

Technical Working Group Meeting on Parent Skills Training for Developmental Disorders

World Health Organization, Geneva, Switzerland
22-23 July 2014



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Technical Working Group Meeting on Parent Skills Training for Caregivers of Children with Developmental Disorders- Meeting Report

Background

Developmental disorders, including autism spectrum disorder, are a group of conditions with onset in infancy or childhood, characterized by impairment or delay in functions related to central nervous system maturation. Most affected children and families live in low- and middle-income countries (LMIC), but services have proven inversely proportional to a country's income (WHO, 2007) with a treatment gap of at least 80% in LMICs (Kieling, 2011). The lack of skilled human resources, especially at the primary health care and community level, is recognized as a major barrier to increasing service provision for children with ASD and other developmental disorders (WHO, 2013). Strengthening the capacity of community-based services for management of autism spectrum disorders and other developmental disorders is among the priorities that Member States signatories of the WHO Resolution on "Comprehensive and coordinated efforts for the management of autism spectrum disorders" recently agreed upon.

The role of parents and caregivers is critical in ensuring optimal child developmental outcomes and positive parenting is related to fewer behavioural problems during childhood and adolescence as well as improved emotional and social competence (Irwin L.G. et al, 2007).

The empowerment of parents and caregivers is increasingly being recognized as a critical component of care interventions for children with developmental disorders. Parenting a child with developmental disorders can be challenging and caregivers of children with developmental disorders more frequently report experiencing feelings of inadequacy and poor self-confidence. Therefore, parent training becomes particularly useful in this context.

Moreover, several systematic reviews of the literature suggest that parents and caregivers are able to learn the necessary skills to deliver psychosocial therapies to their children with developmental disorders and that children benefit from these interventions (Matson, 2009; McConachie, 2007; Oono, 2013). Evidence supports the notion that training for parents and caregivers of children with developmental disorders can be effectively delivered by non-specialists in community settings. Even low intensity programmes lead to improved child developmental and behavioral outcomes as well as improved family wellbeing (Reichow et al, 2013). The WHO mhGAP Intervention Guide for non-specialist service providers recommends parent skills training for management of developmental disorders when available. However, evidence-based parent skills training programmes for caregivers of children with developmental disorders that can be delivered by non-specialist providers, are affordable, and that can be feasibly implemented in low-resource settings, are not yet available to the public.

Objectives of the meeting

The meeting aimed to facilitate an exchange of views on proposed content and delivery strategies of the parent skills training programme and facilitate the establishment of a technical advisory group that will contribute to further development and pilot testing of the programme.

The specific objectives of the meeting were the following:

- To discuss effective programme components and service delivery strategies of parent skills training programmes for parents of 2-9 years old children with developmental disorders, including ASD;
- To exchange information and share experiences about challenges in adapting and implementing parent skills training programs especially in low-resource settings;
- To consult on proposed session content and organization of training modules;
- To discuss next steps regarding further development of the program and pilot testing.

The meeting was attended by 35 professionals with expertise and/or experience in the development, adaptation, implementation and evaluation of parenting programmes and parent-mediated interventions for caregivers of children with developmental disorders.

During day 1, the preliminary findings of a systematic evidence review on critical ingredients of parent skills training (PST) programme for developmental disorders (Reichow et al., 2014) were discussed, along with proposed outline for the programme. Participants shared experiences and lessons learnt about the implementation of parent-mediated interventions for developmental disorders in community and school settings, including capacity building strategies for professionals delivering such interventions, and barriers and opportunities for scaling up PST programmes in low-resource settings.

During day 2, the discussion focused on suggestions and practical implications of addressing comorbidities that often occur in children with developmental disorders, such as child maltreatment, child injury and behavioural disorders, and on strategies for pilot testing and programme evaluation.

Dr Saxena, director of the Department of Mental Health and Substance Abuse, closed the meeting by summarizing key suggestions made on content development, implementation and evaluation of the PST programme, and by presenting planned future actions to be undertaken by the WHO Secretariat in collaboration and consultation with the technical working group.

The Parent Skills Training Programme: Capacity building and implementation tools

This section of the report outlines the findings of the meeting in relation to proposed content and organization of the programme, and strategies to facilitate its implementation in countries.

Target beneficiaries:

It was agreed that the PST programme specifically address caregivers of 2-9 years old children with developmental delay or developmental disorders. It was suggested that the age range can be applied with flexibility allowing caregivers of younger and older children to take part whenever useful.

It was suggested that a 'common element approach' is adopted and the content of the programme focus on strategies that can benefit a group of caregivers with heterogeneous needs.

Primary caregivers of children with developmental delay/developmental disorders will be invited to attend the programme. Other family members will be informed and involved in the programme. It was agreed that minors (siblings) will not be considered among primary beneficiaries of the programme.

Aims and Objectives:

Primary aims of the programme include the following:

- Promote better understanding and acceptance of developmental delay and developmental disorders;
- Help parents apply skills that promote child development and functioning.

Secondary aims of the programme include strengthening caregivers' coping skills and psychological well-being, and reducing child disruptive behaviours.

It is expected that the programme will facilitate stigma reduction against persons with developmental disorders and result in increased inclusion and participation of children with autism spectrum disorders and intellectual disabilities.

Delivery strategies

The PST programme can be delivered by a range of care providers, including specifically non-specialist providers, such as nurses, teachers, social workers, and peer caregivers, at health facility level, at community level or in schools.

It is recommended that the programme is not offered in isolation but as part of a network of community-based child health and development services and community mental health services. Parenting programmes should build on existing resources and services to maximize sustainability.

They should be part of comprehensive care programmes available to families of children with developmental disorders.

Caregivers are referred to the programme by specialists or by non-specialists care providers (including primary care providers and community-based workers) whenever a developmental delay or developmental disorder, including specifically autism spectrum disorders and intellectual disabilities, are identified in the context of child development monitoring or other child care visit.

The programme adopts a family-centred approach and stepped-care model, whereby the specific strengths and needs of families are assessed and considered for ensuring the programme is relevant to them, and families are referred to other available services whenever required.

Based on the findings of evidence reviews (Reichow et al., 2014) and expert advice, the programme will include a combination of group and individual sessions.

It was emphasized the importance of exploiting opportunities for integrating PST within home visits according to the opportunities available in the local context, and the fact that different strategies can be effective in reaching all families in need, particularly the most vulnerable populations. It was suggested that the programme is organized in such a way to allow for adaptation and flexibility to meet the realities of the local context and local health and educational systems.

The engagement of families and communities is paramount to make caregivers' attendance and participation to the programme feasible.

Programme Organization and Content

It is proposed that the program adopts a modular organization, with a limited number of individual (home) and group sessions proposed as 'core' part of the program, possibly followed by additional optional sessions according to the specific needs of the group and availability of resources. The package of materials for facilitators should include guidance on how to assess participants' needs and how to adapt the organization of training accordingly while ensuring quality and fidelity to the programme.

Home visits at the beginning of the programme will be required to assess the families' strengths and needs, help parents set priorities for the programme, and tailor the content of training to the specific situations to the extent possible.

'Core' group sessions (6-7 sessions) will mainly focus on caregivers' knowledge of child development and developmental disorders, skills to improve child communication and engagement in caregiver-child interaction and behaviour management strategies. Optional group sessions may address comorbid conditions and include additional strategies for parent support.

The implementation of the programme in countries will require adaptation of both content of training materials and delivery strategies.

The package of PST programme tools will include the following: i) Facilitator guide; ii) Adaptation guide; iii) Participant manual; iv) Monitoring and evaluation framework; v) Training of trainers manual and supervisors.

Capacity Building for Facilitators and Supervisors of the PST Programme.

The importance of establishing criteria for ensuring facilitators have the required knowledge and skills for the task was emphasized. Selection criteria for facilitators include basic literacy, previous experience with children with developmental disorders, and possibly experience with early childhood development programmes and mhGAP. It was suggested that the programme can be delivered by teams with diverse set of skills and education background. Teams should be well recognized and accepted by the community.

The selection of facilitators will take into consideration factors affecting the sustainability and scalability of the project in the local contexts.

Facilitators will receive initial face-to-face training (2-3 days or more) followed by hands-on training (co-facilitation of PST with the support and supervision of more experienced facilitators/specialists) and brief face-to-face workshop for additional feedback and for competency-based assessment of facilitators' skills.

Training of facilitators should include strategies for conducting a developmental assessment, strategies for collaborative goal setting with families, active coaching and problem-solving. The training of facilitators should also address facilitators' own attitudes towards persons with developmental disorders. Capacity building will adopt competency-based strategies, active coaching, behavioural change techniques and case-based learning.

Continuous support and supervision is a critical element for effective implementation of PST by non-specialist providers. A number of tasks will require consultation with supervisors and joint decision making (e.g. definition of objectives and targets for families; adaptation of the programme to the needs of the group of caregivers).

The use of video-feedback and e-health/m-health approaches can be instrumental for capacity building, assessment of fidelity to the programme, ensuring appropriate mentoring and supervision, and for offering follow up and individualized support to families in-between and at the end of the group sessions.

Planning the field testing of the Parent Skills Training programme

Meeting participants shared their experiences with evaluation of PST programmes and their interest and plans related to field testing of the PST programme.

It was agreed that a monitoring and evaluation framework will be provided along with other implementation tools. A more detailed protocol for the evaluation of implementing the PST programme by research teams will also be developed.

Conclusion and next steps

The next steps will involve developing the set of capacity building and implementation tools of the PST programme, in consultation with the technical working group, and making them available for pilot testing the programme in countries in 2015.

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Annex 1. AGENDA

Technical Working Group Meeting on Parent Skills Training for Caregivers of Children with Developmental Disorders.

Tuesday, 22 July 2014:

09:00 - 09:45	<ul style="list-style-type: none"> - Welcome remarks and introduction (Oleg Chestnov) - Special remarks (<i>Shekhar Saxena, Andy Shih, Alexander Butchart, Bernadette Daelmans</i>)
09:45 - 11:00	<ul style="list-style-type: none"> - Project objectives and meeting expected outcomes (<i>Chiara Servili</i>) - Evidence review on critical ingredients of PST programmes for developmental disorders (<i>Brian Reichow</i>) - Proposed outline of PST programme and key points for discussion (<i>Cary Kogan and Chiara Servili</i>) <p>Chair: <i>Shekhar Saxena</i></p>
11:00 - 11:20	Coffee break
11:20 - 12:40	<p>Parent-mediated interventions for developmental disorders in community and school settings: lessons learnt. Session 1</p> <p>Gauri Divan Connie Kasari Helen McConachie Atif Rahman</p> <p>Chair: <i>Mark Tomlinson</i></p>
12:40 - 13:40	Lunch break
13:40 - 15:00	<p>Parent-mediated interventions for developmental disorders in community and school settings: lessons learnt. Session 2</p> <p>Nicoletta Armstrong Merry Barua Chantal Pallais Zeba Rasmussen</p> <p>Chair: <i>Andy Shih</i></p>
15:00 - 15:20	Coffee break
15:20 - 16:45	<p>Effective learning strategies and barriers/opportunities for scaling up PST programmes in different cultural settings</p> <p>Amina Abubaker Bettina Schwethelm/Deepa Grover Mark Tomlinson</p>

	Chair: Julian Eaton
16:45 - 17:15	Wrap up of day 1
18:00	Reception at Main Cafeteria

Wednesday, 23 July 2014

09:00 - 11:00	Presentation of revised programme outline based on recommendations from day 1 and discussion <i>Atif Rahman and Brian Reichow</i>
11:00 - 11:30	Coffee break
11:30 - 12:30	Practical implications of addressing comorbidities, such as child maltreatment, child injury, behavioural disorders, etc. Judy Hutchings Daniel Maggin Jamie McLaren Lachman Chair: Christopher Mikton
12:30 – 13:30	Lunch break
13:30 – 15:00	Pilot testing and evaluation Jamie McLaren Lachman Chantal Pallais and Julian Eaton Edward Winter Chair: Olayinka Omigbodun
15:00 – 15:30	<i>Coffee break</i>
15:30 – 16:30	Conclusions and next steps Chair: Shekhar Saxena

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Annex 4. List of PST programmes and projects presented during the meeting.

World Health Organization and UNICEF. Care for Child Development: improving the care of young children. Geneva, 2012.

UNICEF Home Visiting Programme for Children with Developmental Difficulties

Gauri Divan, PASS

Usman Hamdani and Atif Rahman, The FaNs for kids project.

Connie Kasari, JASPER

Jamie McLaren Lachman, Judy Hutchings, Lucie Cluver, Catherine Ward, and Frances Gardner. SINOBUYO CARING FAMILIES PROJECT PARENT HANDBOOK. Clowns without borders, South Africa, 2014.

Nicoletta Armstrong, International Child Development Programme

WHO and ICDP Oslo, Improving Mother/child Interaction To Promote Better Psychosocial Development in Children, 1998.