

Reviews

## Omid early intervention Programme for children with Autism Spectrum Disorder and their families in Iran

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Child development research has established the importance of support and services for children with special needs and their families at very early stages after the diagnosis. These services offered in the form of the early intervention programmes. There is a dearth of early intervention programmes for children with autism spectrum disorders and their families in Iran. A parent based early intervention programme has been developed based on several preliminary studies in Iran. This programme is called "Omid early intervention programme for children with Autism". It is based on the social model of service provision and tries to establish a good parent –professional relationship through visiting children in their natural context and engaging parents in the intervention process. The programme consists of four phases which in first phase parents and child communication is considered and a resource kit facilitates the interaction. In the second phase updating parental information on autism is targeted through different workshops. Home visits are considered at the phase three and finally at the phase four the main concern is on the preparing a safe transition from home to school via preparing both parents and pre-school staffs. This programme is under trial right now.

### Introduction

Parents of children with an Autism Spectrum Disorder face many challenges in Iran. The story begins when the first signs of the disorder are seen, generally by 18 months, and the diagnosis is yet to come. During this time many families have to live with uncertainty. Parents may suspect something is wrong with their much-loved child. But from the other hand, in Iranian extended family system any members and relatives may try to console them by assuring that there's nothing to worry about, or they had similar difficulties with their children and it vanished without much efforts. Even some professionals whom they consult, may do this. If families do decide to have their child assessed it can take up to 3 years before they are seen at an Iranian Special Education Organisation (ISEO) evaluation base to be referred to a team specialising in ASD. This will be done in a national screening programme for five to six years old Iranian children whose parents wanted to register them in the first grade of elementary school (1). The screening programme attempts to cover children of all backgrounds within a locality: namely all ethnic and religious groups, urban and rural children. It tries to offer an equal opportunity for the identification of

children with special needs so that they can be offered a special school placement. In 2005 screening for ASD was added to the programme, but it started only in the major cities of 18 selected provinces and later it expanded to cover 24 provinces by 2009. Six provinces are currently outside of the national screening programme for ASD as are many children who live outside the major cities. When the screening results in a suspected ASD, the child is referred for further assessment which is undertaken special education experts from ISEO's testing and evaluation department who have training in psychological assessment.

Throughout all the months maybe years of waiting, parents may receive little advice or guidance on how to help their child's development. When a diagnosis is finally made, it often confirms parents' suspicions and it is a relief in some ways for them to be told why their child has problems. Although some parents find it hard to accept, and may seek the second and third opinions.

### Early Intervention

Internationally early intervention programmes for children with different types of disabilities and their families have proved to be successful. International

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experience has helped to define the essential aims of early intervention programmes. Early intervention schemes can respond to the needs of families who have a child with any disabilities (as well as ASD) in different ways, and a range of responses are needed given the inevitable variation found among families and children with different types of disabilities. The most common ones are: information for parents, parent groups, emotional support, advice and guidance, empowering parents, extending social networks, parental advocacy, support for one another, involvement in assessment and therapy, and training course for parents. There are three simple principals that depict the importance of the family role in the process of early intervention;

- Regardless children's ability or disability, parents are involved in all children's development.
- Nearly all children with disabilities live in families. Family members can spend much more time with the child, hence they need support.
- All children grow into the community by making use of local facilities. There is some resistance for children with disabilities which must be broken down.

With respect to ASD, parents will seek out advice and guidance as soon as they identify a problem. They certainly feel they should get information as soon as they are given a diagnosis of ASD for their child. This help needs to come in different forms to meet the diverse needs of the families.

Present Situation for the children with ASD and their families in Iran

Autism is still so new for the Iranian professionals and service providers and there is still a long way ahead of the policy makers and service providers to offer satisfactory and sufficient services. Services are still not sufficiently developed, therefore parents' feelings of uncertainty and frustrations of not knowing how best to help their child is a part of this story. Findings of research indicates that parents of children with autism spectrum disorders (ASD) in various cultures and countries have significant risks of disturbed health and well-being compared with parents of non-disabled children or children with other types of disabilities (2, 3, 4, 5). Families need help and support in bringing up a child with ASD and the support received by the parents can reduce parental distress (6, 2).

Currently in Iran there are no early intervention programmes for the parents who have a child with ASD; but in affluent countries there are several programmes which their usefulness has been tested in different study and reports (7). Translating a successful, non Iranian programme into Persian or other languages in Iran is possible but these

programmes should be culturally adapted regarding Iranian family values, parental expectations for their child and the methods of child rearing. Culturally specific programmes are intended to facilitate successful parenting within a specific group's culture (8). Therefore having special programmes for Iranian parents around different issues of ASD could be considered as a priority type of basic support for parents of ASD children. Indeed parental culture could be an important issue for early intervention programmes and as Jordan (9) and Gorman (8) commented there are increasingly growing needs for family services to be more applicable to ethnic-minority populations, and also the development of culturally modified intervention programmes. Parents in Iran have little opportunity to get information about ASD in any formal way.

### **Models of disability**

Model of disability is a belief system which determines the attitude towards the disability. There are different models of disability. These models are tools which help defining impairment and provide a base for governments and society to devise strategies to meet the needs of disabled people. Models of disability provide an insight into the attitudes, conceptions and prejudices of service providers on people with disability and reveal the way in which a society provides or limits access to services for them. Disability models are influenced by two main philosophies. First attitude considers disabled people as dependents upon society. This philosophy can result in discrimination, segregation and paternalism. Second philosophy concentrates on the society and what it offers to people with disability as their customers of the services. This attitude leads to choice, empowerment, equality and inclusion (10). Two main models of disability are Medical and Social model of disability.

Medical model considers disability as a result of physical condition which exist in the disabled person whereas social model proposes that systemic barriers, negative attitudes and exclusion by society are the ultimate factors defining who is disabled and who is not (11). ASD as it is explained in ICD-10 and DSM-IV-R is considered as a medical condition. Similar definition is used for ASD in Iran and it is considered as a medical condition which happens to a child. In the medical model, defining and categorising the impairments or limitations in functioning with underrating the social, cultural and physical environments in which people live and which can constrain their lifestyle and levels of functioning is the main focus. Hence when children attend at a clinic, the doctor will conduct medical examinations

and the therapists may use tests to assess their communication or sensory impairments. They may show little interest in wider family circumstances and although they may make recommendations relating to the child, they will probably not feel able to help with other issues that may have a greater impact on the family such as poor housing, mother's depression and unemployed father. This is considering development of a child as a separate issue and paying little attention to interactions between different elements which impact on a child's development.

This model has been to the fore in criticising by the disability activists. They argue that most definitions of a disability stem from a medical emphasis and do not reflect issues which imply that people regardless their levels of abilities they do develop in a variety of contexts and environments which surround them and these play a major role in development. Issues such as lack of access to education, employment and housing are important for people with disabilities. In most of the societies, disability is considered as a stigma and a terminology is used that is devaluing and stigmatising of persons with disabilities (12), and which can easily be used to justify low expectations and denial of opportunities. Expressions like "They're autistic" can sound very dismissive. The focus is on people's deficits with little attention to their talents and competences or how these strengths can be used to overcome or compensate their weaknesses.

Alternative models of disability as it is explained by International Classification of Functioning, Disability and Health (ICF), (13) and "The Declaration on the Rights of Disabled Persons" (14) define disability in a social context. Therefore the social aspects of disability are considered in the modern definitions of disability and it does not consider as a solely 'medical' or 'biological' dysfunction. By including "Contextual Factors", in which environmental factors such as the family in its immediate and extended forms are listed, this definitions record the impact of the environment on the person's functioning. Therefore, they would suggest that ASD like the other types of disabilities is better to be viewed within the family context. A person's functioning is conceived as a dynamic interaction between health conditions and contextual factors both personal and environmental. ICF does not classify people into discrete groups but rather aims to describe the situation of each person within an array of health-related domains (including bodily impairments and illnesses) and in the context of environmental and personal factors that are known to influence their levels of functioning with society. Each person is given an array of codes –

usually between 3 and 18 to describe their particular characteristics.

In the social model, the key assessment is in terms of the type and extent of the accommodations or interventions required to the environments so that the person functions as well as other people in their society. Obvious examples are the provision of lifts instead of stairs and access to hearing aids. Both of these accommodations will reduce the disabilities experienced by either wheelchair users or hearing impaired persons. For people with ASD, the adaptations that will most help them may be more in people's behaviours and expectations.

In this way of thinking about disabilities, the focus of interest in both assessment and treatment is placed on the barriers that prevent people with disabilities to participate fully in society and the supports and adaptations that would enable this to happen. Disabled activists have focussed especially on access to education, employment, community facilities, transport and housing as these are primary determinants of social inclusion in most societies.

This model of disability better reflects the emphasis in Government policy on social inclusion; encapsulated in slogans such as 'full participation' and 'equality of opportunity'.

The main lesson however, is that we need to see the growing child or teenager or adult with ASD as a person not a part from society but a person who is striving to become part of society. Hence our assessments and interventions must be geared to the latter at all times (15).

### **Preliminary Studies**

As a doctoral dissertation a series of activities and studies on the impacts of taking care of a child with ASD in Iran was undertaken (16). To get more knowledge on the existing situation for people with ASD and to update information on ASD in Iran, 3 workshops for professionals in the field of ASD was also performed with the help of the experts from the University of Ulster (17). A survey study undertaken with 43 Iranian parents as to understand their knowledge of ASD and the impact it had on their lives, as well as the advice and guidance they needed (18). This confirmed that the families faced similar stress and health problems as do parents in other countries. However many lacked accurate information about the condition and they had few opportunities to obtain advice and support for themselves as parents.

In another study with 37 parents of children with ASD in Iran (19) it was reported that parental educational sessions provided parents with information that they found useful. The positive

impact of the training sessions on parental general health, parental stress, coping strategies, family functioning and satisfaction with their caring role were found to be statistically significant. The training sessions also influenced parental social networks and their advocacy. Although the findings of the study bode well for the usefulness of parental training programmes in Iran, there are various challenges to having these programmes more widely available for Iranian families who have children with ASD. Based on the collected information and "The Keyhole Early Intervention Project" by "AutismNI" Northern Ireland's Autism charity, an early intervention parent- focused model which is called "Omid"<sup>1</sup> developed in Iran. This programme is under trial at the Autism Child Charity Foundation at the present time. The first phase of the programme is focused on the post-diagnosis information, in which parents are provided with information and advices via some booklets and a resource kit to boost their interaction and communication via everyday life activities and play. The second phase of the programme which is in form of workshops and group educational sessions, focus on parent and full-time carers' knowledge on ASD, different approaches for children with ASD, issues related to advocacy, group discussions and experience exchange to develop knowledge and understanding of ASD. In phase three the main emphasis is on the child, in his natural settings and in home context. This is done as a one to one support of a professional during a home visit. This can be considered as collaboration between professional and families and consideration of families' needs and priorities. The final phase of the programme is to facilitate transition from home to school which is done by preparing both parents and personnel at the kindergarten and preschool level to understand ASD and to manage their behaviour. The detailed explanation on the contents and activities in each phase is explained at the following part;

### **Omid early intervention Programme four phases:**

#### **1. Omid Resource Kit**

This consists of five booklets about ASD and a resource kit of different play and activity materials that families can use with the children. There is also a two- day training course in the use of the kit which is considered for parents to let them know more about the practical usage of the kit. This training aims to provide early years workers with an understanding of connecting through the medium of play with the young child with Autism.

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1- Omid in Persian means hope

#### **2. Parent Training Workshops**

The workshops are considered to supply parents with recent information on ASD , its basic features and causes, to increase parental knowledge about different methods of education and intervention for a child with ASD, to understand parental role in providing support for their child so as to improve their understanding of how to assist his/her social, emotional and academic development, to improve family relationships through being more open to discussion on their ideas and the problems that family members may have and finally to give parents an opportunity to meet and share their experiences with other parents to extend their social network.

These workshops provide parents with an opportunity to meet with other parents in a small group under the guidance of a facilitator with expertise in ASD. The format is one of facilitated peer group discussion over a six- week period. There are several handouts video clips to help parents to meet the predetermined aim of the course. The "Omid Parental Training Workshop" is a doorway to enabling parents or other full-time carers' to recognise their existing skills and strengths and to obtain the practical and emotional support they require. It is aimed at better equipping parents to understand their child, Autistic Spectrum Disorder and some information about the different approaches which is available for the rehabilitation their children in different fields.

#### **3. Omid at Home**

This is a communication-based intervention programme specifically designed for children presenting with ASD. It is based primarily around TEACCH approaches and other communication methods such as PECS and Intensive Interaction. It is designed to be delivered in the child's home by an experienced ASD therapist or teacher who visits the home regularly on 10-15 weekly occasions over a 3-month period. In addition to working directly with the child, guidance is given to parents and they are observed interacting with the child.

Home visits are divided into two types; Initial Visits and Later Visits. "Initial visits" are considered for looking at:

The way that the family are coping, families key concerns for their child, developing knowledge of ASD and its associated features and the way that this features affecting their child. Considering sensory, communication and behavioural issues along with introducing structuring and visual programmes using

the emphasising on the child's strengths is also followed at this level of the visit.

"Later visits" focus on different ways of helping parents to be confident in relating to their child, by means of tailoring programmes to individual child and their family needs. Parents will be guided to use child's strengths of structure and visual aids and they will also be helped to use practical strategies to help with sensory, communication, behaviour aspect of raising a child with ASD.

#### 4. Omid towards the school

The fourth phase of the Omid early intervention programme is training personnel working in early years education about including children with ASD in their pre-school or nursery. The training aims to enhance knowledge about Autism and the intervention strategies which are effective in assisting young children achieve their potential. Parents also will have a short training course to be prepared for their child transition from home to the school.

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#### Conclusion

In summary it can be concluded that there is a need to support parents and carers of children with ASD in Iran. There are different approaches and models in the way that professionals and service providers offer their services to this group of children and their families. The dominant model of service provision for children with ASD in Iran have focused solely on improvement in children, although applications of these approaches could indirectly make parents less distressed through improvements that these approaches cause in children with ASD, it is argued that social models in which the family and cares are also considered could be more beneficial. Omid early intervention programme is based on the social model of service provision for children with ASD and their families and it also tries to establish a good parent –professional relationship through visiting children in their natural context and to enhance the well-being of children with ASD and their families by addressing the needs of the parents as well as the children.