Proposed title:

Living with autism:

Towards a model for engaging siblings of individuals with autism based on mentalizing in Greek population.

Key aspects ;

autism, siblings, mentalizing

1.Rational

I have been recently working as a scientific director of the Day Centre of Messinia for children and adolescents with Autism, the only one of its kind in south Greece and one of the first ones in Greece. It is a Psychic Health Unit supervised by the National Ministry of Health. It was established one year ago by the Association of Parents, Guardians and Friends of children with Autism of Messinia.

We offer our services to 18 families and their children with autism.

As team in our centre we have adopted an eclectic therapeutic approach of some of the most well known approaches.Below I give a brief summary of some approaches.

Traditionally, those working with children with special needs and particularly autism have focused on helping the child master cognitive, language and motor goals in which different approaches in combination are used. These approaches have two common elements: their principles lay on the behaviorist/cognitive notion and have been centred on remediating the child's skill deficits. They are used broadly because of the parental concerns about their children's abilities and can be characterised **as child-centred** services. The foundation for these educationally-oriented programmemes is the behavioural perspective.

Nowadays, much emphasis is placed on the role of the parent as a co-therapist. Parents are trained on how to support their children's learning by using designated activities; this is the so called **family-based model** of intervention. Parents are treated as learners so that in turn they could be their children's teachers.

On the contrary, the **family-centred model** of intervention is believed to respond better to family priorities, empower family members by employing a more holistic approach and demonstrating insight and sensitivity to the family. The main differences between family centred approach and family based approach are the levels of flexibility and responsiveness to the unique needs of each family. There are many fundamental differences between child-centred model and family centred model. Planning must take into account the needs of the parent, the dynamics of the family. The development of the child is viewed in the context of parent-child interaction.

As a result, a central approach of the family-centred programmes is the interactional which places emphasis on the importance of reciprocity in parent- child interaction as a way to reach optimal child development. This approach is based on the notion of the attachment theory and Bowlby's critical contribution that early mother-child relationship can be a secure base for exploration and self enhancement.

All the children that have registered with our programme constitute a quite representative sample of the topical families: most of the times both parents are working and all of the children with autism have at least one brother or sister. By following techniques of programmes such as those described above we try to address their needs.

Through my monthly counseling sessions with parents I get to know more about parental feelings, children's behaviour at home and relationships between children with autism and their typically developing siblings.

Drawn from my personal working experience, I often noted that child-centred interventions are not enough, as they do not improve children's interaction with their family members. In the best case, it seems that they have short-term effects, for example the child is learning some skills, which do not always generalize and cannot transfer outside the context of the session with a professional.

For that reason we aim to teach parents to interact in mutually satisfying ways with their children with autism. I strongly believe that if a professional manages to help the mother establish reciprocal and mutually satisfying interaction with her child later on, this will have a strong positive long-term effect on the child's development.

Parents often express their worries about the 'other child', the sibling of the child with autism. Most of the times they say that their typically developing child often is acting out, acts like their sibling with autism, cannot play with the sibling with autism and is often worried, moody, sad, or angry for extended periods. Moreover, they mention that themselves the parents pay reduced parental attention to the child with typical development. Most of the times parents ask to engage the typically developed child in counseling sessions or role playing in order to teach to the child elements of behavioural intervention in order to cope with the child with autism. Sometimes they even ask for clinical assessment in case something goes <wrong> with their typically developing child.

In order to address these worries in a sufficient way I thought of engaging siblings of children with autism in a **proactive, non pathological way** as they do not (in most cases) present clinical needs under the notion of mentalizing based intervention and to give <voice> to the siblings to express their feelings, needs, thoughts and worries.

By enhancing siblings capacities to mentalize their experiences we may strength:

- Curiosity -genuine interest in others'thoughts and feelings and respect for their perspectives

- Stance of safe uncertainty–also referred to as 'opaqueness'–the open acknowledgment that one frequently does not know what other people are thinking without losing the sense that others'reactions are to some extent predictable

- Contemplation and reflection –ability to reflect on how others think in a relaxed rather than compulsive manner.

- Perspective-taking –acceptance that the same thing can look very different from different perspectives

- Forgiveness –ability to understand others'actions in terms of their mental states

- Impact awareness -awareness of how one's own thoughts, feelings and actions impact on others

- A non-paranoid attitude –others'thoughts not seen as a significant threat and having in mind the possibility that minds can be changed.

- Developmental perspective –understanding that with development one's views of others deepen and become more sophisticated and complex.

- Realistic scepticism -recognition that one's feelings can be confusing. Internal conflict awareness -awareness of having seemingly incompatible thoughts and feelings

- Self-inquisitive stance -curiosity about one's own thoughts and feelings and about how the way other people's minds function relates to oneself.

- Awareness of the impact of affect -insight into how strong emotional states can distort one's understanding of oneself and others.

- Acknowledgment of un-or pre-conscious functioning -recognition that at any one time one may not be (fully) aware of all that one feels,

- Belief in changeability -appreciation that one's views and understanding of others can change in line with changes in oneself

2. Literature Review

Most children grow up with one or more siblings. Sibling interactions are essential and powerful components of child development. Their longitudinal interaction and continuous relationship influence cognitive, social and affective skills. Furman and Buhrmester (1985) suggest that emotional ties between siblings are typically second only to the ties between a child and a parent. Despite theories of various styles of relationship between siblings having developed; for example care-giver relationship, critical relationship or casual relationship, the importance of the sibling relationship is rarely disputed (Bee & Boyd, 2004; Rivers & Stoneman, 2003). It is posited that a siblings relationships' character is generally established in the early childhood years and extends into adulthood (Ross & Cuskelly, 2006).

A review of the literature of autism and family highlighted that a large amount of research has focused on the parental experience of having a child with autism, with fewer studies focusing on having a sibling with autism. Previous studies conducted have all been quantitative in nature and tend not to focus solely on siblings of children with autism, but focus on siblings of children with disabilities in general. Furthermore, the research that has been conducted on sibling relationships within a family with autism child has conflicting findings.. Moreover, the quantitative nature of these studies does not allow for the exploration of ambiguity, or complexity that is evident in the sibling relationship and does not offer an in-depth account from the non-affected sibling's perspective.

Goehner (2007) surmises the effect of being a typical sibling in a family with a child with autism spectrum disorder as feelings of isolation from family along with anger, fear confusion and most of all guilt for having these feelings.

Macks and Reeve (2007) supports that autism spectrum disorder is a severe developmental disorder that presents particularly difficult challenges for the family unit quoting reasons of "restricted family activities. . .inappropriate public behaviour . …… .excessive time, energy and resources spent on child with autism. . ...resentment [from sibling] for not inviting friends home" (p.1061). Should these abnormalities exist within the family unit then one could hypothesize that typical development of a sibling relationship would be altered. Researchers in the field of autism and developmental disorders have typically assumed that the family is affected in various ways by a child with autism. The main assumption is that family faces challenged and this has been translated into focusing primarily on particular impacts on parents such as stress(Hastings ,2003).

Schuntermann (2007) in his review on typical siblings that have a developmentally challenged brother or sister identified the following broader domains that appear to be relevant while assessing siblings functioning:

1. birth order

2. convergence/divergence perspectives on similarities and differences on siblings in a family)

3. triadic parent-child interactions

4. siblings relationships

5. siblings intergenerational settings

6. siblings social settings

Furthermore, research revealed that adaptation is not a unidimensional construct. We have to be aware that a child can show different reactions in different moments and in different domains of functioning. Because many authors conclude that a lot of siblings of children with a disorder do not show more adaptation problems than siblings of normally developing children, it is important to analyse under what circumstances the presence of a child with a disorder has an impact on the place of the sibling on the continuum (McHale et al. 1986, Lobato *et al*. 1988).

Ross and Cuskelly (2006) argued that there is reason to question the assumption that children are affected negatively by having siblings with a disability including autism. Macks and Reeve (2007) found that despite conflicting reports between parents and siblings, siblings of a child with autism reported as having a significantly more positive self-concept than siblings of non-disabled children along with a positive view of behaviour anxiety and personal characteristics. A review of other research by Miller (2001) revealed that factors such as birth order, gender of siblings, severity of disability and other family factors and parental behaviour will affect the sibling relationship. In particular, less parental attention to siblings was not found to increase feelings of jealousy etc. However, Miller's (2001) own research found this not to be the case. He concluded that the overall response by a sibling to a child with autism was very positive, with no apparent feelings of jealousy or rivalry.

Hastings (2003) found boys with siblings who have autism, and also those younger than their sibling with autism, engaged in less prosocial behaviour.

The majority of investigations thus far have focused on negative outcomes of having a sibling with autism while Roeyers and Buysse (2003) highlight that adolescent sisters of siblings with autism have significantly higher positive self-concept in comparison to siblings of typically developing siblings. Unfortunately Hastings (2003) results were not as positive and found negative adjustment outcomes for siblings of children with autism, showing siblings of a child with autism were rated as having more peer problems, overall adjustment problems and lower pro-social behaviours as compared to a normative sample. Furthermore if the sibling was younger than the sibling with autism or if the sibling was male there was further increased prevalence of poor prosocial behaviour and behavioural problems. In the discussion Hastings (2003) contemplates the lack of correlation within the siblings results; some reported large adjustment problems while others had none whatsoever, and suggests further research on sibling specific variables.

The findings of Kaminsky and Dewey (2001) are consistent with those of Hastings(2003), they compared families with children with Down syndrome , autism and typically developing children. Siblings of children with autism were characterised by less intimacy and prosocial behaviours compared to siblings of children with Down syndrome. However the same research also reported no difference in internalizing or externalising behavioural problems between sibling of children with autism and typically developing children.

Fisman, Wolf, Ellison & Freeman, (2000) also focussed specifically on siblings ofchildren with ASD and concluded these siblings are at an increased risk of negative outcomes including depression. Adult siblings of an adult with autism reported lower levels of positive affect and a more pessimistic view of the siblings' outcome than siblings of adults with down syndrome; they also recalled relationships with their parents had been negatively affected (Orsmond & Seltzer, 2007).

It would be useful to think of the influence of a child with a disorder on the siblings as a continuum, with very positive outcomes at one end and very negative outcomes at the other (Powell and Gallagher 1993). Children pick up from an early age that their brother or sister is different, even if they don't understand what actually is wrong. They also notice other people's reactions, especially their parents and grandparents, to him or her. They may be afraid of asking questions, in case they upset their parents even though they have plenty of questions. For example, they may be afraid that they too will 'catch' autism. These questions and worries will change as the child becomes older eg they may fear that when they have children themselves that their child may have autism. Whilst they may have a deep love for their sibling they may also harbour feelings of resentment at the amount of time their parents are spending with the child with autism, and feel that they are being treated unfairly. Feelings of anger, embarrassment and guilt are also normal, as is feeling very protective of their sibling (Anon,1998).

Of course, not all feelings are negative. As Howlin and Yates (1990) describes, there is some evidence that having a sibling with autism is associated with positive self-concept, interpersonal and care-taking skills. Also, and especially for sisters who assume a greater mothering role than do brothers, this extra responsibility does not appear to contribute to poorer adjustment. Higher parental expectations, however, may fall on the lap of typically developing boys (Miller, 2001).

3. Research hypothesis

Children with autism might be experienced by their typically developing siblings as incomprehensive Behaviours exhibited by children with autism may lower the capacity of their typically developing sibling to mentalize Engaging siblings of children with autism in a mentalizing model of intervention will help them overcome difficulties of being entrenched in negative interactions with their siblings with autism in mutually helpful ways and will contribute to overall relatedness among siblings.

4. Aims of current study

The study will address the following aims ; a/to explore relationships between typically developing children and their siblings with autism b/to stimulate and develop sibling's ability to mentalize in moments of stressful non-functional interaction with their siblings with autism c/examine whether mentalizing-based intervention develops siblings ability to overcome difficulties in mutually helpful ways (short-term effects).

5. Methodology

Participants siblings of children with autism. The study will make use of a phenomenological approach, which is useful in exploring the 'lived world' of the participant.

A qualitative research design will be chosen for this study in order to gain a deeper understanding of the participants" experiences and behaviours.

The concept of mentalizing defined by Bateman and Fonagy (2006) as a mental process by which individuals interpret the actions of themselves and others was first introduced in the context of theory and treatment for borderline personality disorder. Is a uniquely human capacity, required for complex social interaction. We mentalize in order to make sense of the actions of oneself and others on the basis of intentional mental states and to understand the other's (or ones' own) behaviour in terms of activity that has taken place inside their minds; so that these hypotheses provide a good explanatory model for actions.

Within the definition we can identify three dimensions of mentalizing ;

Ø Implicit (unconscious operations to imagine self and others mental states)/Explicit(deliberately exercise and conscious focus on mental states).

Ø Self /Other contents (set of intentions, feelings, needs, beliefs, motives, thoughts etc).

Ø Cognitive/affective aspects (content of mentalizing cognitive focused and affectively laden to varying degrees).

For the purpose of this project we will use some techniques under the notion of mentalizing based treatment therapy(Fearon, Targer, Fonagy et all.,2006).

Mentalizing focus provides an integrative framework bringing together the understanding of one's own thoughts and feelings that is central to cognitive therapy, the understanding of thoughts and feelings of others that is central to family therapy and the appreciation of defensive processes and the reluctance to change that is central to psychodynamic therapy.

7. **Data collection**

semi structured interviews thoughts before and after the intervention of parents of the children with autism

structured parental report about siblings relationships

adaptive behavior questionnaire (adapted form Vineland behavioural scales

semi structured interviews thoughts before and after the intervention of siblings of the children with autism

1:1 sessions dialogue focused intervention based on the principles of mentalizing (Fonagy&Bateman guidelines adopted)

a ranking exercise completed by the children before and after the intervention

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