Family Support and Development for People with ASD in Chinese Communities: The Case of Hong Kong

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JP, Associate Professor

Department of Social Work and Social Administration

Faculty of Social Sciences, The University of Hong Kong
Aims and Outline

1. Highlight families with ASD members need support that is timely and evidence-based
2. Report existing family support services in Hong Kong
3. Propose a Family Support Framework
4. Discuss implications for services and research development
Risks and needs of families of people with ASD
Rising global ASD prevalence, and in Hong Kong: Actual increase or raised awareness?

- **Students in mainstream schools**: 1 in 120 (not a population prevalence)
- Projected to further increase at a rate of 20% per year
- **2015/16**: 7,200; **2016/17**: 8,600; **2017/18**: 10,300

Records of Education Bureau (EDB) on number of students with ASD in public sector ordinary schools
ASD strengths and challenges as Spectrum: C (not A nor B!)

A

C: 3 dimensional!
Family challenges change across the life span. Transition adjustments are challenging!

<table>
<thead>
<tr>
<th>Diagnosis:</th>
<th>Schooling:</th>
<th>Work?</th>
<th>Aging</th>
</tr>
</thead>
<tbody>
<tr>
<td>Why? How? What to do?</td>
<td>How to achieve?</td>
<td>Home? Work? Sheltered work?</td>
<td>We are all aging!</td>
</tr>
</tbody>
</table>
Recent HK studies

• 2015 Heep Hong Society survey
  • Perceived parental difficulties of participation in community activities

• 2016 Qualitative study
  • Experiences and emotional well-being of parents of children diagnosed with ASD

• 2016 EdU survey
  • Discriminatory experiences of parents of children with ASD
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

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

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

You can never understand the feeling of facing them 24 hrs a day....
I dare not go out alone even for a meal....
it is hard for you to understand

I cried everyday once I understand what it means by ASD...
my heart feels being pricked all the time and I just wanted to end our lives together.
Families need support!

- **Individuals**
  - Desperate for help
  - Exhaustion
- **Couples**
  - Marital tension
  - Divorce
- **Other children**
  - Feel left out, frustrated
- **Grandparents**
  - Disappointed
  - Worried
- **Families**
  - Discrimination
  - Social isolation

Individual, family and social costs!!

Lots of important but unmet needs!!
The JC A-Connect Family Support Project

The team:
Dr. Sandra Tsang
Dr. Paul Wong
Ms. Karine Ngai
Dr. Samantha Wong
Ms. Wylie Lee
Ms. Yuen Suet Ying
Mr. Ryan Chan
2015-2018 JC A Connect 喜伴同行計劃：
Holistic Support for Children with Autism and Families

支援自閉學生

學習行為明顯進步

香港賽馬會慈善信託基金撥款一億六千一百萬元，為自閉症學生提供全面支援，昨日舉行啟動禮。
Background

- Hong Kong Jockey Club Charities Trust funded the JC A-Connect Autism Holistic Support Project from June 2015-2018
- HK$167.79 million
- 3 components: Family, School, Community
- 6 NGOs
- Website: www.jca-connect.hk
Family Support is **Key** to ASD Support!

Objectives of Family Support Team

1. **Understand** family 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
Examples of support for such families in HK

- Government
  - Maternity and Child Health Centres
  - Child Assessment Services
  - Hospital Authority: Psychiatric services
  - Education Bureau: mainstream and special schools with school social work services, Educational Psychological services, Parent-teacher Association
  - Integrative Family Services Centres
  - Disabilities allowance
  - Housing

- NGOs
  - Early childhood training services
  - Special child care centres
  - Integrated child care centres
  - Self-help groups
  - Social and vocational support, sheltered workshop
  - Hostels
  - Respite services

- Private sector
  - Assessment and training

- Religious organizations
  - Church fellowships

No systematic long term Rehabilitation Programme Plan (RPP):
JC A-Connect Project: 3 key NGOs (Caritas, Heep Hong & SAHK) joined to further expand their services through 18 satellite centres.
Family/Parent Support Programmes provided by 3 NGOs

Service Components and Year 1 Achievement

<table>
<thead>
<tr>
<th></th>
<th>Pledged (Year 1)</th>
<th>Actual (Year 1)</th>
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<tbody>
<tr>
<td>Number of Parent Support Sessions</td>
<td>1,700</td>
<td>Over 2,600</td>
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<tr>
<td>Number of Beneficiaries</td>
<td>8,500</td>
<td>Over 9,100</td>
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More families obtained support!
4 Types of Programmes

Multi-session group Programmes

Type A: ASD-specific coping
- e.g. Memory drill, study skills

Type B: Parenting sense of competence
- e.g. Positive parenting, parent-child art/exercise

Type C: Parent general health
- e.g. Yoga for parents only

Mass Programmes

Type D: Family functioning and support
- e.g. Talks, outings
Evaluation on Existing social services support for such families in Hong Kong
Quantitative evaluation on Selected Programmes: Measures

1. Pre-post structured 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. Programme Satisfaction Rating

3. Fidelity check
Evaluation results on Selected Programmes: 9 months since project commencement

4 Types of Programmes
Type A: ASD-specific coping (n=38)
Type B: Parenting sense of competence (n=56)
Type C: Parent general health (n=42)
Type D: Family functioning and support (Mass Programmes involving family members)

Quantitative results
136 respondents indicated they most preferred Type B Programmes
• Management of child’s behaviour
• Family functioning and social support
• Level of parental sense of competence
• Psychological well-being

Qualitative results
120 parent participants interviewed after Programme completion were very satisfied with the Programmes, especially Type B Programmes
How the Programmes affected the Parents

1. Knowledge and skills enhancement
   - Better understand the nature of ASD and their own children (Type A)
   - More confident to manage and support their child; More competent in solving problems in daily parenting (Type B)

2. Stress and emotional relief
   - Have learnt through others’ experience and sharing of their own thoughts; Peer support gained (Type C)
How the Programmes affected
Family relationship

1. Parent-child relationship improved
   • More adaptive dyadic interactions
   • Improved communication between parent-child dyads
   • More able to appreciate the positive attributes of child

2. Relationship with other family members improved
   • Able to generalize skills from one child to the other, as well as on the interaction with spouse
Observations:
Evidence-informed family support is needed to optimize service input!

Achievements from this evaluation study:
1. Enhanced awareness on evidence-informed services
   - Agency’s awareness on planning
   - Participant’s understanding on filling
2. Enhanced sensitivity on service evaluation outcome indicators
   - Programme satisfaction rating
   - Fidelity check
   - Structured questionnaire
   - Interview/focus group
   - Parent feedback meeting

Limitations from the current evaluation study:
- Centre-based multi-session services only
- Limited access to hard-to-reach parents and fathers
- Small sample size
- Unstable attendance
Visits to Stakeholders and less known but vibrant services!

Over
50 stakeholders
20 sessions of visits and interviews from
October 2015 to Dec 2016
Stakeholders’ views –
(Including professionals, parents, educators, private service providers and high-functioning youths with ASD)

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

- Documented relevant services by other agencies and private service providers, for example:

  - K’s Kids Toy Company
  - The Absolutely Fabulous Theatre showing ASD-Friendly
  - Professional Music Therapy Centre
  - International Centre for Gifted and Talented
  - Louis Programme
Vibrant new initiatives: New HFAs!

Healthy Functioning ASD: ASD in marathon walks to raise funds!

Happy Functioning ASD: ASD-friendly drama, art work and toys!

Helpful Functioning ASD: Volunteering!!
Observations on less-known services

1. Rich experience on serving different target groups
   • Different living area
   • Different socioeconomic status
   • Different strengths and interests

2. Innovative ideas are vibrant
   • Collaboration to document these theories and practice impacts

3. Issue on sustainability of services
   • Documentation of services
   • Evidence-informed intervention
   • Professional training of service providers
Other works by the Family Team

**Family Needs Survey**  
(Symposium 1)

**Aims:**
- Explore categories of needs experienced by parents of children with ASD in Hong Kong
- Understand important and unmet needs perceived by parents

Identified 4 major types of important and unmet needs:
- Professional support for child
- Child’s social health support
- Parent psychosocial support
- Government and community Support

**Systematic Review on Family Interventions**  
(Symposium II)

**Aims:**
- Provide an overview of all existing interventions for parents of children with ASD
- Synthesize essential elements of these parent interventions
- Evaluate the effectiveness of these parent interventions

**Found:**
- Increasing studies since 2011
- Study qualities varied
- Need for more robust studies
- Limited interventions for parents with elder children: Important in aging populations!!
2016 Relevant Family Support Conferences at HKU

2016 March 14
Family Care-giving

2016 July 8
ASD

2016 Oct 20-22
Parenting

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Implications

A blueprint will be useful!
The A-POWER Family Support Framework

「喜伴力行」家庭支援服務框架

3 Prevention levels

Primary prevention

Aim: A (ASD) Power in
Public acceptance
Organized support
Well-being of parents
Evidence-informed intervention
Resilience of family

Secondary prevention

Community
- Community support

Family
- Family functioning and support

Parent
- Parent general health
- Parenting sense of competence

Child
- ASD-specific coping

Tertiary prevention

Child developmental stages

Family life cycle

Social change

Changes

Implications:
- Services
- Research
- Community Ed
- People with ASD and family
Framework Aim

1. To provide a guide-map for services and research development to ensure families of individual with ASD receive proper and effective social services addressing their identified needs.
2. To ensure improvement of parent’s well-being is achieved at a community level.
3. To establish service effectiveness evidence on family support social services.
4. To nurture parents from being helped to self-help, then to help others.

Framework Assertions:
- **A (ASD) Power in**
  - Public acceptance
  - Organized support
  - Well-being of parents
  - Evidence-informed intervention
  - Resilience of family
Key Theories underlying the Framework

1. Public Health Approach *(Winslow, 1920; Last, 2007)*
2. Ecological Model *(Bronfenbrenner, 1986)*
3. Lifespan Perspective *(LeBlanc, Riley & Goldsmith, 2008)*
Public Health Approach (Winslow, 1920; Last, 2007)

3 Prevention levels

1. Primary prevention
   • Keep problems from emerging
   • Universal preventive interventions

2. Secondary prevention
   • Reverse harm from risk exposure
   • Selective interventions

3. Tertiary prevention
   • Reduce harm among individuals with high risk
   • Indicated interventions
4 Foci of intervention

**Individual**
1. Child-centred

**Microsystem**
2. Parent-centred
3. Family-focused

**Macrosystem**
4. Community-based

**Chronosystem:** Changes with time
5 Domains of family support

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<th>3</th>
<th>4</th>
<th>5</th>
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<tbody>
<tr>
<td><strong>ASD-specific coping</strong></td>
<td><strong>Parenting sense of competence</strong></td>
<td><strong>Parent general health</strong></td>
<td><strong>Family functioning and support</strong></td>
<td><strong>Community support</strong></td>
</tr>
<tr>
<td>• Knowledge</td>
<td>• Parent-child relationship</td>
<td>• Physical health</td>
<td>• Cohesion</td>
<td>• Public awareness</td>
</tr>
<tr>
<td>• Information</td>
<td>• Parenting skills</td>
<td>• Mental health</td>
<td>• Flexibility</td>
<td>• Public acceptance</td>
</tr>
<tr>
<td>• Skills</td>
<td></td>
<td>• Social health</td>
<td>• Communication</td>
<td>• Support at societal level</td>
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<tr>
<td></td>
<td></td>
<td>• Spiritual health</td>
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Framework Implications

1. Services
2. Research
3. Community Education
4. People with ASD and family
Example of new services guided by the Framework: Core Programme for new parents for new service providers

Parent Programme
12 hrs (6 x 2 hrs/week)
+ 2 hrs individual follow up

- Enhance understanding of ASD characteristics
- Provide information of current family support services
- Enhance communication skills and relationship building
- Provide care for caregivers

Professional Training on
Feb 16 & 17, 2017
(to conduct Parent Programmes)

Around 12 hrs

- Introduce JC A-Connect Project and the framework
- Introduce the core parent Programme proposed
- Equip workers with necessary knowledge and skills working with parents
- Provide platform for questions, comments and discussion
Theories underlying this new Programme

On Programme content
1. Family-centred Approach (Brookman-Frazee, 2004; Dunst, Trivette, & Hamby, 2007; National Research Council, 2001)
2. The Double ABCX (Lavee, McCubbin & Patterson, 1985) and Family Adjustment and Adaption Response (FAAR) model (Patterson, 1988) on family stress and coping

On Programme delivery
1. Social-cognitive Theory (Bandura, 1986)
## Other implications from the Framework

### Assertions to address: Child ➔ Family

<table>
<thead>
<tr>
<th>Services Needs</th>
<th>Research Needs</th>
<th>Community Education Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Multiple levels: universal, selected, indicated</td>
<td>More systematic exploration of family needs in local contexts</td>
<td>Build on strengths</td>
</tr>
<tr>
<td>Multiple ways of service delivery</td>
<td>More informants</td>
<td>Remove stigmatization</td>
</tr>
<tr>
<td>Developmental stage sensitive</td>
<td>More outcome indicators: physical, psychosocial</td>
<td>Early help-seeking</td>
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<tr>
<td>Culture, gender and age-sensitive</td>
<td>Longer follow-up</td>
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<tr>
<td>Evidence-informed</td>
<td>Public health model: use of psychological screening tool to identify at-risk families</td>
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<tr>
<td>Step up pre &amp; in-service professional training for service providers</td>
<td>Evidence to guide service development and research</td>
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HK ASD Designer Nang’s handicraft brought to US, China and Singapore!
「喜伴力行（A-POWER）家長支援課程」導師專業訓練

本課程由香港大學社會科學學院「喜伴同行」計劃家庭支援項目團隊設計，實在促進腦障礙自閉症接
障礙兒童的家長明白和接納自閉症，加強親職認知和策略，建立良好的親子關係，鞏固家
並提供互助平台，讓家長能互相支持。本計劃現舉辦相關導師訓練課程，詳情如下：

<table>
<thead>
<tr>
<th>日期</th>
<th>2017年2月16及17日（星期四及五）</th>
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<tbody>
<tr>
<td>時間</td>
<td>上午十時至下午五時正</td>
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| 地點 | 香港大學西翼學校賽馬會教學樓11樓，
      | 社會科學院會議廳（2月16日）及社會科學院多功能室（2月17日）。 |
| 目標 | 介紹「喜伴力行（A-POWER）家長支援課程」，收集同工支援家長的經驗、凝聚智
      | 慧；培訓同工對服務腦障礙自閉症兒童家庭的態度、知識、策略及資源等；推廣課
      | 程，使課程能支援更多有需要的家庭。 |
| 講者 | 「喜伴同行」計劃家庭支援項目團隊及參與計劃及執行課程的機構代表。 |
| 對象 | 有志開展腦障礙自閉症兒童家長服務的機構及同工。 |

如欲報名參加，請閲覽下文後頁的報名表，並於2017年1月20日或之前以電郵方式交回

(yysuen@hku.hk)，我們會以電郵回覆報名情況。

如有任何查詢，歡迎致電3917-5014與袁小姐聯繫。

參加者完成兩天訓練後，可獲「喜伴力行（A-POWER）家長支援課程」教材一套。
What Next? A-POWER!
Family Support and Development!

- **Sustainability** of quality services
  - Making services accessible
    - Alternative delivery modes: face-to-face in centre or in home-visits, supported by some on-line sessions
  - Making services evidence-based
    - Provide space for quality services providers to document practice wisdom
    - Support quality research
  - Making services more integrated
    - More cross-sectoral collaborations
- **Support** of emerging quality services
  - Position-sensitive: marital, siblings, grandparents, domestic helpers
  - Gender-sensitive
  - Age-sensitive across the life-span, especially in aging societies
- **Dissemination** of good practices
  - Local and relevant communities

**Efforts from all are Needed!**
References (1)


References (2)


Questions and Comments

thank you!