

Space at home for families with a child with autistic spectrum disorder

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Housing, ASD,
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The interrelationship between the home environment, occupations and wellbeing was explored in relation to the lived experiences of three families with a child diagnosed with autistic spectrum disorder (ASD). Each family had acquired an extra downstairs room through moving or adapting their home, which they dedicated to their child with ASD. This project used diary records and narrative interviews to gain an in-depth understanding of how the room was used, the meaning that the family attached to this additional space and its impact on their occupational engagement.

The findings reflected the complexity of problems experienced by children with ASD and their families. They revealed that dedicated physical space was experienced as important personal, emotional and occupational space for all family members.

This study helps to develop a theoretical understanding of the importance of establishing a good fit between individuals with developmental disabilities and their home environment. It argues that space at home influences the behaviour of children with ASD, the stress levels of their parents and the occupational engagement of all members of their family, and emphasises the importance of adequate space at home for children with ASD and their families.

Introduction

This project arose from discussions about how financial restrictions had limited the availability of discretionary disabled facilities grants (DFGs) to provide time-out rooms for children with autistic spectrum disorder (ASD). Practitioners had anecdotal experience that extra space provided benefits for both children and families, but formal research was both lacking and necessary (Awang 2004).

This small collaborative research project was, therefore, undertaken to explore the lived experience of families with a downstairs room at home dedicated to their child with ASD. It used diary records and narrative interviews with three families to investigate how their room was used, the meaning that the family attached to this additional space and the impact that it had upon family members and their occupational engagement.

Literature review

ASD is a pervasive developmental disorder with an established triad of impairments affecting social interaction, communication and imagination (National Autistic Society 2008). Repetitive disruptive behaviour patterns are often characteristic (National Autistic Society 2008), as are information processing difficulties (Hannah 2004). Research suggests that 95% of children with ASD demonstrate some sensory processing dysfunction, including sensation seeking, auditory filtering and tactile sensitivity (Tomchek and Dunn 2007). These problems affect the way in which they interact with and process the demands of their environment, often resulting in restless or disruptive behaviour, tantrums and a limited attention span (Barker-Dunbar 1998, Adamson et al 2006).

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Literature has also identified a range of difficulties faced by the parents of children with ASD, including high rates of stress and psychopathology, forfeited goals, isolation and difficult child-parent interactions (Wolf et al 1989, Bouma and Schweitzer 1990, Dumas et al 1991, Donenberg and Baker 1993, Sanders and Morgan 1997, Fombonne et al 2001). Children with ASD often require constant attention from their families, who describe their days as 'insane' and 'hectic' (Werner DeGrace 2004, p545). This extreme disruption to daily family life is very stressful (Bouma and Schweitzer 1990) and has a negative impact on family identity and parents' views of their ability to be good parents (Cronin 2004, Segal 2004).

There is a notable interrelationship between the home environment and the experience of people with ASD and their families. One study reported that 40% of mothers judged their home to be unsuitable, usually due to insufficient space (Bromley et al 2004). Other adverse environmental factors identified in the literature include noise, smells, proximity to others and negative reactions from them (Ellis 1990). This study concluded that:

Creating the right environment may not provide the whole answer but it often sets the scene for an improved response to other techniques (Ellis 1990, p147).

Modifying the environment to allow the child greater control could avoid sensory overload and the resultant behavioural problems. The use of a 'quiet space' has been advocated to deal with overpowering sensory environments and to increase self-calming (Myles Smith and Simpson 1998). A separate room can also be very effective to help individuals with ASD 'integrate sensory experiences and gain a sense of themselves as actors in the world' (Jordan 2001, p116). This is supported by an individual with ASD, who actively alters his environment to minimise shutdowns resulting from overload (Williams 1996).

In summary, the literature confirmed the complexity of problems experienced by children with ASD and their families. Although there was clear acknowledgement of the importance of the interrelationship between the environment and the experience of individuals with ASD, there was a dearth of research focused on the home environment. This research, therefore, sought to explore the experience of families with a child with ASD, who were living with a dedicated room at home. The specific objectives were to:

- Identify how the dedicated room was used by the child with ASD and other family members
- Explore the meaning attributed to the room by the family
- Explore the family's perspective on living with a dedicated room, in relation to the child with ASD, the parents and siblings and their occupations.

Method

This qualitative research aimed to explore lived family life and meanings, so it used narrative data collection methods

to gather 'compositions of unfolding meaning' (Hurwitz et al 2004, p1). Participant families were selected using purposive and convenience sampling, with the following inclusion criteria:

- Known to the participating local authority
- Included a child diagnosed with ASD for at least 1 year
- Had obtained a dedicated room at home.

Each of the three participating families was made up of two parents, a son with ASD between 8 and 10 years old and at least one sibling. In each case, it was most convenient to the family for the mother to be interviewed alone. The dedicated rooms had been obtained in three different ways: through moving, or extending with either private or DFG funding. The last one was designed specifically as a time-out room while the others were second living rooms.

Data were collected through a diary recording how the room was used for a fortnight, followed by a narrative interview. All interviews were undertaken with the mothers at their home and encouraged them to narrate their experience of living with the dedicated room and to explore specific events from the diaries. The analysis focused on the meaning of the narrative rather than its structure or interaction (Mishler 1995), using thematic analysis to generate patterns of meaning (Riessman 2006) by identifying recurring themes.

Credibility was increased by using clarifying questions, by taping and transcribing the interviews and by returning them to the family to amend if required. The emerging themes were confirmed by the other research team members and illustrated with direct quotes.

Ethical consent was gained from relevant committees. Special care was taken to preserve confidentiality, necessary in narrative research (Elliott 2005), including the use of pseudonyms. Any investigation into family life can potentially cause distress, especially with the challenges of ASD. This risk was minimised by using narrative interviews, which place the interviewee in control and avoid intrusive questions (Herxheimer and Ziebland 2004).

Findings and discussion

The three boys were known to occupational therapists, who confirmed that they had severely limited social interaction and characteristic behavioural problems, including frustrated outbursts, self-harm, aggressive actions, limited attention span and behaviour suggestive of sensory processing problems. This resulted in significant stress for the parents and occupational disruption to the family. The emergent themes identified that the extra physical space was valued as personal, emotional and occupational space. Table 1 presents these three key themes and further subthemes, together with the family members that they affected.

Each key theme is discussed and illustrated by a table containing relevant quotes from the study.

Table 1. Key themes identified

Key theme	People affected	Subthemes
Personal space	Child	
Emotional space	Child	Importance of a calm environment Space to de-stress – alone – with parents Reduction of frustration
	Parents	Stressful incidents Ongoing levels of stress Coping in the future
Occupational space	Whole family	Domination Lack of routine – sleeping
	Child	Choice Space associated with specific occupations – bedroom Occupational engagement – sleeping – eating
	Parents	Parenting – on guard – setting boundaries/ establishing control – having options Sleep Relaxation
	Siblings	Safe space Choice Homework

Personal space

The first theme (Table 2) showed that the children used the room as their own personal space (defined as space to be alone), which they needed owing to their difficulty with social interaction and being with other people (Ellis 1990, National Autistic Society 2008).

Table 2. Personal space

Person theme applies to	Relevant quotes illustrating the theme
Child	<ul style="list-style-type: none"> ■ David just wanted to be by himself really, not wanting anybody ... there's only so much he can take of having people round him. ■ He doesn't mind them playing with his toys, but it's just taking his space away.

Emotional space

The second theme (Table 3) suggested that the room could provide emotional space (defined as space to control or express their emotions) for both the child and his parents. The calming environment of the dedicated room was contrasted with the previous over-stimulation from single family rooms, reinforcing the significance of the environment

(Ellis 1990, Bromley et al 2004). The boys often chose to use the rooms to de-stress themselves, consistent with the voluntary use of 'quiet space' for self-calming (Williams 1996, Myles Smith and Simpson 1998). The parents also used the room to deal with tantrums (minimising the disruption to the whole family) and recognised that the rooms reduced their sons' overall levels of frustration.

The mothers reported high levels of stress, consistent with the literature (Wolf et al 1989, Bouma and Schweitzer 1990, Werner DeGrace 2004). They confirmed that interaction with their sons was sometimes very challenging (Donenberg and Baker 1993) and appreciated that the room gave them some emotional space after these stressful incidents. It also helped them to manage their general levels of stress: one mother used the room to relax as an alternative to re-starting antidepressants. Awareness of the ongoing stress caused by the long-term dependence of children with ASD (Bouma and Schweitzer 1990) was evident in this study. All mothers reported that space had previously been inadequate for long-term needs, consistent with research (Bromley et al 2004). The extra room had helped them set boundaries, deal with crisis points and feel more able to cope in the future.

Occupational space

The third theme (Table 4) identified changes to the family's occupational space (defined as opportunities to undertake occupations) since obtaining the additional room. The families had all experienced disruption owing to the boys' transitory, noisy and often obsessive behaviour, which had dominated family life, echoing the observation 'autism controls their daily lives' (Werner DeGrace 2004, p545). Lack of routine, most noticeably around sleeping, was identified as a major area of concern. The resultant disruption throughout the night expanded the understanding of the hectic nature of parenting identified by Werner DeGrace (2004). Faced with this high level of occupational disruption, the dedicated room had provided some welcome occupational space for the child, his parents and siblings.

The extra room allowed the boys some choice about their occupations without dominating the family. They made strong associations between physical spaces and specific occupations. The mothers emphasised the inappropriateness of using the bedroom for occupations other than sleeping because it needed to be kept exclusively as a 'sleep room'. The extra room had enabled this to be established and two families reported significant improvement in sleeping and bedtime routines. The mothers felt that the extra room also affected the boys' ability to eat at a table rather than 'on the run', possibly as a result of their sons being generally calmer. This was described as 'brilliant', suggesting its significance in establishing a positive family identity (Segal 2004).

The room contributed to the parents' ability to continue caring for their sons at home by enabling them to undertake their own occupations of parenting, sleeping and relaxing. Parenting these boys was extremely demanding. The mothers reported that they were constantly 'on guard' and noted that

Table 3. Emotional space

People subtheme applies to	Subthemes	Relevant quotes illustrating the subthemes
Child	Importance of calm environment	■ Decorating this room, trying to keep things neutral, plain ... just trying to keep a calm environment, so that things are not too stimulating.
	Space to de-stress – alone – with parents	■ ... he goes in there and gets ready for school, comes home from school, goes in there for his little time out – which I think is like a de-stressing time. ■ If we didn't have this room, I suppose it [temper tantrum] would have to be dealt with in the main living room ... whatever anybody would be doing in the room would have to be stopped because we would just have to deal with David.
	Reduction of frustration	■ He hasn't thrown any furniture since it's been done ... so that's taken all the frustration. ■ I know by him having this room ... keeps him more of a calm and happy child and when David is a calm happy child then we are a calm happy mum, dad and Sara.
Parents	Stressful incidents	■ Once he's calmed down you can ... leave him in this room ... and just go away and say, 'He's over that now – thank God for that.' ■ ... there's been a few times when I've shut the door, I've got to be honest... for my sanity and his safety.
	Ongoing levels of stress	■ ... space all of a sudden becomes very important to get some sanity – to get some sort of – 'Thank goodness he's down there for half hour, an hour', so that you get time to try and re-charge your batteries. ■ I went in there, turned the lights on, took a CD in there and fell asleep on the flexi cushion.
	Coping in the future	■ Without it I would have walked. ■ We couldn't manage him because he was much older, much bigger, much stronger. The writing was on the wall we were going to hit crisis point with him. ■ We definitely needed that room and no regrets. It's made it possible for us to deal with Peter in the house if anything, because we've had that extra space ...

the extra room helped them to 'keep an eye' on their sons, establish boundaries, maintain control and have more options for managing potentially difficult situations. Their sleep had previously been disrupted by their sons' poor sleep patterns, so improvements here resulted in better sleep for the parents. The room also enabled the parents to undertake highly valued relaxing leisure activities, which supported the importance of parents pursuing their own interests (Dumas et al 1991).

The dedicated room also helped to provide siblings with safe space, a choice of occupations and uninterrupted homework time. The mothers were particularly concerned about protecting younger siblings from aggressive behaviour, reflecting the literature (Barker-Dunbar 1998), and reported that additional space increased their younger children's physical and psychological safety. They also emphasised the importance of siblings having space to choose their own occupations and undertake homework.

Conclusion

ASD provides many challenges to the people affected and their families, requiring the combination of a broad range

of interventions, including modification of the home environment. This project explored the lived experiences and meaning attached to space at home by three families with a child with ASD. It revealed that dedicated physical space was experienced as important personal, emotional and occupational space for all members of the family. Although these findings cannot be generalised, they provide valuable qualitative insights and a stepping stone for further research.

The limitations of this research include the interviews being restricted to mothers; a broader family perspective would have included fathers and siblings. Although the restricted verbal communication of the boys excluded them from being interviewed, other projects could usefully explore how people with ASD experience their home environment. Subsequent research could also include a broader range of ages and developmental disabilities.

This study can broaden occupational therapists' understanding of the impact that the physical home environment has on the behaviour of children with ASD, the stress levels of their parents and the occupational engagement of all members of the family. It contributes to the evidence available to justify the need for adequate space at home for children with ASD and their families.

Table 4. Occupational space

People subtheme applies to	Subthemes	Relevant quotes illustrating the subthemes
Whole family	Domination	<ul style="list-style-type: none"> ■ Before we had a room that could be designated for David I suppose David dictated to us ... because his actions would have been far worse than us having a strop or a moan ... there was a lot of frustration for the rest of us just to keep the peace. ■ I guess because you live in it every single day you don't see how quickly, just like that, the child can take over and before you know it you're totally consumed and you think, 'Oh my god, he's just taken over the whole house.'
	Lack of routine – sleeping	<ul style="list-style-type: none"> ■ Peter wouldn't get to sleep until midnight ... and he woke up at say 3 or 4 o'clock in the morning ... sometimes we were lucky and he'd go back to sleep, more often he could be awake then for 3 or 4 hours. ■ Sometimes in the middle of the night he may wake up ... and he's trampolining on our bed.
Child	Choice	<ul style="list-style-type: none"> ■ Because he's got his space ... he gets the choice to do what he wants that makes him feel better in here. ■ It gives David, the chance to choose what he wants without upsetting somebody else.
	Space associated with specific occupations – bedroom	<ul style="list-style-type: none"> ■ ... we can't even sit at the table and do anything nice with John [younger brother who enjoys drawing]. Peter's just gone and squashed all the chalks ... he doesn't like John sat at the table because Peter eats at that table. ■ In the past it was very much a play room so when it was time for him to go to bed he couldn't ... turn over and go to sleep, there was too much stimulation in the room. ■ ... because he would go to bed and he would never go to sleep. He would think he could just play all night long until he dropped in his tracks. ■ I couldn't use his bedroom [after a tantrum] because that would have confused him ... that would just totally ruin all the work that we've done of learning that the bedroom is to sleep and undress.
	Occupational engagement – sleeping	<ul style="list-style-type: none"> ■ ... so by creating this room we were able then to move on and get him in his bed to sleep. We also found that the sleep patterns improved. ■ He's sleeping much much better, he goes down at 8-8.30 at the very latest. He may wake up in the night to spend a penny ... back to sleep and wake up at 7 o'clock in the morning and it's the most Peter has ever slept ever since we've had him.
	– eating	<ul style="list-style-type: none"> ■ He's learnt to sit at the table and eat his food ... you could take him out to a restaurant ... in fact he's better behaved than most children because he knows he's in that place to eat food, sitting on the chair at the table.
Parents	Parenting	<ul style="list-style-type: none"> ■ We do encourage him to use his room ... because if he is in the living room everybody is on guard ...
	– on guard	<ul style="list-style-type: none"> ■ You cannot afford to take your eye off Peter even for 30 seconds because he's capable of hitting John [younger brother] pushing him, causing him injury.
	– setting boundaries/ establishing control	<ul style="list-style-type: none"> ■ ... if he came into the front room with one of these toys that he's obsessively playing with we would say, 'Come on David back in here now.' ■ It would have been a lot more difficult to manage Peter in any way ... if we hadn't had this room built.
	– having options	<ul style="list-style-type: none"> ■ [Anticipating visit from hairdresser] I know in one way or another tonight he's going to be in there [dedicated room], through a paddy or through actually having his hair done in there in front of the mirror. I'm prepared for it and I can use the time out room – it's there ready.
	Sleep	<ul style="list-style-type: none"> ■ We went through years, absolute years of sleep deprivation. ■ ... he was in and out of our bedroom so it was me or my husband carrying him back to bed and we were doing this around twelve times so I thought we can't be doing this ... because we're that dead tired.
Relaxation	<ul style="list-style-type: none"> ■ ... by designating David a room Paul can watch the news at night, switch on his PC without being intruded on by David ... so everybody gets part of what they want to enjoy. 	
	<ul style="list-style-type: none"> ■ ... when he is using this room it is better for us, we can actually watch a bit of TV or we can just sit down and read a paper, we can relax for five or 10 minutes then. 	

Siblings	Safe space	<ul style="list-style-type: none"> ■ ... whereas before he hit and head butted Sara – now he can go in that room so he's away from Sara. ■ ... to protect John and to limit the psychological damage that Peter could do to him at such a young age, as well as physical, ... this room it's been a godsend really.
	Choice	<ul style="list-style-type: none"> ■ I would say it gives all of us the freedom of choice, for things each of us may want to do. ■ ... if she wants to watch High School Musical she's allowed to do that without David coming in and trying to change the channels.
	Homework	<ul style="list-style-type: none"> ■ ... now she can come home from school and quite happily know she is not distracted from sitting on the computer and doing some work. ■ It's made a big impact on Daniel because he's gone back to school ... he's got more time to do his studying now because he's doing his GCSEs and they share a bedroom together.

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Key findings

- Dedicated physical space at home was experienced as important personal, emotional and occupational space for all family members.
- It affects behaviour, sleeping patterns, parental stress and occupational engagement.

What the study has added

This study provides further understanding of the interrelationship between children with ASD and their home environment and how this has an impact on the occupational engagement of the whole family throughout the day and night.

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