

# **Pilot study February 2006**

## **Benefits of Parental Involvement in an Occupational Therapy Group for Children with Sensory Processing and Related Behavioural Difficulties**

### **Introduction**

A study of Parental Satisfaction of the Paediatric Occupational Therapy Service (POTS) in Edinburgh's Child and Family Centres<sup>1</sup> produced some very interesting and informative results, (Brownlee and Munro 2005.) 75% of parents were keen to be given the opportunity to attend their children's OT sessions and 67% expressed a wish to attend a practical advice group, at which they could meet other parents of children with similar needs.

As a result of the main findings of this study, we decided to respond to the expressed parental preferences to treatment approaches. Moreover, a commitment has been made to follow through with the proposed 'future study', looking at stress levels experienced by parents of children who require OT intervention. Esdale (1996) believes that parents becoming more actively involved in their child's treatment could reduce parental stress. This particular area of parental involvement in their children's treatment appears to be under-researched, and there is a paucity of literature available.

There is, however, a great deal of research into parental stress in general, which has established a correlation between stress levels in parents and the level of disability experienced by their children.

A literature search has also shown that the more severe the behaviour difficulties displayed by a child, the greater the likelihood that the parent will be experiencing stress (Baler et al. 2002). Stress was related more to the level of behavioural difficulties than to the level of physical difficulties.

Therapists are attempting to meet their client's sensory needs and wish to influence behaviour, especially with adaptive responding.

*"Sensory Integration also provides a better understanding of their behaviour"*  
(Mathew, 2006: p13)

It is also acknowledged that it is important that parents support their children with Sensory Integration (SI) difficulties. (SI Network leaflet, October 2001).

It is hoped then, that by empowering parents, encouraging social networks and promoting coping strategies in the OT setting, parental stress levels will be reduced. Moreover, parents' perception and understanding of their child's difficulties/behaviours may also improve. A recent paper by Professor Sarah Stewart-Brown (2005) states that parenting programmes help parents to adopt positive discipline strategies, improve problem behaviour and support good family relationships. However, Professor Brown also affirms that these types of programmes are very dependent on the skills of the practitioners who are offering them.

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<sup>1</sup> Run by the Children and Families Department, City of Edinburgh Council

*“Working with parents more than any other aspect of intervention, has the greatest impact on the progress of a child with disabilities”. Hinojosa et al 2002: p556*

Therefore, it is our hypothesis that parental stress level will be reduced if parents are supported to become more involved in their child’s play and thus are able to increase their knowledge, confidence and optimism. We also propose that intensive sensory treatment will improve sensory processing difficulties and improve overall behaviour in a controlled environment. This is recognised by Helitzer et al (2002), who states that as parents become more confident in playing with their child and by being supported by other parents and professionals, their stress levels will be reduced.

Baker et al (2005) suggests that interventions for parents that aim to enhance parenting skills and psychological well-being should be available in preschool. The benefits of early intervention are well documented.

*“Parenting programmes delivered during the first three years of life can be effective in improving a range of outcomes” Stewart-Brown S and Tennant R 2005: p38*

As a high proportion of our children are assessed as having sensory processing difficulties, which, in turn, can lead to behaviour difficulties, we have decided to use a multi modal approach to treatment as there is an agreement that combined methods of treatment work. (Stonefelt and Stein (1998) and Belsky (1998)). For this reason we have decided to combine a sensory processing model with a behavioural model as recommended by Wagner and Helfin (1994) and Ben-Meir (1997).

This study proposes to evaluate how effective an 8-week block of treatment would be in addressing sensory processing difficulties and the child’s ability to cope with the world around them. We would, at the same time, assess their mother/carers levels of stress, pre and post the child’s block of treatment. Parents would actively participate in the sessions with their child and would be very much part of the therapy programme.

*“Working with parents has a greater impact on a child with disabilities than any other aspect of intervention. The majority believed that therapists do not have enough time to spend with parents.” (AJOT, 2002:p558).*

Sensory Processing and Integration programmes are well researched and documented and results prove positive. Cohn ES (2001) found that parents valued the benefits of OT and appreciated being better informed about sensory processing difficulties. However, there is very little research to support the benefits of OT groups for children with Sensory Integration difficulties, which is an area we feel merits further investigation. From this literature review we have devised a pilot programme called **The Fuzzy Wuzzy Group**.

## **FUZZY WUZZY GROUP**

### **Method**

A pre-experimental, ABA qualitative and quantitative method of study has been chosen as the most effective method of assessing improvement in sensory tolerance and possible reduction of parental stress levels. It has been decided to use the following standardised assessments:

Canadian Occupational Performance Measure (Law et al,1991) (COPM)

Infant /Toddler Sensory Profile Questionnaire (Dunn and Daniels, 2002) (ITSPQ)

Parental Stress Index – Short Form (Abindin, 1995) (PSI)

These would be administered prior and post treatment.

From our caseload of children already referred to the POTS, all of whom were referred for different reasons, we selected 13 who had difficulties with various degrees of sensory processing difficulty, (as indicated by the Infant/Toddler Sensory Profile). The sensory processing difficulties resulted in an adverse effect on the child's occupational performance and, to some extent, on the challenging behaviour that is associated with sensory problems.

The parents of the children who met the selection criteria were contacted by letter offering them a place in the group. It was explained that both they and their child would be taking part in a pilot study to examine sensory processing difficulties and potential stress levels. It also enclosed a stamped address envelope to return their consent letter. Follow up phone calls were made to the parents who had not responded. (6 parents agreed to come to the group, 2 of these requesting transport). They were then telephoned to confirm that they had been accepted.

### **Ethics**

Ethical approval was sought from the Research Committee of the Children and Families Department.

It was agreed that children and parents who were not taking part in the group would not be disadvantaged. The children would continue to receive their Occupational Therapy sessions as usual, but not in the group setting, as described in the study. It was also explained that it was permissible to drop out of the study if they so wished and that 1:1 OT sessions would resume.

## **FUZZY WUZZY GROUP**

### **An 8-week Programme for Children who have Sensory Processing and Related Behavioural Difficulties**

#### **Content:**

The theme of the group was the “Teddy Bear’s Picnic”. The format was as follows:

- Pre-planned new senses were introduced each week to both parent and child. (This was available as a handout).
- A coffee break for the parents and snack time for the children was also part of the programme. (Any special dietary requirement/allergy information has requested prior to the group commencing and was taken into consideration).
- Informal discussion time gave the parents time to talk amongst themselves or with professionals, while their children were occupied with snack and group activities.
- Handouts on practical ideas and strategies for sensory problems were available for the parents to take home, if they chose.
- Signalong was used to accompany key words to help the children focus on what was being said and sung.

We were extremely lucky to be offered the assistance of two Nursery Officers who helped run the group along with the two Occupational Therapists. A Post Graduate Occupational Therapist student on placement assisted by completing some of the standardised assessments with the parent prior to the commencement of the study.

Many of the Child and Family Centres close on Wednesdays and the OT’s thought that this would be the best day to hold the group. We could therefore use one of the centres as a venue and the children were more likely to be available to attend. We were also offered an additional vacant room in one of the Centres, with tea/coffee making facilities. Transport was provided as not all the children were geographically close, and many parents did not own a car.

Posters, with the group logo, were used in the centre to direct parents and remind others that the group was running.

To promote group identity, Fuzzy Wuzzy Group T-shirts were designed with the group logo and worn by staff and children each week.

In order to address the behavioural issues, there was continuity and structure within the programme from week to week i.e. the same songs were sung and the same routine followed in each weekly session. Positive praise was given at all times whilst inappropriate behaviour was ignored.

## **Structure of the Fuzzy Wuzzy Group**

The group started with the children sitting on mats, set out in a circle, with their parents beside them. Each child was requested to bring his/her own teddy to the group each week. The Teddy Bear's Picnic song would be played as they approached the room. A welcome song was sung when the children and parents were sitting and settled, everyone holding hands.

The same signifier song was sung each week prior to sensory bags that were handed out to the parents to explore with their child. Each bag contained the same item, a different sense being introduced each week. It was explained to the parents that every child would react differently to the item and that each child's tolerance must be respected and graded according to the child's reaction.

Following the fine motor activity, an auditory, switch-activated liquidiser was introduced and every child was given the opportunity to press the switch to make a drink for snack. This closed the first part of the programme.

The teddy bear's picnic song was played whilst a staff member went round gathering the children's teddy bears and put them in a pram. The teddies were taken away to a hiding place for their picnic behind a screen.

Parents and children then removed their socks and shoes to complete the next part to the programme, which was a gross motor experience. Both children and parents had to follow a sensory tunnel, then path, to find their teddies. This again involved focusing on the seven senses. Once the children found their teddies, they sat down for their snack.

Parents departed to a different room for coffee time and to give them time to evaluate their child's response to the sense of the week. Whilst having coffee, the parents agreed to fill in the sensory sheet noting their child's reaction to the specific sensory experience. At the same time, a staff member completed the snack sheet for the children. This documented the child's response to the food and drink. Occupational Therapists and Nursery Officers alternated attendance at either coffee or snack time each week, in order to get an overview of each child's progress.

When snack was finished, the children were guided back to sit on their mats to continue playing with their sensory toys until the parents were asked to return to the room.

To conclude, the "Well Done" song was sung, with the children sitting on their parent's knees. Deep pressure cuddles were given to help regulate the child and lower his/her sensory awareness levels before going home.

Finally, a teddy bear reward badge was given to the parent and child.

## **Results**

### **Parental Stress Index. Short Form Abidin Third Edition 1993 Psychological Assessment Resources**

Total Stress = Scores above the raw score of 90 are experiencing significant levels of stress

	Pre group Total Stress	Post Group Total Stress
Parent A	92	69
Parent B	85	85
Parent C	65	65
Parent D	98	118

In summary, two out of four parents were less stressed post group whilst one parent showed no change. Parent 4 remained over stressed throughout with her score increasing.

### **Canadian Occupational Performance Measure Law et al 1991**

The parent identifies his/her own problems in Self- Care, Leisure and Productivity from a score out of 10 (10 being the most satisfied/important). The scores are under the headings of Importance, Performance and Satisfaction

Parent A	Importance	Performance		Satisfaction	
		Pre	Post	Pre	Post
Problem 1	9	2	7	2	5
Problem 2	10	1	7	1	5
Problem 3	8	2	6	2	5
Problem 4	10	1	5	1	5
Problem 5	5	1	5	1	5

Parent B	Importance	Performance		Satisfaction	
		Pre	Post	Pre	Post
Problem 1	6	2	2	2	2
Problem 2	9	2	2	2	2
Problem 3	7	1	1	1	1
Problem 4	9	3	5	4	6

Parent C	Importance	Performance		Satisfaction	
		Pre	Post	Pre	Post
Problem 1	10	10	10	10	10
Problem 2	10	5	5	5	5
Problem 3	10	7	7	4	4
Problem 4	10	5	5	3	3

Parent D	Importance	Performance		Satisfaction	
		Pre	Post	Pre	Post
Problem 1	10	3	3	1	1
Problem 2	10	3	3	1	1
Problem 3	5	3	3	1	1
Problem 4	9	4	6	2	8
Problem 5	8	5	6	5	8

Three out of four parents experienced improvement in performance and satisfaction in the reassessment of the COPM, whilst parent 3 remained the same with no change in his/her performance or satisfaction in identified occupational performance activities.

**Infant /Toddler Sensory Profile  
Winnie Dunn  
The Psychological Corporation 2002**

Auditory is from a raw score total of 50	Typical Performance = 43-35
Visual is from a raw score total of 35	Typical Performance = 27-20
Tactile is from a raw score total of 75	Typical Performance = 64-51
Vestibular is from a raw score total of 30	Typical Performance = 23-18
Oral Sensory is from a raw score total of 35	Typical Performance = 33-25

Anything coming above or below the Typical Performance scores indicates a child is either more responsive (lower score) or less responsive (higher score) than peers

	Auditory		Visual		Tactile		Vestibular		Oral	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Child A	29	37	18	22	47	50	14	22	12	24
Child B	33	33	16	16	38	45	12	10	25	26
Child C	28	28	17	22	51	49	10	13	24	24
Child D	34	38	33	34	48	53	16	18	27	27

Prior to the Fuzzy Wuzzy Group all children had low scores meaning they were more responsive to senses than their peers. Post intervention indicated that there was an increase in scores towards the Typical Performance, which meant improvement in tolerance to the senses and better sensory modulation and regulation.

## **Evaluation**

One parent left the group as she could not see the relevance of her child's attendance at this particular group. Another parent left as she felt her child was not benefiting from the group. An examination of the reassessments administered at the end of the 8-week programme confirmed that the remaining 4 sets of parents/children benefited from the group.

At the final group session, the parents were issued with an evaluation sheet that they were asked to take home and return anonymously.

## **Evaluation Sheets**

Comments made were all positive and included such statements as;

- I just wished it went on for longer.
- I wish the sessions were longer.
- I learnt so much from the other parents.
- It is good to know you are not alone.
- I could see the difference it made to my child.
- I understood what OT's did.
- They helped me a great deal and it has made me and A's life easier.
- My child really enjoyed the Fuzzy Wuzzy Group so much so that he still talks about it.
- Seeing my child so excited about this group and getting involved is what I liked most.
- Very interesting to learn that other parents had children with the same issues as my child.
- I am more understanding to his sensory needs.
- All the senses were challenged It was difficult for him at first but became less stressful for us both as the weeks went on.

One parent refused permission to use video recording, therefore, we were unable to evaluate the weekly progress of the group in a manner that we would have found very informative. However we were able to take photographs, which gave some evidence of improvement.

Over the 8 weeks, both professionals and parents noted improvements on the weekly sensory sheets, in the following areas;

- Sensory tolerance to all five senses.
- Anticipation of what was about to happen.
- Co-operation and participation in activities.
- Turn taking skills.
- Interaction with peers.
- Reciprocity with parent and child.

On the first day, the children did not know what was expected of them and the session did not run in a smooth, organised fashion. Tensions were high in the children and this had an adverse effect on some of the children's arousal levels. However, by the final week, all the children knew what they were expected to do, where to sit and what

was about to happen next. The routine of the group remained the same every week, the only things being changed was the sensory stimulus provided. This consistency was of great benefit to the children as it offered the much needed repetition, and predictability, which the children required. It also proved that the children attending the group could begin to tolerate the sensory information offered to them if it was presented in a controlled, fun manner.

### **Conclusion**

Only one parent showed signs of stress prior to the commencement of the group. This is somewhat surprising considering the vast amount of evidence-based research on this topic. It may be that the parents already felt well supported by the Child and Family Centres and that they had adequate provisions in place to meet their needs. In hindsight, it was clear that eight children in the group would have been far too many and that six was the optimum number for a group of this kind. When there were four children remaining, the group also functioned very well, as there was a greater length of time to concentrate on each child as well as his/her parent, especially in the pilot stage.

As the weeks progressed the group naturally relaxed and started to bond. The children started to relate to each other and the parents began to talk and confide in each other more freely.

We believe that this is an interesting, feasible, occupational performance driven, study, which would benefit all Paediatric OT's as well as their clients who have sensory processing difficulties. Although OT's are consulting more with parents, we believe that we can improve our practice and delivery of service by involving the parents more in Occupational Therapy group sessions. We wanted to provide evidence that this method of treatment reduces the parents stress levels, which will, in turn enable the parents to become more empowered, relaxed, happy and optimistic. We also hoped that the parents would enjoy the playing with their children whilst, at the same time, addressing the child's sensory processing difficulties, through a block of intensive treatment.

Whilst this pilot study was looking at ways of actively engaging and empowering parents, in order to reduce parental stress, we firmly believe that this programme would stand very well on its own as a sensory processing programme run by Nursery Nurses/Assistants and Teachers as it addresses areas of the curriculum and is an easily followed programme.

### **Limitations**

- The time of day that the group was run prohibited some families from attending, as the parents had to stay at home for their other children returning from school.
- There was no provision for a crèche. One mother brought a sibling along to the group. However, this was not ideal, as the mother could not concentrate on the child who had the sensory difficulties.

- The OT's should have taken into consideration the cognitive levels of the children attending. This is a factor that will have to be investigated prior to the children attending the group.
- A sensory information sheet should have been issued to parents with the first acceptance letter as, naively, there was an assumption that parents knew more about sensory processing than they actually did.
- A session for the parents only to attend, prior to the group commencing, would also have been beneficial. This could have been used to explain about sensory integration i.e. what it is, how does it affect children, what we can do about it.
- The OT's assumed that the parents would know the purpose of each activity being used in the group without really having to explain it to them. Written and verbal information should have been distributed each week. In order to inform the parent about what was going to be happening in the group and, hopefully, thus relieve any pre-attendance anxieties.
- In carrying out the COPM we should have been focusing more on the child's problems rather than on the parent's problems as completing the Parental Stress Index had already covered parental stress levels.

### **Further study**

Comparison study of SI fortnightly treatment compared with the weekly parent /child blocks of SI, using the same standardised assessments.

Another comparison study using a control group (whose children received no intervention as they were waiting for therapy) and the group programme e.g. a Randomised Control Trial.

Comparing parental stress levels with parents attending the group, with a group who are solely giving helpful information and leaflets, but do not attend.

PSI given to parents' prior to attending a Child and Family Centre and then again while they are attending. (This is something that the staff at the Child and Family Centre could perhaps undertake to evaluate their effectiveness).

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