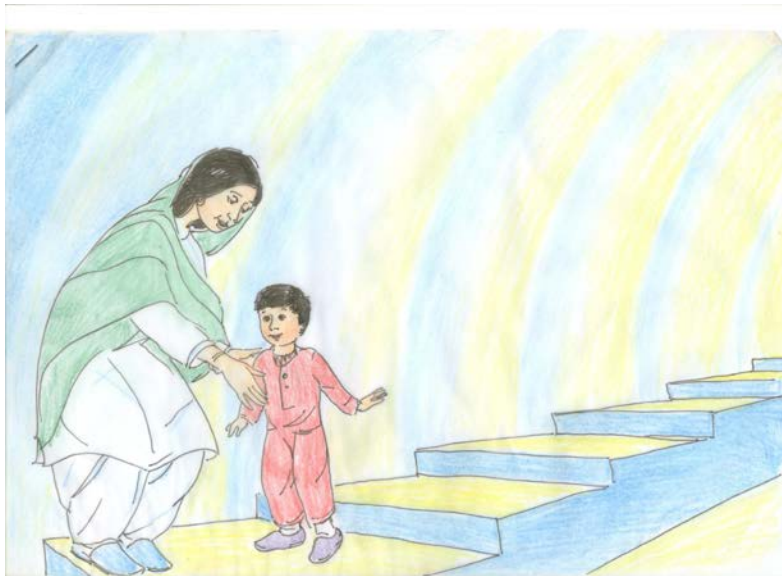


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PASS

Parent-mediated Intervention for Autism Spectrum Disorder (ASD) in South Asia A Manual for Delivery of PASS by a Non-Specialist Facilitator



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Based on the Pre-School Autism Communication Therapy Manual

Illustrations courtesy of Human Development Research Foundation, Rawalpindi

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INTRODUCTION

Getting educated about PASS, Communication and Autism

What is PASS?

PASS is an adapted version of the manualised treatment used in the Pre-school Autism Communication Therapy (PACT) trial (Aldred et al., 2011; Green et al., 2010). In a randomised controlled trial conducted in 2008-2010 in the UK, this PACT intervention produced large benefits in parent interaction behaviours with their child, which led to a significant improvement in the child's communication initiation with their parent, in turn leading to a possible modest reduction in general child autism symptoms on independent assessment.(Green, et al., 2010; Pickles et al., 2014)

PACT is delivered in the UK by trained speech and language therapists. The PASS adaptation was carried out in India and Pakistan by Sangath (Gauri Divan, Vivek Vajaratkar), Goa and the Institute of Psychiatry (Ayesha Minhas, Haleema Sadia, Atif Rahman), Rawalpindi with support from the University of Manchester (Catherine Aldred, Carol Taylor, Jonathan Green). The adaptation for the sub continent involved culturally adapting the content of the intervention but also addressing the shortage of speech and language therapists in this setting. This required the careful extraction of the key elements of the original intervention such that it could be delivered by a lay (non-specialist) facilitator in a low resource setting without sacrificing the essence of the original intervention; the result is the PASS therapy, a culturally adapted version of the original after following rigorous procedures. Information on the original trial and current work can be found at <http://www.medicine.manchester.ac.uk/pact/>.

Theoretical Basis for PASS

PASS is based on the same theoretical basis as the original intervention. It is a parent mediated social communication focused intervention that aims to make specific alterations in the parent and child's communication environment in order to improve the child's social communication, attention and language. It targets pre-linguistic, pragmatic and language development with the aim of improving key communication impairments in Autism; shared attention, understanding and purposeful communication from the child. The rationale is that a child with Autism requires his parent to adapt their method of interaction to match his needs.

This intervention was trialled on children in the age group 2- 9 years with Autism.

Some General Comments about this Manual

In this manual we have taken three liberties

1. We have addressed the child with Autism as 'he' to reflect the increased prevalence in the male gender.

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2. We have addressed the facilitator as ‘she’ to reflect the increased numbers of worker in this area who are female.
3. We often will refer to the parent as ‘she’ since we have found that it is often the mother who will work as the main interface for this intervention.

This has allowed us an ease in writing (as well as in reading) this document; though in reality this gender divide is not always so clear.

Acknowledgements

This manual was developed as part of the work conducted in the PASS Project, supported by an Autism Speaks, through their Global Autism Public Health Initiative Grant No 7773. The project was led by the University of Liverpool and included a collaboration with the University of Manchester, UK, the Institute of Psychiatry Rawalpindi, Pakistan and Sangath, India. The development of this manual was iterative and was done simultaneously to the adaptation of the intervention to address the human resource limitations in developing countries. We would like to thank the PASS facilitators in both countries (Huma Nazir, Mamta Verma, Pooja Jangam, Sara Sheikh, Tahira Jabeen, Tulsi Shet and Zainab Butt) who were in the fore- front of the adaptation process. Percy Cardozo in Goa and Haleema Sadia in Rawalpindi were key contributors to adaptation process which led to the PASS intervention and this manual. As always we thank the families we have worked with, especially for signing up to the unfamiliar process of 'randomisation'.

Understanding Autism Spectrum Disorders (ASD) or Autism

Autism spectrum disorder also called Autism, is a broad term for a group of serious neuro-developmental disabilities emerging in the first years of life. Autism is characterized by significant impairments in two main areas:

- i. Difficulties in the way a child communicates and interacts with others on a social level.
- ii. Restricted, repetitive patterns of behaviour, interests or activities.

How do communication impairments in Autism impact the way the parent and child communicate?

The child with Autism has difficulties in the way he uses language, communicates with and interacts with others (social communication). This has a profound influence on the child’s social development into adulthood. These difficulties in social communication are amongst the first parental concerns, often before the age of 24 months (for example the child being happier alone than with the parent or not coming to the parent for comfort or to share an interest). ‘Core impairments’ include

- A lack of or a delay in non verbal communication (such as pointing or using gestures).

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- A lack, delay or weak signals in communicative intentionality (that is using language to imply a specific idea or intention).
- A difficulty in sharing with another person an interest (Shared Attention) and
- A difficulty in understanding social signals (for example, not understanding the emotions that a face may show when happy or sad).

The important fact in Autism is that these difficulties are present at all times across all settings that the child functions in. The following table shows the communication patterns that develop between a child with Autism and their parent.

General Principals of PASS

Based on normal communication development

- The PASS therapy follows the typical development sequence of language learning which is often disrupted in children with Autism.
- The aim of the intervention is to help parents to adjust their style of communication with their child, by adjusting their responses and words to match their child's communication abilities and needs.
- In PASS, parents gain knowledge about how to identify suitable strategies which would be effective to help shared parent-child interactions, increase the chances of emerging parent-child communication, encourage their child's intention to communicate and support their child's understanding of spoken language. In this way parents are helped to re-adjust abnormal communication development in their child.

Focus on a natural interaction

- PASS promotes natural interactions between a parent and child in a play setting.
- PASS helps parents to recognise and respond to the child's non-verbal and verbal communication signals and helps them in trying to interpret the child's intentions.
- It encourages the parent to modulate her level of support, thereby creating opportunities for the child to be in charge and signal his intentions.

Parent directed

- The PASS therapy is delivered on a partnership basis, building on the parents' skills and promoting the parents' individual strengths.
- Parental independence, decision making, and self belief is encouraged throughout the program.
- The parent is encouraged to identify and set their own goals within the framework of PASS.

Video-aided feedback

- PASS utilises video feedback and a guided-reflective style of therapy.
- All parent-child play sessions are video recorded and followed by a feedback session in which parents are encouraged to identify successful episodes of two way interactions and to understand their positive contributions to these.

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- Video feedback also enables the parent and facilitator to set specific and highly targeted goals at each session which are specific to each parent.

Adapted to parental learning style

- The manner in which feedback is given is matched to parental learning style in order to maximise ease of learning. The parent's learning style may change over the course of the programme and the PASS intervention adjusts to these changes.
- Thus, initially, parents may need more structured guidance to support their observation of positive interactions. Subsequently, parents may adopt a more reflective style once they have gained greater awareness and understanding of their own contribution to a successful range of interactions and have developed confidence in their relationship with the facilitator.

GUIDELINES FOR DELIVERY OF THE PASS INTERVENTION

Setting up a supervisory algorithm

PASS has been developed keeping in mind the philosophy of task sharing; that is the specialist supports well trained non-specialists to deliver the intervention. The fundamental methodology in delivering PASS is a strong supervisory pathway. This means that it is essential that each facilitator or non-specialist is supervised by a PASS specialist during the delivery of the intervention. The Supervisors themselves should be trained in PACT/PASS by established trainers and experienced in delivering the intervention.

Choosing a suitable environment to deliver PASS

The parent and family is given a choice on the location of the sessions (home or in a centre). The locations should be free from distractions; it should have enough free floor space, a small table and chair (or floor mat or any other suitable sitting arrangement). Extra furniture/objects/equipment should be removed if possible.

Choosing suitable play material to deliver PASS

A standard set of specific toys should be put together. These can include plastic boxes with a selection of toys for each session with the child or a bag to transport the toys to the child's home (See each stage for suitable set of toys). The toys should be developmentally appropriate; they should be based on the functional and play level of the child(for example, a child who is enjoying exploring the physical nature of a toy should not be given puzzles even if this may be age appropriate).

Using video recording/feedback equipment

For recording the sessions a floor mounted video camera should be placed in an unobtrusive corner of the room with chairs for viewing video playback. If the session is being conducted in a

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small place it may be better to hold the video camera in your hand during the play session. Make arrangements for a laptop/tablet computer to use for the video feedback.

The initial home visit

This initial home visit will be led by the Supervisor; during which the facilitator will be introduced to the parents. The aim of the home visit is to carry out two the following three functions i) To explore general beliefs and experiences with respect to parenting a child with Autism ii) Setting the stage for the PASS intervention iii) To explore the learning style of the primary parent

Follow up home visit

The primary aim of the second home visit is for the facilitator to establish a relationship with the parent. It should also be used to complete the following activities

The general structure of PASS sessions

Review Session (10 minutes): This part of the session is to review the progress since the previous session. The facilitator aims to understand the successes and difficulties that the parent may have experienced in achieving goals set. It aims to explore and problem solve ways in which home practice can be achieved.

Play Session (10 minutes): During this period the facilitator video tapes the parent and child playing with a box of toys that has been brought to the home.

Feedback (30 minutes): The facilitator reviews the video of the play with the mother. She then asks the mother to identify parts of the play which the mother feels achieved the session goals. In a reflective manner the facilitator gives feedback to the mother aiming to build on positive behaviours observed and comparing them to behaviours that the PASS strategies aim to change.

Goal Setting: (10 minutes): This is achieved collaboratively by finding strategies that were explored during the feedback session. This is also a period when potential parts of the daily routines are identified during which the parent and child can play using PASS strategies.

Writing a Home Program (10 minutes): This is a written program based on a structured template which is left with the mother and becomes her individualised PASS manual. It includes the focus of the session, the description of the session, parent and child targets and goals for home practice and suggestions when practice can be integrated into the day.

An outline of PASS Stages

The PASS therapy has 5 stages that follow a developmental hierarchy. Within each stage the parent is facilitated to use specific evidence based interaction strategies to achieve the aims of stage.

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Stage 1: Establishing Shared Attention in Play

This stage helps the parent and child to experience episodes of mutual shared attention which provide the essential context for communication. Stage 1 strategies encourage the parent to sensitively observe the child's behaviours and recognise and respond to opportunities for shared attention which arise during play.

Stage 2: Creating a harmonious interaction through language

Stage 2 strategies aim at helping to synchronise parent-child communication by the parent adapting the type of language that they use, by responding sensitively and appropriately to their child's signals and helping the parent to recognise these signals as meaningful communication.

Stage 3: Increasing the understanding of language

This stage helps the child to develop his understanding of spoken language, by the parent adopting strategies to introduce language that matches the child's ability to understand. The strategies encourage the parent to use language which matches their child's focus of interest.

Stage 4: Establishing routine and anticipation

Strategies in this stage help the child to learn routines and to anticipate what happens in play and everyday life situations. This stage helps consolidate the parent's skills established in previous stages and helps to expand their child's verbal understanding and participation in familiar interactive play.

Stage 5: Increasing communication functions

This stage helps expand the child's communication functions, by the parent creating opportunities during play which allow their child to initiate communication during the interaction and use communication across a range of functions. The strategies in Stage 5 encourage the parent to pause during predictive routines and thereby encourage their child to fill in the gaps with non verbal or verbal responses.

The original PACT intervention has a **Stage 6** which is primarily for verbal children. This has currently not been adapted for use by a non-specialist but the Supervisor can deliver this stage.

Moving through the PASS Stages

- The therapy always starts at Stage 1 and at least 2-3 sessions focus on this stage.
- This manual provides measurable criteria for progression through the stages. These criteria enable the facilitator and supervisor to judge if the parent and child have accomplished an acceptable level of skill at the given stage.
- The pace of the therapy is judged by the parent –child dyad's readiness to move on.
- Some dyads may need to remain at one stage for a longer time.

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- Not all dyads accomplish the higher stages.
- Parental and child achievements of stage specific goals are identified by the facilitator along with the supervisor before moving on to the next stage.
- At the end of each stage there is criterion for moving to the next stage. The facilitator and supervisor rate the latest play session using the criteria and assess whether the dyad is ready to move to the next stage.

Flexibility in Moving through the Stages

- While the stages are designed to be carried out in order, there is flexibility in the way facilitators can move through the stages.
- Equally, it may be necessary to continue with a stage even when both parent and child have achieved the stage specific goals if this may help in consolidating or developing existing skills further.

Going Back to Earlier Stages

- There may be a need to re-visit an earlier stage of PASS if the parent needs to strengthen specific skills to help accomplish the later stage.
- Revisit an earlier stage to consolidate or reinforce earlier skills e.g. to ensure an ease when moving onto a later stage.

Variable Rate of Progression through the Stages

- Some children (e.g. those who are more verbal) may progress onto the next stage after 1 or 2 sessions. Other children may need a greater number of sessions, particularly at stages 4. The progression is judged on the basis of individual parent and child readiness.

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