



# **Dietary Management of Autism Spectrum Disorder**

Produced by Dietitians in Autism (DA)  
Supported by the British Dietetic Association  
Specialist Paediatric and Mental Health Groups

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Part 1 – November 2010 – Review Date: November 2015  
Part 2 - July 2005 – Review Date: July 2010  
Part 3 – 7: Under development

Each section will be independently reviewed every 5 years  
January 2011



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## 1. Executive Summary

This document has been developed for anyone in the multi-disciplinary team who is involved with the dietary management of Autism Spectrum Disorder (ASD) also referred to as Pervasive Development Disorder (PDD). Many children with ASD have selective eating and therefore self-limiting diets as a direct result of their disorder (Cornish 1998, Cornish 2002). We have therefore included a section on the management of restrictive/ obsessive diets prior to any interventions, as this is a very significant feature of the condition. A number of dietary interventions have been cited for the treatment of ASD and for each of these an explanation is given followed by management and suggested good practice. Details of the evidence examined are tabulated and full appraisal sheets included in appendices.

## 2. Introduction

There is currently a lot of public interest in diet & ASD and access to information is widely available through the internet, consequently there is wide variation in clinical practice with regard to the dietary management of children and adults with ASD.

The term Autism Spectrum Disorder (ASD) refers to a wide continuum of associated cognitive and neuro-behavioural disorders including, but not limited to, three core defining features (American Psychiatric Association 1994):

- Impairment in socialisation.
- Impairment in verbal and non-verbal communication.
- Restricted and repetitive patterns of behaviour.

The prevalence of Autism is 16.8 per 10,000 children (Chakrabarti, & Fombonne, 2001). The prevalence of Autism Spectrum Disorders is of the order of 60 per 10,000 children under 8 years. (MRC Review 2001). Boys are affected more often than girls, 4:1.

## 3. Aims

The purpose of this document is to clarify some of the dietary issues and approaches available for the treatment of ASD.

## 4. Objectives

- To document the various dietary approaches and review the current evidence available for each approach.
- To give recommendations for management and suggested good practice and outcomes of dietetic practice.
- To list the sources of information.

## 5. Method Search

A comprehensive literature search was conducted. The search strategy and dates will be included in each section. The following databases were used.

- Cochrane Library
- National Electronic Library for Health
- MEDLINE
- EMBASE
- CINAHL
- Other databases relevant to each section.

Key words were used as specified for each dietary intervention.

Papers found were cross-searched for other references.

## **Inclusion**

Only clinical papers published in scientific journals were included. Details of these papers together with any excluded papers can be found in each section.

## **Quality Assessment**

A development group was set up comprising of members of the Dietitians in Autism (DA) a sub-group of the Paediatric Group of the British Dietetic Association (BDA). Group members are listed in Appendix 1. Each clinical paper was quality assessed by at least 2 members of the group; the results were discussed and summarised by the authors, one of whom has received training in evidence based practice. The views of interested parties were sought by circulating the draft consensus statement to the Clinical Effectiveness and Quality Committee of the BDA and nationally to interested dietitians, the Paediatric Group and the Mental Health Group of the BDA and Consultants working in the field. Modifications were made where necessary.

Relevant papers cited were critically appraised. Reference was made to the Research Appraisal Checklist (Duffy, 1999).

## **Classification of Evidence**

Each paper was summarised and classified for evidence levels based on the SIGN Classification Levels (SIGN 50: 2001) (Brady, 2000). These were adapted by ourselves to include suitable outcomes for autism.

Following group discussion two factors, the quality of the evidence itself and the importance of the outcomes were used to grade the evidence. See Appendices after each section.

Critical appraisal summary sheets are found after each section.

## **Update**

The DA will be responsible for updating these guidelines. The document has been divided into 8 sections, one for each dietary intervention. Each section will be reviewed independently every 5 years.

## Contents

Part 1	Restrictive/Obsessive diets
Part 2	Gluten/Casein free diets (GF/CF)
Part 3	Use of pre and probiotics
Part 4	Dimethyl Glycine (DMG)
Part 5	Vitamin B6 and Magnesium
Part 6	Vitamin C
Part 7	Essential Fatty Acids/ Evening Primrose Oil
Part 8	'Hunter gatherer diet'

## 6. PART 1

### 6.1 Restrictive/Obsessive diets

**Principle Author: Beverley Spicer BSc Dietetics SRD**

**Original Date: September 2002**

**Re-written November 2010**

### 6.2 Summary

Children with ASD may often present with complex feeding issues that go beyond normal fussy eating behaviours. They also do not usually respond to commonly used behavioural feeding modification methods. This document highlights a variety of strategies and tools for dealing with the most severe feeding problems sometimes found in children with ASD. The complexities are such that multidisciplinary working is essential.

***How should we manage the selective eating in ASD and ensure nutritional adequacy and is there evidence to support this?***

***Original Search January 1980 – June 2000. November 2005 and Updated November 2007***

### Search Strategy

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DATASTAR PSYC: PSYCINFO 1806- 01.11.2007
QUERY 1130
COPYRIGHT BY Am Psychological Assoc, Washington DC, USA
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PSYC 1 ASD
RESULT 38633
PSYC 2 PERVASIVE-DEVELOPMENTAL-DISORDERS#.DE. OR ASD.W..DE.
RESULT 15254
PSYC 3 FOOD ADJ REFUSAL
RESULT 386
PSYC 4 EATING-BEHAVIOR#.DE.
RESULT 7539
PSYC 5 PICA
RESULT 1346
PSYC 6 PICA.W..DE.
RESULT 181
PSYC 7 2 AND (4 OR 6) AND LG=EN AND CHILDHOOD#
RESULT 27
```

## Search Strategy

DATASTAR NAHL: CINAHL (R) 1982 - 31.10.2007  
QUERY 1129  
COPYRIGHT BY CINAHL Information Systems, Glendale CA, USA

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NAHL 1 ASD  
RESULT 3133  
NAHL 2 CHILD-DEVELOPMENT-DISORDERS-PERVASIVE#.DE. OR ASD-DISOR  
DER.DE.  
RESULT 2651  
NAHL 3 FOOD ADJ REFUSAL  
RESULT 66  
NAHL 4 EATING-BEHAVIOR#.DE.  
RESULT 5329  
NAHL 5 2 AND 4 AND LG=EN  
RESULT 14

Plus hand search of references from papers included and journals.

Next review date November 2012

## Inclusion

Details of references included and excluded ( with reasons for exclusion) can be found in tables 1 - 4.

## Comment on Research:

The quality of the research varied but was often disappointing. Many papers describe case studies of 1-3 children. In addition the research often took place in American institutions, where there was a high level of control of child, environment, staff and programme features. Long term follow up did not occur.

Children with ASD in the UK generally live at home and some attend special schools. The conditions are quite different and the possibilities for control and consistency are less.

## 6.3 Introduction

Severely limited eating in children with ASD is complex and often requires a multi-disciplinary and a co-ordinated approach. The professionals that are involved and their respective roles will vary from place to place. The professionals which may be involved include a Dietitian, Community Learning Disability Nurse, Speech and Language Therapist and Occupational Therapist. The group may also include a Psychologist, Paediatric Psychiatrist, Paediatrician and Social Worker. These professionals should have specialist skills and experience.

Generally, children eating regularly less than 20 different foods and those under the age of 5 years appear to be the most vulnerable and will benefit from individual dietary assessment and advice.

Many children with ASD have selective eating and therefore self-limiting diets as a direct result of their disorder.

Children with ASD frequently have very selective eating habits that go beyond the usual 'picky eating' behaviour, seen in most children at specific developmental stages, e.g. their diet may be limited to as few as 2 or 3 foods.

Common Feeding Concerns include:

- difficulty with transition to textures (especially during infancy).
- increased sensory sensitivity (including oral).
- difficulty accepting new foods.
- restricted intake due to colour, texture, packaging and food temperature.
- decreased selection of food over time.
- difficulty with changes in mealtime environment e.g. school/home.
- difficulty with mealtime presentation e.g. specific plate and cutlery, positioning of food on a plate.
- “continually eating” rather than having mealtimes.

Many of these difficulties can be explained as a direct result of the child’s condition:

- an obsessive desire for order.
- an obsession with familiarity e.g.: the packaging of a particular make and flavour.
- increased oral/sensory sensitivity e.g.: rejection of certain textures, spoons etc.
- changes which heighten anxiety e.g.: changes at home and/or school.
- changed visual perception e.g.: confused by choice, distracted by a crumb or shadow on the table.

## 6.4 Assessment of eating behaviours in ASD

11 references provided evidence in this category.

Archer 1990 noted that parental anxiety contributes to poor eating experience. This partly explains why children sometimes eat better in different situations.

Field 2003 found that children with ASD were significantly more likely to have problems with food selectivity by food type, than either children with Cerebral Palsy or Down’s syndrome. Williams 2005 also noted that older children were just as selective as the younger children. This may be because he also observed that parents offer food until it is eaten or stick to what they know the child likes.

Field 2003 also found that food selectivity by type was much more prevalent in the group of children with ASD (62%).

ASD children do have more restricted diets than their peers. Schreck, 2004 found that 72% of Children with ASD were reported to eat a narrow variety of foods. The group also ate significantly fewer foods within each food group. The children with ASD had a tendency to refuse more foods; require more specific utensils and /or presentation. They were more likely to only accept foods of low texture (smooth/soft) and ate a narrow variety of presented foods. None of these features were necessarily linked to the eating and meal habits of the family.

Lukens 2005 found that children with ASD presented with more mealtime behaviour problems than typically developing children. The children with ASD consumed fewer servings of vegetables and had smaller percentages of their recommended nutrient intakes.

Williams 2005 conducted a review of 178 children referred to a feeding programme for the evaluation and treatment of food selectivity. The sample was divided into three groups

1. children with ASD.
2. children with special needs without ASD
3. children without special needs.

Williams found no significant differences between the three groups for any of the types of food consumed or for liquid intake. The children with ASD were more likely to insist on the food being made in a certain way.

Schreck 2006 found no correlation between the degree of ASD and the extent of the limited eating in children with ASD.

However, in 2006 Schreck found that limited eating in the family of a child with ASD correlated with limited eating of the child (the family consistently preferred a wider variety of food items than the child).

### **6.5 Validated Eating and Mealtime behaviour tools.**

Two papers Archer 1991 and Lukens 2005 aimed to validate methods to assess eating and mealtime behaviour. This is useful and necessary for research. However, some Dietitians have found when using these tools in day to day practice that they added little or nothing to normal diet history taking. The tools do not give an overall score for degree of restrictive eating, rather they serve to highlight features of the restriction and associated feeding and mealtime behaviour. The tools do not give any help for detecting possible nutrient deficiencies within a child's diet.

They may be of use for some Dietitians working without the benefit of a multi-disciplinary group as they ask some questions not usually asked in the taking of a diet history.

Archer 1991 developed the Children's Eating and Behaviour Inventory (CEBI) a validated scoring method. This work included children with ASD, but also a host of other conditions. This results in a generic questionnaire and means that when dealing with ASD children questions that rarely have relevance to ASD are included.

Lukens 2005 developed and validated an inventory to assess eating and mealtime behaviour problems in children with ASD. Brief Autism Mealtime Behaviour Inventory-BAMBI was conducted partly to develop a measure of mealtime behaviour problems and also to gather information about the eating behaviour and nutritional intake of children with ASD compared to that of typically developing children. Results supported the reliability and validity of BAMBI.

### **6.6 Sensory Problems**

Smith 2003 looks at the food choices of tactile defensive children. Children with ASD were excluded from this survey. Smith demonstrated a link between tactile defensiveness and food refusal. Use of sensory assessment is recommended and sensory integration techniques are discussed as a possible treatment for food refusal.

### **Sensory Modulation Disorder (SMD)**

There does appear to be a proportion of children with ASD who have SMD.



SMD describes features such as over-responsiveness to a variety of sensory stimuli such as flavour, texture and smell.

## 6.7 Features of Restricted Eating in children with ASD

### Food Choice

Williams 2005 found that starchy food was consumed twice as much as the other food groups across all three groups of children in his study ( See 1.3).

Kerwin 2005 surveyed the parents of 89 children with Pervasive Developmental Disorder (PDD). Parents were asked about their child's eating, GI symptoms and behavioural problems. Over 60% were reported to have strong food preferences. The most frequently reported unusual eating pattern was food selectivity.

Levy 2007 in partnership with a Dietitian analysed three day dietary records reported by a parent or teacher. He found that there was a wide range in protein intake (67% - 436% of the RDA). The source of calories averages at 11% for protein, 59% for carbohydrate and 30% for fat.

Two subjects with high carbohydrate intake (contributing over 80% of their total calorie intake), had lower total calorie intakes and a history of food selectivity.

### Food Jags

A food jag is defined as the insistence on eating the same foods in the same manner over long periods of time. Food jags limit opportunities for the resistant eater to experience new foods and eat a balanced diet. Guidelines for addressing food jags can be found in the book, "Just Take a Bite" by Ernspurger 2004 .

### Pica (Eating non-food items)

Williams 2000 found that children with a 'generally upset' temperament were more likely to have a poor diet. Non demanding children were more likely to have Pica.

Kerwin 2005 found that of the 89 children with PDD over 29% exhibited pica.

### Texture

It has been observed in practice that children often have preferences for a particular texture; this may be crunchy or soft. There is often a reluctance to mix textures, for example a child may not eat cereal with milk, but will eat cereal and milk if they are presented separately.

Older children (11 years +) with ASD may still only eat a single texture meal and will spit out any lumps that may appear in the meal. However the same child may then happily eat a packet of crisps.

Interestingly, although texture is an issue that is commonly encountered in practice, very few of the references relate to this subject.

Schreck 2004 found that children with ASD were more likely to only accept foods of a low texture (smooth or soft). However, Schreck 2006 found that restriction was not related to food texture.

Williams 2000 found that 69% of parents felt that texture influenced food selection.

Ahearn 2001 found that half of their group of children with ASD exhibited low overall levels of food acceptance. Results also indicated food selectivity by food category or food texture.

Field 2003 found that 31% of the research group demonstrated preferences for certain food textures.

### **Specificity about choices of dishes, utensils**

Schreck 2004 found that children with ASD were more likely to be specific about utensils and food presentation.

Williams 2005 (see 1.3) found that children with ASD were much more fussy and demanding of specific food presentation and they insisted on using the same utensils and dishes significantly more than the other groups.

## **6.8 Physical problems**

8 papers provided information and evidence in this category.

### **Gastro-pathophysiology**

Williams 2000 established an association between gastrointestinal problems (GI) and appetite. 23% of the children with GI problems had a poor appetite for food when compared to only 2% of those without GI problems

Levy 2007 also found a high rate of GI symptoms (32 of the 59 subjects reported symptoms) despite a lack of medical causes.

### **Gastro-oesophageal Reflux (GOR)**

Hagopian 1996 describes a child with hiatus hernia, oesophagitis, frequent vomiting (up to 56 times per day) and chronic constipation. There was a clear link between an exacerbation of the child's problems and complete food and drink refusal.

In a survey of parents of children with ASD by Williams 2000, 28% of parents reported that their child had GOR. Williams 2005 found that 14 % of children in the ASD group had reflux. The average across all groups was 22 %. Williams speculated that some children developed a conditioned aversion to eating many foods because they were associated with pain and discomfort from the GOR.

White 2003 reviewed research which considered intestinal pathophysiology in children with ASD. Children are likely to have intestinal symptoms and features which may affect their appetite and do require independent investigation.

Field, 2003 reviewed the records of 349 children (Only 26 of these were diagnosed with ASD). Each child was identified as having one or more functionally defined feeding problems. Food refusal / food selectivity by type / food selectivity by texture / oral motor delays / dysphagia. Predisposing factors included developmental disabilities, gastrointestinal problems, cardiopulmonary problems, neurological problems, renal problems and anatomical anomalies. GOR was the most prevalent condition (50% of the

whole group had GOR), and was the factor most often associated with food refusal. Of the 3 children with ASD who had food refusal, all had GOR.

Kerwin, 2005 surveyed parents of 89 children with PDD about their child's eating, GI symptoms and behaviour problems. Over 60% of the group were reported to have strong food preferences. The results revealed potentially interesting relationships between self-injurious behaviour, pica, feeding problems and intestinal symptoms. About 17% of the study sample may have been experiencing symptoms of reflux. (The figure for typically developing children is about 10%. In children with severe feeding problems 41-56% have reflux.)

The diagnosis and treatment of GOR in children with ASD is crucial to any improvement in their eating. It has often been observed in practice that eating problems can almost entirely be resolved by successful treatment of the GOR.

The nature of ASD itself, especially when combined with a learning disability is such that detection and diagnosis of GOR is not easy and the condition may go unnoticed for prolonged periods of time. Anyone working with eating problems and ASD should consider GOR as an issue as any management without this may be to little effect.

### **Bowel Function**

Field 2003 found constipation to be common in children with ASD and suggested that this was as a result of their poor diet. Field also comments that in his experience resolving constipation in children with ASD can lead to improved feeding

Williams 2005 found that the most common medical issue to have an impact on eating development was constipation.

Levy 2007 hypothesised that an increased frequency of loose stools was related to abnormal intake of carbohydrate. The results did not support this hypothesis. In fact the cohort showed a trend of high carbohydrate intake with firmer stools.

### **Vitamin Deficiencies**

The reference nutrient intake (RNI) is an amount of a nutrient that is sufficient for 97% of people within a group. The Lower Reference Nutrient Intake (LRNI) is an amount of nutrient that is enough for only the few people in a group who have low needs.

Cornish 1998 interviewed parents of 17 children with ASD (aged 3 ½ to 10 years). A 3 day dietary recall and food frequency questionnaire was used. Nutrient intakes fell below the RNI for 9 children in one or more of the following: Vitamin C, Iron, Vitamin D, Riboflavin, Vitamin B6, Calcium and Zinc. 1 child fell below the LRNI for iron. Cornish comments that improving specific nutrient intake should be the first aim of intervention. In 2002 Cornish found that calcium, zinc, iron, fat-soluble vitamins and riboflavin were most frequently at risk.

Monks 2002 in a single case study describes a boy with ASD with a very limited diet who developed limping and periods of muscle pain and inability to walk. On investigation the child was found to have scurvy as a result of a diet deficient in Vitamin C. Muscle atrophy is a normal finding in scurvy.

Dietitians are able to identify and treat many vitamin and mineral deficiencies in the child with ASD using appropriate supplements. This should be a first line treatment followed by further strategies to improve the overall diet of the child.

## 6.9 Management

### General Guidelines

A comprehensive and multi-disciplinary assessment is essential to establish realistic objectives and portray these clearly to family members and any other relevant people. There seems to be a point in time when the child is 'ready to change'. This may also be true of the parent. Changes in the child's self perception and also parent's perception of the child may be influential eg. moving to secondary school may be seen as an opportunity to "grow up" and make positive changes.

Growth spurts such as those seen in adolescence are also influential. Children are often more hungry when growing fast and this may be significant. Also the teenage social scene and peer pressure may have a positive influence on restricted eating as a result of ASD.

### Suggested Good Practice

#### Family Issues to be considered

- Communication issues within the family that may be influencing the child's reluctance to eat
- Parental anxiety, for example the parents may be over cajoling. This is detrimental as it serves to bring attention to an undesired behaviour. Parents often cajole as a natural reaction to poor feeding.
- Family, school, respite and other settings must be considered. Everyone needs to be committed and involved to support the feeding programme. It is important that relevant individuals are involved in the preparation and planning, everyone needs to understand and use the same approach.

#### Health Issues

- Consider referral to a paediatric gastroenterologist if it is felt that there any underlying gastrointestinal problems.
- Assess and monitor dietary intake and growth and correct as appropriate. Knowledge of the composition of different foods, alternative substitutes and supplementation is the expertise the dietitian can bring to ensure the child has an adequate diet. Providing the child is growing adequately the parent should be reassured even if the child is not always meeting the RNI's for micronutrients. Adequate intake of micronutrients may not be easily achieved as supplementation may be refused and a relaxed, practical approach will need to be taken by the dietitian.
- Adherence to healthy eating guidelines is inappropriate for children with such limited diets (as is already recognised for children under 5 years).

#### Sensory Issues

- Children who have a diagnosis of ASD and difficulty with eating are highly likely to have sensory sensitivities. Tastes or textures may be noxious and offensive to the child. An occupational therapist can assess the child's sensory profile to give a clearer picture of the child's sensory needs and develop appropriate intervention.

- Some children may develop their own coping strategies for sensory defensiveness e.g. only eating one texture.
- Poor development in oral motor skills and extreme oral sensitivity are often present and the involvement of a speech and language therapist will be useful to assist in the feeding programme.

### **Communication Issues**

- A speech and language therapist will also assess the child's communication skills.
- The child's comprehension and ability to communicate must be understood to put the feeding programme into practice.
- Communication and social interaction issues will influence the child's ability to eat.

### **Helpful mealtime strategies**

- Establish as calm and comfortable an environment as possible.
- Children with ASD are likely to do best when there is a routine to mealtimes. This needs to be considered for home and school. Establish as calm and comfortable an eating environment as possible
- Some children do better sitting with others who are eating, whilst others will only eat when they are not being watched.
- Whilst children shouldn't be restrained, seating that encourages staying at the table can be helpful.
- Feeding implements should be considered. Think about the shape, colour and material of the spoon.
- Do not assume that the child will automatically refuse a food in a new environment e.g.: they may eat fish fingers at Granny's but not at home.
- Consider addition of condiments and sauces to improve intake. (Ahearn, 2003)

### **Treatment Methods**

The following descriptions of psychological techniques are taken from the references. Many of these papers are written by research psychologists and as such use complicated and precise psychological techniques.

We felt that the high level of control over the research which often took place in institutions in America would be impossible to replicate for the most part in homes and schools in the UK.

However, the following summary of what is often pioneering work in this area provides an invaluable insight and overview of techniques that can be used within programmes in the UK and ideas for approaches with specific children. It also provides a useful basis for further reading.

### **Administration of treatments by parents**

Archer 1990 used the CEBI as a tool to identify changes in parental anxiety around food refusal before and after the intervention. This was a single case study. The child did not have ASD. Brown 2002 describes a parent training programme for chronic food refusal. However the child in this single case study did not have ASD.

Najdowski 2003 involved the parents of an ASD child in this single case study paper. Assessment and treatment was in both home and restaurant setting. The parents in this case study were actively involved in promoting change in their child's behaviour.

## Programme planning

The information gained from the assessment together with the treatment options should be used to formulate the feeding programme.

- Clear instructions should be compiled, if possible with the child. Communicating these to the child is essential. Writing it down clearly for the child and others makes for clarity and consistency. Consideration of communication methods and language is important.
- When considering dietary changes an honest approach should be taken. Covert additions of foods are often detected and refused by the child with ASD and will generate further suspicions and anxiety at mealtimes.
- Any changes in the programme should be proposed and discussed at multidisciplinary meetings however quick decisions may be necessary. Consider using a key worker or core group.
- Setting small goals in stages will allow the child step by step to reach a larger goal, for example:
  - Work to broaden the variety of a child's diet expanding on already accepted food groups eg: different types of breads.
  - Before encouraging a child to eat vegetables, they may need to learn to accept a small amount on their plate first. The amount may be very small 1/8 or 1/4 teaspoon. This allows the child to remain secure with the food they are familiar with.
- Interim assessments and re-planning are often necessary where a chosen approach is not working or the programme has been compromised. (Occasionally this may be that the programme is apparently working well in one venue e.g. school but having negative consequences elsewhere e.g. home)
- Probe assessments can be useful to assess en-route whether programmes can be shortened speeded up, or completed. (Luiselli, 2005) See appendix 3.

**7. TABLES OF RESEARCH AND BOOKS USED FOR RESTRICTIVE/OBSESSIVE DIETS**

**TABLE I - Original Search January 1980 – June 2000**

<b>TITLE OF PAPER</b>	<b>AUTHORS</b>	<b>EVIDENCE LEVEL &amp; KEY FINDINGS</b>
Nutrition Concerns for Children with Pervasive Developmental Disorder/ASD. Center on Human Disability, Nutrition Focus, 1995. <b>10</b> (5) pp1-7.	Quinn, H.P. Levine, K.  Children's Hospital BOSTON, M A.	4N. Use to prompt discussion of practice.
A Balanced Approach towards Healthy Eating in ASD. Journal of Human Nutrition and Dietetics. 1998. <b>11</b> pp501-509.	Cornish, E.  Derby, U. K.	3A. Most of the children despite a restricted diet receive adequate nutrition
Perspectives on the Nutritional Ecology of ASD Children. Journal of ASD & Eating Developmental Disorders, 1986. <b>16</b> (2).	Raiten, D. J.  Massaro, T.	2+N. Overall adequacy of diet similar in ASD Group and control.

**TABLE 2 – Search November 2005**

<b>TITLE OF PAPER</b>	<b>AUTHORS</b>	<b>EVIDENCE LEVEL &amp; KEY FINDINGS</b>
An assessment of Food Acceptance in Children with ASD Or Pervasive Developmental Disorder – Not otherwise specified. Journal of ASD and developmental disorders, 2001 <b>31</b> (5) 505-511	Ahearn, W H; Todd, C. Nault,K: Green, G	<b>3 N</b> Method may help parents/practitioners to work out what children may eat and also considers importance of texture.
Using simultaneous presentation to increase vegetable consumption in a mildly selective child with ASD. Journal of Applied Behavior Analysis, 2003 <b>36</b> 361-365	Ahearn, W H (2003)	<b>3 B</b> Vegetable consumption increased with the use of condiments and was maintained after 1 year.
Assessment and Treatment of Food Aversion in a Four Year Old Boy: A Multidimensional Approach. Canadian Journal of Psychiatry, 1990 <b>35</b> (6) 501- 505	Archer, L A; Szatmari, P (1990)	<b>3 N</b> Paper was concerned with parental anxiety around food refusal rather than ASD behaviours associated with food refusal.
The Children’s Eating Behavior Inventory: Reliability and Validity Results. Journal of Pediatric Psychology, 1991 <b>16</b> (5) 629-642	Archer, L A (1991)	<b>2+ N</b> Validated tool to assess eating and mealtime behaviour. Can be used to screen and measure improvements.
A Parent Training Programme for chronic Food Refusal: A Case Study. British Journal of Learning Disabilities, 2002 <b>30</b> 118-121	Brown, J F; Spencer, K; Swift, S (2002)	<b>3 N</b> Used a food reward to increase the variety of food consumed. Parents were trained to implement the effective procedure. Required long term commitment.
Gluten and Casein Free Diets in ASD: a Study of the Effects on Food Choice and Nutrition. The British Dietetic Association Ltd 2002 Journal of Human Nutrition & Dietetics, <b>15</b> pp 261-269	Cornish, E (2002)	<b>2- N</b> Vitamin and mineral intakes were below the LRNI in some children. No significant differences in energy, protein and micronutrient intakes on a gluten and casein free diet.
Combining Stimulus Fading, Reinforcement, and Extinction to Treat Food Refusal. Journal of Applied Behavior Analysis, 1998 <b>31</b> (4) 691-694	Freeman, KA; Piazza, Cathleen (1998)	<b>3 A</b> This paper used a treatment package in a person centred approach to treating food refusal in ASD.
Treating Total Liquid Refusal with Backward Chaining and Fading. Journal of Applied Behavior Analysis, 1996 <b>29</b> (4) 573-575	Hagopian, L P; Farrell, DA; Amari, A (1996)	<b>3 B</b> Useful description of practical use of backward chaining and a non-food reinforcer.
The Use of a Pica Box in Reducing Pica Behavior in a Student with ASD.	Hirsch, N; Smith Myles, B (1996)	<b>3 N</b> Describes useful method for managing Pica.



Focus on ASD and other Developmental Disabilities, 1996 <b>11</b> (4) 222-225, 234		
Contingency Contacting – Combining Positive Reinforcement and Escape Extinction Procedures to Treat Persistent Food Refusal. Behaviour Modification, 1994 <b>18</b> (1) 106-128	Hoch, T; Babbitt, RL; Coe, DA; Krell, DM; Hackbert, L (1994)	<b>3 B</b> Useful discussion on the ethics of force feeding. Program achieved its aims in a relatively short time.
Food Selectivity and Problem Behavior in Children with Developmental Disabilities. Behavior Modification, 2001 <b>25</b> (3) 443-470	Levin, L; Carr, EG (2001)	<b>2- N</b> Escape behaviours increase initially in relation to the size of the target food portion.
Liquid Fading to Establish Milk Consumption by a Child with ASD. Behavioral Interventions, 2005 <b>20</b> 155-163	Luiselli, J K; Ricciardi, JN; Gilligan, K (2005)	<b>3A</b> Positive reinforcement and paced instructional prompting used to slowly move child from a preferred to target food.
A case of scurvy in an ASD Boy. Journal of Drugs in Dermatology 2002 <b>1</b> :67-69	Monks, G; Juracek, L; Weigand, D; Magro, C; Cornelison, R; Crowson N (2002)	<b>3 N</b> Restricted diets in ASD can lead to deficiency states.
Parental Assessment and Treatment of Food Selectivity in Natural Settings. Journal of Applied Behavior Analysis, 2003 <b>36</b> (3) 383-386	Najdowski, A C; Wallace, MD; Doney, JK; Ghezzi, PM (2003)	<b>3 B</b> A combination of differential reinforcement of alternative behaviours (DRA) escape extinction and demand fading was effective and parents could be involved in promoting change.
An evaluation of Simultaneous and Sequential Presentation of Preferred and Non-preferred Food to Treat Food Selectivity. Journal of Applied Behavior Analysis, 2002 <b>35</b> 259-270	Piazza, C C; Patel, MR; Santana, CM (2002)	<b>3 B</b> Simultaneous methods work better. An interesting idea of placing two items on a spoon for sequential presentation.
A Comparison of Eating Behaviors between Children with and without ASD. Journal of ASD and Developmental Disorders, 2004 <b>34</b> (4)	Schreck, K A; Williams, K; Smith, AF (2004)	<b>2- N.</b> Food preference inventory is interesting and also takes account of foods offered at family meal times
Food Choices of Tactile Defensive children. Applied Nutrition Investigation Nutrition 2005, <b>21</b> 14-19	Smith, A M; Roux, S; Naidoo, NT; Venter, DJL (2005)	<b>2- N</b> Demonstrates a link between tactile defensiveness and food refusal, recommends a sensory assessment and discusses treating food refusal by using sensory integration techniques.

<p>Intestinal Pathophysiology in ASD. Exp Bio Med, 2003 228: 639-649</p>	<p>White, J F (2003)</p>	<p>This was a review of papers, so scores varied. ASD children are likely to have intestinal symptoms/features which may affect their appetite.</p>
<p>Eating Habits of Children with ASD. Pediatric Nursing, 2000 <b>26</b> (3) 259-264</p>	<p>Williams, P G; Dalrymple, N; Neal, J (2000)</p>	<p><b>2- N</b> Children with an “upset” temperament are more likely to have a poor diet. Non-demanding children are more likely to have pica. Parents of “picky eaters” feel texture is important.</p>

**TABLE 3 – Search November 2007**

Reference	Authors	Evidence Level & Key Findings
A balanced approach towards healthy eating in ASD, Journal of human Nutrition & Dietetics, 1998, <b>11</b> , 501-509	Cornish, E (1998)	<b>3 N</b> ASD children had relatively good nutrient intakes and growth patterns, in spite of their restrictive diets. Food refusal and introduction of new foods was the most difficult problem for parents.
The Use of Music with Chronic Food Refusal: A Case Study, Music Therapy Perspectives, 2003, <b>21</b> , 105-109	Dellatan, AK (2003)	<b>3 A</b> Observation of child results in use of music as a positive reinforcer.
Correlates of specific childhood feeding problems. (sourced from reference 26), The journal of Paediatr, Child Health, 2003, <b>39</b> , 299-304	Field, D; Garland, M; Williams, K (2003)	<b>3 N</b> GOR was the most prevalent condition and was the factor most associated with food refusal. 50 % of the group had GOR. Food selectivity by type was more common in children with ASD. Resolving constipation may improve appetite in all children.
Parental Report of Eating Problems and GI symptoms in Children with Pervasive Developmental Disorders, Child's Health Care, 34, <b>3</b> , 221-234, 2005	Kerwin, ME; Eicher, PS; Gelsinger, J (2005)	<b>3 N</b> Approximately 17 % of the paper sample might be experiencing reflux. 25 – 33 % of children experienced constipation. 25% had loose stools. Cycling of amount and variety of food was associated with bowel problems and Pica. Head banging and hitting the ears were significantly associated with feeding behaviours and GI symptoms.
Relationship of Dietary Intake to Gastrointestinal Symptoms in Children with ASD Spectrum Disorders. BIOL. Psychiatry, 2007 <b>61</b> , 492-497	Levy, SE; Souders, MC; Ittenbach, RF; Giarelli, E, Mulberg, AE (2007)	<b>3 N</b> Protein intakes were high 67 – 436% of RDA. Two subjects with very high carbohydrate intake had a lower calorie intake and a history of food selectivity. Calorie intake was 52 and 63% of RDA, both were growing in the normal range.
Development and validation of an inventory to assess eating and mealtime behaviour problems in children with ASD. Originally, read as PHD submission on the internet, then published as Journal of ASD and Developmental Disorders. 2008, <b>38/2</b> , 342-352	Lukens, CT; Linscheid, TR (2005)	<b>2- N</b> Results supports the reliability and validity of the BAMBI. The BAMBI does not give an overall score indicating level of feeding problem, but highlights various relevant feeding difficulty features.
Food Preferences and factors influencing food selectivity for children with ASD spectrum disorders, 2006, <b>27</b> , 353-363	Schreck, KA; Williams, K (2006)	<b>3 N</b> Limited eating in families correlates with limited eating in children. The children's families consistently prefer a wider variety of food items than their children. Found no correlation between the degree of ASD and limited eating.
Comparing Selective Eaters with and without developmental disabilities. Journal of Developmental and Physical Disabilities, <b>17</b> , 3, 299-309, 2005	Williams, KE; Gibbons, BG, Schrek, KA (2005)	<b>3 N</b> Older children were as selective as younger ones. Constipation was the most common medical problem. 22 % had reflux. Parents offer food until eaten or stick to what is liked. Starchy food was consumed twice as much as other food groups.

**Table 4 - Excluded References**

<b>REFERENCE</b>	<b>1<sup>st</sup> AUTHOR</b>	<b>Reason for Exclusion</b>
Nutrition and ASD. Clinical Nutritional Updates, Issue 241, 1-3, 2006	Abor Clinical Nutrition Update 2006	Considers issues other than feeding and restricted diets.
Pilot study of a Moderate Dose Multivitamin /Mineral Supplement for Children with ASD Spectrum Disorder. The Journal of Alternative And Complementary Medicine, <b>10</b> , Number 6, 2004, 1033-1039	Adams, J B; Holloway, C (2004)	Does not look at feeding itself only supplementation
An alternating TMTs comparison of two intensive interventions for food refusal. Journal of Applied Behavior Analysis, <b>29</b> , Number 3, 1996, 321-332	Ahearn WH; Kerwin, MLE; Eicher PS; Shantz, J; Swearingin, W (1996)	Method described, Group felt amounted to force feeding
Sensory defensiveness in persons with development disabilities.	Baranek, G T (1997)	Discusses sensory defensiveness generally. Although eating difficulties are considered as part of the assessment, oral sensitivity is not discussed in enough detail to add anything to the aims of the group.
An audit of referrals of children with ASD spectrum disorder to the dietetic service. The Journal of Human Nutrition & Dietetics, <b>15</b> , 141-144, 2002	Bowers, L (2002)	Research not food related – but useful comments on sensory defensiveness and differences between children and adults. Excluded because audit. Useful background.
Use of an interactive game to increase food acceptance – a pilot study Child: Care, Health & Development, <b>29</b> , 5, 2003, 373-375	Gillis, L. (2003)	Children not ASD
Acquisition of cup drinking using previously refused foods as positive and negative reinforcement. The journal of Applied Behavior Analysis, 2003, 1, <b>36</b> , 89-93	Kelley, M; Piazza, CC; Fisher, WW; Oberdorff, AJ (2003)	1 Boy not ASD. Very complicated.
Empirically supported treatments in Paediatric Psychology: Severe feeding problems. Journal of Pediatric Psychology, <b>24</b> , 3, 1999, 193-214	Kerwin, M L (1999)	Review article of treatment studies of severe paediatric feeding problems – ASD not mentioned.
Failure to thrive. Principles & Practice of Pediatrics, <b>2</b> , 1994, 1048-1051	Kirkland, R T (1994)	All failure to thrive and not relevant.

Reliability Testing of a Children's Version of the Eating Attitude Test	Maloney MJ et al	Not relevant is about eating disorders
Training parents to implement paediatric feeding protocols. Journal of Applied Behavior Analysis, <b>36</b> , 4, 545-562, 2003	Mueller, M M; Piazza, CC; Moore, JW; Kelly, ME (2003)	This is all about training parents but not specific to ASD – Not very useful.
Using a fading procedure to increase fluid consumption in a child with feeding problems. Journal of Applied Behavior Analysis, 2001, <b>34</b> , 3, 357-360	Patel, M R; Piazza, C C; Kelly, ML (2001)	1 Child Gastrostomy fed - Not ASD. Very complicated.
References from the search completed at the end of 2007		
Help! My son eats only macaroni and cheese: Dealing with feeding problems in children with ASD. (From making a difference book). 2001	Ahearn, W (2001)	This is not a research paper but a chapter from a book, therefore it can not be included. The book is referenced in book section.
Use of a social story intervention to improve mealtimes skills of an adolescent with Aspergers syndrome. ASD, 2003, <b>7</b> , 3, 289-295	Bledsoe, R; Smith Myles, B; Simpson, RL (2003)	Focussed on skills like wiping mouth. No discussion of food intake
Using Food Aversion to Decrease Severe Pica by a child with ASD. Behavior Modification, <b>30</b> ,4, 456-471, 2006	Ferreri, SJ; Tamm, L; Wier, KG (2006)	Interesting but not relevant. Dipped toys into Tapioca which child disliked or had an aversion to. Then covered the nursery in tapioca!
Dietary Considerations in ASD Identifying a reasonable approach. Top Clin Nutr, <b>21</b> , 3, 212-225, 2006	Johnson Theresa (2006)	Good general paper but no ideas for increasing food intake.
Reducing Pica by Teaching Children to Exchange Inedible Items for Edibles. Behavior modification, <b>30</b> , 2, 135-158, 2006	Kern, L; Starosta, K; (2006)	Process exchanges Pica inedibles will edibles. May be useful to look at in conjunction with Ref 10 Pica Box.
Prompts and Prompt fading (From making a difference book)	Macduff (2001)	Considers the psychological techniques of Prompts and prompt fading in depth in a variety of situations. Added little to our search for relevant information in restricted eating.
An evaluation of simultaneous presentation and differential reinforcement with response cost to reduce packing. Journal of Applied Behavior Analysis, <b>38</b> , 405-409, 2005	Buckley, SD; Newchok, DK, (2005)	Case study and child had a less restricted diet than those we would generally work with. Emphasis was on reducing packing rather than increasing food variety. Written in a very complex style.

**Table 5 - Other useful reading – Books**

Just take a bite	Lori Ernsperger Tania Stegen-Hanson Future Horizons. <a href="http://www.FutureHorizons-ASD.com">www.FutureHorizons-ASD.com</a> ISBN #1-932565-12-4	2004	
Making A Difference. Behavioural Intervention for ASD	Edited by Catherine Maurice et al	2001	Chapter 5. Has some really useful descriptions of methods and explanations of technical terms
The Fun with Food Programme	Edited by Arlene McCurtin Speechmark Publishing Ltd, 8 Oxford Court, St James Road, Brackley NN13 7XY <a href="http://www.speechmark.net">www.speechmark.net</a>	2007	

## **8. APPENDIX 1 - EXAMPLES OF SUCCESSFUL INTERVENTION WITH CHILDREN WITH ASD**

### **Child 1**

**Diagnosis:** ASD

Original referral made at 2 years 2 months old. Growth was not a problem but diet was limited to crisps, crackers, breadsticks and jaffa cakes of a particular brand.

The child liked to drink and drinks were carried around in a beaker, so were very accessible.

### **Aims**

- To improve nutritional intake
- To change pattern of drinking to promote hunger
- To expand range of foods acceptable to child and encourage less reliance on particular brands of foods

### **Methods**

A juice based supplement was used to promote weight gain. This was later changed to a milk-free supplement. (Milk was being avoided because of eczema). The intake of Calcium was low so a supplement was introduced.

Drinks were limited to particular times which resulted in the child eating more bread and drinking less supplement.

The diet was expanded by offering food that was very similar to the preferred foods. These included rich tea biscuit, dry shreddies, dry bread roll, cheese biscuit, crisps, small amounts of chicken nugget, a particular chocolate.

Mum developed communication around food, firstly by pointing to particular places where food was and later by making and using a communication book with photos of foods.

### **Outcome**

The range of foods continued to expand to include different types of a greater variety of biscuits, bread, crisps. The child also started to eat some chips. The aim was to try 3 new foods every 3 – 4 weeks.

Mum reported that she no longer had to make special trips to the supermarket for the brand of biscuits the child liked.

The diet then further improved to include an even greater range of biscuit.

It was decided to try crunchy fruit and vegetables as this food group was missing in the child's diet. Suggestions were slices of apple, pepper, carrot stick, celery stick.

The child started to occasionally try different foods at school e.g. spaghetti.

The child was able to sit at table with his brother for food rather than walking around with it as before. The child could tolerate sitting with the family for Sunday lunch. In the past the smell would have been too off putting.

The child started to choose from three cereals at breakfast, the lunchbox using symbols and the child started to ask for apples and rolls at home.

The child still tries new foods at school, with no particular pattern. The child is not pushed to try, but if an interest is shown the food is offered.

## Learning Points

- Enabling child to communicate around food was helpful.
- Small changes are progress.
- Widening the choice of 'preferred' or acceptable foods may widen overall choice. It also reduces parental anxiety around packaging and availability.
- Reducing or rearranging fluid intake may encourage hunger.
- Calm mealtime without pressure to eat may encourage sitting at the table and eating.
- Mealtime behaviour (sitting at table, sitting with family, being exposed to strong smells of food) can improve.
- Meeting nutritional needs helps to reduce parental anxiety.

## Child 2

### Diagnosis: ASD and developmental delay.

Work commenced as child entered reception class at a Moderate Learning Disability school.

### Starting point

There were no concerns over the child's height and weight.

### Diet History at school entry

**Breakfast** cereal with honey and milk  
Orange Squash from bottle  
If at nursery – yoghurt – would not eat at home.  
Home – Bottle – milk or orange juice

**Lunch** Cereal  
or Baby Jar – 1<sup>st</sup> stage Banoffee Pie

**3-4 p.m.** Banoffee jar +/- Cereal

**6-7 p.m.** Cereal.

Mum was crushing Children's vitamin supplements into cereal. Milk was full cream and squash was sugar free.

Drinks were all consumed using a bottle, at home and school. Mum described the child as being frightened of the drinking beaker. The child would lick crisps and lick butter off toast.

The child started school in nappies.

### Aims

- To get the child toilet trained.
- To get the child using a beaker or cup rather than a bottle at school.



- To get the child to move on from first stage weaning foods and semi-solid consistency and towards a more age appropriate diet.

## Methods

It was noticed very quickly by school staff that although there was resistance to sitting on the toilet, the child delighted in flushing. Sitting on the toilet was positively reinforced by allowing child to flush. Initial sitting time was very brief, but as confidence grew sitting time was increased and the child was subsequently toilet trained by this method.

Encouraged by this success school continued using positive reinforcement during meal times. Points 1 and 2 use sequential food introduction, points 3 and 4 use simultaneous introduction.

1. "Eat a little 7 month stage banoffee pie then you can have the 4 month stage." (i.e. a little target food then positively re-enforced by preferred food ).
2. Target food was increased and preferred food was decreased, until only target food was given. There was full acceptance of the target food at this stage. Hence the target food became the preferred food.
3. Small amounts of target food were added simultaneously to the preferred food. In other words, tiny amounts of school dinner were added to a small amount of banoffee pie. This would be, a pea or bean mashed or a pea sized piece of mashed potato. The child required ongoing assurance that there was an unadulterated jar waiting for him after he had finished the target food. The child would lift this to look inside and would also smell it.  
This was initially tried covertly, but the child was aware of the change to his preferred food. Thereafter teachers were clear about what they were doing. This resulted in progression instead of resistance from the child. The child would question what the food was. The teacher would answer – yes there is a pea/bean in it.  
Openness and clarity were further improved by adding target foods in front of the child.
4. This continued gradually increasing the amount of target food. (This was by adding more of the school dinner to the target food.) The preferred food was always the positive reinforcer.
5. Once this was established the school started to tackle the use of the bottle at school. The child disliked hard plastic so the following steps were followed:
  1. Made hole bigger on teats.
  2. Bigger still.
  3. Cut end off completely.
7. A routine was established of the child holding the beaker (containing water) to his lips. This was initially to the count of 1, 2, 3 spoken quickly. This was done at breakfast (at school), morning break, lunch and afternoon break i.e. at least 4 times a day. When the child was comfortable with this the time was increased (i.e. 1, 2, 3, 4, 5, 6).

Once the child was comfortable with the beaker and taking in almost all of the water from it the top was sawn off. The child was soon drinking from the beaker and removing the top to drain the final water inside.

The teacher was asked about any distress in the child. Mild distress did occur but after 3-4 days the child would be ok. The teacher described child as 'wittering' – this was mild and ignored.

As food from the dinner increased the amount of banoffee was reduced. The child now has school dinner only. He also tolerates some lumps and bits. He has banoffee as dessert.

### Learning Points

- Teaching staff observed early on a delight in flushing the toilet and made a link with using this as positive reinforcement. The “do this, then you can have this” method was extended to food introduction.
- Covert food introduction was not successful, once teaching staff were open and honest about what they were doing the whole thing worked much better.
- This is a good example of a child centred programme development: anything which did not work well was noted and re-developed.

## 9. APPENDIX 2 – GROUP MEMBERS

The restrictive/obsessive diets section of the document is based on work done by a multi-disciplinary group of health professionals based in Coventry. All members work with children with ASD and selective eating. All group members have a specialist learning disability role.

<b>Name</b>	<b>Role</b>	<b>Employer</b>
Beverley Spicer	Specialist Dietitian	University Hospital Coventry
Judy Hughes	Specialist Dietitian	University Hospital Coventry
Katie Thomas	Specialist Dietitian	University Hospital Coventry
Ann Clarke	Occupational Therapist	Children's community Learning Disability Team. Coventry and Warwickshire Partnership Trust
Gail King	Speech Therapist	Coventry Primary Care Trust

Nurses and psychologists from the Children's Learning Disability Team, Coventry and Warwickshire Partnership Trust have also contributed to this section of the document. The individuals involved have left Coventry and so are not listed above.

## 10. APPENDIX 3 – TREATMENT METHODS

### Functional analysis

This describes examining the current patterns of eating, food avoidance and behaviour patterns within the family or home setting to discover what purpose they serve. Najdowski, 2003 used this to determine what behaviour patterns were being used to maintain food refusal behaviours.

### A behavioural approach

Levin and Carr 2001 suggest that behavioural mismanagement frequently contributes to the onset and maintenance of problematic behaviours at mealtimes, namely negative reinforcement.

Reinforcement can be positive or negative. Reinforcement is part of behavioural therapy but also everyday interactions. **A positive reinforcer** is used to encourage the child, usually towards the taking of a target food. It is usually something that the child really enjoys, such as time on the computer. Reinforcers do need to be restricted at other times to keep them special, but not excluded completely, e.g. restrict for a limited period before the meal ( $\frac{1}{2}$  / 1 hour depending on the reinforcer and the child). **A negative reinforcer** strengthens a particular behaviour by stopping or avoiding a situation or experience which is unpleasant. E.g. a child with GOR discovers that he experiences greater discomfort after drinking orange juice. The pain after drinking the juice results in the child screaming when presented with the drink. The drink is then removed from the child (negative reinforcer). Thus the child learns that by screaming the thing they don't want is removed and may begin to see this as the best way to refuse food. Levin and Carr 2001 suggested that problem behaviour was maintained by **negative reinforcement**.

Negative reinforcement is different to punishment. **Negative Reinforcement** strengthens a behaviour because a negative condition is stopped. **Punishment** on the other hand weakens a behaviour because a negative condition is introduced or experienced as a consequence of the behaviour. It is unlikely that punishment will stop a behaviour. Brown 2002 used a food reward to increase the variety of food consumed in a single case study.

Dellatan 2003 used music as a reinforcer. The tape was left playing whilst food was being swallowed and turned off if the food wasn't swallowed. The tape and music provided a useful positive reinforcer for 3 weeks after which the novelty wore off and books and toys were used in its place.

### Preferred and Target foods

- The preferred food is the food that the child likes and is happy to eat.
- The non preferred food is any food that the child would not choose to eat.
- The target food refers to the food that the multidisciplinary team would like the child to eat.

It is advisable that this is something closely related to, or similar to a food that the child already eats. For example, if one of the child's current preferred foods is one specific brand of sliced white bread, the target food may be a supermarket own brand of a similar bread packaged in a similar way.

Levin and Carr 2001 established preferred and non-preferred foods then used functional analysis to ascertain any links between food preferences and problem behaviour. Initially the target food portion needs to be very small. In fact, it often needs to be miniscule. Hagopian 1996 describes a positive reinforcement programme starting with developing a conscious swallow of saliva; food wasn't used at all until later.

### **Simultaneous and Sequential presentation**

- Simultaneous exposure describes introducing the target food at the same time as the preferred food. E.g. adding mashed potato to child's preferred baby food.
- Sequential exposure describes the process of offering the child the target food first followed by the preferred food. The two foods are not mixed at all.

Ahearn 2003 used simultaneous presentation to increase vegetable consumption in a 14 year old boy with profound ASD. More success was attributed to the use of condiments with the vegetable in this study than the method of presentation.

Piazza 2002 considered simultaneous and sequential presentation in a study of 3 children with ASD. Some of the methods used in this study we considered unethical. This included hiding food and also force feeding. It was felt that both of these approaches may risk putting the child off their preferred food. The choices of foods taken by the children in this study did not increase although the simultaneous method seemed to work better. There was an interesting idea of placing two items on the same spoon for sequential presentation.

In practice a greater level of success has been found with simultaneous over sequential exposure to target food. However honesty is very important during this method. Covert simultaneous exposure is not recommended. Certain preferred foods do not lend themselves to simultaneous exposure. E.g. dry cereal.

In sequential programmes it is important to limit the amount of preferred food prior to the target food being given. However the preferred food is sometimes restricted until after the required volume of target food is eaten. The child then has free choice of the volume of the preferred food. (Ahearn 2003)

### **Escape extinction**

Most of the references that use escape extinction appear in our excluded reference list. This is because it was felt that many of the methods described were unethical and not suitable for use within any setting in the UK. Escape extinction describes preventing the child using a behaviour which enables them to escape from the planned programme. For example when a child shakes her head to avoid contact with the spoon continue to leave the spoon in contact with the mouth until the child realises that the behaviour does not produce the desired effect and ceases to shake their head. This technique can add a high level of stress to the child which can be counter productive especially in children with severe ASD as there is a risk that they will stop eating and drinking completely.

Levin and Carr 2001 noted that escape behaviours in children increase initially in relation to the size of the target food portion.

Najdowski 2003 uses the parents as therapists. The parents found escape extinction acceptable as their child was still managing to eat sufficient calories.

## Contingency contacting

This means close connection, e.g. keeping a spoon in contact with the mouth. (Hoch, 1994). Hoch provides a useful debate on the ethics of feeding programmes and in particular escape extinction. Only two children were used in this study and neither had ASD. It was the only study that offered debate around the issue of force feeding and included parental perceptions of this. The contingency contacting methods used, although NOT force feeding were still very assertive and persistent.

We feel that this would potentially have a damaging impact on children with ASD. Additionally, we felt that this method only worked because the children in the study were able to be controlled because of their size, age, strength and level of disability. This would not be possible in a child larger, older, stronger or with a higher level of functionality. This paper although interesting in some of its methods did leave us asking “did the ends justify the means?”

## Backward chaining and fading

Backward chaining is when the last step of a skill is taught first. Moving on to each previous step only as the last is mastered. For example learning to tie shoe laces would start with the child finishing the bow, then going on to the stage before that.

Hagopian 1996 used backward chaining and fading in a 12 year old boy with total liquid refusal. After 70 sessions the child was drinking 90 cc.

In this study the backward chaining refers to the fact that researchers started by reinforcing the end point of desired behaviour i.e. the swallow. The fading refers to delaying the time when the positive reinforcer is brought in hence increasing the desired behaviour, in this case the drinking of the water.

## Stimulus fading

Stimulus control refers to the extent to which the presence or absence of a stimulus controls the probability of a response. Stimulus fading, in the context of trying to increase food consumption, describes gradually increasing the exposure to food (Freeman 1998).

Freeman 1998 combined stimulus fading with other treatments to treat food refusal. This study replicates a previous study by Riordan 1980. The treatment package described results in the child in this single case study accepting multiple items from 4 food groups. The child was previously described as having severe food refusal.

Luiselli 2005 described liquid fading to establish milk consumption in a child with ASD. This study shows a methodical and gradual approach to changing a child's preferred food, however the method is only of use when exchanging one liquid for another. The main criticism of this paper was that the child was moved from a liquid source of high nutritive value to an alternative liquid of a lesser nutritive value. It did not reduce any of the restrictive nature of the child's diet for example increasing the range of liquid.

## Pica Box

Hirsch 1996 successfully managed pica in a 10 year old girl with ASD by the use of a pica box. The box contained safe alternatives of the types of material this girl was seeking. This resulted in a reduction of inappropriate pica behaviours.

## Probe Assessments

This describes checking at an interim point of study whether the end objective is attainable. Luiselli 2005 used this to check if the child would accept a full concentration of feed once an intermediate concentration was established.

## 11. APPENDIX 4 - CLASSIFICATION OF EVIDENCE

### Quality of Evidence

Excellent	= 1	Evidence from meta-analyses, randomised controlled trials or systematic reviews of randomised controlled trials.
Good	= 2+	Evidence from systematic reviews of case control or cohort studies, or well conducted case control or cohort studies with a low risk of confounding bias or chance. High/moderate probability that the relationship is casual.
Moderate	= 2-	Evidence from case control or cohort studies with a high risk of confounding bias or chance and a significant risk that the relationship is not casual.
Fair	= 3	Evidence from observational studies and non-analytical studies e.g. case reports.
Poor	= 4	Relying on opinions of authorities.
Not Acceptable	= 5	Paper not of suitable scientific quality.

### Importance of Outcomes

A =	Is there any evidence of strong positive outcomes in eating? That is: quantity or variety of food eaten; mealtime behaviour or parental perception of mealtime problems.
B =	Is there any evidence of mild positive behavioural outcomes in any of the three defining features of ASD (as above)?
C =	Is there any evidence of strong positive physical outcomes (e.g. improvement in bowel function)?
D =	Is there any evidence or mild positive physical outcomes (as above)?
E =	Is there no evidence of a positive outcome?
F =	Is there evidence of a negative outcome?
N =	Not applicable or no outcomes were measured.

Evidence of level 1A or 1C are the best and most relevant. Evidence of level 5F is the least useful and least relevant.

## 12. APPENDIX 5 - CLINICAL PAPER APPRAISAL SUMMARY

**Title of Paper:** As assessment of Food acceptance in children with ASD or Pervasive Developmental Disorder – Not otherwise specified. (2001)

**Authors:** Ahern, Castine Nault and Green

**Reference:** Journal of ASD and developmental disorders, 2001 31 (5) 505-511

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**Summary** Replication of a study/technique used by Munk and Repp (1994)- using a direct observational technique- but with 30 children with ASD and PDDNOS- looks at food type/food texture and then refusal/acceptance in individuals with feeding problems- exposed to 12 food items across 6 sessions. Food acceptance, expulsion and disruptive behaviour were recorded on a trial by trial basis. More than half the participants exhibited low overall levels of food acceptance. 4 completely refused, wide ranging patterns of acceptance/refusal.

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**Strengths** Reliable, used lots of participants, Used inter observer rating to ensure objective observations. Did consider food type and texture.

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**Limitations** No control group utilised, perhaps as these children were already involved in such a food programme they may be generally more accepting of this work. Need for a control group. Couldn't completely eliminate texture and memory/experience for certain foods may influence expectation and therefore whether a child will consume a food. The food was not presented in a way they were used to it or by a familiar person.

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**Key points** Using this method may help parents/practitioners to work out what children may eat. Also looks at the importance of texture.

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**Evidence Level\*** 3 N

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### **Recommendations**

This seems like a strong article because it is a replication of a previous technique- offering additional support to Munk and Repp (1994)- so it is a reliable technique



## Clinical Paper Appraisal Summary

**Title of Paper:** Using simultaneous presentation to increase vegetable consumption in a mildly selective child with ASD.

**Authors:** W AHEARN

**Reference** J.Appl. Behavioural Analysis 200336 361-365

---

**Summary** Case study of a 14 yr old boy who showed mildly selective eating (did not eat vegetables). Presented vegetables 5 times consecutively – bite sized pieces. Presented every 30 secs. Always consumed food in 10 secs if accepted. Acceptance of foods increased after adding preferred condiments. Encouraged to use pictures for symbols.

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**Strengths** Suggests that adding the condiment alters a property of the veg - ? colour, taste etc. Child was profoundly ASD.

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**Limitations** Child was only mildly selective with eating. One child in study.

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**Key points** Vegetable consumption increased with use of condiment. 1 year later this change remained.

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**Evidence Level\*** 3B

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**Recommendations** Study needs greater numbers.

## Clinical Paper Appraisal Summary

**Title of Paper:** Assessment and treatment of food aversion in a four year old boy: A multidimensional approach

**Authors:** Archer L and Szatmarip

**Reference:** Can. J Psychiatry Vol 35A August 1990. p 501 - 505

---

**Summary** Case history of a child with pervasive developmental disorder, speech and language delay and behavioural problems. Parents prime concern was problems with eating. Problems from birth and progression into solids. Parental perceptions different from clinical observation. Eating similar to peers at daycare. Problems linked to poor eating experiences, parental anxiety. Intervention approach with parents. CEBI used before and after treatment.

---

**Strengths** Explains how CEBI used. Well written and explained account of eating and feeding problems and parents perception.

---

**Limitations** Single case study. Not very much information regarding intervention. Child not ASD.

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**Key points** Describes use and validity of CEBI – CEBI score improved after intervention. Parental anxiety contributes to poor eating experience – eating is therefore better in a different situation.

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**Evidence Level\*** 3 N

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### **Recommendations**

Paper was concerned with parental anxiety around food refusal rather than ASD behaviours associated with food refusal.

## Clinical Paper Appraisal Summary

**Title of Paper:** The Children's Eating Behaviour Inventory, reliability & validity Results.

**Authors:** Lynda Archer

**Reference:** Journal of Paediatric Psychology 1991. (16) 5 pp629-642

---

**Summary** The paper aimed to validate the Children's Eating Behaviour Inventory (CEBI) developed according to a conceptual framework based upon a transactional/systemic understanding of parent - child relationships. 110 clinic subjects and 206 non-clinic subjects.

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**Strengths** First and only validated and reliable tool to assess eating and mealtime behaviour.

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**Limitations**

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**Key points** Two scores derived.  
1. The total eating problem score.  
2. The total number of items perceived as a problem.  
The CEBI will screen and measure improvements in a child's eating and mealtime problems.

---

**Evidence Level\*** 2 + N

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**Recommendations**

Have a look at CHEAT (provides a measure of child's eating attitudes).

## Clinical Paper Appraisal Summary

**Title of Paper:** A parent training programme for chronic food refusal: a case study

**Authors:** JF Brown, Kate Spencer, Stella Swift

**Reference:** British Journal of Learning Disabilities, 2002 **30** 118-121

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Summary Use of food reward to increase variety of food consumed. Parents trained to implement the procedure. Found to be effective, but required long term commitment.

---

### Strengths

*Parents involved*

*Positive re-inforcement*

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### Limitations

Single case study

Not ASD child

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Key points Positive reinforcement – Premack principle

*Training parents*

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Evidence Level\* 3 N

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### Recommendations

## Clinical Paper Appraisal Summary

**Title of Paper:** Gluten and Casein Free Diets in ASD.

**Authors:** E. Cornish

**Reference:** Journal of Human Nutrition & Dietetics 2002 (15) pp261-269.

---

**Summary** 37 postal questionnaires returned from children with ASD. Aged 3-16. 25 parents never tried dietary exclusion, 12 had – 8 currently using, 4 had used in the past.  
Results showed no significant differences in energy, protein and micronutrient intakes between 2 groups.

---

**Strengths** Well written and concise, useful paper and useful results.

---

**Limitations** Small sample size and only 8 on the diet (29 off). Potential for biased reporting of food intake and 3 day Record may not reflect habitual intake accurately.  
No comment on why children who had tried exclusion diet had stopped. The reason may be that diet became so restrictive.

---

**Key points** Thiamine, Niacin, Vit C, Vit B6 and Folate. Met LRNI in all children.  
Ca, Zn, Fe, Fat soluble vitamins & riboflavine fell below LRNI in 12 children.

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**Evidence Level\*** 2 N

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**Recommendations**

Author suggestions longitudinal prospective study.

## Clinical Paper Appraisal Summary

**Title of Paper:** Combining Stimulus fading, reinforcement, and extinction to treat food refusal.

**Authors:** Freeman and Piazza (1998)

**Reference:** Journal of Applied Behaviour Analysis, 1998 31 (4) 691-694

---

### Summary

A single case study of a 6 year girl, diagnosed with ASD, Cerebellar Atrophy, mild right Hemiplegia and moderate mental retardation and severe food refusal. A treatment package was used combining stimulus fading, reinforcement and escape extinction using guided compliance. By 12 weeks Rene was accepting multiple items from four food groups.

---

Strengths Reliable- as replicated results from a previous study by Riordan (1980) by showing that fading was a useful treatment for food refusal. Used a multi-element

---

Limitations Utilised a treatment package- so it is hard to isolate which technique was most successful. A single case study so it is not possible to generalise. The length of time allocated to the baseline meals and the treatment meals was different and may cause some confusion in the results.

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Key points Person centred approach looking at food refusal in ASD.

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Evidence Level\* 3 A

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### Recommendations

Yes good article- again very person centred but seems to be generalisable as replicated previous findings on fading.

## Clinical Paper Appraisal Summary

**Title of Paper:** Treating total liquid refusal with backward chaining and fading

**Authors:** Louis Hagopian, Debra Farrell, Adrianna Amarni

**Reference:** Journal of Applied Behavior Analysis, 1996 29 (4) 573-575

---

**Summary** The paper discusses a programme of backward chaining for a 12 year old boy with total liquid refusal – also GI problems. A reinforcer (cutting paper) was used, the method was backward chaining and fading. Following 70 sessions he was drinking 90c from a cup.

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**Strengths** Lots of interesting points - GI problems and the use of backward chaining with swallowing being the first step moving backwards to taking liquid through a syringe to using a cup. Also use of a non food reinforcer was successful (cutting paper).

---

**Limitations** One child. Don't have follow up, did things continue to improve?

---

### **Key points**

- Backward chaining
  - Non food reinforcer
  - Swallowing can be difficult to reinforce
  - GI problems
- 

### **Evidence Level\***

3B

---

### **Recommendations**

## Clinical Paper Appraisal Summary

**Title of Paper:** The use of a Pica box in reducing pica behaviour in a student with Autism

**Authors:** Nancy Hirsch, Brenda Smith Myles

**Reference:** Focus on Autism and other Developmental Disabilities, 1996 11 (4) 222-225, 234

---

**Summary** Investigated effect of using a “Pica box” in reducing pica behaviour in a 10 year old girl with ASD and L D. Data collected in school setting – showed reduced number of pica attempts when box available to student.

---

**Strengths** *Study carried out in class environment*  
Clear design – ABAB observations (intervention/non-intervention)  
Responds to need of individual

---

**Limitations** Single case study. Over 30 days only – no long term follow up

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**Key points** For this child, reduced inappropriate pica behaviours. (Not a “cure” for pica)  
Intervention allowed access to normal school activities  
Gives staff positive strategies .

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**Evidence Level\*** 3 N

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**Recommendations**

Specific to Pica, but interesting and useful.



Clinical Paper Appraisal Summary Number

**Title of Paper:** Contingency Contacting - Combining Positive Reinforcement and Escape Extinction Procedures to Treat Persistent Food Refusal

**Authors:** T A Hoch et al

**Reference:** Behaviour Modification, 1994 18 (1) 106-128

---

Summary Two young boys. 1 severe LD (2years old)/1 Dubowitz (3 ½ years old) - neither ASD. Both initially tube fed – no dysphasia. Comparison between baseline/positive reinforcement and contingency contacting. Raised the issue of previous research of forced feeding and related this to contingency contacting.

---

Strengths Well written – questioned previous practices around force feeding and also considered parental perceptions. Well designed and thorough – recording wasted food on bibs etc.

---

Limitations Only two boys – neither ASD. We had concerns re high level of disability in one child. We questioned if contingency contacting would be possible on older children. Plus the potentially damaging affects on children with ASD. Although not forced, still very assertive and persistent. No discussion of any benefits in social aspects of eating.

---

Key points It worked after a relatively short time. Both stopped enteral feeding – but we do wonder at amount of time still needed to feed children orally – i.e. would a combination have been better.

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Evidence Level\* 3 B

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Recommendations

Worth reading – “does the ends justify the means.” Look out for any research on contingency contacting with ASD and/plus older children.

## Clinical Paper Appraisal Summary

**Title of Paper:** Food Selectivity and Problem Behaviour in Children with Developmental Disabilities  
**Authors:** Levin, L; Carr EG  
**Reference:** Behaviour Modification, 2001 25 (3) 443-470

---

**Summary** Paper suggests that often behavioural mismanagement frequently contributes to the onset and maintenance of problematic behaviours at mealtimes, namely negative reinforcement. Also suggestion that behavioural strategies such as positive reinforcement can be effective. This paper addressed two main questions 1) when do problem behaviours occur and, 2) what is the effect of children eating preferred foods before eating the training meal and the effect of positive contingencies in effective intervention.

Uses the term 'establishing operation' to refer to any contextual variable (satiation/deprivation) that alters effectiveness of reinforcing object. So looked at limiting the access to preferred foods prior to intervention in the hope that it will increase the child's motivation to perform the desired response (i.e. consume the target food).

4 children used with ASD and who had food selectivity problems- also displayed problem behaviours.

Procedure: Identified preferred/ non-preferred food and then functional analysis to ascertain link between food preferences and problem behaviour. Then additional assessment to find special foods- which could be used to motivate consumption of non-preferred foods. Looked at presence versus absence of preferred foods prior to training meal and presence versus absence of reinforcement contingency during the meal itself.

---

**Strengths:** Use of randomised design between levels/conditions, carried out in classroom-  
so environmentally valid.

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**Limitations:** Series of single case studies, few participants, only three in the intervention phase

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**Key points:** Functional analysis used to look at problem behaviours and their triggers- increase in problem behaviours when non-preferred foods were offered. In this experiment if food was refused (whether preferred/non-preferred) food was all food items terminated contingent (dependent upon) whether food was refused. This behaviour continued with non-preferred foods suggesting problem behaviour was maintained by negative reinforcement. So withdrawal of non-preferred foods.

2) Escape behaviours increase initially in relation to the size of the target food portion.

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**Evidence Level\*** 2- N

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### **Recommendations**

Good article good easy to read, confirms some of the finding in terms of introducing new food. N.B. Target food was chosen through dietary need not sensory based (child preference).

## Clinical Paper Appraisal Summary

**Title of Paper:** Liquid Fading to Establish Milk Consumption by a Child with Autism

**Authors:** Luiselli et al

**Reference:** Behavioural Interventions 20:155-163 (2005)

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**Summary:** Slowly increasing concentrations of milk. Paediasure was used to move a 4 yr old child with ASD from drinking 50:50 to 100% milk.

---

**Strengths:** Well written and clear study. Child continued to drink 100% of milk at home. School staff used for intervention. Use of probe assessments were useful in determining any possible shortening of the programme.

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**Limitations:** Only 1 child studied.  
Disagree with statement that having her consume milk by itself was considered a dietary advantage that would benefit her nutritionally.

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**Key points:** % milk was increased very slowly and carefully controlled use of probe assessments. Study achieved an cp 100% milk.  
Positive reinforcement and paced instructional prompting was used.

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**Evidence Level\*** 3 A

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**Recommendations :**

May be a useful behavioural strategy for some children. It needs to be evaluated in the light of other research as only 1 child studied. Some useful references cited.  
No more flexibility of diet.

## Clinical Paper Appraisal Summary

**Title of Paper:** A Case of Scurvy in an Autistic Boy

**Authors:** G Monks, Juracek, L, Weigand, D, Magro C, Cornelison, R, Crowson, N

**Reference:** Journal of Drugs in Dermatology 2002 1: 67-69

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**Summary** A case study of an ASD boy with a very limited diet who developed limping and periods of muscle pain and inability to walk due to a diet deficient in Vitamin C.

---

**Strengths** An accurate summary of a case study.

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**Limitations** No research.

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**Key points** A restricted diet could lead to deficiency state.  
Muscle fibre atrophy is a normal finding in scurvy.

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**Evidence Level\*** 3 N

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**Recommendations**

A Dietitian needs to assess children on very limited diets.

## Clinical Paper Appraisal Summary

**Title of Paper:** Parental assessment and Treatment of Food Selectivity in Natural Settings

**Authors:** Najdowski A C, Wallace M D, Doney J K, Ghezzi P M

**Reference:** Journal of Applied Behaviour Analysis, 2003 36 (3) 383-386

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**Summary:** A single case study of assessment and treatment of a boy with ASD in both home and restaurant setting

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**Strengths** Used parents as therapists and primary change agents. Positive results obtained in many settings and over time, which makes the work generalisable and potentially maintained. Little supervision was required. Functional analysis of food refusal helpful in identifying effective treatments for food selectivity. Parents found escape extinction acceptable as Jack still managing to get enough calories. Relevant approach may be useful as a method?

---

**Limitations** 1 child used in the study. Ethical issues surrounding the use of escape extinction. Appears to be more complicated than it needed to be due to Psychological terminology.

---

**Key points** 5 year old boy with ASD. Used functional analysis to examine what maintained his food refusal behaviours. Used combination of DRA and escape extinction and demand fading methods to increase his acceptance and swallowing of non preferred foods. Found that a combination of all three was effective over time and different settings. Showed parents have the potential to become actively involved in promoting change in children's behaviour.

---

**Evidence Level\*** 3B

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**Recommendations**

## Clinical Paper Appraisal Summary

**Title of Paper:** An Evaluation of Simultaneous and Sequential Presentation of Preferred and Non-preferred Food to Treat Food Selectivity

**Authors:** Cathleen Piazza et al

**Reference:** Journal of Applied Behaviour Analysis 2002 35 259-270

---

**Summary** Simultaneous and sequential presentation of preferred and non preferred foods tried to improve children's diets. Simultaneous could involve hiding bits of food in preferred food items. Took 3 children with ASD. Two residential children have more regular sessions and process is more successful than non-resident child.

---

**Strengths** Looked at an issue often considered in Coventry and children sounded similar to our caseload – Involved only children with ASD. Non- preferred and preferred food presented on the same spoon. All three children continued to enjoy preferred food.

---

**Limitations** Some methods would be considered unethical ( hiding food and forcing). There is a risk of putting child off preferred food. Only three children. Sessions completed in false surroundings. Choice of foods not shown to increase (no flexibility of choices) No follow-up

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### **Key points**

- Simultaneous method worked better
  - Interesting idea placing two items on a spoon in the Sequential presentation
- 

**Evidence Level\*** 3 B

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### **Recommendations:**

Useful, consider including some elements

Clinical Paper Appraisal Summary

**Title of Paper:** A Comparison of Eating Behaviours between Children with and without Autism

**Authors:** Schreck K A, Williams K, Smith AF

**Reference:** Journal of ASD and Developmental Disorders 2004  
34 (4) pp433-438

---

**Summary** 72% of Children with ASD were reported to eat a narrow variety of foods. The ASD group ate significantly fewer foods within each category. (Did not extend to families).  
Children with ASD - had a tendency to refuse more foods.  
- required more specific utensils/presentation.  
- were more likely to only accept foods of low texture.  
- ate a narrow variety of presented foods.

---

**Strengths** Statistically very sound – if difficult to understand!

---

**Limitations** Food Preference Inventory – interesting – but no evidence on whether it relates to actual intake.

---

**Key points** Food Preference Inventory is interesting and also takes account of foods offered at family meal times.

---

**Evidence Level\*** 2- / N

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**Recommendations**

## Clinical Paper Appraisal Summary

**Title of Paper:** Food choices of Tactile Defensive Children

**Authors:** Smith AM, Roux S, Naidoo N T, Venter D J L

**Reference:** Applied Nutrition Investigation Nutrition 2005 21 14-19

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Summary The paper looks at children (excluding ASD, Downs syndrome, cerebral palsy and PEG fed children) with tactile defensiveness with a group of typically developing children as a control. They looked at the food habits of both groups of children to see if those with a tactile problem have a more restrictive diet.

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Strengths Assessments may be useful, recommends checking sensory needs of children.

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Limitations Excludes most groups of children with disabilities

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Key points

- Use of sensory assessment recommended
- Link shown between tactile defensiveness and food refusal
- Discusses possibility of treating food refusal using Sensory Integration techniques

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Evidence Level\* **2- N**

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Recommendations

Lack of work with children with learning disabilities makes this irrelevant



## Clinical Paper Appraisal Summary

**Title of Paper:** Intestinal Pathophysiology in Autism

**Authors:** White, J. F.

**Reference:** Experimental Biology and Medicine 2003 228: 639-649

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**Summary** Review (no original data) of recent papers looking at intestinal pathology in ASD.

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**Strengths** Very comprehensive and clear. With an eye on quality of studies being reviewed.

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**Limitations** Not original work. Therefore subjective review of published data. Also son ASD therefore possible non-objective view.

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**Key points** ASD children are likely to have intestinal symptoms/features which may affect their appetite and do require independent investigation.

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**Evidence Level\*** A review quoting papers of ( -2(+ 3 ).  
Outcome – difficult as review – some N, some D.

---

**Recommendations**

## Clinical Paper Appraisal Summary

**Title of Paper:** Eating habits of Children with Autism

**Authors:** Williams P G, Dalrymple N, Neal J

**Reference:** Paediatric Nursing, 2000 26 (3) 259-264

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**Summary** Introduction goes into a bit of detail of the diagnosis of ASD, then a fairly thorough look at children with ASD and links to early childhood, temperament, and other aspects such as links to GI problems and food allergies

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**Strengths** Covers a number of aspects related to ASD how this may effect eating, a very useful overview. Tables useful.

---

**Limitations** Doesn't give any answers, Lots of detail. Doesn't compare to non ASD children.

---

### **Key points**

- More children with 'generally upset' temperament more likely to have a poor diet
  - Non demanding children more likely to have pica
  - Texture thought to be significant by parents of picky eaters
  - Raises the possibility that infant temperament and early feeding patterns (birth to 1yr) seemed to associate with eating problems later in childhood.
- 

**Evidence Level\*** 2-N

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### **Recommendations**

Very useful for an overview to issues – worth including for this. Although doesn't give specific answers

## Clinical Paper Appraisal Summary

**Title of Paper:** A Balanced Approach towards Healthy Eating in Autism

**Authors:** Cornish, E

**Reference:** Journal of Human Nutrition & Dietetics (1998) 11 501-509

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**Summary** Parents of 17 ASD children aged 42 -117, mothers were interviewed and data collected by 3-day dietary recall and food frequency questionnaire. Weight and height measurements were obtained. Nutrients intakes fell below RNI per 9 children – in one or more of the following: Vit C, Fe, Vit D, Niccin, Riboflavin, VitB6, Calcium and Zinc. 1 child fell below LRNI for Iron. 3 children < 4 years did not meet LRNI for Dietary sources of Vitamin D.

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**Strengths** Good overview – useful simple prompt ideas for trying other foods and expanding range – could print off.

---

**Limitations** Small numbers (17). No interventions

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**Key points**

1. Relatively good intakes of nutrients – in spite of restrictive diets.
2. Growth was not untypical of non ASD children – showed normal distribution across percentiles.
3. Improving specific nutrient intake should be the 1<sup>st</sup> aim of intervention
4. Food refusal and introducing new foods is the most difficult problems for parents

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**Evidence Level\*** 3N

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**Recommendations**

Add some bits of introduction of document and reference.

## Clinical Paper Appraisal Summary

**Title of Paper:** The use of Music with Chronic Food Refusal

**Authors:** Deliatan, A K

**Reference :** Music Therapy Perspectives 2003 : 21(2) 105-9

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**Summary:** Case study of 5 year old boy with ASD, chronic infant lung disease, GOR, dysphagia and PDD. He was fed by NG tube until 1 year and 8 months, he then had a gastrostomy.  
Aim was to reduce aversion to oral feeding and improve the occurrence of self feeding behaviour.  
Tape was turned off if food wasn't swallowed. The author is the child's teacher.

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**Strengths** Intervention improves food intake.

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**Limitations:** Case study. Music only promoted feeding for 3 weeks, the programme then used books and toys to reinforce behaviour.

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**Key points** A good example of using observation of the child to determine a positive reinforcer.  
Not really music therapy – simply used music as a positive reinforcer

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**Evidence Level\*** 3 A

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**Recommendations**

## Clinical Paper Appraisal Summary

**Title of Paper:** Correlates of Specific Childhood Feeding Problems

**Authors:** Field d, Garland M, Williams K

**Reference:** The Journal of Paediatric Child Health (2003) 39, 299-304

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**Summary** A review of the records of 349 children. Each was identified as having one or more of five functionally defined feeding problems. Food refusal / food selectivity by type / food selectivity by texture / oral motor delays / dysphagia. Predisposing factors included developmental disabilities, gastrointestinal problems, cardiopulmonary problems, neurological problems, renal disease and anatomical anomalies.

---

**Strengths** Excellent study. Well written and very clear. Relatively large group.

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**Limitations** Only 3 children had ASD and food refusal. Only correlates. Total number of ASD (out of 349) was 26.

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**Key points** Frequency of predisposing factors varied by feeding problem.  
GOR was the most prevalent condition and was the factor most often associated with food refusal. Of the 3 children with ASD who had food refusal – all had GOR.  
Presence of food selectivity by type was much higher for children with ASD (62%).  
Authors comment that in their experience, resolving constipation improves appetite and this leads to improved feeding in ASD.  
50% of whole group had GOR

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**Evidence Level\*** 3 N

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**Recommendations**

Consider with Coventry ASD group, use of the five functionally defined feeding problems.

## Clinical Paper Appraisal Summary

**Title of Paper:** Parental Report of Eating Problems and GI Symptoms in Children with Pervasive Developmental Disorders

**Authors:** Kerwin M E, Eicher P S, Gelsinger, J

**Reference:** Child's Health Care, 34(3), 221-234 2005

---

**Summary** The parents of 89 children with PDD were surveyed about their child's eating, GI symptoms and behaviour problems. Over 60% were reported to have strong food preferences. The most frequent reported unusual eating pattern was food selectivity. Results revealed potentially interesting relationships among self-injurious behaviour, pica, feeding problems and intestinal symptoms.

---

**Strengths** Very clear – well set out. Good details of survey methodology. Good suggestions for practice guidelines.

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**Limitations** Self reported – maybe more representative of parental perception than of actual child behaviour. The respondents may have been more interested in feeding and GI problems – and adopted responses to endorse these items. No control group.

---

**Key points** About 17% of this sample might be experiencing symptoms of reflux (TDC – 10%) 41-56% of children with severe feeding problems have reflux. Cycling in both amount and variety of foods – was associated with bowel problems. 25-33% children experienced constipation. 25% had loose stools. Pica was associated with cycling of food in amount and variety. Head banging and hitting ears (but not pressure near eyes) were significantly associated with feeding behaviours and GI symptoms.

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**Evidence Level\*** 3N

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### **Recommendations**

Future research should determine what factors differentiate a usual eating pattern from a feeding problem in this and other populations.

Future research – to test the hypothesis that these children craved oropharyngeal stimulation, such that when they were in the phase of not eating good, they were engaged in pica to satisfy the need for oral stimulation.

Future research – Is self injurious behaviour a correlate of pain and distress in non verbal children?

Paper suggests the need for routine screening assessment of feeding problems and possible causes.

Practitioners should routinely ask about Pica

Parents may need to be educated to identify and observe GI symptoms.

## Clinical Paper Appraisal Summary

**Title of Paper:** Relationship of Dietary Intake to Gastrointestinal Symptoms in Children with ASD

**Authors:** Levy, S E et al

**Reference:** Disorders, BIOL ,I Psychiatry 2007 61 492 - 497

---

**Summary** 62 subjects 90% male, completed 3 day food record and stool record. Data analysed and fat, protein and carbohydrate compared to normal intakes. Other causes for GI symptoms were ruled out. Wanted to determine if GI symptoms and stool consistency are related to dietary intake. There was a high rate of GI symptoms despite a lack of medical causes. Subjects achieved RDA. Where high CHO intake, children had lower calorie intake and history of food selectivity. 32/59 subjects reported GI problems. High CHO intake was associated with firmer stools.

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**Strengths** Balanced and well written paper. Used Dietitian to analyse 3 day dietary record.

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**Limitations** Dietary data collection was based on parental or teacher report. Not weighed. E.g. 1 Hamburger, this may overestimate protein intake.

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**Key points** Children have adequate intake of CHO, fat, calories and higher protein intakes (67 – 436%). Increased CHO intake was not correlated with loose stools. Two subjects with high CHO intake ( $\geq 80\%$  energy) had lower calorie intake and a history of food selectivity. Calorie intake was 52 and 62 % of the RDA – both sustained growth in the normal range.  
GI symptoms were common 54%

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**Evidence Level\*** 3 N

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### **Recommendations**

Researchers suggest further study is needed to describe the relationship between nutrient intake and GI symptoms, determine nutritional risk factors for children with ASD and selective diets and determine the aetiology of GI dysfunction in children with ASD.

## Clinical Paper Appraisal Summary

**Title of Paper:** Development and validation of an inventory to assess Eating and Mealtime Behaviour Problems with Children with Autism

**Authors:** Lukens C T PhD, Linscheid T R

**Reference:** PhD thesis submission on the internet, then published as Journal of Autism and Developmental Disorders 2008, 109 pages; 3192869 38/2 342-352  
<http://gradworks.umi.com/31/92/3192869.html>

---

**Summary** Study was conducted to develop a measure of mealtime behaviour problems (Brief ASD mealtime behaviour Inventory- BAMBI) and to gather information about the eating behaviour and nutritional intake of children with ASD compared to typically developing children. Subject recruitment and data collection was via the internet and evaluated to determine if online research can be valid.

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**Strengths** Well designed study. Also used 24hr recall interview (presumably over the phone)

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**Limitations** Study carried out over the internet will make it selective to families who have access and are familiar with the use of computers. BAMBI is useful for research, but less useful in clinical practice, particularly when a Dietitian is involved.

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**Key points** Results supported the reliability and validity of BAMBI. Children with ASD presented with more mealtime behaviour problems than typically developing children. Children with ASD consumed fewer servings of vegetables and had smaller percentages of their recommended nutrient intakes. Correlated analysis indicated that characteristics of ASD were positively associated with mealtime behaviour and negatively associated with nutritional intake. Higher levels of mealtime problems were associated with more limited nutritional intake.  
N.B. BAMBI does not give an overall score indicating a level of feeding problem, but highlights individual factors relevant to feeding difficulties in children

The paper supports the validity of web based data collection.

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**Evidence Level\*** 2- N

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**Recommendations**



## Clinical Paper Appraisal Summary

**Title of Paper:** Food Preferences and Factors Influencing Food Selectivity for Children with ASD Disorders

**Authors:** Schreck K A, Williams K

**Reference:** Research in Developmental Disabilities 27 (2006) 353-363

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**Summary** Used informant based questionnaire (same one from 1994 study) Parents of children with ASD (N= 138) to determine: (a) types of feeding problems, (b) food items their children proper, (c) the relationship of feeding problems to family eating preferences, (d) the relationship of diagnosis characteristics of ASD (using GARS) to feeding behaviour.

---

**Strengths** Well designed, well written scientific study, using previously validated questionnaires.

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**Limitations** Recruitment methods may here produced a sample of parents with more concerns for their child's food selectivity. Used self reported food preference – not actual or typical food items eaten.

---

**Key points** Limited eating in family correlates with limited eating in children.  
No correlation between degree of ASD and limited eating.  
Within most food groups, children ate fewer than half of the listed food items.  
Restriction was not related to food texture.  
Children's families consistently prefer a wider variety of food items than their children.  
Families who ate more restrictive diets had children with more restrictive eating.

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**Evidence Level\*** 3 N

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**Recommendations**

- Future research The differentiation of children with ASD, PDD and differing severities of LD could also provide more information on the ideasychnratic eating behaviour of these children.
- Explore whether any modelling is occurring or simply allowing the evidence of novel good items.

## Clinical Paper Appraisal Summary

**Title of Paper:** Comparing Selective Eaters With and Without Development Disabilities

**Authors:** Williams K E, Gibbons B G, Schrek KA

**Reference:** Journal of Developmental and Physical Disability.  
Vol 17 No 3 299-309 2005

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Summary Retrospective review of 178 children referred to a feeding programme for evaluation and treatment of feeding problems. Examined possible differences between typical developing children, children with ASD and children with special needs who do not have ASD

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Strengths Relatively large sample size

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Limitations Retrospective. Observation not intervention

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### Key points

1. There were no significant differences between the three groups for any of the types of food consumed or for liquid intake
2. ASD kids insisted on using same utensils/dishes significantly more than other 2 groups.
3. ASD children also insisted the food be made in a certain way more
4. Starchy food group was consumed twice as much as the other food groups – across all groups of children
5. The three groups had 11, 12, 13 foods in their diet
6. Stress alone as opposed to the sensory stress link may independently affect appetite
7. Older children were just as selective as younger
8. Most common medical issue was constipation. This possibly leads to reduced appetite. Constipation possibly leads to snacking which possible leads to eating only snack foods.
9. 22% had Reflux
10. Parents offer food until eaten or stick to what is liked.

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Evidence Level\* 3N

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Recommendations

## 13. PART 2 GLUTEN/CASEIN-FREE DIET

### 13.1 Summary

The most commonly requested dietary intervention in ASD is Gluten/Casein free (GF/CF) diet. Fourteen papers were originally reviewed between January 1980 and the end of August 2002. Seven further papers have subsequently been reviewed between September 2002 and July 2005. Two of these recent papers described one small trial giving some evidence to support the use of gluten and casein free diets in a sub-group of children with ASD. There is evidence emerging that there may be a link between diet, ASD, gut epithelial changes and altered immune responses, however the studies so far have had small sample sizes and clearly further well constructed and adequately powered randomised controlled trials are urgently needed in this field. There is therefore still insufficient evidence to recommend the use of a Gluten and Casein free diet as a treatment for ASD.

#### ***Is there evidence to support the use of a gluten/casein free diet in the treatment of ASD?***

*Search: January 1980 – July 2005*

*Search Strategy: AUTIS\$, ASD, PDD, PERVASIVE ADJ DEVELOPMENT \$2 ASPERGER\$ AUTISTIC-DISORDER #.D.E. ASPERGER-SYNDROME #.D.E. GLUTEN\$ CASEIN\$ MILK WHEAT GLUTEN #.D.E. CASEIN #.D.E.*

### 13.2 Inclusion

The papers reviewed in this section relate to children.

One paper was unavailable after exhausting all sources, both regionally and nationally. See list of excluded papers Appendix 1.

One paper published in a book was included for background information to the follow-up papers (Knivsberg et al., 1991).

Some papers were not included as no dietary intervention was discussed. See list of excluded papers.

### 13.3 Introduction

A great deal of interest has been generated in gluten/casein-free (GF/CF) diets in the management of ASD (Byron, 1997). However, such major changes to the diet may further complicate the dysfunctional feeding behaviour and marked food selectivity often present in people with autism (as previously discussed in section 5). In addition, for many children with autism, the majority of the foods they will accept are gluten/casein containing foods eg: bread and milk. This must be considered before embarking on such a restrictive diet.

#### **Theoretical Basis for the Gluten/Casein-free Diet**

The diet is based on two theories, which are indirectly related. One is termed the “opioid excess theory” in which excess levels of peptides, derived from casein (casomorphins) and gluten (glutomorphins) are proposed to contribute to characteristic autistic behaviour. Supporters of this theory propose that in 50% of people with autism, abnormal peptides

exist in the urine indicative of by-products from the incomplete breakdown of foods. It is proposed that these excess peptides may be biologically active and that a small proportion cross into the brain and interfere with neurotransmission causing altered or disrupted activity and altered sensory input. These excess peptides are purported to act as toxins. Treatment consists of removing all gluten and casein containing foods from the diet. A minimum trial period of 3 months is recommended with 12 months being the optimum period to determine the effectiveness of the treatment. (Quinn et al., 1995).

A second theory is based on altered enzyme activity due to liver dysfunction resulting in secondary gastro-intestinal malabsorption with eventual impact on the central nervous system (Quinn et al., 1995).

### **13.4 Management**

From the research available at present no clear evidence can be drawn to recommend the use of GF/CF diets for the treatment of autism. However there is a great deal of anecdotal evidence both in the literature and dietetic practice that a gluten/casein free diet may help certain individuals. The wishes of the person with ASD should be taken into account. More research needs to be conducted as there is some evidence of gut epithelial changes (Furlano et al., 2001, Ashwood et al., 2003, Ashwood et al., 2004) and urinary peptide profile abnormalities (Shattock et al., 1990) and altered immune responses (Harumi Jyonouchi et al., 2002, Harumi Jyonouchi et al., 2005) suggesting there may be a link between diet and ASD.

### **13.5 Suggested good practice**

Tell parents about lack of evidence and potential harm and benefits.

Before embarking on such a restrictive diet careful consideration should be given to the current dietary intake of the person with ASD: ie. do they have marked food selectivity and dysfunctional feeding behaviour which will affect the nutritional adequacy of the diet? The possible difficulties of achieving dietary adequacy should be discussed. Ongoing nutritional monitoring is essential otherwise these diets may not be nutritionally adequate over time (Arnold et al., 2003, Cornish 2002). However such behaviour should not necessarily exclude them from trying the diet as it has been observed that sometimes food selectivity improves following a period on the diet.

The person with ASD who wishes to try the GF/CF diet should be supported by a dietitian who will check and advise on the nutritional adequacy of the diet.

A multidisciplinary team approach is strongly recommended both in the management of the diet and the appropriateness of referrals.

Ideally the dietary investigation should take place in 3 stages; baseline period, exclusion period and reintroduction.

During the baseline period the person with ASD follows their regular diet for an agreed specified time period and a behavioural and bowel habit assessment is made either using a diary or a specific questionnaire (a questionnaire is currently being piloted by DA)

During the exclusion period all foods containing gluten and casein are excluded, again for an agreed specified time period. (The Sunderland protocol suggests a minimum of 3

weeks for casein and 3 months for gluten). Behavioural and bowel monitoring as in the baseline period should continue.

Following the agreed dietary trial, consideration should be given to the significance of any changes observed which will justify the continuation of such a restricted diet.

A gluten and/or casein food challenge can be carried out to help determine whether the diet has been effective. The gluten and/or casein restriction can be stopped and excluded foods reintroduced in a systematic way with behavioural and bowel habit monitoring as before. (NB the person with ASD may be resistant to this if it is felt that improvements in behaviour and bowel habits have been seen on the diet)

Once it has been confirmed that the person wishes to stay on the diet, a follow up plan should be agreed.

### **13.6 Conclusion**

Table II gives a summary of the papers reviewed for evidence.

Full appraisal sheets are found in Appendix 4

The early papers by Reichelt and Knivsberg were all based on the same research study. Four of these five papers were not of a suitable scientific quality. The fifth paper provided fair quality evidence, which was not conclusive to support dietary intervention. The two most recent papers were of a randomised control study involving a Dietitian. These were excellent quality and provided some evidence to support the use of Gluten and Casein free diet in a sub group of children with ASD. However the trial had a small sample size. The papers by Shattock et al provided good quality evidence of urinary peptide profile abnormalities, however they were unable to provide evidence to support the use of a Gluten/Casein free diet. Some evidence suggests there may be a link between diet ASD and gut epithelial changes. Work by Furlano et al., (2001) and Ashwood et al., (2003 and 2004) has shown some evidence to support gut epithelial inflammation in ASD. Work by Jyonouchi et al., (2002, 2005) provides some evidence of altered immune responses to some dietary proteins in children with ASD and may help in differentiating those children with ASD who may benefit from dietary intervention.

### **13.7 Recommendations**

Evidence is emerging that there may be a link between diet, ASD, gut epithelial changes and altered immune responses, however the studies so far have had small sample sizes and clearly further well constructed and adequately-powered randomised control trials are urgently needed in this field. There is therefore still insufficient evidence to recommend the use of a Gluten/Casein free diet as a treatment for ASD. It is recommended that a Dietitian should provide support for those individuals who wish to embark on a dietary trial to ensure the diet is nutritionally adequate and advise on the suitability of long-term dietary management.

**TABLE II**

<b>TABLE OF PAPERS USED FOR GLUTEN/CASEIN-FREE DIETS</b>		
<b>TITLE OF PAPER</b>	<b>AUTHORS</b>	<b>EVIDENCE LEVEL &amp; RECOMMENDATIONS</b>
①Children with Autistic Syndromes. Gluten and/or Casein-free diets as a treatment. Trends, Indicators and Results so far. <i>Therapeutic approaches to Autism. Research &amp; Practice. A.R.U.</i> 1991 pp156-166. Included as background to ② and ③	Knivsberg, A. M. Nødland, M. Reichelt, K. L. University of Oslo Madlavoll School NORWAY	5 B. Initiated interest in possible link between diet and ASD.
②as above – a follow up study. <i>Scandinavian Journal of Education Research</i> , 1995 <b>39</b> (3) p223.	Knivsberg, A.M. Nødland, M. Reichelt, K. L. Høien, T. University of Oslo Madlavoll School Center for Reading Research NORWAY	Insufficient scientific evidence.
③Dietary Interventions in Autistic Syndromes. <i>Brain Dysfunction</i> 1990; <b>3</b> pp315-317.	Knivsberg, A. M. Nødland, M. Reichelt, K. L. Wiig, K. Lind, G. As ① NORWAY	Insufficient scientific evidence.
Gluten, Milk Proteins & Autism: Dietary Intervention Effects on Behaviour and Peptide Secretion. <i>Journal of Applied Nutrition</i> 1990; <b>42</b> (1) pp1-10.	Reichelt, K. L. Ekrem, J. Scott, H. Rikshospitalet, Oslo Municipality , NORWAY	2 B. Evidence not conclusive to support dietary intervention.
Probable Etiology and possible treatment of childhood autism. <i>Brain Dysfunction</i> 1991, <b>4</b> pp308-319.	Reichelt, K. L. Knivsberg, A. M. Lind, G. Nødland, M.  University of Oslo Madlavoll School NORWAY	2 B. Cannot support the use of GF/CF Diet.
A Gluten-free Diet as an Intervention for Autism and Associated Spectrum Disorders: Preliminary Findings. <i>Autism © 1999 SAGE Publications and The National Autistic Society</i> ; <b>3</b> (1) pp45-65.	Whiteley, P. Rodgers, J. Savery, D. Shattock, P.  University of Sunderland, U.K.	2 – B. Cannot support the use of GF/CF diet.
Role of Neuropeptides in Autism and their relationships with classical Neurotransmitters. <i>Brain Dysfunction</i> 1990, <b>3</b> pp328-345.	Shattock, P., Kennedy, A. Rowell, F., Berney, T.  Sunderland Polytechnic Prudhoe Hospital	2 – N. The peptide profile in the urine of patients with autism may be abnormal.

	U. K.	
Colonic CD8 and $\gamma\delta$ T-cell Infiltration with Epithelial Damage in Children with Autism. <i>The Journal of Paediatrics</i> 2001; <b>138</b> (3) pp366-372.	Furlano, R., Anthony, A. Day, R., Brown, A. McGarvey, L. Thomson, M., Davies, S. Berelowitz, M. Forbes, A., Wakefield, A. Walker-Smith, J., Murch, S.  Royal Free and University College School of Medicine. LONDON. UK.	2 – N.  Some evidence to support gut epithelial dysfunction in ASD.
Food Allergy and Infantile Autism. <i>Paminerva Medica</i> 1995, <b>37</b> pp137-41.	Lucarelli, S., Frediani, T. Zingoni, A. M., Ferruzzi, F. Giardini, O., Quintieri, F. Barbato, M., D'Eufemia, P. Cardi, E. University of Rome.  ITALY.	2 – B/C.  There may be a relationship between food allergy and ASD.
Reports on Dietary Intervention in Autistic Disorders. <i>Nutritional Neuroscience</i> , <b>4</b> pp25-37.	Knivsberg, A. M., Reichelt, K. L., Nødland, M. University of Oslo Madlavoll School NORWAY.	3 B/D.  Further investigations needed.
Childhood Autism: A Group of Hyperpeptidergic Disorders. Possible Etiology and tentative treatment. <i>F. Nyberg &amp; V. Brantl. B Casomorphins and related peptides 1990. Fyris-Tryck, A. B., Uppsala, Sweden.</i>	Reichelt, K. L., Scott, H., Knivsberg, A. M., Wiig, K., Lind, G., Nødland, M. University of Oslo Madlavoll School NORWAY.	2 – A.  Evidence not conclusive to support dietary intervention.
Urinary Peptide Levels in Autistic children from seven countries and the effect of Dietary Intervention after 4 years. <i>Brain Dysfunction</i> 1997, <b>10</b> pp44-55.	Reichelt, W. H., Knivsberg, A. M., Nødland, M., Stensrud, M., Reichelt, K. L. University of Oslo Madlavoll School NORWAY.	3 B.  Interesting hypothesis but no evidence for Gluten/Casein free diet.
Nature and Consequences of Hyperpeptiduria and Bovine Casomorphins found in Autistic Syndromes. <i>Brain Dysfunction</i> 1994, <b>7</b> pp71-85.	Reichelt, K. L., Knivsberg, A. M., Nødland, M., Lind, G. University of Oslo Madlavoll School NORWAY.	4 N.  Cannot support the use of Gluten/Casein free diet.
On Gluten Free and Casein Free Diet in Autism and the Opioids. Excess Theory: Another Perspective. <i>Ital J. Intellect Impair</i> 1996, <b>9</b> pp139-152	Cocchi, R. (G.I.S.S.T.I.M.M.A.I.) San Costanzo	4 N  Cannot support the use of Gluten/Casein Free diet.

<p>Spontaneous Mucosal Lymphocyte Cytokine Profiles in Children with Autism and Gastrointestinal Symptoms: Mucosal Immune Activation and Reduced Counter Regulatory Interleukin-10.</p> <p><i>Journal of Clinical Immunology</i> 2004. <b>24</b> (6) pp664-673.</p>	<p>Ashwood, P., Anthony, A., Torrente, F., Wakefield, A. J.</p> <p>Royal Free and University College Medical School. LONDON, U.K.</p>	<p>2+ C</p> <p>The study states that given the small sample size the conclusions that can be drawn are limited but clearly the potential of gluten and casein merits further study.</p>
<p>Intestinal Lymphocyte Populations in Children with Regressive Autism: Evidence for Extensive Mucosal Immunopathology.</p> <p><i>Journal of Clinical Immunology</i> 2003. <b>23</b> (6).</p>	<p>Ashwood, P., Murch, A.H., Anthony, A., Pellicer, A.A., Torrente, F., Thomson, M.A., Walker-Smith, J.A., Wakefield, A.J.</p> <p>Royal Free and University College Medical School LONDON, U.K.</p>	<p>2+ C</p> <p>This provides some evidence that children with regressive ASD who were following a gluten/casein free diet had lower mucosal eosinophil infiltration.</p>
<p>Innate Immunity Associated with Inflammatory Responses and Cytokine Production against Common Dietary Proteins in Patients with ASD.</p> <p><i>Neuropsychobiology</i> 2002 <b>46</b> (2) pp76-84.</p>	<p>Jyonouchi, H., Sun, S., Itokazu, N.</p> <p>Department of Paediatrics, University of Medicine and Dentistry of New Jersey, USA</p>	<p>2- D</p> <p>Limited evidence of altered immune responses to some dietary proteins in children with ASD.</p>
<p>Dysregulated Innate Immune Responses in Young Children with Autism Spectrum Disorders: Their Relationship to Gastrointestinal Symptoms and Dietary Intervention.</p> <p><i>Neuropsychobiology</i> 2005 <b>51</b> pp77-85</p>	<p>Jyonouchi, H., Geng, L., Ruby, A., Zimmerman-Bier, B.</p> <p>Department of Paediatrics, New Jersey Medical School, USA</p>	<p>2- D</p> <p>Some evidence to support innate immune defects in the ASD children with GI symptoms. This paper will go some way in helping to differentiate those children with ASD who may benefit from dietary intervention.</p>
<p>① A randomised, Controlled Study of Dietary Intervention in Autistic Syndromes. <i>Nutritional Neurosciences</i> 2002 <b>5</b> (4) PP251-261.</p> <p>② Effect of a Dietary Intervention on Autistic Behaviour. <i>Focus on Autism and Other Developmental Disabilities</i> 2003 <b>18</b> (4) pp247-256.</p>	<p>Knivsberg, A.M., Reichelt, K.L., Høien and Nødland, M.</p> <p>Stavanger University College, Stavanger, NORWAY</p>	<p>1 A</p> <p>Some evidence to support the use of gluten and casein free diets in a sub group of children with ASD. Further research is needed to clarify the use of dietary intervention in these children</p>



## LIST OF EXCLUDED PAPERS FOR GLUTEN /CASEIN FREE DIETS (With reasons for exclusion)

Autism.

*National Institute of Mental Health printed 1997. 97-4023.*

Autism and Communication.

*National Institute on Deafness and Other Communication Disorders.*

(No Dietary Intervention discussed).

L. Adams. Nutrition and its Relationship to Autism.

*Focus on Autism and other Developmental Disabilities 1997 Vol 12 (1) pp53-58.*

(No new research. Literature review only).

P. Ashwood. Intestinal Lymphocyte Populations in Children with Regressive Autism: Evidence for Extensive Mucosal Immunopathology.

*Journal of Clinical Immunology 2003 23 (6) p504.*

(No Dietary Intervention discussed – Further evidence of possible mucosal immunopathology in children with regressive Autism).

Birtwhistle. Autism and a Gluten free/Casein free diet.

*Nutritional Perspectives 2000, 23 (2) pp8-9.*

(Unfortunately we have been unable to obtain this article. We have tried all our usual sources including the British Library and they do not hold this title).

L. Bowers. An audit of referrals of children with autistic spectrum disorder to the dietetic service.

*Journal of Human nutrition and Dietetics 2002 15 pp141-44.*

(No Dietary Intervention Researched).

Breakey. Is Food Intolerance due to an inborn error of metabolism.

*Asia Pacific Journal of Clinical Nutrition 2004 Vol 13 p5175.*

(Unable to source).

M. A. Brudnak. Application of genomeceuticals to the molecular and immunological aspects of autism.

*Medical Hypotheses 2001 Vol 57 2 pp186-191*

(No Dietary Intervention discussed).

M. A. Brudnak. Enzyme-based therapy for Autism Spectrum Disorders – Is it worth another look?

*Medical Hypotheses 2002 58 (5) pp422-428.*

(No Dietary Intervention discussed).

E. Danczak. Glucosamine and Plant Lectins in Autistic Spectrum Disorders: An initial report on six children with uncontrolled diarrhoea.

*Journal of Nutritional & Environmental Medicine 2004 14 (4) pp327-330.*

(No Dietary Intervention discussed).

Fitzgerald. Investigation of possible links between Autism and Coeliac Disease.

*Autism, 1999, 3 (2) pp193-195.* (No dietary intervention discussed).

J. Garvey. Diet in Autism and associated disorders.

*Journal of Family Health Care Vol 12 No 2 2002.*

(Not a research paper).

E. A. Goldberg. The link between gastroenterology and Autism.  
*Gastroenterology Nursing* 2003 Vol 27 1 pp16-19.  
(Not a research paper).

Howlin, P. Prognosis in Autism: do specialist treatments affect long term outcome?  
*European Child and Adolescent Psychiatry* 1997 6 pp55-72.  
(No dietary treatment discussed).

H. Jyonouchi et al. Evaluation of an association between gastrointestinal symptoms and cytokine production against common dietary proteins in children with autism spectrum disorders.  
*The Journal of Paediatrics* May 2005.  
(No Dietary Intervention studies. Reference to testing dietary proteins in relation to all medicated immunity).

Parris M. Kidd. Autism, An extreme challenge to integrative medicine. Part I: The Knowledge base.  
*Alternative Medicine Review* 2002 Vol 7 4 pp292-316.  
(No Dietary Intervention discussed).

Parris M. Kidd. Autism. An extreme challenge to integrative medicine. Part II: Medical Management.  
*Alternative Medicine Review* 2002 Vol 7 6 pp472-499.  
(No new evidence to include).

Parris M. Kidd, An approach to the nutritional management of Autism.  
*Integrative Medicine* 2003 Vol 2 pp36-46.  
(Not a research paper).

Panksepp, J. 1979. A Neurochemical theory of Autism.  
*Trends in Neuroscience (TINS)* July 1979. (No dietary intervention discussed).

Reichelt, K. L. Gluten Free Diet in Infantile Autism.  
*Tidsskrift for den Norske lægeforening* 1991, April 20 3 (10) pp1286-7.  
(Would need translating by approved translator, the cost was prohibitive).

Reichelt, K. L., Hole, K., Hamberger, A., Saelid, G., Edminson, P. D., Braestrup, C. B., Lingjaerde, O., Ledaal, P., Orbeck, H. 1981. Biologically Active Peptide-Containing Fractions in Schizophrenia and Childhood Autism.  
*Neurosecretion and Brain Peptides*, edited by Martin, J. B., Reichlin, S., and Bick, K. L. Raven Press, New York. (No dietary intervention discussed).

Risebro, B. Gluten Free diet in Infantile Autism.  
*Tidsskrift for den Norske lægeforening* 1991, June 10, 3 (15) pp1885-6.  
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*SAGE Publications and the National Autistic Society*, 4(2) pp205-206; 012900 pp1362-3613 (200006) 4(2). (No dietary intervention discussed).

Shattock, P., Lowdon, G. 1991.  
Protein, Peptides and Autism. Part 2. Implications for the education and care of people with Autism.

*Brain Dysfunct* 1991; **4**: pp323-334. (No dietary intervention discussed).

Shattock, P., Whiteley, P. 2001.

How Dietary Interventions could Ameliorate the symptoms of Autism.  
*The Pharmacuetical Journal* **267**. (No dietary intervention discussed).

P. Shattock. Expert opinion on therapeutic targets.

*Biochemical Aspects in Autism 2002 Vol 16 Pt 2 pp175-83*.  
(View only at British Library).

P. Shattock & P. Whiteley. Biochemical aspects in autism spectrum disorders: updating the opioid-excess theory and presenting new opportunities for biomedical intervention.

*Expert Opinion on Therapeutic Targets 2002 Vol 6 Pt 2 pp 175-83*.  
(No Dietary Intervention Researched).

Sponheim, E. Gluten Free Diet in Infantile Allergy.

*Tidssknfft for den Norske laefeforening* 1991, Feb 28 **3** (6) pp704-7.  
(Would need translating by approved translator, cost was prohibitive).

J. F. White. Intestinal Pathophysiology in Autism.

*Department of Physiolog, Emory University, Atlanta, Georgia 30322*.  
(No Dietary Intervention discussed).

P. Whiteley. Pervasive developmental disorders: definition, diagnosis, research and interventions.

*Nurse2Nurse Magazine 2003 Vol 3 10 pp48-50*.  
(No Dietary Intervention discussed).

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MMR and Autism. (No dietary intervention discussed)

Whiteley, P. Autism unravelled conference "The Biology of Autism unravelled".

*Expert opinion on pharmacotherapy 2001 2* (7) p1191-3.

(Unavailable after exhausting all sources available, both regionally and nationally).

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Knivsberg, A. M. Nødland, M. Reichelt, K. L. Children with Autistic Syndromes. Gluten and/or Casein free diets as a treatment. Trends, Indicators and Results so far. *Therapeutic approaches to Autism. Research Practice. A.R.U. 1991.* Pp156-166.

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Raiten, D. J., Massaro, T. Perspectives on the Nutritional Ecology of Autistic Children. *Journal of Autism and Developmental Disorders 1986, 16 (2).*

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Whiteley, P. Rodgers, J. Savery, D. Shattock, P. A Gluten free diet as an Intervention for Autism and Associated Spectrum Disorders: Preliminary Findings.

*Autism © 1999 SAGE Publications and The National Autistic Society; 3 (1)* pp45-65.

## **15. PARTS 3 – 8 - OTHER INTERVENTIONS**

Parts 3 – 7 are currently being researched and will be included once they are completed.

The following intervention was researched as follows:

### **Hunter Gatherer**

Search January 1980 – Nov 2002.

Key words used – Hunter Gatherer/elimination diets and Autism.

No suitable papers were found from the search.

This diet was initiated by Dr John Richer, Consultant Clinical Psychologist at John Radcliffe Hospital, Oxford, but it is not current treatment.

### **Acknowledgements**

The authors would like to thank past and present members of DA for initiating the project and for reading and assessing the papers. Our thanks go to the multidisciplinary group in Coventry who worked on part 1. Also our thanks to the Clinical Effectiveness and Quality Committee of the BDA and interested dietitians of the Paediatric and Mental Health Group of the BDA for their helpful comments. Finally, our thanks go to Christine Cooper and Kathleen O'Sullivan for their hard work and patience in typing this document.

## APPENDIX 1 GROUP MEMBERS

<b>Name</b>	<b>Role</b>	<b>Employer</b>
Janet Gill	Specialist Dietitian	North Warwickshire PCT
Elaine Isherwood	Paediatric Dietitian	South Staffordshire PCT
Dave Rex	Child Health Lead	NHS Highland Dietitian
Beverley Spicer	Specialist Dietitian	University Hospital Coventry
Katie Thomas	Specialist Dietitian	University Hospital Coventry

Also past and present members of DA including: Nicky Calow, Rachel Campbell, Philippa Hewitt, Katrine Hurst, Sandra Adams, Julie Higgins and Zoe Connor.



## 16. APPENDIX 2 - CLASSIFICATION OF EVIDENCE

### Quality of Evidence

Excellent	= 1	Evidence from meta-analyses, randomised controlled trials or systematic reviews of randomised controlled trials.
Good	= 2+	Evidence from systematic reviews of case control or cohort studies, or well conducted case control or cohort studies with a low risk of confounding bias or chance. High/moderate probability that the relationship is causal.
Moderate	= 2-	Evidence from case control or cohort studies with a high risk of confounding bias or chance and a significant risk that the relationship is not causal.
Fair	= 3	Evidence from observational studies and non-analytical studies e.g. case reports.
Poor	= 4	Relying on opinions of authorities.
Not Acceptable	= 5	Paper not of suitable scientific quality.

### Importance of Outcomes

A =	Is there any evidence of strong positive behavioural outcomes in any of the three defining features of ASD (i.e. impairment in socialisation, impairment in verbal and non-verbal communication and repetitive patterns of behaviour)?
B =	Is there any evidence of mild positive behavioural outcomes in any of the three defining features of autism (as above)?
C =	Is there any evidence of strong positive physical outcomes (e.g. improvement in bowel function)?
D =	Is there any evidence or mild positive physical outcomes (as above)?
E =	Is there no evidence of a positive outcome?
F =	Is there evidence of a negative outcome?
N =	Not applicable or no outcomes were measured.

Evidence of level 1A or 1C are the best and most relevant. Evidence of level 5F is the least useful and least relevant.

## 17. APPENDIX 3 – RESTRICTIVE OBSESSIVE DIETS

### Clinical Paper Appraisal Summary

**Title of Paper:** Nutrition concerns for  
Children with PDD/Autism

**Authors:** Quinn, H. P. & Levine, K.  
(Boston, MA)

**Reference:** Nutrition Focus 1995,  
5 (5) pp1-8

---

Summary An article summarising aspects of concern regarding children with ASD who exhibit selective eating habits. Briefly covers food preferences, changes over time, oral sensitivity and environmental factors at mealtimes. Concerns discussed are growth rate and possible effects of medication on nutritional status. Very brief summaries of three alternative therapies; Vitamin B6, DMG and GF/CF are given.

---

Strengths

- helpful basic outline of some of the problems encountered with respect to feeding
- a few helpful management strategies are included
- helpful introduction for those new to the field
- case study included with helpful hints written by a dietitian whose child is diagnosed with ASD.

---

Limitations - authors sample is quoted relating to growth but no sample size or details given.

---

Key Points

- useful behavioural strategies recommended
- reinforces the need for well controlled scientific research to determine effective diet / vitamin or mineral therapies in the management of children with ASD.

---

Evidence Level 4 N.

---

Key Findings A useful paper to prompt discussion of practice. The author's opinion is that a multidisciplinary approach is needed.

## Clinical Paper Appraisal Summary

**Title of Paper:** A Balanced Approach towards Healthy Eating in Autism.

**Authors:** Cornish, E.

**Reference:** Journal of Human Nutrition & Dietetics (1998) 11 pp501-509.

---

Summary An audit was undertaken to investigate the dietary intake of food related behaviour of children diagnosed with ASD. 17 children with ASD, aged 42-117 months were interviewed and data collected by 3 day dietary recall and food frequency questionnaire. Eating habits were found to be extremely prescriptive and nutrient intake fell below RNI levels for 53% of children for 1 or more nutrients.

---

Strengths

- well constructed and written.
- gives practical ideas to help others working with children with ASD.
- gives good insight into the feeding difficulties experienced by parents of children with ASD.

---

Limitations

- small sample size.
- no control group.
- dietary assessments were made using household measures and food models. Is this accurate enough for assessing micronutrients?

---

Key Points

- for the first time an objective description is given of the often bizarre eating patterns/restrictions seen in children with ASD and relates the impact of these to nutritional adequacy.
- provides reassurance that despite what may be considered a poor diet it is not greatly deficient in a whole range of different nutrients.
- nutrient analysis showed intakes fell below RNI levels for 53%, 9 children, in one or more of the following nutrients Vitamin C, Vitamin D, Niacin, Iron, Riboflavin, Vitamin B6, Calcium and Zinc.

---

Evidence Level 3 A.

---

Key Findings Most of the children despite having selective and unvaried diets do not suffer nutrient intakes as low as might be expected.

## Clinical Paper Appraisal Summary

**Title of Paper:** Perspectives on the Nutritional Ecology of Autistic Children

**Authors:** Raiten, D. J. & Massaro, T.

**Reference:** Journal of Autism & Developmental Disorders, 1986, Vol 16, No 2

---

Summary Dietary intake was assessed in 40 Autistic and 34 control children using a seven day diet record. Overall adequacy of diet was similar for both groups. A Questionnaire was also used to obtain data on nutrition and health issues, attitudes and beliefs about nutrition and nutritional knowledge.

---

Strengths Good sample size with controls. Well referenced throughout.

---

Limitations No data on the nutritional analysis. The results could have been written more clearly, particularly the MAR calculation.

---

Key points Overall adequacy of the diet was similar for both groups despite the Autistic group having more food-related idiosyncrasies. More positive attitude of the parents/primary care givers of autistic children was reported in the relationship between diet and behaviour and the importance of nutrition.

---

Evidence Level 2+ N.

---

Recommendations Useful to note that the overall adequacy of the diet was similar for both groups despite the Autistic Group having more food related idiosyncrasies.

## 18. APPENDIX 4 - GLUTEN/CASEIN DIET

### Clinical Paper Appraisal Summary

<b>Title of Paper:</b>	①Children with Autistic Syndromes. Gluten and/or Casein-free Diets as a Treatment. Trends, indicators and Results so Far ② (as above - a follow-up study) ③Dietary Intervention in Autistic Syndromes	<b>Authors:</b> Knivsberg, A.M. Reichelt, K. L. Nodland, M. Hoiem, T. (Norway)	<b>Reference:</b> ①See Table. ②Scandinavian J of Education Research, 1995, <b>39</b> (3) p223 ③Brain Dysfunct 1990, <b>3</b> pp315-327.
<b>Summary</b>	15 children with Autistic Spectrum Disorder were cognitively tested using C-Raven, (a shortened version of Raven's Progressive Matrices) and commenced on a diet (gluten and/or casein-free – combination not specified). They were re-tested after 6 months, 1 year, nearly 3 years and 4 years. ②Urine analysis was also performed but not explained – the result indicated that the children on the diet were better able to understand the information they received, better able to concentrate and were easier to teach.		
<b>Strengths</b>	- suggested a limited reason for the GF/CF diet. Recommended the need for further controlled research.		
<b>Limitations</b>	- small sample, no controls - methodology and results not explained - no rationale given for conclusions drawn - results explained in more detail in ②		
<b>Key Points</b>	- initiated interest in possible link between diet and ASD.		
<b>Evidence Level</b>	5 B		
<b>Recommendations</b>	Although outcomes were cited there is insufficient scientific evidence.		

## Clinical Paper Appraisal Summary

**Title of Paper:** Gluten, Milk Proteins & Autism: Dietary Intervention Effects on Behaviour and Peptide Secretion

**Authors:** Reichelt, K. L., Ekrem, J. Scott, H.

**Reference:** J. Applied Nutr. 1990, 42 (1) pp1–10

---

**Summary** 19 children with autistic syndromes were treated with either gluten-free and milk reduced or milk-free and gluten reduced diets (treatment was based on their urine glycoprotein – peptide complex patterns). Before treatment 5 of 15 fully studied patients had increased levels of antibodies to casein and gluten. The study demonstrated a decrease in urinary peptide secretion in response to diet. Improvement was found in some behaviours and a decrease in epileptic seizures was noted.

---

**Strengths**

- measured both behavioural and biochemical changes (teachers and parents observed behaviour).
- demonstrated high frequency of increased IgA antibodies to milk and wheat proteins in children with ASD – statistically significant.
- reduction in urinary peptide secretions statistically significant after 6 months of dietary restrictions.

---

**Limitations**

- biochemistry not easy to understand
- no control group
- no explanation as to the validity of the special diets

---

**Key Points** Discussion of the hypothesis that one or more peptidase defects could be the genetic disposition in autism.

---

**Evidence Level** 3 B.

---

**Recommendations** Evidence not conclusive to support dietary intervention.

## **Clinical Paper Appraisal Summary**

**Title of Paper:** A Gluten-free Diet as an Intervention for Autism and Associated Spectrum Disorders: Preliminary Findings

**Authors:** Whiteley, P., Rodgers, J., Savery, D., Shattock, P.

**Reference:** Autism© 1999 SAGEPubl'ns & the National Autistic Society **3**, (1) pp45-65

---

**Summary** Study looking at the opioid – excess hypothesis of autism. A gluten-free diet was introduced to children with ASD and monitored over a 5 month period, using psychometric tests and urinary profiling. Results suggested that those on a gluten-free diet showed an improvement in behaviour. However, there was no significant decrease in specific urinary compounds excreted when compared with controls and a gluten challenge group.

---

**Strengths**

- a variety of metabolic and psychological tests were used (references given)
- a variety of tools were used to test behavioural differences
- study approached in a reasonably scientific way

---

**Limitations**

- controls were not properly matched and identified
- results not clearly explained

---

**Key Points**

- trial only for 5 months – suggestion that this may explain the lack of changes to urinary compounds excreted (may need to follow diet for longer).
- some behavioural improvements were noted after 3 months
- although a “controlled” trial – controls not properly identified (see limitations)
- have recommended possible use of controlled trials for further research

---

**Evidence Level** 2 – B

---

**Recommendations** Not enough evidence to support the use of a gluten-free diet.

## **Clinical Paper Appraisal Summary**

**Title of Paper:** Probable Etiology and Possible Treatment of Childhood Autism

**Authors:** Reichelt, K. L., Knivsberg, A., Lind, G. & Nodland, M.

**Reference:** Brain Dysfunction 1991, 4 pp308-319

---

**Summary** Looks at a possible defect of peptidase (specifically casein and gluten) as a genetic disposition in autism disorder. Follow-up of over 2 years of 2 cohorts of children on gluten and casein-free diet showed further improvements in those that remained on diet and regression in those that abandoned diet.

---

**Strengths** - Tried to look at an objective biochemical approach.

---

**Limitations**

- educational method not explained sufficiently
- confusingly written.
- little explanation.
- no control group.

---

**Key Points**

- elevated levels of 1gA antibodies against the proteins casein and gluten.
- further improvements in social relations shown in those that remained on the diet.
- reduction of bizarre behaviour shown in those that remained on the diet.
- regression in social relations/behaviour in those that abandoned the diet.

---

**Evidence Level** 5 B

---

**Recommendations** Cannot support the use of gluten and casein-free diet.



## Clinical Paper Appraisal Summary

**Title of Paper:** Colonic CD8 and  $\gamma\delta$  T-cell Infiltration with Epithelial Damage in Children with Autism

**Authors:** Furlano et al

**Reference:** J. of Paediatrics, 2001, 138 (3) pp366-372

---

**Summary** Transverse colon biopsy specimens were obtained from 21 children with ASD, 15 children with active Crohn's disease, 14 patients with active Ulcerative Colitis. 8 children who were histologically normal and 10 control subjects with Lymphoid Nodular Hyperplasia who had chronic 'abdominal pain'. Each biopsy assessment was scored for colitis, eosinophil density, subepithelial cell debris, epithelial index and intraepithelial lymphocyte numbers. Epithelial changes are compared between groups. Immunohistochemistry confirms a distinct lymphocytic colitis in children with autistic spectrum disorders.

---

**Strengths**

- increases understanding of bowel lesions in ASD.
- will trigger further research on the subject.

---

**Limitations**

- descriptive paper with little or no guidance for clinical management of patients.

---

**Key Points**

- children with ASD have colonic changes
- evidence of a distinctive lymphocytic colitis identified in ASD
- remains unclear whether this inflammation is characteristic for ASD in general or found only in a subgroup with intestinal symptoms. Requires further study.

---

**Evidence Level** 2 – N

---

**Recommendations** Some evidence to support gut epithelial dysfunction in ASD.

This is a paper which will help dietitians deepen their understanding of the biological process associated with ASD.

## Clinical Paper Appraisal Summary

**Title of Paper:** Food Allergy and Infantile Autism

**Authors:** S.Lucarelli et al  
Department of Paediatrics,  
Rome

**Reference:** Pamrinerva Medica 1995  
37, pp137-41

---

Summary This study aims to verify the efficacy of a cows milk-free diet (or other foods which gave a positive result after a skin test) in 36 patients with ASD. High levels of IgA antigens specific antibodies for casein, lactalbumin and  $\beta$ -lactoglobulin and IgG + IgM for casein were found. The results led to a hypothesis that a relationship exists between food allergy and infantile autism.

---

Strengths

- control group present but only for serum levels for specific antibodies and skin prick tests.
- clear way of expressing results of behavioural changes

---

Limitations

- limited number of patients and difficulty in evaluating variations in clinical symptoms relating to diet. Data should be interpreted cautiously.

---

Key Points

- limited evidence to suggest there may be a relationship between food allergy and infantile autism.

---

Evidence Level 2 – B/C (C relates to antibody changes).

---

Recommendations

Limited evidence to suggest there may be a relationship between food allergy and infantile ASD.  
Repeating of study on larger numbers to confirm hypothesis would be useful.

## Clinical Paper Appraisal Summary

**Title of Paper:** Role of Neuropeptides in Autism and their Relationships With Classical Neurotransmitters

**Authors:** Shattock, P., Kennedy, A., Rowell, F., Berney, T.

**Reference:** Brain Dysfunct. 1990, 3 pp328-345

---

Summary This paper outlines how excessive levels of opioids in the CNS might affect and modify the classical neurotransmission systems, and in particular the dopaminergic system, and result in some of the perceptual, social and behavioural difficulties which define autism.

---

Strengths - hypothesis thought out in detail.

---

Limitations - results crude (researchers could not be certain that the tests measured exclusively peptides only).

---

Key Points - a suggestion is that peptides, particularly those of opioid activity have a role in the causation of autism.  
- the peptide profile in the urine of patients with autism can be abnormal.

---

Evidence Level 2 – N.

---

Recommendations The peptide profile in the urine of patients with autism may be abnormal.  
This is a useful paper to read prior to subsequent papers by Shattock.

## Clinical Paper Appraisal Summary

**Title of Paper:** Reports on Dietary Intervention  
in Autistic Disorders

**Authors:** Knivsberg, A.M., Reichelt, K.L. &  
Nødland, M.

**Reference:** Nutritional  
Neuroscience, Vol 4 pp25-37

---

Summary An overview of the various studies done on dietary intervention in autism. Beneficial results are reported in all but one study. The results show a reduction in autistic behaviour, increased social and communicative skills and reappearance of autistic traits after the diet has been broken.

---

Strengths Good overview of the various studies. Well referenced within the text.

---

Limitations The one study which did not have positive results is not included.

---

Key points Shows a general reduction in autistic behaviour, increased social and communicative skills in all but one of the studies.

---

Evidence Level 3 B/D

---

Recommendations Paper recommends further investigations are needed on the effect of dietary intervention in Autism.

## Clinical Paper Appraisal Summary

**Title of Paper:** Childhood Autism: A Group Of Hyperpeptidergic Disorders. Possible Etiology and tentative treatment.

**Authors:** Reichelt, K.L., Scott, H., Knivsberg, A.M. Wiig, K., Lind, G. & Nødland, M.

**Reference:** F. Nyberg & V. Brantl  $\beta$ -Casomorphins & Related peptides . 1990. Fyris-Tryck A.B., Uppsala, Sweden

---

Summary Dietary intervention with Gluten and/or milk protein free diet was tried in 2 groups of children with Autistic Syndromes.

---

Strengths Diets were explained, good psychological tests and chemical assays described in detail. Admits only a preliminary study and that further controlled studies are required.

---

Limitations No indication of the difference and comparisons between the 2 groups. No indication of which children improve on which diet. Statements in the discussion not backed up by the study.

---

Key points Beneficial effects on treatment with a Gluten and/or milk-protein free diet.

---

Evidence Level 2- A.

---

Recommendations Evidence not conclusive to support dietary intervention.

## Clinical Paper Appraisal Summary

**Title of Paper:** Urinary Peptide Levels in Autistic children from Seven Countries, and the effect of Dietary Intervention after 4 years.

**Authors:** Reichelt, W.H., Knivsberg, A.M. Nødland, M., Stensrud, M. & Reichelt, K.L.

**Reference:** Brain Dysfunction  
10 pp 44-55.

---

Summary Urinary samples from children with Autism Syndrome were collected from seven countries. The excretion of peptides (in urine) was analysed. A 4 year study of Autistic children on a gluten and/or milk free diet shows that those on the diet continued to progress developmentally.

---

Strengths Attempts to link the biochemistry of peptide metabolism and excretion with dietary intake of Gluten and Casein.

---

Limitations Very poorly constructed and confusingly written study. The 4 year study is not related to the urine samples of children from the seven countries.

---

Key points The new HPLC method of urine analysis appears to be more accurate.

---

Evidence Level 4 B.

---

Recommendations Interesting to read the hypothesis but provides no evidence base however for the use of Gluten/Casein free diets.

## Clinical Paper Appraisal Summary

**Title of Paper:** Nature and Consequences of Hyperpeptiduria and Bovine Casomorphins found in Autistic Syndromes

**Authors:** Reichelt, K.L., Knivsberg, A.M. Nødland, M. & Lind, G.

**Reference:** Brain Dysfunction 1994; 7 pp71-85

---

Summary A Hypothesis that the high levels of peptides found in the urine of autistic patients which could be due to different peptidases with similar action but different chain lengths, have a genetic disposition.

---

Strengths Detailed hypothesis discussed.

---

Limitations There is a mention of a study but it is not used to explain the hypothesis.

---

Key points None of note to support the use of diet.

---

Evidence Level 4 N.

---

Recommendations Cannot support the use of Gluten/Casein free diet.

## Clinical Paper Appraisal Summary

**Title of Paper:** On Gluten Free and Casein Free Diet in Autism and the Opioids Excess Theory: Another Perspective.

**Authors:** Cocchi, R.

**Reference:** Ital J. of Intellect Impair 1996, **9** pp139-152.

---

Summary A discussion on the opioids excess theory as outlined by Reichelt and another rational proposed by the author.

---

Strengths Given a lot of thought to Reichelt's theory.

---

Limitations Poor English, difficult to understand his meaning.  
The paper is based on his opinion and his work done with Down's Syndrome children.

---

Key points Gluten and Casein Free Diet could be useful but he disagrees with Reichelt's theory.

---

Evidence Level 5N

---

Recommendations A useful paper in his challenging of Reichelt opioids excess theory. However cannot support the use of a Gluten and Casein Free Diet.



## Clinical Paper Appraisal Summary

**Title of Paper:** Intestinal Lymphocyte Populations In Children with Regressive Autism: Evidence for Extensive Mucosal Immunopathology

**Authors:** Ashwood, P., Murch, A. H., Anthony, A., Pellicer, A. A., Torrente, F., Thomson, M. A., Walker-Smith, J. A., Wakefield, A. J.

**Reference:** Journal of Clinical Immunology **Vol 23 (6)** November 2003

---

**Summary** This study examines the histopathology of the gut. Duodenal, ileal and colonic biopsies were taken from 131 children who had gastrointestinal symptoms. 77 children had regressive autism. 54 were non ASD children. Routine stool and serological analysis were performed. Histologically there was a prominent mucosal and eosinophil infiltrate in the ASD children (87%) that was significantly lower (42%) in those on a GF/CF diet. The data provides evidence of a pan-enteric mucosal immunopathology in children with regressive ASD that is distinct from other inflammatory bowel disease.

---

**Strengths**

- extensive statistical analysis
- good sample size
- detailed histological analysis
- control group identified

---

**Limitations** not a randomised control trial.

---

**Key points** Regressive ASD children following a gluten and casein free diet had a statistically significantly lower mucosal eosinophil infiltration than the ASD children who were not on a diet.

---

**Evidence Level\*** 2+C

---

**Recommendations** This provides some evidence that children with regressive ASD who were following a gluten/casein free diet had lower mucosal eosinophil infiltration.

## **Clinical Paper Appraisal Summary**

**Title of Paper:** Spontaneous Mucosal Lymphocyte Cytokine Profiles in Children with Autism and Gastrointestinal Symptoms: Mucosal Immune Activation And Reduced Counter Regulatory Interleukin-10

**Authors:** Ashwood, P. Anthony, A. Torrente, F. Wakefield, A. J.

**Reference:** Journal of Clinical Immunology 2004 **24** (6) pp 664-673.

---

**Summary** This study tested the hypothesis that dysregulated intestinal mucosal immunity with enhanced pro-inflammatory cytokine production is present in ASD children. Duodenal and Colonic biopsies were obtained from 21 ASD children and 65 developmentally normal controls of which 38 had signs of histological inflammation. There was a significantly greater proportion of CD3+TNF $\alpha$ + (pro-inflammatory, cytokine producing lymphocytes) cells in the colonic mucosa in those ASD children who had no dietary intervention compared with those on a gluten/casein free diet.

---

**Strengths**

- Detailed histological statistics
- Control Groups.

---

**Limitations** Not a randomised control trial.

---

**Key points** The data provides further evidence of a diffuse mucosal immunopathology in some ASD children.

The Authors state that the data provides evidence for the potential benefit of dietary and immunomodulatory therapies.

---

**Evidence Level\*** 2+C

---

**Recommendations** The study states that given the small sample size the conclusions that can be drawn are limited but clearly the potential influence of gluten and casein merits further study.

## **Clinical Paper Appraisal Summary**

**Title of Paper:** Innate Immunity Associated with Inflammatory Responses and Cytokine Production Against Common Dietary Proteins in Patients with ASD

**Authors:** Jyonouchi, H. Sun, S. Itokazu, N.

**Reference:** Neuropsychobiology 2002; **46**, 2 pp76-84

---

**Summary** A comparison of the immune responses to dietary proteins was made between 72 ASD children, 24 children with dietary protein intolerance, 15 healthy unrelated children and 26 developmentally normal siblings. The study tested the hypothesis that aberrant innate inflammatory responses to lipopolysaccharide (LPS) produced by intestinal flora, may make ASD children more prone to sensitization to common dietary proteins.

---

**Strengths** Good sample size

---

**Limitations**

- Very poorly written paper
- Dietary intervention was vague
- Results unclear.

---

**Key points** ASD children appear to exhibit excessive or dysregulated innate inflammatory responses to LPS stimuli and this predisposes them to sensitization to dietary proteins.

---

**Evidence Level\*** 2 - D

---

**Recommendations** Limited evidence of altered immune responses to some dietary proteins in children with ASD.

## **Clinical Paper Appraisal Summary**

**Title of Paper:** Dysregulated Innate Immune Responses in Young Children with Autism Spectrum Disorders: Their Relationship to Gastrointestinal Symptoms and Dietary Intervention

**Authors:** Jyonouchi, H. Geng, L. Ruby, A. , Zimmerman-Bier, B.

**Reference:** Neuropsychobiology 2005  
51 pp77-85

---

**Summary** 100 ASD children were on an unrestricted diet and 77 ASD children were on an elimination diet (casein/gluten/soya free diet). There were 43 controls comprising of 30 non-allergic food hypersensitivity children, (14 of which were on unrestricted diet and 16 were on similar elimination diet) and 13 typically developing children were on unrestricted diet. All were aged between 1-10 years. Innate immune responses were assessed by measuring production of proinflammatory cytokine production with endotoxin, a major stimulant in innate immunity in the gut mucosa. The findings indicated intrinsic defects of innate immune responses in ASD children with GI symptoms suggesting a possible link between GI and behavioural symptoms mediated by innate immune abnormalities.

---

**Strengths** An interesting paper giving more information on the innate immune mechanism in children with ASD.

---

**Limitations** very specialised study best understood by immunologists!

---

**Key points** Children with ASD, who also have gastrointestinal symptoms, have defects of innate immune responses.

---

**Evidence Level\*** 2 – D.

---

**Recommendations** Some evidence to support innate immune defects in the ASD children with GI symptoms. This paper will go some way in helping to differentiate those children with ASD who may benefit from dietary intervention.

## Clinical Paper Appraisal Summary

**Title of Paper:** ① A randomised, Controlled Study of Dietary Intervention in Autistic Syndromes.  
② Effect of a Dietary Intervention on Autistic Behaviour

**Authors:** Knivsberg, A. M. Reichelt, K. L. Høyen and Nødland, M.  
Knivsberg, A.M. Reichelt, K. L. Høyen, T. Nødland, M.

**Reference:** ① Nutritional Neuroscience 2002 **5** (4) pp251-261  
② Focus on Autism and Other Developmental Disabilities 2003 **18** (4) pp247-256

---

**Summary** 20 children diagnosed with autism and also abnormal urinary peptide patterns were randomised in two groups matched for age, severity of autism and cognitive levels. The test group followed a gluten and casein free diet. Observations and tests were carried out on all the children for function and development before the experimental period and after 1 year. The development of the group of children on the diet was significantly better than for the controls.

---

**Strengths**

- A randomised control study.
- A dietitian was involved in giving dietary advice and was available to the diet group
- Standardised/recognised tests were used for assessment.

---

**Limitations**

- Double blind cross study may have been better with all children on a gluten and casein free diet and using capsule to administer gluten and casein.
- Small sample size.
- No reference was made to the subject's compliance to the diet.
- Results and explanation of urinary peptide abnormalities not documented.

---

**Key points** Improved development (autistic traits, non verbal cognitive level, linguistic age and motor problems) seen for the group of children on the diet. Authors found the development in the children on the diet promising.

---

**Evidence Level\*** 1 A

---

**Recommendations** Some evidence to support the use of gluten and casein free diets in a sub group of children with ASD. Further research is needed to clarify the use of dietary intervention in these children.

## Clinical Paper Appraisal Summary

**Title of Paper:** Effects of a Gluten Free Diet on Rate Of Learning in Autistic Children in an applied Behavioural Analysis Program.

**Authors:** Pontino, J. L. Schaal, K. Chambliss, C.

**Reference:** US Department of Educational Resources Info Centre EC305958 1998

---

**Summary** Discusses a series of studies on 6-8 children that uses between-subjects and within-subjects analysis to examine the effects of a gluten free diet on the academic achievement of children with Autism aged 4-7 years.

---

**Strengths**

- Good time span on the diet.
- Controls used.
- Analysis performed between-subjects and within-subjects.

---

**Limitations**

- Very small number of subjects in trial.
- Confounding evidence as the parents who selected to be on this diet may also give more stimulation to the children generally.

---

**Key points** No significant performance change was observed between 0-9 months on the Gluten free diet.

---

**Evidence Level\*** 2 – E.

---

**Recommendations**

- No recommendations possible as sample size too small.
- Further research is needed to determine the long term impact of the Gluten free diet on the performance of Autistic Children.

Studies 1-4 show significant improvement in the rate of learning between 1-3 month period comparing rate of learning before and 1 month after Gluten free diet. However Study 5 failed to show improved performance between 0-9 months which raises question about the effectiveness of this treatment.

## **Clinical Paper Appraisal Summary**

**Title of Paper:** Plasma Amino Acids Profiles in Children with Autism: Potential Risk of Nutritional Deficiencies.

**Authors:** Arnold, G L., Hyman, S L.  
Mooney, R A., Kirby, R S.

**Reference:** Journal of Autism and Developmental Disorders  
**33** (4) 2003 pp449-454

---

**Summary** Plasma Amino acid profiles of 36 children with ASD were reviewed to determine the impact of diet on AA patterns. 10 children on GF/CF diet and 26 on unrestricted diets. Age/Gender matched controls of non ASD children.

---

**Strengths** Interesting study which highlights the significance of restricted diets on the protein nutrition.

---

**Limitations** Result not clearly documented.

---

**Key points** No amino acid profile specific to Autism was identified. However children with Autism had more essential amino acid deficiencies consistent with poor protein nutrition.

---

**Evidence Level\*** 2 + D.

---

**Recommendations** Care needs to be taken when seeing children with restricted diets that their protein intake and Amino Acid intake is sufficient



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