Beyond Assessment: Insight gained from assessment to interim support and tool development for children with Autism Spectrum Disorder

JC A-Connect - Hong Kong ASD Conference 2017, Symposium III on “Special Family Support Service”

Presentation:
Child Assessment Service, Department of Health

Â Dr. Estella K.F. Woo (Senior Medical officer; Specialist in Developmental-Behavioral Pediatrics)
Â Dr. Lorinda L. Lam (Clinical Psychologist)
DH Services in Identification of Developmental Problems in Children

<table>
<thead>
<tr>
<th>0-5 years</th>
<th>6-11 years</th>
<th>12-18 years</th>
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</thead>
<tbody>
<tr>
<td><strong>Family Health Service:</strong></td>
<td><strong>Student Health Service:</strong></td>
<td></td>
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<tr>
<td>Child Health Service in Maternal and Child Health Centre</td>
<td>Annual physical and psychological assessment in Student Health Service Centre &amp; Special Assessment Centre</td>
<td></td>
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<tr>
<td>Parenting</td>
<td>Psychological and behavioural assessment</td>
<td></td>
</tr>
<tr>
<td>Developmental Surveillance</td>
<td>Hearing screening</td>
<td></td>
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<tr>
<td>Hearing screening</td>
<td>Vision screening</td>
<td>Vision assessment</td>
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</tbody>
</table>

Suspected developmental, learning or behavioural problem

Multiple complex cases

**Child Assessment Service:**

- **Child Assessment Centres**
  - Multidisciplinary assessment
  - Rehabilitation plan formulation
  - Referral for education and rehabilitation service
  - Parental support

*population served*
ASSESSMENT SERVICE FLOWCHART

Preliminary Interview
Public health nurse will conduct interview to understand the physical, intellectual, behavioral and learning issues of the child.

Team Assessment
The multi-disciplinary team will perform assessments and formulate rehabilitation plan for child.

Referral and Follow Up
The multi-disciplinary team will arrange necessary referrals, interim support and review consultation for the child.
Child Assessment Service
Conditions Newly Diagnosed  2015

Number of referral to CAS  ≈ 10000
ASD newly Diagnosed in 2015  ≈ 2000

* New definition adopted from 2006
Child Assessment Service
Referral Flow Chart

Refer from:
Family Health Service
Medical Practitioner,
Psychologist, etc.

First Appointment by Registered Nurse

Team Intake Conference (TIC)

Single Discipline Assessment
or Team Assessment
- Case Conference
- Parent Interview

Referral

Education Placement
- Pre-school
- SWD & CRSPS

Therapy
- e.g. OT, PT, ST, etc.

Specialist Clinic
- e.g. ENT, Paediatric,
Eye, Psychiatric,

Others
- e.g. Home Help Services
Family Services
Respite Services, etc.

Remedial Services
Adjustment Service, etc.

School Age

Education Bureau

Special School

Re-assessment if necessary
Beyond Assessment: Subspecialty work in Autistic Spectrum Disorder

- Interim Parents' Support Programme
  - For preschool newly diagnosed cases
  - For mainstream primary school children with ASD

- Public and Professional education

- Support for Parent support groups and Parents’ Association

- Research (Hong Kong Assessment Battery of Theory-of-mind) for children
父母臨時支援計劃

學前自閉兒童家長講座
衝破障礙-小學篇：主流小學自閉症兒童訓練定航

Parents Interim Support Program- Preschool
Parents Interim Support Program- School-age
# Parents' Interim Support Programme

## Course Content

<table>
<thead>
<tr>
<th>Preschool Parent Workshop (4 sessions: 2 days); 5-6 rounds/year</th>
<th>School-aged Parent Workshop (5 sessions: 3 ½ days); once per year</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Understanding ASD Features/ Diagnostic issues (Paed)</td>
<td>1. Understanding ASD Features/ Diagnostic issues (Paed)</td>
</tr>
<tr>
<td>2. Overview on intervention strategies with evidence-based (Paed)</td>
<td>2. Underlying difficulties facing children with ASD in learning, social &amp; behaviors</td>
</tr>
<tr>
<td>3. Intervention for social and emotional aspects (Cp)</td>
<td>3. Understanding &amp; Management of emotional and behavioral problems</td>
</tr>
<tr>
<td>4. Understanding &amp; Management of emotional and behavioural problems (Cp)</td>
<td>4. Overview of social skill trainings</td>
</tr>
<tr>
<td>5. Facilitation of play and language skill (ST &amp; OT)</td>
<td>5. Overview of emotional regulations and problem-solving skills</td>
</tr>
<tr>
<td>6. Parents’ sharing &amp; Sharing on community resources(Social worker)</td>
<td>6. Parents’ stress management</td>
</tr>
<tr>
<td>7. Parents’ sharing &amp; sharing on Community resources</td>
<td></td>
</tr>
</tbody>
</table>
Preschool:

1. Core Features of ASD
   - 1. Behavioural analysis and management skills
   - 2. Development (language, play skill;)
   - 3. Social emotional reciprocity
   - 4. Parents’ Emotional Support

School Age:

1. Core Features of ASD
   - 2. Underlying difficulties
   - 3. Skill buildings: Social Cognition; friendship building,
   - 4. Organizational skills more specific
   - 5. Parents’ emotional support and Handling skills
Parental Stress Scale

<table>
<thead>
<tr>
<th></th>
<th>Total participants N</th>
<th>Total Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>2014 School age ws (pre)</strong></td>
<td>40</td>
<td>52.15</td>
</tr>
<tr>
<td><strong>2014 School age ws (post)</strong></td>
<td>31</td>
<td>51.16</td>
</tr>
<tr>
<td><strong>2015 School age ws (pre)</strong></td>
<td>45</td>
<td>53.60</td>
</tr>
<tr>
<td><strong>2015 School age ws (post)</strong></td>
<td>19</td>
<td>53.68</td>
</tr>
<tr>
<td><strong>2016 Pre-school ws (Pre)</strong></td>
<td>79</td>
<td>50.48</td>
</tr>
</tbody>
</table>
Parenting Stress Index (S.K. Cheung, 2000)

<table>
<thead>
<tr>
<th>Sources of stress</th>
<th>Preschool parents’ Rating (Mean Score)</th>
<th>School-age parents’ Rating (Mean Score)</th>
</tr>
</thead>
<tbody>
<tr>
<td>照顧子女所花的時間，較我能付出的多。</td>
<td>4.54 (2)</td>
<td>4.40 (2)</td>
</tr>
<tr>
<td>我有時擔心自己是否已為子女做足要做的事。</td>
<td>4.66 (1)</td>
<td>4.44 (1)</td>
</tr>
<tr>
<td>子女在我一生中帶來很大的壓力。</td>
<td>3.73 (4)</td>
<td>4.04 (5)</td>
</tr>
<tr>
<td>有了子女，使我再沒有甚麼時間和做其他事的餘地。</td>
<td>3.91 (3)</td>
<td>4.13 (3)</td>
</tr>
<tr>
<td>養兒育女是一項經濟重擔。</td>
<td>3.91 (3)</td>
<td>4.04 (5)</td>
</tr>
<tr>
<td>因為有了孩子，我難以兼顧其他方面的責任。</td>
<td>3.75 (5)</td>
<td>4.07 (4)</td>
</tr>
<tr>
<td>子女的行為常令我尷尬和感受到壓力。</td>
<td>3.54 (6)</td>
<td>4.07 (4)</td>
</tr>
<tr>
<td>有了子女，我人生便失去很多選擇和自主的機會。</td>
<td>3.47 (7)</td>
<td>3.51 (6)</td>
</tr>
<tr>
<td>Satisfaction gained from Child-rearing</td>
<td>Preschool parents’ Rating (Mean Score)</td>
<td>School-age parents’ Rating (Mean Score)</td>
</tr>
<tr>
<td>---------------------------------------------------------------------------</td>
<td>----------------------------------------</td>
<td>----------------------------------------</td>
</tr>
<tr>
<td>我很高興能夠為人父母。</td>
<td>1.59</td>
<td>1.89</td>
</tr>
<tr>
<td>我和子女十分親近。</td>
<td>1.67</td>
<td>2.04</td>
</tr>
<tr>
<td>我很喜歡和子女共渡時光。</td>
<td>1.68</td>
<td>1.96</td>
</tr>
<tr>
<td>子女讓我有被愛的感覺。</td>
<td>1.86</td>
<td>2.20</td>
</tr>
<tr>
<td>子女令我對將來感到更肯定和樂觀。</td>
<td>2.56</td>
<td>2.84</td>
</tr>
<tr>
<td>作為一個父母，我感到十分滿足。</td>
<td>2.22</td>
<td>2.42</td>
</tr>
<tr>
<td>我的子女為我帶來樂趣。</td>
<td>1.95</td>
<td>2.09</td>
</tr>
</tbody>
</table>
Insights from Parenting Stress Scale (PSS)

Â Raising a child with ASD is a life-long commitment with high level of stress (emotional and financial stress)

Â Parents facing embarrassment in handling child's behavioral and emotional problems

Â Positive/protective factors: good, enjoyable parent-child relationship & satisfaction as parents

Â Children's growing independence; Parents need to let go and leave hands
Parent Support Work
The Parents Association of Autistic Children in Mainstream Education (PAACME)
http://www.paacme.org.hk/
・ Regular parent sharing (傾情茶聚)
・ Regular talks and trainings for parents and children with ASD
家長會的一點歷史

早在十年之前，劉婉詩與邱瑞華博士，一起為家有自閉症子女的家長籌備建立一個專門為’retoristic disorder children’提供服務的機構。他們的設想及廣泛的知識與經驗，使他們設定的目標能夠被不斷的改變和完成。在這張小圖片中，我們可以看到家長們的潛力，家長們的積極和家長們的學員，由家長們組成的家長會，開始了一個新的旅程。家長們努力於將有關自閉症的知識和技能，帶到課堂，並與學生們一起分享。家長們希望學生們可以得到更好的支

家長會2012-2013年活動

經過若干次家長會的籌備，也得到了家長們的大力
支持。今季我們在2012-2013年在學校下了一定的努力
在這邊我們計劃了家長會的活動，這些活動除了對家長會帶來重要外，也
希望透過活動讓學生們成長，在培養孩子的路上更

2012年1月7日、2月1日、3月3日及7月7日

 المنزل

2012年8月18日及26日

中學生心理工作坊

2012年11月3日

週三晚會（CAS）

2013年1月

講座：自閉症病患父母需分析自閉症程

2013年3月

講座：主講教授，學生於自閉症病患的

2013年4月

有關社區的活動

自閉症病患的預防

2014年6月
Hong Kong Autism Parents Alliance (HKAPA)

目標：旨在凝聚及組織各自閉症家長會的力量，以專業、本土及全面的角度提倡及爭取自閉症人士在香港之服務及福利。作為關顧自閉症人士的一把聲音，我們致力讓社會清晰地明白自閉症人士所面對的困難、有關自閉症的治療模式和服務情況等。
香港自閉症人士家長聯會—融合教育小組」之組成機構包括：

1. 主流教育自閉學童家長會
2. 兒童體能智力測驗服務
3. 明愛康復服務家長諮詢聯會
4. 協康會同心家長會
5. 香港耀能協會「吾懂人情」計劃
6. 學前弱能兒童家長會
Hong Kong Autism Parents Alliance (HKAPA)

• Established in December 2007
• CAS professional staff as advisors
• Regular meeting with the parent group
  • sub working group (on Inclusive Education & Employment)
• Survey on i) use of complementary alternative medicine in children with ASD, ii) Parents’ understanding and participation in Inclusive Education
• Advocacy Work
Inclusive Education Sub group
「融合教育」核心工作小組

Å Survey on Parents’ understanding and participation in Inclusive Education in Hong Kong (家長參與融合教育-問卷調查)

Å 243 Questionnaire received; 189 (Primary School parents); 54 (Secondary School students)
問卷內容：

5 Domains:
- Parents’ Knowledge (家長對融合教育的認識)
- Parents’ Participation (家長參與融合教育的現況)
- Parents- School communication (家長與學校的溝通技巧)
- Parents’ Difficulties and Expectations (家長所遇到的障礙和對融合教育的期望)
問卷結論：

家校溝通困難

家長們最沒信心做到的就是要他們在與校方的意見分歧下，爭取合理的解決方案
家長常遇到的障礙可分成兩類

家長因素:
1) 家長擔心子女被排擠
2) 不認識融合教育的政策，怕子女受到歧視和怕影響與學校的關係

學校因素:
學校對自閉症缺乏認識，學校對融合教育的文化不夠開放和學校過份著重學業成績而忽略學生的社交和成長需要。
家長對融合教育的期望：

1) 學校能因應自閉症學生的社交／溝通／情緒／行為方面的需要，提供適切的支援服務

2) 增強教職員對自閉症的認識和處理技巧

3) 政府可以加強對自閉症學生的專業支援
Inclusive Education Sub group

Meeting with Education Bureau concerning the issues of "Liberal study" in the "New Secondary School Curriculum" (新高中通適課程)

- curriculum, accommodations in exam
- research to enhance thinking and executive skills teaching strategy plan

Institute of Vocational Education (IVE) (SEN support team)

Hong Kong Chinese University (入學最低要求)
SEN support by IVE

- Contact IVE’s Senior Project Coordinator via EDB related working group;

- Aim to communicate feedback parents’ concern regarding the special educational needs of ASD students
Employment Sub group

「就業」核心工作小組

Å Survey on the status of young persons with ASD in Hong Kong

Å Meeting with government departments concerning the needs and supported employment issues in Hong Kong

Å Advocate of their needs through mass media
Public education
Research

Â The Validation of the Chinese Version of the Autism-Spectrum Quotient Children’s Version (AQ-Child) in Hong Kong

Â Developing a Theory-of-Mind (ToM) Skills Assessment Battery for Cantonese-speaking Children in HK
Developed a Theory-of-Mind (ToM) Skills Assessment Battery for Cantonese-speaking Children in HK
Hong Kong Assessment of Theory-of-Mind (HKAToM)

Å Objectives:
Å To investigate the developmental trend of ToM skills in Cantonese-speaking children from preschool to elementary school years

Å To develop a test battery of ToM skills for Cantonese-speaking preschool and elementary school children

Å Subsidiary findings: To examine the validity of this ToM battery in discriminating children with and without social deficits, through study of ASD children with average intelligence and no oral language impairment versus typically developing children.
Project Team:
Coordinator: Dr. Estella WOO (PAED; SMOs/Specialty head)
Members: Lorinda Lam (CP), Pamela CHEUNG (ST), Annie Sheh (CP)

Co-investigator(s):
Dr. Carol TO, Assistant Professor, The University of Hong Kong, Faculty of Education, Division of Speech and Hearing Sciences
Dr. Anita Wong, Associate Professor, The University of Hong Kong, Faculty of Education, Division of Speech and Hearing Sciences
Lifespan perspective of Parents & Children’s Need

**Initial Diagnosis**
- Dealing with the emotional roller-coaster after diagnosis
- Information searching on understanding the diagnosis and training opportunities
- Educational planning
- Parental stress as lifelong commitment

**Early Childhood**
- Educational Planning (mainstream versus special school)
- Searching for further training opportunities

**Childhood**
- Transition to Primary school
- Dealing with increasing social challenges
- Managing emotional challenges due to academic & social challenges

**Adolescence & Young Adulthood**
- Challenges from Education & examination System
- Post-secondary and vocational planning & counselling
- Dealing with puberty issues (emotional and physiological challenges)
- Dealing with growing independence
- Financial planning
Conclusion

Â Parental stress along different stages of lifespan, how can we support the parents’ needs timely and effectively?

Â Parenting as life-long commitment: Parental stress versus Parental satisfaction; How to enhance the latter and nurture good parent-child relationship, while building child’s self-esteem and independence?

Â Needs for evidence-based intervention programs that cater needs of children with different transitional stages

Â Needs for public education and enhance public awareness

Â Needs for collaboration between different sectors and allow channels for communicating parents’ and children’s needs at different transition stages
The End

Thank You