Online Parent Training: A Pilot Programme for Children with Autism and Neurodevelopmental Disabilities in Bangladesh

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ABSTRACT

Purpose: *This study aimed to assess the implementation of an online parent training programme in Bangladesh, designed to enhance parental knowledge of autism and neurodevelopmental disorders and related interventions. In addition, study participants were expected to become "Master Trainers" with the intention of training other parents in their local communities.*

Method: *This survey study assessed parental knowledge and programme effectiveness, such as potential online learning barriers, cultural sensitivities, and general course content feedback after each unit.*

Results: *The programme had an 81% completion rate (with parents completing all but one unit) with an average programme knowledge score of 86%. Parents felt that the course content was moderately difficult, the length of the units was appropriate, and the units were culturally sensitive. They requested more detailed lessons, specific case studies, and adaptation of the curriculum for older children.*

Conclusion: *The pilot programme merits the next phase of development, which includes local adaptation and translation. However, the findings are limited by the small sample size.*

Keywords: *Distance learning, disability, community-based training, development.*

INTRODUCTION

According to the World Report on Disability (2011), "Across the world, people with disabilities have poorer health outcomes, lower education achievements,

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less economic participation and higher rates of poverty than people without disabilities". This is partly attributed to barriers in accessing services, especially among disadvantaged communities. In 2010, 43.7% of the population in Bangladesh was living in extreme poverty (World Bank, 2016). In a country where nearly half of the population lives on less than $1.90/day (World Bank, 2016), key decision-makers have begun to invest their limited resources in better understanding and evaluating the prevalence of, and need for, related supports and services for individuals with Autism and Neurodevelopmental disabilities (AND) and their families. In recent years, the government of Bangladesh has implemented extensive multisectoral measures for the inclusion of persons with AND. The creation of the National Steering Committee on Autism and Neurodevelopmental Disabilities and the Strategic and Convergent Action Plan on Autism and Neurodevelopment Disabilities has provided a national impetus for developing the services crucial for those who require it and their families.

It is difficult to determine the actual number of individuals with AND in Bangladesh because the country lacks formal data collection processes for monitoring disability prevalence. Small government studies in the country have shown the prevalence of autism to be about .84% percent among children; this information is contradictory to census data (Emdad, 2014).However, going by the global autism prevalence rate of 1% of the population presented by the Center for Disease Control and Prevention (CDC), 15.6 million persons in Bangladesh could be affected. A detailed situational analysis conducted by Emdad in 2014, notes the "critical barrier to improving the quality of life of children and families touched by autism is the paucity of expertise to reliably identify and effectively manage these developmental disabilities". Thus, more high-quality studies on the prevalence of AND in Bangladesh are needed.

The World Health Organisation (2014) has identified the lack of skilled human resources in low to middle-income countries as a primary barrier to accessing services for children with AND. Successful interventions that are feasible and affordable are often limited in low-income or rural areas. Train-the-trainer programmes aim to combat this lack of expertise by building a community of trainers that can reach both urban and rural communities. Research shows that empowering parents of children with AND not only improves parental self-confidence, but is also an effective method for delivering beneficial interventions (McConachie & Diggle, 2007; Matson et al, 2009; Oono et al, 2013). In addition, train-the-trainer models have demonstrated that parents can effectively act as

skilled trainers in community settings and instigate improvements in behaviour and family dynamics (Reichow et al, 2013).

When designing parent training programmes of this nature, a number of factors must be considered to ensure an effective pilot programme. Parental ability to access, retain and generalise the presented curriculum is a consistent concern (Matson et al, 2009). External factors that may contribute to parental aptitude and correlate to positive outcomes include socioeconomic status, education, previous experience, ability to carry out the training procedures, and the nature and severity of the child's condition (Matson et al, 2009). Singer et al (2007) add that parental stress is a challenge in parenting children with developmental disabilities, and point to research that shows that access to educational content can improve overall parenting skills and lead to improved results in parent-led training programmes. Though challenges are present, Matson's review (2009) of parent training programmes demonstrates evidence for positive short and long-term success when parents are empowered, educated and given the resources to serve as the primary educators.

The Bangladeshi Parent Empowerment Programme (BPEP)was a pilot programme designed to provide a cohort of Bangladeshi parents of children with Autism and other related Neurodevelopmental Disabilities (AND), designated as "Master Trainers", with a tailored, online, evidence-based curriculum aimed at enhancing parental knowledge of AND as well as related interventions. The project objectives were as follows:

- Identify a group of parents of children with AND to serve as "Master Trainers";
- Develop evidence-based curricula tailored to expand parental understanding of AND, and provide strategies for implementing home and community-based interventions;
- Utilise distance learning tools to share information and exchange knowledge;
- Engage local partners to ensure cultural sensitivity and competence;
- Evaluate the efficacy of distance learning parent training programmes in a developing country;
- Contribute to community engagement and awareness of AND, and provide

families with resources and support to increase their child's community participation;

- Provide local and national decision-makers with data to support continued focus on AND research.

AIM

The aim of this paper is to review the BPEP pilot programme in Bangladesh, explore lessons learned, and identify the next steps in implementation.

METHOD

The Bangladeshi Parent Empowerment Programme (BPEP) was a pilot study designed to provide parents of children with AND with the knowledge and strategies necessary to implement home and community-based interventions as "Master Trainers" in their local communities. The study also sought to evaluate the efficacy of research instruments (online learning platform, tailored curricula) in a developing country that currently lacks formal programmes serving this target population. The work was accomplished in partnership with the International Centre for Diarrhoeal Disease Research, Bangladesh (ICDDR,b).

Sampling

Potential study participants were identified by the Ministry of Health and in-country partners, and included individuals who are active in Bangladesh's Parents Forum, as well as the Kumudini Trust. This resulted in a purposive sample from which eligible participants were selected. Snowball sampling methods were also utilised to recruit additional participants through initial parent volunteers.

Parents were required to meet the following criteria to be eligible for the study:

- Read and write English proficiently;
- Have access to necessary computer technology and supports;
- Commit to the time necessary to complete the training;
- Willingness to train a group of "secondary trainers".

It is important to note that the BPEP pilot programme targeted participants with the capacity and interest to serve as leaders and train additional parents in their home communities. This resulted in a sample population of individuals whose

baseline knowledge of disability and access to resources may not be representative of the broader population of parents of children with disabilities in Bangladesh. Part of the evaluation of this "Master Trainer" programme was to identify criteria for successful participation in the online training. The research team and in-country partner screened 25 potential candidates for the programme, with a final sample size of 16 parent trainers (n=16). The sample included 12 female participants and 4 male participants. The age of the participants ranged from35 to 54 years. Their education levels varied from primary level education to Masters' degrees.

According to the baseline survey that was sent to all participating parents to better understand their needs, the average age of their children with AND was 17.5 years. While the average age may seem high, it is important to note that many of the children have severe autism (or other more severe NDDs) and attend a special school. Additionally, family dynamics and cultural considerations in Bangladesh are such that the children of the parents in this study are not expected to live independently; making the lessons learned through the programme valuable regardless of age. In the survey, parents reported lack of social acceptance and support as the most common barrier they faced on account of their children with disability. They reported feeling frustrated and stressed, but were hopeful.

Ethical Considerations

The research team followed the required Institutional Review Board (IRB) procedures according to the University of Massachusetts Boston (UMB), to obtain approval for the study. The research team asked for consent before the initial online survey was completed. If the parent volunteers chose to continue in the online training module, a more detailed consent form was disseminated, signed, and collected before the training began.

Study Setting

In collaboration with a local partner in Bangladesh- the ICDDR,b - the study began with a parent focus group session to discuss existing and needed services for children with AND, and to assess the feasibility of implementing an online training programme. Parents then participated, via computer, in the online BPEP training, which included a welcome unit and eight lessons (Table 1). In addition, ICDDR,b conducted telephone and in-person follow-up meetings with participants, to assess progress and any barriers encountered throughout the online training.

Table 1: Outline of the BPEP Programme Curriculum

Unit 1: Introduction to the Programme and Introduction to Autism

- Definition of Autism Spectrum Disorder
- Characteristics of ASD
- Prevalence, Diagnosis, and Treatment

Unit 2: Understanding your child: Social Communication Development

Introduce the pyramid (interactive and direct teaching)

- Social Communication Overview
- 4 Domains of Social Communication
- Teaching Techniques (Interactive and Direct)
- Social Communication Checklist

Unit 3: Set Up Your Home for Success: Routines and Structure

Initiative and Independence

- Setting Up your home
- Predictable Routines
- Defined Space
- Limit Distractions/Rotate Toys/TEACCH Images?
- Daily Activity Schedule Survey
- ADLs - Common ADLs - Ways to support OT/PT in Home
- Importance of independence for skill acquisition/development

Unit 4: Interactive Teaching Techniques –

Follow Your Child's Lead, Imitation and Animation

- Why play difficult/make play interactive
- Follow Your Child's Lead
- Imitation
- Animation

Unit 5: Teach Your Child Language

Modelling/Expanding, Obstruction, Turn Taking, Communicative Attempts, Review

- Modelling/Expanding Language (Adjust Your Language/Area of Interest/Focus)
- Overview of Language Development/Goal Setting
- Obstruction
- Turn Taking
- Communicative Attempts
- Direct Teaching
- Prompts/Reinforcement

Unit 6: Sensory Regulation and Activities of Daily Living

- Overview of Sensory Regulation
- Sensory Seeking & Sensory Avoiding
- Methods to increase/decrease sensory arousal
- Intro to Behaviour Management
- Rumbling/ Warning Behaviours
- ABCs

Unit 7: Addressing Problem Behaviours / Direct Teaching and Behaviour Management / Community Outings (Stigma/Awareness/How to Prepare)

- Advance Visits/Community Sensitisation
- Supports (Social Stories/Transition Objects/Routines/Rehearsal/ABC/Picture Schedules) to ensure success
- Community Outing Tips (bring a support person)
- Monitoring the Rumbling/Warning Signs
- Try Again! And Again!
- Safety & Security Issues

Unit 8: Putting It All Together / Creating a community / Teaching others

- How to be a Master Trainer: This programme is a frame for instruction, what to teach is decided by parents
- Creating a supportive parent community
- How to teach others & customisation
- How to find addition resources - special topics
- Special Topics: Lifespan, High Functioning, Puberty, Aggression

Curriculum Design

The curriculum was initially based on Teaching Social Communication to Children with Autism: A Practitioner's Guide to Parent Training (Ingersoll & Dvortcsak, 2010). This decision was based on the success of Project Impact from Michigan State University (Ingersoll & Wainer, 2013) and its approach to easily understandable skill-related development for parents. The initial outline was shared with the in-country partner -ICDDR,b - which received feedback and input from the local participants. A site visit to Bangladesh was conducted to gather further feedback related to content, and the curriculum was tailored accordingly. The outline of the BPEP programme was adapted to the Bangladeshi cultural context and needs (See Figure 1.1).

Distance Learning

Distance or online learning has emerged as a trend in both university and professional development education. A study conducted by Hanover Research (2011) found that "trends in globalisation and the global economy have opened up a new set of potential students who demand access to flexible learning opportunities". For parents of children with AND in Bangladesh, distance learning provides access to specially tailored content from experts in the field residing across the globe. A study evaluating the efficacy of online distance learning in Africa, found that "ICT can be used to increase access to authentic teaching and learning materials" as well as to act as "a bridge to provide access to education and quality professional preparation" (Wakahiu & Kangethe, 2014). Recognising that internet services and access to technology is possibly limited for the majority of those living in under-resourced and/or rural areas, this study intentionally engaged participants with consistent access to the virtual parent training programme, and provided them with the training and skills necessary to then translate the information into community-based training that does not rely on technology for successful implementation. Curricula were adapted to consider the education levels and resources of both the master trainers in the pilot programme and secondary community participants.

The BPEP research team utilised the online learning platform Moodle. "Moodle is a learning platform designed to provide educators, administrators and learners with a single robust, secure and integrated system to create personalised learning environments" (Moodle, 2015). The course was self-paced and members of the in-country team as well as the research team were available for technical support and content clarification as necessary, thus limiting the impact of "digital potholes" that can deter student satisfaction and retention (Fisher & Baird, 2005). The research team also took steps to ensure that factors that lead to failure as defined by Rovai and Downey (2010), including lack of consideration of design, implementation, evaluation and sustainability were evaluated prior to student enrolment.

In developing and adapting the curricula in an online setting, researchers utilised Universal Design for Learning practices and included multiple methods and media for exchanging information. Researchers took measures to construct each lesson in a standardised, step-by-step format, thereby providing participants with a clear and consistent manner in which to approach the content. A visual

representation of the lessons as they appeared to participants is in Figure 1. Each lesson outlined the goals and learning objectives and core content through a narrated visual presentation (PowerPoint) and included video demonstrations of concepts and strategies along with written materials that could be downloaded and saved for later reference. The lessons concluded with a short assessment of knowledge and a feedback survey on satisfaction with the way in which the information was presented. The online learning platform, Moodle, recorded participant knowledge responses and awarded 1 point for each correct answer, with a total of 5 possible points per unit. Grades were calculated based on the raw scores of the knowledge check, and the mean scores per student, unit, and course were computed. Shaded cells indicated that a participant did not complete that unit's knowledge check. Units were linear in design and enabled participants to scaffold their learning and build upon previous weeks' topics, which contributed to overall understanding.

Figure 1: A Visual Representation of the Lessons as they appear on Screen

Research Tools

Participants were given a baseline parent needs survey aimed at evaluating current levels of understanding around terms and behaviours typically associated with AND. Researchers also utilised this tool to gain insight into cultural intricacies and potential communication barriers with participants. The second survey was a unit feedback survey that each of the participants completed after the end of

each module. This survey gathered information about the time taken to complete the module, the difficulty of the content, and any other feedback the participants wanted to give. Lastly, the researchers created a "knowledge check" or measure for establishing receipt and understanding of the information provided in each lesson. Participants completed this step at the close of each module. A final programme questionnaire was adapted from the Incredible Years® Parent Programme Satisfaction Questionnaire.

RESULTS

Overall, the pilot programme was deemed successful enough for local adaptation and translation. Table 2 shows the completion rate of the participants in the online programme. The majority (n=9) of the participants completed each unit in the online training. Four (n=4) of the participants completed all but 1 unit in the course, and three (n=3) participants completed less than 7 units.

Table 2: Knowledge Check Scores by Unit

Knowledge Check Scores										
Participant	Unit 1	Unit 2	Unit 3	Unit 4	Unit 5	Unit 6	Unit 7	Unit 8	Participant Overall Score	Participant Percentage
1	4	4	5	5	5	4	5	5	4.63	92.50%
2	4	5	5	5	4	5	3	5	4.50	90.00%
3	4	5	5	5	5	5	5	5	4.88	97.50%
4	4	5	5	5	5	5	3	5	4.63	92.50%
5	4	5	5	3	4	5	4		4.29	85.71%
6	4	4	5	4	4	4	5	4	4.25	85.00%
7	5	3				4	1	5	3.60	72.00%
8		5	3	4	4	4	3	5	4.00	80.00%
9			5	5	4	5	4	5	4.67	93.33%
10	3	4	4	4	4	4	3	3	3.63	72.50%
11		5	5	5	4	4	4	5	4.57	91.43%
12	4	4	4	4	4	4	4	5	4.13	82.50%
13	4	5	5	5	5	5	5	5	4.88	97.50%
14	4	4	4	5	3	4	3	4	3.88	77.50%
15		4	5	5	4	3	5	5	4.43	88.57%
16	3	3			4	3		5	3.60	72.00%
Unit Mean	3.92	4.33	4.64	4.57	4.20	4.25	3.80	4.73	4.28	85.66%

*shaded cells indicate missing scores

Unit Feedback Survey

According to the unit feedback survey, the participants required1-2 hours, on average, to complete each unit. They felt that the length of each unit was appropriate for 6 of the 8 units; the other units were rated as "a little short". Overall, participants felt that the content of all 8 units was moderately difficult. The power-point presentations and videos, which provided the content and examples for each unit, were perceived to be very useful to the parents. On the whole, the participants felt the training courses were culturally sensitive.

Knowledge Checks

Participant scores on knowledge checks ranged from 3.60- 4.88 (77.00%-97.50%) with an average score of 4.28 (85.66%) (Table 1). Any unit or participant who fell one standard deviation (σX =0.42) below the mean score was examined in more depth to identify potential barriers to participation or misunderstanding of unit content. Three participants (7, 10, and 16) averaged less than 3.86 (77.20%) on their knowledge checks. Two of the participants (7 and 16) did not complete three of the eight units of the online programme. On review of the unit feedback surveys, it was found that participant 10, who also fell below the minimum criteria for accuracy on the knowledge checks, felt all of the units were somewhat hard, had a lower level of education than other participants, and appeared to be less proficient in English language than the rest.

Unit scores ranged from 3.80 - 4.73 (76.00%- 94.67%) with a mean score of 4.31 (82.12%). Any Unit with a participant score one standard deviation (σX=0.34) below the mean score was examined to identify barriers to participant understanding and to assess the Unit's content. The scores on Unit 1 and Unit 7 fell below the minimum standard for accuracy at 3.97 (79.4%). Due to initial difficulties in getting accustomed to the online learning platform, all the participants convened for an in-person introductory lesson that included assistance in navigating the BPEP Moodle website. The participants were led through Unit 1 as a group, to demonstrate the proper techniques for navigating each unit. It is hypothesised that many of the participants did not feel the need to complete Unit 1 again or complete the knowledge check for Unit 1 due to this in-person lesson, resulting in a low Unit score.

In addition, participants' scores fell below the minimum standard of competency for Unit 7, which included content related to addressing problem behaviours, principles of behaviour management, and community outings. Analysis of the

Unit feedback surveys indicated that many participants were confused by the content relating to behaviour management and that the community outing content was not culturally relevant to their setting. In addition, the participants rated the content as somewhat hard and took less than one hour to complete the material.

DISCUSSION

This pilot programme provides a context for applying online training for parents in a developing country. First and foremost, the project's success was dependent on support from in-country partners. The ability to understand specific country needs and the needs of the parents, was critical to the realisation of this pilot programme. The online presentation of information was complex at times. The research team worked closely with a technical team to prepare and design the content, and make it as accessible and as clear as possible. This process of consultation continued throughout the project to ensure that the entire course ran smoothly.

Due to the presentation of the materials online, the research team travelled to Bangladesh to provide orientation before starting the training. The in-country team was then able to assist each master trainer with further orientation to the online modules. Although the technology caused some disruptions, overall the training material was successfully provided to all master trainers.

Training Content

The research team requested feedback from the participating parents about the content that was provided in the online modules. Participants desired an increase in the number of videos per lesson, and the inclusion of more practical examples of the concepts being presented, especially in the Bangladeshi context. They also noted that the training was intended to benefit younger children, whereas most of the children of participating parents were teens and adults. Consequently, they felt that many of the strategies were too elementary for their children. However, the research team's purpose was to create an early intervention programme targeting rural parents with young children, not necessarily to reach the master trainers.

Other anecdotal information from a final survey indicated that participants would have preferred an in-person workshop or Skype sessions and more in-

depth training in order to be better prepared to train other parents. Participants also reported that because autism and neurodevelopmental disabilities are so complex and diverse, it is difficult to create a training programme that targets each child's individual needs; therefore, more resources and examples are needed. The stated benefits of the programme were: decreasing depression and frustration of parents, support of a parent network, increased knowledge about autism, and a programme that would reach other parents who need assistance.

ICDDR,b also gave the research team feedback about the training process. Although they felt it was effective and timely, they recommended that the training programme be systematised through organisations that could be held accountable for outcomes. This suggestion is imperative for the sustainability of the project in Bangladesh. Furthermore, the training content needs to be translated into Bengali and the videos should be re-made to be culturally appropriate, relevant, and understandable to the local population.

CONCLUSION

Due to the lack of human capital in developing countries, parent training programmes are an effective method for disseminating basic content to enhance parental knowledge of AND, and direct support for children with AND. The findings in this study prove that most parents are able to comprehend basic skills needed for addressing communication and behaviour with such children.

To continue BPEP, ICCDR,b is translating the programme into Bengali and creating videos with local parents and children. These tasks will allow for a second group of parents to be trained by the master parent trainers, using the local language. The desired outcome of the project is that a core group of parent trainers will disseminate the training in rural areas of Bangladesh and support parents who have limited resources. Furthermore, the cohort of parents will provide continuous support for each other, to learn and grow in their knowledge and skills pertaining to AND.

Implications and Limitations

It is important to note that the small sample population for this study does not reflect the typical parent population – rural, low socioeconomic status, limited education levels. The study was designed to follow the training module, on completion of which the pilot study participants, with access to technology, baseline knowledge

of disability and capacity for learning new skills and concepts, would then share their knowledge in a community setting that more closely resembles a "typical" population. This pilot programme created a base of knowledgeable trainers, but the researchers were unable to assess whether the larger population would be able to adequately understand the content of such a programme. Furthermore, not every study participant completed all sections of the programme, which created incomplete data for some surveys and training Units.

While the researchers' choice of highly educated parents for the training did not represent the majority of Bangladesh's population, data indicates that a certain level of education and English proficiency were necessary to ensure a thorough understanding of the content. Participant 10, who had a lower education level and limited English proficiency than the others, performed lower on the knowledge checks throughout the course. Ultimately, this trainer may have benefited from receiving the content in Bengali from the "master trainers" in a community-based education setting.

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