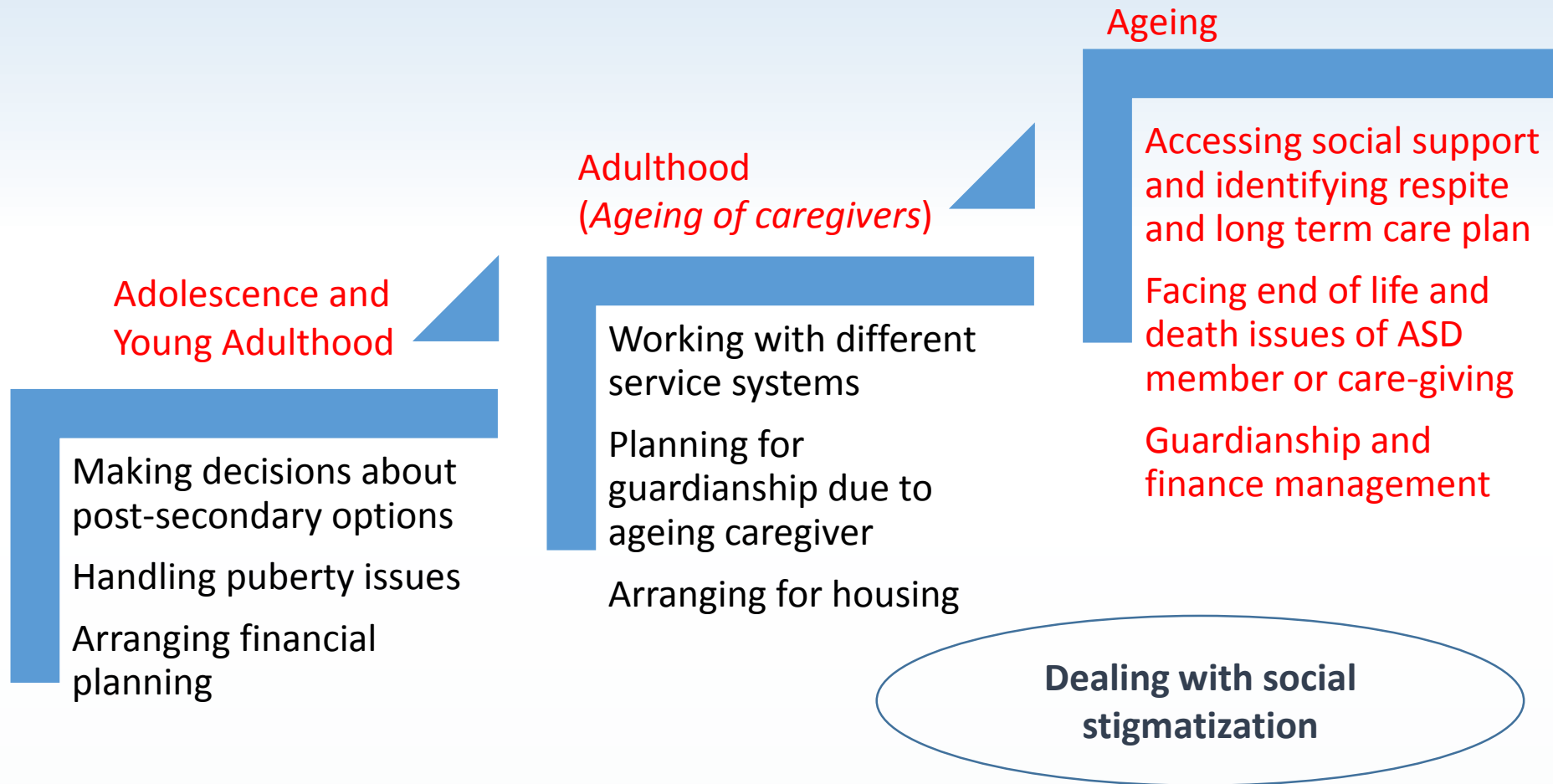
(Benjak, et al., 2009)

5. Family needs change over the life span!

Parents' needs in early childhood



Parent's needs in adulthood and beyond



Risks and needs of such families in HK

Limited studies! E.g. 2016 EdU report

Percentage of parent participants reporting discriminatory experience

| | Because I am a parent of children with ASD... | % of participants |
|----|---|-------------------|
| 1. | People treat me in a different way. | 80.7% |
| 2. | People look down on me. | 71.6% |
| 3. | People don't want to be my friend. | 70.5% |
| 4. | People don't want to visit me. | 68.9% |

Risks and needs of such families in HK

E.g. 2015 Fu Hong Society

- Stereotype and stress faced by parents of adults with ASD
- Parent stress mainly induced by
 - Unpredictable behaviors and emotional problems of their children
 - Stereotype on adults with ASD and their parents
 - Low acceptance towards the adults and their families

Inadequate policies to support families

- Services focus on individuals with ASD, less on their families
- Rights and support for families are advocated by parents, professionals and NGOs



主流教育自閉學童家長會
The Parents Association of Autistic Children in
Mainstream Education



學前弱能兒童家長會
THE PARENTS' ASSOCIATION
OF PRE-SCHOOL
HANDICAPPED CHILDREN



香港關顧自閉聯盟
Hong Kong Autism Awareness Alliance



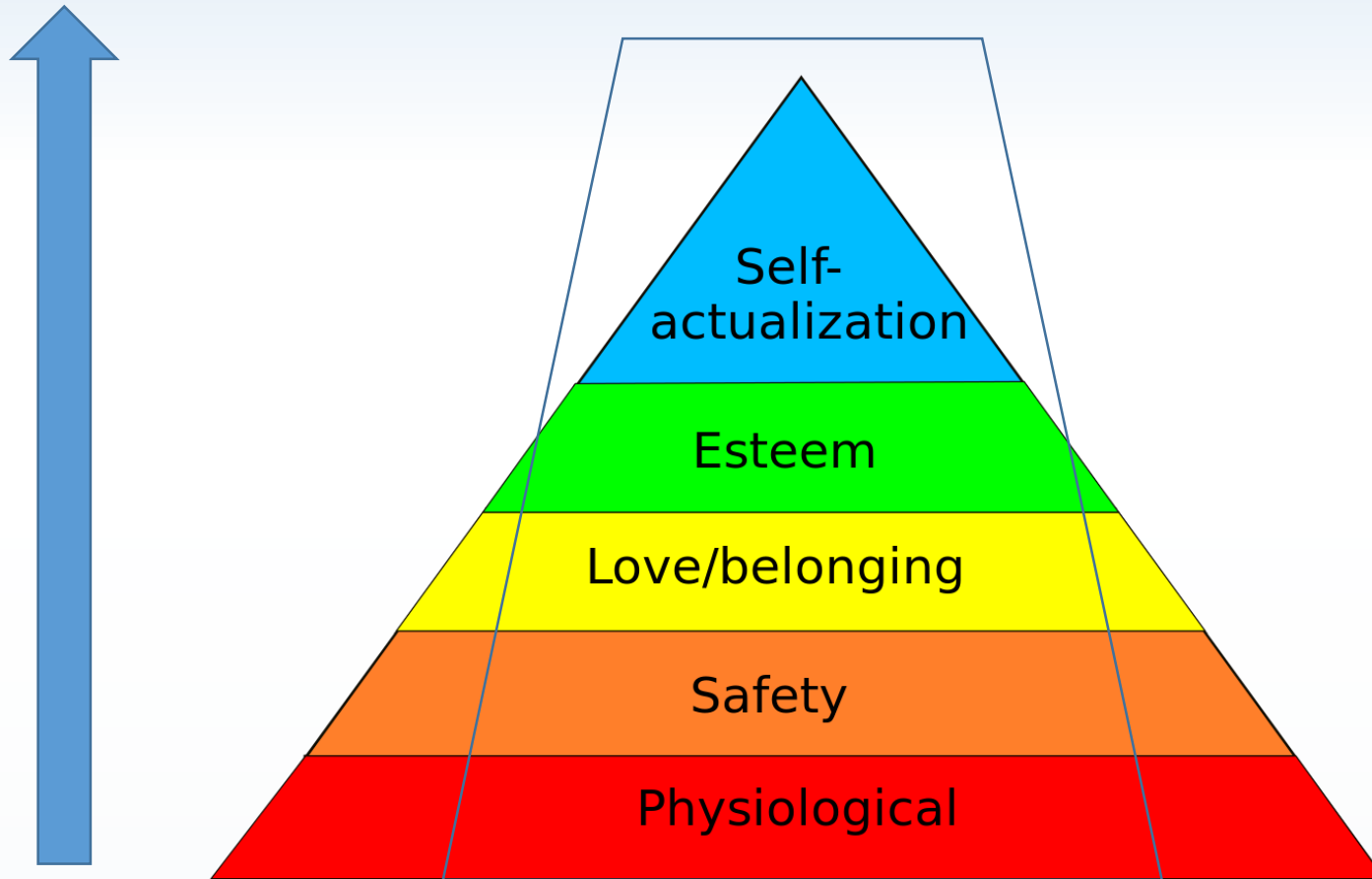
JOCKEY CLUB AUTISM
SUPPORT NETWORK
賽馬會喜伴同行計劃



自閉症人士福利促進會
Society for the Welfare of the Autistic Persons

What do they NEED?

Maslow's hierarchy of needs still useful!



Tasks of the JC A-Connect Family Support Team

Objectives

- 1. Understand** families needs
 - Identify family needs across the life span
 - Review existing family services and projected service gaps
 - Collect stakeholders' views on effective family support
- 2. Evaluate** existing services and identify less-known services
 - Evaluate support services provided by three designated NGOs
 - Identify and compile other less-known family support services
- 3. Enhance** support for such families
 - Propose a family support framework
 - Promote family support
 - Disseminate good practices

1. Understand family needs

1.1 Family Needs Study

- a. Family Needs Survey (quantitative)
- b. Family needs from parent focus groups (qualitative)

1.2 Systematic review on existing family services

Family Needs Survey – Original study

- Six dimensions of parent needs
(Siklos & Kerns, 2006; Arango-Lasprilla, et al., 2010)

| Child-centred Needs | Parent-centred Needs |
|-----------------------|---------------------------|
| Health information | Emotional support |
| Professional support | Instrumental support |
| Involvement with care | Community support network |

Family Needs Survey – Our study

- Target participants
 - Parents of individuals with ASD, across the life span
- Data collection
 - Online and hardcopies distribution
 - Completed questionnaires collected: > 500
- Comparison with Beijing
- Other Chinese communities?

Family Needs reported from HK Focus Groups

| Child-centred Needs | Parent-centred Needs |
|---|--|
| 1. Support for family on waiting list | 1. Support for parent's mental health |
| 2. Prompt and suitable resources for children newly diagnosed | 2. Peer mutual support among parents |
| 3. Responsive assessment and intervention from the Government | 3. Support for father's involvement in caregiving |
| 4. Special support for transition to different developmental stages | 4. Marital and family relationship sustainment and enhancement |
| | 5. Support from the core family (i.e. intergenerational support) |
| | 6. Special support for ageing caregivers |
| | 7. Public awareness and acceptance |

Systematic review on Family Needs and Services

Title

The effectiveness of interventions targeting the psychological well-being of parents having children with Autism Spectrum Disorder (ASD)

Research Questions

1. What interventions have been developed for the psychological well-being of these families?
2. Were they theory-driven?
3. Were they evaluated?
4. What outcomes were achieved?
5. How applicable to Hong Kong?

Systematic review – Flow of study

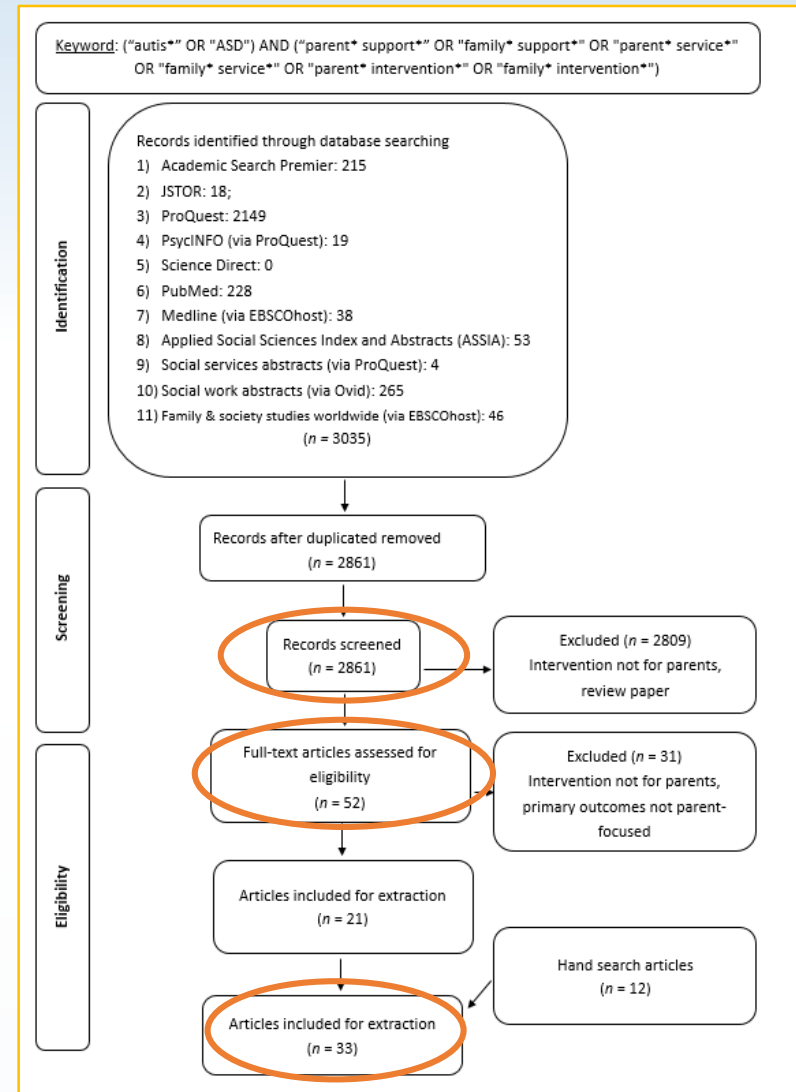
Abstracts reviewed: 2861
Articles reviewed: 33

Inclusion criteria

1. Peer-reviewed journal articles
2. Full-text available
3. Published in English
4. Primary outcomes on psychological well-being of parents having children with ASD

Exclusion criteria

1. Review/systematic review paper
2. Letter or commentary paper



Systematic Review – Key Findings

1. Limited international research and publications

- More on children than their parents
- Effectiveness of interventions under-investigated

2. Varied types of family interventions

- From individual- to group-based support
- From intensive training to general consultation
- From single to multiple sessions
- From mutual support to professional support

3. Limitations on included studies

- Small sample size
- Limited age group, more in early childhood
- Research methods not very rigorous

2. Evaluate existing services and identify less-known services

2.1 Evidence on service effectiveness

2.2 Identify less-known support programs in Hong Kong

Evaluation on Effectiveness of Selected Programs in Caritas, Heep Hong & SAHK

Quantitative evaluation

1. Pre-post questionnaire

- a) Eyberg Child Behavior Inventory (*Eyberg & Ross, 1978*)
- b) General Health Questionnaire -12 (*Goldberg & Williams, 1988*)
- c) Parental Stress Scale (*Berry & Jones, 1995*)
- d) Parenting Sense of Competence (*Gibaud-Wallston & Wandersmann, 1978*)
- e) Kansas Marital Satisfaction Scale (*Schumm, et al., 1986*)
- f) Functional Social Support Questionnaire (*Broadhead, et al., 1988*)

2. Program Satisfaction Rating

3. Fidelity check

Qualitative evaluation

Program-end focus groups

Service Effectiveness - Quantitative

| | | Total number |
|----|--|--------------|
| 1. | Programs evaluated | 37 |
| 2. | Participants enrolled | 242 |
| 3. | Pre-post questionnaires collected (Up to June 2016) | 113 |
| 4. | Focus groups conducted | 20 |

1. Recruitment not easy

- Location of satellite centres
- Help-seeking hesitations

2. “Fans” phenomenon – great supporters of single or multiple NGOs

- Outreach needed for hard-to-reach and hard-to-come parents

3. Research mindset needs enhancement

- Questionnaire completion is a challenge
- Do not complete questionnaires properly

Service Effectiveness – Qualitative from Post-program Focus Groups

Factors facilitating effectiveness

1. Goal-driven and theory-based
2. Clear manual with role play and homework
3. Case analysis and discussion
4. Staff quality – knowledge, experience and attitude
5. Suitable time and venue

Factors hindering effectiveness

1. Wrong expectation
2. Program content not in-depth enough
3. Unstable attendance
4. Program overrun

Documentation on Less-known Services

- All related services provided by three NGOs
- Relevant services by other agencies and private service providers

Insights from less-known programs

- Innovative support ideas are present → needs help to document these theory and practice impact
- Experience on serving different target groups is rich
 - different living area
 - different socioeconomic status
 - different strengths and interests, etc.
- Sustainability of services is an issue

3. Tap Stakeholders' views

Visited/Interviewed 14 Stakeholder/ Groups

| Parents | |
|-------------------------------|---|
| 1. | Parents, some professionals |
| 2. | Fathers group |
| Professionals | |
| 1. | Paediatricians |
| 2. | Clinical psychologists & Educational psychologists |
| 3. | Social workers |
| School representatives | |
| 1. | Special school Principals, teachers, social worker and speech therapist |
| 2. | Mainstream secondary school Principals, teachers, social worker |
| Community sectors | |
| 1. | Private services on home training for parents |
| 2. | Teaching aids and toys company team |
| 3. | Social services coordinators and researchers |

Stakeholders' views – Key findings

| | |
|-----------------------|---|
| On ASD Persons | 1. Long waiting list for diagnosis and services |
| | 2. At a stage of exploring services for ASD vocational support |
| | 3. Inadequate support for individuals with high-functioning ASD |
| On Parents | 1. Insufficient respite care and instrumental support for caregivers |
| | 2. Increasing father involvement |
| | 3. Existing services not systematic and corresponding to parent needs |
| | 4. Lack of services supporting parent mental health |
| On Families | 1. Marital and family relationship at risk |
| | 2. Perception of siblings towards ASD under-investigated |
| | 3. Financial burden on private services |
| On Community | 1. Insufficient public education |
| | 2. Low acceptance on families with ASD member |

4. Knowledge exchange with international scholars and professionals

6 Conferences

- Asia Pacific Regional Conference of International Meeting For Autism Research IMFAR in Shanghai, *November 6-9, 2015*
- Summit on Effects of Economic Growth on Child Health in Chinese Speaking Communities in Guangzhou, *February 27-28, 2016*

Presentation on the Project

- National Rehabilitation Conference in Guangzhou, *March 25 – 27, 2016*
- Singapore Conference on Applied Psychology, *June 14, 2016*
- Changing Practices of Health and Family in Japan in Hong Kong, *June 18-19, 2016*

Observations

Findings and Achievements in the past 10 months

1. Clearer ideas on family needs
→ facilitates proposal on Family Support Framework
2. Networked key stakeholders
→ facilitates implementation of Family Support
3. Established research foundation
→ facilitates future research work & program development

Special issues of interest, e.g.

- Ageing caregivers
- Gender and culture-specific family support
- Marital support:
Parents' marital relationship, and people with ASD as spouse

Way Forward

1. Propose a family support framework
2. Promote family support
3. Disseminate good practices

2016 Relevant Conferences at HKU

2016 March 14
Family Care-giving

PUBLIC POLICY
Symposium on
Family Caregiving in Chinese Societies – A Life Span Perspective
Monday March 14, 2016 | 9:30am - 5pm
Social Sciences Chamber, 11/F, The Jockey Club tower, Centennial Campus, HKU

Keynote: Intergenerational Caregiving as Productive Engagements (9:40am - 10:30am)

Speaker:
 Professor Nancy Morrow-Howell
Charles E. Young Professor of Gerontology
Washington University, St. Louis, USA

Moderator:
Professor Terry Lum
Head, Department of Social Work and Social Administration, HKU

Topic I: Theoretical Constructions of Intergenerational Caregiving (10:45am - 12:45pm)

Speakers:

| | |
|--|---|
| Dr Wylan Lou Soo Professor of Aging, HKU | Dr Esther Goh Department of Social Work National University of Singapore |
| Professor Samson Tse Associate Professor of Social Work and Social Administration, HKU | Professor Cynthia Leung Department of Applied Social Sciences The Hong Kong Polytechnic University |

Moderator:
Dr Rainbow Ho
Clinical Centre on Behavioral Health, HKU

Topic II: Evidence-based Interventions in Enhancing Intergenerational Caregiving (2pm - 3:30pm)

Speakers:

| | | |
|--|---|--|
| Professor Daniel Wong Department of Social Work and Social Administration, HKU | Professor Cynthia Leung Department of Applied Social Sciences The Hong Kong Polytechnic University | Professor Lotus Shyu Yee-ling Professor, School of Nursing CityU Hong Kong, CityU, Taiwan |
|--|---|--|

Moderator:
Dr Sandra Tsang

Details and registration:
www.socsc.hku.hk/pppl/fccs ~All are welcome~

Faculty of Social Sciences
Department of Social Work and Social Administration
The University of Hong Kong

2016 July 8
ASD

CALL FOR Abstracts

Jockey Club Autism Support Network
Hong Kong ASD Conference 2016
Supporting Learning and Development
July 8, 2016 | Hong Kong

The Conference aims to enhance support for children with Autism Spectrum Disorder (ASD), their schools and families. It provides a platform for experts, professionals, educators, caregivers and other interested individuals to share their work and insights on effective support for children and adolescents with ASD.

Keynote Speakers

| | |
|--|---|
| Dr Brenda Smith Myles Consultant The Ohio Center of Autism and Low Incidence (OCALI) and the Zigurat Group United States | Dr Florence Lee Consultant Paediatrician Child Assessment Service Department of Health HSAR Government |
|--|---|

Conference Co-chairs

| | |
|--|---|
| Dr Irene Ho Project Director (School Support) & Assistant Professor Department of Psychology Faculty of Social Sciences The University of Hong Kong | Dr Sandra Tsang Project Director (Family Support) & Associate Professor Department of Social Work and Social Administration Faculty of Social Sciences The University of Hong Kong |
|--|---|

Call for Abstracts
Scholars and professionals are invited to submit abstracts for poster presentation through the online system at the Conference website: **on or before April 29, 2016**.

Abstract Submission (Extended deadline: **April 29, 2016**)

www.socsc.hku.hk/JCA-Connect/hkasd2016

主辦機構 Funded by:
香港賽馬會慈善信託基金
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最高學術機構 Highest Institution:
Faculty of Social Sciences
The University of Hong Kong
香港大學社會科學學院

2016 Oct 20-22
Parenting

ICP21
International Conference on Parenting in the 21st Century
October 20-22, 2016 | Hong Kong
Hall 2, Lee Shau Kee Lecture Centre,
Centennial Campus, The University of Hong Kong

PUBLIC POLICY

Sponsors:

www.socsc.hku.hk/icp21

Keynote & Plenary Speakers

Keynote Speakers



Professor Frank F. Furstenberg Jr.
Department of Sociology, University of Pennsylvania



Professor Carolyn Webster-Stratton
School of Nursing, University of Washington

Plenary Speakers



Professor Kevin Chung
Department of Early Childhood Education
The Education University of Hong Kong



Dr. Sophie Hovighand
Munich Centre for Educational Research in
Developmental Issues
Department of Psychiatry, University of Bonn



Dr. Patrick Lo
Department of Psychiatry and Behavioral Sciences
JFK Faculty of Medicine, The University of Hong Kong



Professor Cynthia Leung
Department of Applied Social Sciences
The Hong Kong Polytechnic University



Dr. Susan Morton
Centre for Linguistic Research,
University of Auckland



Dr. Sandra Tsang
Department of Social Work and Social Administration,
The University of Hong Kong

2017 Jan 9: JC A-Connect: Family Support Conference

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