

# Interventions for Children with Pervasive Developmental Disorders in Low and Middle Income Countries

Richard P. Hastings\*, Janet Robertson† and M. T. Yasamy‡

\*School of Psychology, Bangor University, Bangor, UK; †Centre for Disability Research, Lancaster University, Lancaster, UK;

‡Department of Mental Health and Substance Abuse, World Health Organization, Geneva, Switzerland

Accepted for publication 25 August 2011

**Background** Although interventions for children with pervasive developmental disorders (PDD) have been the focus of research effort and evidence reviews in many Western countries, this evidence has not been assessed in the context of low- and middle-income (LAMI) countries especially in terms of the fit with different cultures and resources.

**Method** As a part of the WHO MH-GAP project, we carried out a systematic review of published literature relating to interventions for PDD in LAMI countries. Given the small amount of direct evidence found, we supplemented the review with findings from existing relevant evidence reviews to draw practical recommendations.

**Results** We found only four controlled studies evaluating an intervention for children with PDD in a LAMI coun-

try. These studies all evaluated different interventions. A systematic search of controlled studies of evidence-based parenting training interventions (Incredible Years and Triple P) in non-LAMI countries identified two studies both indicating successful outcomes.

**Conclusions** The evidence base for interventions for PDDs in LAMI countries is sparse, and to inform practical and future research recommendations, it is important to consider potentially deliverable behavioural parent training interventions. Such interventions need to be explored in LAMI countries when delivered in primary and secondary healthcare contexts.

**Keywords:** autism, intervention, pervasive developmental disorder, systematic review, treatment, World Health Organisation

## Introduction

Pervasive developmental disorders (PDDs) are complex neurodevelopmental disabilities, involving severe and lifelong impairment in multiple areas of development assessed relative to the individual's developmental level or mental age. Within DSM-IV (APA, 1994) and ICD-10 (WHO, 1992), PDDs include autistic disorder, Rett's disorder/syndrome, child disintegrative disorder, Asperger's disorder/syndrome and pervasive developmental disorder – not otherwise specified (PDD-NOS).

Diagnosis of PDDs relies on the presence, as well as the absence, of various key behaviours. The diagnosis of Autistic disorder (Autism) has been influenced strongly by the notion of the triad of impairments identified by Wing & Gould (1979). These impairments form the bedrock of the diagnostic criteria of autism

in DSM and ICD systems. The diagnosis of Asperger's syndrome is focused on social interaction deficits and also restricted or repetitive interests and activities. There is no delay in language development and typical or even enhanced intelligence. Some clinicians and researchers refer to individuals who might meet the diagnostic criteria for Asperger's syndrome as having High Functioning Autism. PDD-NOS has been included in diagnostic symptoms to enable the identification of individuals who do not have all of the features of autism or another PDD, but whose symptoms are clearly characteristic of the PDDs (i.e. marked impairment of social interaction, communication and/or stereotyped behaviours or restricted interests). Autism, Asperger's syndrome and normally PDD-NOS are together sometimes called the Autism Spectrum Disorders (ASDs).

Recent epidemiological data from the UK suggest that ASD has a prevalence of about 1% in children 5–16 years of age (Green *et al.* 2005; Baird *et al.* 2006). Using the UK Office for National Statistics Child Mental Health surveys of 1999 and 2004, Totsika *et al.* (2011) provided a population-based estimate of the prevalence of intellectual disability within children with ASD of 52% (95% CI: 42–62%).

In Kanner's (1943) original report on autism, he observed that it appeared to be a phenomenon associated with higher social achievement in parents. This observation has not survived empirical investigation in Western societies. For example, Tsai *et al.* (1982) reviewed the cases of referrals to an autism diagnostic service in Iowa, USA and assessed fathers' social status. They found no evidence of a difference between paternal social status in the referred group when compared with the Iowa population in general. Furthermore, cases of autism have been reported in many low- and middle-income (LAMI) countries, and prevalence studies in LAMI countries reveal a similar range of estimates as those from Western countries and other high income countries (e.g. Zhang & Ji 2005; Ghanizadeh 2008), and professionals in different cultures identify similar symptoms as important for diagnosis as those found in Western diagnostic systems (Daley & Sigman 2002). These data, although limited, led Daley (2002) to suggest that autism is a universal disorder, occurring in all cultures, but potentially susceptible to cultural influences in its presentation and course.

The impairments present in PDDs, along with associated difficulties such as intellectual disability and significant behaviour problems (Brereton *et al.* 2006; Totsika *et al.* 2011), have a significant impact on the quality of life of affected children. Furthermore, autism in particular is associated with psychological distress and reduced quality of life for family members. Parents of children with autism are at increased risk for stress and mental health problems even when compared with parents of children with other disabilities (Hastings, 2008). Although less marked, siblings of children with autism appear to be at increased risk especially for behaviour problems themselves (Petalas *et al.* 2009). Given the difficulties experienced by children with autism and their family members, there has been considerable interest in interventions that might be used to improve the functioning of the children and positively affect family members' quality of life.

In this review, we summarize the literature on intervention for children with PDDs in LAMI countries. Specifically, we address the question commissioned by the WHO:

*For children with pervasive developmental disorders (including autism), what interventions (including educating and training parents) in primary and secondary health care are effective as compared with treatment as usual?*

We do not address the identification of PDDs or epidemiology of PDDs in LAMI countries. In addition, there was only a very small evidence base identified via the review process. Therefore, to ensure that practical suggestions could be included in the report, we drew on a broader evidence base about interventions focused on training parents of children with PDDs. In this task, we focused on data available via meta-analyses, systematic reviews and UK national guidance developed after robust review and expert consensus processes.

## Method

Searches of electronic literature databases were conducted to identify peer reviewed articles published from 1990 to July 2009 in the English language, which included information from relevant studies in LAMI countries. Eligibility for inclusion of countries was determined by reference to the World Bank List of Economies<sup>1</sup>. In this, economies are divided among income groups according to 2007 gross national income per capita, calculated using the World Bank Atlas method. The groups are: low income, 935 US dollars or less; lower middle income, \$936–\$3705; upper middle income, \$3706–\$11 455; and high income, \$11 456 or more.

The databases searched were: Medline, Cinahl, Web of Science and PsycINFO. In each database, terms for PDDs and associated synonyms were identified. The most appropriate method for searching for research from LAMI countries was also identified. These two searches were then combined to get a pool of literature with information about PDDs and LAMI countries. Within this pool, specific search terms relating to this review were then introduced (i.e. intervention, management, therapy, training etc.). Full details of the search strategies and terms employed can be found in Appendix. All sources identified by searches were first assessed for their relevance to the review objectives via the reading of abstracts. Two researchers completed this process and had 100% agreement on the extraction of articles relevant to the final review. If abstracts were unavailable, or did not provide enough detail to assess

<sup>1</sup>[siteresources.worldbank.org/DATASTATISTICS/Resources/CLASS.XLS](http://siteresources.worldbank.org/DATASTATISTICS/Resources/CLASS.XLS).

the relevance of the source, the full text version was obtained and relevance assessed from this. Data were extracted from the full text of articles identified as being relevant to the review.

The reference lists of all obtained and relevant articles were also hand searched for other potentially relevant sources. No additional articles in English were identified that described PDD interventions in LAMI countries. This gave some confidence to the comprehensiveness of the pool of articles obtained in the absence, given the short time frame for the review, of additional methods used to identify relevant literature.

## Results

Four studies were identified where an intervention for children with PDD was carried out in a LAMI country and evaluated against treatment as usual, another intervention, or included any control group. No study was excluded based on an evaluation of any other characteristic of the research reported therein. Given the very small number of identified studies, the range of interventions and outcome measures used, and the lack of reporting of detailed descriptive statistics in several articles, a formal meta-analytic synthesis of these studies was not appropriate. Thus, the WHO grading criteria for the quality of evidence in systematic reviews could not be applied. Instead, each study is summarized in Table 1 along with a descriptive analysis below. Effect sizes for each of the four studies were calculated by the present authors, if not reported in the original article, and are included in Table 1.

Allam *et al.* (2008) compared the potential facilitating effect of scalp acupuncture to existing language intervention for children with autism in an Egyptian context. The results suggest a moderate to large effect size after 9 months of intervention for receptive but not expressive language outcomes, and also a small effect size only for general attention skills related to language teaching sessions. Given the serious lack of information about the language outcome measure, the validity of these results is unclear. Furthermore, there is no clear hypothesis related to why the scalp acupuncture might facilitate learning of receptive language skills but not expressive skills. The authors suggest that the effect is via 'increased blood flow velocity to the brain' but there was no measurement of this putative effect.

Lal & Bali (2007) also focused on intervention to improve language skills in young children with autism in special schools in Mumbai, India. Language intervention as usual was compared with 14 20–30 min sessions

of individual training using matching procedures and supported by the use of reinforcers for correct responding. Using the total score on a measure the authors developed for the study, we calculated that the intervention apparently had an effect of a moderate to large size. The validity of this conclusion is in question for several reasons, the three most significant probably being the lack of information about the outcome measure (e.g. lack of standardization and psychometric data), the fact that the outcome measure was reported as using similar items to the materials actually used in the intervention sessions, and the lack of diagnostic information on the children within the study.

Miral *et al.* (2008) reported the results of a double-blind randomized controlled trial of two forms of pharmacotherapy for children and adolescents with autism in Turkey. Such interventions are not designed to target the core features of autism but may be used to assist in the management of significant behaviour problems in children with autism. The study was well designed, was reported in a European journal, and used well known and established outcome measures notably the Aberrant Behavior Checklist (ABC: Aman & Singh, 1986) as a measure of behaviour problems. As with the Allam *et al.* (2008) and Lal & Bali (2007) studies, Miral *et al.* did not include a statistical analysis of the data that reflected the two group nature of the design and the repeated measurement from pre- to post-intervention. We calculated an effect size for the total ABC score from information provided within the article, and there was evidence of a large effect on reduction in behaviour problems over 12 weeks in favour of risperidone over haloperidol. The authors also reported that risperidone was associated with fewer negative side effects.

Finally, Wang (2008) evaluated the effects of a parent training intervention in China. The intervention was a 12-week programme focused on education about autism and a range of applied behaviour analysis (ABA) evidence-based practices. Group teaching of parents was combined with a small number of home visits. Only a very brief evaluation measure was used: a 5–7 min videotaped observation of parent–child interaction at pre- and post-intervention. There was evidence of a large and moderate to large effect on parental responsiveness and positive affect, respectively, for the parent training intervention compared with a waiting list control group. This study has a number of design weaknesses that limit the validity of the conclusions that can be drawn: a very brief measure focused only on parent behaviour and not child outcomes, the same researcher carried out the training and the observations, and there

**Table 1** Four controlled intervention studies identified in the review focusing on low- and middle-income countries

Study	Country and classification	Participants	Design	Outcome measures	Results
Allam <i>et al.</i> (2008)	Egypt – LMI	20 children (12 boys and 8 girls) 4–7 years of age. All had a clinical diagnosis of autism and had their autism diagnosis confirmed via Autism Diagnostic Interview with a parent, and a Childhood Autism Rating Scale score above 29. All children were currently in receipt of language therapy from the same therapist twice per week for an unspecified duration each week	Random allocation to one of two groups: 5 boys and 5 girls received standard language therapy 7 boys and 3 girls received language therapy plus scalp acupuncture The scalp acupuncture was administered twice each week for 2 weeks (needles in place for 20 min each session), followed by a 1-week rest. Pattern repeated for 9 months in total (50 acupuncture sessions per child). No other therapeutic interventions in place. Language therapist blind to group status Allocation (not explicitly stated as random) to one of two groups: Communication support as usual Direct teaching using various matching procedures and application of reinforcers/rewards Intervention 20–30 min per session for 14 individual sessions. Only briefly described as involving the following: ‘Exposure to an object (e.g. cup or shoe). Match object or its picture with its picture. Match object or picture/symbol with its appropriate sign. Point/Sign/Name object or picture or symbol when asked’.	An Arabic language test. Reference source is a conference presentation, and no information provided about psychometric properties, or potential ranges of scores in each domain	Separate <i>t</i> -tests showed significant changes in both groups for attention, receptive language skills, and expressive language skills. Using means and SDs provided in the paper, Cohen’s <i>d</i> effect sizes (in favour of acupuncture group) were calculated as follows: Attention = 0.25 Receptive language = 0.75 Expressive language = –0.03
Lal & Bali (2007)	India – LMI	30 children with autism ages 5–10 years in three special schools in Mumbai. Method of diagnosis not reported. All children receiving support for communication in schools via their classroom teachers. Nature of teaching/support not described	Allocation (not explicitly stated as random) to one of two groups: Communication support as usual Direct teaching using various matching procedures and application of reinforcers/rewards Intervention 20–30 min per session for 14 individual sessions. Only briefly described as involving the following: ‘Exposure to an object (e.g. cup or shoe). Match object or its picture with its picture. Match object or picture/symbol with its appropriate sign. Point/Sign/Name object or picture or symbol when asked’.	A tool (The Scale for Communication Skills – SCOMS) generated specifically for the study to assess general communication skills, and receptive and expressive language using materials similar to those used in the intervention. No psychometric data presented	SCOMS scores are reported pre- and post-intervention for the two groups but with no SD provided. SD estimated from <i>t</i> -test data reported in the article. For SCOMS total score, no $2 \times 2$ ANOVA was provided, but an estimate of effect size was obtained using the means provided along with the estimated SD. Effect size Cohen’s $d = 0.78$

Table 1 (Continued)

Study	Country and classification	Participants	Design	Outcome measures	Results
Miral <i>et al.</i> (2008)	Turkey – UMI	30 children with autism 8–18 years of age, 24 boys and 6 girls. Diagnosis using DSM-IV criteria via a consensus between two child psychiatrists. Participants excluded if had epilepsy, a concomitant neuropsychiatric disorder, a psychotic disorder or another pervasive developmental disorders diagnosis	Randomized controlled trial design, double blind, over 12 weeks. One of two pharmacological treatments: Haloperidol (dopamine receptor antagonist) Risperidone (atypical antipsychotic) 1–2-week screening period followed by 10 weeks of drug intervention. Pre- and post-testing carried out. Two children were lost to follow-up from the risperidone group	Main behaviour outcome was the Aberrant Behavior Checklist (ABC; Aman & Singh, 1986), well used in autism and intellectual disability pharmacology studies especially in the USA. Not explicitly stated, but a translated version may have been used and no psychometric data for this are provided	Authors analysed the data using non-parametric tests (no rationale provided) and hence analysed pre-post change in the two groups independently. Authors report fewer side effects (also using well-validated measures) for risperidone. Calculation of effect size for total ABC scores was done based on the reduction in means pre- and post- and SDs reported in the article. Cohen's $d = 1.27$ in favour of the risperidone group

**Table 1** (Continued)

<i>Study</i>	<i>Country and classification</i>	<i>Participants</i>	<i>Design</i>	<i>Outcome measures</i>	<i>Results</i>
Wang (2008)	China – LMI	<p>Advertised for children under 10 years old with a clinical diagnosis of autism. Thirty-nine families responded, 34 gave written consent.</p> <p>Autism confirmed using Chinese versions of the Psycho-Educational Profile – Revised and the Childhood Autism Rating Scales.</p> <p>Two-thirds of parents reported previously having had training provided to them, but precise details are not given in the article</p>	<p>Random allocation of 34 children into two groups (2 girls in each group):</p> <p>Waiting list for intervention (parents later received training) – 5 parents dropped out</p> <p>Parent training – 2 parents dropped out</p> <p>Parent training consisted of 16 h group training and 4 h of individual home visits over 4 weeks.</p> <p>Training carried out by the researcher.</p> <p>First session general education about autism, followed by various applied behaviour analysis topics (principles of behaviour analysis, behaviour change procedures, changing parent behaviour, natural environment teaching, simplifying language, prompting, schedules, functional assessment of behaviour problems)</p>	<p>5–7 min free play videotaped observation 1 week prior to training and then post-training.</p> <p>Coded by the researcher (i.e. not blind) using a recognized parenting behaviour rating scale to assess responsiveness, affect, achievement orientation and directiveness.</p> <p>Inter-rater reliability obtained</p>	<p>Author reports results of ANCOVA of post-test scores using pre-test scores as covariate.</p> <p>Found significant group differences (in favour of intervention group) for responsiveness and affect.</p> <p>Author also reports effect size (Cohen's <i>d</i>) for each of the four outcome scores (where a positive effect = more change in the parent training group):</p> <p>Responsiveness = 0.91 (Positive) Affect = 0.75</p> <p>Achievement orientation = 0</p> <p>Directiveness = -0.18</p>

was no control for therapist contact as an explanation for the findings. As with all of the intervention studies reviewed here, there were also no long-term follow-up data. Thus, it is unclear to what extent parents might have implemented newly learnt skills over time with their child with autism.

#### Further evidence for parent training intervention

The four studies identified through systematic review clearly indicate that it is possible to generate controlled trial evidence for interventions for children with PDDs in at least middle-income countries. None of the studies included in this review were designed to address the question of whether the interventions might be delivered by healthcare workers in primary or secondary care settings potentially under the supervision of mental health workers. In fact, all studies used interventions delivered by experts: acupuncturist, pharmacists and psychiatrists with careful monitoring of drug effects, or behaviour analysts/special education teachers. The availability of such experts throughout LAMI countries is likely to be sparse. Furthermore, given that there is only a single evaluation study associated with each intervention, the quality of supporting evidence is poor. Therefore, it is important to consider other sources of evidence that might help to answer the review question and may lead to some practical suggestions.

In carrying out the searches for this review, a number of articles were identified that provide background information about PDDs and interventions within LAMI countries. Although we did not subject this literature to a systematic review, two themes emerged strongly in published studies that may help to inform a second phase of consideration of the review question. First, the relatively recent recognition of autism as a disorder in several LAMI countries was noted (e.g. Clark & Zhou 2005; Wang 2008). This was associated with a perceived lack of awareness about autism. Lack of awareness about autism was also noted among healthcare workers within several countries including India (Juneja *et al.* 2005; McCabe 2007) and Nigeria (Bakare *et al.* 2008, 2009a,b). Second, a significant problem in LAMI countries is the lack of availability of services for individuals with PDDs (Aluri & Karanth 2002; Clark & Zhou 2005; McCabe 2007; Bakare *et al.* 2009b).

Given these circumstances, large-scale support for intervention for children with PDDs in LAMI countries will probably need to be mediated at the present time via parents and other family members. Wang's (2008) focus was on teaching parents ABA-based intervention

skills. This follows the logic that ABA-based methods have an established evidence base in the education of young children with autism (e.g. Eldevik *et al.* 2009, 2010). Intervention delivery is normally via trained therapists who are professionally supervised by experts but Wang's data, along with a small number of uncontrolled or descriptive studies from LAMI countries (Kalra *et al.* 2005; Yanqing 2006), suggest that training parents may be a viable option. To date, researchers in LAMI countries have designed their own parent training interventions to impart ABA-based skills. In addition, evaluation designs have been very limited. Thus, it is not possible to clearly recommend an approach as one that might be considered evidence based.

#### Parent-mediated interventions for children with PDDs in non-LAMI countries

Looking at the question of parent-mediated interventions for children with ASD more broadly, there was a Cochrane systematic review on this topic in 2003 by Diggle, McConachie and Randle that focused on early interventions (for children 1–7 years of age). Only two studies were found that met the quality criteria for review, and one of these involved an intervention that was primarily delivered by professionals. Thus, clear implications for practice could not be drawn.

In a more recent follow-on systematic review also focused on children 1–7 years of age, McConachie & Diggle (2007) reported data from nine studies, six of which purported to be randomized controlled trials (although only four of these RCTs met Cochrane quality criteria for inclusion in systematic reviews). McConachie and Diggle summarized the evidence from all nine randomized and quasi-randomized studies and found that the interventions evaluated and the methods and measures used varied considerably from study-to-study. Therefore, it was difficult again to draw conclusions for practice. The general conclusions drawn were that: (i) Parent-mediated interventions for children with ASD can work to deliver positive change in the children, (ii) Parent-mediated intervention does work when tested using efficacy designs (RCTs) both in terms of child outcomes and in the reduction of parental distress (notably depression), but (iii) There was no evidence currently that parent-mediated interventions were effective in achieving positive outcomes under conditions of typical practice.

McConachie & Diggle (2007) suggested that we look outside the PDD field for data on parent-mediated intervention that may be applicable. Reviews from the UK

National Institute for Health and Clinical Excellence (NICE) follow an established systemic review procedure to derive implications for clinical practice. Two recent reviews of childhood behaviour problems are consistent in the conclusions about the utility of training parenting skills as evidence-based interventions. In a joint review with the UK Social Care Institute for Excellence (SCIE) in 2006, NICE recommended parent training and education programmes as interventions for children with conduct disorders. In 2009, NICE also recommended parent training as an intervention for children with Attention Deficit Hyperactivity Disorder (ADHD). The ADHD review also concluded that children with ADHD and intellectual disabilities would benefit from parent training interventions. In the conduct disorders review (NICE/SCIE, 2006), an economic analysis was carried out and concluded that group format parent training (for 10 families) for 2 h per week over a 10 week course typically cost between £500 and £720 per family to implement. In the UK context, this is a low cost intervention. Although for LAMI countries, this is likely to seem a high cost, much of the cost relates to the input of healthcare workers to deliver the training programme. Thus, such interventions may be viable in LAMI countries.

To consider how best to use the conclusions of these UK NICE reviews to inform the current report, two questions are important to ask:

1. To what extent might the difficulties associated with PDDs relate to conduct problems and ADHD, and so can we reasonably generalize from the NICE evidence to children with PDDs?
2. What sorts of parent training interventions might be worth evaluating for children with PDDs?

In terms of the first question, recent population-based data from the UK show that children with ASDs have elevated risk for both conduct and ADHD problem behaviours (Totsika *et al.* 2011). Adjusted Odds Ratios (i.e. controlling for a number of other variables including the presence of intellectual disability) for the risk for children with ASD as compared to those without were in excess of four for conduct problems and in excess of 10 for hyperactivity problems. Thus, these problem behaviours are clearly characteristic of children with ASDs. This supports the case for looking to these NICE reviews for an indication of parent training interventions that may lead to positive outcomes for children with PDDs and their families.

In terms of the second question, the guidance from (NICE/SCIE, 2006, pp. 28–29) about the key features of evidence-based interventions included that training pro-

grammes should be: structured and based on learning theory, include ways to build the parent–child relationship, long enough in terms of number of sessions to have an effect, incorporate role play and homework, be delivered by suitably trained and supervised practitioners, and adhere to a clear manual. The NICE committee explicitly noted that two parent training models met all of these criteria: Webster-Stratton's Incredible Years model (Webster-Stratton 2000) and the Triple P model (Sanders 2008).

### Outcomes of the Webster Stratton and Triple P parent training interventions for parents of children with PDDs

We conducted an additional systematic search in Web of Science only for articles using a randomized controlled design of treatment as usual against either the Webster-Stratton Incredible Years or the Triple P programme for children with PDDs or developmental disabilities. The initial search combined terms for the named interventions (Triple P, Webster Stratton, Incredible Years) with terms for PDDs and developmental disabilities more broadly (autis\*, asperger\*, PDD\*, developmental disab\*). Fourteen articles were identified, and the abstracts of these were read to select randomized trials focusing on parents of children with PDDs. One article (Whittingham *et al.* 2009) was obtained that reported data from a randomized controlled trial of the version of Triple P developed for parents of children with developmental disabilities (Stepping Stones). No articles were found that exclusively focused on the evaluation of the Incredible Years (IY) model for parents of children with PDDs. However, a quasi-randomized controlled trial of the IY model (McIntyre 2008) was found focusing on children with intellectual disabilities where 50% of the children in the intervention group were reported by parents to have autism. Both of these articles were retained for review and are described in Table 2.

Whittingham *et al.* (2009) explicitly selected parents of children with PDDs to receive the Triple P Stepping Stones intervention. This parent training format has already been developed and tested for parents of children with developmental disabilities and behaviour problems, and a minor addition to the content was included for the PDD population. Results were encouraging in terms of a large effect size for parent-reported behaviour problems and changes in self-reported parenting behaviours. Intervention effects also appeared to be maintained over 6 months of follow-up. The major weakness of the study was the reliance exclusively on



**Table 2** Evidence-based parent training interventions applied to parents of children with pervasive developmental disorders (PDDs)

Study	Participants	Design	Outcome measures	Results
Whittingham <i>et al.</i> (2009) (Australia)	59 children (47 boys and 12 girls) 2–9 years of age identified via multiple means including advertising. All had a clinical diagnosis of a PDD from a paediatrician (as reported by the parent). PDD diagnosis was confirmed via items developed specifically for the study that address symptoms of autistic disorder, Asperger's syndrome, or PDD-NOS. All children were currently in receipt of treatment as usual in their local area and were asked not to participate in another parenting intervention during the course of the study	Children matched on symptoms and language ability and then parents randomly allocated to one of two groups: Triple P Stepping Stones parenting intervention (29 families) Waiting list control (received Triple P Stepping Stones on a delayed basis) (30 families) Stepping Stones intervention used with addition of Comic Strip Conversations and Social Stories to assist with social understanding in the children with PDD. Small group sessions (4–5 parents of children at a similar level of functioning) plus 1–3 individual sessions focused on parenting skills with the child	Parents completed standard questionnaires with good psychometric properties pre- and post-intervention and also at a 6-month follow-up for the intervention group only. Measures focused on: Problem and frequency (intensity) scores for the child's behaviour Child Behaviour Inventory Parenting style Parenting satisfaction and efficacy	2 × 2 ANOVAs (following significant overall MANOVA) showed significant interaction effects (with reported <i>partial eta squared</i> effect sizes) in the following domains: Eyberg Intensity score = 0.26 Eyberg Problem score = 0.16 Lax parenting = 0.22 Over-reactive parenting = 0.25 Verbose parenting = 0.16 For ease of comparison with other studies in this review, we calculated the Cohen's <i>d</i> effect size for Eyberg intensity scores based on the means and SDs reported in the article. This effect ( <i>d</i> = 0.98) was large. Intervention effects were also maintained to 6-month follow-up

Table 2 (Continued)

Study	Participants	Design	Outcome measures	Results
McIntyre (2008) (USA)	Children with developmental delay ages 2–5 years recruited via advertisements. Inclusion criteria were age, adaptive behaviour standard score between 45 and 85, ambulatory, and living with the primary caregiver for at least 6 months. 57 families were screened and 49 met inclusion criteria. Twelve children in the intervention group were reported by parents to have an autism diagnosis, and 7 in the control group. Five families dropped out of the study	Quasi random allocation (every second family who met inclusion criteria assigned to intervention group). Two groups: Treatment as usual ( $N = 23$ ) Researcher's developmental disability adaptations to the Webster-Stratton Incredible Years basic parenting programme ( $N = 21$ ) Intervention was 12 weekly 2.5 h sessions of 8–12 participants per parenting group. Treatment integrity measures taken in each session confirmed adherence to treatment manual. Two independent coders of the observational data were blind to treatment group and pre-post data	Established measures used for assessment of parent-reported child behaviour problems [Child Behavior Checklist (CBCL) for 1.5–5 years of age], and parent stress and positive impact. Researcher developed a coding scheme for parent-child interaction based on a 15 min session. Scored as a composite of seven parent inappropriate behaviour categories, and event coding of child-directed praise. Inter-rater agreement collected for observations (coded from videotapes) and was good. Measures collected pre- and post-intervention	$2 \times 2$ ANOVA used to analyse the results. Significant interaction effects for parent inappropriate behaviour ( <i>partial et squared effect size</i> = 0.37), CBCL total score (0.11), and CBCL internalizing behaviour scores (0.12). All changes in favour of the intervention group. No significant effects for parent stress or positive perceptions or for child-directed praise. For ease of comparison with other studies in this review, we calculated a Cohen's $d$ effect size for observed parent inappropriate behaviour and CBCL total scores. These effects were very substantial ( $d = 1.81$ ) for parent inappropriate behaviour, and small ( $d = 0.35$ ) for CBCL total scores. Parents of children with autism did not show a differential response to the intervention compared with parents of children with other developmental disabilities

parent-reported changes resulting in no blinded assessment of the impact of the intervention. Therapists implementing the intervention were trained as clinical psychologists but received only minimal training (2 day training and weekly supervision during implementation) to deliver the intervention.

McIntyre (2008) adapted the Webster-Stratton IY basic parenting programme. This was delivered by the researcher (a qualified clinical psychologist). The main, very substantial, intervention effect was on observations of parent-child interaction videotaped in the family home. Coders were blinded to intervention group and pre-post status, and this is a strength of the design. There was only a small effect on parent-reported behaviour problems. It is possible that a follow-up assessment would have shown a sleeper effect for this outcome variable (i.e. negative parenting practices were changed, and over time these might have an impact on child behaviour). Alternatively, the intervention may have changed parents' inappropriate behaviours but it is possible that other parenting behaviours (e.g. the use of praise, which did not change with intervention) are also required before substantial changes in child behaviour will be seen.

These two studies indicate that evidence-based parent training interventions developed for non-PDD populations may be effective for parents of children with PDDs with only minor adaptation. Parent training interventions such as the Triple P and IY models also have well-developed treatment manuals and training procedures in place. Primary and secondary health workers can be trained to deliver these interventions with a good level of fidelity. Thus, these might be candidate interventions for evaluation in LAMI contexts (with appropriate development of culturally sensitive training and delivery methods).

The Triple P model for children without disabilities is broader than a group training format as examined in systematic reviews to date and with the PDD population as described above. A difficulty with parenting programmes is that, although they may have demonstrable efficacy, many families who might benefit do not receive intervention (Sanders 2008). The Triple P system is now described explicitly as a public health model (Sanders 2008). 'The system aims to prevent severe behavioral, emotional, and developmental problems in children and adolescents by enhancing the knowledge, skills, and confidence of parents' (Sanders 2008, p. 507). There are five levels of intervention in the Triple P system that address a continuum of support (Sanders 2008):

Level 1 – a media-based parent information campaign targeted at all parents in a defined area and including the use of outlets such as newspapers, magazines and radio.

Level 2 – a health promotion/brief intervention format focused on parents with a specific concern or looking for general advice. This is likely to be delivered in routine child primary care services or in education contexts. May involve brief group sessions or short telephone or face-to-face contact for advice from a healthcare worker.

Level 3 – a primary care intervention model focused on parents with specific concerns who require more consultation or active skills training. The model is a brief intervention (e.g. 80 min over four sessions) in groups or with a healthcare worker, face-to-face or over the telephone.

Level 4 – is the typical group format intervention, including the Stepping Stones model, designed to support parents who need more intensive input and delivered by people whose role includes regular support for parents of children with behaviour problems.

Level 5 – is an intensive, individually focused intervention for parents and families at particular risk that is also likely to involve direct psychological intervention with parents. This level is typically delivered by specialized mental health workers.

This Triple P levels system is an interesting model to consider in the context of LAMI countries. Given the considerable public health machinery in many LAMI contexts, it may be a framework that would benefit parents broadly. Whether such a model would be the best way to deliver intervention for children with PDDs is a question worthy of further exploration. It would take some time to build an infrastructure such as that described for the Triple P system. Once established, developing services for children with particular needs, including those with disabilities such as PDD, might be facilitated.

## Conclusions and Recommendations

Using a systematic review methodology, we identified only four published studies comparing treatment as usual with an intervention for children with PDDs. Although all four of these studies were carried out in middle-income contexts, no clear implications from practice can be drawn directly from this evidence.

Drawing on a limited database of publications providing background information about PDD in LAMI countries, two issues relevant to PDD intervention were identified:

1. There is a lack of awareness among health and other professionals about PDDs in LAMI countries. Providing training to primary and secondary healthcare workers about PDDs may help to improve the quality of advice and support that they can offer to families. We did not find any evaluation studies of training in PDDs for professionals in LAMI countries. Thus, there is no evidence relating to the hypothesized link to potentially improved advice/support.
2. In LAMI contexts, there is likely to be a paucity of services for children with PDDs and their families. Therefore, interventions are most likely to have to be delivered using parents and other family members as the agents of change.

Both of these points require some additional discussion. In terms of training about PDDs, there are characteristics of these disorders that help to explain typical problems experienced by affected children and may in turn inform effective advice to families. For example, many children with PDDs engage in challenging behaviours when other people change their routines without signalling these changes or preparing the children for change. Such problem behaviours derive directly from the underlying characteristics of autism. A further example would be the awkward and often negatively interpreted social interactions of more able individuals with PDDs. Communicating these quite typical problems and their relationship with the PDDs requires some knowledge of the disorders among healthcare and other workers, and some method of communicating these same points to families.

The focus on delivering training to parents as a specialized intervention model for PDDs might raise questions about the 'responsibility' for intervention being placed on families with very limited resources. However, it is clear that families are currently caring for children with PDDs, and research evidence from various Western and other high income cultures identifies that families experience significant stress when raising a child with PDD. This stress is strongly related to the presence of significant behaviour problems from the child, and the resulting care demands can be a barrier to the participation of parents in the workforce (thus increasing the experience of poverty). Therefore, parent training interventions may well have broader positive effects on families. In essence, practical parenting skills to deal with their child's difficulties may be primarily what families need in any cultural context.

In a context of very limited opportunity to train healthcare workers to improve child health (including child mental health) in LAMI countries, training pri-

mary and secondary healthcare workers in the delivery of practical parenting skills might be a priority beyond PDDs. Children with PDDs, with intellectual disability, sensory disabilities, physical disabilities and physical health problems are all at increased risk of developing significant behaviour problems. Furthermore, the most prevalent child mental health problems are characterized by behaviour problems (i.e. conduct disorders, ADHD). Thus, basic behavioural training in parenting skills may have application for a much larger population of children with mental health problems and disabilities and their families. Outside of LAMI contexts, several recent systematic reviews and meta-analyses indicate that there is evidence for the effectiveness of parent training as an intervention broadly for child disruptive behaviours (e.g. Maughan *et al.* 2005; Thomas & Zimmer-Gembeck 2007; Dretzke *et al.* 2009).

On a cautionary note, evidence from systematic reviews of the predictors or moderators of parent training outcomes suggests that these interventions work less well for families experiencing socio-economic hardship (Lundahl *et al.* 2006; Reyno & McGrath 2006). Despite this caution, there is no direct evidence to suggest that parent training will be ineffective in LAMI contexts (just as there is no evidence that it may be effective) and so the primary implication is the need to carefully consider the context within which intervention might be delivered.

### Recommendations for practice

The evidence reviewed in the present report supports the following recommendations for practice in LAMI countries:

1. Interventions for children with PDDs in LAMI countries should be focused on training parents to manage their children's difficult behaviours and/or to develop their child's skills in domains where deficits are common in PDDs (e.g. language, social skills), as well as to develop their relationships with their child. Although general behavioural parent training is focused on reducing child behaviour problems, the same underlying principles of behaviour change are applicable to the development of skills in domains where children with PDDs (and other disabilities) have deficits, and to building relationships by engaging in play and other social interactions.
2. Parent training is an evidence-based approach that can be applied to a broad range of child mental health problems and child disabilities and thus may represent an opportunity to offer intervention sup-

port to larger numbers of children and their families. More generic parenting skills training could be supplemented by education/training about the nature of PDDs and disorder-specific problems that may emerge.

It is important to recognize the serious limitations in direct evidence to support these recommendations. However, if these or similar recommendations are adopted, WHO may want to consider commissioning an expert group to develop recommendations for the content of broad parent training with or without disorder-specific education/training components. Specifying the boundaries of such a task, as determined by the likely delivery model within LAMI contexts, will be very important. Recommendations about the content of parent training have been developed within the NICE/SCIE (2006) guidance (quoted above). However, these recommendations are unlikely to be realistic within LAMI contexts. The question to be posed to a panel of experts might be in the form of: 'If you had to train, based on the best quality evidence available, healthcare workers in LAMI contexts to deliver parent training programmes to families of children with behaviour problems, what should be the content of such training if it has to be delivered within x days?'

### Recommendations for research

The evidence reviewed in the present report supports the following recommendations for research on specialized interventions for children with PDDs in LAMI countries:

1. The content and methods of evidence-based parent training programmes developed in Western countries should be tested for social validity in LAMI contexts. Parents of children with PDDs, family members and healthcare workers should be asked for their views on the acceptability of existing intervention approaches.
2. Parent training programmes developed in Western countries should then be adapted to local cultural contexts and evidence for their efficacy and effectiveness generated. Important outcomes might include changes in the inclusion of the child with PDD in the life of the community, and/or reduced felt stigma experienced by family members in addition to changes in child and parent behaviour and well-being.
3. Specifically, the Triple P Stepping Stones model and the Incredible Years model should be evaluated within LAMI contexts.

4. A public health approach to parent training should be evaluated within LAMI countries as a way to provide an infrastructure to enable intervention and support for children with PDDs and the families.

Moving beyond the direct evidence (see Recommendations for Practice), there may be a need to conduct evaluation studies of more generic parent training intervention in LAMI contexts that may be applicable to a broad range of conditions (including PDDs) and that may be supplemented by disorder-specific education/training.

### Correspondence

Any correspondence should be directed to Richard P. Hastings, School of Psychology, Bangor University, Bangor LL57 2AS, UK (e-mail: r.hastings@bangor.ac.uk).

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## Appendix – Search Strategy

### MEDLINE & CINAHL

In Medline and Cinahl, Mesh Headings were used in conjunction with word searches as follows:

(MH “child development disorders, pervasive+”)

Exploded term includes:

(MH “autistic disorder”) OR

(MH “asperger syndrome”) OR

(MH “Rett syndrome”)

Combined with Mesh headings for LAMI countries

(MH “Africa+”) OR

(MH “Asia+”) OR

(MH “Europe, Eastern+”) OR

(MH “Central America+”) OR

(MH “South America+”) OR

(MH “West Indies+”) OR

(MH “Pacific Islands+”) OR

(MH “Developing Countries”)

Within this pool of items searches were conducted for the following words:

Treat\* intervene\* manag\* primary secondary education\* train\*

PSYCINFO

In psycinfo Index terms were used as follows:

For PDDs:

Pervasive developmental disorders OR autism OR rett syndrome OR aspergers syndrome

For LAMI Countries:

Terms for low- and middle-income countries were searched as below:

(ZY “afghanistan”) or (ZY “africa”) or (ZY “albania”) or (ZY “algeria”) or (ZY “american samoa”) or (ZY “angola”) or (ZY “armenia”) or (ZY “asia”) or (ZY “azerbaijan”) or (ZY “bangladesh”) or (ZY “belarus”) or (ZY “bhutan”) or (ZY “bolivia”) or (ZY “bosnia-herzegovina”) or (ZY “burkina faso”) or (ZY “burundi”) or (ZY “cambodia”) or (ZY “cameroon”) or (ZY “cape verde”) or (ZY “cape verde islands”) or (ZY “central african republic”) or (ZY “central america”) or (ZY “chad”) or (ZY “china”) or (ZY “colombia”) or (ZY “commonwealth of independent states”) or (ZY “comoros”) or (ZY “cuba”) or (ZY “democratic republic of congo”) or (ZY “djibouti”) or (ZY “dominican republic”) or (ZY “east timor”) or (ZY “eastern europe”) or (ZY “ecuador”) or (ZY “egypt”) or (ZY “el salvador”) or (ZY “equatorial guinea”) or (ZY “eritrea”) or (ZY “ethiopia”) or (ZY “fiji”) or (ZY “gambia”) or (ZY “georgia”) or (ZY “ghana”) or (ZY “guatemala”) or (ZY “guinea”) or (ZY “guinea-bissau”) or (ZY “guyana”) or (ZY “haiti”) or (ZY “honduras”) or (ZY “india”) or (ZY “indonesia”) or (ZY “iran”) or (ZY “iraq”) or (ZY “ivory coast”) or (ZY “jamaica”) or (ZY “jordan”) or (ZY “kenya”) or (ZY “kiribati”) or (ZY “korea”) or (ZY “kyrgyzstan”) or (ZY “laos”) or (ZY “lesotho”) or (ZY “liberia”)

(ZY “madagascar”) or (ZY “malawi”) or (ZY “maldives”) or (ZY “mali”) or (ZY “marshall islands”) or (ZY “mauritania”) or (ZY “micronesia (federated states of)”) or (ZY “moldova”) or (ZY “mongolia”) or (ZY “mozambique”) or (ZY “myanmar”) or (ZY “namibia”) or (ZY “nepal”) or (ZY “nicaragua”) or (ZY “niger”) or (ZY “nigeria”) or (ZY “north korea”) or (ZY “north vietnam”) or (ZY “oceania/pacific islands”) or (ZY “pakistan”) or (ZY “papua new guinea”) or (ZY “paraguay”) or (ZY “peru”) or (ZY “philippines”) or (ZY “republic of congo”) or (ZY “rwanda”) or (ZY “samoa”) or (ZY “senegal”) or (ZY “sierra leone”) or (ZY “solomon islands”) or (ZY “somalia”) or (ZY “south korea”) or (ZY “sri lanka”) or (ZY “sudan”) or (ZY “surinam”) or (ZY “suriname”) or (ZY “swaziland”) or (ZY “syria”) or (ZY “tajikistan”) or (ZY “thailand”) or (ZY “tibet”) or (ZY “togo”) or (ZY “tonga”) or (ZY “tunisia”) or (ZY “turkmenistan”) or (ZY “uganda”) or (ZY “ukraine”) or (ZY “uruguay”) or (ZY “uzbekistan”) or (ZY “vanuatu”) or (ZY “vietnam”) or (ZY “west indies”) or (ZY “yemen”) or (ZY “zambia”) or (ZY “zimbabwe”)

These two searches were then combined with AND. The pool of references identified was <100 and searched directly by hand for relevant items

WORD SEARCHES in MEDLINE, CINAHL, PSY-CINFO & Web of Science

Word searches were run in all databases as follows (Web of Science does not include an index based search facility)

Terms for LAMI as below:

TS = ("developing countr\*") or TS = ("developing nation\*") or TS = ("low income countr\*") or TS = ("low and middle income countr\*") or TS = ("third world") or TS = ("resource poor") or TS = ("LAMI")

AND

Pervasive developmental disorder OR autis\* OR asperger\* OR rett\*



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