

CAPACITY BUILDING FOR CARERS OF CHILDREN WITH LEARNING DISABILITIES

**Shubhangi Vaidya
Assistant Director,
Regional Services Division,
IGNOU, New Delhi, INDIA**

INTRODUCTION

This paper examines the role of open and distance learning in equipping carers of children with learning difficulties with basic skills, attitudes and capacities that will enable them to foster optimal development in their children and an attitude of acceptance and positive coping within the family as a whole. Specifically, it focuses on parents and carers of children with autism in India. Autism is a 'silent disorder' which usually is unaccompanied by physical markers and whose manifestations are behavioural rather than physiological. It is therefore one of the least understood disorders and children affected by it seldom have access to appropriate therapy and interventions. This paper suggests a means of promoting awareness and putting in place basic behaviour-management strategies through an ODL package that will deliver information at the door-steps of carers. It builds upon an existing model already in place in the form of 'Awareness and Training Packages' for parents and carers of children with visual impairment, mental retardation and cerebral palsy developed by IGNOU, the premier Distance Learning University in India, in collaboration with the Rehabilitation Council of India.

To enrich this model, we suggest the incorporation of inputs drawn from a highly popular and successful program conducted by 'Action for Autism', a leading Non Governmental Organisation located in New Delhi, entitled the 'Mother and Child Program' (MCP). It proposes a partnership between an established ODL system and a vigorous NGO which has justifiably earned itself the reputation of being synonymous with the autism movement in South Asia.

The paper begins with a review of the Indian scenario in the context of autism. It makes a case for parental empowerment as a key to child outcomes. It describes the salient features of both, the MCP and the Awareness packages presently available and how these can be creatively integrated in the context of Autism in India.

AUTISM IN INDIA

Autism is a life-long developmental disability that profoundly impacts the social, communicative and imaginative capacities of an individual (Wing 1988). Individuals with autism range from non-verbal, withdrawn aloof people with poor eye contact and odd behaviours like rocking, finger-flicking, flapping, toe-walking etc. to highly verbal, eccentric people with few, obsessive interests and serious difficulties in social behaviour. Almost 50% of autistic people are also mentally retarded and about 85% of them are males.

In India, as in many other developing countries, autism is often confused with mental retardation or mental illness. Medical professionals as well as the lay public are not very conversant with its symptoms or diagnostic criteria (Daley and Sigman 2002; Daley 2004). Even though no full-scale epidemiological study has been conducted in India, it is estimated that anywhere between 2 to 4 million individuals could be afflicted with autism. Daley's (2004) study revealed the difficulties faced by families in understanding what was "wrong" with their children and the long drawn out, often tortuous process of obtaining a diagnosis. After the diagnosis, the issue of appropriate services and rehabilitation emerges.

Currently, the needs of children with autism in India, are not being met in either the regular or special education systems. Children with autism are frequently refused admission in special schools because officials protest that they are not equipped to handle these children. Until 2003, no formal training for autism specific techniques was available in India. Since then, Rehabilitation Council of India (RCI) has established 4 training centres across India, who will annually train approximately sixty to eighty professionals adequately skilled in working with children with autism. Although this is an important beginning, the sheer numbers demand attention on a war-footing. People with autism have a normal life span and many will require supervision after their parents' death. There is thus an urgent need to plan vocational centres and residential homes for these children in preparation for the time when they become adults.

At the same time, the absence of a social security net and the lack of welfare measures mandated by the State, pushes the family into a corner; it is upon the family that the burden of lifelong care and maintenance of the disabled individual falls. The omnipresent question "What happens to child when we are gone?" troubles all families, irrespective of class and other such factors.

PARENTS AS THERAPISTS

It is now frequently acknowledged, that parents are the single most important resource for any child and must be an integral part of the service-delivery and planning process. Given the fact that children spend the early years of life under nearly constant parental supervision, parents can serve as primary educators by directly teaching their children throughout the day in a variety of natural settings.

Parent education includes training the parents in specific procedures to work directly with their children, to teach them specific skills, reduce problem behaviours, pivotal response training, improve non-verbal communication skills, verbal communication skills and increase appropriate play skills. A part of this programme also includes teaching parents to advocate for their children and to provide information and support to other parents (Gupta and Singhal 2005).

Parent education can be beneficial not only for the children but also for the parents. For example, parents can learn techniques to work with their children with autism, to help them overcome their socially avoidant behaviours. Parents with children with autism have reported having lower parenting competence, suggesting that they may feel uncertain about whether they are good parents. Usually, they doubt their competence because their child does not respond as expected. There appears to be increased self-blame as a coping strategy, greater caretaker burden, family burden and more disrupted planning, reported by the mothers of children with autism (ibid: 2005).

They feel stigmatized and ashamed of exposing their children's disruptive behaviour to public view and thus face social isolation. This further impacts upon the possibilities of forging support systems and networking with the community.

In such a situation, awareness and training packages for parents and carers, like the ones developed by IGNOU assume significance. Written in simple, jargon-free language, replete with illustrations and examples, they empower parents both with information and positive attitudes.

Given the paucity of services and programs, they offer a viable alternative to hands-on parent training programs conducted in the face-to-face mode. We shall now examine two parent awareness-cum-training programmes in either mode and discuss the possibilities for their creative integration.

THE 'MOTHER AND CHILD PROGRAM' OF ACTION FOR AUTISM

The pioneering parent driven organization, 'Action for Autism', formed in 1991 by a group of parents of autistic children, is at the forefront of autism rehabilitation, training and advocacy in the Indian sub-continent. Based in New Delhi, it has forged links with disability organizations all over the country and the world.

One of its most popular programs is the 'Mother and Child Program'. Children with their primary carers (usually the mother, but in some cases, the father or a grandparent) spend three months at Action for Autism with their children, aged two upwards. Carers are taught how to 'work' with their children at table-top activities, play, communicate and manage their children's behaviours, by a trained therapist who helps them acquire the skills to set a program in place, and supervises them while they interact with and work with their children. The greatest benefit of this program is that it facilitates bonding between carer and child and introduces creativity and diversity in the time they spend together.

For carers who are exposed for the first time to autism-appropriate teaching methodologies and who learn and share with other similarly placed people, the MCP provides much social, emotional and psychological support.

However, due to the location of the program in Delhi and the sustained commitment of time it requires, it becomes very difficult for families outside Delhi to access. They have to make travel and living arrangements and virtually uproot their families for the duration of the program. It is also difficult for working parents or home-bound ones (say, due to the arrival of a new baby or an ailing parent) to access it.

Despite these limitations, the program has succeeded in building a resource base of carers who come to AFA, train and go back to their towns and cities equipped with skills that they can use not only with their own children, but others in the community.

TRAINING CARERS: THE AWARENESS-CUM-TRAINING PACKAGES IN DISABILITY CONDUCTED BY IGNOU AND RCI

The Indira Gandhi National Open University, established in 1985 by an Act of Parliament, is one of the premier educational institutions of the world. It offers more than 100 Certificate, Diploma, Degree, Doctoral, Awareness-Generating and Training Programmes and has, on its rolls, more than 1.3 million students. The primary objective of IGNOU is to provide access to quality education to all citizens of the country. The University is mandated to widen access to education by offering high quality innovative and need-based programmes at different levels, especially to the disadvantaged segments of society at affordable costs. It is committed to quality in teaching, research, training and extension activities.

The Rehabilitation Council of India (RCI) was set up as a registered society in 1986. Subsequently, the Indian Parliament enacted the Rehabilitation Council of India Act in 1992, and on 22nd June 1993, the Rehabilitation Council of India became a Statutory Body.

RCI has the twin responsibility of standardizing and regulating the training of personnel and professionals in the field of rehabilitation and special education. The Council has so far developed 42 training programmes and accorded recognition to 200 training Institutions throughout the country.

The Awareness-cum-training Packages jointly prepared by IGNOU and the RCI in the areas of Mental Retardation, Visual Impairment and Cerebral Palsy were initiated with a view to reaching families who had little access to information about their child's disability. The aim of the Awareness-cum-Training Packages is to "equip the parents and family members of individuals with disabilities with the knowledge, attitudes, strategies and skills so that they are better equipped to foster the multi-faceted development of those in their care and can have a positive influence on their lives." (Programme Guide, Awareness-cum-Training Packages in Disability: 8)

The specific objectives of the Awareness-cum-Training Packages in Disability are:

- To develop an understanding about disability and an attitude of sensitivity and empathy towards persons with disabilities;
- To develop awareness about the importance of prevention and early detection of disabilities;
- To develop the conviction that the child with disability can learn and benefit from early stimulation and education;
- To learn about strategies and methods for early stimulation, training and education of the child with disability, so as to foster the child's optimal development in all areas – including the development of physical, motor, mental (cognitive), social and communication abilities;
- To develop awareness about how the person with disability may be helped to acquire basic self-help skills with respect to activities of daily living;
- To develop an understanding about how to manage difficult behaviours in the person;
- To know about the various educational options available in the country for education of children with disabilities;
- To facilitate inclusion of the child in the preschool and the primary school;
- To develop awareness about adaptations needed in teaching-learning strategies, methodologies, materials and curriculum, that would benefit the child with disability;
- To develop awareness about viable avenues for economic rehabilitation and some strategies for training the person for a suitable vocation.

While the course material adopts a lifespan perspective, its focus is on the childhood years.

The transaction of the Awareness-cum-Training Packages in Disability with the parents and family members is based on a combination of print material-based learning and face-to-face contact sessions. The print material is self-instructional in nature.

In order to enable the learners to understand the text as well as to provide individualized guidance and practical training to the learners regarding carrying out various activities with the child, a face-to-face programme of a minimum of five days (equivalent to a minimum of 40 hours) is organized by the Implementing Organization.

The Packages are to be implemented and delivered through selected organizations working in the field of disability, which have been identified and approved for the purpose of implementing these Packages jointly by the IGNOU and the RCI. These Implementing Organizations are committed to organizing the contact programme of 40 hours duration and helping the learners understand the course material and apply it with respect to their child.

The Packages in Disability are meant for parents and family members of children with disabilities, specifically those parent learners who are proficient in reading and understanding printed materials, and have writing ability at a minimum level of Standard VIII. In case a person has not studied upto class VIII but has the reading, understanding and writing ability upto that level, the Implementing Organization may consider enrolling such a person. The duration of the program is 3 months, and the cost of course material a nominal Rs. 210/- per package.

AN INTEGRATED MODEL FOR AUTISM

We propose to integrate aspects of both the MCP programme conducted by AFA and the Awareness-cum-Training Packages developed by IGNOU and RCI which caters specifically to the needs of carers of autistic children.

Some of the ground realities that need to be kept in mind are:

- The lack of awareness about autism in large parts of the country
- The notion that autism is 'some kind of mental retardation' and therefore requires the same management and teaching strategies
- The paucity of rehabilitation centres that deal with autism

We suggest that the programme be devised by a team comprising academicians from the ODL system with backgrounds in psychology, human development, special education or allied disciplines, and special educators and therapists from a specialist NGO like Action for Autism. The program may comprise a judicious mix of printed materials, audio and video. The material will focus on the following areas:

- Understanding the underlying deficits of autism
- Implementing a behaviour modification programme accordingly
- Helping the child develop language, communication and social skills
- Helping the child deal with sensory modalities
- Facilitating an inclusive climate at home and in the neighbourhood, so as to integrate the child into the community
- Wherever possible, equipping the child with basic skills that would enable him/her to be absorbed into a mainstream educational setting
- Facilitating the establishment of self-help-groups of parents and carers that can offer help, advice and support to other affected families
- Building capacities for advocacy so that the human rights of people on the autism spectrum can be safe-guarded.

Eligibility criteria, duration etc. are to be in accordance with the other packages. As earlier described, the packages for V.I., M.R. and C.P. developed by IGNOU and RCI are administered through 'Implementing Organisations' who distribute the printed material to learners and organize an equivalent of 40 hours of a face-to-face programme. Due to the paucity of such organizations specifically dealing with autism, it is proposed that the student be distributed the study material directly by the concerned Regional Centre for self-study. Audio-video cassettes, which are part of the course package, will be studied by the learners at home.

However, in order to enable learners to network with each other, an interactive web portal can be set up, through which they can share experiences and offer each other suggestions. For those who do not have ready internet access, a network through snail-mail and telephone can be set up.

Periodic 'tele-conferencing' sessions at the Regional Centres wherein learners can interact both with experts at the University and the NGO as well as each other, can further facilitate contacts and networking.

As this is proposed to be a non-credit programme, the pressure of 'preparing for examinations' will not be there. Learners can, however be encouraged to document their experiences in using the course materials with their children through a written document, a home video, a photo-album etc.

These materials can be made available to other learners and future batches. Indeed, 'best practices' can be incorporated into the course material itself.

Perceived benefits of the program

- The program would be monitored directly by the University, thus ensuring uniformity of standards
- The continuous participation of the NGO through teleconferencing would ensure that state of the art developments in rehabilitation and therapy be made available to learners
- The possibilities of interacting with other similarly placed families would usher the development of Self-Help Groups across the country
- The development of a 'caring community' based on local needs and local resources coupled with technology mediated links with the community of specialist knowledge and expertise.
- Development of a human resource base which can subsequently be given professional training to help cope with the sheer numbers of India's disabled population.

CONCLUSION

The proposal outlined above is an attempt to creatively integrate two already functional training models keeping in mind the unique difficulties of persons with autism, the special challenges that confront their families and the absence of facilities support structures for those thus impaired. It proposes to tap the liberative possibilities of open and distance learning and forge the development of an inclusive, caring community that will show the way to society as a whole.

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