Promoting Quality of Life and Best Outcomes: A Global Perspective on Community Engagement and the Empowerment of Individuals and Families with ASD

Hong Kong ASD Conference 2017: Family Support and Development

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Autism Speaks | New York

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Presentation Overview

• Global context

• Autism Speaks Global Autism Public Health (GAPH) initiative

• Science, tools and resources

• Role and well-being of caregivers

• Caregiver Needs Survey

• Parent Skills Training
Presentation Overview

- **Global context**

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Prior to 2010, most estimates from Western, developed countries 
Best estimates of global ASD prevalence 0.7 - 1% 
Recent estimates 2% or higher
A Global Perspective
Rising Prevalence and Costs

US Per Person Lifetime Cost in
Millions of $USD

With ID

Without ID

US Annual Cost to Society in
Billions of $USD

Buescher et al. 2014
>85% of our families live in LMIC, where the “treatment gap” is typically >90%

Though vastly different communities, many of the challenges are the same; *we can learn from them like they can learn from us*

Unique and more efficient opportunities to address some key scientific questions

**Main Barriers to Progress** –
- Lack of awareness
- Stigma
- Lack of expertise/capacity
- Lack of public health data (more than prevalence...)

*A Global Perspective
Autism is a Global Challenge*
Resolution adopted by the General Assembly

[on the report of the Third Committee (A/62/435)]

62/139. World Autism Awareness Day
United Nations

General Assembly

Distr.: Limited
5 December 2012
Original: English

Sixty-seventh session
Agenda item 127
Addressing the socioeconomic needs of individuals, families and societies affected by autism spectrum disorders and other developmental disorders
Comprehensive and coordinated efforts for the management of autism spectrum disorders
Urges Member States:

– To shift systematically the focus of care away from long-stay health facilities towards community-based non-residential services

– To strengthen different levels of infrastructure including care, education, support, intervention, services and To promote sharing of best practices, knowledge and technology

– To provide social and psychosocial support and care to families

– To recognize the contribution of adults living with ASD in the workforce and support workforce participation

– To identify and address disparities in access to services

– To improve health information and surveillance systems to capture data on ASD and other developmental disorders

– To promote context-specific research on the public health and service delivery aspects of ASD and other developmental disorders
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Support local leaders to address local priorities, using locally-customized solutions

Public and Professional Awareness Advocacy

Public Health Research Tool development

Services and Policy Development Dissemination and Implementation

- **Vodafone Foundation-funded**: ABA therapist training pilot (2010)
- **Albanian Ministry of Health launched**: Southeast Europe Autism Network (SEAN) a collaborative learning and action network (2010)
- **Albanian Children Foundation-funded**: Regional Center for Autism and Developmental Disabilities (2011)
- **SEAN Caregiver Needs Survey report**: SEAN 5th Anniversary meeting (2015)
- **Albanian mental health reform**: Curriculum and community engagement (2015)

- **Ministry of Science & Technology-funded:** “973” autism research project (2011)

- **Ministry of Health-funded:** (1) Professional training program, (2) Prevalence study (2012)

- **China Women’s Development Foundation:** WAAD/LIUB in 50 cities (2015); Parent Skills Training program (2015)

- **Fudan Children’s Hospital hosts:** Asia-Pacific Regional IMFAR, Shanghai (2015)

- **China Brain Project launch:** Autism as an early childhood focus (2015)
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2016

>70 countries with collaborative development activities
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Science, Tools & Resources – Disruptive and cross-cutting

Science

- Community-based participatory research
- Health services research
- Implementation science
- Prevention science
- Epidemiology

Tools & Resources

- Light It Up Blue/World Focus on Autism
- Advocacy Leadership Network (ALN)
- Autism Researchers without Borders (ARWB)
- Caregiver Needs Survey
- WHO-AS Parent Skills Training program (PST)
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Systems Context: “Services Pyramid”

WHO, 2003
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Implementation Science: Integrating Science into Practice

“It takes 17 years to turn 14% of original research to the benefit of patient care” – Balas et. al., 2000

Adapted from Landsverk, 2005 NIMH Mental Health Services Research Conference; Mittman, 2013 Institute for Implementation Research
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Empower Community: Community-based Participatory Research (CBPR)

### Features:

- Complements highly controlled academic research
- Focus on practice
- Involve community stakeholders, especially end-users, in prioritization of research questions, as well as design and implementation of the study
- Share outcomes with community participants and support their use to inform policy development and implementation, and resource allocation

Adapted from: Green, LW, 2014
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• Parent Skills Training
“Your mother and I are feeling overwhelmed, so you’ll have to bring yourselves up.”
Essential role of parents/caregivers in early child development

Science tells us:

• Investments in caregivers’ physical and mental health and nutrition promote child development

• Quality of care is compromised when a caregiver is suffering physically, mentally or economically and is associated with negative outcomes in a child’s growth and development

• Parenting and parent support programs, especially for disadvantaged or vulnerable caregivers enhance child development outcomes
Challenges for parents/caregivers of children with autism

Science tells us:

- Parent well-being is strongly influenced by child behavior and caregiving demands

- Child behavior is a predictor of caregiver psychological well-being and impacts self-perception (e.g., self-efficacy) and family functioning

- Parents of children with autism and other developmental disabilities are at higher risk for mental and physical ill health (e.g., stress, anxiety, depression), which compromises care, for both affected child and unaffected sibling, if any.
Additional factors that influence parents/caregivers well-being

Science tells us:

- Understanding/acceptance – “Cure” vs “Care” (importance of messaging)
- Culture and environment – Stigma, family and community (need for family-centered solutions)
- Access to answers and solutions (i.e. services) – Helplessness and empowerment
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How can we help?

Science tells us:

• Monitor concerns and refer to services as needed

• Targeted interventions that enhances resilience and improves mental and physical health for parents of children with autism* (e.g., psychosocial education)

• Empowerment – Advocacy and better child outcomes

*Da Paz & Wallander, 2016
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2016

43 countries are members of the Autism Speaks Advocacy Leadership Network
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2015

21 countries with recent or pending autism policy
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- Role and well-being of caregivers
- Caregiver Needs Survey
- Parent Skills Training
Caregiver Needs Survey (PI: Amy Daniels)

Aims:

• Engage and give the families and community a voice
• Provide a comprehensive picture of needs of families affected by autism;
• Inform improvements to national systems of care for individuals affected by autism and their families; and
• Leverage findings to secure additional resources to implement a region-wide project related to building capacity in autism research, training and services.
Caregiver Needs Survey

Methods:

• Convenience sample whereby partners identified advocacy and service provider organization in participating countries
• Translation to local language followed by blind back translation
• Primarily paper-based; interviewer administered or caregiver completed
• Survey domains:
  - Demographic characteristics (e.g. parental education)
  - Affected child characteristics (e.g. age at diagnosis; language ability)
  - Service encounters (e.g. past and present health and education service use)
  - Parent/caregiver perceptions (e.g. perceived stigma; primary challenges)
Caregiver Needs Survey

Methods:

• Based on existing population-based surveys on children with special healthcare needs, including:

  - *Interactive Autism Network’s Child with ASD Questionnaire (IAN, 2014)*;
  
  - *Survey of Treatment As Usual, Cost Network (Charman)*;
  
  - *Survey of Pathways to Diagnosis and Services (CDC, 2014)*;
  
  - *National Survey of Children with Special Health care Needs (CDC, 2011)*;
  
  - *Affective subscale, Affiliate Stigma Scale (Mak & Cheung, 2008)*; and,
  
  - *The Support for Member with Disability, Family Quality of Life Survey (The Beach Center on Disability)*.

• Targets primary caregivers of children <18 with diagnosis of ASD
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Southeast Europe Autism Network (SEAN)

- Established in 2010; Tirana Pledge
- 9 countries (Albania, BiH, Bulgaria, Croatia, FYRMacedonia, Kosovo, Montenegro, Romania and Slovenia)
- Observer country: Turkey
- Country Coordinator appointed by MoH
- Annual meeting to share information and resources
- Network project: Caregiver Needs Survey
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Caregiver Needs Survey (Select samples; Total N=834)

Ministry of Education; National; N = 168 caregivers

Clinical Psychiatry Hospital; National; N = 137 caregivers

Albanian Children’s Foundation; National; N = 192 caregivers

Selcuk University, Konya; 4 regions; N = 277 caregivers

University Children’s Hospital; Skopje; N = 60 caregivers
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**SEAN Caregiver Needs Survey**

## Table 4 – Diagnosis*

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Albania (n=192)</th>
<th>Croatia (n=168)</th>
<th>Macedonia (n=60)</th>
<th>Romania (n=137)</th>
<th>Turkey (n=277)</th>
<th>Total (n=834)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at diagnosis, mean (SD)</td>
<td>36.6 (15.8)</td>
<td>70.9 (32.3)</td>
<td>35.3 (14.3)</td>
<td>32.6 (11.2)</td>
<td>39.1 (20.8)</td>
<td>41.0 (22.8)</td>
</tr>
<tr>
<td>Diagnosed by, N (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary care doctor</td>
<td>6 (3%)</td>
<td>1 (1%)</td>
<td>0 (0%)</td>
<td>5 (4%)</td>
<td>4 (1%)</td>
<td>16 (2%)</td>
</tr>
<tr>
<td>Pediatric</td>
<td>2 (1%)</td>
<td>5 (4%)</td>
<td>3 (5%)</td>
<td>2 (2%)</td>
<td>8 (3%)</td>
<td>20 (3%)</td>
</tr>
<tr>
<td>Pediatric specialist</td>
<td>15 (8%)</td>
<td>24 (18%)</td>
<td>22 (37%)</td>
<td>1 (1%)</td>
<td>0 (0%)</td>
<td>62 (8%)</td>
</tr>
<tr>
<td>Psychologist</td>
<td>7 (4%)</td>
<td>9 (7%)</td>
<td>2 (4%)</td>
<td>18 (14%)</td>
<td>8 (3%)</td>
<td>44 (6%)</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>125 (65%)</td>
<td>17 (13%)</td>
<td>3 (5%)</td>
<td>70 (54%)</td>
<td>181 (66%)</td>
<td>396 (50%)</td>
</tr>
<tr>
<td>Neurologist</td>
<td>19 (10%)</td>
<td>4 (3%)</td>
<td>0 (0%)</td>
<td>18 (14%)</td>
<td>21 (8%)</td>
<td>62 (8%)</td>
</tr>
<tr>
<td>Nurse</td>
<td>0 (0%)</td>
<td>20 (15%)</td>
<td>20 (34%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>40 (5%)</td>
</tr>
<tr>
<td>Team of professionals</td>
<td>17 (9%)</td>
<td>49 (36%)</td>
<td>9 (15%)</td>
<td>15 (12%)</td>
<td>1 (0%)</td>
<td>91 (12%)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (1%)</td>
<td>6 (4%)</td>
<td>0 (0%)</td>
<td>1 (1%)</td>
<td>51 (19%)</td>
<td>59 (7%)</td>
</tr>
<tr>
<td>Distance for diagnosis, N (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 25 kilometers</td>
<td>27 (14%)</td>
<td>99 (61%)</td>
<td>47 (80%)</td>
<td>62 (48%)</td>
<td>152 (56%)</td>
<td>387 (47%)</td>
</tr>
<tr>
<td>Between 25-50 kilometers</td>
<td>26 (14%)</td>
<td>14 (9%)</td>
<td>2 (3%)</td>
<td>5 (4%)</td>
<td>58 (21%)</td>
<td>105 (13%)</td>
</tr>
<tr>
<td>Between 50-100 kilometers</td>
<td>49 (26%)</td>
<td>4 (2%)</td>
<td>4 (7%)</td>
<td>18 (13%)</td>
<td>24 (9%)</td>
<td>99 (12%)</td>
</tr>
<tr>
<td>More than 100 kilometers</td>
<td>77 (40%)</td>
<td>34 (21%)</td>
<td>3 (5%)</td>
<td>44 (34%)</td>
<td>38 (14%)</td>
<td>196 (24%)</td>
</tr>
<tr>
<td>I traveled outside the country</td>
<td>13 (7%)</td>
<td>11 (7%)</td>
<td>3 (5%)</td>
<td>1 (1%)</td>
<td>0 (0%)</td>
<td>28 (3%)</td>
</tr>
</tbody>
</table>

* Totals for each country may not add up to complete sample due to missing data
Table 7 – School enrollment for children > 5 years

<table>
<thead>
<tr>
<th></th>
<th>Albania (n=159)</th>
<th>Croatia (n=90)</th>
<th>Macedonia (n=42)</th>
<th>Romania (n=80)</th>
<th>Turkey (n=214)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preschool</td>
<td>40 (35%)</td>
<td>27 (30%)</td>
<td>9 (21%)</td>
<td>30 (38%)</td>
<td>31 (14%)</td>
</tr>
<tr>
<td>Public primary school</td>
<td>27 (17%)</td>
<td>6 (7%)</td>
<td>1 (2%)</td>
<td>25 (31%)</td>
<td>44 (21%)</td>
</tr>
<tr>
<td>Private school</td>
<td>4 (3%)</td>
<td>32 (36%)</td>
<td>7 (17%)</td>
<td>1 (1%)</td>
<td>3 (1%)</td>
</tr>
<tr>
<td>Special school for children with disabilities</td>
<td>13 (8%)</td>
<td>16 (18%)</td>
<td>0 (0%)</td>
<td>13 (16%)</td>
<td>101 (47%)</td>
</tr>
<tr>
<td>Home schooled</td>
<td>0 (0%)</td>
<td>8 (9%)</td>
<td>25 (60%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Not enrolled in school</td>
<td>75 (47%)</td>
<td>1 (%)</td>
<td>0 (0%)</td>
<td>11 (14%)</td>
<td>35 (16%)</td>
</tr>
</tbody>
</table>

Table 10 – Caregiver / family impact*

<table>
<thead>
<tr>
<th></th>
<th>All countries, N (%)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child’s autism has caused financial problems for family</td>
<td>544 (68%)</td>
</tr>
<tr>
<td>Family members have stopped working because of child’s autism</td>
<td>344 (43%)</td>
</tr>
<tr>
<td>Family members have cut down on work hours because of child’s autism</td>
<td>321 (41%)</td>
</tr>
</tbody>
</table>

* Totals may not add up to total N due to missing data
### Table 5. Perceived stigma among caregivers of children with ASD in Southeast Europe

<table>
<thead>
<tr>
<th>Statement</th>
<th>Albania (N=191)</th>
<th>Bulgaria (N=147)</th>
<th>Croatia (N=146)</th>
<th>Turkey (N=274)</th>
<th>All countries (N=758)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel helpless for having a child with autism, N (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strongly disagree</td>
<td>26 (14)</td>
<td>22 (15)</td>
<td>22 (15)</td>
<td>43 (15)</td>
<td>133 (15)</td>
</tr>
<tr>
<td>Disagree</td>
<td>46 (24)</td>
<td>63 (43)</td>
<td>71 (49)</td>
<td>75 (28)</td>
<td>255 (34)</td>
</tr>
<tr>
<td>Agree</td>
<td>77 (40)</td>
<td>48 (33)</td>
<td>39 (27)</td>
<td>83 (31)</td>
<td>247 (33)</td>
</tr>
<tr>
<td>Strongly agree</td>
<td>42 (22)</td>
<td>14 (10)</td>
<td>13 (9)</td>
<td>71 (26)</td>
<td>140 (19)</td>
</tr>
</tbody>
</table>
Preliminary Findings

- The majority of respondents were mothers (79%) with a primary (25%) or a secondary (25%) level education;
- The average age of the child when parents first became concerned was 24.0 months (SD 11.2 months), and the average age at diagnosis was 41.0 months (SD 22.8 months);
- 24% of caregivers reported traveling in excess of 100 km to receive a diagnosis for their child;
- Among children ages five years and older, 21% were not enrolled in school;
- Approximately one-third (33%) of all caregivers reported difficulties or delays in accessing needed care because of issues related to cost, and the majority (68%) reported that their child’s autism had created financial problems for the family. >50% of respondents feel “hopeless.”
Limitations, Conclusion and Next Steps

• Not a representative sample; lower SES likely to be underrepresented
• Diagnosis not always confirmed

• Preliminary findings from the survey provide valuable regional picture of:
  - Lack of awareness; debilitating stigma
  - Lack of access to care and education; lack of capacity
  - Uncertain quality of care
  - Significant economic burden for families

• In depth analysis of within and between country difference is ongoing
• Data collection for Latin America network (>3,000 families from 5 countries) and Morocco (200 families) studies completed.
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Parent-mediated social communication therapy for young children with autism (PACT): long-term follow-up of a randomised controlled trial

Andrew Pickles, Ann Le Couteur, Kathy Leadbetter, Erica Salomone, Rachel Cole-Fletcher, Hannah Tobin, Isobel Gammer, Jessica Lowry, George Vamvakas, Sarah Byford, Catherine Aldred, Vicky Slonims, Helen McConachie, Patricia Howlin, Jeremy R Parr, Tony Charman, Jonathan Green

Summary
Background It is not known whether early intervention can improve long-term autism symptom outcomes. We aimed to follow-up the Preschool Autism Communication Trial (PACT), to investigate whether the PACT intervention had a long-term effect on autism symptoms and continued effects on parent and child social interaction.

6 year follow-up showed sustained gains in symptom severity
Effectiveness of the parent-mediated intervention for children with autism spectrum disorder in south Asia in India and Pakistan (PASS): a randomised controlled trial

Atif Rahman, Gauri Divan, Syed Usman Hamdani, Vivek Vajaratkar, Carol Taylor, Kathy Leadbetter, Catherine Aldred, Ayesha Minhas, Percy Cardozo, Richard Emsley, Vikram Patel*, Jonathan Green*

Summary
Background Autism spectrum disorder affects more than 5 million children in south Asia. Although early interventions have been used for the treatment of children in high-income countries, no substantive trials have been done of the interventions adapted for use in low-income and middle-income countries (LMICs). We therefore assessed the feasibility and acceptability of the parent-mediated intervention for autism spectrum disorder in south Asia (PASS) in India and Pakistan.

Parental synchrony = 1.61; Child initiated communication = .99
Overview: PST Technical Working Group Meeting @ WHO HQ, July, 2014)

Parents know their children best. Leverage that knowledge to engage parents as co-therapists to enhance child outcome and to help meet the “treatment gap.”

More research on parent-mediated intervention in recent years (e.g., Autism Speaks Toddler Treatment Network and GAPH grants)

Additional evidence for decision-making:

- Reichow et al., 2013: PST programs for developmental disorders lead to improved child developmental and behavioral outcomes, and improved family well-being, regardless of intensity.
- Reichow et al., 2014: confirm effectiveness of low-intensity PST programs for developmental disorders; applicability to LMIC; component analysis.
- Kaminski et al., 2008: analysis of PST program components for managing children’s problem behaviors.
- Expert advice and experience
Evidence-base/Best that science can offer:

Principles and strategies from evidence-based intervention packages
Principles of Applied Behavioral Analysis (ABA)

Models:

Joint-Attention, Symbolic Play, Engagement and Regulation (JASPER);
Pivotal Response Teaching (PRT);
Discrete Trial Teaching (DTT).

Courtesy: C. Servili
Target Population:

All parents/caregivers with children 2-9 years of age who have a developmental delay or developmental disabilities, including ASD

Referred by primary healthcare provider, community health workers or specialists
Assumptions:

Some principles of parenting and early interventions strategies can be transferred across different settings.

Many program features will require tailoring to the local context.

Parenting programs should build on existing resources and services and be part of comprehensive and integrated programs.
Adaptation:

Modification of program for implementation to enhance compressibility, acceptability, feasibility and accessibility and relevance

Multi-sectorial collaboration driven by end users (parents and caregivers) feasibility and acceptability

Also enhances integration into existing systems (e.g., health, education, social protection)
Program Objectives:

Promote parent-child connection, communication and learning.

Promote child social, emotional, and cognitive development and reduce disruptive behaviors, both ultimately leading to improved child and family functioning.

Facilitate caregivers’ self-confidence in their parenting role, improve parenting skills and knowledge.

Improve caregiver coping skills and psychological wellbeing.

*We expect that the program will facilitate stigma reduction and result in increased inclusion and participation*
Requirements for Implementation:

Can be delivered by a range of non-specialist providers (such as nurses, teachers, social workers, and peer caregivers), at health facility level, at community level or in schools.

As part a network of community-based child health and development services and community mental health services.

Family-centered approach and stepped-care model, whereby the specific strengths and needs of families are assessed to ensure program is relevant to them, and families are referred to other available services when required.

The engagement of families and communities is paramount to give caregivers attendance and participation to the program feasible.
Training Materials

Learning Techniques:

• Adult learning, participatory techniques
• Video vignettes, case-based learning, modelling, role plays, feedback on parent-child interaction, parent coaching, homework, and self-assessment of progress.
• Feedback on videotaped parent-child interactions, when possible

Program Materials:

• Adaptation guide
• Facilitator guide
• Participant manual
• Homework forms
• M&E framework
• Manual for training of trainers and supervisors
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Parent Skills Training program (PST)

Program Organization:

- Caregivers & Children
- Program Facilitators
- Master Trainers
- WHO/AS PST Team

Courtesy: C. Servili
The PST programme

Caregivers meet every two weeks for 10 group sessions

... to reflect on their child’s strengths and difficulties

... to share their difficulties as caregivers

... and work on their personal goals

In group sessions, facilitators describe and show psychoeducational strategies...

... while three home visits are used to tailor the intervention and coach caregivers

The strategies taught aim to promote the development of...

... communication

... life skills

... inclusion and social engagement

[illustrations taken from the PST Participant Manual; artwork by Miguel Mendez]
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Parent Skills Training program (PST)

- Caregiver Well-being
- Skills
- Behaviour
- Communication
- Play and Routines
- Getting and Keeping Children Engaged

phone phone phone

Courtesy: C. Servili
Global Autism Public Health (GAPH) Initiative
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Parent Skills Training program (PST)

Some participating countries:

- China
- Malaysia (SEAMEO-SEN)
- Philippines
- South Korea
- Pakistan
- Russia
- Iran
- Egypt
- Ethiopia
- Kenya
- Argentina
- Peru
- USA

April 2015: Global Implementer Consultation
Conclusion

• The well-being of parents and caregivers for children affected by autism is critical for optimum child outcome and family functioning.

• Parents and caregivers’ understanding and acceptance of their children’s condition and the ability to readily access answers and solutions influence their mental and physical well-being.

• In addition to greater public and professional awareness, tools and programs like Caregiver Needs Survey and Parents Skill Training empower parents and caregivers by giving them a voice in helping to define priority needs of the community and the skills to help develop and implement feasible and sustainable solutions for their children.
Thank you!!!

“Families Are @ the Heart of Everything We Do”