UNIVERSITY OF SOUTHAMPTON

An investigation of the type of feeding behaviour problems in children diagnosed with autism

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September 2002

Word Count: 19,920

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FACULTY OF SOCIAL SCIENCE

PSYCHOLOGY

Doctorate in Clinical Psychology

AN INVESTIGATION OF THE TYPE OF FEEDING BEHAVIOUR PROBLEMS IN CHILDREN DIAGNOSED WITH AUTISM

by Tom Tutton

Abstract

Feeding problems occur frequently in children with autism and are characterised by a very selective type of problem. Selective feeding behaviours have a *prima facie* link to the diagnostic category of repetitive and stereotyped behaviours in autism. However, studies in this area show inadequate or poorly reported methodology. Only one study has fully explored this link and, although no link was demonstrated, the ability of this study to generalise findings to the wider autistic population was limited. The empirical demonstration that repetitive behaviours are linked to selective feeding problems has implications for the assessment and treatment of feeding problems in autism. The aim of this study was to explore the link between repetitive behaviour and selective and ritualistic feeding problems. Three hypotheses were proposed: a sample of autistic children will have a higher incidence of eating behaviour problems when compared with a matched group of Learning Disability children, these problems will be different in type, and, in the autism group, be associated with compulsive repetitive behaviours and other mediating variables.

A between groups design was employed to compare 25 autistic children to a control group of 17 LD children with a matched for gender, age and adaptive ability. Three experimental measures were used, a measure of total feeding problems, a measure of type of feeding problem, and a measure of repetitive behaviour. The first hypothesis was not supported. The hypothesis that the autism group would have increased selective feeding problems, such as only eating specific types of food, was also not supported. In the autism group, the frequency of selective feeding problems was found to be associated with the total compulsive repetitive behaviours, supporting the hypothesis that repetitive behaviours are implicated in selective feeding problems in autism. Limitations of the study and implications for future research are discussed.

Key Words: Autism, Repetitive Behaviour, Eating and Feeding Problems

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Prepared as if for submission to the Journal of Child Psychology and Psychiatry

Feeding Behaviour Problems in Autism: A Literature Review

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Feeding Behaviour Problems in Autism: A Literature Review

Abstract

This literature review highlights two separate areas of the autism literature, marked by continued disagreement and variation in the classification and description of behaviour. Feeding problems occur frequently in children with autism and are characterised by a very specific selective type of problem that can put them at risk of suffering nutritional deficits. However, the empirical validity and reliability of findings is limited as studies show inadequate or poorly reported methodology. Selective feeding behaviours have a *prima facie* link to the diagnostic category of repetitive and stereotyped behaviours in autism. Despite this, only one unpublished study has explored this link and, although no link was demonstrated, the exclusion criteria and measures used limit the ability of this study to generalise findings to the wider autistic population. The empirical demonstration that repetitive behaviours are linked to selective feeding problems has implications for the assessment and treatment of feeding problems in autism. This literature has a limited empirical base, demonstrating variable benefit for a limited range of problems with unproven generalisation. Successful treatment programmes for problems in autism understand the importance of obsessions and rituals as underlying causes of problems, as having a role in reducing anxiety and as sources of motivation. Research is needed to assess the use of treatments that are effective in other domains of autistic behaviour, on feeding problems in autism, addressing formal diagnostic criteria and underlying psychological characteristics.

Key Words: Autism, Repetitive Behaviour, Feeding Problems, Literature Review

Introduction

Autism is a lifelong syndrome that is categorised formally as part of a broad class of 'Pervasive Developmental Disorder' (PDD) (Volkmar, Klin & Cohen, 1997). Within this category, autism is described pragmatically as an 'autistic spectrum disorder' (ASD), one of three overlapping syndromes, that includes Asperger's syndrome and atypical autism (Medical Research Council, 2001). The term 'spectrum' reflects that autism covers a range of ability levels, from severely impaired to high functioning (Wing & Gold, 1979). Autism is an aberrant developmental cluster with many physical causes, some of which have been identified, however, it is defined currently by a constellation of behaviours that group together. These behaviours involve qualitative abnormalities (i.e. aberrant and not merely delayed development) in a 'triad of impairments' which emerge before three years of age.

Deficits in social behaviours, communicative and imaginative behaviours, and repetitive and stereotyped patterns of interests and activities must be present to confirm the diagnosis of autism. Social impairments involve poor eye contact, limited peer relationships and lack of sharing. Communicative and imaginative impairments involve lack of development of spoken language (or other communication), poor responsiveness to others and lack of make-believe play (APA, 1994). Repetitive and stereotyped behaviour is a term that can encompass a variety of behaviours observed in autism, the most prevalent of which are stereotypy, self-injury and compulsions (Bodfish, Symonds & Lewis, 1999).

The behavioural criteria for the diagnosis of autism are specified in two formal international classification systems. The most recent editions of the American Psychiatric Association 'Diagnostic and Statistical Manual of Mental Disorders' 4th edition (DSM-IV) (APA, 1994) and the World Health Organisation 'International Classification of Diseases' 10th Edition (ICD-10) (WHO, 1992) reflect increasing consensus over the diagnostic criteria for autism. Diagnostic instruments have been developed to allow the systematic collection of behavioural data, providing algorithms that generate DSM-IV and ICD-10 diagnoses (e.g. the Autism Diagnostic Interview-Revised (ADI-R) (Lord, Rutter, & LeCouteur, 1994)). However, to reach a clear diagnosis, detailed cognitive and language assessment, direct observation, medical screening and consideration of other psychosocial factors are also necessary (Howlin, 2000). According to a summary of recent reviews, autism affects approximately 10-30 per 10,000 children under eight years of age (Medical Research Council, 2001) and is more common in males, in a ratio of about 4 to 1 (Gillberg & Coleman, 1994).

This review focuses partly on the repetitive and stereotyped behaviours, cardinal to the diagnosis of autism. Variation in repetitive behaviours between individuals with autism makes behaviour difficult to classify adequately, however, Turner (1999) helpfully sub-divides behaviours into 'lower level' and 'higher level'. Repetition of movement, such as stereotyped movements or repetitive self-injury are considered to be characteristic of lower level behaviours. Higher level behaviours are classed as being more complex, including compulsive behaviours, insistence on sameness or complex repetitive speech patterns such as engaging in a fixed dialogue or excessive talking about certain topics. Accurate definition of these behaviours is essential.

Stereotypy is defined as repetitive and apparently purposeless body movements, body part movements or using the body to move objects, interfering with everyday activities (Bodfish, Symonds, Parker, & Lewis, 2000). Some echolalia can be categorised as stereotypical, involving immediate or delayed repetitive use of speech or vocalisations. Self-injurious behaviour (SIB) involves repetitive motor movements that have the potential to, or result in, injury to the person (Powell et al, 1996). SIB is often viewed as a separate category from repetitive behaviours, however, although these behaviours can occur independently of each other, the intensity of some stereotypic behaviour has been shown to increase, at times, to a point where the it becomes self-injurious (Lewis & Bodfish, 1998).

Compulsions are typically thought of as psychological phenomena, linked with obsessions in the context of obsessive compulsive disorder (OCD). However, individuals with autism often have difficulties verbalising thoughts, so compulsions are defined as repetitive intentional behaviours that appear to follow certain rules (Bodfish et al, 1995). Insistence on sameness behaviours, although similar to compulsions, involve overall repetitive routines and preferences rather than discrete repeated acts. This type of compulsive behaviour is not explicitly defined in the formal diagnostic systems and has received little attention outside of the study of autism (Prior & MacMillan, 1973).

Unfortunately, the study of repetitive behaviours has been impeded as no single instrument that reliably measures the spectrum of seen in autism has existed until relatively recently (Bodfish et al, 2000). Although other reliable instruments have been established, all contained significant behaviour overlap, preventing

distinction between co-occurring behaviours. One measure has been found to have acceptable levels of reliability and validity, the Repetitive Behaviour Scale (RBS) (Bodfish, Symonds, & Lewis, 1999), which compromises four separate behavioural checklists, each listing discrete observable behaviour topographies.

As well as focussing on repetitive behaviours, this paper also reviews an aspect of autistic behaviour that lies outside formal diagnostic criteria, that of aberrant feeding behaviour. Autism is characterised by such features, for example, Rutter, Bailey, Bolton and LeCouteur (1994) highlight the unexplained finding that a learning disability (LD) is present in three quarters of those with autism (although this may be an overestimate as higher functioning individuals are increasingly recognised (NIASA, in press)). Also, sensory abnormalities, such as over or under-sensitivity to certain sounds, visual stimuli or touch, are reported frequently (e.g. Grandin 1996).

Unusual patterns of eating and feeding behaviour were assumed once to be one of the markers of autism. Ritvo and Freeman (1978) described a clinically detailed definition of autism for the National Society for Autistic Children (NSAC), including olfactory and gustatory symptoms, such as repetitive sniffing, specific food preferences and licking of inedible objects. The literature seems to indicate that there is a significantly higher prevalence of feeding problems in the formally diagnosed autistic population than the typically developing or LD populations. De Meyer (1979) found that up to 94% of parents of children with autism reported eating and feeding difficulties during the course of childhood. This compares to between 36% and 45% (Butler & Golding, 1986; Dahl, 1987) of typically developing children, and just over 30% of individuals with a LD (Palmer, Thompson & Linscheid, 1975). Archer and

Szatmari (1991) found a significant difference between autistic children and normal controls in current reported problems (46% autistic vs 25% control) and problems over the last 6 months (58% autistic vs 28% control).

Feeding problems in autism include specific types or patterns of extremely selective or 'faddy' behaviours. These include only eating a severely restricted range of food (involving particular tastes, smells, colours, textures and brands of food), having to eat their meal in the same place and in the same order every mealtime (e.g. National Autistic Society, 1991; Cornish 1998). These extremely selective feeding behaviours have a *prima facie* link to the diagnostic category of repetitive and stereotyped behaviours in autism, and this is recognised frequently by both professionals and parents (e.g. Patterson, Ekvall & Mayes, 1993; Van Bourgondien, 1993; Williams, Dalrymple & Neal, 2000). One parent reports that,

> "It seems undeniable that a significant part of my son's problems is psychological and tied in very closely with the autistic condition. The recognised traits of obsessive behaviour, fear of anything new and desire to control everything within the autistic's world are mirrored almost fanatically in my son's reaction to food" (p.19)(Legge, 2002).

These feeding problems are an important practical area of research and intervention, yet a recent review of autism suggests that these issues have not been the subject of empirical research (Medical Research Council, 2001). This deficit may have occurred for two reasons. Firstly, there is a failure to address the behaviours that lie outside formal diagnostic systems. Secondly, for both feeding problems and repetitive behaviour in autism, it is reported that the absence of an agreed overall

classification system has been a major contributory factor to the variability of published research (Dahl & Sundelin, 1986; Hutchinson, 1999; Wicks-Nelson & Israel, 1991). Classification systems are essential for enhancing communication and allowing critical review (Volkmar, Klin & Cohen, 1997). Therefore, before reviewing the literature on selective feeding problems in autism and exploring links with repetitive behaviours, it is necessary to evaluate the wider literature on the classification of feeding problems.

The classification of feeding problems

An important discrimination is drawn between the classification of feeding, eating and other mealtime behaviours. Other behaviours, such as tantrums, aggression or self-harm can disrupt feeding, may also occur in the absence of food. Eating involves a range of physical structures and processes, including the structures of the oral cavity (jaw, teeth, palate and tongue) which co-ordinate with breathing, sucking, chewing, gagging, biting and swallowing. Eating difficulties such as poor chewing or swallowing can be caused in normally developing children by neuromuscular dysfunction (e.g. cerebral palsy or muscular dystrophy) (Harris, Blissett & Johnson, 2000). Feeding involves adaptive behaviours that determine the quantity and quality of food consumed, self-feeding skills, mealtime interactions, and maladaptive behaviours such as eating non-food (pica) or food stealing. It is these feeding problems that are the focus of this review. In addressing feeding problems, Linscheid, Budd & Rasnake (1995) propose a broad three-part classification system: the cause, type and outcome of feeding problems. These categories are outlined below.

Cause refers to the origins or maintenance of feeding problems. Feeding problems rarely have a single cause and a multi-factoral process is hypothesised (Iatwa, Riordan, Wohl & Finney, 1982). Child, parent and environmental variables such as medical problems, developmental delays, emotional and behavioural factors can all contribute to the types of feeding problems (Dahl, 1987). It is important to note that, in general, individuals with autism do not show the obvious physical problems that characterise many cases of severe learning disability in the absence of autism, although these problems increase in autistic individuals with severe disabilities (Rutter et al, 1994). The rate of known medical conditions suggested as causal or associated with autism is about 10% (Bailey, Phillips & Rutter, 1996), including tublerous sclerosis (TS), fragile X, Down syndrome, Rett's syndrome, cerebral palsy, neurofibromatosis and epilepsy. Some research summaries cast doubt on the strength of association between autism and these conditions (e.g. Dykens & Volkmar, 1997; Rutter et al, 1994). Elimination problems, however, have been associated with autism. One study reports that found 50% of the 46 children surveyed had problems with bowel movement frequency and 54% had problems with stool consistency (either diarrhoea or constipation) potentially affecting feeding behaviour (Whitlely, Rodgers, Savery & Shattock, 1999).

Type (or the nature of problems) refers to the developmental appropriateness of feeding and associated behaviours. Formal classifications systems list three main feeding problems: Pica, Rumination Disorder and Feeding Disorders of Infancy or Childhood (e.g. APA, 1994). The latter category includes persistently failing to eat adequately where weight is not gained or lost over one month (where onset is before age 6 and behaviour is not due to general medical condition or another mental

disorder or lack of available food). When considering the type of feeding problems, formal classification systems can be useful in differentiating different populations. For example, disorders that involve a failure to eat adequately, such as anorexia nervosa, are distinguished from other behaviourally similar problems, such as food refusal and selective eating (Bryant-Waugh & Kaminski, 1993). DSM-IV explains that non-anorexic food refusal (or selectivity) is not often associated with preoccupation with body weight and shape, and food refusers are usually less consistent with their avoidance of food than anorexics, eating preferred foods without difficulty.

Formal classification systems emphasise the importance of recognising a range of factors when considering feeding disorders, however they do not capture the spectrum of feeding problems reported in autism. Anecdotal report suggests three main types of feeding problems are common in autism, the need for sameness and ritual, specific eating behaviours (e.g. messy eating, pica, rumination) and limited and rigid food preferences (Patterson, Ekvall, & Mayes, 1993). To account for this, broader classification systems, encompassing a wide range of autistic mealtime behaviours, have been reported (e.g. Ahearn, 2001; Douglas & Byron, 1996; National Autistic Society, 1991; Palmer, Thompson & Linscheid, 1975). However, none of these classification systems adequately defines the comprehensive range of feeding problems reported in autism.

The use of published validated measures can help overcome variability in the categorisation and measurement of feeding problems in the autism literature. Matson and Kuhn (2001) report that their Screening Tool of fEeding Problems (STEP) is the only relevant measure available. This measure contains a 'selectivity' category that

includes five items such as 'will only eat selected types of food' and 'eats food of only certain textures', but has not been validated with an autistic population. Another measure, the Children's Eating Behaviour Inventory (CEBI) (Archer, Rosenbaum & Streiner, 1991) is also available. The CEBI contains only one item that captures a selective type of feeding problem, 'my child eats food that tastes different'. These measures highlight the problem of classification inconsistency. For example, the behaviour 'asking for food between meals' is described as related to behavioural compliance (Archer and Szatmari, 1991) or related to nutrition (Matson and Kuhn, 2001). Neither measure is widely used in the literature.

Outcome refers to the consequences of feeding problems such as poor growth or malnutrition, which can threaten an individual's health. Malnutrition studies measure the adequacy of a diet compared to national recommended guidelines, assessing, for example, carbohydrate and protein intake, as well as a range of potential vitamins and minerals (e.g. Williams, Dalrymple and Neal, 2000). Although this area of literature does not appear to be directly related to exploring the link between repetitive behaviour and selective feeding problems it is important for the following reason. It could be argued that research that attempts to help develop the assessment and treatment of feeding problems (by exploring links to repetitive behaviour) is unimportant. If selective feeding behaviours cause no nutritional problems then is it necessary to intervene at all? Indeed, it is reported that some challenging behaviours during feeding in children with a LD have been associated with healthy weight status (Aldridge, Pullen & Whelan, 2000). However, Matson and Kuhn (2001) suggest that individuals who are selective either by type, texture, temperature, feeder or location *are* at risk for malnutrition, and many behavioural modification programmes (e.g.

Clancy, Entsch & Rendle-Short, 1969) are based on the assumption that selective feeding behaviours necessitate intervention. To address this issue, a search of the literature was completed to find studies of the outcome of feeding problems in autism. These are reviewed briefly below.

Shearer, Larson, Neuschwander and Gedney (1982) analysed scalp hair samples and a three-day diet record in 12 autistic and 12 normally developing control children. They found the concentrations of most minerals (calcium, zinc, magnesium, copper and lead) were not statistically different and were within typical values found in the literature. The autism group consumed fewer servings from the 'milk' food group and had significantly lower amounts of calcium and riboflavin in their diet. No other significant differences were found. However, the use of hair as a diagnostic tool for assessing mineral nutrition is questioned as many variables can influence mineral levels (Shearer et al, 1982). Raiten and Massaro (1986) assessed the diet of 40 autistic (mean age 10.6) and 34 normal control children (mean age 8.8). A significantly increased intake of all nutrients in the autistic population was found to be an artefact of an older and more proportionately male population. The authors conclude that, in their sample, autistic feeding idiosyncrasies have little impact on quality of the child's diet but that, in the wider population, feeding problems may cause adverse consequences.

Cornish (1998) completed an audit of 17 autistic children referred via a community paediatrician. A 3-day dietary record and an unspecified food frequency checklist were used to assess nutrient intake with 'general questions' asked to identify feeding behaviours. Three children ate fewer than eight different foods, seven children

ate between 10 – 19 foods, and the rest ate 20 or more different foods. Nine of the children had diets that were below the recommended amounts for one or more nutrients, with the most restrictive food choice found in younger children. Williams, Dalrymple and Neal (2000) surveyed 100 parents of autistic children, finding that faddy eating was significantly associated with poor appetite and inadequate nutrition. In an audit of 26 autistic children, Bowers (2002) found that all children, except two cases of marked food selectivity, had nutritional intakes that met or exceeded recommended values for energy and protein, but not for other nutrients.

Review of this literature is characterised by variation in findings and limited methodologies. It appears that selective feeding problems *can* put children at risk of suffering nutritional deficits compared to children in other reviewed populations, although this is not inevitable. The literature contains little information about serious long-term health consequences of feeding problems in autism or if there are any changes with age. Archer, Rosenbaum and Streiner (1990) found no significant difference between a younger autistic age group (2 – 6 years) and an older autistic age group (7 – 12 years). In an unpublished retrospective study of 89 autistic children, feeding problems seemed to originate around the 18-month mark (Legge, 2002). Thirty seven percent of problems originated between the ages of 0-1, 34.8% between 1-2, 17.4% between 2-3, 6.9% between 3-4, 0% between 4-5, and 2.3% between 5-6 years. Only 18% of parents reported that the problems improved with age. A longitudinal study with strong methodology is certainly required.

In typically developing children, it is reported that the majority of non-medical childhood feeding problems are intermittent and transitory, and that prolonged

problems that cause serious negative nutritional deficits are uncommon (O'Brien, Repp, Williams & Christopherson, 1991). Dahl and Sundelin (1986) found the mean duration of feeding problems in their normally developing sample was 5 months (range 1 – 11 months). Therefore, it is possible that feeding problems in autism may have a longer duration than in the typically developing population. The potential risk of nutritional deficits is one reason why treatment of autistic feeding problems is necessary, validating studies in this area of literature.

In summary, two key areas of the autism literature are considered. Firstly, the literature reports a significantly higher prevalence of feeding problems, characterised by features such as extreme selectivity, occurs in the formally diagnosed autistic population compared to the typically developing or LD populations. These problems lie outside the behaviours included in the formal diagnosis of autism and may result in nutritional deficits. Secondly, a *prima facie* link is suggested between the high prevalence of these problems and the repetitive and stereotyped behaviours that are cardinal to the diagnosis of autism. Given the problems already described that arise from poor classification and definition of behaviour, empirical data with a sound methodological basis would appear to be vital in addressing the question as to whether these repetitive behaviours underpin aberrant types of feeding behaviour.

This paper reviews and compares these two areas of the autism literature in the context of other populations. An empirically demonstrated link between types of feeding problems and repetitive and stereotyped behaviours has important practical implications for a third area of literature, the assessment and treatment of feeding problems in individuals with autism. There are a number of reasons why this literature

is important and relevant, and these are discussed following the sections on feeding problems and repetitive behaviours in autism.

Feeding problems in individuals diagnosed with autism

A search of health, psychology and medical literature was completed using CINHAL, Embase, PsychINFO, ClinPSYCH, and Medline databases. Mesh terms included: autism, autistic and ASD, eat(ing), feed(ing), food, diet, problem, difficulty, learning disability, mental retardation, assessment and treatment. A search of secondary references included in published papers was also conducted. Three important topics are apparent in survey of the literature, the type of feeding problem, biological and developmental factors and behavioural and environmental factors. These topics are reviewed in turn below.

The type of feeding problems in autism. This literature was searched for studies categorised as having adequate methodology. Adequate methodology was defined as containing a sample greater than 10, and/or a control group used and/or a validated measure used. This search produced seven studies. Raiten and Massaro (1986) used a non-standardised measure to assess 40 autistic children (mean age 10.6 years) compared to 34 typically developing control children. Increased idiosyncratic feeding behaviour was reported in the autism group. For example, 35% preferred to have food prepared and served in a set way, compared to 12% of control children. A higher percentage of unwillingness to try new foods, refusing highly textured food, messy eating and throwing food were also found in the autism group.

O'Brien and Whitehouse (1990) used an unpublished 28-item semi-structured interview to compare 15 autistic adults with 33 LD adults. The authors found eight autistic participants showed a significant excess of searching for food (defined as constantly looking for food). Five individuals showed 'different' food choice and, of the two cases of pica, both were autistic participants. One of the few significant LD findings was that a group described as depressed ate more food and chose sweeter foods. No other differences were found between participants, for example, in the amount of food eaten or eating between meals.

In developing the Children's Eating Behaviour Inventory (CEBI), Archer, Rosenbaum and Streiner (1990) assessed nine autistic children (aged 2 - 12). Higher problem scores and greater numbers of cases occurred in autistic and LD groups, but no pattern of difference was reported. However, this measure contains only one item that captures faddy types of feeding problem, 'my child eats food that tastes different'. Archer and Szatmari (1991) also used the CEBI in a survey of 14 autistic children (aged 4-6 years). They found items labelled 'behavioural compliance' (e.g. 'asks for food between meals', 'takes food between meals') were most frequently and strongly endorsed, with manual and motor problems much less so. Cornish (1998) found repetitive patterns of feeding, including eating meals in the same place, were preferred in 15 of 17 autistic children (aged 4 - 9). Examples of selective faddy feeding were described by as only eating a certain food in branded packaging, only eating dry foods or apples of one colour (Cornish 1998). In all 17 cases in this study, food refusal and the introduction of new foods was considered the major problem. Replicability of this study is limited as parents were interviewed using unspecified 'general questions'.

Williams, Dalrymple and Neal (2000) surveyed 100 autistic children (aged 22 months - 10 years) using an unpublished questionnaire developed by the authors. Sixty seven percent of respondents described their child as a faddy eater. The most frequently reported problems were trying new foods (69%), mouthing objects (56%), rituals surrounding eating (46%), insisting on routine (44%) and playing with food (43%). Throwing food (36%), pica (33%), eating only one brand (33%) and having to prepare food one way (32%) was also reported in more than a quarter of the sample. Bowers (2002) completed an audit of 26 autistic children referred to the service for dietetic intervention. Twelve cases were referred for nutritional assessment because of concerns about significant food selectivity and aberrant feeding behaviour (14 cases were referred for gluten/casein-free diets). No further details are given about these problems.

Limitations of the research, such as use of unpublished, unspecified or limited measures makes direct comparison between populations problematic and makes it difficult to establish whether problems are indeed autism specific. Anecdotal report suggests that that selective food refusal is more often described in children with LDs than in typically developing children (Ginsberg 1998). Palmer and Horn (1978) noted texture selectivity in 27% of children with feeding problems. The literature reports a varied incidence of faddy eating problems in typically developing children. In a longitudinal survey of 50 typically developing infants with feeding problems (aged 3 - 12 months) three main categories of feeding problems were reported; refusal to eat (28 infants), colic (nine infants) and vomiting (eight infants) (Dahl & Sundelin, 1986). The same children (age two years) showed no differences compared to control children with regard to food dislikes, strong preferences, selective diets or regularity

of mealtimes (Dahl, 1987). Compared to this, Butler and Golding (1986) found 30% of 5-year-olds with feeding problems were faddy eaters.

In summary, review of the literature on the types of feeding problems suggests that a range of problems manifest in individuals with autism. A specific selective type of problem seems to occur in all surveys where specifically measured. It is likely that this occurs at a higher rate than in typically developing children and children with LDs, however, due to empirical limitations, the specificity of the range of these problems to autism remains to be demonstrated. The literature is consistently limited by poor reporting of how diagnosis is confirmed, small or unrepresentative samples used, the limited use of control groups and the use of unpublished or non-validated measures. Other potential variables that can affect feeding problems are often unreported in the literature. To answer the question as to whether repetitive and stereotyped behaviours underpin particular types of feeding behaviour, it is essential to review the literature on other variables that could affect feeding behaviour, including biological / developmental and behavioural / environmental factors.

Biological and developmental factors in feeding behaviour. Much of the literature on feeding problems in autism asks whether there is something about the biological or developmental aspects of autism that might help us understand feeding problems. It is important to review this area of the literature because of its popularity and as there may be something that might better explain autistic selective feeding problems, rather than being related to repetitive and stereotyped behaviours. A number of prominent areas of this literature are reviewed, including gastrointestinal problems, disruption in the development of eating or feeding skills, delay in the

development of normal 'neophobic responses', the role of non-compliant behaviour and the role of intellectual or adaptive ability.

Research over the last decade has established autism as a neuro-developmental disorder (Rutter et al, 1994) with evidence for a genetic basis (Bailey et al, 1995). Typically, causes of disorders are complex, with several factors interacting. There has been considerable interest in the possibility that gastrointestinal factors are implicated in causing autistic behaviour. This explanation contains a plausible biological hypothesis, linking the intake of nutrients with brain chemicals, which affect behaviour and psychological states (Blundell, Hill & Lawton, 1989), however, this is a particularly contentious area of research. Dietary restrictions are popular forms of treatment for autism (Ahearn, 2001) but have been seen as fad diets which can take advantage desperate parents by offering easy answers (Markus, Kunce & Schopler, 1997). Past and present diets (Feingold, 1975; Lewis, 1999) remain popular. Fourteen of 26 autistic children recently referred for dietetic intervention were for gluten and/or casein free diets (Bowers 2002). Reports of clinical improvement in children with autism placed on gluten and/or casein free diets are available (e.g. Whitely, Rodgers, Savery & Shattock, 1999), however no properly controlled large-scale studies have been described in peer reviewed journals, and too little information is often available to enable critical appraisal (Medical Research Council, 2001).

Developmentally, eating skills continue to develop up to the age of three years, at which point the child should have all the basic components of oral skills needed as an adult (Harris et al, 2000). Early exposure to a variety of textures is crucial to the development of normal oral-motor skills and eating problems can

develop because of disruption of sensitive learning periods (Skuse, 1993). Children who have not been fed textured foods during sensitive periods may find certain textured foods difficult, resulting in texture selectivity (Sullivan & Rosenbloom, 1996). However, the literature does not report disruption of oral motor skill development in autism. The development of feeding involves a range of motor skills. In typically developing children finger feeding starts about seven months of age, spoon grasping about 10-12 months, and initial self-feeding by 18-24 months (O'Brien et al, 1991). The literature on delays in self-feeding suggests that between 14% to 20% of autistic children manifest self-feeding problems (Archer & Szatmari, 1991; Williams et al, 2000), occurring less frequently than in children with LDs (Linscheild, 1998). Meaningful comparison between groups is limited as the literature often fails to distinguish between an absence of ability (for example, as a result of motor problems) and a failure to use skills.

Normal sensory development is implicated in the perception of taste and texture and visual appearance (Capaldi, 1996). Typically developing infants start to develop a preference for a variety food in the first year of life initially accepting the majority of new foods given to them by the parent (Harris et al, 2000). The easiest time to get an infant to accept new foods is during this 'window of optimal acceptance' described variably in the literature as between 14 – 20 weeks (Harris et al, 2000) or 4-6 months (Skuse, 1993). After this time, a fear of new foods develops ('the neophobic response') which means that when new foods are presented, a typical reaction is to refuse them. This happens to stop infants eating foods that may not be safe when they start to feed themselves, and, when combined with learning experiences, it helps infants to distinguish food from non-food, preventing pica. Food

refusal in typically developing children is usually a transitory phenomenon and repeated exposure to novel foods helps increase food variety (Birch & Marlin, 1982). It is possible that abnormal sensory development, where a neophobic response does not disappear, could result in selective food refusal. One systematic study found that autistic children are likely to refuse food by categories such as texture, however comparison with control populations are not made (Ahearn, Castine, Nault & Green, 2001). This literature suggests that types of persistent food refusal may be specific to autism, however further research is required to establish causes and to make comparisons with other populations.

A general pattern of non-compliant behaviour is an important variable in the assessment of feeding problems, as problems with feeding might represent this pattern of maladaptive behaviour rather than being a particular feeding problem or a reflection of autistic symptomatology (Iatwa et al, 1982). Food refusal or an unwillingness to try new foods can result from a non-compliant or 'wary of the unfamiliar' temperament (Harris et al, 2000). There is evidence that other behaviours related to a non-compliant behaviour in typically developing children, such as sleep problems (Dahl, 1987) are common in autistic children (Patzold, Richdale & Tongue, 1998). This suggests that a general pattern of non-compliant behaviour is an important variable in feeding behaviour.

The literature highlights the role of general intellectual ability (as measured by an IQ score) and adaptive in feeding problems. O'Brien et al (1991) suggest that the greater the level of learning disability the more prevalent the feeding problem. Lower intellectual abilities are associated with increased physical ailments and feeding

problems can result from frustration in a child who cannot express hunger or food preferences (Burkhart, Fox & Rotatori, 1990). Higher functioning individuals are more likely to be able carry out physical activities with improved self-feeding and abilities to communicate food preferences appropriately. However, the linear relationship between feeding problems and LDs may be an oversimplification for individuals with autism. Archer and Szatmari (1991) found no significant correlation between IQ scores and CEBI scores in their autistic sample, however all children with an IQ below 70 were excluded from their study. Also, levels of practical or adaptive functioning (including daily living skills) may not be determined by IQ in autism (NIASA, in press), suggesting that adaptive behaviour measures (e.g. the Vineland Adaptive Behaviour Scales (Sparrow, Balla & Cicchetti, 1984) should be used in comparable studies.

To recap, biological and developmental factors make links between autism and food and feeding problems. The issues of non-compliant patterns of behaviour and adaptive ability have been shown to be important when considering feeding problems in individuals with autism. High problem feeding scores might reflect a pattern of general non-compliant behaviour or poor adaptive skills rather than being a result of repetitive and stereotyped behaviour. However, biological and developmental factors do not account for the range of feeding problems described in autism, and cannot account for behaviours such as having to eat in the same place every mealtime. It is likely that there is a range of other influences on type feeding problems in autism.

Behavioural / environmental factors in feeding behaviours. Feeding behaviour in all populations is affected by basic learning principles. Pain or discomfort caused

by medical conditions in normally developing children, such as cystic fybrosis, cancer or gastro-oesophageal reflux (GOR) can lead to classically conditioned taste aversions, even after only one 'trial' (Skuse, 1993). Following this, problem behaviours may have their origins in one factor, such as food refusal caused by gastrointestinal pain, and be maintained by another factor such as the attention caregivers deliver when the behaviour occurs (Matson & Kuhn, 2001). Such operant principles propose that child and parent mealtime behaviours can be affected by their antecedents and consequences (Iatwa et al, 1982). The social context of eating can modify food acceptance patterns as children learn via the observation of parents, siblings and peers (Birch, 1989). Observational learning (the acquisition of behaviour by imitation) has been associated with children eating an increased range of foods (Skuse, 1993) and with the development of feeding problems (Iatwa et al, 1982). Also, cultural influences can help define acceptable foods combinations and purposes, for example, children learn through repeated association that particular foods go with other foods (e.g. peanut butter and jam) or are eaten at certain times of day (e.g. breakfast foods).

The autism literature does not report that classically conditioned aversions are prominent in autism. Operant learning principles are highlighted in the autism feeding literature. Treatment studies in the Journal of Applied Behaviour Analysis demonstrate the role of learning principles in the maintenance of food refusal in autism (e.g. Kern & Marder, 1996; Freeman & Piazza, 1998). However, these behavioural causes of feeding problems are not specific to autism and reports summarising feeding problems in LD children suggest that behavioural factors were a major contributory cause in up to half of cases referred to a clinic (Palmer & Horn,

1978). Potential effects of the social impairments that define autism on the observational learning of social and cultural feeding behaviour are not directly reported in the autism literature.

In summary, review of the literature highlights the complexity and range of possible causes of feeding problems in autism. As discussed, this literature suggests that, in linking feeding problems and repetitive behaviours, variables such as patterns of non-compliant behaviour and adaptive ability need to be taken into account. Other areas of investigation, which may be specific to autism that may explain selective feeding behaviour, such as problems caused by sensory or gastrointestinal abnormalities are not empirically demonstrated in the literature. Also, although feeding problems such as oral or other motor problems or conditioned food aversions occur in other comparable populations, they are often not characteristic of autism. Review of the feeding literature in autism suggests that, where measured, a specific selective or 'faddy' type of problem *is* characteristic of autism. In reviewing the literature on feeding problems in autism, no one physical or behavioural variable or combination of variables has been demonstrated to account accurately for the range of selective feeding problems. In search for variables that could better account for autistic feeding problems, the literature on repetitive and stereotyped behaviours is reviewed.

Repetitive and stereotyped behaviour in autism

This review will analyse the variables that affect different topographies of repetitive behaviour and the proposed functions of these behaviours, with an emphasis

on autism specific behaviours. Repetitive behaviours are common in autism. All 224 autistic children (mean age 4.61) studied by Campbell et al (1990) demonstrated repetitive behaviour, with the overall severity of ratings distributed normally. Bodfish et al (2000) found that, compared to a matched group of 34 non-autistic LD group, the group of 32 autistic adults showed a consistently higher percentage of cases with abnormal repetitive behaviour. A significantly higher number and more severe level of lower-level stereotypies and higher-level compulsions were found.

The literature suggests that the level of cognitive ability mediate the occurrence of repetitive behaviours in autism (e.g. Campbell et al, 1990; Bodfish et al 2000). Lower IQ is generally associated with increased repetitive behaviour. More specifically, lower IQ is associated with increased 'lower-level' stereotyped and self-injurious behaviours, while 'higher-level' compulsive rituals were more often noted in individuals with higher IQs (Hashino et al, 1997; Berument et al, 1999). It is these higher-level compulsive repetitive behaviours that appear to relate to the complex type of selective feeding problems reported in autism. Therefore, one would expect individuals with higher IQs to manifest increased feeding problems of the selective or ritualistic type. In assessing higher level repetitive behaviours, McDougle et al (1995) used the Yale-Brown Obsessive-Compulsive scale (YBOCS) (Goodman et al, 1989) to compare 50 autistic adults to an age and gender matched Obsessive Compulsive Disorder (OCD) group. Individuals with autism displayed significantly more ordering, hoarding and touching compulsions and significantly less cleaning, counting and checking compulsions. Multiple insistence on sameness behaviours were found in ten out of ten autistic participants by Prior and MacMillan (1973). However, the sameness questionnaire used in this study contains substantial overlap with items that relate to

general compulsive behaviour (Lewis & Bodfish, 1998).

Lewis and Bodfish (1998) note that there is great variation in repetitive behaviours across individuals with autism and topographically, none of these behaviours is unique to autism, appearing in a range of developmental disabilities, psychiatric and neurological conditions. Repetitive behaviours, similar to those reported in autism are also seen in typically developing children. In a study of 1488 children (aged six months to five plus years), Evans et al (1997) found that compulsive-like behaviour appeared up to 68% of children. This involved behaviour such as eating food in a certain order and insisting food is placed in a certain part of the plate. An age related trend was seen. Two, three and four-year-olds had frequency and intensity scores that were significantly higher than those of younger and older children. Lower-level stereotyped behaviours had a significantly earlier age of onset compared to higher-level compulsive behaviours. As with individuals diagnosed with autism, higher level behaviours require more sophisticated and intentional abilities, and this is hypothesised to account for their later onset and relationship with IQ (Evans et al 1997). To recap, the implication of this is that, in the study of autistic repetitive behaviour and feeding problems, one would expect individuals with higher IQs to manifest increased selective feeding behaviours.

Review of the literature demonstrates that the functions of repetitive behaviours are not well understood. In typically developing children, compulsive-like behaviour is seen as a mechanism for organising, accommodating to and eventually mastering the environment (Grados, Labuda, Riddle & Walkup, 1997). Ongoing problems with compulsive-like behaviours may indicate an overly rigid style when

greater flexibility is needed to master the more complex tasks of later childhood. It is hypothesised that compulsive behaviours may help an individual gain a sense of self-control and regulate emotional states (Evans et al, 1997) and thus the initiation of symptoms are often a result of increased stress in a child's life. Many functions have been posited for abnormal repetitive behaviours in autism, however the functions of repetitive behaviours are far from firmly established (Lewis & Bodfish, 1998). Suggested functions including stress reduction, sensory stimulation, amelioration of impoverished environment or behaviour maintained by reward. Many of these hypotheses only relate to lower level repetitive behaviours. Baron-Cohen (1989) regards repetitive behaviour, including compulsive behaviour, as a coping strategy, allowing for the reduction of anxiety, however the function of higher level repetitive behaviours as an underlying cause of many behavioural problems remains to be empirically demonstrated (Howlin 2000).

In summary, repetitive and stereotyped behaviours have long been a defining feature of autism (Lewis & Bodfish, 1998) with higher-level compulsive repetitive behaviours (which may relate to the complex type of selective feeding problems reported in autism) more likely to include ordering, hoarding and touching compulsions. Reviews of the literature suggest that studies of the phenomenology of the full range of these repetitive behaviours have yet to be completed (Bailey, Phillips & Rutter 1996; Bodfish et al, 2000). Importantly, *no* study was found in the literature on repetitive behaviours in autism that specifically refers to feeding problems. As discussed, review of the literature on feeding problems in autism, no one physical or behavioural variable or combination of variables has been demonstrated to account accurately for the range of selective feeding problems. Therefore, in this review, two

areas of the literature have been examined and yet the question as to whether repetitive behaviours underpin certain aberrant types of feeding behaviour remains to be answered empirically. This occurs despite the fact that numerous studies propose that repetitive behaviours are implicated in the type of feeding problems described in autism (e.g. Archer, Rosenbaum & Streiner, 1991; Cornish, 1998; National Autistic Society, 1991; Patterson, Ekvall & Mayes, 1993; Raiten & Massaro, 1986; Van Bourgondien, 1993; Williams, Dalrymple & Neal, 2000). These studies suggest higher level repetitive behaviours are the specific behaviours implicated in autistic feeding problems. However, despite this consensus, no published study has aimed to investigate this link empirically. As a result, to explore the link between repetitive behaviour and selective feeding problems further, it is necessary to this review a wider literature, including unpublished and theoretical papers.

Feeding problems and repetitive behaviour in autism

In this section the one paper that explicitly links feeding problems and diagnostic categories of autism will be reviewed, and a number of theories of autism will be described with possible links to feeding problems explored.

In an unpublished study, Archer and Szatmari (1991) surveyed 33 autistic children (mean age 5.3), diagnosed using the original Autism Diagnostic Interview, compared to 295 control children (mean age 5.8). The authors used an unpublished 19-item version of the Children's Eating Behaviour Inventory (CEBI) to measure eating problems and the Krug Autism Behaviour Checklist (ABC) (Krug, Arick & Almond, 1978) to assess the severity of autism. A significant positive correlation was

found between total scores on the CEBI and total score from the ABC, suggesting that autism severity and feeding problems are linked. Importantly, significant correlations were found between CEBI total score and certain subscales of the ABC. The social relating, language / communication and self-help subscales were significant, but not the sensory or repetitive behaviour ('body/ object use') subscales.

This finding suggests that feeding problems in autism, as measured by the CEBI, are not associated with repetitive behaviours, as measured by the ABC. However, critical review of this study demonstrates that it was unlikely to be able to link selective faddy eating with repetitive behaviour. The CEBI contains only one item that captures the selective type of feeding problems, and participants with autism and a learning disability were excluded from the study. The likely effect of this exclusion is to reduce the total amount of repetitive behaviour (as lower IQ is generally associated with increased repetitive behaviour). This would make it likely that increased higher-level compulsive rituals would be found (as compulsive behaviour is more often noted in individuals with higher IQs) (Hashino et al, 1997; Berument et al, 1999). However, the ABC only contains one item ('Gets involved in complicated rituals such as lining things up') that measures such higher level repetitive behaviours. This study highlights some of methodological difficulties in conducting research that links the two main areas of this review and may explain partly why so little research has attempted to link the psychological theories that attempt to explain autism and feeding problems.

Psychological theories of autism that attempt to account for the behaviours that characterise autism have been implicated in feeding problems by some

researchers (e.g. Archer & Szatmari, 1991). In order to explain diagnostic impairments in autism, three main cognitive theories of autism have been put forward, focusing on social understanding, control of behaviour and detail-focus. The theory of mind hypothesis (TOM) refers to the everyday ability to attribute mental states (beliefs or desires) in order to understand and predict other people's behaviour (Frith, 1989). This mechanism matures in the second year of life in normally developing children, however, individuals with autism aged four and over seem to be specifically impaired in this ability to 'know what someone else is thinking' according to a range of well-replicated tests (Baron-Cohen, Leslie & Frith, 1985). However, this hypothesis has difficulties accounting for the early age manifestation of autism in some individuals (between 12-18 months) and the small proportion of able and older children who are able to pass the tests (Medical Research Council, 2001).

The Executive Function (EF) hypothesis postulates that individuals with autism have EF deficits, as they have been shown to perform poorly on tests that purport to measure these functions (Russell, 1997). EF is an umbrella term describing a range of abilities such as planning future action, using feedback to monitor and modify behaviour, inhibiting inappropriate responses and shifting between behaviours. It has been suggested that deficits in EF can explain some of the rigid repetitive behaviours seen in autism, individuals find it difficult to generate new activities (Russell, 1997). However, this theory fails to explain why, if rigid behaviour is just a 'default' activity, features such as insistence on sameness are pursued with such intensity (Bailey, Phillips & Rutter, 1996). There is little consensus about which elements of EF are specific to autism as similar deficits appear in other disorders (e.g.

ADHD, conduct disorder) and as some high functioning individuals with autism do not demonstrate deficits (Medical Research Council, 2001).

The Central Coherence (CC) hypothesis refers to the everyday tendency to put information together to extract a higher-level meaning, with humans tending to interpret information in a relatively global way (for example, remembering the gist of a story rather than the details). People with autism seem to show a bias for part over whole and are often better at noticing and recalling detailed information (referred to as 'weak coherence') (Frith, 1989). This theory attempts to explain an uneven profile of abilities and difficulties seen in autism and may be best characterised as a cognitive style rather than an impairment. However, processing information in this way is not always practically useful, as understanding the meaning of everyday information can depend on perceiving context (Medical Research Council, 2001).

These three cognitive theories of autism have been criticised as seeking to account for autism in terms of a single abnormality, with little attempt to integrate findings as a whole (Bailey, Phillips & Rutter, 1996). The literature fails to show how the theories interrelate, whether they describe different aspects of autism or whether one constitutes a primary core difficulty from which the others arise. It is possible to speculate how a range of autism-specific feeding problems can be explained by these psychological theories, however, *no* empirical study in the literature has attempted to explore the role of specific psychological characteristics in causing feeding behaviours.

In summary, despite feeding difficulties reported in up to 94% children with autism during the course of childhood (De Meyer 1979) and numerous studies implicating repetitive behaviours in such problems, this hypothesis has not been adequately researched. Only one unpublished study has attempted to explore this link. Further studies are needed to establish whether specific repetitive behaviours underpin selective feeding problems and to assess the role that theories of autism play in feeding problems. The lack of studies may reflect that selective or other feeding problems in children with autism are seen in the same way as faddy feeding problems in normally developing children, as temporary and transitory.

Some researchers (e.g. Baird, 2001) have suggested that autistic children are best left to 'grow out' of feeding problems. However, considering the nutritional risks that the reviewed literature demonstrates can arise from such feeding problems it may be inappropriate to ignore them. Coping with specific feeding problems cause parents of autistic children significant stress (e.g. Archer & Szatmari, 1991) and reduces opportunities for children to eat outside of controlled environments (Legge, 2002). Government guidelines suggests that health professionals facilitate children with autism to play their full part in society, specifically reducing the barriers that prevent access (Department Of Health, 2001).

There is another good reason why this area of research is important. The failure of research to link feeding problems with the diagnostic criteria for autism has important practical implications for the assessment and treatment of feeding problems in individuals with autism. One of the characteristics of successful treatment programmes for autism is an understanding of the importance and functions of

repetitive behaviours such as obsessions and rituals (Howlin, 2000). The absence of links between feeding problems and diagnostic criteria for autism or cognitive theories would suggest that current assessment and treatment of feeding problems do not demonstrate important theory-practice links (Williams et al, 2000). This area of literature is important as it can demonstrate that exploring the link between repetitive behaviour and feeding problems has practical implications for the lives of those diagnosed with autism. Review of this literature is necessary to allow the evaluation of the empirical base for the treatment of feeding problems and would indicate the extent to which these strategies consider autism specific characteristics (as oppose to reflecting basic practice in the typically developing and LD populations).

Assessment and treatment of feeding problems in autism

Review of the literature on feeding problems in typically developing children demonstrates that the common ingredients in the majority of feeding treatments are reward, appetite manipulation and 'stimulus control procedures' (Iatwa et al, 1982). Rewards are given contingent on the performance of a desired feeding behaviour and often combined with planned ignoring for inappropriate behaviour. The most common positive consequence is offering one or more bites of preferred food, but also include access to television, opportunity to play with toys or tokens. Contingent social attention such as social approval (e.g. praise) seems to function as positive reinforcement for most typically developing and LD children (Linscheid, Budd & Rasnake 1995). Manipulating the feeding schedule to promote appetite includes not allowing food between meals, especially if a child refuses food during meals.

Stimulus control procedures reported in the literature involve two main techniques, shaping and fading, which involve developing gradual progressive changes in behaviour (Iatwa et al, 1982). For example, a shaping procedure for limited variety of food may initially involve reinforcing acceptance of any foods, with the child needing to accept small amounts of new foods to continue to receive reinforcement (Linscheid, Budd & Rasnake 1995). Fading involves the gradual removal of prompts to establish more independent performance of behaviour, and is reported as a useful strategy for teaching self-feeding skills (Williams, Dalrymple & Neal, 2000). Peer group modelling and training parents using handouts or parenting manuals are effective strategies for encouraging children to eat an increased amount and range of foods (O'Brien et al, 1991; Skuse, 1993).

Review of published treatment studies with Learning Disabled (LD) individuals suggests that a range of similar treatment strategies are used, including withholding food, using a preferred food, social reinforcement and praise, fading, shaping and ignoring aberrant behaviour (Ginsberg, 1988; Matson & Kuhn, 2001). Shore et al (1998) report four case studies of children who showed one type of problematic faddiness, food selectivity by texture. Treatment consisted of praise contingent on accepting bites of food, 15 seconds of toy play contingent on swallowing, escape extinction for non-acceptance. Initial meals were presented at the texture the child had been consuming prior to treatment, with texture gradually increased. The programme was effective in increasing consumption of higher texture food, but with individual differences in how quickly it was possible to reduce prompts.

A search of the literature on the assessment and treatment of feeding problems in autism produced only one treatment study with more than ten participants and a number of relevant single case studies. Clancy, Entsch and Rendle-Short (1969) describe an assessment and treatment regime for 12 autistic children (age 16 months to 7 years). A one-week assessment was completed in an inpatient unit where mother and child were observed and records of food and fluid intake were kept. Treatment consisted of attempting to feed children regularly at mealtimes, away from others and with only water allowed between meals. Preferred foods were used to disguise the taste of less preferred foods. If the child did not show interest in eating, the food was taken away without hesitation and the process was repeated. When the child accepted the modified food, feeding was reinforced via play. Children initially consistently refused the modified food (mean refusal period = 3 days) with one child refusing food for up to 10 days. Physical signs of starvation were observed, causing significant parental stress. There was a wide variation in improvement from child to child but generally, once children started to eat the new foods, it is reported that they gained confidence and liking for them.

Stroh, Robinson and Stroh (1986) completed three single case treatment studies with children with autism (age 5, 5 and 7 years) based on Clancy et al (1969). They used a reduced stimulus environment, with minimal verbal contact, and started giving the child small amounts of bland easily digestible food. Again, if food was not accepted by the child, it was taken away without comment. Eventually, all children accepted the food, with some initial weight loss in two of the three children. The study reports other behaviour changes such as improved sleep. Stroh, Robinson and Stroh

(1986) note that the child with increased cognitive abilities seemed to make faster and more significant change.

Freeman and Piazza (1998) used stimulus fading, reinforcement and escape extinction to treat food refusal with one six-year-old girl with autism and severe behaviour problems. Food refusal was discouraged by a series of verbal and physical prompts, including physically guiding the girl to bring a spoonful of food to her mouth. Acceptance of food was followed by verbal praise and consumption of all the food was reinforced by termination of the meal. The process was initiated with small amounts of preferred foods and gradually altered to include increased amounts of preferred and non- preferred foods. At the end of treatment the girl was consuming a more varied and larger quantity of food. The study was completed on an inpatient unit with no measure of generalisation to the home setting, and the authors report that there is a dearth of research evaluating treatment protocols implemented in the home or community settings (Freeman & Piazza, 1998).

This literature illustrates that published treatment studies for autistic individuals use the same strategies to those recommended for typically developing and LD children. The use of a reduced stimulus environment and communication with minimal verbal contact appeared to be the only autism specific strategies. Perhaps as a result, interventions demonstrate variable success as well as containing significant limitations. Children with autism can demonstrate difficulties transferring skills from one environment to another (Frith, 1989), however, no published treatment study demonstrates generalisation to outpatient settings. Also, any modern study proposing appetite manipulation that causes the physical signs of starvation would be unlikely to

be granted ethical approval, and the stress caused to parents reduces the likelihood of parental co-operation (Clancy et al, 1969).

Guides on the assessment and management of feeding problems in children with autism are available for parents, carers and schools (e.g. Ahaern, 2001; Dickinson & Hannah 1998; National Autistic Society, 1991; Richman, 2001), however, few are empirically based or contain autism specific recommendations. For example, the National Autistic Society (1991) recommends three types of approach; graded change, the use of favoured foods as a reward, and assisted feeding. In this guide these principles are be applied to autism-specific faddy behaviours. This guide suggests that problems with a range of food, such as only drinking red drinks, can be treated by introducing gradual change, for example by diluting the drink to lighten the colour. Also, Richman (2001) recommends the assessment of a child's diet, including recording food texture, colour and taste.

Other interventions that have been shown to be effective in other areas of autism, which might address anxiety that is hypothesised to underlie repetitive and stereotyped behaviours (Baron-Cohen, 1989), are recommended infrequently. The TEACCH approach has been shown to be effective with children with autism in other settings (Jordan, Jones & Murray, 1998) and is hypothesised to prevent feeding problems by improving the degree of structure in the child's environment, reducing the amount of noise and distractions present (Cloud, 1993; Van Bourgondien 1993). It is possible that such approaches for the management of autistic behaviours (including strategies that directly or indirectly address repetitive and stereotyped behaviours)

may be effective in addressing feeding problems. The limited literature in this area suggests that it is a worthy area of further research.

To recap, review of this literature demonstrates that current recommendations for the assessment and treatment of feeding problems in autism have a limited empirical base. Treatments that have been shown to be effective in other domains of autistic behaviour have not been reported in treating feeding problems. Treatments that are based on typically developing and LD children utilising learning principles, show variable benefit in a limited range of problems and the generalisation of changes are unproven. The full range of feeding problems reported in autism has not been addressed and the formal diagnostic criteria or psychological theories are seldom implicated. All these factors suggest that there are important areas for future research.

Future Research

The literature review has highlighted two separate areas of the autism literature, marked by both continued disagreement and variation in the classification and description of behaviour (Dahl & Sundelin, 1986; Hutchinson, 1999; Wicks-Nelson & Israel, 1991). Feeding problems occur in up to 94% of children with autism (De Meyer 1979), an important practical area of research and intervention (Legge, 2002). A range of feeding problems manifest in individuals with autism, including playing with food, self-feeding difficulties, taking food between meals and pica (Kinell, 1985). Added to this, a very specific faddy type of problem, characterised by unwillingness to try new foods, food refusal, selectivity by the colour, appearance, taste, texture and brand of food and rituals surrounding eating such as insisting on

food being prepared and served in a set way, occurs in all studies were measured. Future research needs to explore the role of biological, developmental or behavioural factors in producing this particular type of feeding problems. The empirical validity and reliability of findings relating to feeding problems in autism is limited by poor reporting of how diagnosis is confirmed, small samples and limited control groups and the use of unpublished non-validated measures. One published scale, the STEP (Matson & Kuhn, 2001) contains a five-item 'selectivity' subscale that could measure faddy feeding behaviours, but has not been used with an autistic population.

These selective and ritualistic feeding behaviours have a *prima facie* link to the diagnostic category of repetitive and stereotyped behaviours in autism. Repetitive and stereotyped behaviours are a key diagnostic criteria for autism that include a wide range of repetitive behaviours, including higher level behaviours such as compulsive adherence to specific, non-functional routines or rituals (WHO, 1992). Reviews of the literature suggest research is needed to study the phenomenology of the full range of repetitive behaviours, and the relationship between the different categories of behaviour, using standardised item-independent measures (Bailey, Phillips & Rutter 1996; Bodfish et al, 2000). One scale has been found to have acceptable levels of reliability and validity, without item overlap, but has been used in a limited number of studies (Bodfish, et al, 2000).

There is some consensus in the literature that repetitive and stereotyped behaviours, especially compulsivity and 'insistence on sameness', are implicated in selective faddy feeding problems. Despite this consensus, only one unpublished study has explored this link (Archer & Szatmari 1991) and this study finds a link between

autism severity and feeding problems. However, although no link was demonstrated between the repetitive behaviour and feeding problems, the exclusion criteria and measures used limited the ability of this study to generalise findings to the wider autistic population.

The need for future research to develop treatments for selective and ritualistic feeding problems has been questioned (Baird, 2001). However, studies demonstrate that this type of faddy feeding problems can put children with autism at risk of suffering nutritional deficits compared to children in other reviewed populations (e.g. Williams, Dalrymple & Neal, 2000). Additionally, selective feeding behaviours reduce opportunities for children to eat outside of controlled environments (Legge, 2002) and cause considerable parent stress (Archer & Szatmari, 1991). It is suggested that successful treatment programmes for problems in autism understand the importance of obsessions and rituals as an underlying causes of problems, and that repetitive behaviours have a role in reducing anxiety and can be used as sources of motivation (Howlin, 2000). Currently, the recommended methods of assessment and treatment of feeding problems in autism has a limited empirical basis, demonstrating variable benefit for a limited range of problems with unproven generalisation. Research is needed to assess the use of treatments that are effective in other domains of autistic behaviour, on feeding problems in autism, addressing formal diagnostic criteria and underlying psychological characteristics.

One prerequisite research step is the demonstration of an empirical link between repetitive behaviour, a defining diagnostic category of autism, and another high frequency behaviour reported in autism, selective and ritualistic feeding

problems. It is necessary that research is methodologically reliable and valid, enabling generalisation of findings. Published validated measures, that are able to assess and discriminate accurately between different types of feeding and repetitive behaviour, should be used in research. Participant diagnosis should be assessed and reported using a validated diagnostic or secondary screening instrument. Variables that mediate both feeding and repetitive behaviour should be assessed and reported, including a measure of adaptive intellectual ability and a measure of non-compliant behaviour (Archer & Szatmari, 1991; Bodfish et al 2000; Campbell et al, 1990). To demonstrate the specificity of this link between repetitive behaviour and selective and ritualistic feeding problems a group of individuals with autism should be compared to a control group. Given the frequency of occurrence of learning disabilities in individuals with autism and the high prevalence of repetitive behaviours in individuals with LDs, the most reasonable control group for individuals with autism would be the LD population (Bodfish et al, 2000; Rutter et al, 1994).

Conclusions

This review brings together two previously independent areas of literature. Feeding problems occur in up to 94% of children with autism and are an important practical area of research and intervention however, have not been the subject of empirical research (Medical Research Council, 2001). Selective and ritualistic feeding behaviours are characteristic of autism, and have a *prima facie* link to a cardinal diagnostic category autism, that of repetitive and stereotyped behaviours. The empirical demonstration that repetitive behaviour underpins aberrant feeding problems in autism has implications for the assessment and treatment of feeding

problems in autism. However, this link has not been demonstrated by research, which has been restricted in scope and has contained methodological limitations.

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Empirical Paper

An investigation of the type of feeding behaviour problems in children diagnosed with autism

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Prepared as if for submission to the Journal of Child Psychology and Psychiatry

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Running Header:

Autism and Feeding Problems

An investigation of the type of feeding behaviour problems in children diagnosed with autism

Abstract

Feeding problems occur frequently in children with autism and are characterised by a very selective type of problem. Selective feeding behaviours have a *prima facie* link to the diagnostic category of repetitive and stereotyped behaviours in autism. However, studies in this area show inadequate or poorly reported methodology. The empirical demonstration that repetitive behaviours are linked to selective feeding problems has implications for the assessment and treatment of feeding problems in autism. The aim of this study was to explore the link between repetitive behaviour and selective and ritualistic feeding problems. Three hypotheses were proposed. 1. A sample of autistic children will have a higher incidence of eating behaviour problems when compared with a matched group of LD children. 2. These problems will be different in type. 3. In the autism group, selective feeding behaviours will be associated with compulsive repetitive behaviours and mediating variables such as non-compliant behaviour, adaptive ability, level of LD and autism severity.

A between groups design was employed to compare 25 autistic children to a control group of 17 children with a Learning Disability matched for gender, age and adaptive ability. Three experimental measures were used, a measure of total feeding problems, a measure of type of feeding problem, and a measure of repetitive behaviour. The first hypothesis was not supported. The hypothesis that the autism group would have increased selective feeding problems, such as only eating specific types of food, was also not supported. In the autism group, the frequency of selective feeding problems was found to be associated with the total compulsive repetitive behaviours, supporting the hypothesis that repetitive behaviours are implicated in selective feeding problems in autism. However, suggestions made in the literature that 'insistence on sameness' behaviours are implicated in selective feeding problems was not confirmed. Limitations of the study and implications for future research are discussed.

Key Words: Autism, Repetitive Behaviour, Feeding Problems

Introduction

Autism is a lifelong syndrome that is categorised formally as part of a broad class of 'Pervasive Developmental Disorder' (PDD) (Volkmar, Klin & Cohen, 1997). Within this category, autism is described pragmatically as an 'autistic spectrum disorder' (ASD)(Medical Research Council, 2001) reflecting that autism covers a range of ability levels, from severely impaired to high functioning (Wing & Gold, 1979). Autism is defined by a constellation of behaviours that group together and these criteria are specified in two formal international classification systems. The most recent editions of the American Psychiatric Associations 'Diagnostic and Statistical Manual of Mental Disorders' 4th edition (DSM-IV) (APA, 1994) and the World Health Organisations 'International Classification of Diseases' 10th Edition (ICD-10) (WHO, 1992) reflect increasing consensus over the diagnostic criteria for autism.

DSM-IV criteria diagnose autism on the basis of qualitative abnormalities (i.e. aberrant and not merely delayed development) in a 'triad of impairments' which emerge before three years of age. Deficits in social, communicative / imaginative behaviours, and repetitive and stereotyped patterns of interests and activities must be present to confirm the diagnosis of autism. Social impairments involve poor eye contact, limited peer relationships and lack of sharing. Communicative and imaginative impairments involve lack of development of spoken language (or other communication), poor responsiveness to others and lack of make-believe play (APA, 1994).

Repetitive and stereotyped patterns of interests and activities, one area of focus in this study, encompasses a range of behaviours that varies between individuals with autism, the most prevalent of which are stereotypy, self-injury and compulsions (Bodfish, Symonds & Lewis, 1999). These behaviours can be difficult to classify and define adequately, however, Turner (1999) helpfully sub-divides repetitive behaviours into 'lower level' and 'higher level'. Repetition of movement, such as stereotypy and repetitive self-injurious behaviour (SIB) are considered to be characteristic of lower level behaviours. Higher level behaviours are described as more complex, including compulsions and 'insistence on sameness'. As individuals with autism often have difficulties verbalising thoughts, compulsions can be defined behaviourally as repetitive intentional actions that appear to follow certain rules (Bodfish et al, 1995). Insistence on sameness behaviours, although similar to compulsions, involve overall repetitive routines and preferences rather than discrete repeated acts. This type of compulsive behaviour is not explicitly defined in the formal diagnostic systems and has received little attention outside of the study of autism (Prior & MacMillan, 1973).

Reviews of the literature suggest that studies of the phenomenology of the full range of these repetitive behaviours in autism have yet to be completed (Bailey, Phillips & Rutter 1996; Bodfish et al, 2000), however there are some relevant and important findings. It is reported that repetitive behaviour occurs more frequently in autism than in comparable populations. For example, Bodfish et al (2000) found that, compared to a matched group of 34 non-autistic LD group, the group of 32 autistic adults showed a significantly higher number and more severe level of, both lower level and higher level repetitive behaviours. Added to this, the type of repetitive behaviour is mediated by the autism severity and IQ, with more severe autism and

lower IQ generally associated with increased repetitive behaviour (Campbell et al, 1990; Bodfish et al 2000). Importantly, lower IQ is associated with increased lower level stereotyped and self-injurious behaviours, while higher level compulsive rituals were more often noted in individuals with higher IQs (Hashino et al, 1997; Berument et al, 1999). To investigate higher level compulsive behaviour, McDougle et al (1995) used the Yale-Brown Obsessive-Compulsive scale (YBOCS) (Goodman et al, 1989) to compare 50 autistic adults to an age and gender matched Obsessive Compulsive Disorder (OCD) group. Individuals with autism displayed significantly more ordering, hoarding and touching compulsions and significantly less cleaning, counting and checking compulsions. Therefore one would expect autistic individuals with higher IQs to exhibit increased higher level repetitive behaviour, specifically of an ordering or hoarding type.

As well as focussing on repetitive behaviours, this paper also investigates an aspect of autistic behaviour that lies outside formal diagnostic criteria, aberrant feeding behaviour. This is an important area of study that seems under-researched. Unusual patterns of eating and feeding behaviour were assumed once to be one of the markers of autism. Ritvo and Freeman (1978) described a clinically detailed definition of autism including a category of repetitive sniffing, specific food preferences and licking of inedible objects. De Meyer (1979) reports that up to 94% of parents of children with autism reported feeding difficulties during the course of childhood. This compares to between 36% and 45% (Butler & Golding, 1986; Dahl, 1987) of typically developing children, and just over 30% of individuals with a LD (Palmer, Thompson & Linscheid, 1975). Feeding problems in autism frequently include a specific type of extremely selective or 'faddy' behaviours. Anecdotal report suggests three main types

of feeding problems are common in autism: the need for sameness and ritual at mealtimes, specific eating behaviours (e.g. messy eating, pica, rumination) and limited and rigid food preferences (Patterson, Ekvall, & Mayes, 1993). These problems have a *prima facie* link to the diagnostic category of repetitive and stereotyped behaviours in autism, particularly to higher-level compulsive repetitive behaviours. This link is recognised frequently by both professionals and parents (e.g. Legge, 2002; Van Bourgondien, 1993; Williams, Dalrymple & Neal, 2000).

In reviewing both the literatures on repetitive behaviour and feeding problems in autism it is apparent that an absence of an agreed overall classification system has been a major contributory factor to the variability of research (Dahl & Sundelin, 1986; Hutchinson, 1999; Wicks-Nelson & Israel, 1991). It is noted that the use of published validated measures can help overcome variability in the categorisation and measurement of these behaviours. However, no single instrument that reliably measures the spectrum of repetitive behaviours seen in autism has existed until relatively recently (Bodfish et al, 2000). One measure has been found to have acceptable levels of reliability and validity, the Repetitive Behaviour Scale (RBS) (Bodfish, Symonds, & Lewis, 1999). Matson and Kuhn (2001) report that their Screening Tool of fEeding Problems (STEP) is the only relevant feeding measure available. Another measure, the Children's Eating Behaviour Inventory (CEBI) (Archer, Rosenbaum & Streiner, 1991) is also available, however, neither measure is used widely in the literature. Confusion over the classification of behaviour is highlighted, as, for example, the behaviour 'asking for food between meals' is described as either related to behavioural compliance (Archer & Szatmari, 1991) or related to nutrition (Matson & Kuhn, 2001).

Despite the frequency of feeding problems, some researchers have suggested that autistic children are best left to 'grow out' of these behaviours (e.g. Baird, 2001). The implication of this is that research and intervention in this area is unnecessary. However, review of the literature appears to demonstrate that overly selective or rigid feeding problems can put children at risk of suffering nutritional deficits (Bowers, 2002; Cornish, 1998; Williams, Dalrymple & Neal, 2000) and, considering this risk, it may be inappropriate to ignore them. Additionally, coping with selective feeding problems can also cause parents of autistic children significant stress (e.g. Archer & Szatmari, 1991) and reduces opportunities for children to eat outside of controlled environments (Legge, 2002). It is important that research into feeding problems in autism reflects current government guidelines that suggest health professionals remove the barriers that prevent children with autism accessing the wider community (Department Of Health, 2001).

To recap, review of the literature suggests that feeding problems are more common in individuals with autism than other populations. Anecdotal studies suggest that ritualistic and selective types of behaviours characterise feeding problems and that these relate to autistic repetitive behaviour. However, this practical issue has not been the subject of good empirical research (Medical Research Council, 2001) and the relevant literature is limited by poor methodology. Methodological limitations, such as small or unrepresentative samples used and the use of unpublished or non-validated measures are highlighted in the following review of the relevant literature.

Raiten and Massaro (1986) used a non-standardised measure to assess 40 autistic children (mean age 10.6 years) compared to 34 typically developing control

children. Increased 'idiosyncratic' feeding behaviour was reported in the autism group, for example, 35% preferred to have food prepared and served in a set way, compared to 12% of control children. O'Brien and Whitehouse (1990) used an unpublished 28-item semi-structured interview to compare 15 autistic adults with 33 LD adults. The authors found eight autistic participants showed a significant excess of searching for food (defined as constantly looking for food), and, of the two cases of pica, both were autistic participants. In developing the CEBI, Archer, Rosenbaum and Streiner (1990) assessed nine autistic children (aged 2 - 12). Higher scores and greater numbers of cases occurred in autistic and LD groups, but no pattern of difference was reported. However, this measure contains one item that captures faddy types of feeding problem, 'my child eats food that tastes different'. Cornish (1998) found feeding rituals and repetitive patterns of behaviour in 15 of 17 autistic children (aged 4 - 9). Replicability of this study is limited as parents were interviewed using unspecified 'general questions'. Williams, Dalrymple and Neal (2000) surveyed 100 autistic children (aged 22 months - 10 years) using an unpublished questionnaire developed by the authors. Sixty-seven percent of respondents described their child as a 'faddy' eater.

Although it seems likely autistic selective feeding problems do occur at a higher rate than in typically developing or LD children, the specificity of these problems to autism remains to be demonstrated. The ability to assess, compare and generalise findings is made difficult due to empirical limitations of the research. Studies are limited further by failing to include or account for other variables that might affect feeding behaviour. These include physical and developmental factors, the role of general patterns of behaviour and general intellectual or adaptive ability.

Physical and developmental factors make links between autism and feeding problems, particularly the issues of general patterns of behaviour and intellectual ability. In general, individuals with autism do not show the obvious physical problems that characterises many individuals with severe learning disabilities who are not diagnosed with autism (Rutter et al, 1994). Patterns of behaviour are described as an important variable in the assessment of feeding behaviour, as feeding problems might be a reflection of a general pattern of maladaptive behaviour (Iatwa et al, 1982). There is evidence that other behaviours related to a pattern of non-compliant behaviour in typically developing children, such as sleep problems are common in autistic children (Dahl, 1987; Patzold, Richdale & Tongue, 1998). O'Brien et al (1991) suggest that the greater the level of learning disability the more prevalent the feeding problem. However, this linear relationship between feeding problems and LDs may be an over-simplification for individuals with autism. Levels of practical or adaptive functioning (including daily living skills) may not be determined by IQ in autism (NIASA, in press), and may be better represented by measures of adaptive behaviour (e.g. the Vineland Adaptive Behaviour Scales (Sparrow, Balla & Cicchetti, 1984).

No single variable or combination of these variables has been demonstrated to account for the range of autistic feeding problems of problem, however, the variables described (physical problems, general non-compliant behaviour, age and adaptive ability) need to be taken into account. Numerous studies propose that repetitive behaviours best explain in the type of feeding problems described in autism, specifically implicating insistence on sameness and resistance to change (e.g. Archer, Rosenbaum & Streiner, 1991; Cornish, 1998; National Autistic Society, 1991; Patterson, Ekvall & Mayes, 1993; Raiten & Massaro, 1986; Van Bourgondien, 1993;

Williams, Dalrymple & Neal, 2000). Despite this consensus, only one study, which has not been formally published, has investigated specifically aberrant feeding behaviour and the diagnostic criteria of autism.

Archer and Szatmari (1991) surveyed 33 ICD-10 diagnosed autistic children (mean age 5.3), compared to 295 control children (mean age 5.8). The authors used an unpublished 19-item version of the Children's Eating Behaviour Inventory (CEBI) to measure eating problems and the Krug Autism Behaviour Checklist (ABC) (Krug, Arick & Almond, 1978) to assess the severity of autism. They found items labelled 'behavioural compliance' (e.g. 'asks for food between meals', 'takes food between meals') were most frequently and strongly endorsed, with manual and motor problems much less so. Importantly, significant correlations were found between CEBI total score and certain subscales of the ABC. The social relating, language / communication and self-help subscales were significant, but not the sensory or repetitive behaviour ('body/ object use) subscales.

This finding suggests that feeding problems in autism, as measured by the CEBI, are not associated with repetitive behaviours, as measured by the ABC. However, critical review of this study demonstrates that it was unlikely to be able to link selective feeding with repetitive behaviour. Firstly, the CEBI contains only one item that captures faddy type of feeding problems. Secondly, participants with autism and a learning disability were excluded from the study. Research into repetitive behaviour in autism suggests that higher IQ is generally associated with decreased total repetitive behaviour as well as increased higher level compulsive behaviour. Therefore, the likely effect of the exclusion of individuals with a LD is to reduce the

amount of total repetitive behaviour whilst increasing the proportion of higher-level compulsive behaviour (Berument et al, 1999; Hashino et al, 1997). The ABC however only contains one item that measures such higher level repetitive behaviours.

An empirically demonstrated link between types of feeding problems and repetitive and stereotyped behaviours has important practical implications for a third area of literature, the assessment and treatment of feeding problems in individuals with autism. The absence of links between feeding problems and diagnostic criteria or cognitive theories of autism would suggest that current assessment and treatment of feeding problems may not demonstrate important theory-practice links (Williams, Dalrymple & Neal 2000). A number of published treatment studies (e.g. Freeman & Piazza, 1998; Kern & Marder, 1996) and guides (e.g. Ahaern, 2001; Dickinson & Hannah 1998; National Autistic Society, 1991; Richman, 2001) are available to inform the assessment and management of feeding problems in children with autism. Both studies and guides contain significant limitations. For example, no treatment study demonstrates the generalisation of improvements to outpatient settings and guides recommend dated treatment protocols that capitalise on deprivation effects (using hunger) that have ethical and compliance difficulties (Clancy, Entsch & Rendle-Short 1969).

One of the characteristics of successful treatment programmes for autism is an understanding of the importance and functions of repetitive behaviours such as obsessions and rituals (Howlin, 2000). Many functions have been posited for abnormal repetitive behaviours in autism, however the functions of repetitive behaviours are far from firmly established (Lewis & Bodfish, 1998). In one of the few

hypotheses that can account for higher level repetitive behaviour, Baron-Cohen (1989) regards repetitive behaviour as a coping strategy, allowing for the reduction of anxiety. However, treatment for feeding problems in autism is characterised by the same strategies as those recommended for typically developing and LD children, with only the use of a reduced stimulus environment and communication with minimal verbal contact appearing to be autism specific.

In conclusion, feeding problems in autism involves two separate areas of the literature that have been marked by continued disagreement and variation in the classification and description of behaviour (Dahl & Sundelin, 1986; Hutchinson, 1999; Wicks-Nelson & Israel, 1991). A very specific faddy type of problem, characterised by unwillingness to try new foods, food refusal, selectivity by the factors such as the colour, texture or brand of food, and rituals surrounding eating such as insisting on food being prepared and served in a set way, occurs in all studies were measured. The empirical validity and reliability of findings relating to feeding problems in autism is limited by inadequate methodology. These selective feeding behaviours and have a *prima facie* link to the diagnostic category of repetitive and stereotyped behaviours in autism. Reviews of the literature suggest research is needed to study the phenomenology of the full range of repetitive behaviours (Bailey, Phillips & Rutter 1996; Bodfish et al, 2000). There is some consensus in the literature that repetitive and stereotyped behaviours, especially compulsivity and 'insistence on sameness', are implicated in faddy feeding problems. Despite this consensus, only one unpublished study has explored this link (Archer & Szatmari 1991) and, although no link was demonstrated, the exclusion criteria and measures used limited the ability of this study to generalise findings to the wider autistic population. The assessment and

treatment of feeding problems in autism have a limited empirical base, demonstrating variable benefit for a limited range of problems with unproven generalisation.

One prerequisite research step is the demonstration of an empirical link between repetitive behaviour, a defining diagnostic category of autism, and another high frequency behaviour reported in autism, selective and ritualistic feeding problems. Methodological issues, such as the use of published validated measures and the assessment of variables that mediate both feeding and repetitive behaviour, need to be addressed (Archer & Szatmari, 1991; Bodfish et al 2000; Campbell et al, 1990). Given the frequency of occurrence of learning disabilities in individuals with autism and the high prevalence of repetitive behaviours in individuals with LDs, the most reasonable control group for individuals with autism would be the LD population (Bodfish et al, 2000; Rutter et al, 1994).

Therefore, the aim of this study is to explore the link between repetitive behaviour and selective and ritualistic feeding problems. Three hypotheses are proposed. 1. A sample of autistic children will have a higher incidence of feeding behaviour problems compared with a matched group of LD children. 2. These problems will be different in type. 3. In the autism group, the selective feeding behaviours will be associated with compulsive repetitive behaviours and mediating variables such as non-compliant behaviour, adaptive ability, level of LD and autism severity.

Method

Design

A between groups design was employed. The groups were an experimental group consisting of children with autism and a control group of LD children who are not diagnosed with autism. The independent variables were the group that the children were assigned to (autism or control) and the measures used for assessing other mediating variables. The dependent variables were the measures of feeding and repetitive behaviour used. Parents of the selected children were interviewed using all measures and demographic information collected.

Participants.

The experimental group of autistic children (N=25) were compared to the control group of LD children (N=17). Inclusion criteria specified that all participants in the study should be between two to 18 years of age and have a formal diagnosis of autism using DSM-IV criteria (APA, 1994) or (for the comparison group) a LD in the absence of autism. Individuals with physiological or uncontrolled medical complications that significantly affect eating behaviour or prevent expression of choice or action were excluded. Two of the autism participants were excluded from the study because of ongoing medical complications.

In the LD group, children with a range of disabilities were recruited, including a diagnosis of general developmental delay, Down syndrome, Soto's syndrome, Fragile X, tuberous sclerosis and neurofibromatosis.

Down syndrome (DS) occurs as a result of an additional chromosome 21. DS is associated with a number of medical problems, including increased risks of hearing and vision defects, heart abnormalities and of developing Alzheimer-type dementia in later life (Rutter, 1987). It is also associated with varied developmental difficulties including delayed motor and cognitive skills. Soto's syndrome is a rare genetic disorder characterised by excessive physical growth during the first two to three years of life. The disorder may be accompanied by mild learning disability, delayed motor, cognitive, and social development, low muscle tone and speech impairments (Rutter, 1987). Certain behavioural patterns may also be present including phobias, aggression, obsessions, adherence to routine, autistic-like behaviour and attention deficits.

Fragile X is caused by abnormality of the X chromosome, which can result in mild to severe LD. Other problems include difficulties with the social use of language, with speech anomalies, repetitive behaviour, attention deficits and over-activity, and autistic-like features ((Rutter, 1987)). These can include poor eye contact, hand flapping, social anxiety and an insistence on routine. Tuberous sclerosis derives its name from the tuber-like growths on the brain, which calcify with age and become hard or 'sclerotic'. Whilst 40-50% of people with TS have normal intelligence, the remainder have learning and developmental problems ranging from mild to severe. About 25% of people with TS are also diagnosed as autistic with another 25% showing sub-clinical features of autism (Rutter, 1987). Neurofibromatosis is a genetic disorder that causes people to develop tumours of the nervous system. There are eight subtypes, with at least 85 % represented by Type I (NF1) (Rutter, 1987). Learning

disability, macrocephaly and bony abnormalities can manifest, although these vary greatly between individuals.

The functional adaptive abilities of the two cohorts were assessed using the Vineland Adaptive Behaviour Scales (VABS) Parent Survey Edition (Sparrow, Balla & Cicchetti, 1984). Adaptive behaviour is seen as the performance of daily activities required for personal and social sufficiency and is defined by typical performance, not ability. For example, if a person has an ability to perform a skill but seldom does, adaptive behaviour is considered to be inadequate in that area. The VABS is a 297-item semi-structured interview designed to assess adaptive behaviour in three domains, socialisation, communication and daily living skills. Addition of the three domains produces a total 'Adaptive Behaviour Composite' (ABC). For each domain and the ABC, standard scores (mean = 100; standard deviation = 15) and age equivalents can be calculated.

The concept of adaptive behaviour has its roots in defining LD. The manual for the VABS suggests that the ABC standard score may be used in conjunction with an estimate of intellectual functioning in deciding whether an individual should be classified as having a LD. Also, because of substantial overlap between the VABS and some IQ tests (e.g. Kaufman Assessment Battery for Children) "valid comparisons can be made between scores obtained from the two instruments" (p.4). However, levels of practical or adaptive functioning (including daily living skills) may not be determined by IQ in autism (NIASA, in press) and so in this study the VABS ABC score is considered a measure of adaptive ability. Assessments that rely on parent report may sometimes overestimate skills but ensure that a cognitive profile

is available for all children (NIASA, in press). The VABS also has a maladaptive behaviour scale, used in this study to assess whether feeding problems might represent a wider pattern of non-compliant behaviour. The VABS has been standardised on a large sample (4800+) of normal children (two to 18 years) and supplementary groups, including children with LDs. This scale is frequently used in comparable autism and LD studies (e.g. Gillham, Carter, Volkmar, & Sparrow, 2000; Szatmari et al, 2002).

The groups were screened using the Autism Screening Questionnaire (ASQ) (Berument, Rutter, Lord, Pickles & Bailey, 1999), which is based on the algorithm used to construct the Autism Diagnostic Interview-Revised (ADI-R) (Lord, Rutter, & LeCouteur, 1994). The ADI-R is considered to be the 'gold standard' diagnostic parental interview (MRC, 2001) and is designed to reflect ICD-10 criteria. The ASQ consists of 40 questions on reciprocal social interaction, language and communication and repetitive and stereotyped patterns of behaviours, including a question about self-injurious behaviour and current language functioning. A score of '1' is given for the presence of abnormal behaviour and a score of '0' for its absence with the total scores ranging from 0-39 (one item on current language functioning is not scored).

In a diagnostic validity study (Berument et al, 1999), 160 individuals with a diagnosis of Pervasive Developmental Disorder (PDD) were compared with 40 individuals with non-PDD diagnoses. The ASQ demonstrated good concurrent validity, with highly significant correlation coefficients with the ADI ($p < 0.01$) and good construct validity, with high discriminant ability to differentiate autism from non-PDD conditions ($p < 0.01$). The research suggested 15 or more as the standard optimal cut-off score for differentiating from other diagnoses (sensitivity 0.85,

specificity 0.75), however, the ASQ was not particularly effective in differentiating autism from other PDDs and a higher cut-off (22 or more) was recommended (sensitivity 0.75, specificity 0.60).

A form was designed by the researcher to collect information that the literature suggests might be correlates of feeding problems or affect feeding behaviour (Appendix 1). This includes other family members with specific feeding requirements, allergy or food intolerance, special diet, such as avoiding gluten (in wheat) or casein (in dairy produce), medications and cultural or religious issues (e.g. Ahearn, 2001; Archer, Rosenbaum & Streiner, 1990; Bowers, 2002; Cornish, 1998).

Experimental measures.

Three experimental measures were used, a measure of total feeding behaviour problems (the CEBI), a measure of type of the feeding behaviour problem (the STEP), and a measure of repetitive behaviour (the RBS).

The Children's Eating Behaviour Inventory (CEBI) (Archer, Rosenbaum & Streiner, 1991) assesses the type and severity of feeding problems and covers a broad age span and a range of developmental disorders (Appendix 2). The CEBI was developed according to a systemic understanding of parent-child relationships. The questionnaire has been used in a limited number of surveys in the literature including by Archer and Szatmari (1990) and is recommended for use by Linscheid, Budd and Rasnake (1995) and Hutchinson (1999). The inventory consists of two domains. The first domain is a child domain (28 items) that assesses food preferences, motor skills

and behavioural compliance. The second is a parent and family domain (12 items) that assesses child behaviour controls, thoughts about the child and interactions between family members. Each item consists of a 5-point Likert scale measuring frequency of behaviour and respondents are asked to indicate whether the behaviour is regarded as a problem. Two scores are derived, a total eating problem score (minimum 40, maximum 200) and a percentage of items perceived to be a problem.

The scale was standardised on 206 typically developing children, 104 children with disorders that are at risk for feeding problems, and six children who were referred to clinic for feeding problems. This sample included nine children with a diagnosis of autism (six with IQs below 68 and three above 68). The test- retest correlation coefficient was good for the total eating measure ($r = 0.87$, $p<0.05$) and items perceived to be a problem ($r = 0.84$, $p<0.05$), however, no inter-rater tests were conducted. Construct validity was demonstrated as total eating scores and the mean percentage of items perceived to be a problem were significantly higher for the high risk group than the typically developing group. The median score for Archer, Rosenbaum and Streiner's (1991) autistic group was 93, with 50% of cases falling between 84 – 111. The cut-off point for defining a feeding problem was 16% of items perceived to be a problem.

The Screening Tool of Feeding Problems (STEP) (Matson & Kuhn, 2001) is designed as a screening tool for early identification of feeding problems for individuals with LDs. The scale has been used in a preliminary study (Matson & Kuhn, 2001) and is currently being further validated (Kuhn & Matson, in review). Twenty-three items are rated on a 3-point Likert scale on two dimensions, frequency

and severity. All items are worded such that positive endorsement indicates a problem. The scale is divided into five types of feeding problem: aspiration, selectivity, feeding skills, food refusal related behaviour problems and nutrition related behaviour problems. The selectivity category includes five items such as 'will only eat selected types of food' and 'eats food of only certain textures'. The scale produces a 'frequency' total score and 'frequency x severity' total score for each category.

The scale was standardised on 570 individuals with LDs with of varying levels of disability, mean age 46 years (range, 10-87 years). Test- retest reliability was found to be moderately high overall ($r = 0.72$, $p<0.05$) and slightly lower for each category, (averaging $r = 0.59$, $p<0.05$). Inter-rater reliability was found to be moderately high overall ($r = 0.71$, $p<0.05$) and slightly lower for each category (averaging $r = 0.68$, $p<0.05$). The authors report that the STEP is the only standardised method for identifying individuals with LDs and feeding problems and so concurrent validity was not assessed.

The Repetitive Behaviour Scale (RBS) (Bodfish, Symonds & Lewis, 1999) is a rating scale that compromises four separately developed behavioural checklists, each listing a set of discrete observable topographies of the respective behaviour (Appendix 3). The RBS has been used in a number of studies by the authors including Bodfish, Symonds, Parker & Lewis (2000), measuring varieties of repetitive behaviour in individuals diagnosed with autism. The scale includes: the stereotypy checklist and compulsive behaviour scale (Bodfish *et al*, 1995), the self-injury checklist (Powell *et al*, 1996) and the tic checklist (Bodfish *et al*, 1996). The

compulsive behaviour scale consists of 5 categories: ordering (e.g. arranging objects in pattern, insistence on routine), completeness (e.g. must have doors open or closed), cleaning / hoarding, checking / touching (e.g. repeatedly opens and closes drawers), and counting.

The RBS provides a set of scores that corresponds to the total number and severity of topographies endorsed for each checklist (except the tic checklist which is not included in the total score) and a total topography and severity score. Each checklist has been shown to have acceptable levels of inter-rater reliability (total topography $r = 0.82$, $p<0.05$ total severity $r = 0.58$, $p<0.05$) and test-retest reliability (total topography $r = 0.93$, $p<0.05$ total severity $r = 0.71$, $p<0.05$). The construct validity of the RBS has been investigated against clinician's assessment of behaviour (low false positive rate = –1.9% to 2.8%) and structured observations of behaviour (mean agreement = 92%). Discriminant validity was demonstrated by low correlations with ratings scales that measure different repetitive behaviours that are drug induced and criterion validity was demonstrated by good correlation with other published stereotyped behaviour ($r = 0.68$, $p<0.05$) and self injury subscales ($r = 0.77$, $p<0.05$).

In summary, three experimental measures were used, a measure of total feeding behaviour problems (the CEBI), a measure of type of the feeding behaviour problem (the STEP), and a measure of repetitive behaviour (the RBS).

Procedure

The study received ethical approval from the University of Southampton (Appendix 4). The VABS and STEP were purchased through the University of

Southampton and the authors of the RBS and CEBI were contacted for permission to use the scale. Permission was received and standardisation, administration, scoring and interpretation information was sent to the researcher concerning both scales. The 40-item version of the CEBI was copied from the original article and typed into a similar format. An electronic copy of the ASQ was obtained via a senior researcher at the University of Southampton. Minor alterations were made to improve the presentation of the ASQ and to allow the items to fit on three pages.

The participants were recruited via two means. Firstly, the heads of two schools, a specialist school for children with autism and a school for children with severe learning disabilities (SLD), within the local education authority were approached for permission to recruit participants. Head teachers of these schools excluded some participants from the study, for example where parents had indicated unwillingness to participate in previous research. All parents approached were sent an information sheet and consent form (Appendix 5). Thirty-two forms were sent to parents from the autistic school, producing 15 participants. These participants were contacted first and the data collected in an attempt to allow the control participants from the LD school to be matched for gender, age and then ability. Twenty-eight forms were later sent to parents of children at the LD school producing only three participants, resulting in a lower number of participants in the LD group.

Secondly, participants in a nation-wide postgraduate study at the University of Southampton who had indicated willingness to participate in further research were contacted. Twenty forms were sent to parents of autistic children (producing 12 participants) and 24 forms were sent to parents of LD children (producing 14

participants). When the consent forms were returned, all parents were contacted by telephone to arrange a suitable interview time and to complete the personal details form, screening for exclusion criteria.

Parents of the children recruited via schools were interviewed over the telephone to collect the information for the VABS and RBS. To ensure consistency, each interview was completed according to an interview script (Appendix 6) prepared by the researcher. Interviews lasted between 32 – 45 minutes depending on the level of child's disability and nature of repetitive behaviour. To reduce inconvenience to parents, the other measures (STEP, CEBI and ASQ) were sent to the parents with a questionnaire instruction sheet (Appendix 7) and a freepost envelope for them to complete in their own time. As the VABS had already been completed by a postgraduate researcher, all parents of children recruited via the University of Southampton were interviewed over the telephone for all other measures, with interviews lasting between 35 – 44 minutes. All interviews were completed by the researcher, a final year trainee clinical psychologist with experience in administering standardised interviews with parents. The researcher received additional training on the completion of the VABS over the telephone by an experienced researcher at the University of Southampton.

Two of the parents contacted through the schools expressed a preference for all the information to be collected face to face, so the researcher travelled to the houses of these individuals to collect the information. The parent of one child, contacted via the University of Southampton, preferred all questionnaires (the VABS having already been completed) to be sent by post and so an individual questionnaire

completion form was designed to ensure that the RBS was completed accurately. Four sets of questionnaires were not returned one month after they were posted, so parents were sent a reminder by post. All sets of questionnaires were subsequently returned.

All questionnaires were scored by the researcher. All participants were assigned a number to allow anonymity. Apart from the VABS, in which only the standardised and age adjusted scores were entered, every individual questionnaire item was entered into the database. The data were screened according to recommendations by Tabachnick & Fidell (1996). Firstly, the accuracy of data entry was checked, randomly selecting 3 participants from the autism group and 2 from the LD group (10%+ of the data) and checking collected information with data entered. No discrepancies were found. Secondly, the issue of missing data was addressed. Four items of missing data were found in autism group on the CEBI. The missing data were from four separate participants and included four different CEBI questions, therefore no participants were excluded from the study. A conservative approach was taken to missing data replacement, with the median value of each missing score calculated for the appropriate scale or subscale. Thirdly, the data were checked for outliers. No outliers were found.

Finally, the data were analysed to see if the cohorts were normally distributed. The distributions of the data were compared against the normal distribution curve on a series of frequency histograms. Whilst some of the data appeared normally distributed, much of the data appeared to be skewed positively, with some bimodal distribution. As a result a decision was made not to transform the data to a normal distribution, as transformation of bimodal data is problematic (Clegg, 1982). Non-

parametric analyses were subsequently conducted. Although the disparity in number of participants between groups is likely to reduce the chance of finding significant results slightly, a decision was made not to match group numbers, as few other effects would be expected on the tests performed on the data (Clegg, 1982).

Descriptive statistics for each experimental measure are reported, and a series of Mann Whitney U tests were conducted to explore differences between the groups. A series of Spearman's Rho correlations was used to the test the hypothesis that selective feeding problems are linked to compulsive repetitive behaviours. The same statistical test was used to explore the role of other variables that the literature suggests can affect feeding behaviour, non-compliant behaviour, age, adaptive ability and severity of autism.

Results

Participant Characteristics

In the autism group, 21 male and four female children (mean age = 10.4 years, range 2¾ - 16) were recruited, a ratio of 5 to 1. This ratio reflects the fact that autism is more common in males in a ratio of about 4 to 1 (Gillberg & Coleman, 1994). Eighteen (72%) of the autism participants were categorised as being reliably diagnosed (e.g. using the ADI-R or by a multi-disciplinary team) with seven (28%) less reliably diagnosed (e.g. by an individual clinician). In the LD group there were 14 male and three female children (mean age = 9.9, range 3 – 17). The numbers of LD participants with specific disabilities included general developmental delay (N= 11),

Down syndrome (N= 2), Soto's syndrome (N=1), Fragile X (N=1), tuberous sclerosis (N=1) and neurofibromatosis (N=1).

Eight percent (N= 2) of the autism group and six percent (N= 1) of the LD group had other family members with specific feeding requirements, including fussy eating and vegetarianism. Thirty two percent (N= 8) of the autism group and 12% (N= 2) of the LD group were reported to have an allergy or food intolerance. The majority of these were wheat and/or dairy allergies with two nut allergies and one fruit allergy. Twenty percent (N= 5) of the autism group and 12% (N= 2) of the LD group were reported to be on a special diet, avoiding or reducing gluten (in wheat) or casein (in dairy produce) or other allergens. Twenty four percent (N= 6) of the autism group and 18% (N= 3) were reported to be taking medications. The side effects of these medications were investigated. Seven participants were taking Carbamazepine (trade name Tegretol) for epilepsy, which can cause nausea (White & Ashworth, 2000), however no parent reported such adverse effects. One child was taking Methylphenidate (trade name Ritalin), which is a central nervous system stimulant and has the potential to cause reduced appetite and gastrointestinal upset (White & Ashworth, 2000). These problems were not reported in this participant. Therefore medication was not considered a significant factor. No cultural or religious issues were reported that could affect feeding behaviour such as food choice.

The mean Vineland Adaptive Behaviour Scale standardised scores for both cohorts are presented in Table 1 below.

Insert Table 1 about here

In this study, the entire autistic group scored above 15 on the Autism Screening Questionnaire (mean total score = 28, range 19 – 35). This result acts as a secondary confirmation of autism diagnosis. Eight percent of the sample (N=2) failed to reach the higher cut-off (22 or more). Sixty-five (N= 11) of the LD group scored below the ASQ cut off point of 15 (mean total score = 12, range 4 – 24). The six participants who scored 15 or above (and 1 of these who scored above the higher cut off point) suggest that some autistic behaviours were or are present in the LD group. As secondary screening measures can falsely identify some individuals, and are not sufficient to diagnose disorders such as autism (Medical Research Council, 2001), no participants were excluded from the LD group.

Table 2 illustrates participant characteristics. In order to compare the groups for gender, a Chi-square test was completed. The two groups did not differ significantly on gender (χ^2 (25,17)= 0.02, p> 0.05). In order to compare the groups for chronological age, adaptive ability (VABS ABC), non-compliant behaviour (VABS maladaptive) and autism severity (ASQ total score), four Mann Whitney U tests were conducted. The two groups did not differ significantly on age (U(25,17)=198, p> 0.05) or VABS ABC (U(25,17)= 175, p> 0.05). A significant difference was found between the two groups on VABS maladaptive behaviour (U(25,17)= 84, p< 0.01) with increased maladaptive behaviour in the autism group. Although there were autistic traits found in the LD group, a significant difference was found between the

two groups on ASQ severity ($U(25,17)=8$, $p< 0.01$) as expected, with higher ASQ scores in the autism group.

Insert Table 2 about here

It is concluded that the two groups were adequately matched for gender, chronological age and a measure of adaptive ability (VABS).

Experimental Measures

The mean total scores for the Children's Eating Behaviour Inventory (CEBI) are reported in Table 3. For the autism group, the mean CEBI total score was 84 and the mean percentage of items perceived to be a problem was 10. For the LD group, the mean CEBI total score was 82, and the mean percentage of items perceived to be a problem was 11. Twelve percent (N= 3) of the autism group scored above the cut off score of 16% of behaviours perceived to be a problem. Forty-seven percent of the LD group scored above the cut off score of 16% of behaviours perceived to be a problem. There were no statistically significant differences between the groups on mean CEBI total score ($U(25,17)=184$, $p> 0.05$) or mean CEBI percentage of items perceived to be a problem ($U(25,17)=184$, $p> 0.05$).

Insert Table 3 about here

The mean total scores for the Screening Tool of feeding Problems (STEP) frequency and severity subscales are reported in Table 4. A statistically significant difference was found between the groups on the STEP skills frequency subscale ($U(25,17)=134$, $p< 0.05$). Despite a difference in mean scores, no statistically significant difference was found between the groups on the selectivity frequency subscale ($U(25,17)=145$, $p> 0.05$). No other statistically significant differences were found on the other subscales of the STEP.

Insert Table 4 about here

It is concluded that the autism group was not found to have a higher incidence of total feeding behaviour problems, as measured by the CEBI, when compared with the matched group of LD children. In relation to the type of feeding problems, as measured by the STEP, although differences were found between the two groups (the LD group was found to have an increased frequency of feeding skills problems), the autism group did not have increased selective feeding problems.

The mean scores on subscales of the Repetitive Behaviour Scale (RBS) are reported in table 5. A statistically significant difference was found between the groups on the mean RBS total topography ($U(25,17)=121$, $p= 0.02$) and total severity ($U(25,17)=87$, $p= 0.01$) scores. A statistically significant difference was found between the groups on the mean RBS stereotyped behaviour topography ($U(25,17)=124$, $p= 0.02$) and stereotyped behaviour severity ($U(25,17)=89$, $p= 0.01$)

scores. No statistically significant differences were found between the groups on other subscales of the RBS.

Insert Table 5 about here

The relationship between the selective feeding problems in the *autistic* group, and compulsive repetitive behaviours is described in Table 6. A statistically significant positive correlation was found between the STEP selectivity frequency subscale scores and the total RBS compulsive behaviour topography scores ($r(25)= 0.47$, $p< 0.05$) and STEP selectivity frequency subscale scores and the total RBS compulsive behaviour severity scores ($r(25)= 0.43$, $p< 0.05$). In looking at specific types of repetitive behaviour, a statistically significant positive correlation was found between the STEP selectivity frequency subscale scores and RBS 'cleaning / hoarding' behaviours ($r(25)= 0.50$, $p< 0.01$), a statistically significant positive correlation was found between the STEP selectivity frequency subscale scores and the RBS 'completeness' behaviours ($r(25)= 0.45$, $p< 0.05$). No other statistically significant associations were found between RBS and STEP subscales.

Insert Table 6 about here

To recap, compared to the LD group, the autistic group scores on the RBS showed significantly increased total topographies of repetitive behaviour, increased

severity of these behaviours and increased stereotyped behaviours, supporting reports in the literature (e.g. Bodfish et al, 2000). Importantly, in the autism group, the frequency of selective feeding problems was found to be associated with the total type and severity of compulsive repetitive behaviours. Selective feeding problems were specifically associated with cleaning / hoarding and completeness behaviours.

In summary, the first hypothesis was not supported, as the autism group was not found to have a higher incidence of total feeding behaviour problems when compared with the matched group of LD children. In terms of the type of feeding problems, there was only one significant finding: the LD group was found to have an increased frequency of feeding skills problems, such as not being able to feed independently or difficulties with chewing or swallowing. The hypothesis that the autism group would have increased selective feeding problems, such as only eating specific types of food, was not supported. Finally, in the autism group, the frequency of selective feeding problems was found to be associated with the total type and severity of compulsive repetitive behaviours, and specifically associated with cleaning / hoarding (e.g. hides, collects or hoards objects) and completeness (e.g. must have doors open or closed) behaviours. This supports the hypothesis that repetitive behaviours are related to selective feeding problems in autism.

Variables contributing to feeding problems in *autism*

A measure of non-compliant behaviour (VABS maladaptive behaviour scores) was compared to the measure of total feeding problems (CEBI total) and to the measure of selective feeding problems (STEP selectivity scales). Firstly, it was

expected that VABS maladaptive scores might correlate positively with total CEBI problem scores as the CEBI contains a large number of 'behavioural compliance' items. It is likely that increased general behavioural problems (resulting in high VABS maladaptive scores) also lead to behavioural problems at feeding times (resulting in higher total CEBI scores). A statistically significant positive correlation was found between VABS maladaptive scale scores and total CEBI score ($r(25)= 0.41$, $p< 0.05$). This suggests that non-compliant behaviour has a significant role in the total amount of feeding problems in this autistic group and that some feeding problems may occur as part of a general pattern of non-compliant behaviour.

Secondly, the selective feeding measure (STEP selectivity scale) was compared to a measure of non-compliant behaviour (VABS maladaptive scale). The VABS maladaptive behaviour scale was not statistically significantly associated with STEP selectivity (frequency) scores ($r(25)= 0.03$, $p> 0.05$) or STEP selectivity (severity) scores ($r(25)= -0.05$, $p> 0.05$). This suggests that selective feeding behaviour is not significantly related to general problematic behaviour in this autistic group.

Age was found to statistically significantly negatively correlate with total CEBI scores ($r(25)= -0.53$, $p< 0.01$) and with total STEP selectivity frequency scores ($r(25)= -0.54$, $p< 0.01$) and total STEP selectivity severity scores ($r(25)= -0.49$, $p< 0.01$). Adaptive ability, as measured by the VABS ABC, was not statistically significantly correlated with CEBI total score ($r(25)= 0.03$, $p> 0.05$) or STEP selectivity frequency scores ($r(25)= 0.8$, $p> 0.05$). Autism severity, as measured by the ASQ total score, was not significantly correlated with CEBI total score ($r(25)=$

0.19, p> 0.05), the STEP selectivity frequency score (r(25)= 0.19, p> 0.05) or the STEP selectivity severity score (r(25)= 0.02, p> 0.05). This suggests that variables such as general non-compliant behaviour and age can be important mediating variables when considering links to some feeding problems, with adaptive ability or autism severity being less significant variables.

Discussion

The aim of this study was to explore the link between repetitive behaviour and selective and ritualistic feeding problems. Three hypotheses were proposed. 1. A sample of autistic children will have a higher incidence of eating behaviour problems when compared with a matched group of LD children. 2. These problems will be different in type 3. In the autism group, selective feeding problems will be associated with compulsive repetitive behaviours and other mediating variables. The first hypothesis, that sample of autistic children will have a higher incidence of eating behaviour problems when compared with a matched group of LD children was not supported. The autism group was not found to have a higher incidence of total feeding behaviour problems. In terms of the type of feeding problems, the second hypothesis that the autism group would have increased selective feeding problems, such as only eating specific types of food, was not supported. In relation to the third hypothesis, that repetitive behaviours are implicated in selective feeding problems in autism, the frequency of selective feeding problems was found to be associated with the total type and severity of compulsive repetitive behaviours in the autism group. Selective feeding problems were specifically associated with cleaning / hoarding (e.g. hides, collects or hoards objects) and completeness (e.g. must have doors open or closed)

behaviours. This supports the third hypothesis. In addition, other mediating variables were implicated in feeding problems. General non-compliant behaviour was shown to relate to overall feeding problem scores, but not selective feeding behaviour and a younger age was shown to increase general and selective feeding problems.

The finding that there were no overall differences in the amount of feeding problems between the groups contrasts with suggestions in the literature that feeding problems are more common in autism (e.g. De Meyer, 1979; Palmer, Thompson & Linscheid, 1975). It is difficult to compare findings directly as no published study could be found that uses the Children's Eating Behaviour Inventory (CEBI) to compare an autism group with a LD group. This finding should be considered in terms of the limitations of the study. The participants from either group were not randomly selected and parents selected themselves for participation in the study. Therefore they are not necessarily representative of the wider autism and LD populations. During the study, one parent of a child with a LD returned a consent form saying that they did not think they would help the study, as their child had no feeding difficulties. If this parent is representative of other parents, it is possible that, for both groups, the incidence of feeding problems found is higher than in the wider population. However, the fact that the mean autism CEBI total score in this study is lower than in a comparable study (mean total in this study = 84, Archer, Rosenbaum & Streiner, (1991) mean total = 93) suggests that this is not the case. Additionally, the self-selection of participants would be likely to affect both groups equally, thus reducing any artificial group differences that might affect results.

The finding that the LD group had an increased frequency of feeding skills problems is predicted by the literature. Individuals with autism do not show the obvious physical problems that characterise many cases of severe learning disability in the absence of autism, (Rutter, Bailey, Bolton & LeCouteur, 1994) and manual and motor problems are not frequently or strongly endorsed in the autism population (Archer & Szatmari, 1991). This finding occurred despite the exclusion of any individuals with physiological or uncontrolled medical complications that could significantly affect eating behaviour or prevent expression of choice or action.

This study was not able to support suggestions in the literature that increased selective feeding problems would be found in the autism group. Mean scores of the frequency of selective behaviour were higher in the autism group (autism mean = 2.40, LD mean = 1.41), however the difference was not statistically significant. There are a number of possible explanations for this finding. It is possible that selective problems are not as common as expected in the autism group, or are more prevalent than predicted in the LD group. The low mean Screening Tool of feeding Problems (STEP) selectivity frequency score for the autism group (mean = 2.40, range 0 – 10) suggests that the former explanation is more likely. In considering these explanations, however two important factors should be taken into consideration, the ability of the STEP scale to capture the full range of feeding problems in autism and the overlap between the groups in terms of behaviours that diagnose autism.

The STEP is a short screening measure designed to identify a range of eating and feeding problems and is the only available standardised measure of the type of selective feeding problems. The selectivity category includes five items that measure

selectivity by food type, temperature, and texture and by the setting and feeder. The STEP contains one overall item that measures food selectivity 'he/she will only eat selected types of food' and two specific items (relating to texture and temperature). These items do not discriminate between a range of selective feeding problems described in the literature on feeding problems in autism, including refusal of new foods, selectivity by the brand, colour, smell of food or aspects of the appearance of food such as not eating a biscuit that contained nuts. The STEP contains two questions that relate to rituals surrounding feeding. The selectivity by feeder item was endorsed infrequently, reflecting that, as manual and motor problems are not often reported in the autism population, few participants were fed by a parent. This leaves one item, a preference for a specific setting to capture the range of rituals described in the autism literature, including, insisting on eating food in a certain order, not allowing portions of food to touch on the plate, having to have food prepared one way and selectivity by plate, chair or cutlery. Therefore it is likely that the STEP measure does not capture the full range of feeding problems that occur with autistic individuals.

In an attempt to prevent overlap between the groups, to validate autism diagnosis in the autism group, and to confirm that individuals in the LD group were not autistic, the ASQ was used. The entire autistic group scored above the cut off point for autism screening on the ASQ, with the range of scores reflecting a spectrum of autism severity. This supports the diagnosis of these participants, although two participants failed to reach the higher cut-off score that would differentiate autism from other Pervasive Developmental Disorders. However, six participants in the LD group also scored above the cut off point for autism screening, suggesting that some autistic behaviours were present in the LD group. Four of these participants did not

have any specific diagnosis other than general developmental delay. Although participants with high ASQ scores were not excluded from the study, as secondary screening measures can falsely identify some individuals and are not sufficient to diagnose disorders such as autism, results may have been confounded by the overlap between groups in behaviours that diagnose autism. Exclusion of participants in the autistic group that failed to reach the higher cut off score on the ASQ and the participants in the LD group who scored above the lower cut off score on the ASQ might have changed the findings of the study. This process was not completed, as exclusion of participants would have reduced group numbers, particularly in the LD group, placing constraints on the statistical reliability of the results.

The finding that the frequency of selective feeding problems in the autism group was associated significantly with an over all measure of compulsive repetitive behaviours, confirms anecdotal suggestions made in the literature (e.g. Patterson, Ekvall & Mayes, 1993; Van Bourgondien, 1993; Williams, Dalrymple & Neal, 2000), however, this association does not prove causality. The frequency of selective feeding problems was associated specifically with cleaning / hoarding and completeness behaviours. This does not confirm suggestions made in the literature that insistence on sameness (as measured by the RBS 'ordering' item) is implicated in selective feeding problems (e.g. Cornish, 1998).

A range of variables have been implicated in feeding problems in autism. The finding that a pattern of general maladaptive behaviours was positively correlated with overall feeding problems suggests that some feeding problems might only represent a wider general pattern of behaviour (Iatwa *et al*, 1982). Further research is

necessary to demonstrate which feeding behaviours are specifically associated with non-compliant behaviour however, selective feeding problems were not found to be associated with general maladaptive behaviour. Increased overall feeding problems and selective feeding behaviour were negatively correlated with age. This confirms anecdotal evidence that feeding problems are more prevalent in younger children (Legge, 2002) and contrasts with published findings that there were no significant differences between a younger age group (2 – 6 years) and an older age group (7 – 12 years) (Archer, Rosenbaum & Streiner, 1990). The poor association between adaptive ability or autism severity and overall feeding problems or selective feeding behaviour again fails to replicate other findings that these variables are linked (Archer & Szatmari, 1991).

These results should be considered within the limitations of this study. A number of factors would have improved the methodological validity of the study. The participants from either group were not randomly selected and therefore are not necessarily representative of wider autism and LD populations. This can be seen as all of the autism participants were categorised by scores on the VABS as having a learning disability, whereas research suggests that three quarters or less of individuals diagnosed with autism have a learning disability (NIASA, in press; Rutter, Bailey, Bolton & LeCouteur, 1994). Matched group sample size and increased sample size would have made statistical analysis more robust. The poor response from the parents of the LD children at the local school may have been due to a number of reasons. It is possible that the opinion of one parent of a child with a LD, that as their child displayed no feeding problems, that they would not be useful to the study, may have characterised other parents. The collection of the LD data during the school holidays

may have reduced the opportunity for participation. Any future studies would benefit from specifying on information sheets that even those without feeding problems are eligible. Greater numbers of participants could have been obtained using school staff however, the measures specify that informants should have known the participant for at least six months and have a good knowledge of participants in a range of different environments. The head teachers of the schools involved in the study reported high staff turnover and limited opportunity for school staff to view a range of representative adaptive behaviours, suggesting that feeding problems were often prevented as parents prepared school lunches.

Methodological validity would have also been improved through better group matching, as, although the groups were not significantly different in relation to chronological age, gender and adaptive ability there was a significant difference between the groups on the measure of non-compliant behaviour. This means that the findings that show differences between groups, such as in self-feeding skills or total repetitive behaviour, may relate to non-compliant behaviour. Better definition of both groups would have made the study more robust. Twenty-two percent (N= 7) of the autism group were not categorised as being reliably diagnosed, however, as an exploratory study that is limited in scope, it was impractical to have completed a gold standard diagnostic assessment such as the Autism Diagnostic Interview-Revised (ADI-R) (Lord, Rutter, & LeCouteur, 1994) on all participants. The exclusion of participants diagnosed with autism that fell below the higher autism screening cut off and LD participants who scored above the lower autism cut off would have prevented over lap between groups on ASQ scores, however would have significantly reduced the LD group size. As the ability of the STEP screening measure to capture the full

range of feeding problems was limited, a series of exploratory questions and formal analysis of qualitative comments made by parents would have facilitated further exploration of this area. However, because of the methodological limitations of previous research this study was designed particularly to use only valid and reliable published measures. The results of this study highlight the limits of these measures as tools to measure autistic feeding behaviours and this has implications for future research, particularly the development of a questionnaire designed specifically for the assessment of autistic feeding behaviour.

The limitations of the study facilitate recommendations about the methodology of future studies. Within these limitations, this study highlights the range of feeding problems reported in the autism literature (e.g. Raiten & Massaro, 1986; Williams, Dalrymple & Neal, 2000) including selective and ritualistic behaviours. These problems are not well understood in the literature, compared to the less frequently occurring skill deficits or aspiration problems, suggesting that they are a focus of future research investigating autism and feeding problems. Repetition of this study with the same participants would give valuable information about the longitudinal development of feeding problems across a range of ages.

The finding that overall compulsive repetitive behaviours are associated with selective feeding problems empirically confirms suggestions in the literature and should help facilitate the development of a testable theoretical model to explain the range of aberrant eating behaviours within the autistic population. However, finding that 'insistence on sameness' behaviour is not associated with selectivity suggests that more research is necessary to fully understand the relationship between specific

repetitive behaviours and selective eating. Although, in addressing repetitive behaviour, this study has focussed on autism at a diagnostic level, it highlights certain characteristics of the literature on theories of autism. That the functions of repetitive behaviours are far from firmly established (Lewis & Bodfish, 1998) highlights the inability of cognitive theories of autism to fully account for the range of behaviours that occur and the difficulties in testing these hypotheses. Baron-Cohen (1989) suggests that repetitive behaviour, including compulsive behaviour, is a coping strategy, allowing for the reduction of anxiety that arises as a consequence of an impaired theory of mind in autism. As feeding is often an unpredictable social situation that an individual with an impaired theory of mind might find stressful, it is possible that increased repetitive behaviour in the form of adherence to routine could give a sense of security. However, theory of mind is unlikely to account for the range of feeding problems described and it is possible to speculate how certain autistic feeding problems can be explained plausibly by other psychological theories. The three cognitive theories of autism have been criticised as seeking to account for autism in terms of a single abnormality, with little attempt to integrate findings as a whole. Similarly, it seems likely that to gain a fuller understanding of the factors that underpin the range of selective or ritualistic feeding behaviours in autism an integrated multi-theoretical model will have to be constructed.

There are also practical implications for the assessment and treatment of feeding problems in autism. Interventions that have been shown to be effective in other areas of autism, which might address anxiety that is hypothesised to underlie repetitive behaviours (e.g. Baron-Cohen, 1989) are seldom recommended in studies or guides for managing feeding problems in autism. One of the characteristics of

successful treatment programmes for autism is an understanding of the importance and functions of repetitive behaviours such as obsessions and rituals (Howlin, 2000). The TEACCH approach has been shown to be effective with children with autism in other settings (Jordan, Jones & Murray, 1998) and is hypothesised to prevent feeding problems by reducing anxiety by improving the degree of structure in the environment and reducing the amount of distractions (Cloud, 1993; Van Bourgondien 1993). The efficacy of such an approach could be tested in a series of single case treatment studies and could help further develop research into theoretical aspects of autism.

In summary, the aim of this study was to explore the link between repetitive behaviour and selective and ritualistic feeding problems. Three hypotheses were proposed. 1. A sample of autistic children will have a higher incidence of feeding behaviour problems compared with a matched group of LD children. 2. These problems will be different in type. 3. In the autism group, the selective feeding behaviours will be associated with compulsive repetitive behaviours and mediating variables such as non-compliant behaviour, adaptive ability, level of LD and autism severity. This study provides evidence to support the hypothesis that repetitive behaviours, cardinal to the diagnosis of autism, are implicated in the type of selective feeding problems in autism. Further systematic research is necessary to replicate these findings and explore the relationship between specific repetitive behaviours and selective feeding problems more closely. The link between repetitive behaviours and selective eating has implications for the assessment and treatment of feeding problems in autism, suggesting that interventions described in the literature, which characteristically do not address repetitive behaviours, could usefully be enhanced.

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Table 1: mean VABS standardised scores (mean = 100; standard deviation = 15).

VABS scores	Communication	Daily Living Skills	Socialisation	Maladaptive Behaviour Scale	Adaptive Behaviour Composite
Autism					
mean	38	37	42	15	37
(range)	(19-86)	(19-77)	(19-85)	(5-34)	(19-77)
LD mean	43	44	48	9	42
(range)	(20-93)	(20-103)	(20-103)	(2-15)	(20-98)

Table 2: Participant characteristics

Group	n	Gender			Chronological age (years)	VABS ABC	VABS Maladaptive	ASQ Total
		Male	Female					
Autism	25	21	4	M	10.44	36.92	15.00	27.68
				SD	3.96	17.68	6.60	4.38
				Range	2 - 16	20 - 77	5 - 34	19 - 35
LD	17	14	3	M	9.94	41.76	8.71	12.00
				SD	4.52	21.23	3.95	5.74
				Range	3 - 17	20 - 98	2 - 15	4 - 24

Table 3: Mean CEBI total scores and mean percentage of items perceived to be a problem

Group	Total score		% of items perceived to be a problem
Autism	M	84.1	10.0
	Range	50-119	0-52
LD	M	82.1	10.6
	Range	61-115	0-30

Table 4: Mean total scores for STEP frequency (F) and severity (S) subscales

STEP subscale	Aspiration		Selectivity		Skills		Food refusal		Nutrition related	
	F	S	F	S	F	S	F	S	F	S
Autism mean (range)	0.16 (0-2)	0.12 (0-2)	2.40 (0-7)	1.28 (0-6)	1.68 (0-8)	0.96 (0-5)	1.52 (0-5)	0.96 (0-5)	2.68 (0-7)	1.72 (0-8)
LD mean (range)	0.35 (0-3)	0.35 (0-3)	1.41 (0-7)	1.06 (0-6)	3.00 (0-10)	2.06 (0-8)	1.47 (0-4)	1.24 (0-4)	2.59 (0-6)	2.29 (0-6)
Range possible on scale	0-4	0-8	0-10	0-20	0-16	0-30	0-5	0-15	0-10	0-20

Table 5: Mean total scores for RBS Topography (T) and Severity (S) subscales

RBS subscale	Stereotyped		Self-Injury		Compulsive		Total	
	T	S	T	S	T	S	T	S
Autism mean (range)	2.68 (0-7)	3.92 (0-10)	0.88 (0-5)	1.88 (0-12)	1.80 (0-5)	5.52 (0-15)	5.36 (1-13)	11.32 (0-23)
LD mean (range)	1.35 (0-5)	0.82 (0-6)	0.29 (0-2)	0.24 (0-2)	1.12 (0-3)	2.94 (0-14)	3.06 (0-9)	3.18 (0-16)
Range possible on scale	0 - 10	0 - 28	0 - 8	0 - 28	0 - 5	0 - 28	0 - 23	0 - 84

Table 6: RBS compulsive scale & STEP selectivity correlations for the autism group

RBS subscale	Ordering	Complete-ness	Clean / Hoard	Check / Touch	Counting	Total (T)	Total (S)
STEP selectivity (F)	0.14	0.45 *	0.50 **	0.25	-0.05	0.47*	0.43*
STEP selectivity (S)	0.15	0.28	0.26	0.24	-0.11	0.31	0.33

* p= 0.05, ** p= 0.01

Appendices

Appendix 1

Personal Details Form

Personal Details Form

Client ID:

1. **Name**:

2. **Today's date**:

3. **Date of Birth / Age**: /

4. **Gender**: M / F

5. Person completing questionnaires:

6. Relationship to child:

7. **Family** in the household:
(Number of adults / children in the house – age)

8. Does anyone else have unusual food preferences / special feeding requirements (relationship to child / age):

9. Does _____ have any **allergies** / food intolerance?: **Y / N**

10. Is _____ on a **special diet** / take any supplements: **Y / N**

11. Does _____ have any **medical problems** that might effect eating?: **Y / N**

12. Does _____ take any **medications**?: **Y / N**

I. _____ II. _____

III. _____ IV. _____

13. Are there any **cultural / religious** issues that might effect _____'s eating? **Y / N**

14. Is your child receiving any **treatments / interventions** for autism?: **Y / N**

15. **Autism diagnosis**: Was _____ formally diagnosed with Autism?:

Appendix 2

Children's Eating Behaviour Inventory

The Children's Eating Behaviour Inventory

HOW OFTEN DOES THIS HAPPEN?	**Never** **1**	**Seldom** **2**	**Sometimes** **3**	**Often** **4**	**Always** **5**	*Is this a problem for you ?*
1. The child chews food expected for their age	1	2	3	4	5	*Yes / No*
2. The child helps to set the table	1	2	3	4	5	*Yes / No*
3. The child watches TV at meals	1	2	3	4	5	*Yes / No*
4. I feed the child if they don't eat	1	2	3	4	5	*Yes / No*
5. The child takes more than ½ hour to eat a meal	1	2	3	4	5	*Yes / No*
6. Relatives complain about the child's eating	1	2	3	4	5	*Yes / No*
7. The child enjoys eating	1	2	3	4	5	*Yes / No*
8. The child asks for food which they shouldn't have	1	2	3	4	5	*Yes / No*
9. The child self feeds as expected for their age	1	2	3	4	5	*Yes / No*
10. The child gags at mealtimes	1	2	3	4	5	*Yes / No*
11. I feel confident the child eats enough	1	2	3	4	5	*Yes / No*
12. I find meals stressful	1	2	3	4	5	*Yes / No*
13. The child vomits at meals	1	2	3	4	5	*Yes / No*
14. The child takes food between meals without asking	1	2	3	4	5	*Yes / No*
15. The child comes to the table within 1 or 2 mins when called	1	2	3	4	5	*Yes / No*

HOW OFTEN DOES THIS HAPPEN ?	**Never** **1**	**Seldom** **2**	**Sometimes** **3**	**Often** **4**	**Always** **5**	*Is this a problem for you ?*
16. The child chokes at mealtimes	1	2	3	4	5	*Yes / No*
17. The child eats quickly	1	2	3	4	5	*Yes / No*
18. The child makes food for themselves when not allowed	1	2	3	4	5	*Yes / No*
19. I get upset when the child doesn't eat	1	2	3	4	5	*Yes / No*
20. At home the child eats food they shouldn't have	1	2	3	4	5	*Yes / No*
21. The child eats foods that taste different	1	2	3	4	5	*Yes / No*
22. I let the child have snacks between meals if they don't eat at mealtimes	1	2	3	4	5	*Yes / No*
23. The child uses cutlery as expected for their age	1	2	3	4	5	*Yes / No*
24. At friend's homes the child eats foods they shouldn't eat	1	2	3	4	5	*Yes / No*
25. The child asks for food between meals	1	2	3	4	5	*Yes / No*
26. I get upset when I think about our meals	1	2	3	4	5	*Yes / No*
27. The child eats chunky foods	1	2	3	4	5	*Yes / No*
28. The child lets food sit in their mouth	1	2	3	4	5	*Yes / No*
29. At dinner I let the child choose the foods they want from what is served	1	2	3	4	5	*Yes / No*

If you are a single parent, skip to Question 34

HOW OFTEN DOES THIS HAPPEN ?	**Never** **1**	**Seldom** **2**	**Sometimes** **3**	**Often** **4**	**Always** **5**	*Is this a problem for you ?*
30. The child's mealtime behaviour upsets my spouse	1	2	3	4	5	*Yes / No*
31. I agree with my spouse about how much the child should eat	1	2	3	4	5	*Yes / No*
32. The child interrupts conversations at meals	1	2	3	4	5	*Yes / No*
33. I get upset with my spouse at meals	1	2	3	4	5	*Yes / No*
34. The child eats when upset	1	2	3	4	5	*Yes / No*
35. The child says when they are hungry	1	2	3	4	5	*Yes / No*
36. The child says they'll get fat if they eat too much	1	2	3	4	5	*Yes / No*
37. The child helps to clear the table	1	2	3	4	5	*Yes / No*
38. The child hides food	1	2	3	4	5	*Yes / No*
39. The child brings books or toys to the table	1	2	3	4	5	*Yes / No*

If you have one child, skip Question 40

40. The child's behaviour at meals upsets other children	1	2	3	4	5	*Yes / No*

THANK YOU

Archer, Rosenbaum & Streiner (1991)

Appendix 3

Repetitive Behaviour Scale

Stereotyped Behavior

(DEFINITION: apparently purposeless movements or actions that are repeated over and over again in bouts or periods of activity)

Instructions: Read each item carefully. Place a "checkmark" next to each behavior that this person has displayed within the past month. Be sure to check all that apply.

____	WHOLE BODY	(Body rocking, Body swaying)
____	HEAD	(Rolls Head, Nods Head, Turns Head)
____	EYE / VISUAL	(Covers eyes, Looks closely or gazes at hands or objects)
____	EAR / HEARING	(Covers ears)
____	MOUTH	(Grinds teeth, mouths or chews objects, Puts hand(s) in mouth)
____	LOCOMOTOR	(Turns in circle(s), Whirls, Jumps, Bounces)
____	VOCALIZATIONS	(Repetitive verbalization or vocalization, Echolalia)
____	HAND / FINGER	(Flaps hands, Wiggles or flicks fingers, Claps hands, Waves or shakes hand or arm)
____	OBJECT USAGE	(Spins or twirls, Twiddles or slaps or throws objects, Lets objects fall out of hands)
____	OTHER	(Maintains a set body posture, Walks on tip-toes, Breathes forcefully, Smells or Sniffs unusually, Rubs surfaces, Taps, touches, or rubs body part(s), Twirls hair) Other (*describe*):_____

this person is *not currently* engaging in any of the above stereotyped behaviors, skip to the next page.
Otherwise, please continue answering the questions below.

Instructions: Circle the number next to the answer that you feel best describes this person. Base your answer for each question on your interactions with, and direct observations of, him or her over the past month.

(1) How often does this person engage in stereotyped behavior?

0 = Less than once every 3 hours.
1 = Once every 1 to 3 hours.
2 = Once every 30 minutes to 1 hour.
3 = Once every 15 to 30 minutes.
4 = More than once every 15 minutes.

(2) When the stereotyped behavior is blocked, can it be stopped?

0 = Yes, with no distress.
1 = Yes, with mild distress.
2 = Yes, with moderate distress.
3 = Yes, with severe distress.
4 = No.

(3) Will he or she stop a stereotyped behavior when a preferred activity is available?

0 = Always.
1 = Usually.
2 = Sometimes.
3 = Rarely.
4 = Never.

(4) How often is it necessary for someone to do something to manage his / her stereotyped behavior?

0 = Never.
1 = Sometimes.
2 = Often.
3 = Physical intervention is necessary.
4 = Strenuous physical intervention & struggling is needed.

(5) Does stereotyped behavior cause problems at his or her school, work, or other activities?

0 = No. School / work is never missed due to repetitive behaviors.
1 = Yes. He/she is often late for school / work because of repetitive behaviors.
2 = Yes. He/she is often late completing school / work tasks.
3 = Yes. He/she is unable to complete school / work tasks, or leaves activities prematurely.
4 = Yes. He/she is unable to attend school / work.

(6) Does stereotyped behavior cause problems with self-care / personal hygiene tasks or training?

0 = No.
1 = Yes. Hygiene is occasionally poor.
2 = Yes. There are frequent delays in self-care tasks.
3 = Yes. There is decreased participation in self-care tasks.
4 = Yes. He / she does not participate in self-care tasks.

(7) Does stereotyped behavior affect leisure time or time spent with others?

0 = No.
1 = Yes. He / she has sometimes given up opportunities for socializing or leisure.
2 = Yes. He / she has often refused to interact with others or engage in leisure activities.
3 = Yes. He / she needs to be constantly urged to take part in any social or leisure activity.
4 = Yes. He / she is unable to take part in any social or leisure activity.

Self-Injurious Behavior

(DEFINITION: repetitive behavior that has the potential to cause redness, bruising, or other injury to the body)

Instructions: Read each item carefully. Place a "checkmark" next to each behavior that this person has displayed within the past month. Be sure to check all that apply.

____ HITS SELF WITH BODY PART (e.g. slaps head or face)
____ HITS SELF *AGAINST* SURFACE OR OBJECT (e.g. bangs head on floor or table)
____ HITS SELF *WITH* OBJECT (e.g. bangs head or face with toys)
____ BITES SELF (e.g. bites hand or wrist or arm)
____ PULLS (e.g. pulls hair or skin.)
____ RUBS OR SCRATCHES SELF (e.g. rubs or scratches marks on arm or leg)
____ INSERTS FINGER OR OBJECT (e.g. eye-poking)
____ OTHER form of self-injury (*describe)*: _____

If this person is *not currently* engaging in any of the above self injury behaviors, skip to the next page.
Otherwise, please continue answering the questions below.

Instructions: Circle the number next to the answer that you feel best describes this person. Base your answer for each question on your interactions with, and direct observations of, him or her over the past month.

(1) How often does this person engage in self injury behavior?

0 = Less than once every 3 hours.
1 = Once every 1 to 3 hours.
2 = Once every 30 minutes to 1 hour.
3 = Once every 15 to 30 minutes.
4 = More than once every 15 minutes.

(2) When the self injury behavior is blocked, can it be stopped?

0 = Yes, with no distress.
1 = Yes, with mild distress.
2 = Yes. with moderate distress.
3 = Yes. with severe distress.
4 = No.

(3) Will he or she stop a self injury behavior when a preferred activity is available?

0 = Always.
1 = Usually.
2 = Sometimes.
3 = Rarely.
4 = Never.

(4) How often is it necessary for someone to do something to manage his / her self-injury?

0 = Never.
1 = Sometimes.
2 = Often.
3 = Physical intervention is necessary.
4 = Strenuous physical intervention & struggling is needed.

(5) Does self injury behavior cause problems at his or her school, work, or other activities?

0 = No. School / work is never missed due to self injury behaviors.
1 = Yes. He/she is often late for school / work because of repetitive behaviors.
2 = Yes. He/she is often late completing school / work tasks
3 = Yes. He/she is unable to complete school / work tasks, o leaves activities prematurely.
4 = Yes. He/she is unable to attend school / work.

(6) Does self injury behavior cause problems with self-care / personal hygiene tasks or training?

0 = No.
1 = Yes. Hygiene is occasionally poor.
2 = Yes. There are frequent delays in self-care tasks.
3 = Yes. There is decreased participation in self-care tasks.
4 = Yes. He / she does not participate in self-care tasks.

(7) Does self injury behavior affect leisure time or time spent with others?

0 = No.
1 = Yes. He / she has sometimes given up opportunities for socializing or leisure.
2 = Yes. He / she has often refused to interact with others or engage in leisure activities.
3 = Yes. He / she needs to be constantly urged to take part in any social or leisure activity.
4 = Yes. He / she is unable to take part in any social or leisure activity.

Compulsive Behavior

(DEFINITION: repetitive behavior that takes the form of a ritual / routine, or involves insistence on things being done "just so" or remaining "just so".)

Instructions: Read each item carefully. Place a "checkmark" next to each behavior type that this person has displayed within the past month. Be sure to check all that apply.

____ ORDERING
(Arranges certain objects in a particular pattern or place; Insists on a certain routine of events or activities; Insists on dressing, grooming, or cleaning in a certain order)

____ COMPLETENESS
(Must have doors opened or closed; Takes all items out of a container or area; Insists on doing a particular chore; Puts on / takes off garments; Insists on wearing certain clothes; Repeats rising up/down from chair; Repeats going in /out of door)

____ CLEANING / HOARDING
(Excessively cleans certain body part; Picks at lint or loose threads; Has certain bathroo... routine; Hides, collects or hoards objects)

____ CHECKING / TOUCHING
(Repeatedly opens and closes or checks doors or drawers; Touches / taps items)

____ COUNTING
(Counts items or objects, Counts to a certain number or in a certain way)

this person is *not currently* engaging in any of the above compulsive behaviors, skip to the next page.
Otherwise, please continue answering the questions below.

Instructions: Circle the number next to the answer that you feel best describes this person. Base your answer for each question on your interactions with, and direct observations of, him or her over the past month.

(1) How often does this person engage in compulsive behavior?

0 = Less than once every 3 hours..
1 = Once every 1 to 3 hours.
2 = Once every 30 minutes to 1 hour.
3 = Once every 15 to 30 minutes.
4 = more than once every 15 minutes.

(2) When the compulsive behavior is blocked, can it be stopped?

0 = Yes, with no distress.
1 = Yes, with mild distress.
2 = Yes, with moderate distress.
3 = Yes, with severe distress.
4 = No

(3) Will he or she stop a compulsive behavior when a preferred activity is available?

0 = Always.
1 = Usually.
2 = Sometimes.
3 = Rarely.
4 = Never

(4) How often is it necessary for someone to do something to manage his / her compulsive behavior?

0 = Never.
1 = Sometimes.
2 = Often.
3 = Physical intervention is necessary.
4 = Strenuous physical intervention with struggling is needed.

(5) Does compulsive behavior cause problems at his or her school, work, or other activities?

0 = No. School / work is never missed due to repetitive behaviors.
1 = Yes. He/she is often late for school / work because of repetitive behaviors.
2 = Yes. He/she is often late completing school / work tasks.
3 = Yes. He/she is unable to complete school / work tasks, or leaves activities prematurely.
4 = Yes. He/she is unable to attend school / work.

(6) Does compulsive behavior cause problems with self-care / personal hygiene tasks or training?

0 = No.
1 = Yes. Hygiene is occasionally poor.
2 = Yes. There are frequent delays in self-care tasks.
3 = Yes. There is decreased participation in self-care tasks.
4 = Yes. He / she does not participate in self-care tasks.

(7) Does compulsive behavior affect leisure time or time spent with others?

0 = No.
1 = Yes. He / she has sometimes given up opportunities for socializing or leisure.
2 = Yes. He / she has often refused to interact with others or engage in leisure activities.
3 = Yes. He / she needs to be constantly urged to take part in any social or leisure activity.
4 = Yes. He / she is unable to take part in any social or leisure activity.

Other Repetitive Behaviors

(DEFINITION: other apparently purposeless behaviors, actions, or movements that are repeated in a similar manner over and over again in bouts or periods of activity)

Instructions: Read each item carefully. Place a "checkmark" next to each behavior that this person has displayed within the past month. Be sure to check all that apply.

____ EXCESSIVE DRINKING / POLYDIPSIA
(frequently consumes fluids, strives to consume fluids)

____ EATING INEDIBLE MATERIALS / PICA
(frequently eats inedible materials – e.g. paper, string, dirt, etc)

____ BIZARRE / DEVIANT GROOMING
(unusual dress or grooming; wears inappropriate or excessive clothing, inappropriately cuts body hair, checks hair, teeth, face, etc in mirror excessively)

____ HAIR-PULLING
(holds, strokes, twirls, pulls own hair)

____ NAIL-BITING
(frequently keeps finger or fingers in mouth & bites parts of nail off)

____ OVEREATING / BINGING / HYPERPHAGIA
(frequently eats excessive amounts of food, covertly eats food, steals food to eat later, stuffs food into mouth)

____ VOMITING / RUMINATION
(frequently vomits for no apparent reason; vomits / purges food eaten recently; frequently regurgitates, re-chews & re-swallows food)

____ PACING / EXCESSIVE WALKING
(frequently walks or runs for no purpose back & forth across room or into / out of rooms)

____ POSTURING / MAINTAINING A SET POSTURE
(holds odd & purposeless facial or body positions for extended periods)

____ REPETITIVE / OBSESSIVE SPEECH PATTERNS
(frequently repeats a sentence verbatim & in same tone; engages in a fixed dialogue; repeats a question to evoke a fixed reply; excessive talking about certain people, objects or events)

____ PECULIAR LIP OR TONGUE MOVEMENTS
(repetitive odd, unusual, purposeless movements of lip or tongue)

____ RESTLESS, NERVOUS MANNERISMS
(frequently unable to sit still; repetitive, purposeless movements of hands, arms, feet, or legs while trying to sit still or while trying to stand still)

SCORING SECTION:

Subscale	Topography Score (# endorsed, excluding any endorsed as "other")	Severity Score (sum of items 1-7)
Stereotyped Behavior		
Self-Injurious Behavior		
Compulsive Behavior		
Other Repetitive Behavior		XXXXXXXXXXXXXXXXXX

OVERALL SCORE:	Total # of Topographies =	Total Severity Score =

Appendix 4

Ethical Approval

University of Southampton

Department of Psychology

University of Southampton
Highfield
Southampton
SO17 1BJ
United Kingdom

Telephone +44 (0)23 8059 5000
Fax +44 (0)23 8059 4597
Email

14 February 2002

Tom Tutton
Department of Clinical Psychology
University of Southampton
Highfield, Southampton

Dear Tom,

Re: **An investigation of the incidence and type of eating and feeding behaviour problems in autistic children compared with children with intellectual disabilities**

The above titled application, which was recently submitted to the departmental ethical committee, has now been given approval.

Should you require any further information, please do not hesitate in contacting me on 023 8059 3995.

Yours sincerely,

Kathryn Smith
Ethical Secretary

cc. Janet Turner

Appendix 5

Information Sheet and Consent forms

University of Southampton

Department of Psychology

Doctoral Programme in Clinical Psychology

University of Southampton
Highfield
Southampton
SO17 1BJ
United Kingdom

Telephone +44 (0)23 8059 5321
Fax +44 (0)23 8059 2588
Email

Information regarding a clinical research study comparing the feeding habits of children with learning disabilities to children with autism

Dear Parent / Guardian,

I am a trainee Clinical Psychologist studying at the University of Southampton. As part of my doctoral degree I am completing a piece of research that compares the eating habits of non-autistic children with a learning disability to those of children with autism.

About the study

Studies suggest that there is a high rate of eating and feeding behaviour problems among children with learning disabilities and children with autistic spectrum disorders and that *this issue causes more parental stress than any other childhood issue*. My study should help advance our understanding and facilitate more effective treatments for children with feeding behaviour problems, reducing parent stress.

Your role

The study would involve the completion of two questionnaires specifically about eating and feeding, a number of questionnaires about wider behaviours such as adaptive skills, communication and repetitive behaviours and some basic details about your child. The study can be completed in two ways:

1. Via one (or two) telephone interviews lasting, in total, approximately 60 minutes, *or*
2. A visit to your home that would take no more than 75 minutes.

The interviews can be completed at any time on any day. Permission for involvement in this study can be withdrawn at any time and would not require any justification. Your participation in this study would be anonymous and a copy of the findings would be available for your information. This project will be supervised by Dr Tony Brown at the University of Southampton.

Consent

I would be most grateful for your participation. *Please indicate whether you are willing to participate in this study by signing and returning the enclosed consent form.* I will then contact you. If you require any further information or have any questions or queries, please do not hesitate to contact me,

Thank you,

Tom Tutton
Trainee Clinical Psychologist
University of Southampton

Dr Tony Brown
Clinical Psychologist
University of Southampton

Department of Clinical Psychology, University of Southampton, SO17 1PN Tel: 023 8059 5321
Email: tt1@psy.soton.ac.uk Home Tel : 023 8058 5654

University of Southampton

Department of Psychology

Doctoral Programme in Clinical Psychology

University of Southampton
Highfield
Southampton
SO17 1BJ
United Kingdom

Telephone +44 (0)23 8059 5321
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Email

CONSENT FORM

Clinical research study comparing the feeding habits of children with learning disabilities to children with autism

Your full name: .....

Please complete the following:

Have you read the information sheet ?	Yes / No
Have you been offered the opportunity to contact the researcher and discuss this study ?	Yes / No
Have you received enough information about the study ?	Yes / No

Do you understand that you are free to withdraw from the study :

- At any time
- Without having to give a reason for withdrawing — Yes / No

Do you agree to take part in this study ? — Yes / No

I, ... hereby consent to take part in a clinical research investigation about which I have received written information.

Signed : _____ Date : ___ / ___ / _____

Appendix 6

Interview Script

☎Telephone interview

[Write name of parent and child in appropriate spaces / complete s/he, Mr/s]

Hello, is that Mr/s _____? Hi, this is Tom Tutton, is it still convenient for you to talk to me now about my research project ? …

There are three main areas that I would like to ask you about.

1. Firstly, I have some basic demographic details to collect and some questions about any other factors that might effect _____'s feeding, such as allergies or special diets.

2. Then, for a maximum of ½ hour, I have a questionnaire to complete called the '*Vineland Adaptive Behaviour Scales*'. This is a measure of what is called 'adaptive behaviour'. This means, what somebody does to take care of *themself* and to get along with others, as opposed to what others do for them. This includes how independent someone is and how they get along socially.

3. Then, to finish, there is a short measure called the '*Repetitive Behaviour Scale*', looking at a range of behaviours, such as ordering things, repeated movements or any self-injury.

I'll talk you through each questionnaire as best as I can, but please feel free to ask any questions at any time, as any feedback is always useful. Does this make sense ?

OK, as I mentioned I have some basic questions to start off…

[Go to Personal Details Form + see 2.1 prompts for PDF]

OK, that completes the 1st section, now the Vineland scales. As I mentioned, this is a measure of what somebody does to take care of *themself* and to get along with others. It is important for you to know that there are no right or wrong answers, and that

children perform different activities at different ages. The focus of these questions is *not* what _____ *can* do, but what s/he actually *does*. I'll ask you whether _____ does something usually or most of the time … sometimes or only part of the time … or not at all. Is this OK? I'll ask about four areas today, _____'s

· communication,
· his/her daily living skills, [practical skills in taking care of yourself]
· his/her play and leisure and
· any behaviours that cause problems of worry.

Are you ready to start? What age level do you think _____ functions at developmentally?

[Check function age vs age of child - Go to appropriate Vineland start point]

OK, that completes the Vineland scales. Is everything OK so far? There is only the short Repetitive Behaviour Scale to complete now and then we're done. There are 4 types of repetitive behaviour I'll ask about, and I'll define each one carefully and ask whether _____ displays any of a list of these behaviours. This is followed by a few questions about the frequency and effects of these behaviours. Is this OK?

[Go to Repetitive Behaviour Scale – compulsive sheet]

OK, congratulations, we have completed the interview. Thank you very much for your time. If it is OK, I will send the other questionnaires to you in the post, with instructions about how to fill them out & a Freepost envelope. If you have any questions about filling them out you can always leave a message at the University for me and I will get back to you.

Thanks again for you time

Appendix 7

Questionnaire Instruction Sheet

Thank you very much for agreeing to fill out these questionnaires. Before you start please read this sheet on how to fill out the questionnaires, it should save you time!

There are **3** questionnaires to fill out (*see examples below*). Please read the highlighted instructions closely as each questionnaire is completed slightly differently. You don't have to fill out any personal information (as I have this information and the questionnaires are coded to protect confidentiality). Please return the completed questionnaires in the FREEPOST envelope provided.

---

1. **CONFIDENTIAL**

QUESTIONNAIRE ON BEHAVIOUR AND SOCIAL COMMUNICATION
FOR PEOPLE AGED SIX and OVER (B)

Thank you for taking a few minutes to complete this questionnaire. A few questions ask about several related types of behaviour: please tick yes if any one of these was present. Although you may be uncertain about whether some behaviours were present or not, please do answer 'yes' or 'no' to every question on the basis of what you think.

	YES	NO
1. Is he now able to talk using short phrases or sentences?	☐	☐

If NO, proceed to question 9.

2. Does he ever talk with you just to be friendly (rather than to get something)?	☐	☐

---

2. **The Children's Eating Behaviour Inventory**

HOW OFTEN DOES THIS HAPPEN?	Never 1	Seldom 2	Sometimes 3	Often 4	Always 5	*Is this a problem for you ?*
1. The child chews food expected for their age	1	2	3	4	5	*Yes / No*

3.

SCREENING TOOL OF FEEDING PROBLEMS (STEP)

Client's name and residence: _____

F= How often has this behaviour occurred during the last month

0 Not at all
1 Between 1 and 10 times
2 More than 10 times

SV= How serious has this behaviour been during the last month

0 Caused no harm / problems
1 Caused minimal harm or problems
2 Caused serious injury or problems

		F	SV
1	He/she cannot feed himself / herself independently	_____	_____
2	Problem behaviours (e.g. aggression, self-injury, property destruction) increase during meal times	_____	_____

If the are any problems, please leave a message at the University, or my Home
Tel Uni: 023 8059 5321 Tel Home: 023 8058 5654