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<th>Preliminary findings of the Jockey Club Autism Support Network (JC A-Connect) Project - Family Support Team</th>
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<tbody>
<tr>
<td><strong>Author(s)</strong></td>
<td>Tsang, SKM; Wong, PWC</td>
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<td>The 2016 Hong Kong ASD Conference, Hong Kong, 8 July 2016.</td>
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Preliminary Findings of the Jockey Club Autism Support Network (JC A-Connect) Project - Family Support Team

Dr. Sandra Kit-man TSANG, Project Director
Dr. Paul Wai-ching WONG, Co-Investigator
JC A-Connect (Family Support Team)
Faculty of Social Sciences, The University of Hong Kong

Hong Kong ASD Conference 2016: Support Learning and Development
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

**Initial Diagnosis**
- Managing emotions at diagnostic phase
- Navigating in a complex system for information and interventions
- Accessing early intervention services

**Early Childhood**
- Identifying and accessing evidence-based interventions
- Making decision about schooling
- Dealing with parental stress: all children, including the one with ASD or other challenges

**Childhood**
- Learning about special education rights and services
- Creating social opportunities for child and family

**Dealing with social stigmatization**

*Myers, et al., 2009; Brown, et al., 2012; DeGrace et al., 2014; Russa, Matthews & Owen-DeSchryver, 2014*
Parent’s needs in adulthood and beyond

Adolescence and Young Adulthood
- Making decisions about post-secondary options
- Handling puberty issues
- Arranging financial planning

Adulthood (Ageing of caregivers)
- Working with different service systems
- Planning for guardianship due to ageing caregiver
- Arranging for housing

Ageing
- Accessing social support and identifying respite and long term care plan
- Facing end of life and death issues of ASD member or care-giving
- Guardianship and finance management

Dealing with social stigmatization

Myers, et al., 2009; Brown, et al., 2012; DeGrace et al., 2014; Russa, Matthews & Owen-DeSchryver, 2014
Risks and needs of such families in HK Limited studies! E.g. 2016 EdU report

Percentage of parent participants reporting discriminatory experience

<table>
<thead>
<tr>
<th>Because I am a parent of children with ASD...</th>
<th>% of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. People treat me in a different way.</td>
<td>80.7%</td>
</tr>
<tr>
<td>2. People look down on me.</td>
<td>71.6%</td>
</tr>
<tr>
<td>3. People don’t want to be my friend.</td>
<td>70.5%</td>
</tr>
<tr>
<td>4. People don’t want to visit me.</td>
<td>68.9%</td>
</tr>
</tbody>
</table>

The Education University of Hong Kong; March 2016
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
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)

<table>
<thead>
<tr>
<th>Child-centred Needs</th>
<th>Parent-centred Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health information</td>
<td>Emotional support</td>
</tr>
<tr>
<td>Professional support</td>
<td>Instrumental support</td>
</tr>
<tr>
<td>Involvement with care</td>
<td>Community support network</td>
</tr>
</tbody>
</table>
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

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

<table>
<thead>
<tr>
<th></th>
<th>Total number</th>
</tr>
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<tbody>
<tr>
<td>1. Programs evaluated</td>
<td>37</td>
</tr>
<tr>
<td>2. Participants enrolled</td>
<td>242</td>
</tr>
<tr>
<td>3. Pre-post questionnaires collected (Up to June 2016)</td>
<td>113</td>
</tr>
<tr>
<td>4. Focus groups conducted</td>
<td>20</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Parents, some professionals</td>
</tr>
<tr>
<td>2. Fathers group</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>Professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Paediatricians</td>
</tr>
<tr>
<td>2. Clinical psychologists &amp; Educational psychologists</td>
</tr>
<tr>
<td>3. Social workers</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>School representatives</th>
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</thead>
<tbody>
<tr>
<td>1. Special school Principals, teachers, social worker and speech therapist</td>
</tr>
<tr>
<td>2. Mainstream secondary school Principals, teachers, social worker</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Community sectors</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Private services on home training for parents</td>
</tr>
<tr>
<td>2. Teaching aids and toys company team</td>
</tr>
<tr>
<td>3. Social services coordinators and researchers</td>
</tr>
</tbody>
</table>
## Stakeholders’ views – Key findings

<table>
<thead>
<tr>
<th>Stakeholders</th>
<th>1. Long waiting list for diagnosis and services</th>
</tr>
</thead>
<tbody>
<tr>
<td>On ASD Persons</td>
<td>2. At a stage of exploring services for ASD vocational support</td>
</tr>
<tr>
<td></td>
<td>3. Inadequate support for individuals with high-functioning ASD</td>
</tr>
<tr>
<td></td>
<td>1. Insufficient respite care and instrumental support for caregivers</td>
</tr>
<tr>
<td>On Parents</td>
<td>2. Increasing father involvement</td>
</tr>
<tr>
<td></td>
<td>3. Existing services not systematic and corresponding to parent needs</td>
</tr>
<tr>
<td></td>
<td>4. Lack of services supporting parent mental health</td>
</tr>
<tr>
<td>On Families</td>
<td>1. Marital and family relationship at risk</td>
</tr>
<tr>
<td></td>
<td>2. Perception of siblings towards ASD under-investigated</td>
</tr>
<tr>
<td></td>
<td>3. Financial burden on private services</td>
</tr>
<tr>
<td>On Community</td>
<td>1. Insufficient public education</td>
</tr>
<tr>
<td></td>
<td>2. Low acceptance on families with ASD member</td>
</tr>
</tbody>
</table>
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 June 14
Family Care-giving

2016 July 8
ASD

2016 Oct 20-22
Parenting
2017 Jan 9:
JC A-Connect: Family Support Conference

Contact:

Dr. Sandra Kit-man TSANG, JP
Department of Social Work and Social Administration, HKU
Email: sandratsang@hku.hk
Telephone: (+852) 3917-1090
Website: www.jca-connect.hk


