Development and evaluation of a questionnaire for feeding problems and gastrointestinal symptoms in children with Autism Spectrum Disorders and the impact of these problems on family life

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DECLARATION

I declare that the thesis entitled ‘Development and evaluation of a questionnaire for feeding problems and gastrointestinal symptoms children with Autism Spectrum Disorders and the impact of these problems on family life’ is entirely my own work.

The research was carried out from September 2008 to September 2012 at Newcastle University. All activities in this thesis are original unless acknowledged in the text or by reference.

The thesis has not been previously submitted at this university or any other universities.

ABSTRACT

Managing feeding problems and gastrointestinal (GI) symptoms in children with Autism Spectrum Disorders (ASD) is a challenging process for professionals and parents especially if they become persistent and longstanding. These problems may have psychosocial and financial impacts on family life. To date, there is no structured questionnaire available to assist community professionals to identify these problems in a systematic manner.

The primary aim of this research was to develop an interviewer-based questionnaire for community professionals (the 'Brief structured questionnaire for the Early identification of Feeding problems and GI symptoms in primary school children with ASD (BEFG-ASD)). The secondary aim was to evaluate the psychometric properties of the BEFG-ASD. The development process of the BEFG-ASD included a comprehensive literature review, items and scales construction, specialist review, a modified Delphi technique and a pre-testing with professionals and parents. 42 items within 15 sub-domains of feeding problems, GI symptoms and the impact were selected. The panel experts in the Delphi technique (n=20) rated the items as either 'important' or 'very important' (Mean score: 1.0-2.0).

The final draft of the BEFG-ASD was field-tested with 48 professionals and 74 parents of primary schoolchildren with ASD (aged 4-11) in North East England. Responses from the field-testing were used to evaluate the psychometric properties of the BEFG-ASD. Face validity and content validity was established. Internal consistency of the 42 items was good (Cronbach's alpha: 0.85) but varied across domains. Test-retest reliability and inter-rater reliability of domains and items was satisfactory. Criterion validity and construct validity of the BEFG-ASD also varied across domains and sub domains.

The BEFG-ASD is the first questionnaire developed for use by community professionals. Further research and clinical practice will increase our understanding of its properties and utility in different population and settings.

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LIST OF ABBREVIATIONS

ASD	Autism Spectrum Disorders
ASD-CC	Autism Spectrum Disorders-Co morbidity for Children
ALSPAC	Avon Longitudinal Study of Parents and Children
BEFG-ASD	Brief structured questionnaire for the early identification of feeding problems and gastrointestinal symptoms in young children with ASD
BAMBI	Brief Autism Mealtime Behaviour Inventory
BDA	British Dietetic Association
BSC	Bristol Stool Chart
CAM	Complementary and alternative medicine
CAMHS	Child and Adolescent Mental Health Services
CEBI	Children's Eating Behaviour Inventory
CDC	Child Development Centres
CLDT	Child and Learning Disabilities Team
DASLNE	Database of children with autism living in North East England
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders Fourth Edition
DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition Text Revision
FACE	Family Advocacy and Coordination Effort
FD	Feeding disorder
FP	Feeding problems
HFFQ	Harvard Food Frequency Questionnaire
GERD	Gastro esophageal reflux disease
GI	Gastrointestinal
GFCF	Gluten free casein free diet
GOR	Gastro oesophageal reflux
GSC	Gut symptom checklist

LIST OF ABBREVIATIONS

ICF	International Classification of Functioning, Disability and Health
ICD-10	Tenth Revision of the International Classification of Diseases and related health problems
ICF-CY	International Classification of Functioning, Disability and Health - Child and Youth Version
IP	Intellectual Properties
IFS	Impact on Family Scale
IRQ	Invention Record Questionnaire
MHF	Mental Health Foundation
NAS	National Autistic Society
NHS	National Health Service
NRES	National Research Ethics Service
PACTS	Pediatric Ambulatory Care Treatment Study
PDD-NOS	Pervasive Development Disorder - Not Otherwise Specified
PIG	Paediatric Interest Group
QAS-99	Questionnaire Appraisal System 1999
RD	Rumination Disorder
R&D	Research and Development
STEP	Screening Tool for Feeding Problem
SCQ	Social Communication Questionnaire
UK	United Kingdom
USA	United States of America
WHO	World Health Organization
WIAI	Wellbeing in Autism Index
YAQ	Youth/Adolescent Food Frequency Questionnaire

CHAPTER 1. INTRODUCTION

Chapter 1. Introduction

1.1. Definition of terms

There are several main terms used in the present research. These include Autism Spectrum Disorders (ASD), feeding problems, gastrointestinal (GI) symptoms and the impact of feeding problems and GI symptoms.

ASD is an umbrella term to include “autism”, “atypical autism”, “autistic disorder”, “pervasive developmental disorder not otherwise specified (PDD-NOS)”, and “Asperger syndrome’ (World Health Organization, 1992; American Psychiatric Association, 1994a; Le Couteur, 2003; National Institute of Mental Health, 2007; Scottish Intercollegiate Guidelines Network, 2007; National Institute of Health and Clinical Excellence, 2011). Clinicians and researchers in published studies have used the diagnostic criteria in the Mental and Behavioural Disorders of the International Classification of Diseases and Health Related Problems, 10th Edition[1] (ICD-10) (World Health Organization, 1992) and the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition[2] (DSM-IV) (American Psychiatric Association, 1994a) to diagnose ASD.

Feeding problems are defined as “child is unable or refuses to eat certain foods because of the neuromotor dysfunction, eating behaviour or psychosocial factors” (Samour, 2005). The child also has difficulties or fails to eat or drink sufficient quantity or variety of foods to meet their nutritional needs and growth (Piazza and Carroll-Hernandez, 2004). To date, there is a wide range of terms used for feeding problems described in children with ASD. The terms include food selectivity or food refusal, food sensitivity,

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[1] **ICD-10 Categories (F84):**
F84.0- Pervasive developmental disorders include childhood autism
F84.1- Atypical Autism
F84.2- Rett’s syndrome
F84.3- Other childhood disintegrative disorder
F84.4- Overactive disorder associated with mental retardation and stereotyped movements
F84.5- Aspergers Syndrome
F84.8- Other pervasive developmental disorders
F84.9- Pervasive developmental disorder, unspecified

[2] **DSMV-IV Diagnostic code**:
299.00- Autistic Disorder
299.80- Rett’s Disorders

mealtime behaviour, food cravings, food dislikes, pica and abnormal eating habits (Cornish, 1998; Matson and Bamburg, 1999; Ahearn et al., 2001; Cornish, 2002; Kuhn and Matson, 2002; Schreck et al., 2004; Kerwin et al., 2005; Schreck and Williams, 2006; Keen, 2007; Adams et al., 2008; Johnson et al., 2008; Lockner et al., 2008; Lukens and Linscheid, 2008; Martins et al., 2008; Valicenti-McDermott et al., 2008; Herndon et al., 2009; Jyonouchi, 2009; Matson and Fodstad, 2009; Matson et al., 2009; Nicholls and Bryant-Waugh, 2009; Bandini et al., 2010; Cermak et al., 2010; Provost et al., 2010; Sharp et al., 2010).

Gastrointestinal (GI) symptoms in children with ASD is the term used in this research to refer to constipation, diarrhoea, abdominal pain, vomiting and associated problems such as toileting and weight problems (Heyman et al., 1999; Horvath et al., 1999; Lightdale et al., 2001; Black et al., 2002; Afzal et al., 2003; Kuddo and Nelson, 2003; Molloy and Manning-Courtney, 2003; Goldberg, 2004; Erickson et al., 2005; Pallanti et al., 2005; Valicenti-McDermott et al., 2006; Levy et al., 2007; Valicenti-McDermott et al., 2008; Nikolov et al., 2009; Smith et al., 2009; Buie et al., 2010b).

Impact is defined as “any restriction in participation experienced by child or family as a result of a child’s health condition or disability” (Jessen et al., 2003). In the present research, impact will be used as a term to describe different aspects of some of the effects of feeding problems and GI symptoms on parent’s life. These include stress related to managing feeding problems and GI symptoms; the impact on financial status of the parent/ carer and the impact of feeding problems and GI symptoms on family (including siblings of the child).

Professionals are the term used in this research to refer to all service providers working within the health system and outside the health system. These include health professionals, education practitioners and other workers who are involved in the management of children with ASD in the community (World Health Organization, 2007).

1.2. Background

Autism Spectrum Disorders (ASD) are common lifelong neuro developmental disorders that are increasingly recognised and diagnosed in early childhood population (Le Couteur, 2003; Baird et al., 2006; National Institute of Mental Health, 2007; Newschaffer, 2007; Williams et al., 2008; Yates and Le Couteur, 2009; National Collaborating Centre for Women's and Children's Health and National Institute for Health and Clinical Excellence (NICE), 2011). The characteristics of children with ASD include impairments across three main areas: social communication, social interaction, and repetitive stereotype behaviours. Other characteristics include language impairment, cognitive impairment, sensory impairment, and rigidity in behaviour and thinking (Le Couteur, 2003; Yates and Le Couteur, 2009; NICE, 2011).Most recent studies conducted in United Kingdom (UK) have confirmed that ASD affects approximately 1% of children (Baird et al., 2006; Williams and Brayne, 2006; Williams et al., 2008; Baron-Cohen et al., 2009), which is similar to the prevalence of ASD in the United States of America (USA)(Kogan et al., 2008). According to Sun and Allison (2010), the prevalence of ASD in Asian countries such as Japan and China has increased over time. The prevalence of ASD for six countries (China, Japan, Israel, Iran, Taiwan and Indonesia) ranges from 0.3% to 2.5 % (Sun and Allison, 2010). The differences in the reported prevalence rates for ASD in the different countries are probably related to different methodologies and diagnostic procedures used in each study. Thus, the apparent increase in prevalence rates of ASD among children over the past decade in many countries is also likely to reflect increased awareness, improved detection and an acceptance of the broader spectrum of ASD (Scottish Intercollegiate Guidelines Network, 2007; Yates and Le Couteur., 2009; NICE, 2011).

It is also increasingly recognised that children with ASD often have additional medical, developmental and mental health problems such as sleep disorders, feeding problems, GI symptoms, learning disabilities, anxiety and emotional lability. Many of these problems can also be experienced by typically developing children and children with other disabilities. There is an emerging literature highlighting the rates and different types of feeding problems and GI symptoms among young children with ASD (Table 1.1 and Table 1.2). The design of the majority of the studies from 1998 to 2010 are observational (cross sectional, case control) and conducted in a range of different settings and treatment programme from child general population community samples, educational/schools samples to clinic settings such as dietary treatment programmes. Sample sizes range from 17 to 349 participants of children with ASD aged range from 2 years to 18 years. Several studies used children without ASD or typically developing children or children with other disabilities as comparison groups (Field et., 2003; Schreck et al., 2004, 2006; Martin, Young and Robson., 2008; Johnson et al., 2008; Bandini et al., 2010; Smith et al., 2009; Black et al., 2002; Sandhu et al., 2009; Afzal et al., 2003). The most common methods for collecting information about feeding problems and GI symptoms were parental self-report questionnaires. Some studies used direct interviews, clinical reports from multidisciplinary feeding programme, direct observation methods or audit of referrals (Field et al., 2003; Kerwin et al., 2005; Ahearn et al., 2001; Cornish, 1998; Afzal et al., 2003; Black et al., 2002). The majority of the studies developed their own non-validated parent self-report questionnaires to report the rates and types of feeding problems and GI symptoms. The details of findings from these studies of feeding problems and GI symptoms are discussed in Chapter 2-Literature Review.

Feeding problems amongst regularly developing young children in early childhood (i.e. the first five years) are common but with considerable variation between individuals and patterns of change over time (Nicholls and Bryant-Waugh, 2009; Fox and Joughin, 2002). Feeding problems such as food refusal, selective eating and inappropriate texture of food in the child population have also been shown to become more obvious and intense as children get older and especially as they move into primary school age (between the ages of 5 and 12 years) (Fox and Joughin, 2002). There are likely to be many factors influencing this increase in severity and intensity of the feeding problems and eating habits of these older children. These factors include the child's level of increased physical activities, exposure to other lifestyle and environmental factors (home, schools, family, and/or siblings) compared with the experiences of infants or toddlers (Fox and Joughin, 2002; Nicholls and Bryant-Waugh, 2009). Similar patterns of increasing levels of severity and intensity have also been identified among primary school children children with ASD (Nicholls and Bryant-Waugh, 2009). Field et al (2003) reported rates of feeding problems in children with ASD and children with disabilities (under 12 years old) as high as 40% to 80%. This rate is higher than the rates reported in typically developing children (usually in the order of 25% to 45 %) (Nicholls and Bryant-Waugh, 2009; Cermak et al., 2010). Similarly, Matson et al (2009) reported rates of feeding problems among school children with ASD (aged 3 to 16 years) of 59% compared to atypically and typically developing children (Rate: 1-28%). In summary, the results reported in the studies included in this review indicate that many primary school aged children with ASD can experience several types of feeding problems such as food selectivity, food refusal, food sensitivity, difficult mealtime behaviour, food cravings, food dislikes and pica (Cornish, 1998; Matson and Bamburg, 1999; Ahearn et al., 2001; Cornish, 2002; Kuhn and Matson, 2002; Schreck et al., 2004; Kerwin et al., 2005; Schreck and Williams, 2006; Keen, 2007; Adams et al., 2008; Johnson et al., 2008; Lockner et al., 2008; Lukens and Linscheid, 2008; Martins et al., 2008; Valicenti-McDermott et al., 2008; Herndon et al., 2009; Jyonouchi, 2009; Matson and Fodstad, 2009; Matson et al., 2009; Nicholls and Bryant-Waugh, 2009; Bandini et al., 2010; Cermak et al., 2010; Provost et al., 2010; Sharp et al., 2010). Further, there are some studies reported a range of different types of food selectivity by type, texture, brand, appearance and presentation (Cornish, 1998, 2002; Field et al., 2003; Shreck et al., 2004). In addition, some children also had food refusal, dysphagia and gastroesophaegal reflux (GOR) similar to children with Cerebral Palsy and Down Syndrome (Field et al., 2003). In addition, there are reports that for some children with ASD the feeding problems may overlap or perhaps interact with additional GI symptoms, and possibly also with some ASD characteristics such as behavioural rigidity and sensory difficulties (Lukens and Linscheid, 2008; Kerwin et al., 2005; Valicenti McDermott et al., 2008). The results of the studies has shown that feeding problems in primary school children are more intense, can take many forms and distinct compared with typically developing children other children with neurodisabilities. Therefore, further research is needed to understand how best to manage a combination of feeding problems and other co-occurring problems.

Turning to gastrointestinal symptoms (GI) in children with ASD, again several studies have reported a wide range of symptoms in young children with ASD aged from 2 years to 18 years (Table 1.2). In summary, the reported symptoms include constipation, chronic abdominal pain, gaseousness, reflux, vomiting and diarrhoea (Heyman et al., 1999; Horvath et al., 1999; Lightdale et al., 2001; Black et al., 2002; Afzal et al., 2003;

Kuddo and Nelson, 2003; Molloy and Manning-Courtney, 2003; Goldberg, 2004; Erickson et al., 2005; Pallanti et al., 2005; Valicenti-McDermott et al., 2006; Levy et al., 2007; Valicenti-McDermott et al., 2008; Nikolov et al., 2009; Smith et al., 2009; Sandhu et al.,2009). However there is little consistency in the findings with rates of GI symptoms among children with ASD (under 18 years old) ranging from 9% to 90% compared with typically developing children (up to 30%). There are likely to be several reasons for these inconsistent findings. Several different methodologies have been used to identify GI symptoms. Some studies used abdominal radiograph data from a general practice database, (Black et al., 2002; Afzal et., 2003) and others included children recruited from a clinical sample (Levy et al.,2007; Valicenti-McDermott et al., 2008; Nikolov et al., 2009) or longitudinal study (Sandhu et al., 2009). The majority of studies used questionnaires (self-report or interviews), and diagnostic criteria to identify a range of GI symptoms in children with ASD. Valicenti-McDermott et al (2006) in a cross sectional study reported that 70% children with ASD (below 18 years old; mean age: 7.6 years) had experienced one or more GI symptoms compared with typically developing children (28%) and other children with developmental disabilities (42%). In addition, children who had GI symptoms also had food selectivity problems (Valicenti-McDermott et al., 2006; Valicenti Mc-Dermott et al., 2008). Similarly, Kerwin et al (2005) also has reported that in a community sample of children with PDD-NOS investigated for abdominal pain, constipation and diarrhoea were also described as suffering from feeding problems. These studies (Valicenti-McDermott et al., 2006; Valicenti-McDermott et al., 2008; Kerwin et al., 2005) suggest that primary school children with ASD are likely to have a combination of feeding problems and GI symptoms and perhaps there may be a relationship between the two sets of problems and/or other impairments. Further, Nikolov et al (2009) reported that children with ASD (aged 5-17 years) with GI symptoms showed greater symptom of anxiety, irritability and had severe behavioural problems (such as tantrum, aggressive behaviour and self-injurious behaviour). These findings have shown that it is important to consider these behavioural problems as part of the identification of GI symptoms.

Smith et al (2009) in their clinic-based study of primary school children with ASD (9 – 12 years) reported that parents of children with ASD are more likely to express concern about their child's GI symptoms (35% for ASD group and 12% for special school group. Although the types of reported GI symptoms are similar to those reported in typically developing children, there is some evidence that managing these types of problems may be more challenging and difficult for parents of children with ASD especially as the children enter school life. Further research is needed to support evidence on a range of GI symptoms in primary school children with ASD. The details of findings of some studies on GI symptoms are summarised in Table 1.2 and critically appraised in more detail in the Chapter 2.3 of this thesis.

Table 1.1. Feeding problems in children with Autism Spectrum Disorders (ASD)

Study	Purpose	Participants characteristics (diagnosis and age)	Comparison group and sample size	Recruitment Procedure /methods	Results (Types of feeding problems and rate)
Cornish (1998)	To determine abnormal feeding patterns and dietary intake of children with ASD	17 ASD 4- 10 years	None	Clinical sample 3 day dietary recall Food frequency questionnaire	Food selectivity : 59% Introduction to new foods (food refusal) and difficult mealtime behaviours as common problems., Children ate less than 20 foods, low nutrient intakes
William et al (2000)	To investigate eating habits of children with Autism and PDD-NOS	100 Autism and PDD-NOS Age range: 22 months to 10 years	None	Community sample- The Autism project Questionnaires: self-report (NVQ*)	Two thirds of parents reported food refusal and difficult mealtime behaviours
Cornish (2002)	To determine the effects of selective diet on food choices	37 ASD Age range:3 years to 16 years	None	Clinical sample Questionnaires: self-report (NVQ*)	Food selectivity: 89% 32% to 50% of children had nutrient deficiency
Schreck and William (2006)	To determine the types of feeding problems, food preference and the relationship to family eating preference	138 ASD (Autism, Asperger's Syndrome, PDD-NOS) 4 years to 12 years	238 typically developing children	Community sample Questionnaires :self-report) The CEBI** (VQ***)	Food refusal ;57%, Restricted variety: 72%, Specific utensil requirements=14%, oral motor problems =23%
Ahearn et al (2001)	To identify categories of feeding problems in children with ASD	21 Autism; 9 PDD-NOS 3-14 years	None	Direct observation and data collection for education and diet treatment programme	Food selectivity by type or texture:57% Low to moderate food acceptance (food refusal): 87%

NVQ* = Non Validated Questionnaire; CEBI**=The Children's Eating Behaviour Inventory (Archer, Rosebaum and Streiner, 1991); VQ***=Validated Questionnaire

Table 1.1. Feeding problems in children with Autism Spectrum Disorders (ASD)

Study	Purpose	Participants characteristics (diagnosis and age)	Comparison group and sample size	Recruitment Procedure /methods	Results (Types of feeding problems and rate)
Field et al (2003)	To describe feeding problems in a clinical sample	26 ASD 1 month - 12 years	349 Children with Down Syndrome and Cerebral Palsy	Clinical sample Audit of clinical reports of children from a feeding programme	Food selectivity by type: 62%, by texture: 31% Children with ASD also had food refusal, dysphagia and gastro oesophageal reflux (GOR)
Kerwin et al (2005)	To examine potential relationship among parental reports of feeding problems, GI symptoms and behavioural problems in children with ASD	89 ASD (Autism, Asperger's Syndrome, PDD-NOS) 30 months - 18 years	None	Community sample Questionnaires: self-report (NVQ*)	Strong food dislikes, food selectivity, aggressiveness during meal time : 50-75% (Self-injurious behaviours: head banging, ear hitting, eye pressuring, spitting foods) Pica: 20%
Martin, Young and Robson (2008)	To assess feeding problems and eating behaviours in children with ASD, typically developing children with ASD siblings and typically developing children with siblings who did not have disability	58 ASD 2 years -12 years	31 Typically developing children with ASD siblings 31 Typically developing children with siblings who did not have disability	Questionnaires: self-report (NVQ*)	50% of children with ASD refused to eat fruits and vegetables compared to other group, relationship between mother's eating behaviour and child's eating behaviour Food selectivity, food neophobia among children with ASD compared to other group. Parents of children with ASD had negative perceptions of the child's dietary intake.

NVQ* = Non Validated Questionnaire

Table 1.1. Feeding problems in children with Autism Spectrum Disorders (ASD)

Study	Purpose	Participants characteristics (diagnosis and age)	Comparison group and sample size	Recruitment Procedure /methods	Results (Types of feeding problems and rate)
Herndon et al (2009)	To evaluate nutritional intake of children with ASD	46 ASD 3 years -8 years	31 typically developing children	Children recruited from hospitals, clinics and schools 3-days food diary	64% of children with ASD had limited consumption of foods Children with ASD ate less dairy products than typically developing children
Bandini et al (2010)	To determine food selectivity between children with ASD and typically developing children	58 ASD 3 years - 11 years	53 Typically developing children	Children recruited from CHAMPS**** Questionnaires: interview (NVQ*) Harvard food frequency (VQ***) food record	Children with ASD displayed more food refusal and had more limited food repertoire, significant association between limited food repertoire and nutrient deficiency (r=-0.33, p=0.0006)
Provost et al (2010)	To determine specific food preferences in children with ASD	24 ASD 3years -6 years	24, typically developing children	Questionnaires (self-report) (NVQ*)	Food sensitivity or specific food preferences: 95% Food preference based on food colours (33%), food packaging (25%), food textures (71%), food temperatures (46%)

NVQ* = Non Validated Questionnaire , VQ***=Validated Questionnaire; CHAMPS**** =Children’s Activity and Meal Patterns Study

Table 1.2. Gastrointestinal symptoms in children with Autism Spectrum Disorders (ASD)

Study	Purpose	Participants characteristics (diagnosis and age)	Comparison group and sample size	Recruitment Procedure /methods	Results (Types of GI symptoms and rate)
Black et al (2002)	To identify rate of GI symptoms	96 ASD mean age: 4 years Matched for age, gender and index date (date of first recorded diagnosis of ASD)	449 children without ASD	Computer recorded data from UK General Practices Database Clinical interview	GI symptoms (diarrhoea, pain) in children with ASD: 9%, similar across both groups
Molloy and Manning-Courtney (2003)	To identify patterns of GI symptoms	137 ASD 2 - 8 years	None	Community sample Questionnaires (NVQ*)	24% (n=33) children with ASD had at least one GI symptom, chronic diarrhoea (n=17), constipation (n=12), vomiting (n=9), abdominal pain (n=3)
Afzal et al (2003)	To investigate the diagnosis of severe constipation in children with ASD and without ASD	103 ASD (core Autism and Asperger's Syndrome) Age: $\leq$18 years	29 children without ASD	Clinical sample Abdominal radiographs Children with ASD referred to paediatric gastroenterology service Retrospective study	36% children with ASD had moderate or severe constipation with acquired mega rectum 61% of children with ASD received gluten free and casein free diet, casein free or gluten free

NVQ* = Non Validated Questionnaire

Table 1.2. Gastrointestinal symptoms in children with Autism Spectrum Disorders (ASD)

Study	Purpose	Participants characteristics (diagnosis and age)	Comparison group and sample size	Recruitment Procedure /methods	Results (Types of GI symptoms and rate)
Horvath et al (1999)	To evaluate the structure of function of the GI tract in children with ASD	36 ASD (Autism and PDD-NOS) Age: 2.5 years	None	Clinical sample Clinical investigations (e.g. gastrointestinal endoscopy, histology)	Abdominal pain : 69%, n=25 Chronic diarrhoea: 58%, n=21 Bloating:58%, n=21
Valicenti-McDermott et al (2006)	To compare prevalence of GI symptoms in children with ASD, typically developing children and children with developmental disabilities	50 ASD 1 year-18 years	50 typically developing children 50 children with developmental disabilities	Clinical sample (paediatric programmes, clinics, private practices) Structured interviews	70% GI symptoms in children with ASD, 28% in typically developing children, 42% other developmental disabilities Food selectivity: 60% in children with ASD, 22% typically developing children, 36% other developmental disabilities
Valicenti-McDermott et al (2008)	To compare GI symptoms in children with ASD with language regression and without language regression	100 ASD children with and without language regression Age: 1 year- 18 years	Children without language regression 100 ASD	Clinical sample self- report Questionnaires (NVQ*)	68% children with language regression experienced one or more GI symptoms (abdominal pain, constipation and diarrhoea at least once per week) Food selectivity: 62%
Smith et al (2009)	To investigate GI symptoms in children with ASD and children in mainstream school	Mean age: 51 ASD (ASD, childhood autism, atypical autism, Asperger's Syndrome) Mean age :9.7 years (SD 3.7), Mainstream children, Mean Age:10.0 years (SD 3.2), Special school children Mean Age: 12.6 years (SD 3.5)	112 typically developing children 35 Children with learning disabilities and other developmental disabilities	Clinical sample self-report Questionnaires (NVQ*)	Constipation: 25% Diarrhoea:27% Flatulance rate: 24% Rates are similar across all groups, no significant difference between groups Parents of children with ASD are more concerned about GI symptoms

NVQ* = Non Validated Questionnaire

Table 1.2. Gastrointestinal symptoms in children with Autism Spectrum Disorders (ASD)

Study	Purpose	Participants characteristics (diagnosis and age)	Comparison group and sample size	Recruitment Procedure /methods	Results (Types of GI symptoms and rate)
Nikolov et al (2009)	To evaluate GI symptoms in ASD (PDD-NOS and Asperger's Syndrome)	ASD (PDD-NOS Asperger syndrome) Boys=145, girls=27 Age range: 5 years - 17 years	None	Clinical sample (Children enrolled in a randomised clinical trial) Structured Interview using screening questionnaires (NVQ*)	23% children had GI symptoms (moderate or severe)- constipation and diarrhoea
Sandhu et al (2009)	To investigate whether children with ASD have bowel symptoms consistent with underlying enterocolitis	78ASD Age: up to 42 months (stool patterns recorded at 4 weeks and 6, 18, 30 and 42 months of age	78 typically developing children	Avon Longitudinal Study of Parents and Children (ALSPAC) Community sample Questionnaires (Information on stool patterns)	50% diarrhoea in children with ASD, prevalence increased with age compared to typically developing children No major differences in stool colour and consistency

NVQ* = Non Validated Questionnaire

Based on the evidence, feeding problems and GI symptoms among young children with ASD seem to be common but the rates of the problems vary between studies. It is striking how little systematic research has been undertaken to inform community professionals who may be trying to support families how best to proceed with these difficulties. Although the reported nature of the feeding problems and GI symptoms in young children with ASD seems to be similar for typically developing children, children with a variety of different disabilities and children/young people with ASD, there is some suggestion that these problems are more prevalent and intense in children with ASD (Cermak et al., 2010). Thus, managing feeding problems and GI symptoms in young children with ASD is likely to be particularly challenging for both professionals and parents or carers (Field et al., 2003).

Findings from past studies have shown that feeding problems and GI symptoms in primary school children with ASD are complex compared to other groups of children with neurodisabilities, and more likely to involve a complex combination of several individual and family factors, for example physical health, ASD characteristics, developmental delay, and parental feeding practices (Field et al., 2003; Valicenti Mc-Dermott et al., 2006). Therefore, the identification of feeding problems and GI symptoms in children with ASD seems likely to be complex and challenging especially as these problems may also be associated with the child’s individual functioning and his/her ASD characteristics , such as the patterns of any sensory issues and rigidity behaviours (Lukens and Linscheid, 2008; Cermak et al.,2010; Seiverling, Williams and Sturmey, 2010). Further, children with ASD are likely to have additional and co-morbid problems such as communication difficulties, deleopmental delay, physical health problems which may affect how the child and parent cope with any feeding problems and GI symptoms (Cermak et al., 2010). In addition, parental feeding practices, levels of parental anxiety/ other mental health disorders and perceptions about their child’s feeding problems or GI symptoms may also influence the identified rates or types of feeding problems and GI symptoms among young children with ASD (Field et al., 2003; Martin, Young and Robson, 2008., Smith et al.,2009; Kerwin et al., 2005). From all of this evidence, there is a need for more detailed and systematic investigation of both problems. A specific tool such as a structured questionnaire might be needed to identify feeding problems and GI symptoms in primary school children with ASD. It could be used for the systematic collection of data about feeding problems and GI symptoms of children with ASD and would be a valuable addition to both clinical/community practice and further systematic research in these complex areas of child development. A new structured questionnaire with good reliability and validity when used in community services would be a valuable measure for professionals working directly with families and ASD researchers.

Feeding problems and GI symptoms are likely to have a financial and psychosocial impact on both affected children and their families, and may also have an additional financial burden. Studies of parents of young children with ASD have consistently reported higher rates of stress for the parents of the children with ASD (aged 4-11 years) compared to the rates reported by parents of children with other disabilities (Hastings and Johnson, 2001; Davis and Carter, 2008; Williams et al., 2008). High cost and time needed to manage their child's behaviour and implement the range of specific interventions or therapies may contribute to the stress and burden experienced by these parents or carers (Goin-Kochel, Mackintoch and Myers 2009). However, there is very little published evidence of the impact of feeding problems and GI symptoms on the family life of children/young people with ASD. Parents of primary school children with ASD (4-11 years) have reported that they felt more isolated and that eating out as a family, going out and socialising were particularly difficult (Cornish, 1998; Williams et al., 2000; Kerwin et al., 2005). To date, the evidence (albeit limited) does indicate that feeding problems and GI symptoms are increased among primary school children particularly between aged 4-11 years old. Some authors recommend that feeding problems and/or GI symptoms should be identified before they become entrenched (Kerwin et al., 2005; Cermak et al., 2010; Myers et al., 2007). Indeed, some studies report that feeding problems and GI symptoms among children with ASD aged 4-11 years old are often persistent and longstanding (Field et al., 2003; Kerwin et al., 2005; Valicenti-McDermott et al., 2008). Persistent problems may have other impacts for the children, their families and friends. The findings suggest that first, further research and systematic investigation is required to understand these complex interactions in primary school children with ASD. Second, professionals who are supporting primary school children with ASD and their families when investigating for the presence of possible feeding problems and GI symptoms, should also identify and consider the impact of these problems on the individuals concerned and the family as a whole. Therefore, this age (4-11 years old) is the ideal age range to study feeding problems or GI symptoms.

At present, there is no structured questionnaire that community based professionals can use to systematically enquire about feeding problems, GI symptoms and the impact of these problems at an early stage, before these problems become entrenched. The questionnaire should also covered a wide range of feeding problems and GI symptoms reported in past studies, brief, straightforward, and can be used by a range of professionals in the community including teachers at schools. Indeed, there are few questionnaires available to assess feeding problems in children with disability and children with ASD. Two questionnaires - the Screening Tool for Feeding Problem (STEP) (Kuhn and Matson, 2002) and the Children's Eating Behaviour Inventory (CEBI) (Archer et al., 1991), are not used by professionals in health or education settings. Neither of the questionnaires includes GI symptoms in children with ASD nor assesses the impact of feeding problems and GI symptoms on family life. The only validated questionnaire designed specifically for parents of children with ASD is the Brief Autism Mealtime Behaviour Inventory (BAMBI) (Lukens and Linscheid, 2008). This questionnaire is also a parent self-report questionnaire and it provides an assessment of mealtime behaviours, but does not cover the wider spectrum of feeding problems and GI symptoms reported by parents or the impact of these problems on family life. One published validated measure of GI symptoms identified in this review for children with ASD is the Gut Symptom Checklist (GSC) (Wilson et al., 2009). This checklist assesses the child's bowel habits and associated eating behaviours using the parents' report. However, it does not assess the impact of this problem on the child's family life. From the literature search, only one published validated measure of impact in childhood disability (related to eating or feeding) was identified, which is the Generic Lifetime Assessment Questionnaire (LAQ-G) by Jessen et al (2003). The LAQ-G assesses a broad concept of the impact in childhood disability on employment, family finance, travel, care burden and stress on parents and siblings of children with disability living in UK. However, this questionnaire does not include any specific aspects of feeding problems or GI symptoms.

The majority of the studies summarised in Table 1.1 and Table 1.2 studies have shown that feeding problems and GI symptoms in children with ASD are widespread difficulties. The strengths of the research to date include various designs, methods of the recruitment and settings (clinics and community) to study feeding problems and GI symptoms. Findings have shown that there was a wide range of feeding problems and GI symptoms in young children with ASD particularly in primary school aged children. However, the limitations of the studies are that some studies used a small sample size and this sample was not representative to the ASD children population. Another limitation is that each study used different technique/questionnaires or diagnostic criteria to assess feeding problems and GI symptoms. The majorities of the questionnaires used in past studies were parent self-report questionnaires and developed by the author(s) for the particular study and there is no report of any evaluation of the psychometric properties of the measure, except the use of CEBI questionnaire by Schreck and Williams (2006). The details of the critical appraisal for the validated measures are discussed in Chapter 2.6.

In addition, there are very limited validated questionnaire for research utility or clinical settings in order to gather information on feeding problems or GI symptoms in primary school children with ASD aged 4-11 years old. Although self-report questionnaires are relatively easy to administer and quick to complete, the most important disadvantage of this method is that professionals and researchers are not able to clarify or discuss particular concerns with parents. Self-report questionnaires may also not be accessible by parents with limited literacy skills (Bowling, 2009). From the available literature, feeding problems and GI symptoms in children with ASD are described as complex and parents may report their concerns about many feeding problems or GI symptoms to various professionals (Cermak et al., 2010). The professionals could be health and education professionals, social workers or other community workers. This means that all these different types of professionals (irrespective of their professional discipline) may need to be able to ask parents about the range of feeding problems and GI symptoms in a systematic way to obtain the information needed to guide decisions about the appropriate use of early access to information, possible referral for further assessment, treatments or interventions for the child and their family.

There is an emerging evidence base for the potential benefits of early identification of young children with ASD and the outcomes of psycho-educational, behavioural and social communication interventions for young children with ASD (McConachie and Diggle, 2007; Twatchtman-Reilly et al., 2008). Early identification of additional difficulties such as feeding problems is likely to increase awareness of these problems and the need to identify effective interventions to reduce the burden on affected individuals and their families or carers (Twatchtman-Reilly et al., 2008). In clinical or school settings, it is likely to be useful to gather information about feeding problems and GI symptoms from the parents as soon as parents become aware and are concerned about these problems. For children with significant social communication difficulties such as ASD, expectation is that they are increasingly likely to received a diagnosis from the age of 4-6 years onwards. Thus, for parents who also have concerns about their child's feeding and GI symptoms, they may also mention these concerns to various professionals. To facilitate this task, an interviewer-based brief structured questionnaire (with good reliability and validity) designed specifically for use by professionals in a variety of community settings (clinical or school settings) would be a valuable resource for the professionals to support young primary school children with ASD (aged 4-11 years) and their families. In this way, feeding problems and GI symptoms could be identified as early as possible. The present research also attempts to measure the impact of feeding problems and GI symptoms on family life of primary school children with ASD, which has not been measured in any other studies. Such information will increase the knowledge and awareness among researchers in ASD field and all professionals who are supporting primary school children with ASD and their families.

The primary aim of this research project is to develop a valid and reliable structured questionnaire (interviewer-based) for use by community professionals to identify in a systematic way any feeding problems and/or GI symptoms in primary school children with ASD, and the impact of these problems on the family. In the present research, the principles used to guide the development of the new health questionnaire derived from several resources. This include recommendations and guidelines for questionnaire and health measurement identified from the published literature (Oppenheim, 1992; Boynton and Greenhalgh, 2004; Bowling, 2009; and Streiner and Norman, 2008), advice from the researchers and clinicians in ASD field from United Kingdom and United State of America. Firstly, the content of questionnaire development was identified following a critical appraisal of the available published research and clinically relevant literature on feeding problems and GI symptoms among primary school children with ASD (aged 4-11 years). Secondly, the selection of domains, items and response, questionnaire format and content of a health questionnaire was guided by the recommendations by Streiner and Norman (2008). The third principle was to involve the relevant service users (parents of primary school children with ASD) and service providers (health and education professionals) to inform the content and the form of the questionnaire. In this present research, the parents of young children with ASD and the professionals from different backgrounds that work with them were involved and consulted throughout all stages of the development work of the new questionnaire (see Chapter 3.5.1- 3.5.5 in the thesis for more details). The fourth principle was that the draft design of the questionnaire (both the format and content) should be pre-tested with the target population and modified according to the feedback from professionals who administered the questionnaire with the parents of children with ASD (aged 4-11 years). The final principle that was used to inform the development of this research was that the questionnaire must be shown to be reliable and valid. This was the secondary aim of this research to evaluate the psychometric properties of the new health questionnaire including the reliability and validity of the questionnaire. This work was guided by the published evidence on establishing reliability and validity for a new health questionnaire (Terwee et al., 2009). If these principles for the development of a new health questionnaire are successfully completed then, according to Streiner and Norman (2008) and Oppenheim (1992), the questionnaire should be reliable and valid for use in the identified subject population. The users (researchers and professionals in the community) can be confident that the new questionnaire should be able to measure what it is supposed to measure and yield consistent results/ outcomes over time. Further details of the development work using these principles of questionnaire development are discussed in Chapter 3.5.

The new brief structured questionnaire was developed for a range of community-based professionals in different community settings (e.g. child development centres, child and adolescent mental health clinic or nurseries/ schools or other community settings).

This questionnaire could be used to identify a range of feeding problems and GI symptoms and provide a framework for a structured discussion about these problems between a professional working in different community settings and the parent of a primary school aged child with ASD. The information obtained from this structured questionnaire could then inform the child's care plan, allow the parent and professional access to information about feeding problems and GI symptoms commonly reported amongst children aged 4-11 years, and/or when support appropriate referral for further assessment or access to appropriate support, treatment and management.

Alongside the new questionnaire, an information pack was also developed which it was hoped would be useful for professionals as a resource for themselves and for the parents they had interviewed. The information pack includes some general information about feeding problems in ASD, food and mood and a list of relevant websites. It was envisaged that if the questionnaire is used by a range of community based professionals in different settings (including schools), it would be helpful for the professionals to have some appropriate, relevant and reliable information to share immediately with the parents, if the parents described feeding problems or GI symptoms during the interviews. Thus, the use of the questionnaire and information pack might in future increase knowledge and awareness of a broad range of feeding problems and GI symptoms in young children with ASD identified at an early stage, facilitate access to appropriate support for the children and their families and identify those children that might require further specialist assessment or intervention. It was envisaged that this new questionnaire (and information pack) could be used alongside other assessment tools for children with ASD, as part of current practice.

1.3. Structure of the thesis

This thesis comprises 7 chapters. Chapter 1 describes the definition of terms used in the present research, the background of the research, principles of questionnaire development and the underpinning conceptual framework of feeding problems, GI symptoms and the impact based on the International Classification of Functioning, Disability and Health (ICF) framework as defined by the World Health Organisation

(WHO) (World Health Organization, 2001). In this chapter, aims and specific objectives are also described.

Chapter 2 comprises a comprehensive literature review of feeding problems, GI symptoms, impact of ASD in childhood population and some evidence on the impact of feeding problems and GI symptoms. Chapter 2 also provides a critical appraisal of the available questionnaires for feeding problems, GI symptoms and the impact of these problems.

Chapter 3 is the methods section, which describes the mixed qualitative and quantitative methods used in the three phases of the research: i) The development of the questionnaire; ii) The field-testing of the questionnaire and iii) The evaluation of the questionnaire. In this chapter, ethical considerations, intellectual properties, concept of the questionnaire, recruitment process and consent, settings, participants, sample size of the field-testing, data management and analysis are described.

Chapter 4 is the results of the development of the questionnaire (Phase I). This describes the selection and construction of the domains, sub domains and items of the questionnaire. This chapter also discusses the findings of the review process of the draft questionnaire with professionals and parents of children with ASD.

Chapter 5 is the results of the descriptive findings from the field-testing (Phase II). The chapter highlights the response rate and demographic characteristics of participants, number of feeding problems, GI symptoms and different impact of these problems based on the responses of interviews using the new questionnaire.

Chapter 6 covers the results of the evaluation of the questionnaire. This includes the results and discussion of psychometric properties analyses (internal consistency, test-retest reliability, inter-rater reliability, initial factor structure, criterion validity and construct validity). This chapter also discusses the feedback from the telephone interviews with professionals about the questionnaire. The final chapter of this thesis is Chapter 7, which includes the overall discussion, the direction of future research work and conclusions.

1.4 International Classification of Functioning, Disability and Health framework

In the present research, the International Classification of Functioning, Disability and Health (ICF) framework by the World Health Organisation (WHO) (World Health Organization, 2001) and the ICF children and youth version (ICF-CY) (World Health Organization, 2007) are used to structure the approach to feeding problems, GI symptoms and the impact of these problem on family life for children with ASD. The overall concept of disability linked to the ICF-CY and the definition of the impact will be discussed in the following sections. The operational definitions of the range of feeding problems and GI symptoms will be discussed in Chapter 3 of this thesis.

Disability is defined as “difficulties in three areas of human functioning, which include i) impairments, ii) activity limitations and iii) participation restrictions” (World Health Organization, 2001). This definition was developed to incorporate the previous concepts of the ‘social model[iii]’ and the ‘medical model[iv]’ of disability. Disability is complex because it varies according to age, gender, socioeconomic status, cultural background, geographical area and health condition (World Health Organization, 2001). The degree of a disability for any individual with disability also depends upon the relationship between various environmental factors (Colver, 2005). Indeed, children with disabilities and their families may require a variety of services whereby the economic and social cost can be substantial (Blackburn et al.; National Dissemination Center for Children with Disabilities, 2009; Government Equalities Office, 2010). Colver (2005) highlighted the importance of the environment to facilitate participation and improve quality of life for children with disability. In this context, environmental factors include family, friends, education system and health system, which affects participation of children with disability (World Health Organization, 2001).

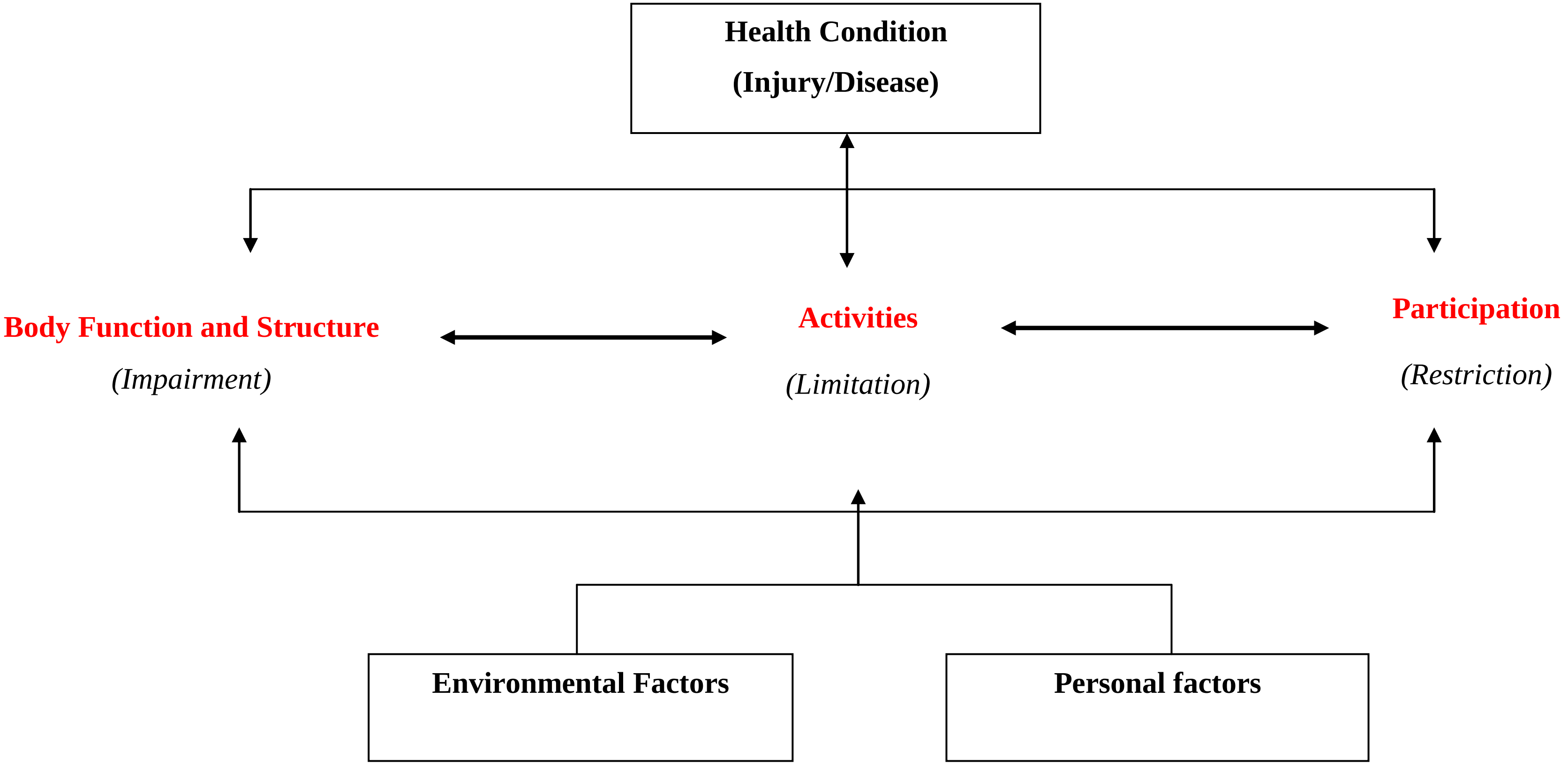
[iii] According to the social model, disability is caused by the society. The barriers that prevent any individual playing a part in society are the problem. These barriers exist in education, communication systems, transportation, health services and social support services.

[iv] According to the medical model, people are defined by the illness or medical condition. Disability is located within the individual and requires medical interventions to enable the person to adapt to the society.

In 2001, the International Classification of Functioning, Disability and Health (ICF) was introduced by the WHO to provide a new concept for the classification and measurement of disability based on three components of disability: impairments, activity limitations and participation limitations (World Health Organization, 2001). The ICF has been used as an international standard or framework and contains a comprehensive list of domains and classification for the “body functions and structures”, “activities”, “participation”, “personal factors” and “environmental factors”. This interaction is important to enhance communication, promote better understanding, and encourage collaboration among health practitioners who are supporting individuals with disability. It also promotes interdisciplinary team approaches for the planning, treatment and intervention for this special group. The ICF framework can be used for research purposes when assessing individual functioning, health outcome measurements of treatment for monitoring health conditions in disabled populations.

In 2007, the ICF for children and youth (ICF-CY) was introduced to describe disability in the childhood population (World Health Organization, 2007). The interaction of concepts of disability in the ICF-CY is shown in **Figure 1.1**. The ICF-CY may be used to verify and clarify individual differences across the autism spectrum, and to track the developmental issues of children with ASD according to age group. However, there is no published evidence on the application of the ICF-CY in children with ASD who also have feeding problems and GI symptoms. The present research did not use the ICF-CY framework to assess the functional outcomes or health outcomes of children with ASD. This framework was used to structure the research approach to feeding problems, GI symptoms and possible relationship between these problems, in order to investigate the impact of feeding problems and GI symptoms on the family of children with ASD (see chapter 1.4.1).

Figure 1.1 Interaction of concepts of disability based on the International Classification of Functioning, Disability and Health for Child and Youth (ICF-CY) 2007



1.4.1. *The conceptual framework of feeding problems, GI symptoms and the impact of these problems on family life*

The conceptual framework for the impact of feeding problems and GI symptoms in children with ASD using the ICF-CY framework is illustrated in **Figure 1.2**. The ICF framework is very relevant when providing for the needs of children with ASD. In this framework, components of body function and structures are associated with feeding problems and GI symptoms in children with ASD, which involve the sensory functions and functions of the digestive, metabolic and endocrine systems symptoms. Feeding problems and GI symptoms in children with ASD may have some impact on several domains of “body functions and structures”, “activities & participation” and “environmental factors”. Activities and participation of children with ASD are also associated with environmental factors. In the context of the present research, environmental factors include parents/carers of children with ASD, siblings, friends, education system and health system. This conceptual framework has shown that feeding problems and GI symptoms in children with ASD may likely to affect the activities and participation of the children and their families. The classifications of the ICF-CY body function, body structures and environmental factors related to feeding problems and GI symptoms are shown in **Table 1.3**.

1.4.2. *Definition for the impact of feeding problems and GI symptoms on family life*

Feeding problems and GI symptoms are likely to impact on the financial, social life, family life and stress for the parents/caregivers of children with ASD. The present research will define the impact of feeding problems and GI symptoms in children with ASD using the ICF-CY framework, and the definition of impact by Jessen et al (2003) and Stein and Riessman (1980). According to Jessen et al (2003), impact is defined as “any restriction in participation experienced by child or family as a result of a child’s health condition or disability”. The authors have used this definition to explore the impact on employment, finance, travel, care burden and stress for parents and siblings of children with disabilities. These topics will be discussed in Chapter 2.

Table 1.3 Classifications related to feeding problems and GI based on the ICF-CY body function, body structures and environmental factors

Body Function	Classification
Chapter 2 Sensory functions and pain	b250-taste function b255-smell function b265-touch function b270- sensory functions related to temperature b279-additional sensory functions
Chapter 5 Functions of the digestive, metabolic and endocrine systems	b515-digestive functions b530-weight maintenance functions b539-functions related to the digestive system
Body Structures	
Chapter 5 Structures related to the digestive, metabolic and endocrine systems	s598-structures related to the digestive, metabolic and endocrine systems, other specified s599- structures related to the digestive, metabolic and endocrine systems, unspecified
Environmental factors	
Chapter 3 Support and relationship	e310- immediate family e320-friends e355- health professionals e399-support and relationship, unspecified
Chapter 5 Services, systems and policies	e580- health services, system and policies e585- education and training services, system and policies

Another definition of the impact that has been considered in the present research was the definition of the impact for children with chronic illness on family life developed by Stein and Riessman (1980). These authors designed the Impact on Family Scale (IFS) in an attempt to assess the effect of a child’s illness or health condition on the family unit in the Pediatric Ambulatory Care Treatment Study (PACTS), USA. In the development work of IFS, four dimensions of impact were defined: “Financial (changes in the financial status of the family)”, “social (the quality and quantity of interaction with others outside the family), “familial (the quality of interaction within the quality unit)”, and “personal strain (subjective burden experienced by the primary caretaker)”.

Parents/caregivers are asked to rate their opinion about living with their child with an illness using a 4-point Likert scale ranging from 1 (Strongly Agree) to 4 (Strongly Disagree). The IFS is a parent/carer self-report questionnaire with good reliability and validity. In 2003, the authors (Stein and Jessop, 2003) revised the psychometric properties of the IFS and measured the impact in three separate studies of children with different chronic disorders: Sharing the Experience of Parenting (STEP)[v], Pediatric Ambulatory Care Treatment Study (PACTS) [vi] and Family Advocacy and Coordination Effort (FACE)[vii]. These studies used the same definition of chronic illness, as “a physical condition lasting 3 or more months or necessitating a period of continuous hospitalization of at least 1 month”. The authors found that the IFS questionnaire was a valid and reliable measure of the parental perception of the impact of the child’s illness on the family, and related to both the psychological and social outcomes of chronic illness (Stein and Jessop, 2003).

Although the IFS questionnaire was used in a group of children with chronic illnesses, the sub domains of the impact in the IFS were found to be relevant to the present research work. These include the impact of child’s illness on the financial, stress, family life and social life of the parents/carers. These sub domains could be adapted to the impact of feeding problems and GI symptoms on family life of children with ASD. For this reason, the IFS was used to investigate this aspect of validation of the

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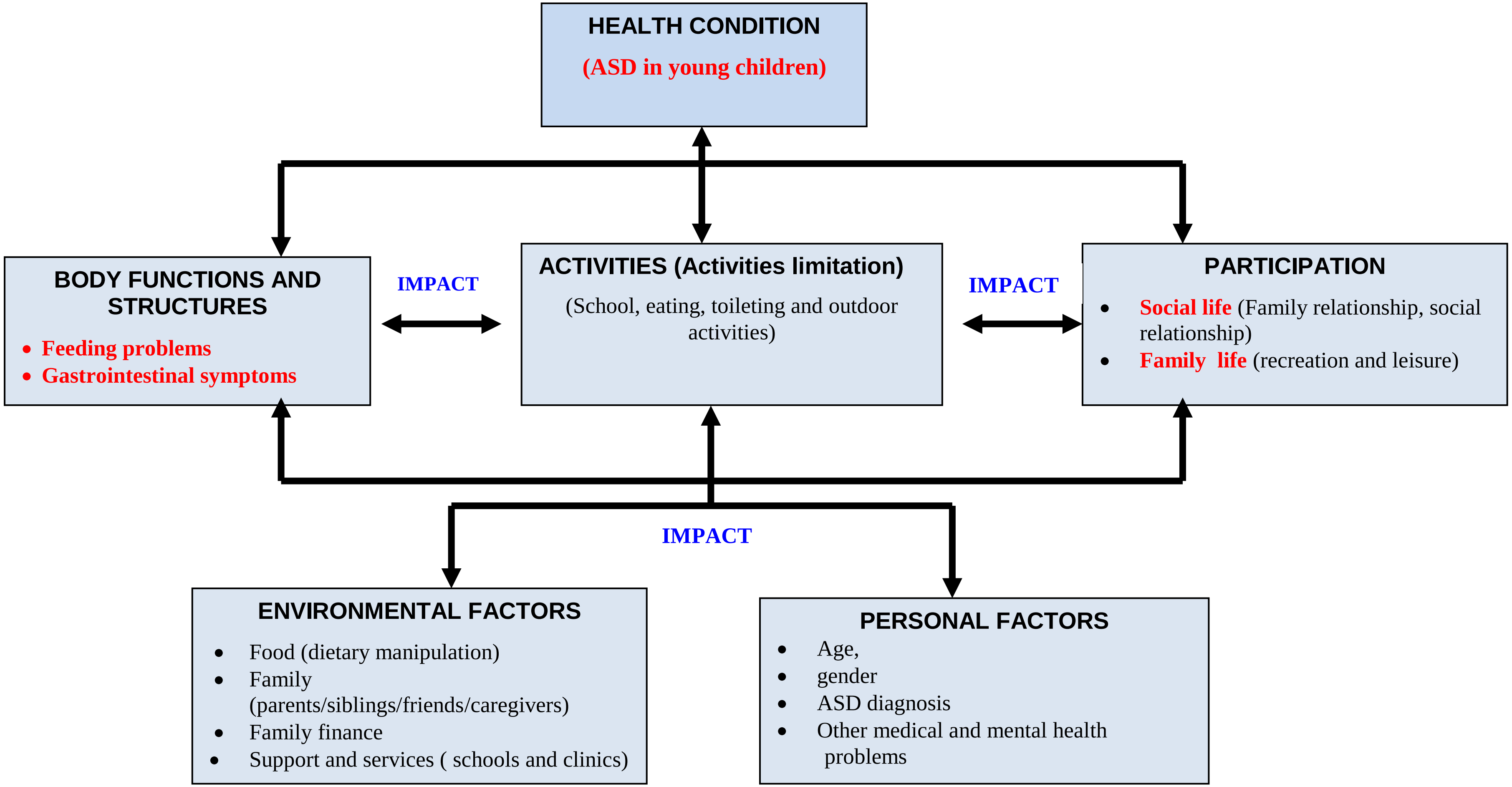
[v] STEP is a longitudinal study to investigate the effectiveness of a support intervention for mothers of children with chronic physical health conditions such as diabetes or asthma (Stein and Jessop, 2003)

[vi] PACTS is a randomised trial of paediatric home care program for children with chronic physical disorders (more than 100 different condition/illness) (Stein and Jessop, 2003)

[vii] FACE is a randomised trial to investigate the relative effects of a lay family advocate and a control group of children with asthma and meningomyelocele (Stein and Jessop, 2003)

new questionnaire developed in the present research. However, some wordings was modified with the author agreement. Thus, ‘my child’s illnesses now reads ‘my child’s ASD’ and a similar substitution was made in the scale of the original IFS. The detail of the modified IFS will be described in Chapter 3.6.2.2.

Figure 1.2 Conceptual framework of feeding problems, GI symptoms and the impact of these problems



1.5. Research aims

The present research has one primary aim and one secondary aim.

1.5.1. *Primary aim*

To develop a structured questionnaire for the early identification of feeding problems and GI symptoms in young children with ASD, and the impact of these problems on family life.

1.5.2. *Secondary aim*

To evaluate the psychometric properties of the questionnaire through field-testing with a range of professionals working with parents of primary school children with ASD in community settings in the North East England.

1.6 Specific objectives

Specific objectives of the research were:

1.6.1. To develop a structured questionnaire for the early identification of feeding problems, GI symptoms in primary school children with ASD (aged 4-11 years) and the impact of these problems on family life.

1.6.2. To evaluate the psychometric properties of the questionnaire;

- reliability of the questionnaire in terms of internal consistency, test-retest reliability and inter-rater reliability.
- validity of the questionnaire in terms of content validity, face validity, factor structure for domains of feeding problems, GI symptoms and the impact of these problems, construct validity and criterion validity.

1.6.3. To describe feeding problems and GI symptoms in children with ASD (aged 4-11 years) and the impact of these problems on family life, identified by professionals in the field-testing.

1.6.4. To obtain feedback from professionals about the questionnaire and the information pack.

CHAPTER 2. LITERATURE REVIEW

Chapter 2. Literature review

2.1. Introduction

Autism Spectrum Disorders (ASD) are common lifelong neurodevelopmental disorders with considerable financial and psychosocial impact on the children and their family (Järbrink, 2007; Knapp et al., 2009). Children with ASD are characterised by a broad range of impairments across three main areas of functioning: social communication, social interaction and repetitive stereotyped behaviours (Le Couteur, 2003; National Institute of Mental Health, 2007; Scottish Intercollegiate Guidelines Network, 2007, National Collaborating Centre for Women's and Children's Health and National Institute for Health and Clinical Excellence (NICE), 2011). Other related characteristics include language impairment, cognitive impairment, sensory impairment, rigidity in thinking and, limited creative and imaginative play.

In addition, children with ASD often have other co-occurring medical and mental health problems such as learning disabilities, seizures, anxiety, mood problems, behavioural problems, sleep disturbance, feeding problems, gastrointestinal (GI) symptoms, allergies and other metabolic disorders (Le Couteur, 2003; Williams and Brayne, 2006; National Institute of Mental Health, 2007; Newschaffer, 2007; Scottish Intercollegiate Guidelines Network, 2007; Valicenti-McDermott et al., 2008; Ibrahim et al., 2009; Emond et al., 2010; Kozlowski, 2011). One set of common difficulties among children with ASD are feeding problems and GI symptoms.

In this chapter, these difficulties will be discussed further. The aim of this review is to explore relevant evidence on feeding problems, GI symptoms in young children with ASD and the impact of these problems on family life, which support the development work of the new questionnaire. In this chapter, aetiology of ASD and aetiology of feeding problems and GI symptoms are not considered in detail, as these aspects were not covered in the development work of the new questionnaire. Therefore, published studies and reports were considered mainly on:

- rates of feeding problems and GI symptoms particularly among primary school aged children with ASD
- terms and definitions of feeding problems and GI symptoms

- range of feeding problems and GI symptoms and the possible impact of these problems
- early identification of feeding problems and GI symptoms
- existing validated questionnaires for assessing feeding problems, GI symptoms and the impact of these problems.

2.2 Feeding problems in young children with ASD

Feeding problems are common in typically developing children, children with disabilities and children with ASD. Nicolls and Bryant-Waugh (2009) have reported that feeding problems affect about 20-30% of typically developing children and as high as 40%-80% among children with disabilities including children with ASD (Field et al., 2003). Feeding problems in the childhood population appears to be complex, difficult to categorise (Keen, 2007; Nicholls and Bryant-Waugh, 2009) and often arise for a variety of factors (Field et al., 2003; Keen, 2007; Martins et al., 2008; Nicholls and Bryant-Waugh, 2009). According to a study by Field et al (2003), several factors were identified as influencing feeding problems in 349 children under 12 years old. These included lack of feeding skills, sensory problems, lack of child’s motivation and parental feeding practices. The authors reported that these factors were also closely related to the child’s developmental disabilities and other medical problems such as GI symptoms and neurological problems.

Matson et al (2009) reported a specific profile of feeding problems among children with ASD aged 3 to 16 years. They studied the relationship of feeding problems to core autism symptoms in children with PDD-NOS (n=40), autism (n=72), atypically developing (n=53) and typically developing children (n=114) using a parent self-report checklist called the Autism Spectrum Disorders-Co morbidity for Children (ASD-CC). They found that the rate of feeding problems and mealtimes behaviour difficulties among children with ASD were as high as 59% compared to atypically and typically developing children (Rate: 1-28%). Field et al (2003) also found that 62% (n=16) of 26 children with ASD aged between 1 month to 12 years in their study had significantly higher rates of feeding problems (food selectivity by type of foods) compared to children with Down Syndrome (n=1, 5% of 21 children) and Cerebral Palsy (n=6, 14% of 44 children). The authors also reported several factors related to feeding problems in these ASD children, which included GI symptoms, other medical conditions (constipation, diarrhoea, gastro oesophageal reflux (GOR)), congenital problems (such as congenital heart disease, dysplasia and asthma) and developmental delays (mild speech delay, multiple handicaps and oral motor delays). Although the methodologies of these two studies are different, the studies indicate that the rate of reported feeding problems in children with ASD are likely to be higher than for typically developing children or those with other developmental disabilities.

However, the literature is somewhat confusing, as many studies and reviews have used different terms to define feeding problems in children with ASD. The terms used include ‘feeding disorders’, ‘eating disorders’, ‘feeding difficulties’, ‘eating difficulties’ or ‘feeding and eating behaviours problem (Cohen et al., 1976; Cornish, 1998; Williams et al., 2000; Ahearn et al., 2001; Levin and Carr, 2001; Cornish, 2002; Collins et al., 2003; Schreck et al., 2004; Kerwin et al., 2005; Williams et al., 2005; Ferreri et al., 2006; Schreck and Williams, 2006; Levy et al., 2007; Patel and Curtis, 2007; Keen, 2007; Levy and Hyman, 2008; Lockner et al., 2008; Lukens and Linscheid, 2008; Martins et al., 2008; Schmitt et al., 2008; Williams et al., 2008; Herndon et al., 2009; Matson and Fodstad, 2009; Matson et al., 2009).

The differences in the terms used in these studies are influenced by the lack of a standard definition for the range of feeding problems in children with ASD. Some studies have used the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition Text Revision (DSM-IV-TR)(American Psychiatric Association, 1994b), diagnoses of “Feeding and Eating Disorders of Infancy and Early Childhood”: i)feeding disorder (FD); ii)pica and iii) rumination disorder (RD). This is a separate definition from the definitions for eating disorder in both DSM-IV[viii] and ICD-10[ix].

[viii] DSM-IV Diagnostic criteria of eating disorders
307.10-Anorexia nervosa
307.51-Bulimia nervosa
307.50- Eating disorder not otherwise specified

[ix] ICD-10 Category of eating disorders (F50)
F50.0- Anorexia nervosa
F50.1- Atypical anorexia nervosa
F50.2- Bulimia nervosa
F50.3- Atypical bulimia nervosa
F50.4- Overeating associated with other psychological disturbances
F50.5- Vomiting associated with other psychological disturbances
F50.8- Other eating disorders
F50.9- Eating disorder, unspecified

Eating disorder in DSM-IV and ICD-10 does not identify the additional associated complexities such as behavioural, psychological and social factors related to feeding problems (Keen, 2007; Nicholls and Bryant-Waugh, 2009). Further, the classification in DSM-IV-TR is still limited and does not cover the range of feeding problems commonly reported in past studies in children with ASD.

Many studies focus on food selectivity or food refusal, food sensitivity, problematic mealtime behaviour, food cravings, food dislikes and idiosyncratic food preferences (Cornish, 1998; Ahearn et al., 2001; Cornish, 2002; Schreck et al., 2004; Schreck and Williams, 2006; Keen, 2007; Adams et al., 2008; Lockner et al., 2008; Lukens and Linscheid, 2008; Martins et al., 2008; Valicenti-McDermott et al., 2008; Herndon et al., 2009; Matson and Fodstad, 2009; Matson et al., 2009; Nicholls and Bryant-Waugh, 2009; Bandini et al., 2010; Cermak et al., 2010; Provost et al., 2010; Sharp et al., 2010). A smaller number of studies compare rates of pica, nutritional intake and parental dietary practices between children with and without ASD (Matson and Bamburg, 1999; Kuhn and Matson, 2002; Schreck et al., 2004; Kerwin et al., 2005; Johnson et al., 2008; Martins et al., 2008; Herndon et al., 2009; Jyonouchi, 2009). The findings of these studies will be discussed further in the following section of this review. The following groups of feeding problems in these studies were considered in the present research to structure the thinking and understanding about the range of these problems in young children with ASD.

2.2.1. *Food selectivity, food sensitivity and idiosyncratic food preferences*

Field et al (2003) described feeding problems in a clinical sample of 349 children with Autism, Down Syndrome and Cerebral Palsy aged from 1 month to 12 years. The authors identified five different types of feeding problems: i) Food refusal; ii) Food selectivity by texture; iii) Food selectivity by type; iv) Oral motor delays and v) Dysphagia (problems with swallowing). The feeding problems in the children with ASD (n=26) were more multifactorial than for the other group of children with disabilities (n=323). The most common feeding problems among children with ASD were food selectivity by food type (n=16) and texture (n=8), and children with ASD also had food refusal, dysphagia and GOR. This finding suggest that there might be something specific about feeding problems in children with ASD, requiring a different set of questionnaires to assess specific types of feeding problems in children with

ASD. However, the sample of children with ASD in this study is small (7%) and findings need replicating in larger sample.

Bandini et al (2010) defined 3 aspects of food selectivity: “food refusal”, “limited food repertoire” and “high-frequency single food intake”. They compared food selectivity between 53 children with ASD and 58 typically developing children age 3 to 11 years, using a modified version of the Youth/Adolescent Food Frequency Questionnaire (YAQ)[x] and a 3-day food record in both groups of children. In this study, children with ASD displayed more food refusal and had a more limited food repertoire compared with typically developing children. Inadequate intake of Vitamin D and calcium was also more common in children with ASD. As expected, there was a significant association between limited food repertoire and nutrient deficiency ($r=-0.33$, $P=0.0006$; linear regression $R^2=0.13$). This finding raises the possibility that children with ASD might be at higher risk of nutrient deficiency and malnutrition, but this finding needs replication in larger studies.

Cornish (1998) reported similar results, in a small study of 17 children with autism aged 4 to 10 years in UK. This study described ‘food refusal’ and ‘introduction to new foods’ as the most difficult feeding problems reported by parents. Williams et al (2000) investigated eating habits of 100 children with autism and PDD-NOS aged from 22 months to 10 years. Approximately two thirds of parents reported that their children refused to try new foods and showed difficult behaviours during mealtime. Schreck and Williams (2006) also reported ‘food refusal’ as a major feeding problem when comparing the eating behaviours between children with autism (n=138) and typically developing children (n=238) aged 4 to 12 years. They found a range of feeding problems in children with autism, which included not only ‘food refusal’ but also ‘specific food preferences’ such as problems related to the texture of food, the presentation of food and the utensils used. Interestingly, Schreck and Williams (2006) have also described food refusal and specific food preferences, as ‘idiosyncratic food preferences’, and these problems are related to ‘food sensitivity’ and related to their family’s eating preferences.

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[x] The YAQ is a parental self-report questionnaire based on the original Harvard Food Frequency Questionnaire (HFFQ) developed by Willet (1998). The modified YAQ consists of 131 types of food compared with the original HFFQ (126 items).

Ahearn and colleagues (2001) in a study of 30 children with PDD-NOS and autism (aged 3 to 14 years) registered for a private education and diet treatment programme, indicated that half of the children (n=15) showed an abnormal pattern of 'food selectivity' and 'food sensitivity' especially on specific texture of food such as starchy and pureed food. In addition, Adams et al (2008) have reported the findings (using parent self-report questionnaires) in a group of 52 children with ASD and autism aged 3 to 5 years. They found that the common feeding problems among children with ASD included food preference related to specific texture of food (38.3%) and salty flavours (66.7%). They also found that over half of the children (54.5%) refused to eat food when the packaging has changed and 29% refused to eat if different foods on the plate were touching each other.

Provost et al (2010) using parent self-report questionnaires found that 95% of children with ASD (n=23) were reported by parents to have a range of specific food preferences or food sensitivity. The types of food preferences included preference based on food colours (n=8, 33%), food packaging (n=6, 25%), food textures (n=17, 71%) and certain food temperatures (n=11, 46%). Children with ASD who have problems of food refusal or selective eating may be also fearful of trying new foods. Martin, Young and Robson (2008) claimed that children with ASD were more likely to have food selectivity and fear of trying new foods (food neophobia) compared to typically developing children. In addition, according to Nicholls and Bryan-Waugh (2009), food selectivity or food refusal among children with ASD might relate to 'food neophobia'. The findings raise a possibility that there might be something more specific about the types of feeding problems among children with ASD. Food selectivity and food sensitivity may indeed be related to some of core features of autism (Martin, Young and Robson, 2008). Both these consideration need to be explored further.

2.2.2. *Pica*

Pica or 'eating non-food substances' has been recognised as one of the feeding problems in children with ASD and other disabilities (Matson et al., 2009; Kerwin et al., 2005). Stiegler (2005) and Matson et al (2011) studying teenagers and adult with disabilities and reported rates of pica from 20%-27%. The types of pica included eating paper, clothing, cigarette butts and linens. Kerwin et al (2005) revealed diverse feeding problems among 89 children with Pervasive Developmental Disorders. The study found that the majority of the children (50-75%) demonstrated ‘strong food dislikes’, ‘food craving’, ‘food selectivity’, ‘aggressiveness during meal time’ and ‘pica’; with 20% of children with PDD had pica. Interestingly, the findings also showed a potential relationship between aggressive behaviour, pica and other food related problems, together with a cycle of eating habits among children lasting from one week to six weeks, which seemed to be related to gastrointestinal symptoms (diarrhoea and constipation). Although the study was conducted in a small sample of children with PDD-NOS, the findings suggest that pica should be included as one of types of feeding problems to be considered when investigating young children with ASD.

2.2.3. *Problematic mealtime behaviours*

Several studies have reported problematic mealtime behaviour among children with ASD. The types of problem behaviours include self-injurious behaviour, aggressive behaviour or disruptive behaviour during mealtime (Kerwin et al., 2005; Johnson et al., 2008; Lukens and Linscheid, 2008; Williams et al., 2008; Provost et al., 2010). Kerwin et al (2005) reported that feeding problems and gastrointestinal symptoms were often associated with self-injurious behaviours. The study involved 89 children with PDD-NOS, Asperger’s Syndrome and Autism aged 3-17 years. The self-injurious behaviours among these children included head banging, head hitting, ear hitting and eye pressuring (Kerwin et al., 2005). The authors also reported young children with ASD have more problematic mealtime behaviours compared to older children such as spitting and throwing foods. Johnson et al (2008) in a small study of 19 children with ASD reported that these children had more problematic mealtime behaviours compared to 15 typically developing children. The children with ASD were more likely to throw food and scream, as well as feeding problems such as refusing foods of certain texture, colour and food groups. Although the study was conducted in a small sample size, the authors were able to claim that managing these different types of problematic mealtime behaviour in ASD children was more challenging for parents compared to managing these mealtime behaviours in typically developing children.

Provost et al (2010) also studied problematic mealtime behaviour using parent self-report questionnaires in a small sample of 24 children with ASD (3-6 years old) and

24 children with typically developing children matched by age, gender and ethnicity. The study revealed different types of problematic mealtime behaviour among children with ASD compared to typically developing children, which included ‘leaving the table frequently’ (n=14, 59%), ‘resisting sitting at the table’ (n=11, 49%), ‘throw/dump food’ (n=8, 33%) and ‘frequent tantrums’ (n=6, 25%). Parents of children with ASD expressed their concern and difficulties’ managing their child’s eating behaviour in different settings or locations compared to parents of typically developing children. This included eating difficulties at school, fast food restaurants, regular restaurants, picnics and at relatives and friends’ homes. The findings highlight the importance of including aspects of mealtime behaviours within any assessment of an early identification of feeding problems by professionals in the community

2.2.4. *Feeding problems and nutritional intake*

Martin, Young and Robson (2008) reported that nutritional intake in children with ASD’s was slightly different from typically developing children. They assessed feeding problems and eating behaviours in 3 groups of children: 58 children with ASD, 31 typically developing children with ASD siblings and 106 typically developing children with siblings who did not have disability, using parent self-report questionnaires. They found that almost half of children with ASD refused to eat fruits and vegetables compared to other group of children in this study. Interestingly, they found that there was a relationship between the mother’s eating behaviour and the child’s eating behaviour in all groups of children particularly on children’s avoidance of food and picky behaviour. However, the study also found that the frequency of feeding problems among children with ASD was higher than frequency of feeding problems in typically developing children. Further, the findings suggested that parental dietary restriction and eating behaviour might affect the overall nutritional intake of their child with ASD. This raises the interesting consideration that for children with ASD, potentially the core features of the disorder may be important when considering the identification of feeding problems.

Herndon et al (2009) report findings on the evaluation of the nutritional intake of both children with ASD (n=46) and typically developing children (n=31) using 3-days food diaries. They found that the children with ASD ate less dairy products than typically developing children. For more than half of ASD children (64.3%), the limited consumption of foods or dietary restriction was associated with allergy, bowel problems, child food preference and behavioural problems. However, there was no significant difference between the nutrient intake of children with ASD and the typically developing children except for calcium intake. Unfortunately, this study did not investigate the nutritional impact of exclusion diets such as the gluten free or casein free diet (GFCF). This aspect needs to be addressed in more details as it may relate with parental dietary practices or restrictions. Herndon et al (2009) have also found that children with ASD who have dietary restrictions are at higher risk of other nutrient deficiencies such as vitamin B_6 and calcium, as a consequence of poor dietary intake of certain key groups of foods. Bandini et al (2010) also reported significant correlations between nutrient deficiency such as Vitamin D and calcium.

Emond et al (2010) showed that children with ASD recruited from the Avon Longitudinal Study of Parents and Children (ALSPAC) ate less fruits and vegetables than the typically developing children. However, when they compared feeding symptoms, dietary pattern and growth among 79 children with ASD and 12,901 typically developing children as a control group, they found that the energy intake and growth of the ASD children was not significantly different from typically developing children despite their feeding problems and limited food consumption. This finding needs to be considered carefully. The dietary and energy intake of the children in ALSPAC was only based on the food frequency questionnaire completed by parents when the child was 38 months of age. No other methods were used to assess the actual energy or dietary intake of each child such as food diary/record or 24-hour dietary recall. Despite this limitation, it is still important to consider and address the nutritional intake as part of the overall identification of feeding problems, since children with ASD may be at risk of inadequate intake of particular foods and nutrients.

2.2.5. *Parental feeding practices and perception about feeding problems*

Parent self-report measures have been the main source of information to identify feeding problems. However, an unresolved research question is whether the problems reported by parents are just in relation to feeding problems of their child or whether the parents' perceptions and feeding practices might also have influenced the identified rates and/or the impact of managing these problems. Young children with

ASD rely on their parents/carers to prepare and provide their food. According to Field et al (2003), parental feeding practices do need to be considered when identifying children's feeding problems. Martin, Young and Robson (2008) also stated that the majority of parents/carers of children with ASD were likely to have some negative perceptions of their child's dietary intake, although their child's growth was normal and the nutrient intake was found to be sufficient.

Lockner et al (2008) also reported that parents of 20 preschool children with ASD (aged 3 to 5 years) were concerned about their child's feeding problems, and had more negative perceptions about their child's diet than parents with typically developing children. The parents of children with ASD described their children's diet as 'not healthy' and lacking in adequate nutrients probably because of their concern about their child's feeding problems. Indeed, 60% (n=12) of children with ASD were given supplements (vitamin and minerals) by their parents compared to 25 %(n=5) of the typically developing children. Interestingly, Williams et al (2008) have identified 17dimensions of parent feeding practices and found that limited intake of foods among children was predicted by parents' feeding practices ($R^2=0.20$ $p=0.000$). Parents of young children with ASD became more lenient and practiced 'meal rules' and 'use non-food rewards'. This may have been because of the difficulties in managing their child's diet. These parent behavioural strategies may also be in response to their child's ASD specific behaviours. These finding suggest that professionals working to support parents with children with ASD may need to consider parental feeding practices and/or dietary restrictions alongside child specific behaviours, and whether the types of feeding problems may link with ASD specific behaviours.

2.2.6. *Dietary manipulation*

With increasing awareness of ASD, more information about the diagnosis and interventions for ASD is available for parents and carers. This includes information from health professionals and other sources such as the internet about dietary manipulation and complementary and alternative medicine (CAM) (Wong and Smith, 2006; Srinivasan, 2009; Christon et al., 2010). According to Christon et al (2010), CAM is defined as additional therapies or treatments to support prescribed interventions. Although there is no clear evidence on the effectiveness of some types of dietary manipulation or CAMs, many parents use dietary supplements and special diets for their children, with or without specific advice from health professionals (Wong and Smith, 2006).

Wong et al (2006) compared the pattern of use of CAM therapies between 50 children with ASD and 50 children without a diagnosed developmental disability or physical disability. They found that more than half of the parents of children with ASD (n=26, 52%) used CAM therapies for their children compared to children without ASD (n=14, 28%). Parents used different therapies to treat their children including the use of mineral and vitamin supplements. Christon et al (2010) used online questionnaires with 248 parents of children and adults with ASD (aged 21 months – 21 years). They found that 29.4% (n=73) of parents used special diets such as the gluten free or casein free diet or diet rich in omega 3. 27% (n=67) of parents also gave special vitamins to their children such as Vitamin B6, magnesium, calcium. These findings are in keeping with clinical reports and the results of several on-line surveys that parents use dietary supplements or change their child’s diet, with or without specific guidance from health professionals. Clinical best practice would recommend that professionals need to identify whether parents have received appropriate advice on dietary manipulation or supplement intake from health professionals, as part of the identification of the overall feeding problems in any child with ASD.

In summary, the reported rates of feeding problems in children with ASD in published studies have varied and a wide range of different feeding problems has been identified. The rates and different feeding problems are influenced by differences in the definitions used, recruitment of children, sample size, age criteria of comparison groups and the methodologies used to identify feeding problems. Many children with ASD seem to experience several different types of feeding problems and often these include aspects of rigidity or sensory awareness of the food characteristics and the feeding environment. These features may be related to the particular features of ASD. This possible relationship between the characteristics of the feeding problems and the child ASD presentation needs much more research investigation.

2.3. Gastrointestinal symptoms among children with ASD

This section will consider the evidence for a range of GI symptoms in children with ASD. These include GI symptoms such as constipation, diarrhoea, abdominal pain and vomiting), possible relationship of GI symptoms and feeding problems, and recommendations about GI symptoms for children with ASD.

2.3.1. *Rate of GI symptoms*

Over the past decade, several studies have reported increased rates of GI symptoms among children with ASD compared with typically developing children. The reported rates of symptoms (constipation, chronic abdominal pain or gaseousness, reflux or vomiting and diarrhoea) have ranged from 9 % to 90% (Heyman et al., 1999; Horvath et al., 1999; Lightdale et al., 2001; Black et al., 2002; Afzal et al., 2003; Kuddo and Nelson, 2003; Molloy and Manning-Courtney, 2003; Goldberg, 2004; Erickson et al., 2005; Pallanti et al., 2005; Valicenti-McDermott et al., 2006; Levy et al., 2007; Valicenti-McDermott et al., 2008; Nikolov et al., 2009; Smith et al., 2009; Buie et al., 2010b). In a study of 137 children with ASD aged 2 to 8 years, Molloy and Manning-Courtney (2003) found that 24% (n=33) of the children had at least one GI symptom. Among these children, 12% (n=17) were reported to suffer from diarrhoea, 9% (n=12) constipation, 7% (n=9) vomiting and 2% (n=3) abdominal pain. Nikolov et al (2009) replicated these findings and reported that 23% of 172 children with PDD-NOS and Asperger’s Syndrome (aged 5-17 years) had GI symptoms. The authors recruited the children enrolled in a randomised clinical trial conducted by the Research Units on Paediatric Psychopharmacology Autism Network in USA. The child’s past and current GI symptoms were identified based on their medical histories. One of the limitations of this study is that the rate of the GI symptoms was reported among children who also had severe behavioural problems (such as tantrum, aggressive behaviour and self-injurious behaviour). However, the finding also raises the possibility that anxiety and ASD specific behaviour characteristics may contribute to the rate and intensity of GI symptoms among children with ASD

Other studies have reported higher rates of GI symptoms among children with ASD. In the ALSPAC study (Sandhu et al., 2009), the authors reported a prevalence of diarrhoea of 50% in 78 children with ASD during their early years (up to 42 months), and that the prevalence of diarrhoea and constipation of ASD children increased with age compared to typically developing children. Valicenti-McDermott et al (Valicenti-McDermott et al., 2008) similarly reported that 68% of 100 children with ASD aged 1 to 18 years experienced one or more GI symptoms. In contrast, Black et al (2002) using computer recorded data from general practices located throughout the United Kingdom (UK) reported lower rates of GI disorders. In this case control study, the authors studied 96 children with ASD and 449 children without ASD, matching on age at index (the date of first recorded diagnosis of autism in the cases and the control). Only 9% (n=9) of 96 children with ASD had a record of a definite GI disorder. This figure was similar to children without ASD (9% (n=41) of 449 children. The GI disorder included diarrhoea, pain and food intolerance. The lower rate reported in this study was for young children with ASD (mean age: 4 years). A further limitation of this study was that there was no standardised questionnaire used by health practitioners to interview parents. This is likely to have affected the diagnosis of GI related problems among these children compared to other studies.

One study highlighted the importance of constipation. Afzal et al (2003) studied abdominal radiographs of 103 autistic children (core autism and Asperger’s Syndrome) and 29 typically developing children (aged below 18 years), to investigate the diagnosis of severe constipation with acquired mega rectum. The authors reported that 54.4% of the children with ASD showed moderate to severe faecal loading compared to typically developing children in the control group (24.1%). Interestingly, 61.2% of the children with ASD in this study were receiving gluten free and casein free (GFCF), casein free (CF) or a gluten fee (GF) diet. The intake of dairy protein was a significant predictor of constipation. This finding suggests that many parents used an elimination diet as part of their management of their child’s behaviour and/or ASD. This finding needs replicating to identify why these children were on special diets.

2.3.2. *Feeding problems and GI symptoms*

Several studies have reported that children with ASD experienced both GI symptoms and feeding problems (Kerwin et al., 2005; Pallanti et al., 2005; Levy et al., 2007; Valicenti-McDermott et al., 2008). Valicenti-McDermott et al (2008) reported food selectivity occurred in 62% of children with autism who had GI symptoms. Kerwin et al (2005) also found that children with PDD-NOS with feeding problems experienced abdominal pain, constipation and diarrhoea at least once per week. Both findings suggest that there may be a possible relationship between the two sets of problems. However, none of these studies reported the rates of this combination of symptoms in other groups of children.

However, other studies have not replicated this potential overlap of difficulties. Levy et al (2007) specifically examined the relationship of dietary intake (calorie, carbohydrate, protein and fat) and gastrointestinal symptoms in a cohort of children with ASD (n=62) as part of a clinical sample of young children (aged 3-8 years) recruited to investigate the effect of human synthetic secretin. They found that the rate of GI symptoms was high (54%) but only a weak relationship between nutritional intake and stool consistency. The intake of fibre and fluid may be associated with GI symptoms but this component was not examined in this study. The authors suggested that there is a need to understand the risks of dietary factors such as nutrient intake for children with ASD who have feeding problems and GI symptoms. At the present time, it remains unclear whether children with ASD who have feeding problems and GI symptoms are at increased risk of other health problems.

Smith et al (2009) compared GI symptoms between 51 children with ASD recruited from York Children Services in UK, with 112 typically developing children in mainstream schools and 35 children with learning disabilities and other developmental problems in special schools. The rate of constipation in children with ASD was 25%, diarrhoea was 27% and flatulence rate was 24%. These rates of GI symptoms are similar for the other groups of children (Smith et al., 2009). However, 35% of parents of children with ASD expressed their concern about their child’s GI symptoms. Although the rate of GI symptoms was similar to typically developing children, these findings raise an important issue that for parents of children with ASD they may have more difficulties managing the GI symptoms especially when their child may also have feeding problems.

In summary, to date the reported rates of gastrointestinal symptoms in children with ASD in published studies have varied. There are likely to be several reasons for these inconsistent findings including the differences in recruited samples of children with ASD, sample size, choice of comparison groups and the methodologies used to identify GI symptoms. Evidence for a relationship between feeding problems and gastrointestinal symptoms also remains unclear. It appears that the presence of GI symptoms in children with ASD may also be associated with some of the ASD specific behavioural characteristics problems. For parents it is likely to be a challenging process for parents to identify, observe or manage these symptoms without support from health professionals (Myers et al., 2007).

2.3.3. *Recommendations for GI symptoms*

In 2010, a consensus report and recommendations for the identification, evaluation and treatment of GI symptoms in children with ASD were developed (Buie et al., 2010a; Buie et al., 2010b) to inform health professionals who are working with children with ASD in the USA. The authors recommended a thorough evaluation for the identification of constipation, chronic diarrhoea, gastroesophageal reflux disease (GERD) and abdominal pain in children with ASD. However, the recommendations do not include the assessment of the impact of the GI symptoms on children with ASD and their families.

2.4. Impact of feeding problems and GI symptoms on family life

ASD is a lifelong disorder and will have a financial and psychosocial impact on children with ASD and their families (Curran et al., 2001; Hastings and Johnson, 2001; Jarbrink and Knapp, 2001; Croen et al., 2006; Lecavalier et al., 2006; Ganz, 2007; Järbrink, 2007; Myers et al., 2007; Sharpe and Baker, 2007; Davis and Carter, 2008; Jungbauer and Meye, 2008; Kogan et al., 2008; Knapp et al., 2009; Stuart and McGrew, 2009). According to Jarbrink and Knapp (2001), the estimated average lifetime cost fornation or government to support children with ASD in the United Kingdom was £2.9 million. Knapp et al (2009) has highlighted that high economic cost such as loss of family income, high out-of-pocket expenses and time spent in delivering care for young children with ASD affects the quality of life for affected children with ASD and their families. In addition to the financial burden of raising a child with ASD and additional difficulties, these factors are also likely to have some impact on the social, psychological, emotional and economic functioning of all families of children with ASD.

The time and effort to manage intervention or therapy for a child, as well as financial resource and other burden to families are also likely to contribute to stress among parents or carers of children with ASD(Dunn et al., 2001; Hastings and Johnson, 2001; Ganz, 2007; Sharpe and Baker, 2007; Davis and Carter, 2008; Stuart and McGrew, 2009). Stuart and McGrew (2009) studied the burden among 78 caregivers of children with ASD (mean age: 4 years) using web-based and paper-based questionnaires. Burden was defined and measured based on three domains, which include ‘individual caregiver’, ‘marital relationship’, and ‘the family as a whole’. The individual caregiver and family burden were highly correlated (r=0.8). The authors reported four predictors that were strongly associated with family burden. These include severity of symptoms of ASD, demands on the family as carer, lack of social support and parent’s negative judgement of caring their child with ASD.

Davis and Carter (2008) examined associations between child’s ASD characteristics and parenting stress. The authors found that 39% of 54 mothers and 28% of 54 fathers of toddlers with ASD (18-33 months of age) had a significant level of stress but there was no significant relationship between stress among parents and the child’s behaviour (such as impulsitivity and aggression). In this study, parents were new to the ASD diagnosis. Their child received the ASD diagnosis on average about 3 months prior to the study. This finding raised a possibility that stress among parents may have been related to the child’s recent diagnosis.

Stuart and McGrew (2009) have highlighted the importance of care providers attending to parents’ concerns in managing difficulties of their children, so that appropriate information could be given when the problems were identified. Despite the increasing evidences on the awareness of feeding problems or gastrointestinal symptoms in children with ASD, there has been little systematic evidence on the psychosocial and financial impact of managing feeding problems and gastrointestinal symptoms in children with ASD (Leach et al., 2008). Kerwin et al (2005) reported that 30.3% of 89 parents with children with PDD-NOS (aged 3-17 years) also reported mealtimes as a stressful experience and 38.2% of parents reported that their child’s eating behaviour has a negative impact on their lifestyle. Cornish (2002) had identified that 75% of families of 37 children with autism felt more isolated and had particular difficulties in socialising, eating out and going on holiday. William et al (2000) also reported similar findings that 41.1% parents had problems to eat as a family at different settings. Provost et al (2010) found that 54 % (n=13) of 24 children with ASD showed difficult behaviour problems that led to difficulties eating out in settings outside the home such as in school or restaurants, and 46% (n=11) had behaviour that led to difficulty eating out at friends' home. All authors highlighted the importance of identifying these types of parental concerns and the impact of feeding problems and GI symptoms, when assessing affected children and their families.

In summary, although there is emerging evidence of feeding problems and GI symptoms among young children with ASD, there was little evidence on the impact of feeding problems and GI symptoms on family life. These difficulties are likely to or may have some psychosocial and financial impacts on families or carers of children with ASD. In addition, managing feeding problems and GI symptoms among ASD children seems likely to be a possible source of extra stress among parents. Therefore, the impact of feeding problems and GI symptoms is important to identify as part of the overall management of ASD. This issue needs to be explored further in a systematic way.

2.5. Early identification of feeding problems and GI symptoms

There is evidence that managing feeding problems and GI symptoms in children with ASD can be a challenging process (Twatchtman-Reilly et al., 2008; Buie et al., 2010b). Twatchman-Reilly (2008) highlighted that behavioural issues ('repetitive and ritualistic behaviour' and 'executive function difficulty') and physiological issues ('sensory processing' and 'gastrointestinal') are associated with feeding problems. Feeding problems and GI symptoms may affect the nutritional intake and nutritional status of children with ASD (Geraghty et al., 2010). It may well be that feeding problems and GI symptoms unrecognised at an early stage, are likely to become entrenched.

There is an increasing awareness amongst parents and professionals and an emerging evidence base that the early identification of young children with ASD and access to appropriate educational, behavioural and therapeutic intervention may improve the outcomes for these children (McConachie and Diggle, 2007; Laud et al., 2009; Green et al., 2010). Early identification of feeding problems and GI symptoms and the management of these difficulties could be incorporated in these interventions. Sharp et al (2010) suggested the use of behavioural intervention to treat severe feeding problems with a structured and comprehensive approach involving a multidisciplinary team. The team would or could consist of paediatrician, gastroenterologist, school nurse, teacher, paediatric dietitian, child psychologist, occupational therapist, speech language therapist or other professionals who work closely with ASD children and their families (Linscheid, 2006; Cermak et al., 2010; Seiverling et al., 2010). This shows that a range of professionals in health and education settings may be able to identify feeding problems and GI symptoms at an early stage. With this in mind, professionals working to support families of children with ASD need to include in their assessment a consideration of feeding problems and GI symptoms, so that appropriate timely advice, referral and specific intervention can be planned for the child and family.

2.6. Standardised measurements related to feeding problems, GI symptoms and the impact of these problems on family life

Despite published literature describing a wide range of feeding problems and gastrointestinal symptoms in children, there is no standardised questionnaire for professionals working in the community with young children with ASD and their family to use for the early identification of feeding problems and GI symptoms in children with ASD and the impact of these problems on family life. The available existing measures will be discussed in the next sub section of this review.

2.6.1. *Children's Eating Behaviour Inventory (CEBI)*

The most widely used questionnaire to assess feeding problems for typically developing children and children with intellectual disabilities is the Children's Eating Behaviour Inventory (CEBI) (Archer et al., 1991). CEBI is a parent self-report questionnaire that focuses on eating and mealtime behaviours for children aged 2 to 12 years. It has 40 items; 28 assess child food preferences, motor skills and behaviours, and 12 items assess parental behaviour controls, cognition and attitudes to feeding their child. The CEBI has adequate psychometric properties but it does not address other feeding problems in children with ASD such as pica, problematic mealtime behaviours, food sensitivity or parental feeding practices.

2.6.2. *Screening Tool for Feeding Problems (STEP)*

Another widely used questionnaire to assess feeding problems in disability population is the Screening Tool for Feeding Problem (STEP) designed by Matson and Kuhn (2001). STEP was developed to measure feeding problems in adult with disabilities. It has 23 items focusing on five dimensions: aspiration risk, food selectivity, feeding skills, food refusal and nutrition related behaviour problems. In 2011, it was adapted by Seiverling et al (2011) as STEP-CHILD and the authors evaluated the psychometric properties of the adapted version in children with ASD (n=43), children with other special needs (n=51) and other children without special needs (n=48) aged 2 to 18 years, referred to a hospital-based feeding clinic in USA. The STEP-CHILD is a parent self report questionnaire and includes 15 items and 6 subscales: chewing problems, rapid eating, food selectivity, vomiting and stealing food. The authors suggested that the STEP-CHILD could be used to measure feeding problems in children with disabilities. However, this questionnaire also does not cover the full range of feeding problems described in children with ASD and does not include the GI symptoms or the impact of these problems reported in previous studies (Special note: STEP-CHILD was published after the present research work was conducted. The present research started in 2009).

2.6.3 *The Brief Autism Mealtime Behaviour Inventory (BAMBI)*

The only published questionnaire for the study of mealtime behaviours in young children with ASD identified in my literature review is the Brief Autism Mealtime Behaviour Inventory (BAMBI) developed by Lukens and Leincheid (2008). The BAMBI assesses the frequency of mealtime behaviour problems in children with ASD. It consists of 18 items, and is a parent self-report questionnaire. Parents/caregivers were invited to access the questionnaire using a web-based inventory and to rate their child’s mealtime behaviour in the last 6 months, using a 5-point Likert scale ranging from 1(Never/Rarely) to 5 (At Almost Every Meal). A frequency score can be calculated using the total score of the 18 Likert responses. Higher scores represent more problematic mealtime behaviour. The BAMBI has three domains: ‘Limited Variety’, ‘Food Refusal’ and ‘Features of Autism’. The ‘Limited Variety’ domain consists of eight items related to limited food preferences, the ‘Food Refusal’ has five items related to rejection of food and the ‘Features of Autism’ has 5 items related to behavioural characteristics or associated features of autism.

The internal consistency for the 18 items questionnaire of BAMBI was reported by authors as high (Cronbach's coefficient alpha=0.88), with good test-retest reliability (r(33) =0.87, p<0.01) and inter-rater reliability (r(16)=0.78,p<0.01) (Lukens and Linscheid, 2008). BAMBI has been shown to discriminate mealtime behaviour between children with ASD and typically developing children (F (1,106) =72.91, p<0.01). The BAMBI does not cover other feeding problems such as pica and parental dietary practices and gastrointestinal symptoms or the wider consideration of parent feeding practices.

2.6.4 *The Gut Symptoms Checklist (GSC)*

The only published validated measure, identified in this literature review for GI symptoms in children with ASD is the Gut Symptom Checklist (GSC), developed by Wilson et al (2009). This questionnaire has been used in the Wellbeing in Autism Index (WIAI) study (Leach et al., 2008). The GSC is a parent self-report measure that consists of 30 items. Parents report the presence of gastrointestinal symptoms in their children with ASD (aged 3-11 years) over the last four weeks, using a 4-point Likert response (from 0=Never to 3=Always). In addition to gastrointestinal symptoms, there are questions on regurgitation of food and restricted eating habits. However, it does not cover a range of feeding problems in children with ASD reported in previous studies or the impact of feeding problems or GI symptoms.

2.6.5 *The Generic Lifestyle Assessment Questionnaire (LAQ-G)*

This literature review has shown that there is no standardised questionnaire to measure the impact of feeding problems and gastrointestinal symptoms of children with ASD on their family life. The Generic Lifestyle Assessment Questionnaire (LAQ-G) measures the impact of child disabilities on the lives of children and their families (Jessen et al., 2003). Jessen et al (2003) developed the LAQ-G to capture the financial and social impact of children with disabilities (including cerebral palsy, autism, emotional and behavioural difficulties and other health conditions) using a standardised questionnaire. The LAQ-G is a parent/caregiver self-report questionnaire. It has 53 items, grouped into six domains: 'communication', 'mobility', 'self-care', 'domestic life', 'interpersonal interactions and relationships' and 'community and social life'. The questions explore the impact on parent/carer employment, finance, travel, care burden and stress for parents and siblings of children with disabilities. A frequency score can then be calculated using the total score of three, four or five response options ranging from score 0 to score 4. The internal consistency for each of the six domains of LAQ-G was generally adequate (Cronbach's coefficient alpha=0.71, 0.88. 0.91, 0.66, 0.69, 0.84). LAQ-G has been shown to discriminate children with and without disability ($p<0.05$) but there has been no published evaluation of the utility of the questionnaire in clinical practice. Also, the LAG-Q does not include any aspect of impact of feeding problems or gastrointestinal symptoms in young children with ASD.

2.7. Summary

In this review, several important aspects of feeding problems and GI symptoms in children with ASD, and the impact of these problems have been identified;

1) There is an emerging literature highlighting a variety of feeding problems and gastrointestinal (GI) symptoms among young children with ASD. However, the relationship of these problems are still not clear. Feeding problems and GI symptoms are likely to affect the dietary intake and nutritional status of a child with ASD. If feeding problems and GI symptoms are not identified early, children with ASD may be at risk of nutritionally related medical problems or other health risks.

2) Based on the literature review, feeding problems and GI symptoms are likely to affect the child's development and appear to become increasingly challenging and difficult to manage if they become persistent and longstanding. The evidence highlights why professionals need to identify feeding problems and GI symptoms at an early stage.

3) There is little published data on the overall impact of feeding problems and GI symptoms on family life. These difficulties may contribute to the financial and psychosocial impact on both the children and their family. Some studies have indicated that parents of children with ASD had difficulties in managing ASD and suffer from stress. This aspect of impact needs to be carefully investigated to provide an increased evidence base to inform parents and professionals (service providers). Managing feeding problems and GI symptoms may well add extra

stress to parents or carers. Early identification of feeding problems, GI symptoms may also increase awareness of the impact of these problems among professionals and parents, which could lead to effective interventions to reduce the burden on affected individuals and their families or carers.

4) The rates of feeding problems and GI symptoms in children with ASD are high in most studies indicating that feeding problems and GI symptoms are widespread difficulties. Although some studies reported similar rates to those seen in typically developing children and children with other disabilities, managing these difficulties in young children with ASD is likely to be a particular challenge for both professionals and parents or carers. For all these reasons, professionals in the community need to identify feeding problems, GI symptoms and the impact of these problems on their families in a systematic way.

5) There is no questionnaire that community based professionals can use to systematically enquire about these problems (feeding problems, GI symptoms and the impact of these problems) at an early stage. Professionals need to gather basic information and clarify parents/carers' concern about feeding problems and GI symptoms in children with ASD before the problems become entrenched. Therefore, the development of a new questionnaire that covers aspects on feeding problems, GI symptoms and their impact would support these needs.

CHAPTER 3. METHODS

Chapter 3. Methods

3.1. Introduction

The main aim of the research is to develop a questionnaire for the early identification of feeding problems and GI symptoms in primary schoolchildren with ASD, and the impact of these problems on family life. The secondary aim is to evaluate the psychometric properties of the questionnaire.

A ‘structured questionnaire’ is defined as a questionnaire that contains items or questions which respondents must answer in a specific way, by choosing a predetermined set of responses (Streiner and Norman, 2008). The questionnaire developed and tested in the present research is called the ‘**B**rief structured questionnaire for the **E**arly identification of **F**eeding problems and **G**astrointestinal (GI) symptoms in primary school children with **A**utism **S**pectrum **D**isorders **(BEFG-ASD)**’. The BEFG-ASD does not collect detailed information of feeding problems and GI symptoms or the impact of these problems on family life but facilitates the professional by collecting basic information about these conditions. The structured format of the BEFG-ASD will allow professionals to conduct structured interviews with parents of children with ASD. In this context, ‘structured interview’ is a term used in the present research, so professionals (interviewer) could ask the same set of questions, in the same order using the same words. In other words, the interviews using the BEFG-ASD will be standardised.

The research process has involved mixed quantitative and qualitative methods. This chapter describes the concept of the BEFG-ASD and the three phases of the research namely:

a) Phase I- Development of the BEFG-ASD
b) Phase II- Field testing of the BEFG-ASD
c) Phase III- Evaluation of psychometric properties of the BEFG-ASD and the feedback from professionals who used the questionnaire (during the field-testing Phase II) with parents of primary school children with ASD (aged 4-11 years). A flow chart of the study is shown in **Figure 3.1.**

3.2. Ethical considerations

The Newcastle & North Tyneside 1 Research Ethics Committee on behalf of the National Research Ethics Service (NRES) and the Faculty of Medical Sciences Ethics Committee at Newcastle University both provided a positive ethical opinion for this research in June 2010 (Reference Number: REC 10/H0906/20).

Site-specific information (SSI) for National Health Services (NHS) Research and Development (R&D) approvals were gained from nine (9) NHS Trusts across North East England. The NHS Trusts included Northumberland and Tyne and Wear NHS Foundation Trust, Northumbria Healthcare Foundation NHS Trust, NHS North of Tyne-Commissioning Trust, NHS North of Tyne- Provider Trust, NHS South of Tyne and Wear Trust, Gateshead Health Foundation Trust, South Tyneside NHS Foundation Trust, Newcastle upon Tyne Hospital NHS Foundation Trust and City Sunderland Hospital NHS Trust.

3.3. Intellectual properties of the BEFG-ASD

The intellectual properties (IP) for the BEFG-ASD were registered with Newcastle University in October 2009 using the Invention Record Questionnaire (IRQ). Based on the evaluation of the final product by the IP evaluation officer in 2012, it was decided that the BEFG-ASD would be freely available for researchers and clinicians through the Newcastle University website and the Ministry of Health Malaysia website.

3.4. Concept of the BEFG-ASD

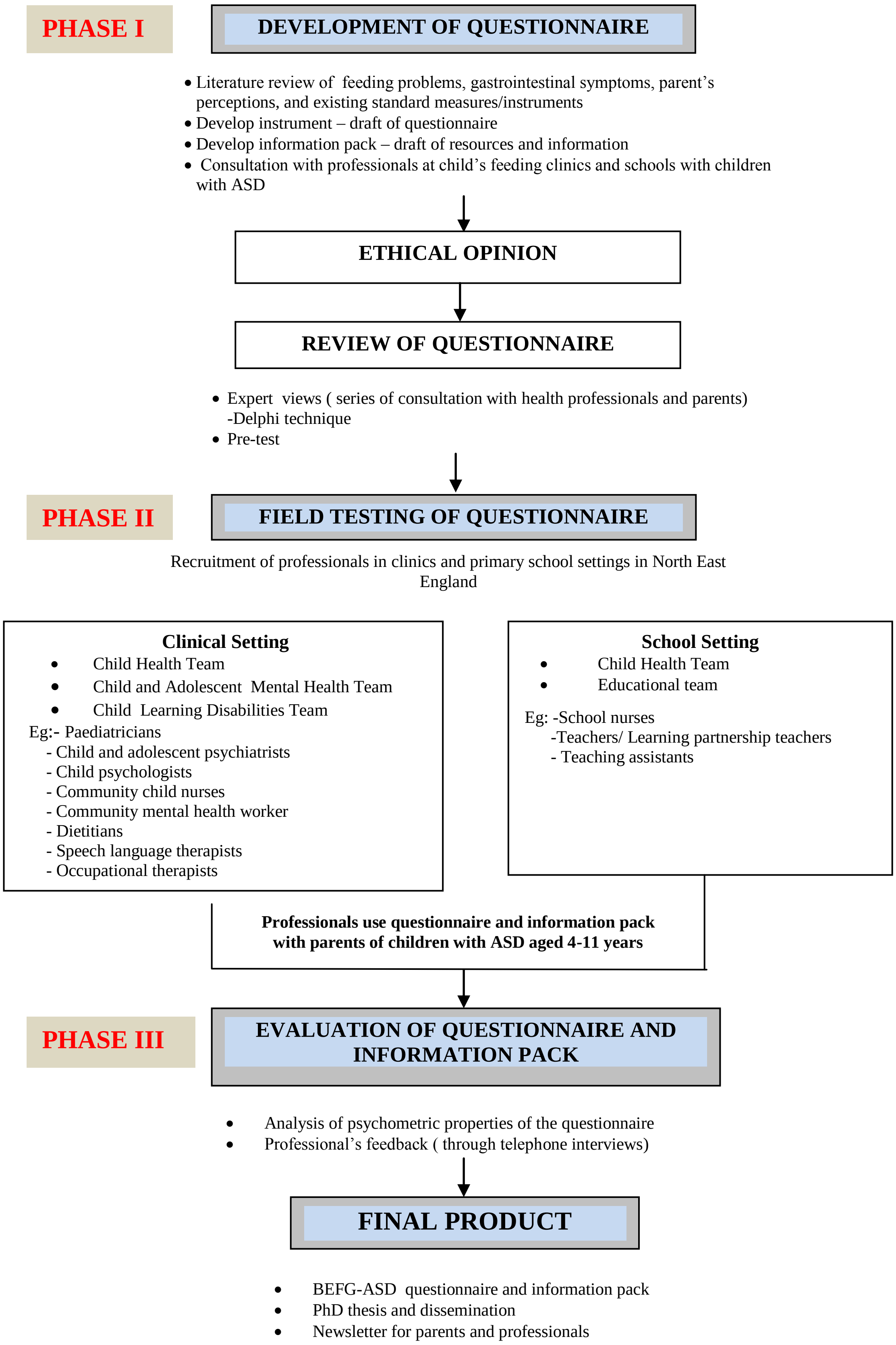
Following a comprehensive literature review (Chapter 2) and using the International Classification of Functioning, Disability and Health, Child and Youth version (ICF-CY) framework, the development work for the BEFG-ASD was undertaken. The characteristics of the BEFG-ASD include:

- It is an **interviewer-administered structured questionnaire (face-to-face)** for use by a range of professionals in health, education and other local authority support services in the UK who work with children with ASD and their families;
- It will identify the various **feeding problems and GI symptoms** that have been reported by parents of primary schoolchildren (aged 4-11) with ASD;

- It will also identify and measure the **impact of feeding problems and GI symptoms on family life**;
- It is not a diagnostic instrument or test but is designed to support professionals to **clarify parents' concerns** in a systematic way.

Alongside the BEFG-ASD, an information pack was also developed as a resource for professionals working with parents of children with ASD in the community. The information pack contains general information sheets on food and eating problems in children with ASD and learning disabilities (Version 2009/2010) published by the British Dietetic Association (British Dietetic Association, 2009). Details of the information pack will be explained in sub section 3.5.3.

Figure 3.1 Study flow chart



PHASE I

DEVELOPMENT OF QUESTIONNAIRE

- Literature review of feeding problems, gastrointestinal symptoms, parent's perceptions, and existing standard measures/instruments
- Develop instrument – draft of questionnaire
- Develop information pack – draft of resources and information
- Consultation with professionals at child's feeding clinics and schools with children with ASD

ETHICAL OPINION

REVIEW OF QUESTIONNAIRE

- Expert views (series of consultation with health professionals and parents) -Delphi technique
- Pre-test

PHASE II

FIELD TESTING OF QUESTIONNAIRE

Recruitment of professionals in clinics and primary school settings in North East England

Clinical Setting

- Child Health Team
- Child and Adolescent Mental Health Team
- Child Learning Disabilities Team

Eg:- Paediatricians
- Child and adolescent psychiatrists
- Child psychologists
- Community child nurses
- Community mental health worker
- Dietitians
- Speech language therapists
- Occupational therapists

School Setting

- Child Health Team
- Educational team

Eg: -School nurses
-Teachers/ Learning partnership teachers
- Teaching assistants

Professionals use questionnaire and information pack with parents of children with ASD aged 4-11 years

PHASE III

EVALUATION OF QUESTIONNAIRE AND INFORMATION PACK

- Analysis of psychometric properties of the questionnaire
- Professional's feedback (through telephone interviews)

FINAL PRODUCT

- BEFG-ASD questionnaire and information pack
- PhD thesis and dissemination
- Newsletter for parents and professionals

3.5. Phase I- Development of the BEFG-ASD

The development work started in 2009 and the details of the methods used are described in this section. The procedures included the selection of domains and sub-domains, item and scale construction, review of items and structure of the questionnaire and a pre-test of the final draft, following the recommendations of Streiner and Norman (2008) **(Figure 3.2)**.

3.5.1. *Domain, sub-domains and items selection*

The initial selection of items for the BEFG-ASD was derived from various sources. These include the ICF-CY framework, a comprehensive literature review, a review of equivalent measures or questionnaires previously used with children with disability, a review of measures previously used for the investigation of feeding problems and GI symptoms in children with ASD, and consultation with clinicians and researchers both in United Kingdom (UK) and United States of America (USA), working in the ASD field.

3.5.1.1. Conceptual framework based on the International Classification of Functioning, Disability and Health (ICF)

The ICF conceptual framework of functioning, disability and health was chosen to inform the consideration of feeding problems and GI symptoms in children with ASD and the impact of these problems on the family life. This conceptual framework was used as the theoretical underpinning of the development of the BEFG-ASD (see Chapter 1, 2 and 4).

3.5.1.2. Comprehensive literature review

A comprehensive literature search was conducted on feeding problems, GI symptoms in primary school aged children with disability and with ASD. A search was also made to investigate the impact of these problems on family life. Early recognition, identification and diagnosis of ASD and parents’ perception of the impact of disability and disorder on family life were also reviewed.

The first literature review included published scientific journals, reports, books and reviews from 1997 – 2009. Other sources included information from members of the supervisory team and experts in the relevant clinical and research fields. In 2010, a supplementary literature review was undertaken and in 2011, the final update of the literature review was conducted.

The literature search was conducted using:

(i) electronic databases of Medline Embase/Ovid, ISI Web knowledge and Scopus;

(ii) several research websites such as the researchautism.net, the Autism Research Institute (ARI) and the Database of Children of Autism Living in the North East England (Daslne);

(iii) relevant peer reviewed journals including Journal of Developmental Disabilities, Autism, Journal of Autism and Developmental Disorders (JADD), Child: Care, Health and Development, Paediatrics, Human Nutrition and Dietetics, Research in Autism Spectrum Disorders and Research in Developmental Disorders

(iv) bibliographic search of books, reports, summaries, newsletters, and references from selected articles from the Newcastle University library catalogue.

Inclusion criteria for the search were articles in English published from 1990 to 2011 and related to children with ASD below 18 years old. Key terms used in the search were:

(i) Autism Spectrum Disorders (ASD), autism, autistic disorder, atypical autism, pervasive developmental disorder not otherwise specified (PDD-NOS) and Asperger syndrome;

(ii) feeding problems, feeding difficulties, eating problems, feeding disorders, eating disorders, selective eating, food sensory problems, food texture, food pattern, food refusal, mealtime behaviour and pica;

(iii) gastrointestinal symptoms, gut problems, bowel problems, constipation, diarrhoea, abdominal pain, nausea and vomiting;

(iv) impact, burden, cost impact, caregiver problems, financial burden, economic burden, stress, social problems and family life.

Based on the results of the literature reviews, operational definitions for sub domains of feeding problems, GI symptoms and the impact of these problems on family life were developed. Items within the sub domains were selected and formatted into questions. These sources informed the writing of the questionnaire for the three sections of the BEFG-ASD: Section A) Feeding problems, Section B) GI symptoms and Section C) The impact of feeding problems and GI symptoms on family life of children with ASD.

3.5.1.3. Review of equivalent measures or questionnaires used with children with disability

As part of the literature review, specific reviews were conducted to identify any instruments or questionnaires on feeding problems, GI symptoms and impact on family life in children with disability. Two measures were considered as they are relevant to the present research: the Children's Eating Behavior Inventory (CEBI) and The Generic Lifestyle Assessment Questionnaire (LAQ-G). Both questionnaires are parent self-administered questionnaires. Neither CEBI nor LAQ-G was designed for use by community professionals to identify feeding problems and GI symptoms in children with ASD, and the impact of these problems in a systematic way (see Chapter 2). Therefore, these questionnaires were not suitable for use in the present research.

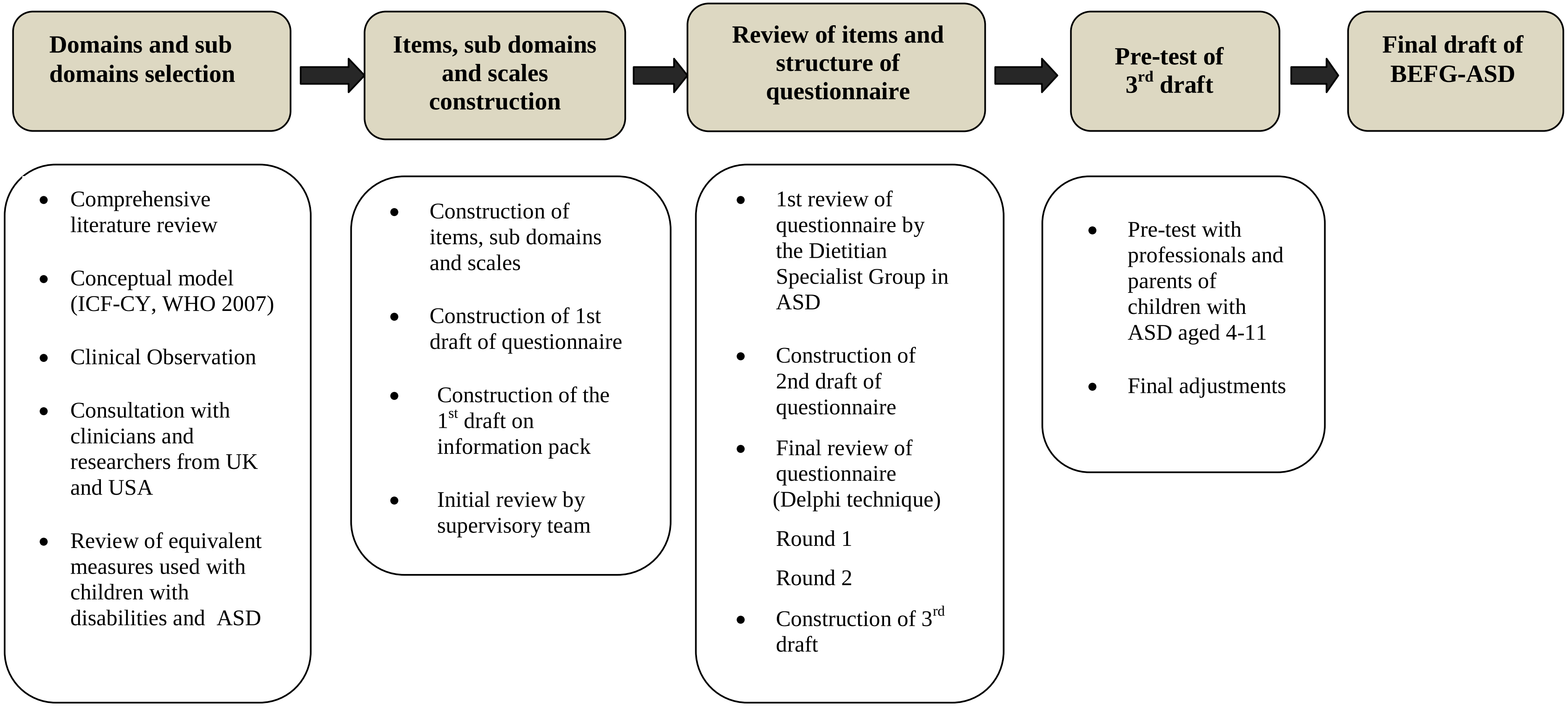
3.5.1.4. Review of measures or questionnaires for feeding problems and GI symptoms in primary school children with ASD

Two validated questionnaires related to aspects of feeding problems and GI symptoms that have been developed for use in primary school children with ASD were identified: the Brief Autism Mealtime Behaviour (BAMBI) and the Gut Symptom Checklist (GSC). Both questionnaires are parent self-administered questionnaires and have been used in research studies (Chapter 2.6). However, no questionnaire was identified that could be used by professionals working in the community with children with ASD and their families to ascertain the wide spectrum of feeding problems and GI symptoms in children with ASD described in the literature, and the impact of these problems on family life.

3.5.1.5. Consultation with clinicians and other researchers in the field of children with ASD

In 2009, several sources were consulted including clinicians and researchers working with children with ASD and children with disabilities at Sheffield Hallam University, Newcastle University, the UK Paediatric Community Research Group, the Dietitians in Autism Group (DAG) from the British Dietetic Association (BDA), and the UK National Autistic Society. International researchers from Ohio State University, Albert Einstein College of Medicine and Rowan University in USA who have conducted research in the field of ASD and feeding problems were also contacted, to seek their opinion on previous measures (BAMBI and CEBI) and questions related to feeding problems and GI symptoms in young children with ASD field (Kerwin et al., 2005; Lukens and Linscheid, 2008; Valicenti-McDermott et al., 2008). The results of these consultations confirmed the need for a brief standardised questionnaire that covers feeding problems and GI symptoms in children with ASD and the impact of these problems on family life, which could be used by community professionals working in a variety of settings.

Figure 3.2 Phase I. Development process of the BEFG-ASD



3.5.2. *Items, sub domain and scale construction*

Based on the information from all sources (as described above), operational definitions for the domains and sub domains of feeding problems, GI symptoms and the impact of these problems on family life, to be included in the questionnaire were constructed. An initial set of 25 items was identified. This led to drafting 25 main questions across the three sections in the questionnaire:

Section A) Feeding problems
Section B) GI symptoms
Section C) Impact of feeding problems and GI symptoms

Several resources informed the design of the draft of the questionnaire (Oppenheim, 1992; Boynton and Greenhalgh, 2004; Lipowski, 2008; Mccoll and Thomas, 2008; Streiner and Norman, 2008; Bowling, 2009). The draft questionnaire was designed in the English language.

3.5.2.1. Construction of items, scales and first draft of the questionnaire

Members of the supervisory team (consisting of a child and adolescent psychiatrist, a consultant paediatrician, a paediatric gastroenterologist, a paediatric dietitian and an academic public health specialist) reviewed the initial items. Further revision of the structure of the draft questionnaire was undertaken using the Questionnaire Appraisal System (QAS-99) by Willis and Lessler (1999), to identify potential problems in the wording and the structure of questions. Qualifying questions for the main items in Section A and Section B were also identified. The first draft of the BEFG-ASD was constructed and the details of the first draft will be described in Chapter 4.

3.5.2.2. Construction of first draft of the information pack

Together with the BEFG-ASD, an information pack was developed as a resource to support professionals working with children with ASD and their families. The information pack contained a picture and information on food and diet for young children with ASD. The first draft of the information pack consisted of:

i) 'Eat Well Plate' picture **(Appendix 1)**
ii) 'Diet and Autism Spectrum Disorder' information sheet **(Appendix 2)**
iii) 'Food and Mood' information sheet **(Appendix 3)**
iv) 'Diet, behaviour and learning difficulties' information sheet **(Appendix 4)**
v) List of useful websites for parents **(Appendix 5)**

The ‘Eat Well Plate’ picture and the information sheets were selected in 2009 based on the advice from members of the Dietitians in Autism Group (DAG) from the British Dietetic Association (BDA) UK. A list of useful websites for ASD was compiled based on suggestions from members of the supervisory team and members of the DAG.

3.5.3. *The first review of items and structure of questionnaire*

3.5.3.1. First review of questionnaire by the Specialist Group in ASD

The first draft of the BEFG-ASD (and the information pack) was presented to the Dietitian in Autism Group annual quarterly meeting, a specialist group of the British Dietetic Association in June 2009. Members of the group were invited to discuss the content and format of the BEFG-ASD. Feedback was compiled during the meeting and the permission to use the dietary information sheets from the BDA website was granted. Feedback included standardisation of responses for items in each section, sequence of items, qualifying questions and format of the questionnaire. For example, members suggested removing the headings/title of each sub domain across all sections. All feedback were then considered and the first draft of the BEFG-ASD was revised.

3.5.3.2. Construction of second draft of the questionnaire

Based on the feedback from the first review, the second draft of the BEFG-ASD was constructed. Additional items were added following the discussion and agreement with members of the supervisory team. Structure of the BEFG-ASD and arrangement of some of the questions was also revised. The second draft of the BEFG-ASD (and information pack) was then reviewed using the Delphi technique to gather the opinions and feedback from two types of ‘expert’ (parents group and professionals group).

3.5.4. *The second review of the BEFG-ASD*

Once a positive ethical opinion had been received (REC 10/H0906/20), the second review of the draft questionnaire and information pack was undertaken. In the questionnaire development process, several different methods were identified that could be used to review or examine the questionnaire items and responses. These included using an expert panel (Delphi technique), qualitative interviews or focus groups (Bowling, 2009; Streiner and Norman, 2008; Oppenheim, 1992). Each method has its own strengths and limitations, and these are summarised in Table 3.1.

According to Bowling (2009), focus groups can take many forms when used to as part of the development work for a new questionnaire. For this work, the role of the investigator would be to facilitate the discussion about aspects of the questionnaire and to ensure that all the views are recorded. All participants need to be given an opportunity to put forward their views during the discussion. For this reason, it is easier to use a homogenous group who all need to be available at the time that the focus group takes part. However, for the development work for the BEFG-ASD, this method would have been difficult to conduct. Several potential problems with the logistic arrangements were considered in detail. Feedback from a heterogeneous group consisting of service users (parents of primary school children) and providers (community professionals) from a range of different locations across the North East was required to ensure the broadest range of opinions about the BEFG-ASD. Similar difficulties were also likely to occur if qualitative individual interviews were used as the method chosen for the review process during the questionnaire development. Although qualitative interviews can be conducted using a structured or semi structured format to gain information about the development work(Oppenheim, 1992; Bowling, 2009), several sets of individual one to one interviews with parents and professionals in different settings would need to be conducted in order to gather the necessary opinions about each stage in the development of the BEFG-ASD. Further to maximise the value of the information obtained from each interviews is time consuming and resource intense with the transcription costs of all interviews and the time required for the detailed thematic analysis. In addition, participants in both focus group and qualitative interviews are not anonymised. In the review process of the BEFG-ASD, anonymised responses from all participants was considered essential to ensure that all participant felt confident that their opinions and the individual feedback on each questions/item in the BEFG-ASD was provided anonymously. Thus, participants felt confident to provide frank and honest feedback based solely on their own knowledge or experience. The third methodology reviewed and considered for the development phase of this questionnaire was the Delphi technique (also referred to as the Delphi method). The Delphi technique is a structured process designed specifically for combining the opinions of individuals or heterogeneous groups of panel experts who have expertise in the particular area or topic of interest and who may not be available all in the same place or at the same time(Linstone and Turoff, 1975; Keeney et al., 2001; Thangaratinam and Redman, 2005; Hsu and Sandford, 2007; Yousof, 2007). For the Delphi technique, participant responses are anonymised and participants can be contacted using various means such as letters, e-mail, group discussion or meeting (face to face). In this way, opinions from heterogeneous groups of expert (professionals and parents of children with ASD) can be gathered efficiently at a particular time. The method of the Delphi technique and the details of the second review are also discussed in the following section of this chapter (3.5.4.1). For this research, taking into account the resources available for the project, the geographic spread of experts (parents and professionals) from across the North East and further afield , and the need to have independent detailed feedback from each 'expert', it was decided that the Delphi method was the most appropriate method for the review of the development work for the BEFG-ASD .

Table 3.1. Different methods considered during the development work of the BEFG-ASD

Methods	**Advantages**	**Disadvantages**	**Procedures**
Focus Group	Can be used in many forms and in different settings	Works best with homogeneous group of participants Sample too large- participants are more likely to break off to talk in sub-groups Sample too small- difficult to keep the conversation going on Participants are not anonymised, and thus a risk that responses may be subject to bias ethical and privacy reasons	Discussion should be guided by open ended questions designed to elicit common responses by the participants
Qualitative interviews	Can be undertaken in many forms and at different settings Privacy –participants not feeling intimidated	Time consuming process Interviews can only be conducted one at a time Participants responses are not anonymised	In depth interview (structured or semi structured) to obtain detailed information on a topic that might be gathered from a questionnaire
Delphi technique	Combination of mixed qualitative and quantitative approaches Participants responses are anonymised can be used with heterogenous groups of participants	Definition of 'expert' Appropriate experts need to be identified for the review	Usually involves two or more rounds of review depending on the topic, resources and time frame. The classic first round of the Delphi technique starts with a set of open-ended questions.

3.5.4.1. Introduction of the Delphi Technique

The Delphi technique is a well recognised procedure to obtain views and opinions about complex topics where there is little published or existing evidence on the subject under study (Thangaratinam and Redman, 2005). The Delphi technique has been used in various healthcare research fields including clinical medicine, nursing, medical education and health care services (Keeney et al., 2001; Thangaratinam and Redman, 2005; Hsu, 2007; Hsu and Sandford, 2007). The advantage of the Delphi technique is that it provides a methodology for engaging a number of experts from different settings without having to facilitate bringing them all together.

The published literature recommends that the Delphi technique involve two or more rounds of review depending on the topic, resources and time frame of the project (Hsu, 2007; Hsu and Sandford, 2007). In each round, a summary of results of the previous rounds is included and evaluated by panel members. The classic first round of the Delphi technique starts with a set of open-ended questions. However, the approach can be modified depending on the research aims. Hsu and Sandford (2007) recommended that round one can be conducted using a questionnaire based on a comprehensive literature review. This procedure was adopted in the present research.

The sample size for the Delphi technique depends on the objectives and duration of the particular project. The published literature suggests a minimum sample of 10 participants for each panel of experts (Thangaratinam and Redman, 2005; Hsu, 2007).

3.5.4.2. Objectives of the Delphi Technique

Objectives of the Delphi technique were:

i. To seek opinions and feedback from parents and professionals to generate an ‘expert’ review of the second draft of the BEFG-ASD and incorporate the outcome of the Delphi technique to produce the final version of the BEFG-ASD for use in the field-testing.

ii. To maximise the content validation and to assess face validity of the BEFG-ASD in a systematic way.

Based on these objectives, the modified Delphi technique was conducted in two rounds and took place from beginning of July 2010 until mid of September 2010

(Figure 3.3-Delphi flow chart). Each round took approximately 4 weeks to complete. For both rounds, a structured review format was designed (see **Appendix 6** and **Appendix 7**)**.** This format contained questions representing domains, sub domains and items for feeding problems, GI symptoms and the impact from the second draft of the BEFG-ASD**.** One panel of professional experts and one panel of parent experts were recruited. Members of the Paediatric Interest Group (PIG), British Dietetic Association (BDA), the Community Paediatric Research Group and research supervisory team members made recommendations for professionals to be approached to join the professional's expert panel. The National Autistic Society (NAS) North East Branch coordinator recommended that two local North East Parent Support Groups be approached to assist with recruitment for the parent expert panel. These procedures succeeded in recruiting sufficient members for each group as described below.

Sample size of the modified Delphi technique was based on the literature (Thangaratinam and Redman, 2005; Hsu and Sandford, 2007; Yousof, 2007). The aim was to recruit a minimum of 10 participants for each panel of experts. Invitation letters were sent to 20 professionals from various paediatric clinical backgrounds in UK (Paediatric Dietitians, Mental Health Dietitians, Researchers in Child Health and Nutrition, Child Psychologists and Paediatric Gastroenterologists). Fifteen parents of children with ASD from two Parent Support Group were invited to take part using the invitation letters and emails.

Once expression of interest had been received, information sheets were sent to potential expert panel members to explain the procedure of the Delphi technique and written consent forms were gathered. Each member of the expert panels (parents and professionals) reviewed the BEFG-ASD on two separate occasions using a structured review format. The format for the review for professional experts was sent through the post or e-mails, based on the preference of expert panel members. The format for the review for parent experts was distributed in two parent support group meetings and through the post.

3.5.4.3. First Round of the Delphi technique

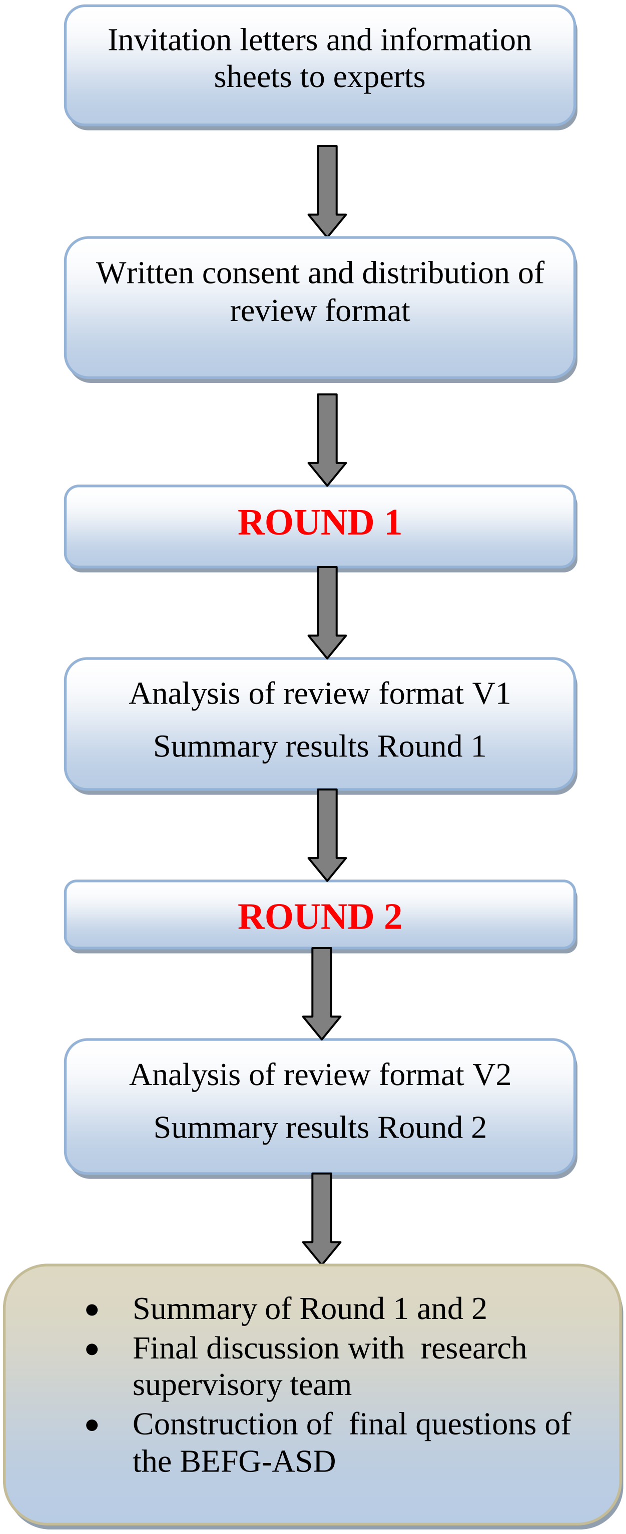
In the first round, each expert was given a review format Version 1 (**Appendix 6**).This format contained questions representing domains, sub domains and items for feeding problems, GI symptoms and the impact from the second draft of the BEFG-ASD**.** Each expert was asked to rate the importance of questions from Section A (Feeding problems), Section B (GI symptoms) and Section C (Impact on family life) of the BEFG-ASD, and the five information sheets included in the information pack. For each question in the review format, 5 point Likert scale from '1-very important', '2-important', '3-less important', '4-not important' and '5-don't know' was used. Experts were also asked to write any additional comments or suggestions for each question on the review format.

Each expert was given 14 days to complete the format. Review formats were collected and responses were analysed using Microsoft Office Excel 2010. Mean scores and standard deviations for each question were calculated and a summary of the first review was produced Questions with score of 3.0 and below (which means 'less important to not important') were considered for further opinion by experts. In the first round of the Delphi, all suggestions to modify the BEFG-ASD were accepted and the first review summary was produced. The draft BEFG-ASD was modified based on these suggestions and a second review format Version 2 was produced based on the revised version of the questions **(Appendix 7)**. The review format Version 2 contained additional items and qualifying questions for the BEFG-ASD, which derived from the first review.

3.5.4.4. Second Round of the Delphi technique

In the second round of the Delphi technique, each expert was given the first review summary and the second review format (Version 2). Experts were asked to rate their opinions for a second time on the importance of questions from the first round of the Delphi summary. Additional questions were included in the second review format. These included questions about the question flow of the BEFG-ASD, wording of each question and supplementary questions. There were also questions on the clarity of each question, and whether the questions in each section included the most relevant issues about feeding problems, GI symptoms and the impact of these problems for young children with ASD and their families.

Figure 3.3 Delphi Flow Chart



Similar to the first round of the Delphi technique, each expert was given 14 days to complete the second review format. Review formats were then collected and responses analysed using Microsoft Office Excel 2010. Mean scores and standard deviations for questions were calculated. After the analysis, experts were contacted through e-mails to inform them of the end of the review and were asked to confirm their final opinion based on the group's response given in the second round of the Delphi technique.

Feedback, mean scores of opinion from the first round and second round of the Delphi technique were discussed with research supervisory team members. Based on the discussion, the content of the BEFG-ASD was refined and finalised. The third draft of the BEFG-ASD was constructed. The outcome of the final review will be discussed further in Chapter 4 (sub chapter 4.8).

3.5.5. *Pre-test of the BEFG-ASD*

The third draft of the BEFG-ASD was pre-tested with a group of health professionals and parents of children with ASD aged 4-11 years old in Newcastle and Tynemouth. Six professionals were purposely recruited by key contacts at the Northumberland Tyne and Wear NHS Foundation Trust and the Newcastle upon Tyne Hospital NHS Trust and one special school. Participating professionals were asked to conduct interviews with parents at their own work settings. After the interviews, the professionals (who conducted the interview) questioned these parents face-to-face on several aspects of the draft BEFG-ASD including:

- Length of the interview
- Structure and format of questions
- Wording of questions and supplementary question

Professionals involved with the pre-test were also asked to give their feedback on the same aspects of the BEFG-ASD. Based on this feedback from the pre-test, some further small adjustments were made to the wording and the final draft of the BEFG-ASD was constructed**.**

The readability of the BEFG-ASD was also examined using the Flesh Reading Ease, the Flesh-Kincaid Grade level and Gunning Fog's Index using the Microsoft Office 2010. 'The Flesh Reading Ease' is a way to assess the grade level of the reader and to assess the difficulty of a reading passage written in English, and ‘The Gunning Fog’s Index’ can check the complexity of the sentences in the document (Scott, 2010). The readability analysis considered in the present research included total word counts, average sentences per paragraph, words per sentence, present of passive sentences, and whether or not the questionnaire could be read and understood by individuals. The details of the final draft of the BEFG-ASD will be discussed in Chapter 4.

3.6. Phase II- Field-testing of the BEFG-ASD

The purpose of the field-testing was to gather data on the utility of the BEFG-ASD when used by a range of professionals in the community, and to establish the reliability and validity of the questionnaire. The design of the field-testing was cross sectional. The psychometric properties of the BEFG-ASD were investigated based on the parents' responses as recorded on the questionnaire by the professionals during the interviews. The field-testing was conducted with community professionals and parents of primary school children with ASD. After the field-testing, a sub group of these professionals were selected at random for follow-up telephone interviews. Once the professionals had administered the BEFG-ASD, they then gave the information pack to parents. The details of the field-testing will be discussed in this section.

3.6.1. *Target participants and recruitment for the field-testing*

The target participants for the field-testing were professionals working with parents of children with ASD in a range of community settings in North East England. Professionals in the field-testing were identified by key professionals from the Community Child Health Team or Child, Adolescent Mental Health Team, within the participating NHS Trusts and special schools. Professionals recruited parents of primary school children with ASD (aged 4-11 years) based on their current caseloads through convenience sampling.

The recruitment of professionals for the field-testing took place from mid November 2010 until mid of September 2011. Overall, 120 information sheets and invitation letters were sent to different professional groups using contacts from key professionals at Newcastle University and Child Development Centers (CDC), Child and Adolescent Mental Health Services (CAMHS), Child and Learning Disabilities Team (CLDT) working in the different Trusts, and some local special schools in North East England. Invitation letters and information sheets were also available at training events/conferences/seminar son ASD in North East.

Several strategies to support recruitment and interest from professionals were used. These included:

1. Reminder e-mails and prompt letters to professionals who did not respond to the first invitation;
2. Attending several continuing professional team meetings and school-based meetings;
3. A £10 shopping voucher (token of appreciation) was given to each participating professional and parent after they completed the interviews.

Once professionals indicated their interest using the expression of interest reply slips, an individual training session was arranged for each professional. Meetings with the professionals were arranged at their own settings to explain about the study, the BEFG-ASD and information pack, and recruitment of parents based on their current caseloads. In the session, each participating professional was given a study pack to recruit parents.

The study pack consists of information sheet for parents, invitation letter for parents, consent form for parents, field-testing flow chart, two sets of the final draft of the BEFG-ASD and self-report questionnaires. The details of the self-report questionnaires will be described in further sub-chapter 3.6.2. The procedure to conduct the interview and each section of the BEFG-ASD was also explained. After the training session, professionals were given 2-4 weeks to familiarise themselves with the study pack and the BEFG-ASD. After the training session, professionals were asked to give their written consent using consent forms.

Professionals arranged the time for the interviews based on the convenience of the parent. The face-to-face interviews were conducted at the professional’s own clinic or school setting such as consultancy room or meeting room. Using the BEFG-ASD, parents were asked about possible feeding problems and GI symptoms of children with ASD.

3.6.2. *Parent self-report questionnaires for validity test*

The review of the literature and other procedures described in section 3.5 had revealed three parent self-report questionnaires for parents, which were used in the field-testing of the BEFG-ASD. These include the Brief Autism Mealtime Behaviour Inventory (BAMBI) (Lukens and Leincheid , 2008) (**Appendix 8**), the Gut Symptom Checklist (GSC) (Wilson et al, 2009) (**Appendix 9**) and the modified Impact on Family Scale (IFS) (**Appendix 10**) based on the original IFS by Stein and Riessman (1980) (**Appendix 11**). The BAMBI, GSC and the modified IFS were used to test the criterion validity and construct validity of the BEFG-ASD. The psychometric properties of the BAMBI and the GSC have been described earlier in Chapter 2. For the present research work, the BAMBI, the GSC and the IFS were printed as one self-report questionnaire booklet.

In the present research, another parent self-report questionnaire was used in the field-testing. The Social Communication Questionnaire (SCQ) (Rutter et al., 2003) was used to verify the diagnosis of ASD in those children identified by the professionals and teachers (**Appendix 12**). In the field-testing, the SCQ was given to the parents through professionals.

3.6.2.1. Social Communication Questionnaire (SCQ)

The SCQ is a brief parent self-report questionnaire that can be completed by the parent in less than 10 minutes. It has 40 items on symptoms associated with ASD, across the three domains: ‘communication’, ‘reciprocal social interaction’ and ‘restricted, repetitive and stereotyped patterns of behavior (Rutter et al., 2003). The items were based on the Autism Diagnostic Interview-Revised version (ADI-R) (Lord et al., 1994). Each item is scored 0 or 1, with 1 being the presence of the ASD symptom. The SCQ has good reliability, sensitivity, specificity and has been shown to discriminate between primary school aged children with and without ASD (Rutter et al., 2003; Chandler et al., 2007; Charman et al., 2007). The cut off score of $\geq$15.0 was used as an indication of scores among children with ASD.

3.6.2.2. Impact on Family Scale (IFS) - Modified Version 2010

The original Impact on Family Scale (IFS) was developed by Stein and Riessman (Stein and Riessman, 1980) to assess the impact of a child’s illness or health condition on the family. The IFS consists of 31 items, which considers four dimensions of impact: “Financial (changes in the financial status of the family)”, “social (the quality and quantity of interaction with others outside the family), “familial (the quality of interaction within the quality unit)”, and “personal strain (subjective burden experienced by the primary caretaker)”. The IFS is a parent/carer self-report questionnaire. Parents/caregivers are asked to rate their opinion about living with a child with illness using a 4-point Likert scale ranging from 1 (Strongly Agree) to 4 (Strongly Disagree). In the present research, the IFS questionnaire was modified (with permission from the original author). The sentence ‘my child’s illness’ in each question was modified to ‘my child’s ASD’ in order to measure the impact of child’s ASD on the family. In the modified version of the IFS the response option, ‘not applicable’ was added. This was added because some of the questions in the original IFS may be not applicable to parents of children with ASD (such as ‘travelling to hospital’, ‘time is lost from work’)

3.6.3. *Inclusion and exclusion criteria of participants*

3.6.3.1. Inclusion criteria of professionals

- Professionals who work with primary school aged children with ASD (4-11 years) in the community
- Type of professionals included:
    - Members of a community based ‘Child Health Team’ or ‘Child and Adolescent Mental Health Team such as paediatrician, dietitian, community mental health worker, child psychologist, child and adolescent psychiatrist, community child nurse, district nurse, social worker, speech and language therapist and occupational therapist.
    - Staff based in education settings such as school nurse, teacher/learning partnership teachers, teaching assistant at mainstream school or special school

3.6.3.2. Exclusion criteria of professionals

- Professionals who do not work with primary school aged children with ASD (4-11 years) in the community

3.6.3.3. Inclusion criteria of parents/caregivers

- Parents/caregivers of children with a clinical diagnosis of ASD aged 4-11 years (the term ASD includes Autism, Asperger Syndrome, Pervasive Developmental Disorder - not otherwise specified (PDD-NOS) and ASD).
- Parents/caregivers who have children with ASD born between December 2000 and December 2007.
- Parents/caregivers who live with their child with ASD and are involved in many/most of their child's activities over the past 3 months such as schooling, eating, toileting and playing.

3.6.3.4 Exclusion criteria of parents/caregivers

- Parents/caregivers who do not live together with their child with ASD and are not involved in many/most of their child's activities over the past 3 months such as schooling, eating, toileting and playing.
- Parents/caregivers who cannot speak and write English.

3.6.4. *Administration of the field-testing*

In order to evaluate the reliability and validity of the BEFG-ASD, the field-testing was conducted in two ways as below.

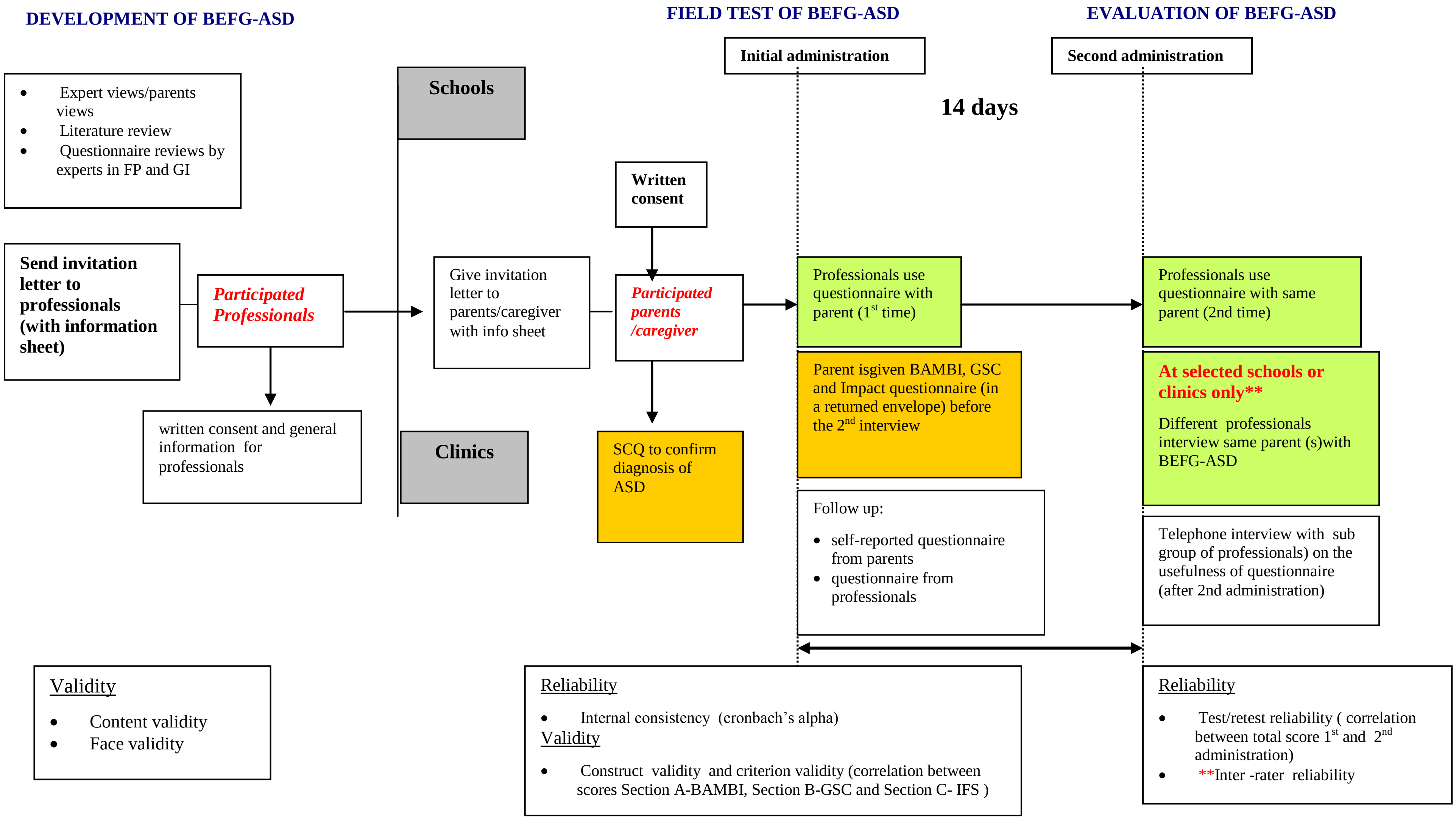
3.6.4.1. Field Testing 1(FT1)

Professionals (e.g. health and educational professionals) were asked to identify parents of children with ASD from their current caseload. All professionals were recruited from Child Development Centers, Child and Adolescent Mental Health Services, Child and Learning Disabilities Team at the NHS Trust(s) and special schools. The professionals conducted interviews using the BEFG-ASD with the same parent twice approximately 14 days apart. Data collected from the FT1 was used to investigate the test re-test reliability of the BEFG-ASD. Participating parents were also asked to complete the SCQ and parent self-report questionnaires (the BAMBI, the GSC and the modified IFS). These self-report questionnaires were compiled as a booklet and the booklet was given to each parent at the end of the first interview with the professional.

3.6.4.2. Field Testing 2 (FT2)

Another group of professionals identified a group of parents from their current caseloads. The pairs of professionals each interviewed the same parent on two different occasions approximately 14 days apart. Data collected from the FT2 was used to investigate the inter-rater reliability of the BEFG-ASD. Participating parents were also asked to complete the booklet containing three self-report questionnaires and the SCQ. The overall work plan to establish the reliability and validity test of the BEFG-ASD is illustrated in **Figure 3.4**.

Figure 3.4 Work plan to establish reliability and validity of the BEFG-ASD



3.6.5. *Sample size for the field-testing*

The sample size for the field-testing of the BEFG-ASD was determined using the available evidence on precision, variance and regulatory considerations for estimating reliability and validity for a new questionnaire (Cicchetti, 2001; Terwee et al., 2007; VanVoorhis and Morgan, 2007). General articles on 'rule of thumb' for determining sample size and the characteristics of good psychometric tests were reviewed (Cicchetti, 2001; Terwee et al., 2007). The literature suggested that 30 to 50 participants from the population of interest would give acceptable parameter estimates (Cicchetti, 2001; Terwee et al., 2007; VanVoorhis and Morgan, 2007). Past studies associated with questionnaire development in populations of children with disabilities were also reviewed. The examples reviewed were the Brief Autism Mealtime Behaviour Inventory (BAMBI) (Lukens and Linscheid, 2008) and Generic Lifestyle Assessment Questionnaire (LAQ-G) (Jessen et al., 2003).

Lukens and Linscheid (2008) used a sample of 50 participants for the preliminary investigation of the psychometric properties of BAMBI and 108 parents of children with ASD for the planned analyses for factor structure, reliability and validity based on their pilot study. In addition, they used 15% of the sample (n=16) to evaluate the inter-rater reliability. Jessen et al (2003) reported that a minimum sample of 30 children in each group was needed in their study to investigate the psychometric properties of the LAQ-G and to support the comparison between groups. This study also reported participant response rate of 52% for cases and 19% controls. Both the BAMBI and the LAQ-G are parent self-report questionnaires and sample size in these studies range from 30 to 150 depending on different type of analysis conducted (Jessen et al., 2003; Lukens and Linscheid, 2008).

The target minimum sample size for the FT1 was 50 professionals to interview up to 50 parents of children with ASD. In the field-testing 2 (FT2), the aim was to target 5 pairs of professionals to interview up to 50 parents of children with ASD. Each pair of professionals was expected to interview 5 to 10 parents from their current caseloads as this range (5-10 parents) is practical for the professionals. Based on the parents' response rate reported by Jessen et al (2003) the estimate for likely recruitment rate and participant interest rate for professionals and parents in this research was 50%.

Using 20% expected drop-out of professionals in the field-testing based on Jessen et al (2003), 120 professionals were approached to achieve the required target sample size of 50 professionals and 50 parents of children with ASD for the field-testing.

3.6.6. *Telephone interview with professionals*

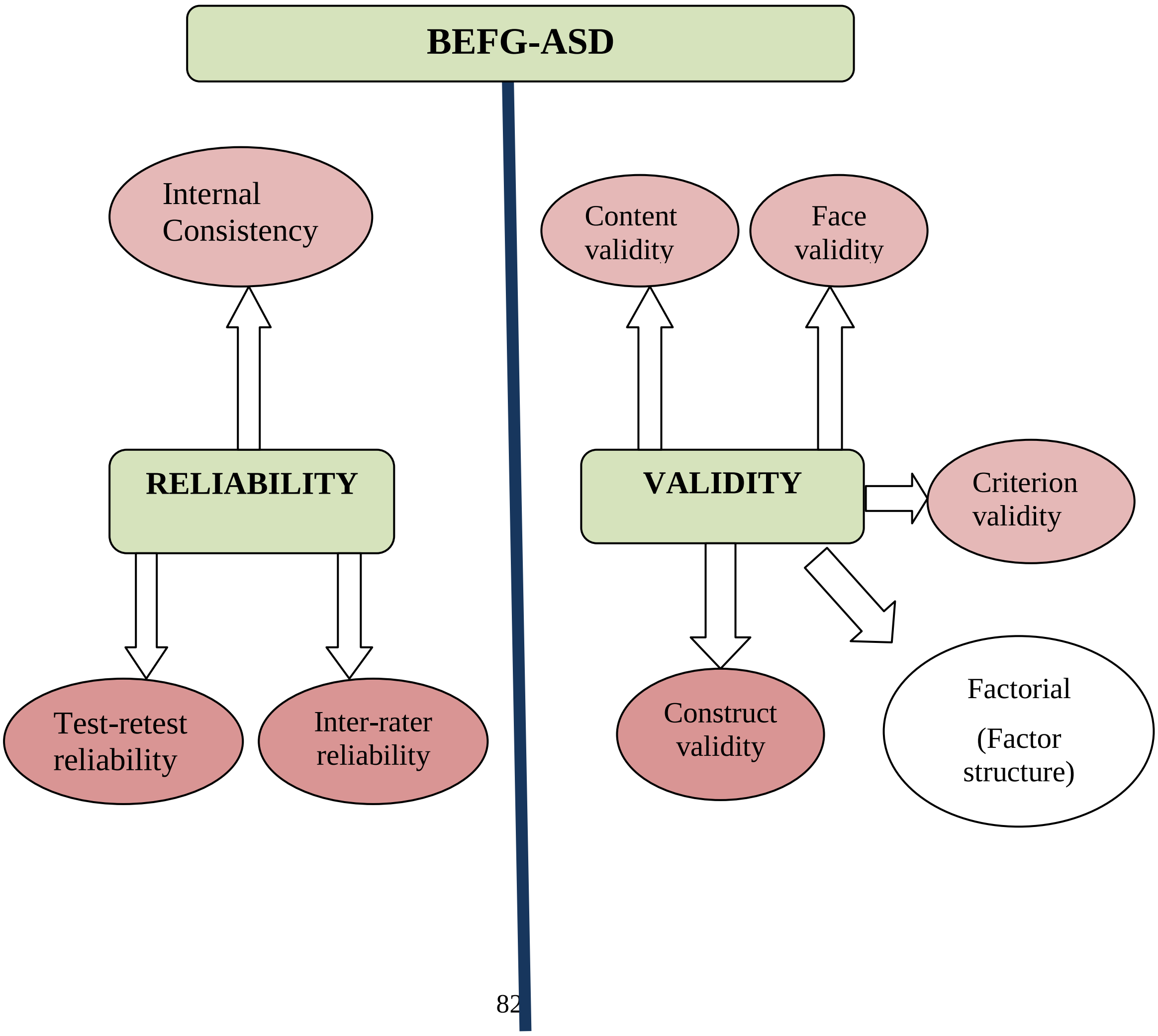
Feedback from professionals about the interview process using BEFG-ASD and information pack was obtained using telephone interviews. A sub-group of professionals were re- contacted approximately 2 to 4 weeks after they had completed the interviews with parents to take part in the telephone interviews. The permission to contact some professionals was obtained from during the training sessions. From this pool of professionals who had agreed to be contacted, a random sample was contacted for a telephone interview. The interviews were conducted using a brief telephone interview questionnaire (**Appendix 13**) designed specifically for this research project. This method was chosen to minimise the inconvenience for professionals and ensure that the same topics of interest were covered in all interviews. To ensure anonymity, a research volunteer (undergraduate psychology student) was trained to conduct these telephone interviews with participating professionals.

Professionals were asked what criteria they had used to select the parents of children with ASD from their caseload. Their opinion and feedback on the utility of the BEFG-ASD (and information pack) was also obtained. The information obtained from the telephone interviews also informed the evaluation of the content and face validity of the questionnaire. The details of the content of the telephone interview will be discussed in Chapter 6, section 6.5.

3.7. Phase III- Evaluation of psychometric properties of the BEFG-ASD

After the field-testing, all the data from the completed BEFG-ASD questionnaires collected during the field-testing together with the self-reported parent questionnaires were collated, entered and analysed using the Statistical Packages for Social Sciences (SPSS) software, Version 19.0 and the Stata software Version 11.0. The evaluation of the psychometric properties of the BEFG-ASD included aspects of the reliability and the validity of the BEFG-ASD. These include factor analysis, internal consistency, test-retest reliability, inter-rater reliability, criterion validity and construct validity (**Figure 3.5**). Two aspects of validity of the BEFG-ASD (content validity and face validity) were established in the development work of the BEFG-ASD and were informed by the feedback from the telephone interviews. This will be discussed further in Chapter 4.

Figure 3.5 Components of analysis of the reliability and validity of the BEFG-ASD



3.7.1 *Definitions of reliability and validity*

Reliability is defined as the degree to which an instrument (such as a questionnaire) produces the same information on repeated use. This also indicates the stability of the questionnaire, consistency of the questionnaire over time or across raters, and the reproducibility of the information obtained when using the questionnaire (Marx et al., 2003; McColl and Thomas, 2008; Streiner and Norman, 2008). Using this definition, in the present research work, the reliability of the BEFG-ASD that would be evaluated were the internal consistency, test-retest and inter-rater reliability.

3.7.1.1 Internal consistency

Internal consistency is the extent to which items of the questionnaire are measuring the same thing; this reflects the homogeneity of the items and scales of the measures (McColl and Thomas, 2008).

3.7.1.2 Test-retest reliability

Test-retest reliability assesses the consistency of the measurement in which the same rater administers the same questionnaire to the same respondents at different time or occasion (Marx et al., 2003).

3.7.1.3 Inter-rater reliability

Inter-rater reliability assesses the degree of agreement between different raters who administer the same instrument/questionnaire to the same respondents at different time or on different occasions (McColl and Thomas, 2008).

Validity is defined as the degree to which the instrument or questionnaire measures what it has been designed to measure (Mccoll and Thomas, 2008; Streiner and Norman, 2008). There are different types of validity. These include content validity, face validity, criterion validity, construct validity, convergent validity or divergent validity (discriminate validity) and concurrent validity. For this research, the face validity, content validity, criterion validity and construct validity of the newly developed questionnaire (the BEFG-ASD) have been evaluated. Factor structure (factorial) as one component of validity was also considered in order to explore the underlying structure of the BEFG-ASD. The present research focused on these five aspects of validity in order to examine the full scope of the questions and scale of the

BEFG-ASD in a balanced way, taking into consideration the time and other resource constraints of the research.

3.7.1.4. Content validity

Content validity is defined as the degree to which the instrument or questionnaire fully measures the construct of interest (McColl and Thomas, 2008). This involves a review of all items in the questionnaire by a representative sample of content experts or panel reviewers for clarity and comprehensiveness of the instrument, and to agree which items should be included in the final instrument or questionnaire. Content validity is not based on the scores derived from the measurement of the questionnaire but by judgement about the items by experts.

3.7.1.5. Face validity

Face validity is a component of validity when target participants or individuals reviewing the instrument conclude that it measures the characteristics of the instrument (McColl and Thomas, 2008).

3.7.1.6. Criterion validity

Criterion validity is assessed by determining the correlation between scores of the measure against other criterion measures, such an existing ‘gold standard’ measure (Streiner and Norman, 2008).

3.7.1.7 Construct validity

Construct validity is the degree to which an instrument/questionnaire measures the underlying theoretical construct that it is intended to measure (Streiner and Norman, 2008). It can be assessed in various ways, by determining the association between the factor scores of the questionnaire and the prediction of other similar tests of the construct.

3.8. Statistical analyses

Several statistical analyses were conducted to describe the demographic characteristics of professionals, parents and children with ASD, the SCQ mean scores, and number of feeding problems, GI symptoms and the impact of these problems reported among children with ASD. In the evaluation of the psychometric properties, different types of reliability and validity analyses were performed based on scores given to each response. The analysis plan for the psychometric properties includes:

- Exploratory Factor Analysis (EFA) to explore the structure and factor loadings of the BEFG-ASD
- Internal consistency of items in the BEFG-ASD based on Cronbach's coefficient alpha.
- Test re-test reliability of items in the domain of feeding problems, GI symptoms and impact of feeding problem were evaluated using Intra Class Correlation (ICC) coefficient and kappa coefficient.
- Inter-rater reliability of items in the domain of feeding problems, GI symptoms and impact of feeding problem were evaluated using Intra Class Correlation (ICC) coefficient and kappa coefficient. For the inter-rater reliability, the ICC was calculated based on a variance component model.
- Criterion validity and construct validity using Person correlations product moment between scores of each domain and other existing measures; i)feeding problems (Section A) and BAMBI; ii) GI symptoms (Section B) and the GSC and iii) Impact of feeding problems and GI symptoms on the family life (Section C) with the modified IFS.

Descriptive statistics were obtained for all domains, sub-domains and items of the BEFG-ASD. The distributions of data were checked and were approximately normally distributed. For this reason, the decision was made to use parametric statistics. In all analyses, p values of <0.05 (two-tailed significant test) were considered statistically significant.

Feedbacks about the BEFG-ASD and information pack from telephone interviews with professionals were also analysed and will be discussed further in Chapter 6.

CHAPTER 4

RESULTS

DEVELOPMENT OF THE BEFG-ASD

Chapter 4- Results

Development of the BEFG-ASD

4.1. Introduction

In this chapter, results of activities and analyses in Phase I – Development of the BEFG-ASD of the research project will be described (see also Figure 3.1 in Chapter3). The results will include the description of the domains, sub-domains and operational definitions of the different types feeding problems, GI symptoms and the impact of these problems on family life. The details of the items of the BEFG-ASD and results of the modified Delphi technique will be discussed. The results of the pre-test, the readability statistics of the questionnaire and the final version of the BEFG-ASD will also be described.

Phase I sought to answer the following question:

1) What are the relevant items for each domain of feeding problems, GI symptoms in primary school children with ASD and the impact of these problems?

4.2. Description of domains, sub domains and items of the BEFG-ASD

In the development work (Phase I), a range of feeding problems, GI symptoms in children with ASD and the impact of these were identified using various strategies including a comprehensive literature review and conceptual framework the International Classification of Functioning, Disability and Health, Child and Youth version (ICF-CY). The BEFG has three domains. Each domain was represented in one of three sections of the questionnaire:

Domain 1: Feeding problems (Section A)
Domain 2: Gastrointestinal (GI) symptoms (Section B)
Domain 3: The impact of feeding problems and GI symptoms (Section C)

4.2.1. *Domain 1: Feeding problems (Section A)*

In a comprehensive literature review undertaken in 2009 and 2010, definitions, terms and key findings from past studies, guidelines and reports were reviewed. Based on the review, operational definitions for six different types of feeding problems were identified as being relevant for the present research: ‘food selectivity’, ‘food sensitivity’, ‘problematic mealtime behaviours’, ‘food neophobia’, ‘signs of pica’ and ‘parental dietary practices and restriction’. These types of feeding problems were used as the sub domains of feeding problems (see **Table 4.1**) within the BEFG-ASD. Food sensitivity was subdivided to separate ‘physical characteristics of the food’ and ‘the child’s food environment’.

4.2.2. *Domain 2: Gastrointestinal (GI) symptoms (Section B)*

Four types of GI symptoms were identified from the literature review: ‘constipation’, ‘diarrhoea’, ‘regular abdominal pain’ and ‘vomiting’. These types of GI symptoms formed the sub domains of GI symptoms included in the BEFG-ASD. In addition, following consultation with clinicians and international researchers in the field of children with ASD (Chapter 3.5.1.5), weight issues related to GI symptoms were suggested as additional sub domain of GI symptoms to be included in the BEFG-ASD. Details of the operational definitions for the six sub domains of GI symptoms used are shown in **Table 4.2**.

4.2.3. *Domain 3: Impact (Section C)*

Four types of possible impact of feeding problems and GI symptoms on family life were identified based on the literature review using the International Classification of Functioning, Disability and Health Child and Youth Version (ICF-CY) framework (World Health Organization, 2001). These include impact on social life of parent/carer, social life of family (including siblings), financial and stress in managing feeding problems and GI symptoms. The operational definitions used for the different types of impact are presented in **Table 4.3**.

Table 4.1 Domain 1: Feeding problems in children with ASD and operational definitions for the BEFG-ASD

FEEDING PROBLEMS				
No	**Type**	**Terms/definitions from literature reviews**	**References**	**Operational definition for the BEFG-ASD**
1.	Food selectivity	• Picky /Fussy/Choosy eating • Extreme faddy eating • Limited intake of foods across categories of foods / not eating variety of foods • Selectivity by texture- refusal to eat food textures that were developmentally appropriate • Selectivity by food types • Eating limited of food that was nutritionally inappropriate • Multiple/ strong food dislikes • Food selectivity/rejection of food items by food category or food texture • Food refusal • Food preferences –' dry' or 'wet' form of foods • Idiosyncratic food preferences – taste and texture preferences • Pervasive eating disorder – difficulty in accepting change • Repetitive patterns of food choice • Eating only certain foods • Resisting trying new foods • Being picky eater • Have favourite food textures • Low level of food acceptance • Abnormal food acceptance based on category of food	1. Cornish (1998) 2. Ahearn et al (2001) 3. Cornish (2002) 4. Kuhn and Matson (2002) 5. Field et al (2003) 6. Shreck et al (2004) 7. Kerwin et al (2005) 8. Shreck and Williams (2006) 9. Lockner et al (2008) 10. Nicholls and Bryant-Waugh (2008) 11. Keen (2008) 12. Martins and Young (2008) 13. Valicenti-Mc Dermott et al (2008) 14. Matson and Wilkins (2008) 15. Provost (2010)	**Food selectivity** Child showing limited consumption and specific preference/ selection of foods based on food groups/category of foods Child also has preference for same foods at each meal and refuses to eat certain types of food **(strong food dislikes**)

Table 4.1 Domain 1: Feeding problems in children with ASD and operational definitions for the BEFG-ASD

No	Type	Terms/definitions from literature reviews	References	Operational definition for the BEFG-ASD
2.	Food sensitivity	• Sensitive to colour, taste, texture, smell, packaging of food, presentation, shape • Sensory hypersensitivities such as temperatures • 'Ritualistic eating behaviour'- require specific utensils and food presentation • 'Rituals surrounding eating'- sensitive to surrounding area and food- e.g. only eating one type of food at a time, 'untouched' food, position on plate, food only prepared by particular person • Sensory sensitivity	1. Cornish (1998) 2. Shreck et al (2004) 3. Paul et al (2007) 4. Martins and Young (2008) 5. Herndon et al (2009) 6. Cermak et al (2010)	**i) Food physical characteristics** Child rejects of foods due to physical characteristic such as texture, smells, colour, packaging, temperature and shape **ii) Child's food environment** Child insists on having: • food served in particular way • food cooked by certain person • eat meals at the same place
3.	Problematic mealtime behaviours	• Unusual feeding behaviour (i.e. 'continually eating', excessive drinking, lots of chewing • Aggressive behaviour during mealtime • Self-injurious • Repetitive behaviours • Short attention span • Hyperactivity • Specific eating behaviour/mealtime behaviour	1. Cornish (1998) 2. Kerwin et al (2005) 3. Lukens and R. Linscheid (2008) 4. Lockner et al (2008)	**Problematic mealtime behaviours** Child behaviours have occurred at least once a week at mealtime including: • disruptive behaviour (spitting out food, screaming, shouting) • aggressive behaviour (kicking/hitting family members) • self-injurious behaviour (biting self, head banging on table)

Table 4.1 Domain 1: Feeding problems in children with ASD and operational definitions for the BEFG-ASD

No	Type	Terms/definitions from literature reviews	References	Operational definition for the BEFG-ASD
4.	Food neophobia	• Fear of trying new or unfamiliar foods • Food phobias – fear of swallowing food, vomiting or choking • Tendency to avoid new foods or unfamiliar foods	1. Pliner (1994) 2. Martins and Young (2008) 3. Nicholls and Bryant-Waugh (2008)	**Food neophobia** Child fears of trying new or unfamiliar foods Child may show signs to vomiting, choking and fear of swallowing foods
5.	Signs of pica/pica	• Eating non- food item • Cravings non-food item • Eating of non-nutritive substances over an extended period of time • Eating of non-nutritive substances is inappropriate to the developmental level • Eat things that are not meant to be eaten	1. Kuhn and Matson (2002) 2. Kerwin et al (2005) 3. Nicholls and Bryant-Waugh (2008) 4. Matson and Wilkins (2008) 5. DSMV-TR (2000)	**Signs of pica** Licking, craving, chewing or eating of non-nutritive substances over an extended period such as plastic, hair, wood, cloth, dirt.
6.	Parental dietary practices and restriction	• Restrictive diets by parents imposed by special diet (eg; GFCF, allergy) • Limitation in variety of food groups taken by family • Family's food acceptance pattern • Use of vitamin and mineral supplement	1. Cornish (2002) 2. Herndon et al (2009) 3. Provost (2010)	**Parental dietary practices and restriction** Dietary practices and restriction of child's diet imposed by parents such as use of special diet, vitamin and other supplements, limitation/avoidance of certain food provided to the child.

Table 4.2 Domain 2: Gastrointestinal symptoms among children with ASD and operational definitions for the BEFG-ASD

GASTROINTESTINAL SYMPTOMS				
No	**Type**	**Terms/definitions from literature reviews**	**References**	**Operational definition for the BEFG-ASD**
1.	Constipation	Constipation • < 2 stools per week with difficulty passing stools for at least 3 consecutive weeks • Hard stools daily or less frequently • Bowel action less than 3 complete stools per week (Type 3 or 4 based on Bristol Stool Chart), hard large stool, 'rabbit droppings (Type 1) Chronic constipation • Infrequent or painful defecation, less than 2 times per week for more than 2 months; hard, pebble-like stools	1) Valicenti-Mc Dermott et al (2008) 2) Autism Speaks Gastrointestinal Statement (2007) 3) Molloy & Manning (2003) 4) NICE Clinical Guideline 99 – Constipation in children and young people (June 2010)	**Constipation** Bowel actions less than 3 times per week (Type 3 or 4) Hard large stool 'Rabbit droppings' – *Type 1 * Bristol Stool Chart (BSC) classification of stool patterns.
2.	Diarrhoea	Diarrhoea • Passage of 2-5 soft large stools per day that may contain undigested food • A change in bowel habit for the individual child resulting substantially more frequent and/or very loose or watery stool • The passage of three or more loose or liquid stools per day (more frequent passage than is normal for the individual) Chronic diarrhoea • Very loose stool to watery stools regardless of frequency, persisting for at least 3 consecutive weeks	1) Autism Speaks Gastrointestinal Statement (2007) 2) Molloy & Manning (2003) 3) WHO (2009) 4) NICE Clinical Guideline 84– Diarrhoea and vomiting in children younger than 5 years (April 2009)	**Diarrhoea** Passage of stools more than 3 times per day Loose or liquid stools -*Type 7 * Bristol Stool Chart(BSC) classification of stool patterns.

Table 4.2 Domain 2: Gastrointestinal symptoms among children with ASD and operational definitions for the BEFG-ASD

GASTROINTESTINAL SYMPTOMS				
No	**Type**	**Terms/definitions from literature reviews**	**References**	**Operational definition for the BEFG-ASD**
3.	Abdominal pain	Frequent abdominal pain • At least 3 episodes of abdominal pain that occurs over a period of at least 3 months, not associated with diarrhoea or constipation	1) Valicenti-Mc Dermott et al (2008) 2) Autism Speaks Gastrointestinal Statement (2007	**Abdominal pain** Child has regular abdominal pain * pain not associated with diarrhoea or constipation
4.	Vomiting	Frequent vomiting • Once per week for 3 months Chronic reflux or vomiting • History of recurrent emesis or reflux documented by pH study or barium study	1) Valicenti-Mc Dermott et al (2008) 2) Molloy & Manning (2003)	**Vomiting** Child frequently vomits (at least once a week)
5.	Weight issues	• Issue on weight loss associated with GI symptoms • Parental concerns on weight loss	1) Kerwin et al (2005)	**Weight loss** Child has issue on weight loss Parent concerns about the child's weight loss

Table 4.3 Domain 3: Impact feeding problems and GI symptoms and operational definitions for the BEFG-ASD

No	Type	Terms/definitions from literature reviews	References	Operational definition for the BEFG-ASD
1.	Impact on family life of children with disabilities	Impact “any restriction in participation experienced by child or family as a result of a child’s health condition or disability”	Jessen et al (2001)	**Impact of feeding problems on family life** • ‘restriction of parent’s/carer’s life (including social activities)’ • ‘extra stress in managing feeding problems’, • ‘significant contribution in the finances of the parent/carer’ • ‘restriction of family life’” **Impact of GI symptoms on family life** • ‘restriction of parent’s/carer’s life (including social activities)’ • ‘extra stress in managing GI symptoms’, • ‘significant contribution in the finances of the parent/carer’ • ‘restriction of family life’- activities for siblings or family members
2.	Impact on family life of children with chronic illness	Impact on family life “Financial changes in the financial status of the family”,social (the quality and quantity of interaction with others outside the family), “familial (the quality of interaction within the family unit)”, and “personal strain (subjective burden experienced by the primary caretaker)”.	Stein and Reissman (1980) Stein and Jessop (2003)	

4.3. Construction of items, sub domains and scales for the BEFG-ASD

4.3.1. *Item selection*

Based on the literature review, 15 sub-domains of feeding problems, GI symptoms and impact were identified and defined. To cover these sub-domains, an initial pool of 25 items was developed. The selection of these 25 items was included in the first draft of the questionnaire (BEFG-ASD Version1) (**Appendix 14**). The items were formatted into questions and grouped within the three-domain sections: Section A (Domain 1: Feeding problems), Section B (Domain 2: GI symptoms) and Section C (Domain 3: Impact of feeding problems and GI symptoms) (see **Table 4.1-4.3**).

4.3.2. *Time scale*

The duration of feeding problems and GI symptoms to be identified by professionals using the BEFG-ASD was also determined. Within the literature, feeding problems and GI symptoms in children with ASD are described as persistent and longstanding (at least up to 6 months). For the first draft of the BEFG-ASD, definite problems were defined as having to be present for at least the last 3 months (90 days). This is to distinguish the transient problems from more longstanding problems among the children.

4.3.3. *Item scaling*

Scaling definitions for ASD relevant validated measures were reviewed. These included the Brief Autism Mealtime Behaviour Inventory (BAMBI), the Gut Symptom Checklist (GSC), the Generic Lifestyle Assessment Questionnaire (LAQ-G) and the Impact of Family Scale questionnaire (IFS). Each of these questionnaires has been described in Chapter 2 and Chapter 3 of this thesis. The questionnaires used a variety of scaling responses.

For this research, a dichotomous scale (responses of ‘Yes’ and ‘No’) has been used for Section A (Domain 1: Feeding problems) and Section B (Domain 2: GI symptoms). This is the format of most existing parent self-report questionnaires. A yes/no response allows a considerable number of questions to be asked in a relatively short period of time. For Section C (Domain 3: Impact of feeding problems and GI symptoms) an adjectival scale was chosen with a fixed choice of one of five types of responses ranging from ‘a great deal’ to ‘not applicable’. The adjective scale was included to allow professionals to clarify and discuss the detail of the impact of feeding problems or GI symptoms with parents. It was anticipated that the additional information might well be useful when considering further referrals or specific intervention for the particular child and family.

In summary, the BEFG-ASD was designed using a brief structured questionnaire format (rather than parent self-report questionnaire) so that it provided professionals with a framework for a systematic discussion or dialogue with parents about feeding problems, GI symptoms and the impact of these problems on family life.

4.3.4. *Instruction to administer the BEFG-ASD*

A set of instructions for professionals on how to administer the BEFG-ASD was also designed and included in the first draft of the BEFG-ASD Version 1 (**Appendix 14**). The general instruction for professionals about how to administer the questions for each section was included at the beginning of each section of the BEFG-ASD.

4.3.5. *Information pack*

The first draft of the information pack was developed as a resource for professionals and parents. Written permission was given by the British Dietetic Association (BDA) to include four dietary information sheets downloaded from the BDA websites. The information sheets entitled ‘Eat well food plate’, ‘Diet and ASD’, ‘Diet, behaviour and learning difficulties’ and ‘Food and Mood’, as described in the earlier Chapter 3 (see *3.5.2.2*). In addition, an information sheet of relevant websites on ASD was compiled. Information on relevant health and ASD related topics such as research updates and evidence-based interventions especially related to eating was included for professionals and parents (**Appendix 1 – Appendix 5**).

4.4. First review of the BEFG-ASD by the specialist group

The first draft of the BEFG-ASD (and information pack) was presented at the Dietitian in Autism Group annual quarterly meeting in June 2009, to a specialist BDA group (see Chapter 3.5.3). Twelve members of the BDA group discussed the content of the BEFG-ASD using their expert clinical perspectives as paediatric dietitians working with children with ASD, and their knowledge of the published literature. Feedback and suggestions were collated and recorded during the meeting.

The key feedback findings were:

- Members agreed with the concept of the BEFG-ASD and content of questions in the first draft of the questionnaire
- The practicalities of how the BEFG-ASD would be used by a range of community based professionals in the community were considered. The group endorsed the decision to use a dichotomous scale for Section A and B. The structure would allow professionals to identify a range of problems in a systematic way.
- Members suggested removal of the sub headings in each section so that all questions can be grouped together as one section.
- Nine questions on feeding problems and GI symptoms were recommended to refine and expand range of problems included. Members had no comments for questions in the impact section.
- Members also endorsed the utility of the set of five information sheets (for information pack) as a useful resource for both professionals and parents working in the community.

Based on this feedback, some modifications were made and the second draft of the BEFG-ASD was constructed (BEFG-ASD Version 2) **(Appendix 15)**. The format and arrangement of the items was also revised. 34 items were included in the second draft of the BEFG-ASD. No changes were made to the information pack.

4.5. Results of the Delphi technique

A modified Delphi technique was undertaken to review the second draft of the BEFG-ASD (and information pack) using two panels of experts in feeding problems and GI symptoms. The method of the modified Delphi technique has been described in the Chapter 3.5.4. Out of 35 invitations to various child health professionals and parents of children with ASD, 20 (50%) agreed to participate in the final review of the BEFG-ASD (and information pack).

4.5.1. *Results of Delphi technique – First round*

Nine professionals (child psychologist (n=1), paediatric gastroenterologist (n=1), paediatric dietitians (n=6) and a researcher in child health nutrition (n=1)) and eleven parents of children with ASD recruited from two North East parent support groups, participated in the Delphi round 1. Other key information about the experts is not collected. All members (n=20) returned the completed review formats by post and e-mail. Mean scores for each question within each domain of the BEFG-ASD were calculated. A summary report of Round 1 for professional experts and parent experts was produced (**Appendix 16** and **Appendix 17)**. Both panels reviewed and rated the items in all sections of the BEFG-ASD as either ‘important’ or ‘very important’ (Score range: 1.2-2.1) as shown in **Table 4.4**.

Table 4.4 Mean score of BEFG-ASD items and information pack in the modified Delphi technique.

	ROUND 1 (n_{profes}=9, n_{parent}=11) (Mean score and *Standard Deviation)				**ROUND 2(n_{profes}=7, n_{parent}=9) (Mean Score and *Standard Deviation)**			
	Feeding problems domain	GI symptoms domain	Impact domain	Info Pack	Feeding problems domain	GI symptoms domain	Impact domain	Info Pack
PARENTS	**1.7 (0.33*)**	**1.2 (0.22*)**	**1.5 (0.50*)**	**1.7 (0.59*)**	**1.6 (0.54*)**	**1.5 (0.58*)**	**1.4 (0.40*)**	**1.8 (0.67*)**
PROFESSIONALS	**1.9 (0.45*)**	**1.8 (0.33*)**	**2.1 (0.93*)**	**1.9 (0.5*)**	**1.7 (0.44*)**	**1.7 (0.41*)**	**1.4 (0.4*)**	**1.5 (1.04*)**

Score indication:

1. *Very important*
2. *Important*
3. *less important*
4. *Not important*

Written feedback and comments were collated. The key comments were summarised:

1) Time scale of the BEFG-ASD

- 70% professional experts (n=6) commented on the duration of identification of the problems. The consensus of the experts' opinion was that 90 days was too long and stated that definitely established problems could be identified once they had been present for one month (30 days). However, the parent experts did not comment on time scales. The professionals recommendations that one month was much more in keeping with the primary aim (Chapter 1.5.1) and specific objective of this research project (Chap 1.6.1). This was accepted and the timescale was adjusted accordingly. However, the adjustment of the timescale to 30 days has some potential limitations for certain aspects of the data collection using the BEFG-ASD. Some symptoms such as growth faltering, weight loss or severe abdominal pain are accurately identified as longer-term problems associated with or secondary to dietary intake or other severe pathologies. These symptoms require a longer duration of symptoms to verify the diagnosis. For example Buie et al (2010), report that abdominal pain in children with ASD aged 4 to 18 years can only be diagnosed accurately if the child has lost weight and the pain is present for more than 30 days to 60 days. Therefore using the cut-off of reporting feeding problems and GI symptoms that have been present for 30 days, is in keeping with the aim of early identification rather than identifying more so-called 'entrenched 'problems and symptoms. If however a parent does report weight loss (of 30 day duration), this may well indicate severe pathology and if accompanied by reports of other feeding problems such as pica, mealtime behaviour and food selectivity, this would indicate a child at high risk of nutrient deficiencies who would definitely require further assessment and referral for further investigations by health professionals.

2) Additional items

- Parent experts suggested 5 new items : 'cutlery control', 'sensitive to food smell', 'food served by certain person', 'foods not touching each other' and 'toileting behaviour related to abdominal pain'.
- Professional experts suggested 3 new items: ''sensitive to food smell', 'foods not touching each other' and weight gain.

- Parent experts suggested one item on the impact : '<u>impact of feeding problems and GI symptoms on their family life</u>'

These additional items were then included as questions because they had already been identified in the literature review, although it was recognised that this also led to an increase in the total number of questions in the BEFG-ASD , which in turn was likely to increase the time required to complete the questionnaire.

3) <u>Supplementary questions for items</u>
    - Both professional and parent experts suggested supplementary questions to clarify items in Section B (GI symptoms domain). These were more details about the types of stools for constipation and diarrhoea, types of medication used to treat constipation and diarrhoea, child's behaviour related to toileting problems and abdominal pain. These were all included.
    - Professional experts recommended the Bristol Stool Chart (BSC) to be used so that professionals could clarify with parents what was meant by constipation and diarrhoea using the illustrations on the chart (**Appendix 21**). The use of the BSC was also recommended by the NICE Guideline Number 99 (National Institute for Health and Clinical Excellence, 2010) to support health professionals to assess constipation and diarrhoea. The recommendation to use the BSC was accepted. The BSC was used alongside Section B – GI symptoms of the BEFG-ASD questionnaire, in order to support professionals to verify questions on constipation (Q1) and diarrhoea (Q2) reported by the parents. The use of BSC was likely to be especially useful to support those professionals who did not have sufficient clinical knowledge or experience such as teachers, community workers or teaching assistants to clarify what is meant by diarrhoea and constipation, with the parents. In this way, the identification of these particular GI symptoms among community professionals is more likely to be consistent and standardised.

    - One professional expert also suggested supplementary questions to clarify responses of 'a great deal' and 'quite a lot' in Section C (Impact domain), highlighting that the details of the supplementary questions would assist professionals to discuss additional supports for parents. The supplementary questions were included so that the clarity of the questions in the domains could be improved and more details could be gathered by professionals to increase their understanding.

4) Information pack
    - 40% of parent experts (n=4) suggested the removal of the "The Eat Well Food Plate" picture in the information pack. In their opinion, the picture was not appropriate for parents of children with ASD. They indicated that the message from the picture could be misleading and distressing for some parents, particularly if children with ASD might have difficulties eating the variety of food in the picture. However, the professional experts did not comment on this picture. Considering all this, the picture in the information pack was included in the second review, in order to seek further opinion from the experts.

At the end of the Round 1, the third draft of the BEFG-ASD included 42 items. It was this 42 questions version that was used in the review format for the Delphi technique Round 2. The second review format (Version 2) was sent to all panel experts together with the summary report of Round 1. Members of both expert panels were asked to review the additional questions in the BEFG-ASD and re-rate their opinion on the importance of all questions, and provide feedback on the content of the information pack (including the food picture) using the second review format.

4.5.2. *Results of Delphi technique – Second round*

Seven out of the 9 professionals and 9 out of 11 parents returned the second review format (Version 2) (n=16). Four experts declined to be involved with the second round of the review due to work commitments and tight schedules. Both panels reviewed and rated all questions in the 3 sections of the BEFG-ASD as 'important' to 'very important' (Score range: 1.4-1.8) as shown in **Table 4.4.** For the second round, professional experts and parent experts agreed on all new questions derived from round 1 of the Delphi. Both panels agreed on the revised duration (one month) for the early identification of problems. In round 2, both panels also agreed on 8 new questions added in the BEFG-ASD and rated these items as 'important' to 'very important'. No further additional items were suggested in round 2 of the Delphi. The written comments were then compared with round 1 and a summary of review from both rounds was produced (**see Appendix 18**).

Parent experts again suggested the removal of the “The Eat Well Food Plate” picture from the information pack. Professional experts recommended that more information should be included if the picture was to remain in the information pack. For these reasons, ‘The Eat Well Food Plate’ picture was removed.

At the end of the Delphi process, all panel experts were contacted through e-mails to inform them of the final outcome and the completion of the modified Delphi technique. All agreed with the content and format of the third draft of the BEFG-ASD (BEFG-ASD Version3) (**Appendix 19**). The final development task was the readability statistics of the BEFG-ASD. This will be discussed in the next section.

4.6. Readability of the BEFG-ASD Version 3

The final stage of the questionnaire development was to assess the readability of the BEFG-ASD. It is essential to ascertain whether the questionnaire is suitable for the target participants (Oppenheim, 1992; Boynton and Greenhalgh, 2004; Terwee et al., 2007). In this research, target participants are parents/caregivers of children with ASD and the community professionals working to support them. It is essential to check the readability of the questionnaire so that missing responses and unreliable answers can be avoided (Terwee et al., 2007). The readability statistics of the BEFG-ASD Version 3 were checked using the Microsoft Office 2010 using three assessments: the Flesh Reading Ease, the Flesh-Kincaid Grade level and the Gunning for Index. The average total words per sentence in the BEFG-ASD were 12.9, which indicated that short sentences had been used throughout the questionnaire. The rate of passive sentences was low (5%). The Flesh Reading Ease was 68.9 and the Flesh-Kincaid Grade Level was 6.8. All these results mean that a layperson should be able to understand all questions. The Gunning for Index for the BEFG-ASD indicated that an adult who had received 12 years of formal education could use or understand the BEFG-ASD.

4.7. Results of the pre-test of the BEFG-ASD Version 3

The pre-test of the third draft of the BEFG-ASD was conducted with a group of health professionals (n=6) and parents of children with ASD aged 4-11 years (n=10) in Newcastle, Northumberland and North Tyneside. None had been involved in the development work. Health professionals recruited were dietitians (n=2), psychiatrists (n=2), a teacher (n=1) and a community nurse (n=1). The professionals interviewed parents face-to-face using the third draft of the BEFG-ASD (Version 3) in their usual work settings (clinics and school). At the end of the interview, parents were asked by professionals to give their feedback about the questions, the format of the BEFG-ASD (Version 3) and the information pack. Professionals were also asked to give their written feedback on similar aspects. In this pre-test, the average time taken to conduct the BEFG-ASD was 25 minutes (range 10-40 minutes). Overall, parents who described their child as having definite feeding problems and/or GI symptoms took longer to answer the BEFG-ASD compared to those parents whose children did not have many problems. However, parents and professionals reported that the items were easy to understand and acceptable.

Three professionals suggested some further adjustments of the wording for the general instructions, the sequence of the questions, and some extra supplementary questions for Section B (GI symptoms) and Section C (impact). As a consequence, the order of the questions in the BEFG-ASD was adjusted. Further minor adjustments to the structure and format of the BEFG-ASD were made leading to the final version of the questionnaire (Version 3.1) (**Appendix 20**).

4.8. Description of the BEFG-ASD Version 3.1

The final version of the BEFG-ASD still retains three sections (for the three domains) and 42 main questions (42 items):
Section A: Feeding problems (25 items)
Section B: GI symptoms (9 items)
Section C: The impact of feeding problems and GI symptoms on family life (8 items)

The final version of the BEFG-ASD also includes 23 supplementary questions across the three sections of feeding problems, GI symptoms and the impact, based on the outcome of the modified Delphi technique. The operational definitions of the sub domains based on the findings and feedback from all the development work were revised. Details of all items and supplementary questions (in italics) for the final version of the BEFG-ASD are shown in **Table 4.5, Table 4.6 and Table 4.7**.

Table 4.5 The BEFG-ASD (Final version 3.1) Section A: Feeding problems

No	Sub domain	Operational Definition	Description of item/question
1.	Food Selectivity	Limited consumption and specific preference/ selection of foods based on food groups/category of foods over the past one month Child also has preference for same foods at each meal and refuses to eat certain types of food (strong food dislikes)	Q1 –Refuses to eat foods that family regularly eat Q2- Insists on similar foods for most meals/every meal Q3- Preparation of different foods is required for the child compared with other family members
2.	Food Sensitivity (food physical characteristics)	Child rejects of foods due to physical characteristic such as texture, smells, colour, packaging, temperature and shape over the past one month	Q4 –child insists on food physical characteristics (general) Q5- child has strong preference for foods with particular textures Q6 – child has strong preference for foods with particular flavours Q7- child is sensitive to food smells Q8- child insists food served in a particular way Q9 – child insist specific utensils or crockery for eating or drinking Q10- child has problems handling crockery
3.	Food Sensitivity (child's food environment)	Over the past one month, child insists on having: • food served in particular way • food cooked by certain person • eat meals at the same place • foods are not touching each other on the plate	Q11- food must be cooked by a certain person Q12- food must be served by a certain person Q13- different foods must not touch each other on the plate Q14- meals must be eaten at the same place Q15- refuses to eat with certain family members at mealtimes

Table 4.5 The BEFG-ASD (Final version 3.1) Section A: Feeding problems

No	Sub domain	Operational Definition	Description of item
4.	Problematic mealtime behaviours	Behaviours that occurred over the past one month (at least once a week) at mealtime which include: • Disruptive behaviour (spitting out food, screaming, shouting) • Aggressive behaviour (kicking/hitting family members) • self-injurious behaviour (biting self, head banging on table)	Q16- disruptive behaviour during mealtimes more than once a week Q17- aggressive or violent behaviour during mealtimes more than once a week Q18- self injurious behaviour during mealtimes more than once a week
5.	Food neophobia	Fear of trying new or unfamiliar foods that could lead to vomiting, choking and fear of swallowing foods over the past one month	Q19- reluctant to eat new food Q20- fearful of swallowing or shows signs of choking
6.	Signs of pica	Licking, craving, chewing or eating of non-nutritive substances over an extended period (over the past one month) e.g. plastic, hair, wood, cloth, dirt.	Q21- eats or licks non-food items
7	Parental dietary practices and restriction	Dietary practices and restriction of child's diet by parents imposed by use of : • special diet • use of vitamin and other supplements. • limitation/avoidance of certain food taken by child	Q22- change of diet as part of ASD treatment Q23- use of dietary supplement Q24- food avoidance Q25 –parent did not receive any advice on managing feeding problems (in the past 12 months) (supplementary questions) *Who gave advice* *Type of advice*

Table 4.6 The BEFG-ASD (Final version 3.1) Section B: Gastrointestinal (GI) symptoms

No	Sub domain	Operational Definition	Description of item
1.	Constipation	Bowel actions less than 3 times per week over the past one month (Type 3 or 4) 'Rabbit droppings' – Type 1 Use of the Bristol Stool Chart (BSC) to confirm stool patterns.	Q1- Bowel motion/passage less than 3 times a week (supplementary questions) *Q1.1-type of poo* *Q2- use of medication or therapy to treat constipation* *Q2.1-type of medication* Q3- accidents in opening bowels
2.	Diarrhoea	Passage of stools more than 3 times per day over the past one month, loose or liquid stools (Type 7). Use of the Bristol Stool Chart (BSC) to confirm stool patterns.	Q4- Bowel motion/passage more than 3 times a week (supplementary questions) *Q5-type of poo* *Q6- use of medication or therapy to treat diarrhoea* *Q6.1- type of medication*
3.	Abdominal pain	Child has regular abdominal pain (at least once a week over the past one month) * pain also not associated with diarrhoea or constipation	Q7- Regular abdominal pain (supplementary questions) *Q8- Child complains of abdominal pain more than 3 times a week* *Q9-Abdominal pain that disrupts daily activity* *Q10- use of medication or therapy to treat abdominal pain* *Q10-use of medication or therapy to treat diarrhoea*
4.	Toileting behaviour	Child also has toileting behaviour over the past one month	Q11- child refuses to go to the toilet (due to pain) Q11.1- child's behaviour

Table 4.6 The BEFG-ASD (Final version 3.1) Section B: Gastrointestinal (GI) symptoms

No	Sub domain	Operational Definition	Description of item
5.	Vomiting	Child frequently vomited (at least once a week over the past one month)	Q12-vomits at least once a week (supplementary questions) *Q12.1- vomiting related to drinking or eating* *Q12.2- amount of vomit* *Q12.3- colour of vomit*
6.	Child's growth	**Parental concern on child's growth** Parent's concern on the child's growth which includes any aspect of weight or height issues **Weight issues** Child has weight loss over the past one month. Child has weight gain over the past one month.	Q13- parent's concern about child's growth (supplementary questions) *Q13.1-parent's concern* Q14- child's weight loss (supplementary questions) *Q14.1-parent tries to reduce child's weight* *Q14.2- amount of weight loss* *Q14.3- what are parent concerns on weight loss* Q15- child's weight gain (supplementary questions) *Q15.1- amount of weight gain* *Q15.1- what are parent concerns on weight gain*

Table 4.7 The BEFG-ASD (Final version 3.1) Section C: Impact of Feeding problems and gastrointestinal (GI) symptoms

No	Sub domain	Operational Definition	Description of item
1.	Impact of feeding problems on family life	'restriction of parent's/carer's life (including social activities)', 'extra stress in managing feeding problems', 'significant contribution in the finances of the parent/carer' and 'restriction of family life' over the past one month	Q1- feeding problems restrict parent's life Q2- feeding problems have placed extra stress Q3 – feeding problems have had significant impact on finance Q4- feeding problems have affected family life
2.	Impact of feeding problems on family life	'restriction of parent's/carer's life (including social activities)', 'extra stress in managing GI symptoms', 'significant contribution in the finances of the parent/carer' and 'restriction of family life' over the past one month	Q5- GI symptoms restrict parent's life Q6- GI symptoms have placed extra stress Q7- GI symptoms have had significant impact on finance Q8- GI symptoms have affected family life
			(supplementary questions) *-Details of the impact* *Q9- support for parents* *Q10-Coping with difficulties of having child with ASD*

4.9. Discussion

The primary aim of the present research was to develop a brief structured questionnaire for the early identification of feeding problems, GI symptoms in primary school children with ASD and the impact of these problems on family life. This chapter describes the outcome of the process of the development work of the BEFG-ASD. This has involved several different activities, informed by the recommendations of and good criteria for health questionnaire development by Streiner and Norman (2008), Terwee et al (2007) and Openheim (1992).

The operational definitions for the different sub domains for the BEFG-ASD were constructed based on a comprehensive literature review and the consultations with different experts in ASD. A variety of terms used to describe feeding problems were identified and also a lack of definition in both the DSMV-IV (American Psychiatric Association, 1994a) and DSMV-IV-TR (American Psychiatric Association, 1994b) and the ICD-10 (World Health Organisation, 1992). Despite this limitation, a considerable range of feeding problems and GI symptoms are described in the literature although it is difficult to conclude whether the types of problems are the same in children with ASD, or how much to attribute the problems to aspects of the underlying ASD behaviours. The main concern in this development work was whether there is a subgroup of children with ASD for whom these feeding problems or GI symptoms may be of particular aetiological significance. The conclusion drawn from the development work was that more research needs to be undertaken in all three areas, and that until these problems are investigated in a standardised manner, it will not be possible to make progress in this field of study. Therefore, working operational definitions for the identified sub domains of feeding problems, GI symptoms and the impact were devised and summarised for the present research work.

The evidence on the impact of feeding problems and GI symptoms is very limited. For this research, some components of the IFS measure published by Stein and Riessman (1980) were adapted. This work is a first attempt to develop a measure to investigate the impact of feeding problems and GI symptoms on family life. In the review process (modified Delphi technique), professionals and parents agreed that feeding problems and GI symptoms have different types of impact on their life as parents/carers of children with ASD and their families. Further research is needed to evaluate the impact of feeding problems and GI symptoms in primary school children with ASD and their families.

In the present research, the review by the dietitian specialist group in ASD and the expert groups involved in the modified Delphi technique, led to an expansion of the content of the BEFG-ASD. Although several methods have been reported in the literature as suitable procedures in the design and review of a new questionnaire such as focus groups or in-depth interviews (Bowling, 2009; Oppenheim, 1992, Streiner and Norman, 2008), the Delphi technique was chosen as the procedure for conducting the second review of the BEFG-ASD (see Chapter 3.5.4 for the details of the critical appraisal). The Delphi technique provided the method for gathering opinions from both professionals and parents of children with ASD in a systematic way for the evaluation of the content validity of the questionnaire. The Delphi technique was able to gather opinion from both professionals and parents of children with ASD and also maximised the content validity of the questionnaire in a systematic way. However, there are some methodological limitations of the Delphi technique used in this research which should be noted. First, the sample of professional experts did not include all relevant professional groups. Although it is hoped that the different individual professionals who took part have views shared by their colleagues, it may be that they have different experiences and knowledge from their professionals peers. Second, the sample of parents may also have particular experience or children with specific difficulties on feeding problems or GI symptoms that could affect their opinion in this topic. Third, the selection of the professional and parent experts was based on the recommendations from key professionals (purposive sampling), taking into consideration the time and other resource constraints of the research. According to Thangaratinam and Redman (2005), the representativeness of the panel experts in the Delphi technique should be determined by the qualities of the experts rather than the number. Random sampling from a wider group of professionals and parents would not have been appropriate as the recruitment was constrained by the specific topic of interest. In the present research, the Delphi was conducted with approximately the recommended number of experts per group (N=20), and the members represented both service providers (professionals) and users (parents of children with ASD).

Another criterion for the development work of the BEFG-ASD was to design a brief and structured questionnaire, so that professionals from a range of disciplines could identify feeding problems, GI symptoms and the impact of these problems in a systematic way, as part of their overall assessment and management of ASD. The readability statistics of the BEFG-ASD was checked as part of the content validity, with the aim of reducing the risk of unreliable answers and misinterpretations of questions. The results have shown that a range of professionals in the community should be able to use the BEFG-ASD and parents should be able to understand all questions if asked by the professionals.

In summary, although uncertainties remain about the aetiology and the severity of feeding problems and GI symptoms, the different sources used in this research have supported the need for a new brief structured questionnaire that could assist community professionals. The content validity and face validity of the BEFG-ASD has been adequately established in this development work.

CHAPTER 5

RESULTS

DESCRIPTIVE FINDINGS

Chapter 5- Results

Descriptive findings

5.1. Introduction

In this chapter, the descriptive findings of the field-testing of the BEFG-ASD (Phase II) will be described. This includes the recruitment and response rates, the demographic characteristics of participants in the field-testing (professionals, parents and children with ASD), the total number of feeding problems, GI symptoms in the children with ASD and the scores of the impact of these problems on family life.

The descriptive analyses sought to answer the following questions:

1) How many feeding problems and GI symptoms among children with ASD were identified by professionals using the BEFG-ASD?
2) What are the impacts of feeding problems and GI symptoms on family life of children with ASD identified by professionals using the BEFG-ASD
3) How do feeding problems and GI symptoms relate to the impact?

5.2. Recruitment and response rate of the field-testing

One hundred and twenty information sheets and letters of invitation were sent to different professional groups using contacts from key professionals at Newcastle University and key contacts at Child Development Centers (CDC), Child and Adolescent Mental Health Services (CAMHS), Child and Learning Disabilities Team (CLDT) working in the different NHS Trusts, and some special schools in North East England.

The overall recruitment and response rate of field-testing is shown in **Figure 5.1**. Seventy expression of interest reply slips and e-mails were received from professionals. Demographic information of professionals was recorded on the interest reply slips, including the professional's job title and work address. Of the 70 professionals who expressed an interest, 61 agreed to participate in the field-testing and gave informed consent. Of these 61 professionals, 49 were health professionals from different health disciplines and 12 were teachers from four special schools recruited across North East England. The demographic characteristics of professionals are described in **Table 5.1**. Three professionals agreed to participate in both field-testing 1 (FT1) and field-testing 2 (FT2).

5.2.1. Response rate of professionals and parents in the field-testing 1(FT1)

Overall, 54 out of 61 professionals (89%) agreed to participate in the FT1. Of these 54 professionals, 41 professionals were able to complete both interviews for FT1. Thirteen professionals withdrew from the field-testing (FT1) due to either work commitments or problems recruiting parents of children with ASD from their current caseloads. The 13 professionals include paediatricians (n=3), clinical psychologists (n=2), dietitians (n=2), community workers (n=2), one speech language therapist, one nurse, one occupational therapist and one 'child and adolescent psychiatrist'. There appeared to be no differential attrition of any particular professional group. Overall, 41 out of 54 professionals have completed the field-testing work for FT1 and conducted both interviews with parents of children with ASD (**Figure 5.1)**.

In the FT1, professionals recruited parents/carers from their current caseloads. Each parent was given an information sheet about the study. The demographic information of parents/carers and children with ASD was recorded on 'parent interest reply slips' by the parents. This included the name of parent/carer, relationship with child, name of child, child's age, child's ASD clinical diagnosis and child's gender. Parents gave their informed consent to their own professional. Forty-seven parents/carers of children with ASD were recruited by professionals and completed the first interview using the BEFG-ASD. Of these 47 parents, 43 (91%) parents/carers completed the second interview. The parents also completed the self-report questionnaires, which included the Social Communication Questionnaire (SCQ), the Brief Autism Mealtime Behaviour Inventory (BAMBI), the Gut Symptoms Checklist (GSC) and the modified Impact Family Scale (IFS).

5.2.2. Response rate of professionals and parents in the field-testing 1(FT2)

Ten professionals agreed to participate in the FT2 (Three professionals had also taken part in the FT1). The professionals were teachers, teaching assistants and Dietitians (**Figure 5.1)**. Similar to the FT1, professionals recruited parents/carers from their current caseloads. Demographic information of parents/carers and children with ASD was recorded on ‘parent interest reply slips’ and each parent gave informed consent to their professional.

Twenty-seven parents/carers of children with ASD were recruited by professionals and completed the first interview using the BEFG-ASD. 26 (96%) parents/carers were also able to complete the second interview (**Figure 5.1)**. Parents also completed the self-report questionnaires (SCQ, BAMBI, GSC and IFS).

Overall, for both FT1 and FT2, 74 parents of primary school children with ASD were recruited. Most were biological mothers (n=65). Other categories included biological fathers (n=4), foster parents (n=4) and one caregiver from a local authority children home **Table 5.1**. However, one parent was excluded because the child’s age was less than 4 year. Data for this child was excluded from all analyses.

Figure 5.1 Recruitment of professionals and parents in the field-testing of the BEFG-ASD

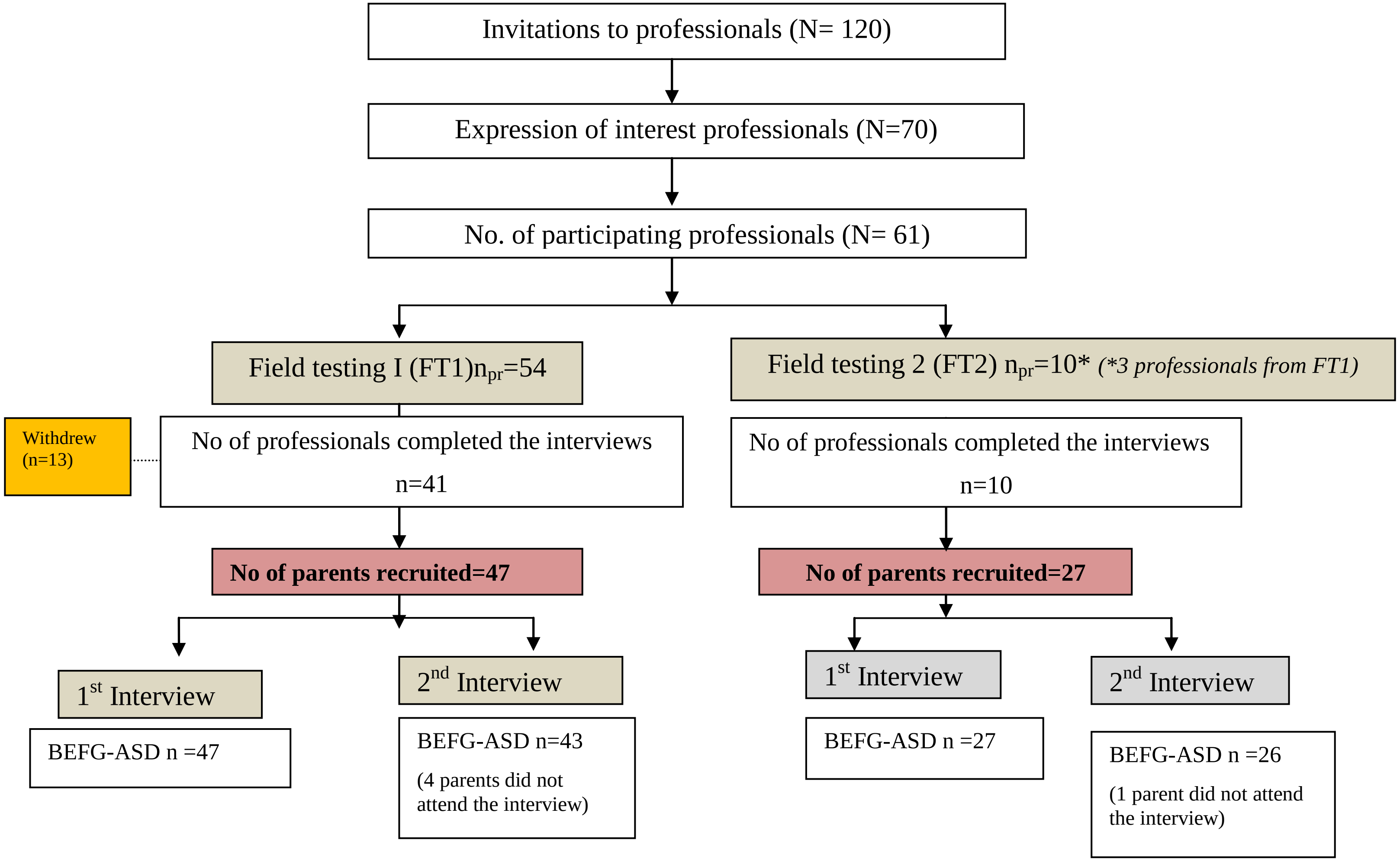


Table 5.1 Demographic information of professionals and parents in the field-testing (FT1 and FT2) of the BEFG-ASD

Professionals	Job Title	Frequency (N=61)	Percentage (%)
Health professionals (n=49)	Clinical psychologist	11	18%
	Child psychiatrist	7	11%
	Nurse (school nurse, community nurse)	7	11%
	Paediatrician	7	11%
	Speech language therapist	3	6%
	Occupational therapist	4	7%
	Paediatric dietitian	5	8%
	Others (Project community worker/ mental health worker)	5	8%
Educational practitioner (n=12)	Teachers /Learning partnership teachers/ teaching assistants	12	20%
Total		**61**	**100%**

Parents/carers		Frequency (N=74)	Percentage (%)
Relationship to child	Biological mother	65	88%
	Biological father	4	5%
	Foster parent	4	5%
	Caregiver	1	2%
Total		**74**	**100%**

5.3. Demographic characteristics of children with ASD

The results of the descriptive findings for feeding problems, GI symptoms in primary school children with ASD and the impact of these are based on characteristics of children with ASD whose parents took part in the field-testing (FT1 and FT2). All the descriptive findings are taken from parents responses from the first interview with the professional. The sample of parents and children with ASD recruited in this study cannot be considered as a representative sample of primary schoolchildren with ASD living in North East England.

Mean age of the children was 7 years and 3 month with the median age was 8 years old (n=23%). 86% (n=63) of children were male and most children had a clinical diagnosis of autism (n=59, 81%). Other clinical diagnoses recorded by professionals were ASD (12%), Asperger Syndrome (6%) and PDD-NOS (1%) (**see Table 5.2).**

The children's reported ASD diagnoses were verified using the Social Communication Questionnaire (SCQ). Out of 73 parents, 89% of parents (n=65) completed the SCQ (9 parents refused to answer the SCQ). Of the 65 parents, there were a further 7 parents who did not answer all questions in the SCQ. These incomplete SCQs were excluded from the analysis. Mean SCQ scores for the sample of children (n=58) in the present research was 25.4 (SD: 6.08). It was found that 4 children (6%) had SCQ score of less than 15.0. Based on the SCQ manual, the recommended cut-off score for children with ASD is 15.0 and above (Rutter et al., 2003). However, a lower SCQ cut off score ($\geq$11.0 or $\geq$12) has been suggested for younger children (Corsello et al., 2007). Thus, the overall SCQ mean scores for this sample are well within the range of scores reported for children with ASD.

Table 5.2 Demographic characteristics of primary school children with ASD

Characteristics of children	**Cases (N=73)**
Age (years)	
N	73
Mean	7.3
Standard Deviation	2.05
Minimum	4.0
Maximum	11.0
Gender	
Male	63(86.3%)
Female	10 (3.7%)
ASD Diagnosis (recorded by professionals)	**Cases (N=73)**
Autism	59 (80.8%)
ASD	9 (12.3%)
Asperger	4(5.5%)
PDD NOS	1 (1.4%)
SCQ Scores	**Cases (N=58)**
Mean	25.4
Standard Deviation	6.08
Minimum	12.0
Maximum	36.0

5.4. Feeding problems

Data on feeding problems were analysed based on parents' responses to the 25 main questions in Section A of the BEFG-ASD (Feeding problems) from the first interview with professionals. These 25 questions are items within the feeding problems domain. Prior to the analyses, each item with 'Yes' and 'No' answer was converted into a score of 1=Yes and 0=No. A reverse score of 0=Yes and 1=No was given for item 25 (parent received advice from professional). Total number of feeding problems was identified based on those parents who answered 'Yes' for each item.

Based on the descriptive analysis, all parents (100%) reported that their children had 2 or more feeding problems (range 2 – 21 feeding problems) in the last 4 weeks. More than one third of the children were reported by their parents to have experienced 11 to 18 feeding problems **(see Table 5.3)**.

Table 5.3 Number of feeding problems among children with ASD (N=73)

Number of feeding problems per child	Number of children (n)	Percentage (%)
Without feeding problems	0	0%
With feeding problems	73	100%
2 feeding problems	2	(2%)
3 to 6 feeding problems	9	(12%)
7 to 10 feeding problems	21	(29%)
11 to 14 feeding problems	23	(32%)
15 to 18 feeding problems	15	(21%)
19 to 21 feeding problems	3	(4%)
Total (n)	73	(100%)

Table 5.4 summarises the parents' responses to the 25 feeding problems organised within the 7 sub domains of the BEFG-ASD. Parents reported that more than half of the children had problems related to 'food selectivity' (child refused to eat family food,

child insisted similar food at most meals and child required specific food preparation) and'food sensitivity based on child's food environment' (child insists food served in particular way and child has problems with cutlery control). More than one third of children also had 'food sensitivity based on physical characteristics' (insisted food on particular textures, flavours and smells). The majority of the children (82%) were also reluctant to eat new foods, which is described as a sign of 'food neophobia'.

More than one third of the children had regular problematic mealtime behaviours (at least once a week). Based on the examples recorded by professionals, these included disruptive mealtime behaviours such as shouting, spitting and throwing foods, and aggressive behaviours such as kicking siblings, throwing cutlery at family members and scratching tables. 14% of children had frequently shown self-injurious behaviours which included biting own hands, pulling own hair and banging head on table during mealtimes. The proportion of children who had 'signs of pica' (eat, lick or chew non-food items) was also high (53%). The non-food items included wood, stationary, bus stops, baby wipes, papers, play dough, mother's hair, furniture and tyres on vehicles.

More than half of the parents (53%) avoided giving their children particular foods such as sweets, soft drinks, cakes and salty foods such as crisps. However, the majority of parents (86%) reported that they have not changed their child's diet in the past 4 weeks. Despite the many feeding problems reported by parents, the majority of parents (62%) had not received any professional advice on feeding problems in the past 12 months.

5.4.1. *Missing data*

One parent did not respond to one question of food sensitivity and two parents did not answer one question on 'food neophobia' (**Table 5.4**). These parents reported to professionals that it was difficult to give a definite answer to the question because their child's feeding behaviour was not consistent in the area covered by that question in the previous one month. However, these were the exceptions, parents were usually able to answer all the questions in Section A of the BEFG-ASD.

Table 5.4 Feeding problems in children with Autism Spectrum Disorders (N=73)

Sub domains and items of feeding problems		Frequency		
		Yes	No	No answer
Food selectivity				
1. Child refused to eat similar foods during family mealtimes (*Q1)	Count	57	16	-
	%	78%	22%	-
2.Child insists similar food at most meals (Q2)	Count	52	21	-
	%	71%	29%	-
3.Special food preparation for the child(Q3)	Count	49	24	-
	%	67%	24%	-
Food sensitivity (physical characteristics)				
4. Child insists on food with particular character (brands, packaging, colour, shapes) (Q4)	Count	30	43	-
	%	41%	59%	-
5.Child has strong preference on particular textures (Q5)	Count	33	40	-
	%	45%	55%	-
6.Child has strong preference on food flavours (Q6)	Count	35	38	-
	%	48%	52%	-
7.Child is sensitive to food smells (Q7)	Count	29	44	-
	%	40%	60%	-
8.Child insists food served in particular way (Q8)	Count	40	33	-
	%	55%	45%	-
9.Child insists to use of specific cutlery (Q9)	Count	31	42	-
	%	43%	57%	-
Food sensitivity (child's food environment)				
10.Child has problems with cutlery control (Q10)	Count	44	29	-
	%	60%	40%	-
11.Child insists food is cooked by certain person (Q11)	Count	11	62	-
	%	15%	85%	-
12. Child insists food is served by certain person (Q12)	Count	12	60	1**
	%	16%	82%	2%
13. Child insists foods are not touching each other on plate (Q13)	Count	27	46	-
	%	37%	63%	-
14. Child insists meals in the same place (Q14)	Count	32	41	
	%	44%	56%	
15. Child refused to eat with family members (Q15)	Count	33	40	
	%	45%	55%	

Table 5.4 Feeding problems in children with Autism Spectrum Disorders (N=73)

Sub domains and items of feeding problems		Frequency		
		Yes	No	No answer*
Problematic mealtime behaviours				
16.Child frequently shown disruptive mealtime behaviour (at least once a week) (Q16)	Count	32	41	
	%	44%	56%	
17.Child frequently shown aggressive behaviour (at least once a week) (Q17)	Count	26	47	
	%	36	64	
18.Child frequently shown self-injurious behaviour (at least once a week) (Q18)	Count	10	63	
	%	14%	86%	
Food neophobia				
19. Child reluctant to eat new food (Q19)	Count	60	13	
	%	82%	18%	
20. Child shows fearful of swallowing foods(Q20)	Count	16	55	2**
	%	22%	75%	3%
Signs of pica				
21. Eat or lick non-food items (Q21)	Count	39	34	
	%	53%	47%	
Parental dietary practices				
22. Parent changed diet as part of child's ASD treatment (Q22)	Count	10	63	
	%	14%	86%	
23.Parent gave supplements to child (Q23)	Count	27	46	
	%	37%	63%	
24.Parent avoids particular food for child (Q24)	Count	39	34	
	%	53%	47%	
25. Parent did not receive any advice on feeding and child's diet (Q25)	Count	45	28	
	%	62%	38%	

* Question number in the BEFG-ASD

* *Parents were unable to give a 'Yes/No answer to this question

5.5. Gastrointestinal (GI) symptoms

The number of GI symptoms was analysed based on parent's responses to 9 main questions (Q1, Q3, Q4, Q7, Q11, Q12, Q13, Q14, Q15) from Section B (GI symptoms) of the BEFG-ASD (**Table 5.5**). These main questions represent the 9 items within the 7 sub domains of the GI symptoms. 75% of parents reported that their child had one or more GI symptoms (range 1 – 8 GI symptoms). Of these children, 54% had 2 to 4 GI symptoms per child. 4% of children had more than four (4) symptoms.

Table 5.5 Number of GI symptoms among children with ASD (N=73)

Number of GI symptoms per child	Number of children (n)	Percentage (%)
Without GI symptoms	18	25 %
With GI symptoms	55	75%
1 symptoms	13	(18%)
2 symptoms	19	(26%)
3 symptoms	13	(18%)
4 symptoms	7	(10%)
5 to 8 symptoms	3	(4%)
Total (n)	**55**	**(100%)**

Table 5.6 summarises the parents' responses to each item according to the 6 sub domains in Section B (GI symptoms) of the BEFG-ASD. The number of children reported by their parents to have GI symptoms was less than the number of children reported to have feeding problems. However, nearly one third of children suffered from constipation. Some children also had diarrhoea (n=14), abdominal pain (n=12) and vomiting (n=3). Parents also reported concerns about their child's growth and 39% of parents were worried about their child's weight.

Table 5.6 GI symptoms in children with Autism Spectrum Disorders (N=73)

Gastrointestinal symptoms		Yes (n)	No (n)	No answer (n)
Constipation				
1) Child suffered from constipation (Q1)	Count	25	48	-
	%	34%	66%	-
2) Child had accidents in opening bowel (Q3)	Count	19	51	3**
	%	26%	70%	4%
Diarrhoea				
3) Child suffered from diarrhoea (Q4)	Count	14	59	-
	%	19%	81%	-
Abdominal pain				
4) Regular abdominal pain observed by the parent (Q7)	Count	12	61	-
	%	16%	84%	-
Toileting behaviour				
5) Child refused to go to toilet (Q11)	Count	14	57	2**
	%	19%	78%	3%
Vomiting				
6) Child frequently vomited (at least once a week) (Q12)	Count	3	70	-
	%	4%	96%	-
Growth and weight issues				
7) Parent concerned about growth (Q13)	Count	22	51	-
	%	30%	70%	-
8) Child lost weight (Q14)	Count	10	63	-
	%	14%	86%	-
9) Child gained weight (Q15)	Count	18	53	-
	%	25%	73%	-

* * Question number in the BEFG-ASD

* *Parents were unable to give a 'Yes/No answer to this question

5.5.1. *Missing data*

Three parents did not answer the item 'accidents in opening bowel' and two parents did not answer the item 'child frequently refused to go the toilet'. These children all wore nappies and for this reason, the parents stated that it was difficult for them to answers these questions.

5.6. Impact of feeding problems and GI symptoms on family life

Further analysis was conducted to identify the impact of feeding problems and GI symptoms using parent's responses to the 8 main questions in Section C of the BEFG-ASD (Impact). These questions are the 8 items of the impact of feeding problems and GI symptoms. The professional rated the parents' responses on a scale ranging from 'a great deal' to 'not applicable'. These responses were converted to an ordinal scale with 4='a great deal' to 0='not applicable'. The impact data was normally distributed.

5.6.1. *Impact of feeding problems*

The impact of feeding problems on family life is shown in **Table 5.7**. Although the mean scores for each item range between 1.5 – 2.4 ('not at all' to 'only a bit'), the commonest rating (mode score) for 2 impact items ('feeding problems of child restrict parent's life' and 'managing feeding problems have placed extra stress on parents') was 'quite a lot'.

Table 5.7 Impact of feeding problems (N=73)

	Feeding problems of child restrict parent's life	Managing feeding problems had placed extra stress on parents	Feeding problems had significant impact on finances of the parent	Feeding problems affected family life
N	73	73	73	73
Mean Score	2.4	2.3	1.5	2.1
Std. Deviation	1.2	1.2	1.1	1.2
Mode	3.0	3.0	1.0	2.0

Scale of impact: 0=not applicable, 1= no/not at all, 2= only a bit, 3= quite a lot, 4=a great deal

Details of each item of the impact of feeding problems are summarised on **Table 5.8** to **Table 5.11.**

The majority of parents (n=52) reported that feeding problems did restrict their life as parents/carers (**Table 5.8**). 50% (n=37) of parents reported the impact was 'quite a lot' and 'a great deal'. Using the BEFG-ASD questionnaire, professionals asked parents the details for 'quite a lot' and 'a great deal' responses. Parents reported difficulties attending personal and social activities such as going out with friends, going out with spouse, going to work and attending functions.

Table 5.8 Feeding problems of child restrict parent's life (N=73)

Scale	Frequency (n)	Percent (%)
not applicable	5	6.8
not at all	16	21.9
only a bit	15	20.5
quite a lot	22	30.1
a great deal	15	20.5
Total	73	100.0

Table 5.9 shows that the majority of parents (n= 52) reported that managing feeding problems had placed some extra stress on them (score 'only a bit', 'quite a lot' and 'a great deal'. 37% (n=27) of parents reported that stress in managing feeding problems was 'quite a lot'. Based on the details recorded by professionals, parents particularly mentioned that the difficulties in managing their child's feeding problems at school, home, in restaurants and on special occasions (birthday party or family day) placed extra stress on them.

Table 5.9
Managing feeding problems had placed extra stress on parents (N=73)

Scale	Frequency (n)	Percent (%)
not applicable	5	6.8
not at all	16	21.9
only a bit	13	17.8
quite a lot	27	37.0
a great deal	12	16.4
Total	73	100.0

Despite the impact on parents/carers' life and stress, more than half of parents/carers (55%) reported that feeding problems had no significant impact on their family finances (**Table 5.10**). However, there were also parents who reported that the impact of feeding problems on their finances were ‘quite a lot’ and ‘a great deal’ (n=14). Based on written information recorded by professionals, parents had reported that for example, they had to purchase particular types or brands of foods for their child due to the food selectivity problems.

Table 5.10 Feeding problems had significant impact on finances of the parent (N=73)

Scale	Frequency (n)	Percent (%)
not applicable	8	11.0
not at all	40	54.8
only a bit	11	15.1
quite a lot	9	12.3
a great deal	5	6.8
Total	73	100.0

The majority of parents (n=51) also reported that feeding problems had affected their family life such as eating out and going for holiday as a family (**Table 5.11**). 37% (n=27) parents reported that the impact was ‘quite a lot’ and ‘a great deal’.

Table 5.11 Feeding problems affected family life

Scale	Frequency (n)	Percent (%)
not applicable	7	9.6
not at all	15	20.5
only a bit	24	32.9
quite a lot	17	23.3
a great deal	10	13.7
Total	73	100

5.6.2. *Impact of GI symptoms*

The analysis of the impact domain of the BEFG-ASD was based on responses from those parents who reported GI symptoms among their children (n=55). Eighteen parents reported no GI symptoms among their children (**see section 5.5**). For those parents who did report GI symptoms, the mean impact scores were consistently smaller than the impact of feeding problems (**Table 5.12)**. The commonest rating for all the impact items was ‘no/not at all’.

Table 5.12 Impact of GI symptoms (N=55)

	GI symptoms of child restrict parent’s life	Managing GI symptoms had placed extra stress on parents	GI symptoms had significant impact on finances of the parent	GI symptoms affected family life
N	55	55	55	55
Mean Score	1.4	1.4	1.0	1.0
Std. Deviation	1.3	1.3	0.9	1.3
Mode	1.0	1.0	1.0	1.0

Scale: 1= no/not at all, 2= only a bit, 3= quite a lot, 4=a great deal

The details of the impact of GI symptoms were analysed (**Table 5.13** to **Table 5.16**). Only 21 parents reported that GI symptoms restricted their life as parents/carers. About 33% (n=18) parents reported that the impact was ‘quite a lot’ and ‘a great deal’. Based on the details recorded by professionals during the interviews, the restriction included limited personal and social activities such as going out with friends, going out to work and attending functions.

Table 5.13 GI symptoms of child restrict parent’s life (N=55)

Scale	Frequency (n)	Percent (%)
not at all	34	61.8
only a bit	3	5.4
quite a lot	12	21.8
a great deal	6	11.0
Total	55	100.0

One third of parents (n=25) reported that managing GI symptoms have placed extra stress on them. 29% reported that the impact was ‘quite a lot’ or ‘a great deal’ (**Table 5.14**).

Table 5.14 Managing GI symptoms had placed extra stress on parents (N=55)

Scale	Frequency (n)	Percent (%)
not at all	30	54.6
only a bit	9	16.4
quite a lot	8	14.5
a great deal	8	14.5
Total	55	100.0

76% of parents reported that managing the GI symptoms had no significant impact on their finances **(Table 5.15**). However, 13% (n=7) reported that there was an impact of GI symptoms on their finances. These parents reported that they had to spend a lot of money to purchase nappies for their children.

Table 5.15 GI symptoms had significant impact on finances of the parent (N=55)

Score	Frequency (n)	Percent (%)
not at all	42	76.4
only a bit	6	10.9
quite a lot	6	10.9
a great deal	1	1.8
Total	55	100.0

Table 5.16 shows the impact of GI symptoms on family life of children with ASD. More than a third of parents reported that there was an impact of GI symptoms on family life, and 30 % reported that the impact was ‘quite a lot’ and ‘a great deal’. These parents reported difficulties in doing outdoor activities as a family. They also reported that the GI symptoms also affected activities for other children in the family.

Table 5.16 GI symptoms affected family life (N=55)

Score	Frequency (n)	Percent (%)
not at all	32	58.0
only a bit	6	11.0
quite a lot	11	20.0
a great deal	6	11.0
Total	55	100

5.7. Relationships of feeding problems, GI symptoms and impact

Further analysis was conducted to explore the relationship between feeding problems and GI symptoms, and the impact of these problems on family life. The total scores of each domain (feeding problems and GI symptoms) and the impact sub domains were normally distributed. For this reason, parametric tests were used. Correlations between the two variables (scores of feeding problems domain and GI symptoms domain) and the impact domains were calculated using the Pearson Product Moment Correlation (Streiner and Norman 2008). Two-tailed significant test was chosen because there was no indication from the literature on the direction of any possible relationship of these variables.

A significant positive correlation was found between the scores of feeding problems, GI symptoms and the impact ($r=0.51$, $p<0.001$). This finding indicates that feeding problems and GI symptoms do have a definite impact on the family of children with ASD. However, this general finding could not identify whether specific types of problems contribute to the level of the impact. This cannot be studied in this sample and was not a focus of this thesis. Further studies and analyses are needed to explore the relationship of individual items and/or combinations of items and the impact.

5.7.1. *Relationship between feeding problems and the impact of feeding problem*

A strong positive correlation was identified between feeding problems and the impact of feeding problems on family life ($r=0.58$, $p<0.001$). This was expected because all the children in this sample were reported to have feeding problems. The majority of the children had many problems (between 7 - 21 feeding problems) and parents reported that these problems adversely affected the family.

5.7.2. *Relationship between GI symptoms and the impact of GI symptoms*

Although the earlier descriptive findings indicated fewer parents reported GI symptoms, and those that did reported that the impact of GI symptoms was smaller than for feeding problems, there was a strong positive statistically significant correlation between GI and the impact of GI symptoms on family life ($r=0.56$, $p<0.001$). These results provide preliminary evidence (in this albeit unrepresentative sample) of the importance of asking carefully about both feeding problems and GI symptoms in children with ASD and the impact of these problems on the family.

5.8. Discussion

In the field-testing phase, professionals successfully used the BEFG-ASD with parents of primary school children aged 4-11 years. The response rate of participating professionals was 53%. This response rate was encouraging and in keeping with a previous questionnaire development study of children under 18 years with Cerebral Palsy and other disabilities undertaken in North East England (Jessen et al., 2003). However, the recruitment process used in this study had its own strengths and limitations. For the present research, professionals were asked to recruit parents of children with ASD from their current caseloads (purposive sampling). Overall, this was successful with the majority of participating professionals able to recruit parents in this way. However, there are several potential limitations of this process. For example, professionals might have developed their own criteria for deciding which parents to approach, such as the ones that they thought were most likely to agree to be interviewed. They also might select parents who have children with particular characteristics such as known feeding problems or GI symptoms, rather than for instance approaching each parent as they were booked into the clinic.

Another concern about this approach is whether parents felt under any sense of obligation to take part, which in turn might have led to the potential for response bias. This will be considered together with further information about the professionals' experience (feedback from telephone interview) and will be discussed in Chapter 6. According to Bowling (2009), the limitation of the purposive sampling is that this technique is an example of non-probability sampling. This means that sampling error could not be calculated and the degree to which this recruited sample of children with ASD is representative or not, of the larger ASD children population of this age group remains unknown. In addition, the sample only included children in the age range of 4-11 years and not other groups such as older children aged 12-18 years. Furthermore, children recruited to this research were all attending some form of state special school. No children were attending secondary mainstream school and no children were recruited direct from primary care services. recruited. A further limitation of the research was the choice of inclusion/exclusion criteria of parents. For example, parents/caregivers who could not speak and write English were excluded from the field-testing of the BEFG-ASD. This is likely to have meant that some families with English as a second language or parents with special education needs were inevitable excluded from taking part in the study. This in turn means that aspects of feeding problems and GI symptoms, and the impact of these problems among vulnerable groups from the non-English background living in the North East could not be identified in this research. The advantage of including a broader range of ethnic groups would be to increase the likely overall response rate (Bowling, 2009; Oppenheim, 1992). However, this might be less effective in the North East of England compared to other parts of the country as a consequence of the limited ethnic diversity in this part of the country. The impact of feeding problems or GI symptoms in the relevant ethnic minority groupings could not be determined in this research. Therefore, in the future it will be important to include those parents from non-English speaking groups in future research so that the rates of feeding problems and GI symptoms among the various different groups can be identitifed and the psychometric properties of the BEFG-ASD evaluated further in the various parent sub-groups. In future studies, the BEFG-ASD might also be translated into different languages for pilot use in these different ethnic groups. However, the costs for the interpreter to translate the questionnaire and to be involved in the interview process would need to be budgeted into future studies.

A reasonably broad range of professionals used the BEFG-ASD with parents of children with ASD. Professionals working in both health and special education settings took part and were able to use the BEFG-ASD. However, the sample of professionals cannot be considered a representative sample of community professionals in North East England. First, the recruitment of professionals was based on purposive sampling using existing contacts from key professionals in community child health, child and adolescent mental health services and special schools. This meant that there were no professionals working in primary care, local authority services or in mainstream school settings. This field-testing should be undertaken to replicate the properties of the BEFG-ASD before the questionnaire could be used to investigate the rates of feeding problems and GI symptoms among primary school children with ASD in either a UK community settings or further afield.

Despite these limitations, the present research has demonstrated that the BEFG-ASD could be administered by a range of professionals working with primary school aged children with ASD and their families. This evidence supports the face validity of this new questionnaire.

In the present research, the group mean Lifetime Version scores data using the SCQ verified the clinical ASD diagnoses (Rutter et al., 2003). The SCQ has been used in many studies and has acceptable sensitivity and specificity for a diagnosis of autism/ASD (Eaves et al., 2006; Corsello et al., 2007). Using the published cut-off scores (of 15.0) as reported by the authors, the diagnosis of 94% of ASD children was verified. Another study has reported a lower cut-off score for younger children (Chen et al., 2009), and some studies have also suggested that a lower cut-off scores from 11.0 to 15.0 may be more appropriate for younger aged children with ASD (Eaves et al., 2006; Allen et al., 2007; Corsello et al., 2007). If a lower cut-off (such as 12.0) is used in the present research, all the children's ASD clinical diagnosis in this research would have been verified. A potential limitation of using the SCQ in this research was that all children have already received a clinical diagnosis of ASD, so parents were likely to have had previous experience of the diagnostic process and the sort of questions asked by professionals. Responses to questions about social interaction, language, communication and repetitive behaviors may reduce the risk of inappropriate scoring. In the present research, one of the limitations of using the SCQ was that 16 parents (20%) refused or missed out some questions. It might be a burden to for some parents to complete the SCQ during the field-testing work. Despite this limitation, the clinical ASD diagnoses of the children were verified.

Based on the parent's responses using the BEFG-ASD, in this sample feeding problems occurred in all children. This was an unexpected findings compared to the rates reported by other researchers (Cornish, 1998; Matson and Bamburg, 1999; Williams et al., 2000; Ahearn et al., 2001; Field et al., 2003; Schreck et al., 2004;

Kerwin et al., 2005; Adams et al., 2008; Johnson et al., 2008; Herndon et al., 2009; Matson and Fodstad, 2009; Provost et al., 2010). However, the types of feeding problems reported by parents were consistent with the previous published studies (Ahearn et al., 2001; Field et al., 2003; Kerwin et al., 2005; Bandini et al., 2010; Provost et al., 2010). Interestingly, most children were reported to have several different feeding problems. Some parents reported as many as 21 different problems. Despite this, the majority of parents had not received any advice from health professionals about these problems. Parents reported this absence of support even though they were being interviewed by their current professionals. This finding might also be considered to add to the face validity of the interview process using the BEFG-ASD. However, whether or not this is a representative sample, this finding has implications for current clinical and other practice. According to the parents, their current health and education professionals seem unaware of their concerns about feeding problems or GI symptoms. This will be considered further in Chapter 6 (feedback from telephone interview).

GI symptoms were reported in 75% of children with ASD. This is consistent with other published studies (Kerwin et al., 2005; Valicenti-McDermott et al., 2008). All these findings however need to be considered cautiously. The high proportion of feeding problems and GI symptoms among the children in the field-testing could be influenced by several factors. First, the recruitment of parents was based on the professional’s current caseloads (convenience sampling). Professionals may have recruited parents where they suspected problems. If this was the case, this potential selection bias could have affected the rates of symptoms reported. Certainly, professionals are likely to have approached parents they would expect to cooperate with the research request and process. However, it is hard to anticipate in what way this might have affected the reported rates of problems or the impact ratings. Second, the children with ASD attending special schools are likely to be those with more severe difficulties and other associated medical conditions, which may in turn affect the reported rates of feeding problems and GI symptoms among these children. However, data on the ASD severity, learning difficulties or additional behaviour problems are not available for this research. This could be investigate in other studies.

Although the sample of the children with ASD in the present research is not a representative sample, the findings still need to be considered and may well have implications for the current practice. However, as Twatchman-Reilly et al (2008) highlighted behavioural issues reported by parents are not the only factors associated with feeding problems in children with ASD. Other problems such as the ASD features and other co-morbid health and mental health problems need to be considered as part of the complex and challenging task of managing the difficulties (Twatchtman-Reilly et al., 2008). Further, in this research, many children were reported to have both feeding problems and GI symptoms, which suggest that any management plan will need to keep this in mind.

Turning to the impact, more than half of the parents reported that managing the feeding problems and the GI symptoms added additional stress to them. Feeding problems and GI symptoms also were reported to impact on both the parents/carers' life and family life. In addition, a strong and significant relationship was found between feeding problems, GI symptoms and the impact of these problems. This finding needs to be replicated in other studies to identify how these problems (feeding problems and GI symptoms) interrelate with the impact.

CHAPTER 6

RESULTS

EVALUATION OF THE BEFG-ASD

Chapter 6. Results

Evaluation of the BEFG-ASD

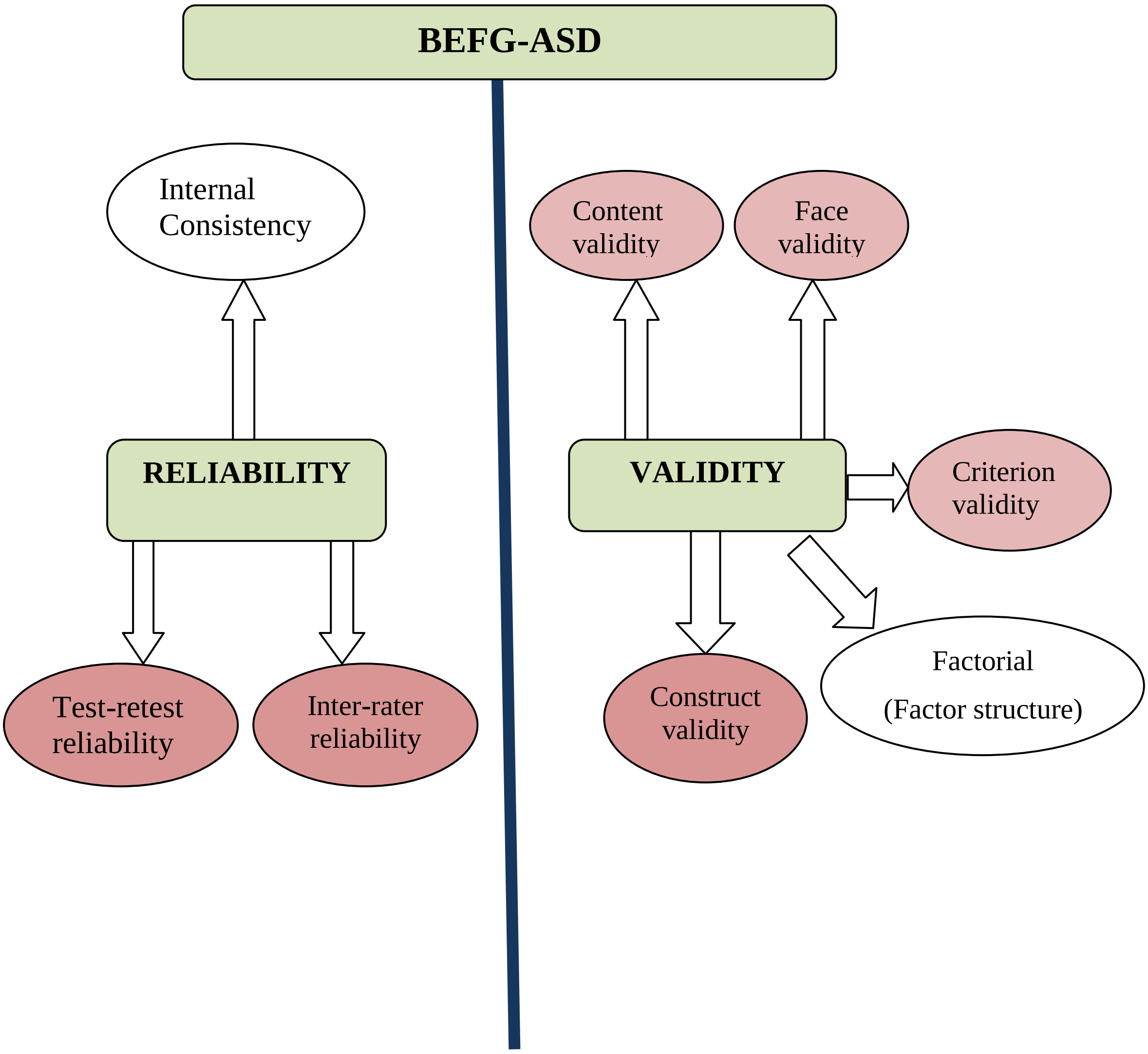
6.1. Introduction

This chapter will discuss the results of the evaluation of the BEFG-ASD. This includes the overall data management, analyses of psychometric properties of the BEFG-ASD and feedback from professionals who used the questionnaire and information pack. The analyses of the psychometric properties were based on the parent responses from the field-testing, which were recorded by the professionals during each interview using the BEFG-ASD. The analyses will focus on:

i) Internal consistency
ii) Test-retest reliability
iii) Inter-rater reliability
iv) Factor structure (exploratory factor analysis)
v) Criterion reliability
vi) Construct validity.

The aspects of reliability and validity of the BEFG-ASD included in the present research have also been summarised in Figure 3.5 in Chapter 3.7 and Chapter 3.8 (**Figure 6.1)**. In the evaluation of the psychometric properties of the BEFG-ASD, ‘internal consistency’ has been considered as one aspect of the reliability and ‘factor structure’ as one aspect of the validity in order to structure the results and discussion of the various analyses.

Figure 6.1 (Figure 3.5) Components of the analysis of reliability and validity of the BEFG-ASD



The evaluation of the BEFG-ASD sought to answer the following questions:

1) Do the items in the BEFG-ASD produce consistent scores and correlate well with one another?

2) What is the agreement of scores for domains, sub domains and items of the BEFG-ASD when administered by same professional on two separate occasions?

3) What is the agreement of scores for domains, sub domains and items of the BEFG-ASD when administered by two different professionals with same parent?

4) How do the BEFG-ASD domain scores correlate with other published measures (Brief Autism Mealtime Behavior Inventory (BAMBI), the Gut Symptom Checklist (GSC) and the modified Impact on Family Scale (IFS) used to assess mealtime behaviours, GI symptoms in primary school children with ASD, and impact of these problems on family life?
5) What are the factors and underlying structure of the BEFG-ASD?
6) What is the experience of community professionals using the BEFG-ASD and information pack?

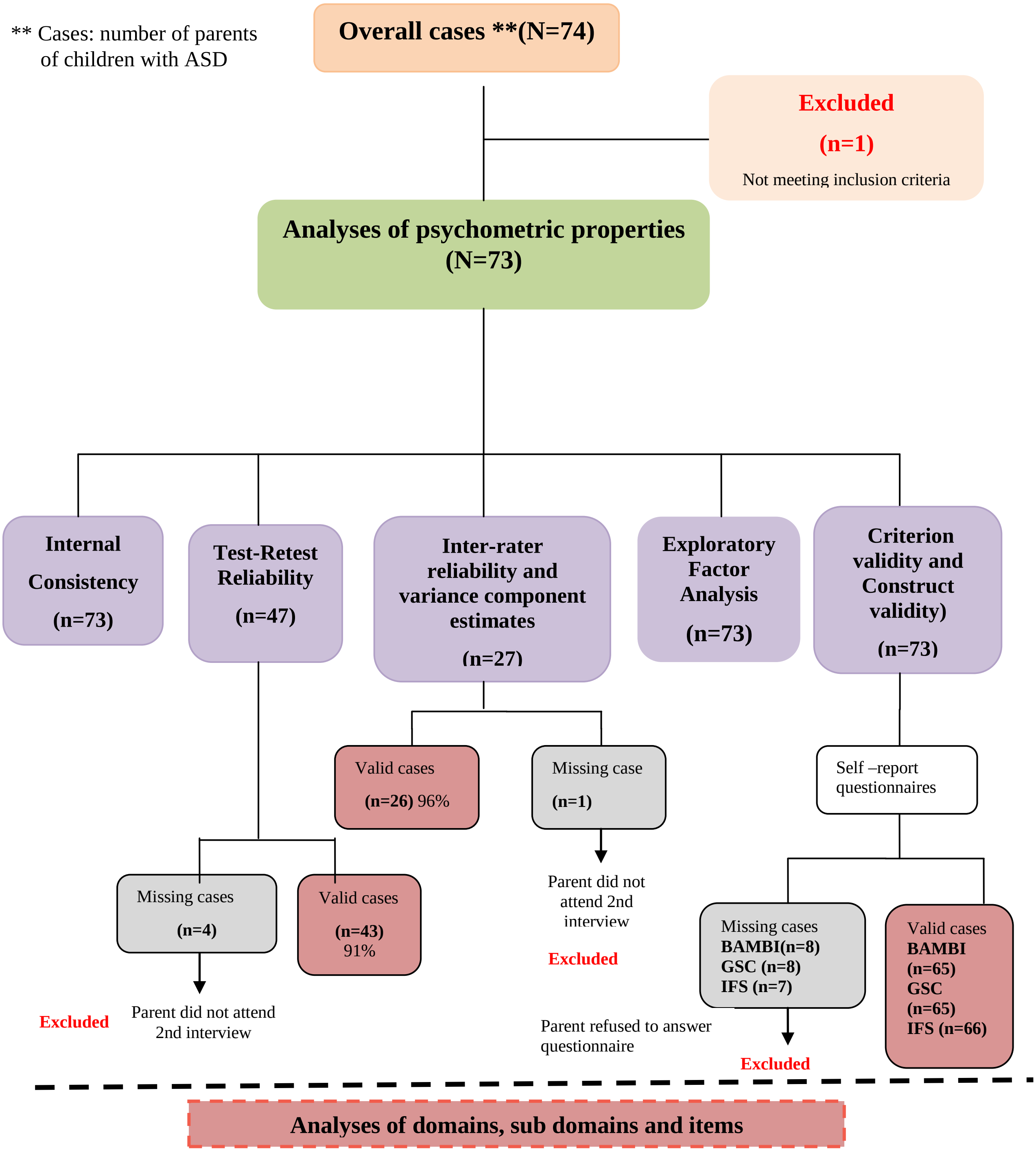
6.2. Data management

Prior to the analysis of psychometric properties, the distributions of the data were checked. Responses of parents/carers of children with ASD (N=74) from the interviews using the BEFG-ASD in the field-testing 1 (FT1) and field-testing 2 (FT2) were used for different types of analyses. Data were examined for outliers, data entry errors (double entry) and missing cases was excluded from the analyses (**Figure 6.2)**. Missing cases referred to those parents who did not attend the second interview, and parents who refused to answer the self-report questionnaires (BAMBI, GSC, IFS). In some BEFG-ASD interviews, some parents did not answer certain questions. The missing value was recorded in the results of the analyses in order to understand the potential for non-response to particular questions in the BEFG-ASD. Data were analysed using the Statistical Packages for Social Sciences (SPSS) software, Version 17.0 and the Stata software Version 11.0.

Scoring of responses for each domain of the BEFG-ASD was determined. For feeding problems and GI symptoms, the answer ‘Yes’ was given score as 1 and ‘No’ as 0. A reverse score was given for item 25 of feeding problems domain. In section C, scores used in this section were 4= ‘great deal’, 3=’quite a lot’, 2=a bit, 1=not all/no and 0=not applicable. Scores for BAMBI (Lukens and Linscheid, 2008) used in the analysis were 1=’never/rarely’, 2=’seldom’, 3=occasionally, 4=’often’ and 5=’at almost every meal’. A reverse score was used for item 3, 9, 10 and 15 of the BAMBI (items: ‘my child remains seated at the table until the meal is finished’, ‘my child is flexible about mealtime routines’, ‘my child is willing to try new foods’ and ‘my child accepts or prefers a variety of foods’. The score for this item was 5= ‘never/rarely’, 4=

'seldom', 3= 'occasionally', 2= 'often' and 1= 'at almost every meal'. The score of GSC (Wilson et al., 2009) was 0='never', 1= 'occasionally', 2= 'frequently' and 3= 'always'. In the original IFS (Stein and Reissman, 1980), the score for each response was 4= 'strongly agree', 3= 'agree', 2= 'disagree', 1= 'strongly disagree'. The present research used a modified IFS with 5 scales, and the score given for each response was 4= 'strongly agree', 3= 'agree', 2= 'disagree', 1= 'strongly disagree' and 0= 'not applicable' (see Chapter 3.6.2).

Figure 6.2 Overall data management and analyses



6.3. Reliability

6.3.1. *Internal consistency*

Internal consistency of all items in the BEFG-ASD and items in each sub domain was evaluated using Cronbach's alpha. Cronbach's alpha as it is a common measure used to determine the internal consistency and correlation of items in a questionnaire (Field, 2005). In the context of the present research, Cronbach's alpha indicates whether parents of children with ASD responded in the same way to items in the BEFG-ASD. A value of Cronbach's alpha between 0.70-0.90 demonstrates good reliability without redundancy (Streiner and Norman, 2008). Based on the analysis, the overall Cronbach's alpha for all items in the BEFG-ASD was 0.85 (**Table 6.1)**. This result indicates that parents responded to the different items of the BEFG-ASD in the same way. In contrast, the Cronbach's alpha for Section B (GI symptom domain) was a bit low compared to feeding problems and the impact domain. This is in keeping with clinical practice. Although each symptom is related to GI function, they may also occur separately (for example: constipation and diarrhea) and potentially have different aetiologies. Despite this, the overall Cronbach's alpha indicated that the BEFG-ASD has good internal consistency.

Table 6.1
Internal consistency for domains of the BEFG-ASD (N=73)

Domains	Items	Cronbach's alpha
Overall	**42**	**0.85**
1. Feeding problems	25	0.75
2. Gastrointestinal (GI) symptoms	9	0.55
3. Impact of feeding problems and GI symptoms	8	0.85

The internal consistency for the 15 sub-domains was also explored using the Cronbach's alpha and range from 0.15-0.95 (**Table 6.2)**. Three sub domains ('food neophobia', 'parental dietary restriction', and parental concern on child's growth had poor internal consistency (Cronbach's alpha (<0.5). The item-total correlation for each item was also examined. Some items in these sub domains were found to have a low item-total correlation. (**Table 6.3- Table 6.5**).

A low Cronbach's alpha value and low item-total correlation was expected for some items (such as 'problems with cutlery control', 'dietary advice' and 'child's weight gain) since these items are measuring different aspects of child or parent behaviour. For example, items about parental dietary restriction may be directly related to a child specific feeding problem. Parents might be trying to manage a feeding problem or believe in a particular restriction diet or course of supplements as a treatment for ASD. Further, the item ('parent did not receive any advice') is not an aspect of their child's feeding problem(s). However, these items are also important to be identified by professionals in order to assist the planning for further treatment or referral of the child. Similarly, some sub domains of GI symptoms include items such as 'parental concern on child's growth', 'child lost weight, 'child gained weight' that were included as additional areas of more general concern about the child's health, although these may be influenced by other GI symptoms or even perhaps feeding problems. These aspects will be considered further under discussion (6.6) and in Chapter 7. For all these various reason, all items were used in the further analyses of reliability and validity.

Table 6.2
Internal consistency for sub domains of the BEFG-ASD (N=73)

Sub domains	Items	Cronbach's alpha
Feeding problems		
Food selectivity	3	0.82
Food sensitivity based on food physical characteristics	7	0.61
Food sensitivity based on child's food environment	5	0.66
Problematic mealtime behaviour	3	0.62
Food neophobia	2	0.15
Sign of pica	1	-
Parental dietary restriction	4	0.31
GI symptoms		
Regular constipation	2	0.47
Regular diarrhoea	1	-
Regular abdominal pain	1	-
Toileting behaviour	1	-
Regular vomiting	1	-
Parental concern on child's growth	3	0.16
Impact of feeding problems and GI symptoms		
Impact of feeding problems	4	0.84
Impact of GI symptoms	4	0.95

Table 6.3 Item-total correlation for the feeding problems domain

No	Item	Item-total correlation
1.	Refused to eat family food at most meals	0.40
2.	Similar food at most meals	0.51
3	Special food preparation	0.39
4	Insist on food with particular character	0.47
5	Strong preference on particular textures	0.43
6	Strong preference on food flavours	0.38
7	Sensitive to food smells	0.21
8	Insist food served in particular way	0.43
9	Use of specific cutlery	0.46
10	Problems with cutlery control	0.02
11	Insist food is cooked by a certain person	0.35
12	Insist food served by a certain person	0.38
13	Insist food are not touching each other on plate	0.45
14	Insist meals in the same place	0.29
15	Refused to eat with family members	0.51
16	Frequently shown disruptive mealtime behaviour (at least once a week)	0.33
17	Frequently shown aggressive mealtime behaviour (at least once a week)	0.30
18	Frequently shown self injurious behaviour (at least once a week)	0.24
19	Reluctant to eat new foods	0.28
20	Fearful of swallowing foods	0.25
21	Sign of pica (lick or eat non-food items)	0.14
22	Parent changed diet as part of ASD treatment	0.19
23	Parent avoid particular food for child	0.40
24	Parent gave supplement	0.07
25	Parent did not receive any advice about managing feeding problems	-0.29

Table 6.4. Item-total correlation for GI symptoms domain

No	Item	Item-total correlation
1.	Constipation	0.23
2.	Accidents in opening bowel	0.38
3	Diarrhoea	0.20
4	Regular abdominal pain (observed by parents)	0.36
5	Refused to go to toilet	0.40
6	Frequently vomited (at least once a week)	0.36
7	Parent concerned about growth	0.25
8	Child lost weight	0.12
9	Child gained weight	-0.04

Table 6.5 Item-total correlation for impact domain

No	Item	Item-total correlation
1.	Feeding problems restrict parent's life	0.39
2.	Feeding problems have placed extra stress	0.57
3	Feeding problems had significant impact of finance	0.43
4	Feeding problems affected family life	0.58
5	GI symptoms restrict parent's life	0.72
6	GI symptoms have placed extra stress	0.75
7	GI symptoms had significant impact of finance	0.63
8	GI symptoms affected family life	0.70

6.3.2. *Test-retest reliability*

Test-retest reliability was conducted to evaluate the reproducibility and consistency of scores of the BEFG-ASD, when the same professional interviews a parent(s) on two separate occasions approximately 2 weeks apart (Time 1 and Time 2) (Terwee et al., 2007). Data from the field-testing 1 (FT1) was used in the analysis (Chapter 5.2.1). 41

professionals interviewed 43 parents at two separate times. 39 professionals interviewed one parent and 2 professionals interviewed 2 parents on both occasions. The decision about time period of approximately 2 weeks between the first and second administration was chosen in an attempt to balance the risk of recall of previous responses when the questionnaire refers to the last 4 weeks, with the likelihood of clinical change over the same time period (Marx et al., 2003; Terwee et al., 2007).

Based on 43 responses, test-retest for each domain of the BEFG-ASD at Time 1 and Time 2 was evaluated using intraclass correlation coefficients (ICC). ICC can estimate correlations of items in each domain between Time 1 and Time 2 (Terwee et al., 2007; Streiner and Norman, 2008). Mean time interval between Time 1(T1) and Time 2(T2) was 16 days (range: 11-23 days). The results have shown that the time interval between the first interview and the second interview varied among the professionals. The 95% confidence intervals of ICCs were also calculated. Mean score for each domain at T1 and T2 was calculated (Feeding problems: mean score T1=11.79, SD: 4.36, T2=11.35. SD: 5.29, GI symptoms: mean score T1=2.04, SD: 1.71, T2=1.67, SD: 1.57, Impact: mean score T1=13.62, SD: 6.87, T2=13.88, SD: 7.07). Terwee et al recommended a value of at least 0.70 for ICC to indicate good test retest reliability. Based on the analysis, ICC for each domain of the BEFG-ASD was between 0.7-0.9 (see **Table 6.6**), which indicated good test retest reliability.

Table 6.6

Intraclass correlation coefficient (ICC) for test retest of each domain (Time 1 and Time 2), N=43

Domain	Items	(n)	Intraclass correlation coefficient (ICC)	95% Confidence Interval	
				Lower bound	Upper Bound
Feeding problems	25	43	0.89	0.81	0.94
Gastrointestinal (GI) symptoms	9	43	0.69	0.50	0.82
Impact of feeding problems and GI symptoms	8	43	0.88	0.79	0.93
Total item	**42**				

Test retest reliability for each item in the BEFG-ASD (for Time 1 and Time 2) was then explored using kappa coefficient in order to compensate and correct for the proportion of the agreement that might occur by chance (Terwee et al., 2007). In this analysis, a general kappa was used to measure reliability of nominal data (Yes/No) in Section A (feeding problems domain) and Section B (GI symptoms domain). Weighted kappas were used for the ordinal data in Section C (Impact domain). The scale for the items ranging from 0.0 to 4.0, using a weighted kappa takes into account the different types of disagreement between the scales (Terwee et al., 2007).

The kappa values for all 42-items across the BEFG-ASD ranged from 0.4 - 1.0 (**Table 6.7**). These scores indicate 'fair to almost perfect' agreement betweenTime1 and Time2 (Altman, 1991). Four items (Items: parent gives supplement to child, child gain weight, feeding problems restrict parent's life and feeding problems affected family life) had low kappa value less than 0.4. There are several possible explanations about these values. Probably the most likely is that either the parents' or the child's behaviour has changed within the 2 interviews. For example, a parent might start a dietary supplement with their child but abandon this procedure for a whole variety of reason. However, for the majority of items, the ICC and kappa value of the test-retest reliability was satisfactory.

6.3.2.1. Missing data

There were some parents who were not able to give answer ‘Yes’ or ‘No’ for six items of the BEFG-ASD (items: ‘child insists food served by a certain person’, ‘parent concerned about growth’, ‘child lost weight’, ‘child gain weight’, ‘GI symptoms restrict parent’s life’ and ‘GI symptoms affected family life’. However, the non-response rate was small, less than 5% of the overall data. For this reason, no special measures were used to deal with the missing data. Overall, the majority of the parents were able to respond to all the questions (items) in the BEFG-ASD.

Table 6.7 Test retest kappa coefficient for the BEFG-ASD items (N=43)

No	Item	n	Missing*	Kappa
1.	Refused to eat family food at most meals	43	-	0.81
2.	Similar food at most meals	43	-	0.73
3	Special food preparation	43	-	0.78
4	Insist on food with particular character	43	-	0.53
5	Strong preference on particular textures	43	-	0.49
6	Strong preference on food flavours	43	-	0.53
7	Sensitive to food smells	43	-	0.76
8	Insist food served in particular way	43	-	0.72
9	Use of specific cutlery	43	-	0.49
10	Problems with cutlery control	43	-	0.49
11	Insist food is cooked by a certain person	43	-	0.85
12	Insist food served by a certain person	42	1*	0.42
13	Insist food are not touching each other on plate	43	-	0.85
14	Insist meals in the same place	43	-	0.73
15	Refused to eat with family members	43	-	0.53
16	Frequently shown disruptive mealtime behaviour (at least once a week)	43	-	0.48
17	Frequently shown aggressive mealtime behaviour (at least once a week)	43	-	0.49
18	Frequently shown self injurious behaviour (at least once a week)	43	-	0.44
19	Reluctant to eat new foods	43	-	0.74
20	Fearful of swallowing foods	43	-	0.58
21	Sign of pica (Lick or eat non-food items)	43	-	0.95
22	Parent changed diet as part of ASD treatment	43	-	0.60
23	Parent avoid particular food for child	43	-	0.62
24	Parent gave supplement	43	-	0.35

No	Item	n	Missing*	Kappa
25	Parent did not receive any advice about managing feeding problems	43	-	0.72
26	Constipation	43	-	0.65
27	Accidents in opening bowel	43	-	0.88
28	Diarrhoea	43	-	0.66
29	Regular abdominal pain (observed by parents)	43	-	0.44
30	Refused to go to toilet	43	-	0.76
31	Frequently vomited (at least once a week)	43	-	1.00
32	Parent concerned about growth	42	1	0.65
33	Child lost weight	42	1	0.81
34	Child gain weight	39	4	0.38
35	Feeding problems restrict parent's life	43	-	0.38**
36	Feeding problems have placed extra stress	43	-	0.56**
37	Feeding problems had significant impact of finance	43	-	0.56**
38	Feeding problems affected family life	43	-	0.38**
49	GI symptoms restrict parent's life	42	1	0.67**
40	GI symptoms have placed extra stress	43	-	0.54**
41	GI symptoms had significant impact of finance	43	-	0.59**
42	GI symptoms affected family life	42	1	0.58**

*missing values indicates no answer given for the particular item
** weighted kappa used for 8 items in the impact domain.

Note*:* Interpretation of kappa value (Altman, 1991)
Poor agreement=less than 0.2
Fair agreement= 0.2 to 0.4
Moderate agreement= 0.4 to 0.6
Good agreement= 0.6 to 0.8
Very good agreement= 0.8 to 1.00

6.3.3 *Inter-rater reliability*

The inter-rater reliability refers to the degree of agreement between the scores of two professionals who have interviewed the same parent using the BEFG-ASD approximately 2 weeks apart. Responses from the field-testing 2 (FT2) were used to undertake this analysis (Chapter 5.2.2). In the FT2, each pair of recruited professional were asked to recruit 5 to 10 parents. However, two pairs of professionals (P3 and P4) were only able to interview three and two parents respectively (**Table 6.8**).

Table 6.8 Pairs of professionals for inter-rater reliability test

Pair of professional (N=10)	Number of parents interviewed (N=26)
P1 : A and B (teacher + teacher)	5
P2: C and D (teacher + teaching assistant)	10
P3 :E and F (teacher + teacher)	3
P4 :G and H (dietitian + dietitian)	2
P5: I and J (teaching assistant + teaching assistant)	6

The inter-rater reliability for each domain of the BEFG-ASD was calculated using the ICC (Terwee et al., 2007). The variance components of the sample (parents responses of children with ASD), the interviewers (professionals) and error (within sample) were considered in order to calculate the ICC for the data. Mean time interval between interviews by professional 1 and professional 2 was 17 days (range: 10-20 days). The ICC for the inter-rater reliability of each domain has indicated a good inter-rater reliability **(Table 6.9).**

Table 6.9 Intraclass correlation coefficient (ICC) for inter-rater reliability of the BEFG-ASD (N=26)

Domain	Items	Intraclass correlation coefficient (ICC)	95% Confidence Interval	
			Lower bound	Upper Bound
Feeding problems	25	0.88	0.84	0.92
Gastrointestinal (GI) symptoms	9	0.96	0.91	1.00
Impact of feeding problems and GI symptoms	8	0.74	0.70	0.78
Total item	**42**			

The inter-rater reliability for each item of the BEFG-ASD was measured using the kappa coefficient (**Table 6.10**). Based on these analyses, kappa value for items ranged 0.4 – 0.9 which indicated ‘fair to almost perfect’ agreement between the 2 professionals who used the BEFG-ASD with the same parent(s).

Several factors/potential limitations need to be considered when trying to understand these findings. First, although the recommended minimum sample size for any reliability analysis for ICC or use of the kappa statistics is 50 participants (Kottner et al., 2011, Terwee et al., 2007), only 26 parents were successfully recruited despite many more professionals have been approached over the recruitment period. Second, the pool of professionals and parents were almost exclusively recruited from special school settings. Further replication of the inter-rater reliability of this measure will be needed in a larger sample of professionals and parents ideally from a range of clinical and education settings (including mainstream). Despite these limitations, it is important to note that in this small sample, the inter-rater reliability the BEFG-ASD was satisfactory. According to Kimberly and Winterstein (2008), the inter-rater reliability is optimised when raters are trained to apply the criteria of the questionnaire. In the present research, individual training and briefing for the clinical professionals and teaching staff was provided prior to the use of the BEFG-ASD.

Table 6.10
Inter-rater reliability kappa coefficients for the BEFG-ASD items (N=26)

No	Item	n	Missing*	Kappa
1.	Refused to eat food at most meals	26	-	0.68
2.	Similar food at most meals	26	-	0.82
3	Special food preparation	26	-	0.62
4	Insist on food with particular character	26	-	0.80
5	Strong preference on particular textures	26	-	0.79
6	Strong preference on food flavours	26	-	0.90
7	Sensitive to food smells	26	-	0.81
8	Insist food served in particular way	26	-	0.64
9	Use of specific cutlery	26	-	0.89
10	Problems with cutlery control	26	-	0.80
11	Insist food is cooked by a certain person	26	-	0.45
12	Insist food served by a certain person	26	-	0.45
13	Insist food are not touching each other on plate	26	-	0.67
14	Insist meals in the same place	26	-	0.81
15	Refused to eat with family members	26	-	0.89
16	Frequently shown disruptive mealtime behaviour (at least once a week)	26	-	0.38
17	Frequently shown aggressive mealtime behaviour (at least once a week)	26	-	0.42
18	Frequently shown self injurious behaviour (at least once a week)	26	-	0.80
19	Reluctant to eat new foods	26	-	0.56
20	Fearful of swallowing foods	23	3	0.77
21	Sign of pica (Lick or eat non-food items)	26	-	0.82
22	Parent changed diet as part of ASD treatment	26	-	1.00
23	Parent avoid particular food for child	26	-	1.00

No	Item	n	Missing*	Kappa
24	Parent gave supplement	26	-	0.44
25	Parent did not receive any advice about managing feeding problems	26	-	0.40
26	Constipation (over one month)	26	-	0.62
27	Accidents in opening bowel	26	-	0.74
28	Diarrhoea	26	-	0.46
29	Regular abdominal pain (observed by parents)	26	-	0.36
30	Refused to go to toilet	26	-	1.00
31	Frequently vomited (at least once a week)	26	-	1.00
32	Parent concerned about growth	26	-	0.70
33	Child lost weight	26	-	1.00
34	Child gain weight	26	-	0.74
35	Feeding problems restrict parent’s life	26	-	0.51**
36	Feeding problems have placed extra stress	26	-	0.71**
37	Feeding problems had significant impact of finance	26	-	0.72**
38	Feeding problems affected family life	26	-	0.58**
49	GI symptoms restrict parent’s life	26	-	0.47**
40	GI symptoms have placed extra stress	26	-	0.44**
41	GI symptoms had significant impact of finance	26	-	0.43**
42	GI symptoms affected family life	26	-	0.43**

*missing values indicates no answer given for the particular item

** weighted kappa used for 8 items in the impact domain.

Note*:* Interpretation of kappa (Altman DG,1991)
Poor agreement=less than 0.2
Fair agreement= 0.2 to 0.4
Moderate agreement= 0.4 to 0.6
Good agreement= 0.6 to 0.8
Very good agreement= 0.8 to 1.00

6.4. Validity

6.4.1. *Factor structure*

In the development work, the sub domains and items of the BEFG-ASD were constructed based on various sources including the literature review, review by specialist group. Finally, 15 sub domains and 42-items were confirmed following the second review using the modified Delphi technique and the pre-test of the BEFG-ASD **(Figure 6.3)**. Using the field-testing data collected from all 73 interviews (first interview), an Exploratory Factor Analysis (EFA) was conducted as one of the procedures to explore the underlying factor structure of the questionnaire (Field, 2005).

For the EFA, the Principal Component Analysis (PCA) was used as an extraction method for the variance factors. The PCA was chosen in order to explore the data and to generate future hypotheses about the structures of the variables (items) and their relationship (Field, 2005). The extraction of factors in each domain is based on Eigenvalues. Factors with Eigenvalues greater than 1.0 was used as a threshold to retain the factors (Field, 2005). Scree plots were also used to examine the Eiganvalues plot and component matrix was used to explore the number of factors in the BEFG-ASD. Three EFAs were conducted separately for each domain (feeding problems, GI symptoms and Impact) to determine the actual factor loadings. A rotational strategy was also used to obtain a clear pattern of loadings using the Varimax Rotation Method with Kaiser normalisation (Field, 2005). In the analysis using the SPSS, initial considerations of the sample size and intercorrelation of items were checked using the Kaiser-Meiyer-Olkin (KMO) and Bartlett's test sphericity. Data with small coefficients below 0.3 were suppressed, so that all of the variables (items) that load highly onto the same factor are displayed together (Field, 2005).

6.4.1.1. Factor analysis of feeding problems domain

Based on the eigenvalues of greater than 1.0, the majority of items of feeding problems were loaded into one factor solution. 15 items were loaded onto Factor 1 and accounted for 86% of variance. The items were examined and were related to the sub domains of 'food sensitivity', 'food selectivity' and 'food neophobia'. In addition, there were 6 subset of loadings with small percentage of variance (**Table 6.11)**. 3 items related to problematic mealtime behavior loaded onto Factor 2 and accounted for 7% of the variance. In the analysis, 2 items consumed loaded onto Factor 4 (2% of the variance). These 2 items were related to the sub domain of parental dietary practices. Another 2 items loaded onto Factor 3 (2% of the variance). These items were related to the sub domain of ‘parental dietary practices’ and ‘food neophobia’. One item on ‘cutlery control’ was loaded on Factor 5 (1% of the variance), although in the development work, this item proposed as an aspect of ‘food sensitivity’. Another single item ‘parent did not receive any advice from professionals’ loaded onto Factor 6 (1% variance). Finally, the item related to signs of pica loaded onto Factor 7 and accounted for a further 1% variance.

The results of the EFA identified one factor solution with 15 feeding problems items loaded onto one factor and 10 items loaded onto subset of 6 factors. In the development work, 7 sub domains for feeding problems were identified. Interestingly, in the factor analysis, the majority of items of feeding problems loaded on one factor, which is similar to items in 3 sub domains of the BEFG-ASD (food selectivity, food sensitivity, food neophobia). This finding raises a possibility that these 16 items may seem to be specific to feeding problems among children with ASD. In addition, 3 items on the problematic mealtime behaviours loaded onto the same factor. However, 3 single item appeared to be fairly independent of all other items (Item: ‘problems with cutlery control’, ‘child eat or lick non-food items’ and ‘parent did not receive professional advice on feeding or child’s diet’). This result is consistent with the earlier analysis (see Table 6.3). These items are not highly correlated with the other items. In addition, these items (such as ‘problems with cutlery control’ and ‘parent did not receive professional advice’) are not aspects of feeding problems but were included in Section A of the BEFG-ASD as additional areas of general concerns about the child’s health and nutritional status.

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Figure 6.3

Construct of the BEFG-ASD (based on literature and Delphi) – 15 sub domains/factors of feeding problems, GI symptoms and Impact

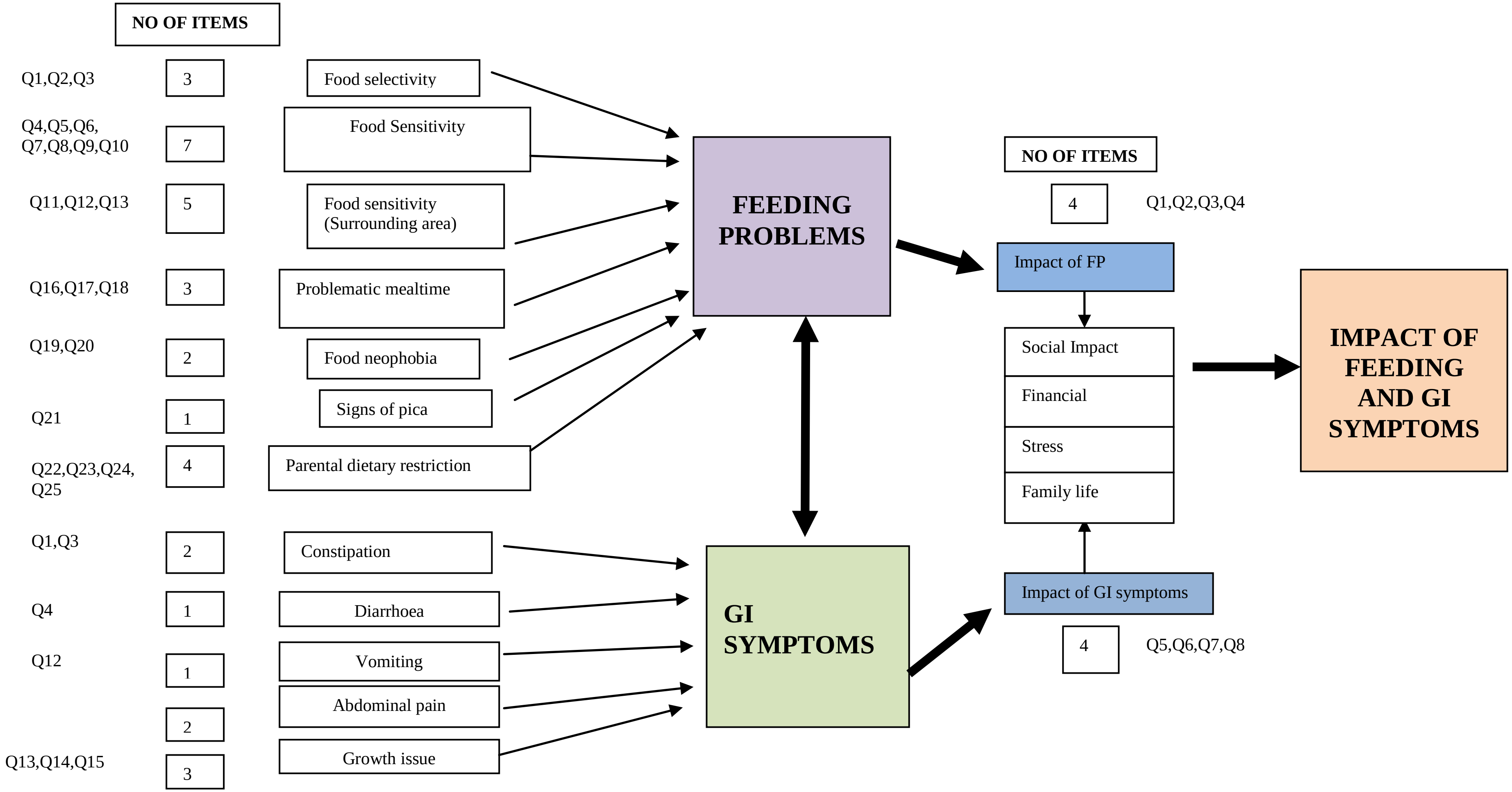

Table 6.11 Exploratory factor analysis of feeding problems

Item description	Factor						
	1	2	3	4	5	6	7
1. Child refuse to eat several foods that family regularly eat	0.617						
2. Similar food at most meals	0.723						
3. Special food preparation	0.579						
4. Insist on food with particular character	0.617						
5. Strong preference on particular textures	0.463						
6. Strong preference on food flavours	0.435						
7. Sensitive to food smells	0.394						
8. Food served in particular way	0.619						
9. Use of specific cutlery	0.502						
10. Problems with cutlery control				0.545			
11. Child insist food is cooked by certain person	0.454						
12. Child insist food is served by certain person	0.484						
13. Child insist foods are not touching each other on plate	0.614						
14. Child insist meals in the same place	0.362						
15. Child refused to eat with family members	0.558						
16. Child frequently shown disruptive mealtime behaviour		0.331					
17. Child frequently shown aggressive behaviour		0.362					
18. Child frequently shown self injurious behaviour		0.328					
19. Child reluctant to eat new food	0.452						
20. Child fearful of swallowing foods			0.334				
21. Child eat or lick non-food items							0.671
22. Parent changed diet as part of child's ASD treatment			0.492				
23. Parent gave supplement to child						0.507	
24. Parent avoid particular food for child						0.380	
25. Parent did not receive professional advice on feeding or child's diet					0.476		

6.4.1.2. *Factor analysis of GI symptoms domain*

In the analysis, three factors of GI symptoms were identified **(Table 6.12)**. 3 items related to diarrhea, accidents in opening bowels and child gain weight were loaded on Factor 2 and accounted for 37% of the variance. Two items related to constipation and abdominal pain were loaded on Factor 3 and accounted for 35% of variance. Four (4) items related to toileting issue, vomiting, parental concern on growth and weight loss consumed loaded on Factor 1 and accounted for 28 % of variance. Based on the analysis, factor extracted of GI symptoms were not similar to the sub domains based on the literature review and the Delphi technique. Although in the earlier analysis the majority of items were highly correlated with each other (Table 6.5), the underlying structure of the GI symptoms domain is not clear. The interpretation of findings for this group of symptoms is difficult as each item represents different aspect of GI symptoms.

Table 6.12 Exploratory factor analysis of GI symptoms

Items	**Factor**		
	1	2	3
Child suffered from constipation			.790
Accidents in opening bowel		.673	
Child suffered from diarrhoea		.747	
Regular abdominal pain observed by the parent			.716
Child refused to go to toilet	.560		
Child frequently vomited	.602		
Parent concerned about growth	.761		
Child lost weight	.778		
Child gained weight		.361	

6.4.1.3. *Factor analysis of the impact domain*

Table 6.13 shows the results of the EFA for the impact of feeding problems and GI symptoms. Based on the analysis, four items related to the impact of feeding problems were loaded onto Factor 2 and accounted for 90% of variance. Four items related to impact of GI symptoms loaded on Factor 1 and accounted for 10 % of the variance. This is consistent with the results of the earlier analysis (Table 6.6).

Table 6.13 Exploratory factor analysis of the impact

Items	Factor	
	1	2
Feeding problems of child restrict parent’s life		.827
Managing Feeding problems have places extra stress on parents		.871
Feeding problems had significant impact on finance of the parent		.493
Feeding problems affected family life		.884
GI symptoms of child restrict parent’s life	.901	
Managing GI symptoms have places extra stress on parents	.942	
GI symptoms had significant impact on finance of the parent	.917	
GI symptoms affected family life	.890	

In summary, the EFA is useful to describe variability among factors in each domain of the BEFG-ASD and extracted relevant factors of feeding problems and the impact. The overall outcome of the EFA of each section of the BEFG-ASD has shown that 12 factors were extracted. One possible interpretation of the results of the EFA is that some items could be grouped into a number of sub domains. However, there are items (within each domain) that should not be included with other items. For example, the feeding problems can be divided into two or three separate sub domains but items such as ‘‘problems with cutlery control’, ‘child eat or lick non-food items’ and ‘parent did not receive professional advice on feeding or child’s diet’ should not be included in feeding problems domain. However, the results of the factor analysis should be considered as a preliminary finding of the factor structure of the BEFG-ASD. Kline (1998) and Terwee et al (2007) recommended a minimum sample of 100 for factor analysis or subjects-to-variables (STV) ratio of two for each item. In the present research, the sample size is small and further factor analysis in a relatively large sample is needed to provide more evidence on the structure of the BEFG-ASD.

6.4.2 *Criterion validity*

Criterion validity is important to compare the ability of the BEFG-ASD to identify feeding problems, GI symptoms and the impact with other published ‘gold standard’ measures (Chapter 2.6.3, 2.6.4 and 3.6.2). The main challenge in this aspect was that there is no ‘standard criteria’ or ‘gold standard’ for an interviewer-based questionnaire on feeding problems, GI and the impact of these problems for children with ASD.

For this reason, the criterion validity of each domain of the BEFG-ASD was evaluated by comparing the scores of each domain with parent self-report measures from previous studies. Thus, the criterion-related validity of the total score of Section A (feeding problems) was compared with the total score of the BAMBI; the total score of Section B (GI symptoms) with the total score of the GSC and; and the total score of Section C (Impact) with the total score of the modified IFS. The distribution of the total score data for each domain and these self-report questionnaires were normally distributed. Therefore, parametric tests (Pearson correlations) were used to analyse the correlations of the scores.

There was a significant moderate correlation between Section A of the BEFG-ASD and the BAMBI (r=0.58, p<0.01) as shown in **Table 6.14**. The moderate significant correlation is encouraging and not unexpected since the feeding domain section of the BEFG-ASD covers many more aspects of feeding problems than just problematic mealtime behaviours (25 items out of 42 items of the BEFG-ASD)

Table 6.14 Criterion validity correlation between Section A, BEFG-ASD and BAMBI

		Total Score Section A	Total Score BAMBI
Total Score Section A (Feeding problems) Items: 25	Pearson Correlation	1.000	**.577****
	Sig. (2-tailed)	.	.000
	N	73	65
Total Score BAMBI Items:18	Pearson Correlation	**.577****	1.000
	Sig. (2-tailed)	.000	.
	N	65	65

**. Correlation is significant at the 0.01 level (2-tailed).

There was a significant low correlation between total score of Section B of the BEFG-ASD and total score of the GSC, r=0.39, p<0.01 as shown in **Table 6.15.** This correlation was expected to be low, since the items in Section B (GI symptoms domain) of the BEFG-ASD do not cover the range of GI symptoms and other problems included in the GSC (such as regurgitation of food and restricted eating habits)

Table 6.15 Criterion validity correlation between Section B, BEFG-ASD and GSC

		Total Score Section B	Total Score (GSC)
Total Score Section B Items: 9	Pearson Correlation	1	**.391****
	Sig. (2-tailed)		.001
	N	73	65
Total Score Gut Symptom Checklist (GSC) Items:30	Pearson Correlation	**.391****	1
	Sig. (2-tailed)	.001	
	N	65	65

**. Correlation is significant at the 0.01 level (2-tailed).

Table 6.16 shows the correlation between the total score of Section C, BEFG-ASD and the total score of the modified IFS. There was a significant positive correlation of scores between Section C and the modified IFS. As expected, the correlations were low since the modified IFS covers much broader topic of ‘living with a child with ASD’ rather than the focused impact of feeding problems and GI symptoms.

Table 6.16 Criterion validity correlation between Section C, BEFG-ASD and IFS

		Total Section C (Impact)	Total Impact (ICF)
Total Section C (Impact) Items: 8	Pearson Correlation	1	**.384****
	Sig. (2-tailed)		.001
	N	73	66
Total Impact (ICF) Items: 25	Pearson Correlation	**.384****	1
	Sig. (2-tailed)	.001	
	N	66	66

**. Correlation is significant at the 0.01 level (2-tailed).

6.4.3. *Construct validity*

In the analysis, the construct validity was investigated using predictions relating to 4 sub domains from Section A (Feeding problem domain), 5 sub domains from Section B (GI domain) and 2 sub domains from Section C (Impact domain) with the total scores of the BAMBI, GSC and the modified IFS (see **Table 6.17, 6.18** and **6.19**). In addition, the construct validity of factor 1 and factor 2 of feeding problems derived from the factor analysis was also investigated with the total scores of the Social Communication Questionnaire (SCQ). These factors are equivalent to the 4 sub domains of feeding problems (food selectivity, food sensitivity, food neophobia and problematic mealtime behaviours) (see **Table 6.17**). The analysis of construct validity was based on the total scores using Pearson correlation.

For feeding problems, there was a strong and positive correlation between scores of the problematic mealtime behaviour sub domain with mealtime behaviours reported in the BAMBI (r=0.63, p=<0.01). This is evidence of good construct validity for the BEFG-ASD problematic mealtime behaviours sub domain. There were also a significant but weak correlation between scores of the food selectivity, food sensitivity and food neophobia sub domains with scores of the BAMBI (food selectivity: r=0.34, p=<0.01, food sensitivity: r= 0.43, p=<0.01). There was also a weak positive correlation between food sensitivity and food neophobia with the SCQ total scores, but the correlation was not significant (see **Table 6.17**). This weak correlation between food sensitivity, food neophobia and the SCQ total scores is interesting since it might suggest a possible autism specific relationship between certain types of feeding problems and ASD. This needs further investigation (see discussion- section 6.6). Although the correlation is weak but there may be a possibility that food sensitivity is associated with the repetitive and stereotypes patterns of behaviours of ASD.

Table 6.17 Correlation between sub domains, factor loadings of feeding problems (BEFG-ASD) with BAMBI and SCQ

Factor solution	Sub domain		Total score food selectivity	Total score food sensitivity	Total score problematic mealtime behaviour	Total Score BAMBI	Total score SCQ
Factor 1 Items:15	Food selectivity Items: 3	Pearson Correlation	1	.432**	.116	**.341****	**.115**
		Sig. (2-tailed)		.000	.328	.005	.390
		N	73	73	73	65	58
	Food sensitivity and food neophobia Items: 12	Pearson Correlation	.432**	1	.285*	**.425****	**.361****
		Sig. (2-tailed)	.000		.015	.000	.005
		N	73	73	73	65	58
Factor 2 Items:3	Problematic mealtime behaviours Items: 3	Pearson Correlation	.116	.285*	1	**.628****	**.171**
		Sig. (2-tailed)	.328	.015		.000	.198
		N	73	73	73	65	58

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

To evaluate the construct of the GI symptoms of the BEFG-ASD, correlations between scores of six items of GI symptoms and scores of 20 items of GSC were evaluated as shown in **Table 6.18**. Twenty items of the GSC and 6 items within 5 sub domains of GI symptoms (constipation, accidents in opening bowel, diarrhoea, abdominal pain, toileting problems and vomiting) were used. There was a significant moderate correlation between GI symptoms in the BEFG-ASD and the GSC (r=0.49, p=<.01), suggesting reasonable construct validity for the constipation, diarrhoea, abdominal pain, toileting behaviour and vomiting sub domains.

Table 6.18 Correlation between items 'GI symptoms' and GSC

		Total score GI symptoms	Total score GSC
GI symptoms (Section B BEFG-ASD) Sub domains: Constipation, diarrhoea, abdominal pain, toileting behaviour, vomiting) Items: 6[a]	Pearson Correlation	1	**.485**[**]
	Sig. (2-tailed)		.000
	N	73	65
Gut symptoms (GSC) Items:20[b]	Pearson Correlation	**.485**[**]	1
	Sig. (2-tailed)	.000	
	N	65	65

**. Correlation is significant at the 0.01 level (2-tailed).

a.Items: constipation, accidents in opening bowel, diarrhoea, regular abdominal pain, toileting behaviour, vomiting

b. Items: loose poo, diarrhoea, constipation, alternating constipation and diarrhoea, bulky poo, pellet-like poo, large amounts of poo, _ucous poo, pale poo, poo that floats, undigested food in poo, foul smelling poo, frequent flatulence, abdominal distension/bloating, abdominal discomfort prior to passing a motion, general abdominal discomfort, rash around anus, regurgitation of food, vomiting

Table 6.19 Correlation between 'Impact of feeding problems', 'impact of GI symptoms' and 'IFS'

Subdomain		Total score Impact Feeding problems	Total score Impact GI symptoms	Total score Impact (IFS)
Impact Feeding problems Items:4	Pearson Correlation	1	.274*	**.517****
	Sig. (2-tailed)		.019	.000
	N	73	73	66
Impact GI symptoms Items:4	Pearson Correlation	.274*	1	**.146**
	Sig. (2-tailed)	.019		.241
	N	73	73	66

**. Correlation is significant at the 0.01 level (2-tailed).

There was a significant moderate correlation between impact factor of feeding problems and the IFS (r=0.52, p=<.01), indicating reasonable construct validity of the impact of feeding problems domain, but weak correlation between the impact of GI symptoms and the impact in the IFS (**Table 6.19**). In summary, the results of the criterion validity and the construct validity of the BEFG-ASD varied across sub domains.

6.5. Feedback from telephone interviews with professionals

Feedback from a sub group of professionals who had used the BEFG-ASD in the field-testing was gathered within one to two months after the interviews. A trained research volunteer (undergraduate psychology student) conducted telephone interviews to gather feedback from professionals, using a standardised telephone interview questionnaire designed specifically for this research project (Chapter 3.6.6). Prior to conducting the telephone interviews, the student was trained in the use of the questionnaire and practice telephone interviews were conducted with a member of the supervisory team.

30 professionals were approached and 20 professionals took part in the telephone interviews. These professionals represented 40% of the 48 professionals involved in the field-testing. This sub-group represented the range of professionals that took part in the field-testing (nurse (n=4), clinical/child psychologist (n=4), teacher/teaching

assistant (n=4), paediatrician (n=2), psychiatrist (n=2), occupational therapist (n=2), speech language therapist (n=1) and community project worker (n=1). All had experience with children with ASD and on average seeing 38 children per year (range: 6 - 100 children). The average time taken for these professionals to complete the BEFG-ASD with parents was 30 minutes (Range: 10 - 60 minutes). This finding is similar with the reported average time taken in the pre-test of the questionnaire.

Professionals were asked how they had selected parents from their current caseloads. 50% of professionals stated that they had selected parents according to the inclusion criteria (n=10). Several professionals used additional criteria such as ‘parents were friendly and receptive’ (n=4), ‘easy to contact parent’ (n=4) and recommended by senior consultant or through local parent training courses such as ‘Early Bird training’ (n=2). Three quarters (n=15) had selected parents without prior knowledge whether the child had any feeding problems or GI symptoms. Only 5 professionals had selected parents who had children with feeding problems and/or GI symptoms.

6.5.1 *Professionals’ feedback about the BEFG-ASD*

Professionals were asked whether the BEFG-ASD was easy to use and useful to their current practice or not. All professionals (n=20) reported that the BEFG-ASD was easy to use. Most professionals (n=19) felt that the BEFG-ASD was useful for their current practice. One (n=1) teacher felt that the BEFG-ASD was not useful for her as she was already aware of the child’s problems.

Professionals were then asked to rate their opinion using a scale from ‘not useful’ to ‘very useful’, on the usefulness of the BEFG-ASD to identify feeding problems, GI symptoms and the impact of these problems in a systematic way. The majority of professionals reported that the BEFG-ASD was ‘useful’ and ‘very useful’ (**Table 6.20).**

Table 6.20 Opinion of professionals about the BEFG-ASD (N=20)

Aspect	Not useful (n,%)	Somewhat useful (n,%)	Useful (n,%)	Very useful (n,%)
BEFG-ASD helps to identify feeding problems in a systematic way	1 (5%)	1(5%)	9(45%)	9 (45%)
BEFG-ASD helps to identify GI symptoms in a systematic way	3(15%)	1(5%)	6(30%)	10(50%)
BEFG-ASD helps to identify the impact of feeding problems in a systematic way	2(10%)	4(20%)	7(35%)	7(35%)
BEFG-ASD helps to identify the impact of GI symptoms in a systematic way	4 (20%)	2(10%)	7(35%)	7(35%)

Professionals were also asked whether the BEFG-ASD is useful in increasing their awareness of feeding problems, GI symptoms and the impact of these problems. Again, the majority of professionals reported that the BEFG-ASD was useful in increasing their awareness about feeding problems (n=16), GI symptoms (n=15) and the impact of these problems (n=18). All professionals (n=20) agreed that the BEFG-ASD offered something unique to support professionals working in the community and should be used for training of professionals in the early identification of feeding problems and GI symptoms in children with ASD. Majority of professionals (n=18) agreed that they would use the BEFG-ASD as part of their overall management for children with ASD.

6.5.2. *Feedback from the open-ended questions*

The professionals were asked why they thought the BEFG-ASD was useful to them and in what way it had increased their awareness of feeding problems, GI symptoms and the impact of these problems. The interviewer (research volunteer) recorded this information verbatim. The written feedback was collated and summarised through. Key terms emerged from the feedback will be discussed within 3 aspects:

i) Format of the BEFG-ASD

Three key terms were used to describe the format of the BEFG-ASD from the telephone interview (**Table 6.21**). This includes ‘structured’, ‘focus’ and ‘easy to use’. Two professionals felt that the BEFG-ASD was too long and time consuming. However, the same 2 professionals thought that it was hard to repeat the interview for the second follow up due to work commitment.

ii) Scope of questions

Two key terms were used frequently: ‘comprehensive’ and ‘highlighting relevant concerns’ (**Table 6.22**). Two professionals made specific comments about the questions on toileting in Section B (GI symptoms), indicating that constipation and diarrhoea were not applicable for children who were not yet toilet trained and still in nappies. The professionals indicated that it did not seem appropriate to go through these questions with the parents.

iii) Face-to face interview with parents

Two positive key terms emerged from the feedback; ‘enabled discussion with parents’ and ‘increased knowledge and awareness’ (**Table 6.23**).

Table 6.21 Key terms emerged from the open-ended questions about the format of the BEFG-ASD

Structured	
P6	*"formalised questions so I didn't miss bits"*
P8	*"good to have them [Section A, B and C] separate, yet all in one questionnaire"*
P10	*"helped to identify it[feeding problems] systematically"*
P15	*"structured, stage by stage"*
P16	*"structured, allowed deeper assessment"*
P17	*"space for qualitative feedback[for impact]"*
P17	*"Questionnaire [BEFG-ASD] gave structure to the discussion"*
P1	*"structured and explicit"*
P5	*"Questions allow to probe further in a structured way"*
P18	*"structure allowed clinician to think different areas especially impact on family*
Focus	
P1	*"better insight information on child and their problems"*
P16	*"very individual"*
P6	*"gave practitioner insight into impact of identified issues to child and family"*
P7	*"the impact section is emotive part of questionnaire for parent"*
P8	*"focuses on exact problems appropriately therefore more applicable to therapy*
P11	*"useful to have questionnaire to focus on these. Highlighting relevant issues"*
P13	*"Useful for psycho education"*
Easy to use	
P5	*"easy to use. Good design"*
P12	*"relatively short. Therefore did not take too long to administer.*
P1	*"not labour intensive"*
P2	*"accessible language"*
P18	*"Instruction clear"*
P6	*"parents found it useful"*

P: Professional who answered the open-ended questions

Table 6.22 Key terms emerged from the open-ended questions about the scope of the BEFG-ASD

Comprehensive	
P1	*"The questionnaire highlighted typical problems that exist"*
P2	*"comprehensive yet concise"*
P2	*"lots of information without parent feeling overwhelmed"*
P4	*"covers all main areas of feeding and GI and impact.*
P3	*"comprehensive coverage"*
P15	*"format ensured comprehensive assessment"*
P20	*"content of questionnaire was so comprehensive, therefore built on knowledge of practitioner"*
P8	*"helped the person giving the interview to comprehensive assessment. Therefore can direct interventions"*
Highlighting relevant concerns	
P1	*"questionnaire allows mum to express over stress level regarding mealtimes"*
P1	*"The questionnaire highlighted typical problems that exist"*
P7	*"the impact section is emotive part of questionnaire for parent"*
P13	*"confirming clinical formulation [about feeding problems and GI symptoms]"*
P10	*"in consultation, mother reported difficulties with child's feeding issues and now this affected other family meals, couldn't go out for food"*
P11	*"useful to have questionnaire to focus on these [feeding problems and GI symptoms]. Highlighting relevant issues"*
P13	*"parent's assessment of own's child's feeding problems, and what was relevant to them"*
P3	*"given that caseloads are significant increased now, less information available. Therefore, questionnaire [BEFG-ASD] ideal at gathering info[information]"*
P16	*"gave opportunity for parent to express concerns".*
P9	*"helpful in exploring issues further. Identified anxiety referring to GI symptoms"*
P12	*"differentiated between feeding problems and GI symptoms"*
P13	*"separate GI and feeding problems. Highly relevant"*

P: Professional who answered the open-ended question

Table 6.23. Key terms emerged from the open-ended questions about the interview process of the BEFG-ASD

Increased awareness and knowledge	
P2	*"content of questionnaire was so comprehensive, therefore built on knowledge of practitioner"*
P3	*"given that caseloads are significant increased now, less information available. Therefore, questionnaire [BEFG-ASD] ideal at gathering info[information"*
P5	*"reinforced knowledge of issues [feeding problems, GI symptoms and impact]*
P6	*"not a typical presentation in current caseload"*
P8	*"more aware of areas of questionnaire"*
P6	*"not a typical presentation in current caseload"*
P12	*"I didn't consider this[impact of feeding problems and GI symptoms] previously*
Enabled discussion with parents	
P1	*"questionnaire allows mum to express over stress level regarding mealtimes"*
P8	*"gave discussion on how feeding problem impact family life, which is not normally discussed"*
P10	*"in consultation, mother reported difficulties with child's feeding issues and now this affected other family meals, couldn't go out for food"*
P11	*"parents related well with the questions. The interview flowed much better. Got much more out of assessment than usual"*
P12	*"parents have more opportunities to ask/answer questions"*
P16	*"gave opportunity for parent to express concerns". Questions themselves stimulate discussions"*
P13	*"questionnaire given room for clinician to elaborate"*
P14	*"specific questions encourage clinician to ask questions that not normally asked"*
P7	*"helped parents look at the bigger picture"*

P: Professional who answered the open-ended question

6.5.3. *Professionals' feedback about the information pack*

The professionals were also asked whether they utilised the information pack in the field-testing with parents. All professionals (n=20) gave the information pack to parents and found the information pack was easy to use. **Table 6.24** shows that all professionals also agreed that the information pack was useful in their current practice to support parents' concerns about feeding problems.

Table 6.24 Opinion of professionals about the information pack (N=20)

Aspect	Not useful (n,%)	Somewhat useful (n,%)	Useful (n,%)	Very useful (n,%)
The information pack is useful for current practice (N=20)	-	1(6%)	6(30%)	13(65%)
The information pack is useful for professionals to support parent's concern about feeding problems (N=20)	-	-	4(20%)	16(80%)

Based on the feedback, three key terms about the information pack emerged. These include 'comprehensive', 'accessible' and 'user friendly' (see **Table 6.25)**. Three professionals made critical comments that 'the information pack lacked information on GI symptoms', 'some information is more relevant to health professionals', and the print was too small (for 'food and mood' sheet).

Several professionals gave suggestions to improve the information pack:

- More information about local services
- More information on how to manage feeding problems and GI symptoms
- Information on local parents supports networks

This feedback from the professionals is encouraging and indicated that professionals used the information pack with parents after the BEFG-ASD interviews. Most professionals reported that the BEFG-ASD and information pack were useful and practical in their current practice. However, just 20 professionals took part in the telephone interviews. This feedback, although collected by a trained volunteer who had not previously met the professionals, was not anonymised. In addition, there was no feedback gathered from the parents themselves who were interviewed by the professionals. Despite these limitations, the feedback from the telephone interviews has maximised the content validity and face validity of the BEFG-ASD.

Table 6.25. Key terms about the information pack

Comprehensive	
P2	*“comprehensive and concise”*
P2	*“comprehensive range of information”*
P4	*“comprehensive”*
P3	*“reinforced issues that were discussed”*
P17	*“the diet and ASD is great”*
Accessible	
P10	*“good info in one place”*
P12	*“accessible”*
P11	*“lots of information that was accessible”*
P15	*“gave some more information to the parent”*
User friendly	
P6	*“easy read for parents”*
P7	*“easy to read. Colourful. Not too heavy”*
P12	*“looks nice”*
P16	*“sign posting to online information”*
P18	*“well designed. Easy to read.”*
P18	*“aesthetically pleasing”*
P14	*“parent‘s feedback was very positive. It was very useful”*

6.6. Discussion

The secondary aim of the present research was to evaluate the psychometric properties of the BEFG-ASD questionnaire through field-testing with a range of professionals working with parents of primary school children with ASD in community settings. This chapter covered the results of the evaluation of the BEFG-ASD, including the evaluation of the psychometric properties of the BEFG-ASD, and feedback from the telephone interviews with a sub group of professionals. A number of statistical analyses were conducted to investigate specific aspects of the psychometric properties of the BEFG-ASD. These included internal consistency, test-retest reliability, inter-rater reliability, factor analysis, criterion validity and construct validity of the BEFG-ASD. The evaluation of the usefulness of the BEFG-ASD and information pack was also conducted using a structured telephone interview questionnaire.

The BEFG-ASD is a new questionnaire designed for a range of professionals in the community to identify feeding problems, GI symptoms of primary school children with ASD. In the present research work, important aspects of both the reliability and validity of the BEFG-ASD were identified and evaluated based on relevant literature for evaluating the reliability and validity of questionnaire (Terwee et al., 2007; Kimberlin and Winterstein, 2008; Streiner and Norman, 2008; Kottner J et al., 2011) and advice from the Newcastle University statistics department.

The majority of reliability and validity analyses of the BEFG-ASD were conducted based on scores of the BEFG-ASD derived from the parents’ responses, recorded by professionals during the interviews conducted using the BEFG-ASD during the field-testing (N=73). The internal consistency of the BEFG-ASD was very good (Cronbach’s alpha: 0.85) (Streiner and Norman, 2008). However, further evaluation of the internal consistency of each domain and sub domains in the BEFG-ASD revealed different outcomes. Despite this, the overall Cronbach’s alpha indicated that the BEFG-ASD has good internal consistency.

The results of the item-total correlation of each item varied across domains. This is not surprising since parents may have responded to the various questions on feeding problems and GI symptoms in different ways. In addition, some of the items within the sub domains are not specific feeding problems and GI symptoms but provide useful information as part of the early identification of feeding problems and GI symptoms among children with ASD.

The exploratory factor analysis (EFA) of each domain, the analyses indicates an underlying structure of the BEFG-ASD of 7 factors for feeding problems, 3 factors for GI symptoms and 2 factors for the impact section. The EFA results revealed that two factors made up of 18 feeding problems items (explained by 86% and 7% of the variance). For the GI symptoms domain, although the EFA results indicated 3 factor solutions, this also raised a possibility whether any of these sub domains might be reasonably grouped together.

The reliability analyses revealed that the BEFG-ASD has acceptable test-retest reliability and inter-rater reliability. These aspects were assessed based on the ICC for each domain and kappa coefficients for each item of the BEFG-ASD. For the inter-rater reliability analysis, a variance component model based on the different variance components of sample (parents of children with ASD), interviewers (professionals) and error (within sample) to calculate the ICC. Using this approach, an unbiased estimate of reliability can be provided (Streiner and Norman, 2008). The kappa value for each item of the BEFG-ASD ranged from 0.4-0.9 for test-retest, and 0.4-1.0 for inter-rater reliability, suggested ‘fair to almost perfect’ agreement (Altman, 1991).

In the validity analysis, the criterion and construct validity of the BEFG-ASD was evaluated using 3 different published parent self-report measures. Terwee et al (2007) recommend a correlation threshold of at least 0.70 for good criterion validity. There was a low to moderate correlation between scores of feeding problems, GI symptoms and the impact with the BAMBI, GSC and the modified IFS respectively. The results were expected as the BAMBI, the GSC and the modified IFS are not considered as a ‘gold standard’ or ‘standard reference’ for feeding problems, GI symptoms and the impact. The present research has demonstrated that the BEFG-ASD showed a reasonable criterion validity and construct validity.

Schreck and Williams (2006) reported that there was no relationship between food selectivity and the degree of ASD severity. However, the result of the construct validity of the BEFG-ASD with the SCQ provides preliminary evidence that food sensitivity and food neophobia may be associated with the total scores of the SCQ. Further analysis would be required to explore this association, perhaps using the BEFG-ASD with different ASD clinical diagnosis and severity.

One of the limitations of the validity analyses in this research is that the BEFG-ASD has only been used with parents of children with ASD. Further studies to evaluate the discriminative validity and expected differences in changes between ‘known’ groups (such as other children with disabilities or typically developing children) are required, as recommended by Terwee et al (2007). Parents involved in the field-testing were parents of children with ASD predominantly Autism. The nature of the problem and the impact for children across the spectrum of severity of ASD has not been investigated in this research, including children with typically developing children, developmental disabilities of any other diagnostic group. Therefore, the nature of the problems and the impact need to be investigated further in order to support evidence on the validity of the impact.

The last aspect of the evaluation of the BEFG-ASD was the feedback about the BEFG-ASD and the information pack using a standardised telephone interview questionnaire with a sub group of professionals (N=20), who had used the BEFG-ASD to interview parents during the field-testing. The professionals identified both advantages and some limitations of the BEFG-ASD and information pack. The overall feedback was encouraging, and as such has contributed to the content validity and face validity of the BEFG-ASD.

Another limitation of the psychometric analysis for the BEFG-ASD is the sample size. Although the recommended minimum sample size for reliability analysis for ICC or kappa is 50 participants (Kottner et al., 2011), only 43 parents for the test-test reliability and 26 parents for the inter-rater reliability were successfully recruited. The recruitment of professionals was dependant on the key contacts from the available child and adolescent health services and mental health services within the NHS Trusts. Parents were recruited by professionals based on their current caseloads (convenience sampling), which contributed to the sampling bias and recruitment bias. Kline (1998) and Terwee et al (2007) also recommended a minimum sample of 100 for factor analysis or subjects-to-variables (STV) ratio of two for each item to ensure the stability of the variance. The sample size for the field-testing was limited due to recruitment procedures and ethical considerations to conduct this research. Therefore, further research with a larger sample size is needed to provide additional evidence on the reliability and validity of the BEFG-ASD.

In summary, in this research the BEFG-ASD has shown to have good internal consistency and acceptable test-retest reliability and inter-rater reliability. The telephone interviews have also enhanced the content validity and face validity of the BEFG-ASD. The criterion validity and construct validity varied across domains and several sub domains of the BEFG-ASD. The results of the psychometric properties analyses are encouraging. The relevance of each item for clinical practice, has also been considered and as a consequence of this evaluation process, all items in the BEFG-ASD have been retained.

CHAPTER 7.

DISCUSSION AND CONCLUSION

Chapter 7. Discussion and conclusion

7.1. Introduction

This research aimed to develop and evaluate a new questionnaire - the **B**rief structured questionnaire for the **E**arly identification of **F**eeding problems and **G**astrointestinal (GI) symptoms in primary school children with **A**utism **S**pectrum **D**isorder (ASD), and the impact of these problems on family life (**BEFG-ASD**). The BEFG-ASD is an interviewer-based (face-to-face) structured questionnaire developed to be used by community professionals who are working with children with ASD and their families. The BEFG-ASD was designed to identify feeding problems and GI symptoms and to measure the impact of these problems on family of children with ASD.

Alongside the BEFG-ASD, an information pack was also developed as a resource for professionals working with parents of children with ASD in the community. In this final chapter, the main findings from the mixed quantitative and qualitative methods of the three phases of the research will be discussed. The three phases were i) Phase I: development of the BEFG-ASD; ii) Phase II: field-testing of the BEFG-ASD; and iii) Phase III: evaluation of psychometric properties of the BEFG-ASD. The implications of the findings, the strengths and limitations of the research, next steps and potential directions for future research work will be considered, and the conclusion for this research is presented.

7.2. Highlights of the main findings

7.2.1. *Why the BEFG-ASD is important*

Over the past decade, researchers have described a range of feeding problems and GI symptoms among children with ASD. Children with ASD have been reported to show many different feeding problems mainly around food selectivity, food sensitivity and mealtime behaviours. Children with ASD also reported to show many gastrointestinal symptoms such as constipation, diarrhoea and abdominal pain. Feeding problems and GI symptoms are common in all children and although the types of reported problems are similar to those seen in typically developing children and children with a range of other disabilities, the extent of the problems in children with ASD is not known.

Managing feeding problems and GI symptoms in children with ASD are likely to be more challenging to both professionals and parents. According to Martins, Young and Robson (2008), managing and treating feeding problems among children with ASD may take a longer time compared to typically developing children because the frequency of feeding problems is much higher and the problems appear simultaneously. It is important to appreciate the complexity of the core features of ASD are also likely to contribute to the challenges in the management of feeding problems or GI symptoms. Children with ASD have impairments in communication, social interaction and repetitive behaviours. The aetiology of ASD remains unclear but includes genetic and environmental factors. Children with ASD also have other co-existing difficulties such as impaired sensory processing, behavioural problems, emotional and sleep problems, which affect the daily living of these children (Cermak et al., 2010). In addition, there is a wide variability in the degree to which these symptoms or difficulties manifest. Thus, for children with ASD there may well be many additional factors contributing to the aetiology of their feeding problems and GI symptoms compared to typically developing children.

The results of the present research have shown that the primary school children with ASD whose parents took part in the study, were reported to have a wide range of feeding problems and GI symptoms. Both types of difficulties may also impact on the dietary intake and nutritional status of the children. According to Geragthy et al (2010), there are many factors affecting the nutritional status of children with ASD. These include medical/nutritional and behavioural factors that warrant careful consideration and identification among professionals. Family feeding practices, dietary restriction and parental stress may also influence the nutritional status of children with ASD (Geragthy et al., 2010). For all these reasons, a specific measure such as the BEFG-ASD might provide a useful tool for community professionals. Although the BEFG-ASD does not assess the nutritional status of the children, community professionals can identify a considerable range of feeding problems and GI symptoms in children with ASD to inform appropriate planning or referral for further assessments.

At present, one of the challenges for professionals to identify feeding problems in children with ASD is that the definitions of these problems are not standardised.

According to Seiverling, Williams and Sturmey (2010), the categories and definitions for the range of feeding problems in children with ASD in the International Classification of Diseases (ICD-10, WHO 1992), the DSM-IV(American Psychiatric Association, 1994a) and DSM-IV-TR (American Psychiatric Association, 1994b) are still not adequate. In the present research, operational definitions for 15 types or sub domains of feeding problems and GI symptoms were developed. These operational definitions may have a wider usefulness as a way to bring together the various definitions and terms for feeding problems and GI symptoms in children with ASD reported in earlier studies. If adopted, professionals may use these definitions alongside the upcoming Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-V) in the overall assessment and diagnosis of health conditions in children with ASD.

All the questionnaires identified during the course of this research are parent self-report questionnaires. According to Seveirling, Williams and Sturmey (2010), parent self report questionnaires are practical when used by professionals and researchers. This type of questionnaire can be completed quickly and does not require specific training for the professionals. However, the importance of an interviewer-based questionnaire for professionals should not be under estimated. Although there is no specific recommendation for the suitable type of approach to identify feeding problems and GI symptoms, a face-to-face interview provides an opportunity for active discussion between the professionals and the parents. Face-to-face interviews can be either structured or semi structured (Bowling, 2009).

The advantages of a structured questionnaire format include that both the training to administer the interview reliably and the interview itself can be undertaken in a relatively short time frame. Further using a structured interview format has been shown to reduce variability in administration and the potential source of error among interviewer (professionals) and interviewee (parents) (Oppenheim, 1992; Le Couteur and Gardner, 2008; Bowling, 2009). In addition, use of a structured interview could assist health professionals to collect specific information for clinical assessment, treatment or intervention plan (Le Couteur and Gardner, 2008). Importantly, the interviewer (professionals) can ensure that the interviewee (parents) answers all questions.

Thus, a new questionnaire focussing on feeding problems, GI symptoms and the impact of these problems, if shown to have adequate reliability and validity could provide a way for professionals to gather consistent information about these issues. This questionnaire might in turn inform suitable treatment or intervention planning. This research (albeit using a convenience sample) has demonstrated that a range of community professionals from different background (including those working in special education settings) were able to use the BEFG-ASD with parents to identify feeding problems and GI symptoms among primary school children with ASD as part of their current practice.

However, any type of questionnaire has its own limitations. For example, there is a risk that the professional conducting the interview may bias the responses given by the parent. There is also a possibility that not all parents want to be asked about feeding problems or GI symptoms face-to-face, but might prefer to answer a self-report questionnaire or for research purposes answer anonymously (William, 2003). Although, time taken to conduct an interview could be a considerable constraint for professionals, the BEFG-ASD as a structured interview minimises this risk.

Although the main aim of the present research was to develop a questionnaire, additional research questions were identified such as whether particular feeding problems or GI symptoms might be related to particular aspects of the ASD phenotype. These aspects or features include for example sensory abnormalities, rigidity, restricted or repetitive behaviours. Lukens and Linscheid (2008) claimed that repetitive behaviours and the child’s rigidity (such as child’s preference for similar types of food or child insists similar food texture) could lead to extreme restrictions in the types of food consumed by the children with ASD.

Children with ASD may have difficulties in learning to use feeding utensils due to the impairments in social interaction and communication (Lukens and Linscheid, 2008). Although, the relationship of behavioural issues and feeding problems is still not clear, there is a possibility that sensory abnormalities in children with ASD may contribute to food selectivity and food sensitivity (Cermak et al., 2010; Curtin et al., 2010; and Bandini et al., 2010). Chen, Rodgers and McConachie (2009) reported that the amount of restricted and repetitive behaviours in children with ASD was associated with the degree of sensory abnormalities. With this in mind, the results from the psychometric properties are interesting as the findings have shown that food selectivity, food sensitivity and problematic mealtime behaviours may be associated with some of the ASD features. Further work is needed to investigate this possibility in more detail. The BEFG-ASD could be used as a measure in future research, for the investigation of the relationship between sensory abnormalities, rigidity, restricted or repetitive behaviours and feeding problems and GI symptoms within the population of young children with ASD.

7.2.2. *Reliability and validity of the BEFG-ASD*

Both validity and reliability concepts are equally important to be addressed when a new questionnaire is being developed (Terwee et al., 2007; Streiner and Norman, 2008; Kottner et al., 2011). Three types of reliability evaluated in the present research were internal consistency, test re-test reliability and inter-rater reliability. Validity of the BEFG-ASD was evaluated based on the content validity, face validity, factor structure, criterion validity and construct validity.

In the development work of the BEFG-ASD, sub domains and items were selected based on a thorough process including a two-stage literature review (2009 and 2010) prior to the formatting of items to questions for the BEFG-ASD. Consultation with other researchers and clinicians prior to the development work was undertaken and supported the need to develop a new questionnaire for professionals. The views of professionals and parents of children with ASD were also considered to confirm the 42 items and questions of the BEFG-ASD. Through these processes, the data available for the investigation of the content validity was maximised, as recommended by Terwee et al (2007).

In this research, the face validity was established through the pre-testing and an extension of the field-testing of the BEFG-ASD with a range of community professionals and the parents of primary school children with ASD. This was achieved from the feedback (using telephone interviews conducted by a trained researcher but not myself) obtained from a sub group of professionals. The feedback covered both advantages and some limitations of the BEFG-ASD and information pack. This information will also allow me to consider whether some refinements of questions would be useful. Thus, the telephone interviews enhanced the content validity and face validity of the BEFG-ASD. Streiner and Norman (2008) have stated that face validity provides essential information about whether a questionnaire can attract potential participants, and how to reduce dissatisfaction, and increase cooperation among the participants conducting the questionnaire. A careful consideration was given to the feedback from professionals who took part in the research. This information contributed to the investigation of both face validity and content validity, and demonstrated good cooperation and commitment among professionals in the field-testing.

Overall, the results of the psychometric analyses show that the BEFG-ASD is a reliable and valid questionnaire to identify feeding problems and GI symptoms of primary school children with ASD, and measure the impact of these problems on family life in North East England. Cronbach's alpha was used to assess the internal consistency of the BEFG-ASD domains and sub domains. The internal consistency for the 42 items of the BEFG-ASD was good (Cronbach's alpha: 0.85,) but varied across the three domains (Feeding problems: 0.75; GI symptoms: 0.55; Impact: 0.85). Cronbach's alpha for Section B (GI symptoms domain) was lower when compared to feeding problems and the impact domain. There are several possible reasons for this finding. The inter-item correlations for some of the items in the feeding domains and GI symptoms domain were low (such as problems with cutlery control, dietary advice for parent, constipation, weight loss, diarrhoea). Five items in the GI symptoms had a very low value of inter-item correlation (0.04- 0.25) which indicated that these items are not well correlated with each other within the GI domain. This was expected since these items are measuring different aspects of child or parent behavior. Indeed the low value of internal consistency of GI symptoms was not unsurprising. Although the literature identifies that there is likely to be overlaps between several of the types of different feeding problems with each other and with GI symptoms, this is clinically less likely to be the case for some of the individual GI symptoms (some of which such as weight loss, are usually only identified as the longer term complication). For example, a parent is unlikely to report that their child is both constipated and is suffering from diarrhoea. There are some clinical situations when medically a severely constipated child may experience loose bowels (but this problem is different from the usual types of diarrhoea). There may however also be clinical situations when these different symptoms do co-occur. For all these reasons, it is important to retain all the GI symptoms as the information about each symptom and possible combinations of symptoms are relevant to the understanding of the severity and range of problems and the identification of the impact of these problems for affected children and their families. Lukens and Linscheid (2008) reported similar variations of the Cronbach's alpha. In the evaluation of the BAMBI, the overall Cronbach's alpha was 0.88, and somewhat lower values for the sub domains ranging from 0.63 to 0.88 (Lukens and Linscheid, 2008). Therefore, the variation of the Cronbach's alpha is useful in order to provide better insight on the correlations of the items and how parents have responded to the questions in each section of the BEFG-ASD.

The BEFG-ASD has been shown to have good test-retest reliability and inter-rater reliability with ICC across three domains was greater than 0.70. Test-retest reliability and inter-rater reliability across each item also varied, with kappa coefficient range of 0.4-1.0. According to Streiner and Norman (2008), besides ICC, other forms of reliability coefficient may be used such as Pearson Product-Moment Correlation and Cohen's kappa. In this research, both ICC and kappa were considered as alternative methods because each section of the BEFG-ASD has different types of scale. Kappa coefficient explicits the proportion of responses in two agreement cells (yes/yes, no/no), rather than the agreement expected by chance (Streiner and Norman, 2008). However, according to Terwee et al (2007), the ability of the questionnaire to detect clinically important changes over certain period (responsiveness) is also important to be evaluated as part of the reliability and validity test. This aspect of reliability and validity has not been covered in the present research but further evaluation of the responsiveness of the BEFG-ASD may be useful to enhance the understanding of the psychometric properties of the BEFG-ASD.

In the present research, the underlying factor structure of the BEFG-ASD, content validity, face validity, criterion validity and construct validity were evaluated using different approaches. Selecting appropriate validated measures for the investigation of the construct validity and criterion validity of the questionnaire was a particular challenge for this research. The best approach to evaluate the validity of the BEFG-ASD was considered and three published questionnaires were chosen. Streiner and Norman (2008), and Terwee et al (2007) have previously recommended that criterion validity is best assessed by comparing a new measure with an existing ‘gold standard’ scale. However, no measures or scales that could be considered as ‘gold standard’ scales for comparison with the BEFG-ASD were identified. The BAMBI (Lukens and Linscheid, 2008), GSC (Wilson et al., 2009) and the IFS (Stein and Riessman, 1980) are not considered as ‘gold standard’ but rather as a reference questionnaire for each section of the BEFG-ASD. According to a review by Williams (2003), in the data analysis of questionnaire development, it is important to keep the analyses focused. In these analyses, the distribution of the data and range of responses within each section of the BEFG-ASD were compared with the other published validated measures (BAMBI, GSC and the modified IFS) using parametric tests (Pearson Product-Moment Correlation) used in the analyses. Bivariate analyses using simple cross-tabulations were used to examine possible associations between domains and subdomains of the BEFG-ASD and other questionnaires. Low to moderate positive correlations were expected for the criterion validity and construct validity because of the differences between the domains and sub domains of the BEFG-ASD and the three published measures.

One of the limitations of the reliability and validity analyses in the present research was that the research was restricted to primary school children with a clinical diagnosis of ASD (aged 4-11). In this field-testing, the majority of the children had a clinical diagnosis of autism. No other information about the levels of everyday functioning of these children was obtained. Therefore, further investigation of the utility of the BEFG-ASD with age groups of children with ASD of different age groups (below 4 years or older children 11-18 year old), levels of ability, co-morbidities and other conditions will be needed to provide more evidence on the psychometric properties of the BEFG-ASD.

7.3 Implications for clinical practice – from dietetic perspective

The findings of the present research have provided some supportive evidence for the early identification of feeding problems, GI symptoms and the impact and the BEFG-ASD and the usefulness of this information to enhance the understanding and knowledge about these difficulties among the professionals and the parents. A range of professionals in the community (working in health and education settings) using the BEFG-ASD were able to identify feeding problems and GI symptoms. This finding has several implications for current practice. These implications within the context of the health and education system in the UK and in another country (Malaysia) will be discussed.

According to Silverman (2010) and Dovey et al (2010), feeding problems in children are complex, and caused by a broad range of factors including developmental factors, biological disorders, behavioural difficulties and physiological factors. Typically, in treatment settings (for example at the feeding clinics), dietitians are required to assess growth and nutrient intake of the child, identify nutrition concerns with the parents and any potential risks for the nutritional status of the child (Silverman, 2010). Dietitians work with several key professionals who conduct various assessments when dealing with these complex feeding problems among children (Cermak et al., 2010; Dovey et al., 2010). For example, in the UK, assessments are often conducted by a paediatrician, speech and language therapist, clinical psychologist, dietitian, physiotherapist and occupational therapist.

Assessment of feeding problems in children with ASD can be more complex and challenging, requiring additional information such as the behavioural, developmental and functional aspects of the presentation of the child and the family (Seiverling, Williams and Sturmey, 2010). In addition, other factors may be associated with the feeding problems among children with ASD such as GI symptoms, sensory issues, family mealtimes, parental dietary practices and other associated conditions should be considered in the assessment (Cermak et al., 2010). Structured assessments and comprehensive treatment approaches involving a multidisciplinary team are likely to be needed to treat severe feeding problems or GI symptoms in children with ASD (Buie et al., 2010b; Sharp et al., 2010). It has been recognised that feeding problems related with food sensitivity, food selectivity and mealtime behavior may affect the energy and dietary intake of children with ASD (Geraghty et al., 2010). Although there is insufficient evidence for the effective management of feeding problems among children with ASD (Geraghty et al., 2010), there is an early emerging evidence that access to appropriate educational, behavioural, psychosocial and therapeutic interventions may improve particular aspects of the outcomes of children with ASD (McConachie and Diggle, 2007; Laud et al., 2009; Green et al., 2010). Some other interventions use mixed behavioural approaches such as sensory-based therapy.

Although these interventions may not have been rigorously evaluated, they are often involved occupational therapist, speech language therapist and clinical psychologist.

Some parents of children with ASD have specific concerns about their child's growth or inadequate dietary intake (Cermak et al., 2010). Thus, feeding problems and GI symptoms identified using the BEFG-ASD could be incorporated and these interventions might be planned using the input of a dietitian. The BEFG-ASD could provide useful information to inform whether a paediatrician, paediatric gastro enterologist or a paediatric dietitian referral is required. For example, paediatric community dietitians can provide initial anthropometric assessment (weight and height status) and information on the total dietary intake (such as energy intake and macronutrients or micronutrient intake) using food records and/or 24-hour diet recalls. If the child has sensory issues or has prolonged selective diet, the child is more likely to be at risk of nutritional inadequacy. In these situations, nutritional support and appropriate dietary advice may be helpful for parents. This information can be gathered and dietitians can then discuss this information with other relevant professionals such as the occupational therapist or the child psychologist about the child's responses to different types of sensory input such as tactile/texture input.

Dietitians can also suggest whether the child requires vitamin or mineral supplementation if there is a risk of nutrient deficiency. In this way, growth and nutritional status of the child can be monitored regularly. In addition, parents may discuss their concern or worry about how to manage their child's feeding problems or GI symptoms. It is important for the dietitian to appreciate this type of concern so that effective interventions with other professionals can be planned.

Dovey at al (2010) has recently formulated a clinical decision-making model for the diagnosis of feeding problems for children based on a single assessment. This model has been shown to be useful in the clinic setting and can be used to develop a management plan for the treatment of children with ASD. This model has already included autism- related food refusal and sensory issues related to food refusal. The BEFG-ASD may be useful to be incorporated into this model so that the professionals in the community can adapt this model to formulate different strategies for the wider range of feeding problems or GI symptoms identified by the BEFG-ASD.

In Malaysia, the majority of specialist (clinical psychologist, paediatric dietitian, physiotherapist, speech language therapist and paediatrician) are based in hospital settings. The number of multidisciplinary specialists teams based in a community settings such as in schools or health clinics is still not adequate to provide services for children with disability (including children with ASD). A measure such as the BEFG-ASD that could be used by a variety of professionals working in the community could provide a feeding problems and GI symptoms profile at an early stage to guide decisions about whether further referral and assessment to the specialist team at the hospital is necessary or not. In this way, early interventions and management of these problems can be planned to treat feeding problems or GI symptoms before they become entrenched. Communication between health professionals, teachers and other community workers at the community settings (such as schools, community clinics, community based rehabilitation centers and family and child's health clinic) about feeding problems and GI symptoms will also be enhanced. The BEFG-ASD could provide useful information to inform the professionals to discuss appropriate interventions or treatment for the children and their families. In addition, the feedback from some professionals in my research suggested that the BEFG-ASD could also be used in ASD training to raise the knowledge and awareness among professionals about the range of feeding problems, GI symptoms that these children can experience and the potential impact of these difficulties on family life. The BEFG-ASD could also be used to increase awareness of the lack of current support for families trying to manage these extra problems in additions to their child's ASD and any other co occurring problems. However, before the BEFG-ASD can be used in any of these situations, new development work to translate and back-translate the questionnaire will be required. Once this work has been completed further evaluation of the psychometric properties of the BEFG-ASD will be necessary to investigate the reliability and validity of this questionnaire in different languages.

7.4. Strengths and limitations

7.4.1 *Application of the International Classification of Functioning, Disability and Health Child and Youth version (ICF-CY) framework*

In the development of the BEFG-ASD, the ICF-CY (World Health Organization, 2007) framework was used to inform the consideration of feeding problems, GI symptoms and the impact of these problems on family life of primary school children with ASD. Using this conceptual framework, several sources of impact on feeding problems and GI symptoms on the family of children with ASD were highlighted. These included personal factors (child's age, gender, child's ASD diagnosis) and environmental factors (the financial aspect of the family, education system, health system and the structure of the family) relevant for the day-to-day care of the child. This framework informed the conceptualisation of the categories of impact of feeding problems and GI symptoms that were included in the development work of the BEFG-ASD. The association of contributing factors for the impact of feeding problems and GI symptoms in children with ASD can be determined using this framework. For example, stress in managing feeding problems and GI symptoms among parents/carers may occur through the limitation of the child's activities (school, eating, toileting and outdoor activities) and/or limited participation of the child in terms of social life and family life (other siblings or family members).

The literature review indicated that there is evidence that parents of children with ASD experience high rates of stress compared to parents of typically developing children and those with children with other neurodevelopmental disorders (Hastings and Johnson, 2001; Davis and Carter, 2008). Further, Knapp and colleagues in the first study to investigate the economic costs of ASD suggest that the amount of time spent caring for a child with ASD and the high economic costs incurred are likely to contribute to the stress levels reported by parents or carers (Knapp et al., 2009). The severity of ASD, the management of any associated medical and mental health problems of the child, the demands placed on the family and lack of social support have all been cited by different authors and researchers as contributing factors to parental stress (Dunn et al., 2001; Hastings and Johnson, 2001; Davis and Carter, 2008).

One of the limitations of this research is that 'extra stress' were not defined and stress related with the management of the child's ASD has not been captured in details. In the present research, there was a correlation between feeding difficulties and SCQ scores, which might indicated that those children with more feeding difficulties had more severe ASD characteristics. This correlation suggest that parents of children with ASD might have additional difficulties in managing children with ASD with severe characteristics such as learning disabilities, behavioural problems and social or communication problems . This is likely to contribute to the level of stress among parents or carers. Parents might already experienced extra stress in day to day management of the severity of their child and might just rating their overall stress, rather than stress in managing feeding problems and GI symptoms. However, this is the first attempt to ask parents whether in their opinion the different types of feeding problems and GI symptoms may have had specific impacts on family life. Different types of impact were identified, and for this questionnaire, the focus was the identification of early problems (defined as present for 30 days). In this research, parents were asked about the specific impact of feeding problems and GI symptoms at the end of the interview by the professionals, after talking about feeding problems and GI symptoms in some detail. General findings (Chapter 5.6) have shown that parents have responded differently to the impact questions and able to differentiate each type of the impact of feeding problems and GI symptoms. Findings from this research have highlighted that there are some impacts of feeding problems and GI symptoms on family life of children with ASD. It was interesting to note from the informal feedback from the telephone interviews, that there were no comments (from the professionals) in relation to what ‘extra stress’ might mean. Parents did not seem to have any difficulties attempting to answer the questions about the impact section. Indeed, at least one professional stated that they had not been aware of the impact of the feeding problems and GI symptoms until they specifically asked parents about it.

The relationship of feeding problems and the SCQ scores is still not clear because the general functioning and the severity of the impairments of the children are not gathered in this research. The impact of feeding problems and GI symptoms compared with the impact of the ASD characteristics and severity needs further investigation or replication in other research. Further research is needed to investigate whether parents or caregivers were able to differentiate the stress associated with the child’s feeding and GI difficulties from the general day-to-day challenges of parenting a child with ASD. The aspect of the impact of feeding problems and GI symptoms in the BEFG-ASD questionnaire could be modified and developed further. The use of the ICF-CY conceptual framework could be extended in future researches to explore other possible areas of impact of feeding problems and GI symptoms on children with ASD and their families.

7.4.2. *Sample size and recruitment*

In the development work, expert professional and parent panels (n=20) were purposely recruited using key contacts to undertake a modified Delphi technique. The Delphi technique does not use a random sample and indeed the required sample size is usually guided by both the purpose of the project and the period available for data collection (Yousof, 2007). Although the conduct of the Delphi technique has been criticised in terms of the methodology, sample size, reliability and validity of the approach, Keeney et al (2001) and Thangaratinam and Redman (2005) have stated that the Delphi is not a replacement for thorough methodology in scientific research, but rather a mixed quantitative and qualitative method to gather opinion or consensus about specific area or health topic. In the present research the expert panels of parents and professionals endorsed the content of the BEFG-ASD and expended the number of items for the BEFG-ASD.

The sample size of this research could be considered as relatively small for some analyses of psychometric properties such as Factor Analysis (n=73) and inter-rater reliability (n=26). The implication is that some analyses such as inter-rater reliability and Factor Analysis were conducted in a small sample size despite the recommendation of 50 participants for reliability analysis and 100 participants for factor analysis (Terwee et al., 2007). However, the present research provides preliminary findings of psychometric properties for the factor analysis and inter-rater reliability of the BEFG-ASD. Further evidence is a larger sample size is needed to support the evidence on the reliability and validity of the BEFG-ASD. The available published evidence on establishing reliability and validity for a new health questionnaire, and by the findings of similar research studies conducted in the North East informed the proposed sample size for the field-testing. This led to an expected recruitment rate of 50% of expressions of interest responses by professionals. Professionals and parents were recruited using a purposive sampling procedure. Therefore, the sample of professionals and parents recruited to this research cannot be considered a representative sample of professionals and the children with ASD population in North East England. In future studies, it will be important to identify the rates of feeding problems and GI symptoms (as reported by parents) using a representative sample of primary school children. Despite this limitation, the sample of professionals recruited in the field-testing did include a reasonable number of the different professional groups who work in the community with children with ASD and their families, including professionals working in special school settings. Cicchetti (2001) identified that often the main difficulties for reliability studies are problems with recruitment and maintaining the interest of participants. Taking all these factors into consideration, an overall recruitment response rate of 50% could be considered good for this type of research. A further complication was that professionals were asked to recruit parents from their current caseloads. However, the response rate of parents who completed both interviews was very encouraging.

Parents of children with ASD who were not able to speak and write English were not recruited because the BEFG-ASD was developed in the English language. Although the use of interpreters may be possible for these parents, it would be time consuming and costly to include them in this research. For the present research, it was decided that it was not possible to extend the work to include interpreters and also not appropriate at the current development stage of the research.

7.5 Next steps and potential direction of future research and clinical application

The BEFG-ASD was found to be valid and reliable when used by a range of community based professionals to identify feeding problems and GI symptoms. Based on the limitations described earlier (i.e. sample size and recruitment), possible clinical and research application of the BEFG-ASD and information pack to extend the evaluation of the psychometric properties could be undertaken in a more representative sample of children with ASD, different settings (such as main stream schools and general practice), and with different child populations (such as typically developing children and children with other types of disabilities).

The next steps of this research works include:

- Field-testing of the BEFG-ASD in other age group of children with ASD such as older children (aged 12-18) and toddlers (aged 1-3). At present, the BEFG-ASD was field-tested among parents with primary school children with ASD aged 4-11 years old. It will be useful to obtain reliable information about the rates of feeding problems, GI symptoms and the impact of these problems across different groups of children with ASD. If the study to be undertaken again, the field-testing should be conducted in a representative sample of children with ASD.

- Further field testing of the BEFG-ASD to compare feeding problems and GI symptoms among children with ASD, children with typical development, children with learning disabilities and children with other neurodisabilities or neurodevelopmental disorders (such as Cerebral Palsy and Down Syndrome) recruited in a systematic manner from community sample and across the other age range of children with ASD, and also in primary school children with ASD in mainstream school. In addition, future research should compare the utility of the BEFG-ASD in other group of children such as typically developing children. It is important to know whether all questions in the BEFG-ASD are suitable for children across the age and ability range with a wide spectrum of diagnoses, skills and needs. Such research work could provide valuable additional data and information on the psychometric properties of the BEFG-ASD but also offer the opportunity to gather systematic data across research and clinical settings with the longer-term goal of understanding these types of problems.
- In addition to identifying the total number and range of feeding problems and GI symptoms, identifying a threshold for the level of severity of the symptoms or impact for children who require referral for further assessment or investigation is also useful. In the present research, the development of possible clinical cut off scores could not be determined for feeding problems or GI symptoms, as the focus of this thesis was the development and evaluation of the psychometric properties of the BEFG-ASD. If a replicated threshold score could be identified for particular groups (or subgroups) of children, in future this information could inform professional understanding and clinical practice.
- For the present research, the BEFG-ASD and information pack were designed in English language. The utility of the questionnaire is unknown for non-English speaking community settings in different countries such as in Asian countries. Before further research can be undertaken , for instance in another country (such as Malaysia), the next step would be for the BEFG-ASD and information pack to be translated into different languages (for example Malay, Chinese and Indian language). This process would need to include both the

direct translation into the chosen language followed by an independent back-translation to ensure the accuracy of the new version and some modification of the information provided in the information pack so that it is appropriate for the new context. Once this process has been completed, field-testing among an ‘equivalent’ target population of community based professionals and parents of primary school children with ASD in those countries could be undertaken. In this way, the psychometric properties of the BEFG-ASD and the usefulness of the information pack could be evaluated in each new cultural and ethnic context.

Further research work to include the use of the BEFG-ASD within intervention evaluation research or qualitative research would help establish both the rates of these problems in children with ASD and how the impact of these types of problems may also affect the benefits of other interventions. In this way, the nature of the impact can be explored further. In the present research, food selectivity, food sensitivity, food neophobia and problematic mealtime behaviours were all correlated with the BAMBI but only food sensitivity and food neophobia were significantly correlated with the total SCQ. These findings are tantalising but not as yet straightforward to interpret. For example, it may be useful to examine further whether any particular patterns of presentation of feeding problems and GI symptoms are related to specific features or characteristics of the symptoms, and behaviours seen in individuals with ASD.

If the BEFG-ASD found to be reliable in community samples, the BEFG-ASD and information pack could be utilised by professionals working in the community in different settings (clinic or schools) alongside other assessments such as in the ASD diagnosis or learning assessment. The initial information on range of feeding problems or GI symptoms could be discussed with the parents before problems become entrenched, giving parents and professionals access to information such as further referral to child’s feeding team or other specialists.

7.6 Conclusion

The aims and specific objectives of the present research were met. The BEFG-ASD is the first questionnaire developed for use by community professionals who are working with children with ASD and their families. The findings have shown that a range of feeding problems and GI symptoms in young children with ASD (aged 4-11) was identified by various professionals in the community. In addition, professionals were also able to identify the impact of feeding problems and GI symptoms on family life using the BEFG-ASD. In this research, the majority of the ASD children had many dietary problems (between 7-21 feeding problems) and GI symptoms (between 1-8 symptoms). Findings from this research have shown that primary school children with ASD (aged 4-12) exhibit a wide range of feeding problems and GI symptoms. Parents also had reported that these problems adversely affected their family. The information on the impact of difficulties in managing feeding problems and GI symptoms among primary school children with ASD are useful to provide a better understanding about these problems.

The present research has demonstrated that it is essential to have a specific questionnaire to identify feeding problems, GI symptoms and the impact of these problems in a systematic way. Most professionals reported that the BEFG-ASD and information pack were useful and practical in their current practice. Indeed, types of feeding problems and GI symptoms in primary school children with ASD are too broad. Therefore, each problem needs to be identified as early as possible before the problem become entrenched, so that further assessments, referrals or specific treatments can be planned for the children and their families. At the start of this research, the literature review and advice from clinical and research experts identified the need for a new tool designed for use with primary school aged children with ASD aged 4 -11 years old. Following the development of the new tool (the BEFG-ASD), the preliminary findings reported in this thesis indicated that the new BEFG-ASD was found to have adequate psychometric properties when used by a range of professionals in the community in North East England. Professionals are likely to collect relevant information on feeding problems and GI symptoms.

The BEFG-ASD is the first questionnaire developed for use by community professionals. However, the BEFG-ASD has its own limitations and further refinements are possible. The usefulness of the BEFG-ASD to other groups of children is still unknown. It might be worth to compare whether the BEFG-ASD could be used in other age groups of children with ASD, or children with other disabilities. Further research and clinical practice will increase our understanding of its properties and utility in different population settings.

In conclusion, a new valid and reliable structured questionnaire for community professionals called the BEFG-ASD has been successfully developed together with an information pack. It is envisaged that the BEFG-ASD could be used by different community based professionals in UK and further afield (e.g.: Malaysia), alongside other assessment tools for children with ASD.

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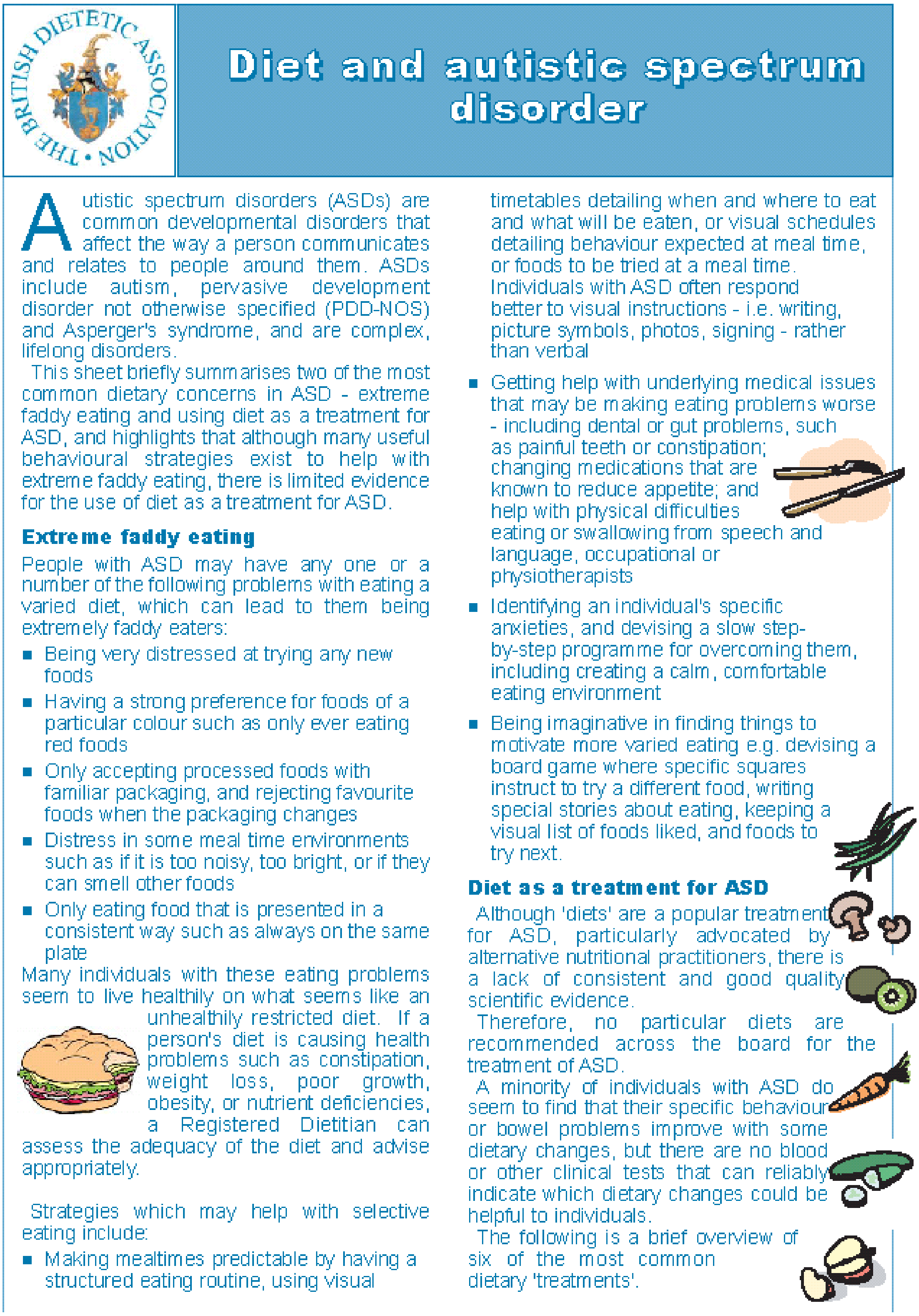
APPENDICES

Appendix 1. 'Eat Well Plate' picture

Appendix 2. Diet and ASD



THE BRITISH DIETETIC ASSOCIATION

Diet and autistic spectrum disorder

Autistic spectrum disorders (ASDs) are common developmental disorders that affect the way a person communicates and relates to people around them. ASDs include autism, pervasive development disorder not otherwise specified (PDD-NOS) and Asperger's syndrome, and are complex, lifelong disorders.

This sheet briefly summarises two of the most common dietary concerns in ASD - extreme faddy eating and using diet as a treatment for ASD, and highlights that although many useful behavioural strategies exist to help with extreme faddy eating, there is limited evidence for the use of diet as a treatment for ASD.

Extreme faddy eating

People with ASD may have any one or a number of the following problems with eating a varied diet, which can lead to them being extremely faddy eaters:

- Being very distressed at trying any new foods
- Having a strong preference for foods of a particular colour such as only ever eating red foods
- Only accepting processed foods with familiar packaging, and rejecting favourite foods when the packaging changes
- Distress in some meal time environments such as if it is too noisy, too bright, or if they can smell other foods
- Only eating food that is presented in a consistent way such as always on the same plate

Many individuals with these eating problems seem to live healthily on what seems like an unhealthily restricted diet. If a person's diet is causing health problems such as constipation, weight loss, poor growth, obesity, or nutrient deficiencies, a Registered Dietitian can assess the adequacy of the diet and advise appropriately.

Strategies which may help with selective eating include:

- Making mealtimes predictable by having a structured eating routine, using visual timetables detailing when and where to eat and what will be eaten, or visual schedules detailing behaviour expected at meal time, or foods to be tried at a meal time. Individuals with ASD often respond better to visual instructions - i.e. writing, picture symbols, photos, signing - rather than verbal
- Getting help with underlying medical issues that may be making eating problems worse - including dental or gut problems, such as painful teeth or constipation; changing medications that are known to reduce appetite; and help with physical difficulties eating or swallowing from speech and language, occupational or physiotherapists
- Identifying an individual's specific anxieties, and devising a slow step-by-step programme for overcoming them, including creating a calm, comfortable eating environment
- Being imaginative in finding things to motivate more varied eating e.g. devising a board game where specific squares instruct to try a different food, writing special stories about eating, keeping a visual list of foods liked, and foods to try next.

Diet as a treatment for ASD

Although 'diets' are a popular treatment for ASD, particularly advocated by alternative nutritional practitioners, there is a lack of consistent and good quality scientific evidence.

Therefore, no particular diets are recommended across the board for the treatment of ASD.

A minority of individuals with ASD do seem to find that their specific behaviour or bowel problems improve with some dietary changes, but there are no blood or other clinical tests that can reliably indicate which dietary changes could be helpful to individuals.

The following is a brief overview of six of the most common dietary 'treatments'.

Appendix 2. Diet and ASD

Exclusion diets or food avoidance

1. Gluten-free and casein-free (GFCF) diet

Involves: Avoiding gluten - a protein contained in wheat, barley and rye, and a similar protein in oats. Bread, pizza, pasta, pastry, biscuits, some breakfast cereals, and some processed foods contain gluten. Plus avoiding casein - a protein in cow's milk and similar proteins in goat's and sheep's milk. Yogurt, cheese, butter, some margarines, ice-cream, milk chocolate, biscuits, and some processed products contain casein.

The theory: People with ASD have a gut which is abnormally 'leaky', creating an intolerance to these proteins which affects mental function, and influences behaviour.

The evidence: Well-respected independent reviews of the evidence have found the evidence inconclusive. There is evidence that supports and refutes the use of this diet.

2. Exclusion of food additives

Involves: Avoiding a wide range of food additives, which commonly include colourings (E100-E199), the flavour enhancer monosodium glutamate (MSG, E621), the sweetener aspartame (E951), flavourings (not given E-numbers), benzoate preservatives (E210-219) and caffeine.

The theory: That people with ASD are intolerant to these additives, which affects their behaviour.

The evidence: There is no evidence that people with ASD should avoid food additives. All food additives are regulated by the government for safe use in the UK, but some people show intolerance to individual or groups of food additives numbers.

3. Exclusion of phenolic compounds and foods high in salicylates

Involves: Exclusion of a wide range of foods including cheese, chocolate, tomatoes, oranges, bananas, yeast extract, some food colourings and many other fruits and vegetables.

The theory: That some individuals lack the enzymes needed to break down compounds in these foods, affecting symptoms of ASD.

The evidence: There is no evidence to suggest that avoiding these foods is beneficial.

4. Yeast-free diet

Involves: There is no standard 'yeast free' diet, but it often excludes natural and refined sugars (including fruit), fermented foods such as breads, vinegar, alcohol, cheese, soy sauce, coffee and processed meats.

The theory: Eating less yeast and sugar reduces the growth of yeasts in the gut, which in theory make the gut more leaky and make an individual suffer from intolerances.

The evidence: Yeast overgrowth in the gut is usually treated by prescribed medications, and there is no evidence that eating less sugar and dietary yeasts (which are not the same as gut yeasts) helps.

Supplements

5. High doses of vitamin B6 and magnesium

The theory: Individuals with ASD have an abnormal vitamin B6 metabolism, and so need high doses to correct this.

The evidence: There is some weak evidence for improvement in ASD behaviour following high doses of vitamin B6 and magnesium, but well respected independent reviews of the evidence have found the evidence inconclusive.

6. Fish oil and other fat supplements rich in omega 3 fats

The theory: Omega 3 fats improve cell membranes in the brain, and improve some aspects of brain function.

The evidence: There is some evidence that omega 3 fat supplements improve other neurodevelopmental disorders such as mood disorders, learning difficulties and developmental coordination disorder, but none specifically for ASD. There are no studies showing whether longer term use of fish oils maintains these changes, or carries any health risks not yet identified. More studies are needed to see whether these effects are greater than achieved by eating a healthy diet containing fish as recommended for the general population.

Appendix 2. Diet and ASD

The drawbacks of using diet as a treatment for ASD

- Although the perception is that dietary change is much safer than the use of medications, excluding foods without making sure the diet stays balanced can cause dietary deficiencies, weight loss and poor growth. The risks increase as more foods are excluded, and children who are extreme faddy eaters can be at high risk of having an inadequate diet.
- Taking individual vitamins or minerals at high doses can sometimes be harmful. The levels of vitamin B6 recommended are often above the recommended upper safe dose. These levels have been linked to nerve damage in a small number of people, and there is a particular risk that some individuals with ASD do not feel pain or aren't able to communicate that they are feeling pain, so would not recognise the tingling which could warn of nerve damage.
- For individuals who find change very upsetting, dietary changes may be hard to achieve, even slight changes such as taking capsules.
- Supplements and dietary changes can be costly.

It is always best to discuss treatment changes with a doctor.

The role of a Registered Dietitian in diet and ASD

Registered Dietitians can provide tailored, holistic advice and support on achieving a healthy, balanced diet including the use of vitamins and minerals to supplement a diet if needed, and can support individuals with ASD who decide to try diet as a treatment. Registered Dietitians work in the NHS and privately, liaising with other health and education professionals where needed.

Ask your family doctor for a referral to a local dietitian or find a freelance dietitian in your area through www.dietitiansunlimited.co.uk.

For more information about ASD: National Autistic Society www.nas.org.uk

To find a private dietitian: www.dietitiansunlimited.co.uk

For Government advice on the recommended and safe doses of vitamins and minerals: www.eatwell.gov.uk

Further information about diet and ASD visit www.nutritionnutrition.com

Written by Zoe Connor, specialist paediatric dietitian, on behalf of Dietitians' Autistic Spectrum Interest Group (DASIG)

This Food Factsheet is a public service of The British Dietetic Association intended for information only. It is not a substitute for proper medical diagnosis or dietary advice given by a Registered Dietitian (RD). To check that your dietitian is Registered check www.hpc-uk.org.
Other Food Factsheets are available from www.bda.uk.com.
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Appendix 3. Food and Mood

Food and Mood

We all have good days and bad days; we all have foods we like more, or like less. But is there a connection between feeling fine and the foods we have eaten? Do some foods make us feel grumpy? Is it possible to plan a diet for a good mood?

Vitamins and minerals

When diets are very limited and inadequate, and result in deficiency states, effects on mood and brain function are well documented. Anaemia (low levels of haemoglobin in blood) can occur due to inadequate intakes of iron, which results in feeling weak, tired and lethargic all the time. This can be treated with iron supplements. The risk of anaemia is reduced with the regular intake of red meat and fish, and can also be helped with avoiding tea drinking with meals.

Deficiency of the B vitamins thiamin and niacin causes mood problems including fatigue, and feeling depressed or irritable.

Low intakes of some micronutrients may also affect mood. Studies have suggested that not having enough of the vitamin folate can increase the chances of feeling depressed, and this may be particularly important in older people. Folate is found in liver, green vegetables, oranges and other citrus fruits, beans and in fortified foods such as yeast extract and breakfast cereals; folic acid tablets are also effective.

Intakes of selenium in the UK have been in decline in recent years, and are often below the recommended levels. Some studies have shown that this may increase the incidence of depression and other negative mood states. A supplement may help improve mood in some people not getting enough selenium from foods. Good food sources of selenium include Brazil nuts, meat, fish and eggs.

Where there is the suspicion that intakes of one or several vitamins/minerals is inadequate, the use of supplements at safe levels can be an effective treatment strategy; in the longer-term, however, looking at eating more of particular foods rich in a nutrient is usually the best way to support good long term health.

Carbohydrate

The glucose in our blood comes from the carbohydrates we eat (both from sugars and starches) and is needed to fuel muscles and for the brain. Not having enough glucose in blood (hypoglycaemia) makes us feel weak and tired and 'fuzzy minded'; this may happen when not enough food is eaten, and is a particular risk for diabetics and sports people. Having enough glucose in blood is the basis for the advice to eat breakfast and to consume regular meals containing some carbohydrate throughout the day; the ability to concentrate and focus comes from the adequate supply of energy to the brain.

However, once blood glucose is in the normal range there does not seem to be any improvement in mood or ability to concentrate with further increases in glucose, that is with eating more or different types of carbohydrate.

There is a messenger chemical in the brain called serotonin, which improves mood and how we feel. More serotonin is made when more of an amino acid called tryptophan enters the brain, and some researchers claim that this happens from eating foods that are high in carbohydrate and low in protein. This theoretical 'carbohydrate craving" to improve mood has been used to explain the eating of sweet comfort foods such as cakes and chocolate; in practice there is not enough evidence to support this effect.

Do some foods contain substances that are 'drug-like'?

Caffeine, found in coffee and cola drinks, acts as a stimulant and can improve alertness and feelings of energy, and counter the effects of fatigue. Too much caffeine may cause the adverse effects of irritability and headache.

Suggestions that chocolate contains particular mood-enhancing substances are often made, but measured pharmacological effects do not seem to explain the popularity of this food as a comforter.

Feeling ok or feeling fantastic?

There are many ways that foods can affect how we feel, just as how we feel has a large influence on what foods we choose. Some of the mood/food effects are due to nutrient content, but a lot of effects are due to prevalent associations of foods with pleasure and reward (chocolate) or diet and deprivation (plain foods). Some foods have religious, economic and cultural significance which will influence how we feel when eating them. Feeling good comes from a diet that provides adequate amounts of carbohydrate at regular times to keep blood glucose levels stable, and that contains a wide variety of protein and vitamin and mineral containing foods that support the many vital functions of the body. Plenty of fruits and vegetables and wholegrain cereal foods, with some protein foods will support a good supply of nutrients for good health and good mood.

By Ursula Arens, Dietitian

This Food Fact sheet is a public service of The British Dietetic Association intended for information only.
It is not a substitute for proper medical diagnosis or dietary advice given by adietitian.
To check that your dietitian is registered check www.hpc-uk.org.
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Appendix 4. Diet, behaviour and learning disabilities

THE BRITISH DIETETIC ASSOCIATION

Diet, Behaviour and Learning in Children

Reports in the media often tell us that changing a child's diet can improve their behaviour, improve their concentration, and even make them more intelligent.

Unfortunately there are no magic nutritional pills to take, but the evidence suggests that enjoying regular meals and a healthy balanced diet helps a child to have the best chance at optimal mental and behavioural performance. Regular physical activity or exercise is equally important - aim for at least an hour a day.

The basics of a healthy diet for children:

- 3 meals a day - breakfast, lunch and dinner with 1 or 2 snacks as well, if needed
- A variety of fruit and vegetables - offer at least 5 portions a day (a child's portion of fresh fruit or vegetables is about the size of their fist)
- For calcium - 3 servings a day of dairy foods such as milk, cheese or yogurt. Other calcium-rich foods include calcium-fortified soya milk, sesame seeds, kidney beans, haricot beans, almonds, brazil nuts, canned sardines or pilchards, figs and spinach
- Starchy carbohydrate foods at each meal (cereals, potatoes, rice, bread, pasta, noodles, yam, etc) - and offering wholegrain varieties sometimes
- For protein and iron, eat some meat, fish, poultry, beans, lentils, eggs or soya every day
- Limit sugary and fatty foods such as soft drinks, sweets, chocolate, crisps, biscuits and fried food
- Keep well hydrated by drinking plenty of fluids - ideally about 6-8 cups a day - water or milk are best for the teeth

What about fish, fish oils and omega-3 fatty acids?

For their bodies to get enough of the healthy fats called omega-3 fatty acids, it is recommended that children eat 2 portions of fish a week including one serving of oily fish such as mackerel, kippers, pilchards, trout, salmon, sardines, herring or fresh tuna (omega 3 fatty acids are extracted from canned tuna during processing in the UK). Other sources of omega-3 fatty acids are:

- Breast milk and most infant formulas
- Dark green leafy vegetables
- Wholegrain cereal products such as granary bread
- Some nuts and seeds - linseeds/flax, walnuts, pecans, peanuts and almonds (to avoid choking in under fives give chopped rather than whole nuts)
- Some brands of eggs, margarines, milks and bread which are specifically enriched with omega 3 fatty acids
- Some vegetable oils - rapeseed/canola oil, linseed/flax oil, walnut oil and soya oil

Researchers are investigating whether taking omega-3 fatty acid supplements could help with concentration, and learning problems such as dyslexia and autistic spectrum disorders (ASD). The results of the research to date are inconclusive.

If giving omega-3 fatty acid supplements to a child consider:

- Whether they are suitable for the age of your child (check on the packaging)
- Whether the amount of vitamin A in them (combined with any other supplements given) is safe - the safe upper limits for infants is 0.3mg/day, for 1-3 years 0.6mg/day, for 4-6 years 0.9mg/day, 6-12 years 1.4mg/day and 12-18 years 1.8mg/day
- If they are safe to take if the child is on medication or has a medical condition such as epilepsy or haemophilia - consult a doctor
- Whether they been purified to reduce the harmful pollutants sometimes found in fish oils
- Some researchers think that high doses of supplements need to be taken daily for 3 months for their effects, if any, to be seen

How about other vitamins and minerals?

If a child is eating a balanced diet as described above, there is not usually any need to take additional vitamin or mineral supplements. However, for under-fives, a daily supplement of vitamins A, C and D is recommended – these are available under the 'Healthy Start programme.

Iron-deficiency is common in children and young

Appendix 4. Diet, behaviour and learning disabilities

people, causing tiredness and therefore affecting concentration and mood. Iron-deficiency can be prevented by eating plenty of iron-rich foods such as red meat, fish, eggs, nuts, seeds, beans, green vegetables, dried fruit and fortified breakfast cereals. A family doctor can test blood for iron-deficiency, and prescribe a short course of iron supplements if necessary.

What about food allergies and intolerances?

Some children find that particular foods or drinks make them 'hyperactive', disruptive or irritable. For some it is a particular food, for others, stimulants such as caffeine which is found in energy drinks and chocolate, or others a particular food additive or E-number.

One research study found that giving a large group of healthy preschool children a drink containing a number of additives (the colourings sunset yellow (E110), tartrazine (E102), carmoisine (E122), and ponceau 4R (E124) and the preservative sodium benzoate (E211)) caused an increase in 'hyperactive behaviour' in some children compared to when given they were given a drink without these additives in, although this study was not conclusive and research is ongoing.

Unfortunately there are no tests available on the NHS or privately that reliably indicate which foods or additives an individual may be 'intolerant' to in this way.

The most reliable way to investigate whether a child has a food intolerance is first to follow a healthy diet as described above, then to keep a diary of the foods and drinks the child has eaten, plus a diary of their behaviour throughout the day. Looking back on this diary over a period of weeks can highlight if there are particular foods or drinks regularly eaten or drunk just before times when behaviour is worse, or indeed if the behaviour is related to anything else.

The next step is to remove from the diet, any food suspected to be causing problems. After a couple of weeks give the child the food to eat regularly again. Suspect an intolerance if there was both an improvement in their behaviour or symptoms while the food was avoided, and the symptoms reappeared after they ate the food again.

Before cutting a nutritious food or food group out of a child's diet in the long-term, it is best to weigh up the benefits of avoiding a food with the impact avoiding a food would have on the child's lifestyle and nutritional intake. It is advisable to seek support from a registered dietitian, who can advise on maintaining a varied and nutritionally balanced diet.

Finding a Dietitian...

Registered Dietitians can provide tailored, holistic advice and support on achieving a optimally healthy, balanced diet including the use of vitamins and minerals to supplement a diet if needed, Registered Dietitians work in the NHS and privately, liaising with health and education professionals where needed. To be referred to an NHS dietitian, contact your family doctor.

To find a private dietitian visit: www.dietitiansunlimited.co.uk

For further information on healthy eating at all ages visit www.eatwell.gov.uk

This Food Fact sheet is a public service of The British Dietetic Association intended for information only.
It is not a substitute for proper medical diagnosis or dietary advice given by a dietitian.
To check that your dietitian is registered check wwwhpc-uk.org.
Other Food Fact sheets are available from www.bda.uk.com
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Appendix 5. List of useful websites for parents

LIST OF USEFUL RESOURCES ON AUTISM SPECTRUM DISORDERS

NO	RESOURCE AND WEBSITE	BRIEF DESCRIPTIONS
1.	**The National Autistic Society (NAS)** http://www.nas.org.uk/	This website provides information on Autism, Asperger Syndrome, activities, publications and useful services for parents or families.
2.	**Research Autism** http://www.researchautism.net	This website provides useful information on the evidence-based interventions for ASD.
3.	**Database of children with Autism Spectrum Disorder living in the North East England (Dasl^{n}e)** http://www.ncl.ac.uk/daslne http://www.ncl.ac.uk/daslne/newsletters.htm	Dasl^{n}e provides useful information on the database of more than 700 children with ASD living in North East England. The website has information for parents and families including the event/conference, data summaries, research update, newsletters and other information. The newsletters can be downloaded from the link and contains various topics on sleep, eating, anxiety and research updates. It also has useful contact for the Dasl^{n}e Parent Advisory Group.
4.	**The British Dietetic Association (BDA)** http://www.bda.uk.com/foodfacts/index.html	This website provides links on food facts topic related to ASDs such as 'Diet and ASD, 'Diet, behaviour and learning difficulties and 'Food and Mood'. Parents can access other information on food labelling, health claims and healthy eating for their children.
5.	**National library for Health – NHS** http://www.cks.library.nhs.uk http://www.cks.library.nhs.uk/patient_information_leaflet/diarrhoea http://www.cks.library.nhs.uk/patient_information_leaflet/constipation	This website provides general information on various health topics and is a source of evidence-based information on common conditions managed in the primary care setting.
6.	**Contact a Family- for families with disabled children (Cafamily)** http://www.cafamily.org.uk	This website provides support and information for parents with disabled children. There is a wide range of publications and stories from parents that are useful for families and professionals.
7.	**Brain & Body Nutrition** http://www.brainandbody.co.uk	This website provides up-to-date information about diet and ASD. It is a useful resource for professionals and parents/carers of children with ASD and ADHD. Various topics are covered in this website and it is regularly updated.

Appendix 6. Review format for the Delphi technique Version 1 (First Round)

REVIEW FORMAT (FIRST- VERSION 1)

THE BEFG -ASD

The Brief structured questionnaire for the Early identification of Feeding problems and Gastrointestinal symptoms in primary school children with Autism Spectrum Disorders (ASD) and the impact of these problems on family life

Appendix 6. Review format for the Delphi technique Version 1 (First Round)

GENERAL INFORMATION

- The purpose of the review is to get an opinion from you about the BEFG-ASD. The **BEFG-ASD** is a **B**rief structured questionnaire for the **E**arly identification of **F**eeding problems and **G**astrointestinal symptoms of school children with **Autism Spectrum Disorders (ASD)** and the impact of these problems to family life.

- The new instrument is designed for professionals to use with parents/caregivers of **children with ASDs aged 4 -11 years** when there are concerns about feeding problems or gastrointestinal (GI) symptoms. Alongside the instrument, there is an information pack containing dietary information sheet (adapted from the British Dietetic Association/National Dietitian In Autism Group) and list of websites about ASD.

- The BEFG-ASD has three sections:

    - **A: Feeding problems**
    - **B: GI symptoms**

    - **C: Impact on family life**

- Please refer to the draft of the BEFG-ASD and information pack when you are answering the form below. For each section please choose one of the categories: **'1- very important, 2- important, 3- less important, 4- not important, 5-not sure/don't know when scoring each question.**

- Please circle your chosen option. You can write any comments in the end of feedback column provided.
- **Thank you for helping me develop this instrument**

Appendix 6. Review format for the Delphi technique Version 1 (First Round)

SECTION A- FEEDING PROBLEMS

Instruction: Please circle your chosen option.

No	**Section A (from the BEFG-ASD)**	**very important question**	**important question**	**less important question**	**not important question**	**not sure/ don't know**	**Comment/Feedback**
Q1	In the last 3 months, is there any food that your family regular eats that your child refuses to eat?	1	2	3	4	5	
Q2	Does your child insist on eating similar foods for most meals?	1	2	3	4	5	
Q3	Do you have to **prepare special foods** for your child (compared with other family members) in the last 3 months?	1	2	3	4	5	
Q4	Does your child insist that most of his/her foods has **particular physical characteristics** in the last 3 months ?(e.g.:smell, certain shape, colour, temperature, brand or packaging)	1	2	3	4	5	
Q5	Does your child have a strong preference for foods with **particular textures**? (e.g.: soft/ hard/ lumpy/ crunchy foods)	1	2	3	4	5	
Q6	Does your child have a strong preference for foods with **particular flavours**? (e.g.: salty/ spicy/ sweet/ sour foods)	1	2	3	4	5	
Q7	Does your child insist that his/her food is **served in a particular way**?	1	2	3	4	5	

Appendix 6. Review format for the Delphi technique Version 1 (First Round)

No	Question (from the BEFG-ASD)	very important question	important question	less important question	not important question	not sure/ don’t know	Comment/Feedback
Q8	Does your child insist that he/she uses specific utensils or crockery for eating or drinking?	1	2	3	4	5	
Q9	Has your child insisted that his/her food is cooked by a certain person?	1	2	3	4	5	
Q10	Has your child insisted on eating his/her meals in the same place?	1	2	3	4	5	
Q11	Has your child refused to eat with family members during mealtimes?	1	2	3	4	5	
Q12	Has your child shown any of the following behaviours during mealtimes at least once a week in the last 3 months? e.g.: kicking, hitting, shouting, scratching others, spitting out food)	1	2	3	4	5	
Q13	Has your child shown any self- injurious behaviour during mealtimes at least once a week? (such as. biting self, hitting self)	1	2	3	4	5	
Q14	Has your child had any disruptive behaviours during mealtimes at least once a week? (e.g. pushing/throwing utensils/ throwing food)	1	2	3	4	5	
Q15	Has your child ever appeared frightened/ fearful of trying to eat new or unfamiliar foods ?(e.g.:child seems fearful of swallowing food or shows signs of choking	1	2	3	4	5	

Appendix 6. Review format for the Delphi technique Version 1 (First Round)

No	Section A (from the BEFG-ASD)	very important question	important question	less important question	not important question	not sure/ don't know	Comment/Feedback
Q16	Does your child show craving for any non-food items? (e.g. paper, wood, plastic)	1	2	3	4	5	
Q17	Have you used any medically prescribed special diet as part of your child's treatment in the last 3 months? (e.g. gluten free casein free diet, yeast free diet, diet for allergy)	1	2	3	4	5	
Q18	Do you give any vitamin, mineral or other supplements to your child in the last 3 months?	1	2	3	4	5	
Q19	Do you avoid giving your child any particular foods?	1	2	3	4	5	
Q20	Have you received any advice from health professionals on managing feeding or any aspect of your child's diet?	1	2	3	4	5	

PLEASE PROCEED TO SECTION B

Appendix 6. Review format for the Delphi technique Version 1 (First Round)

SECTION B- GASTROINTESTINAL SYMPTOMS

Instruction: Please circle your chosen option.

No	Section B (from the BEFG-ASD)	very important question	important question	less important question	not important question	not sure/ don't know	Comment/Feedback
Q1	In the last 3 months, has your child suffered from constipation (defined as bowel motion/passage less than 2 times a week)?	1	2	3	4	5	
Q1.1	If yes, does he/she say it hurts to open his bowels?	1	2	3	4	5	
Q1.2	Please describe what you noticed about his/her stool/ faeces/poo (e.g. hard poo, pellet-like poo, bloody poo)	1	2	3	4	5	
Q1.3	Has your child had any 'accidents' with his/her bowels (in opening his/her bowels) in the last 3 months?	1	2	3	4	5	
Q1.4	In the last 3 months, have you used any laxatives to treat his/her constipation?	1	2	3	4	5	
Q2	In the last 3 months, has your child shown or complained about diarrhoea (which is bowel motion /passage of 2-5 times per day)?	1	2	3	4	5	
Q2.1	If yes, please describe what you noticed about his/her stool/ faeces/ poo.(e.g. loose poo, mucousy poo, bloody poo)	1	2	3	4	5	

Appendix 6. Review format for the Delphi technique Version 1 (First Round)
PART B- GASTROINTESTINAL SYMPTOMS
Instruction: Please circle your chosen option.

No	**Section B (from the BEFG-ASD)**	**very important question**	**important question**	**less important question**	**not important question**	**not sure/ don't know**	**Comment/ Feedback**
Q2.2	Do you use any medication to treat his/her diarrhoea?	1	2	3	4	5	
Q3	In the last 3 months, has your child shown or complained about abdominal pain (more than 3 times a week)?	1	2	3	4	5	
Q3.1	Does the abdominal pain disrupt daily activity of your child? (eg: stopping child from playing, sleeping or going to school)	1	2	3	4	5	
Q3.2	Do you use any medication to treat his/her abdominal pain?	1	2	3	4	5	
Q4	In the last 3 months, has your child shown or complained about vomiting (at least once week)?	1	2	3	4	5	
Q4.1	If yes, is it related to meals?	1	2	3	4	5	
Q4.2	How much does she/he vomits?(e.g. great amount/quite a lot/a bit) …………	1	2	3	4	5	
Q4.3	What does` the vomits look like? (e.g.: green, brown or red colour(with blood)	1	2	3	4	5	

Appendix 6. Review format for the Delphi technique Version 1 (First Round)

No	Section B (from the BEFG-ASD)	very important question	important question	less important question	not important question	not sure/ don’t know	Comment/Feedback
Q5	In the last 3 months, has your child lost weight?	1	2	3	4	5	
Q5.1	If yes, how much is the weight loss?	1	2	3	4	5	
Q5.3	Did you worry about his/her weight loss?	1	2	3	4	5	

PLEASE PROCEED TO SECTION C

Appendix 6. Review format for the Delphi technique Version 1 (First Round)

SECTION C- THE IMPACT ON FAMILY LIFE

Instruction: Please circle your chosen option.

No	Section C (from the BEFG-ASD)	very important question	important question	less important question	not important question	not sure/ don't know	Comment/Feedback
Q1	Has your child's feeding problems affected the financial aspects of the family?	1	2	3	4	5	
Q2	Do you think that the feeding problems restrict your social life in any way?	1	2	3	4	5	
Q3	Do you think that the demands of managing feeding problems of your child have placed any extra stress on you?	1	2	3	4	5	
Q4	Has your child's gut problems affected the financial aspects of the family?	1	2	3	4	5	
Q5	Do you think that the gut problems restrict your social life in any way?	1	2	3	4	5	
Q6	Do you think that the demands of managing gut problems of your child have placed any extra stress on you?	1	2	3	4	5	

PLEASE PROCEED TO INFORMATION PACK

Appendix 6. Review format for the Delphi technique Version 1 (First Round)

THE INFORMATION PACK

Instruction: Please circle your chosen option.

No		**very important**	**important**	**less important**	**not important**	**not sure/ don't know**	**Comment/Feedback**
S1	Food plate –eat well picture	1	2	3	4	5	
S2	Diet and Autism Spectrum Disorder – information sheet	1	2	3	4	5	
S3	Diet, Behaviour and Learning in Children – Information sheet	1	2	3	4	5	
S4	Food and Mood - Information sheet	1	2	3	4	5	
S5	List of useful websites about ASD	1	2	3	4	5	

ADDITIONAL COMMENT:

……

……

Appendix 7. Review format for the Delphi technique Version 2 (Second Round)

PR-		

REVIEW FORMAT (SECOND-VERSION 2)

THE BEFG -ASD

The Brief structured questionnaire for the Early identification of Feeding problems and Gastrointestinal symptoms in primary school children with Autism Spectrum Disorders (ASD) and the impact of these problems on family life

Appendix 7 Review format for the Delphi technique Version 2 (Second Round)

GENERAL INFORMATION

- The purpose of the review is to get an opinion from you about the BEFG-ASD. The **BEFG-ASD** is a **B**rief structured questionnaire for the **E**arly identification of **F**eeding problems and **G**astrointestinal symptoms of school children with **Autism Spectrum Disorders (ASD)** and the impact of these problems to family life.

- The new instrument is designed for professionals to use with parents/caregivers of **children with ASDs aged 4 -11 years** when there are concerns about feeding problems or gastrointestinal (GI) symptoms. Alongside the instrument, there is an information pack containing dietary information sheet (adapted from the British Dietetic Association/National Dietitian In Autism Group) and list of websites about ASD.

- The BEFG-ASD has three sections:
    - **A: Feeding problems**
    - **B: GI symptoms**
    - **C: Impact on family life**

- Please refer to the draft of the BEFG-ASD and information pack when you are answering the form below. For each section please choose one of the categories: **'1- very important, 2- important, 3- less important, 4- not important, 5-not sure/don't know when scoring each question.**

- Please circle your chosen option. You can write any comments in the end of feedback column provided.

- **Thank you for helping me develop this instrument.**

Appendix 7. Review format for the Delphi technique Version 2 (Second Round)
SECTION A- FEEDING PROBLEMS

Instruction: Please circle your chosen option.

No	**Section A (from the BEFG-ASD)**	**very important question**	**important question**	**less important question**	**not important question**	**not sure/ don’t know**	**Comment/Feedback**
Q1	In the last 3 months, is there any food that your family regular eats that your child refuses to eat?	1	2	3	4	5	
Q2	Does your child insist on eating similar foods for most meals?	1	2	3	4	5	
Q3	Do you have to **prepare special foods** for your child (compared with other family members) in the last 3 months?	1	2	3	4	5	
Q4	Does your child insist that most of his/her foods has **particular physical characteristics** in the last 3 months ?(e.g.:smell, certain shape, colour, temperature, brand or packaging)	1	2	3	4	5	
Q5	Does your child have a strong preference for foods with **particular textures**? (e.g.: soft/ hard/ lumpy/ crunchy foods)	1	2	3	4	5	
Q6	Does your child have a strong preference for foods with **particular flavours**? (e.g.: salty/ spicy/ sweet/ sour foods)	1	2	3	4	5	
Q7	Does your child insist that his/her food is **served in a particular way**?	1	2	3	4	5	

Appendix 7. Review format for the Delphi technique Version 2 (Second Round)

No	Question (from the BEFG-ASD)	very important question	important question	less important question	not important question	not sure/ don’t know	Comment/Feedback
Q8	Does your child insist that he/she uses specific utensils or cutlery for eating or drinking?	1	2	3	4	5	
Q9	Does your child have control of cutlery while eating or drinking?	1	2	3	4	5	
Q10	Has your child insisted that his/her food is cooked by a certain person?	1	2	3	4	5	
Q11	Has your child insisted that his/her food is served by a certain person?	1	2	3	4	5	
Q12	Has your child insisted on eating his/her meals in the same place?	1	2	3	4	5	
Q13	Has your child refused to eat with family members during mealtimes?	1	2	3	4	5	
Q14	Has your child shown any of the following behaviours during mealtimes at least once a week in the last 3 months? e.g.: kicking, hitting, shouting, scratching others, spitting out food)	1	2	3	4	5	
Q15	Has your child shown any self- injurious behaviour during mealtimes at least once a week? (such as. biting self, hitting self)	1	2	3	4	5	
Q16	Has your child had any disruptive behaviours during mealtimes at least once a week? (e.g. pushing/throwing utensils/ throwing food)	1	2	3	4	5	
Q17	Has your child ever appeared reluctant of trying to eat new or unfamiliar foods ?(e.g.: child seems fearful of swallowing food or shows signs of choking)	1	2	3	4	5	

Appendix 7. Review format for the Delphi technique Version 2 (Second Round)

No	Section A (from the BEFG-ASD)	very important question	important question	less important question	not important question	not sure/ don't know	Comment/Feedback
Q18	Does your child show craving for any non-food items? (e.g. paper, wood, plastic)	1	2	3	4	5	
Q19	Have you used any medically prescribed special diet as part of your child's treatment in the last 3 months? (e.g. gluten free casein free diet, yeast free diet, diet for allergy)	1	2	3	4	5	
Q20	If yes, who give the advice on how to proceed with the special diet? (e.g. dietitian/ paediatrician/other health professionals)	1	2	3	4	5	
Q21	Do you give any vitamin to your child in the last 3 months?	1	2	3	4	5	
Q22	If yes, what type of vitamin?	1	2	3	4	5	
Q23	Do you give any mineral or other supplement to your child in the last 3 months?	1	2	3	4	5	
Q24	Do you avoid giving your child any particular foods?	1	2	3	4	5	
Q25	If yes, why you avoid that particular food?	1	2	3	4	5	
Q26	Have you received any advice from health professionals on managing feeding or any aspect of your child's diet?	1	2	3	4	5	
Q27	If yes, who give the advice?	1	2	3	4	5	
Q27	What type of advice given by the professional?	1	2	3	4	5	

Appendix 7. Review format for the Delphi technique Version 2 (Second Round)

SECTION B- GASTROINTESTINAL SYMPTOMS

Instruction: Please circle your chosen option.

No	Section B (from the BEFG-ASD)	very important question	important question	less important question	not important question	not sure/ don't know	Comment/Feedback
Q1	In the last 3 months, has your child suffered from constipation (defined as bowel motion/passage less than 2 times a week)?	1	2	3	4	5	
Q1.1	If yes, does he/she say it hurts to open his bowels?	1	2	3	4	5	
Q1.2	Please describe what you noticed about his/her stool/ faeces/poo (e.g. hard poo, pellet-like poo, bloody poo)	1	2	3	4	5	
Q1.3	Has your child had any 'accidents' with his/her bowels (in opening his/her bowels) in the last 3 months?	1	2	3	4	5	
Q1.4	In the last 3 months, have you used any laxatives to treat his/her constipation?	1	2	3	4	5	
Q1.5	If yes, what type of laxative that you used to treat his/her constipation?	1	2	3	4	5	
Q2	In the last 3 months, has your child shown or complained about diarrhoea (which is bowel motion /passage of 2-5 times per day)?	1	2	3	4	5	
Q2.1	If yes, please describe what you noticed about his/her stool/ faeces/ poo.(e.g. loose poo, mucousy poo, bloody poo)	1	2	3	4	5	

Appendix 7. Review format for the Delphi technique Version 2 (Second Round)

SECTION B- GASTROINTESTINAL SYMPTOMS

Instruction: Please circle your chosen option.

No	Section B (from the BEFG-ASD)	very important question	important question	less important question	not important question	not sure/ don’t know	Comment/Feedback
Q2.2	Do you use any medication to treat his/her diarrhoea?	1	2	3	4	5	
Q.2.3	If yes, what type of medication given to treat his/her diarrhoea?	1	2	3	4	5	
Q3	In the last 3 months, has your child shown or complained about abdominal pain (more than 3 times a week)?	1	2	3	4	5	
Q3.1	Does the abdominal pain disrupt daily activity of your child? (eg: stopping child from playing, sleeping or going to school)	1	2	3	4	5	
Q3.2	Do you use any medication to treat his/her abdominal pain?	1	2	3	4	5	
Q4	In the last 3 months, has your child shown or complained about vomiting (at least once week)?	1	2	3	4	5	
Q4.1	If yes, is it related to meals?	1	2	3	4	5	

Appendix 7. Review format for the Delphi technique Version 2 (Second Round)

No	**Section B (from the BEFG-ASD)**	**very important question**	**important question**	**less important question**	**not important question**	**not sure/ don't know**	**Comment/Feedback**
Q4.2	How much does she/he vomits?(e.g. great amount/quite a lot/a bit) ………………………………………….	1	2	3	4	5	
Q4.3	What does` the vomits look like? (e.g.: green, brown or red colour(with blood)	1	2	3	4	5	
Q5	In the last 3 months, has your child refused to go to the toilet?	1	2	3	4	5	
Q5.1	If yes, has she/he shown any of this behaviour? (e.g. lying on floor, sweating or gripping with pain?)	1	2	3	4	5	
Q5	In the last 3 months, has your child lost weight?	1	2	3	4	5	
Q5.1	If yes, how much is the weight loss?	1	2	3	4	5	
Q5.3	Did you worry about his/her weight loss?	1	2	3	4	5	

Appendix 7. Review format for the Delphi technique Version 2 (Second Round)

SECTION C- THE IMPACT ON FAMILY LIFE

Instruction: Please circle your chosen option.

No	**Section C (from the BEFG-ASD)**	**very important question**	**important question**	**less important question**	**not important question**	**not sure/ don't know**	**Comment/Feedback**
Q1	Has your child's feeding problems affected the financial aspects of the family?	1	2	3	4	5	
Q2	Do you think that the feeding problems restrict your social life in any way?	1	2	3	4	5	
Q3	Do you think that the demands of managing feeding problems of your child have placed any extra stress on you?	1	2	3	4	5	
Q4	Has your child's gut problems affected the financial aspects of the family?	1	2	3	4	5	
Q5	Do you think that the gut problems restrict your social life in any way?	1	2	3	4	5	
Q6	Do you think that the gut problems restrict your social life in any way?	1	2	3	4	5	

PLEASE PROCEED TO INFORMATION PACK

Appendix 7. Review format for the Delphi technique Version 2 (Second Round)

THE INFORMATION PACK

Instruction: Please circle your chosen option.

No		very important	important	less important	not important	not sure/ don’t know	Comment/Feedback
S1	Food plate –eat well picture	1	2	3	4	5	
S2	Diet and Autism Spectrum Disorder – information sheet	1	2	3	4	5	
S3	Mood and Behaviour – Information sheet	1	2	3	4	5	
S4	Managing eating - Information sheet	1	2	3	4	5	
S5	List of useful websites about ASD	1	2	3	4	5	

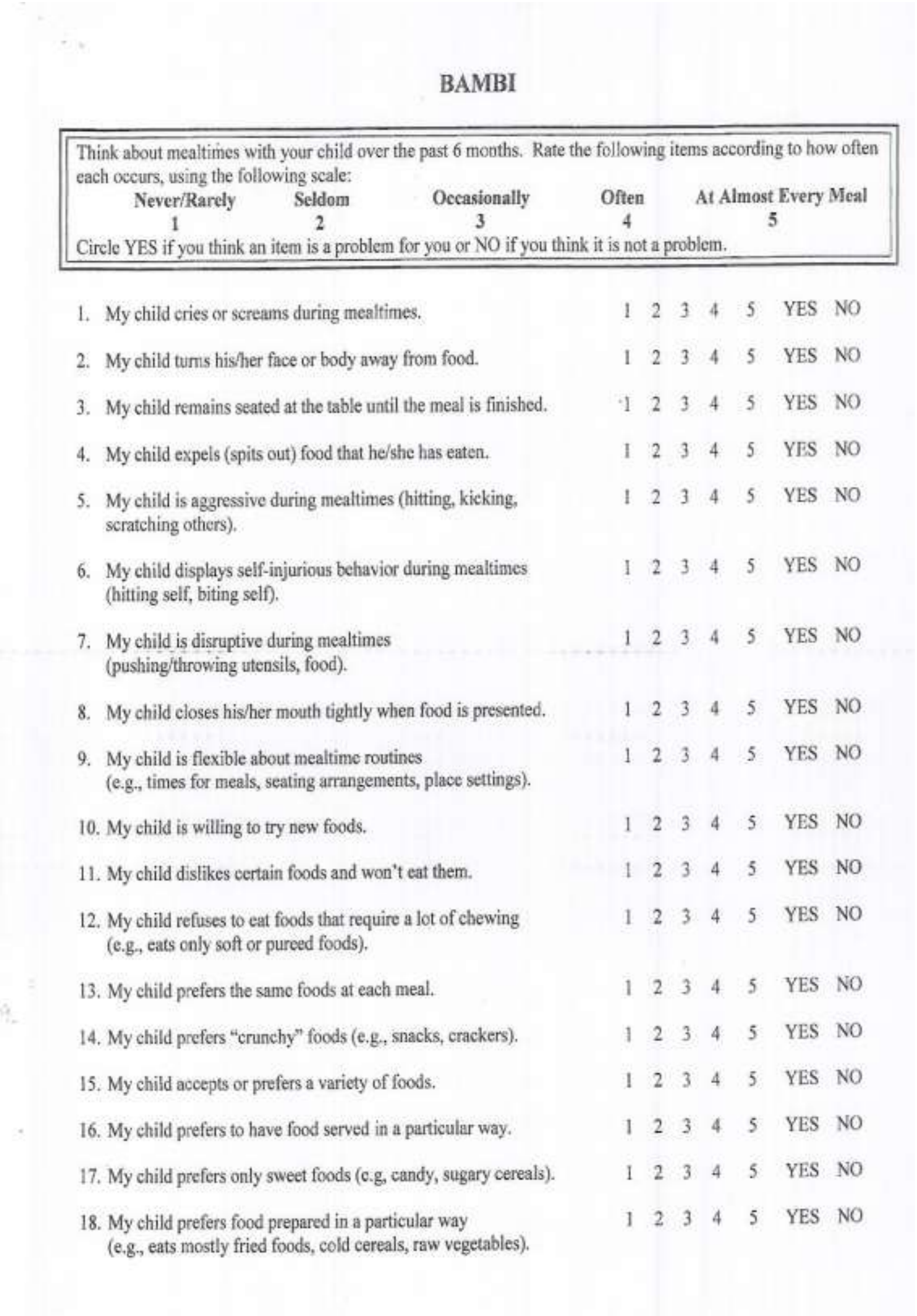
ADDITIONAL COMMENT:

……

……

THANK YOU FOR YOUR OPINION

Appendix 8. The Brief Autism Mealtime Behaviour (BAMBI)



BAMBI

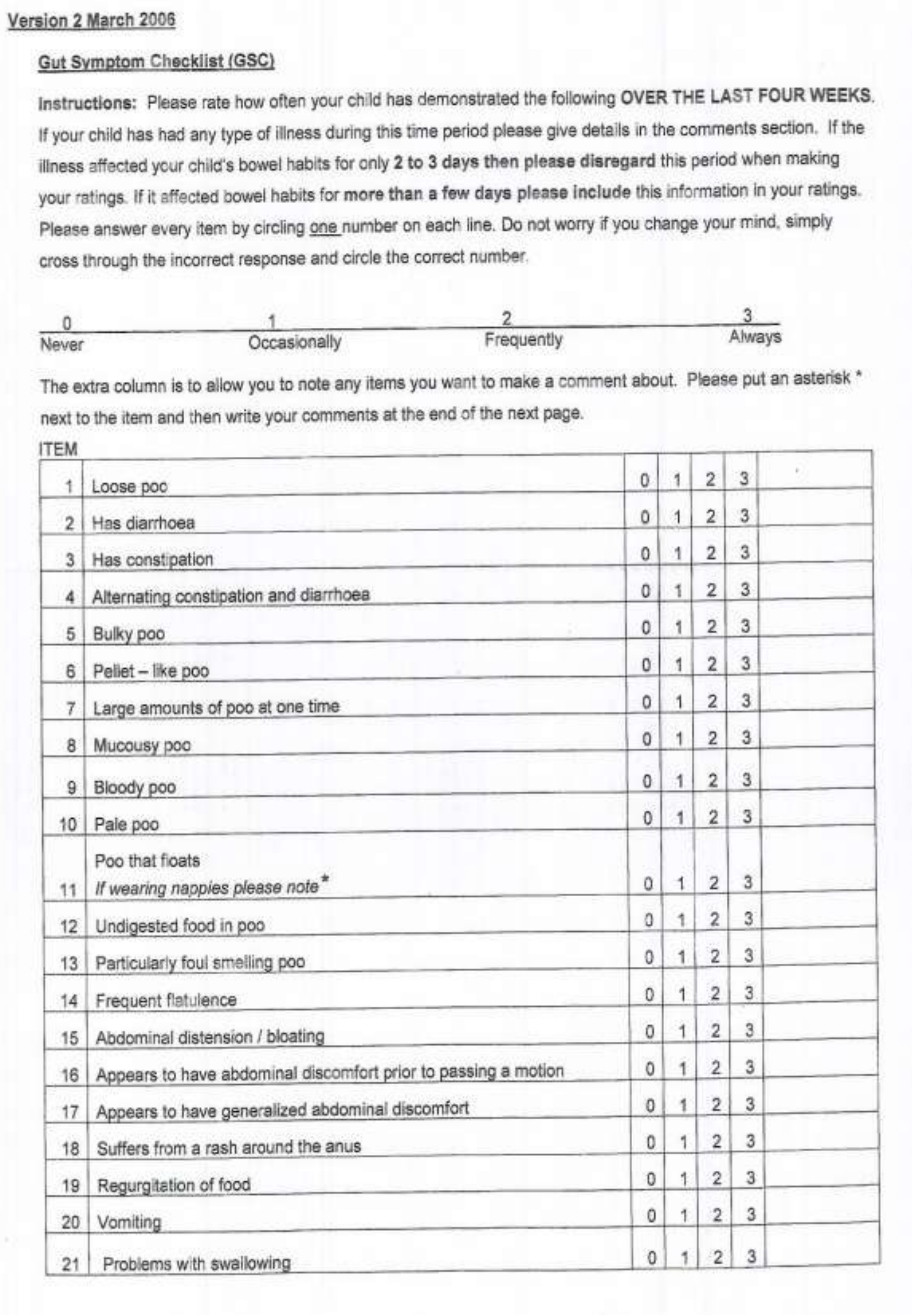
Think about mealtimes with your child over the past 6 months. Rate the following items according to how often each occurs, using the following scale:

Never/Rarely	Seldom	Occasionally	Often	At Almost Every Meal
1	2	3	4	5

Circle YES if you think an item is a problem for you or NO if you think it is not a problem.

1. My child cries or screams during mealtimes.	1	2	3	4	5	YES	NO
2. My child turns his/her face or body away from food.	1	2	3	4	5	YES	NO
3. My child remains seated at the table until the meal is finished.	1	2	3	4	5	YES	NO
4. My child expels (spits out) food that he/she has eaten.	1	2	3	4	5	YES	NO
5. My child is aggressive during mealtimes (hitting, kicking, scratching others).	1	2	3	4	5	YES	NO
6. My child displays self-injurious behavior during mealtimes (hitting self, biting self).	1	2	3	4	5	YES	NO
7. My child is disruptive during mealtimes (pushing/throwing utensils, food).	1	2	3	4	5	YES	NO
8. My child closes his/her mouth tightly when food is presented.	1	2	3	4	5	YES	NO
9. My child is flexible about mealtime routines (e.g., times for meals, seating arrangements, place settings).	1	2	3	4	5	YES	NO
10. My child is willing to try new foods.	1	2	3	4	5	YES	NO
11. My child dislikes certain foods and won't eat them.	1	2	3	4	5	YES	NO
12. My child refuses to eat foods that require a lot of chewing (e.g., eats only soft or pureed foods).	1	2	3	4	5	YES	NO
13. My child prefers the same foods at each meal.	1	2	3	4	5	YES	NO
14. My child prefers "crunchy" foods (e.g., snacks, crackers).	1	2	3	4	5	YES	NO
15. My child accepts or prefers a variety of foods.	1	2	3	4	5	YES	NO
16. My child prefers to have food served in a particular way.	1	2	3	4	5	YES	NO
17. My child prefers only sweet foods (e.g, candy, sugary cereals).	1	2	3	4	5	YES	NO
18. My child prefers food prepared in a particular way (e.g., eats mostly fried foods, cold cereals, raw vegetables).	1	2	3	4	5	YES	NO

Appendix 9. The Gut Symptom Checklist (GSC)



Version 2 March 2006

Gut Symptom Checklist (GSC)

Instructions: Please rate how often your child has demonstrated the following **OVER THE LAST FOUR WEEKS**. If your child has had any type of illness during this time period please give details in the comments section. If the illness affected your child's bowel habits for only **2 to 3 days then please disregard** this period when making your ratings. If it affected bowel habits for **more than a few days please include** this information in your ratings. Please answer every item by circling one number on each line. Do not worry if you change your mind, simply cross through the incorrect response and circle the correct number.

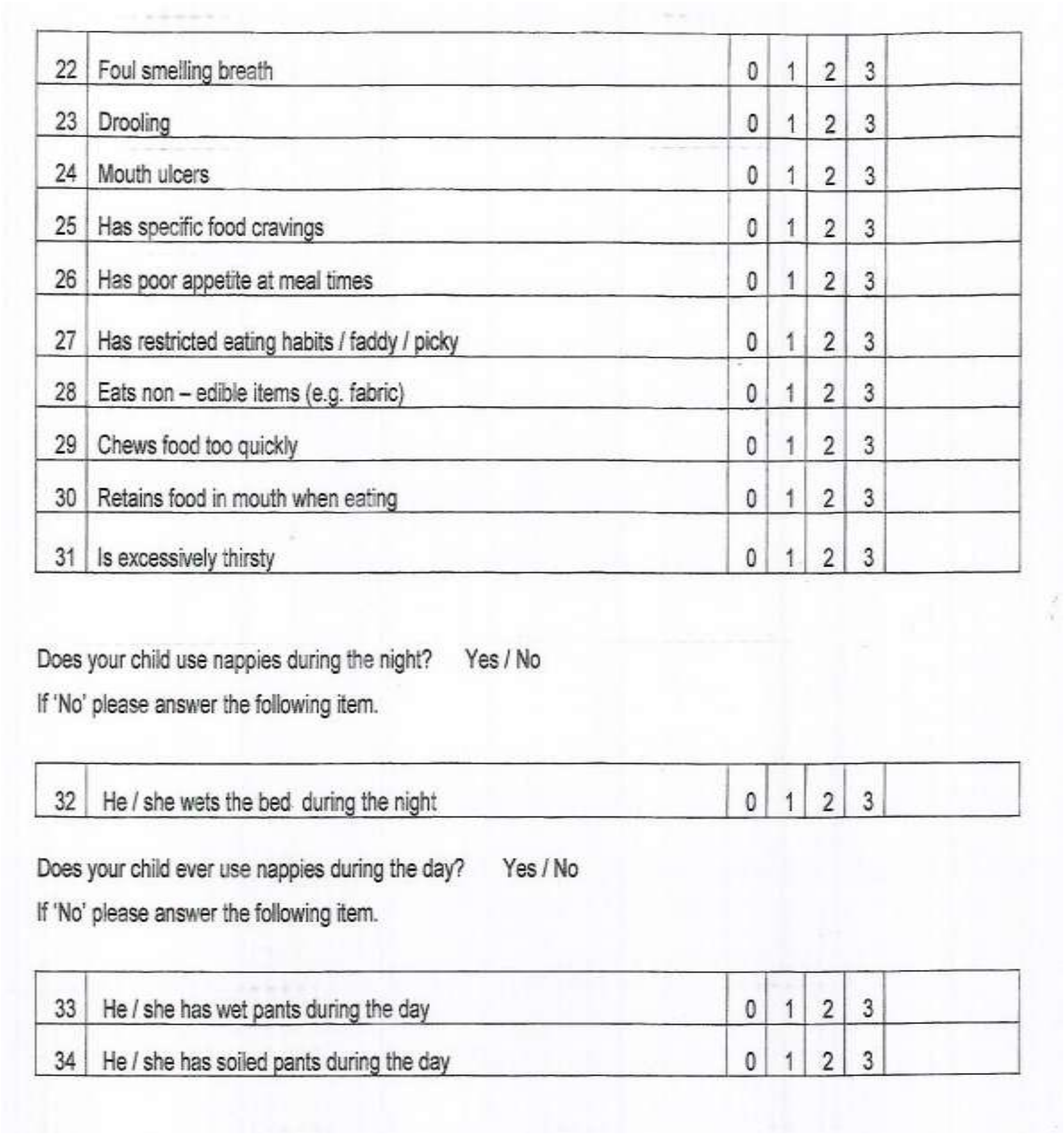
0	1	2	3
Never	Occasionally	Frequently	Always

The extra column is to allow you to note any items you want to make a comment about. Please put an asterisk * next to the item and then write your comments at the end of the next page.

ITEM

1	Loose poo	0	1	2	3	
2	Has diarrhoea	0	1	2	3	
3	Has constipation	0	1	2	3	
4	Alternating constipation and diarrhoea	0	1	2	3	
5	Bulky poo	0	1	2	3	
6	Pellet – like poo	0	1	2	3	
7	Large amounts of poo at one time	0	1	2	3	
8	Mucousy poo	0	1	2	3	
9	Bloody poo	0	1	2	3	
10	Pale poo	0	1	2	3	
11	Poo that floats *If wearing nappies please note* *	0	1	2	3	
12	Undigested food in poo	0	1	2	3	
13	Particularly foul smelling poo	0	1	2	3	
14	Frequent flatulence	0	1	2	3	
15	Abdominal distension / bloating	0	1	2	3	
16	Appears to have abdominal discomfort prior to passing a motion	0	1	2	3	
17	Appears to have generalized abdominal discomfort	0	1	2	3	
18	Suffers from a rash around the anus	0	1	2	3	
19	Regurgitation of food	0	1	2	3	
20	Vomiting	0	1	2	3	
21	Problems with swallowing	0	1	2	3	

Appendix 9. The Gut Symptom Checklist (GSC)



22	Foul smelling breath	0	1	2	3	
23	Drooling	0	1	2	3	
24	Mouth ulcers	0	1	2	3	
25	Has specific food cravings	0	1	2	3	
26	Has poor appetite at meal times	0	1	2	3	
27	Has restricted eating habits / faddy / picky	0	1	2	3	
28	Eats non – edible items (e.g. fabric)	0	1	2	3	
29	Chews food too quickly	0	1	2	3	
30	Retains food in mouth when eating	0	1	2	3	
31	Is excessively thirsty	0	1	2	3	

Does your child use nappies during the night? Yes / No

If 'No' please answer the following item.

32	He / she wets the bed during the night	0	1	2	3	

Does your child ever use nappies during the day? Yes / No

If 'No' please answer the following item.

33	He / she has wet pants during the day	0	1	2	3	
34	He / she has soiled pants during the day	0	1	2	3	

Appendix 10 Impact on Family Scale (IFS) - Modified Version

IMPACT ON FAMILY QUESTIONNAIRE

Below are statements that people have made about living with a child with Autism Spectrum Disorder (ASD). For each statement, please tell us whether you would **strongly agree, agree, disagree or strongly disagree**. Please circle or tick your option. If the question is not applicable to you, please select 'not applicable'.

		Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
1.	ASD is causing financial problems for the family	1	2	3	4	5
2.	Time is lost from work because of hospital appointments	1	2	3	4	5
3.	I stopped working because of my child's ASD	1	2	3	4	5
4.	Additional income is needed in order to cover medical expenses	1	2	3	4	5
5	Because of the ASD, we are not able to travel out of the city	1	2	3	4	5
6.	People in the neighbourhood treat us specially because of my child's ASD	1	2	3	4	5
7.	We have little desire to go out because of my child's ASD	1	2	3	4	5
8.	It is hard to find a reliable person to take care of my child	1	2	3	4	5
9.	Sometimes we have to change plans about going out at the last minute because of my child's state	1	2	3	4	5
10.	We see family and friends less because of my child's ASD	1	2	3	4	5

Appendix 10 Impact on Family Scale (IFS) - Modified Version

		Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
11.	Because of what we have shared we are a closer family	1	2	3	4	5
12.	Sometimes I wonder whether my child should be treated “specially’’ or the same as a normal child.	1	2	3	4	5
13.	My relatives have been understanding and helpful with my child	1	2	3	4	5
14.	I think about not having more children because of my child’s ASD	1	2	3	4	5
15.	My partner and I discuss my child’s problem together	1	2	3	4	5
16.	I don’t have much time left over for other family members after caring for my child	1	2	3	4	5
17.	Relatives interfere and think they know what’s best for my child	1	2	3	4	5
18.	Our family gives up things because of my child’s condition	1	2	3	4	5
19.	Fatigue is a problem for me because of my child’s condition	1	2	3	4	5
20.	I live from day to day and don’t plan for the future	1	2	3	4	5
21.	Nobody understand the burden I carry	1	2	3	4	5
22.	Travelling to hospital is a strain on me	1	2	3	4	5

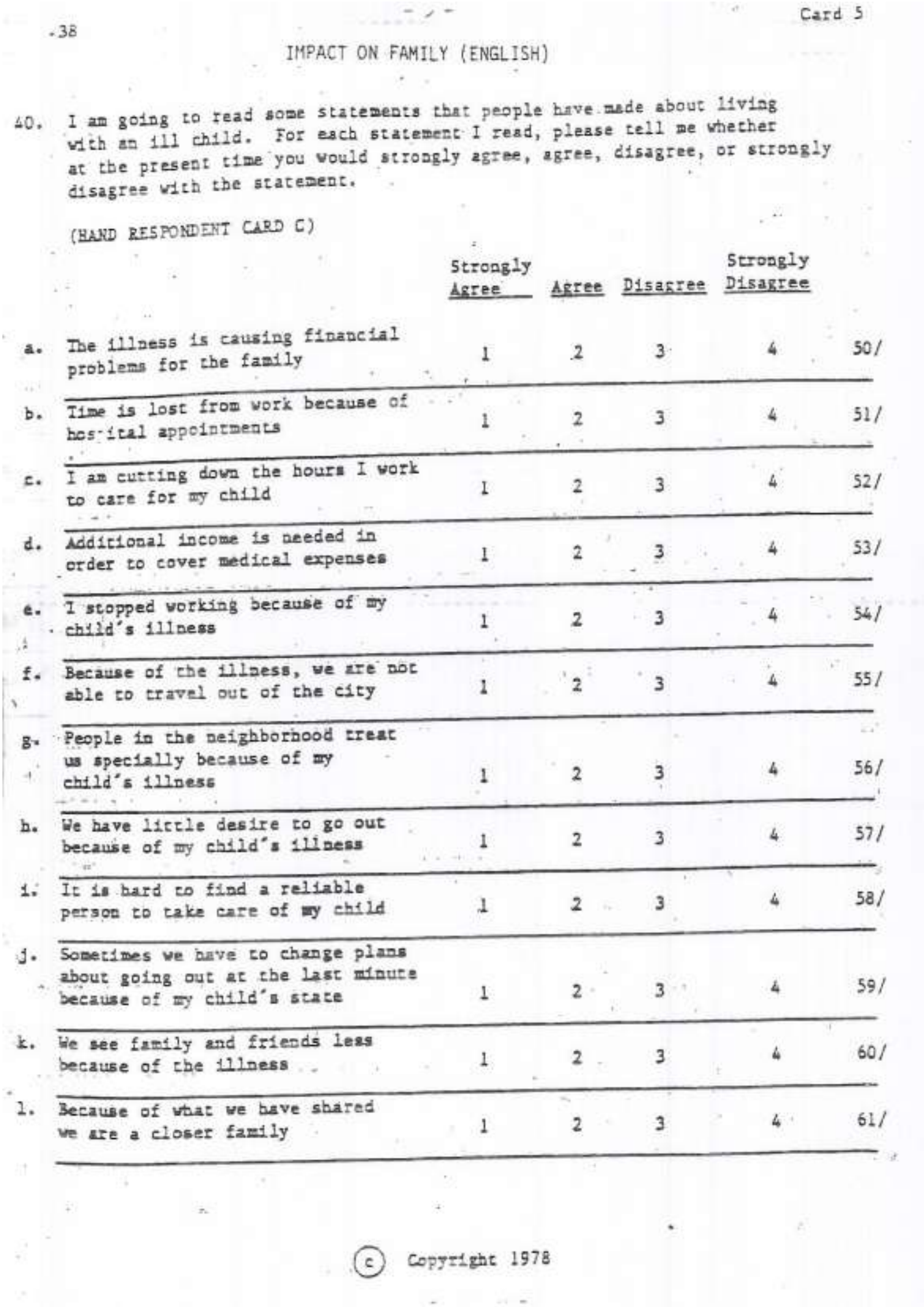
Appendix 10 Impact on Family Scale (IFS) - Modified Version

23.	Learning to manage my child's condition has made me feel better about myself	1	2	3	4	5
24.	I worry about what will happen to my child in the future (when he/she grows up, when I am not around)	1	2	3	4	5
25.	Sometimes I feel like we live on a roller coaster (in crisis when my child has problems, OK when things are stable)	1	2	3	4	5

Do you have any other children? (If yes, please answer Q 1 to Q7. If No, please circle Not applicable)

		Strongly Agree	Agree	Disagree	Strongly Disagree	Not Applicable
1.	It is hard to give much attention to the other children because of the needs of my child	1	2	3	4	5
2.	Having a child with ASD makes me worry about my other children's health	1	2	3	4	5
3.	There is fighting between the children because of my child's special needs	1	2	3	4	5
4.	My other children are frightened by his/her ASD	1	2	3	4	5
6.	My other children seem to have more illness, aches and pains than most children their age	1	2	3	4	5
7.	The school grades of my other children suffer because of my child's ASD	1	2	3	4	5

Appendix 11 Impact on Family Scale (IFS)



.38

Card 5

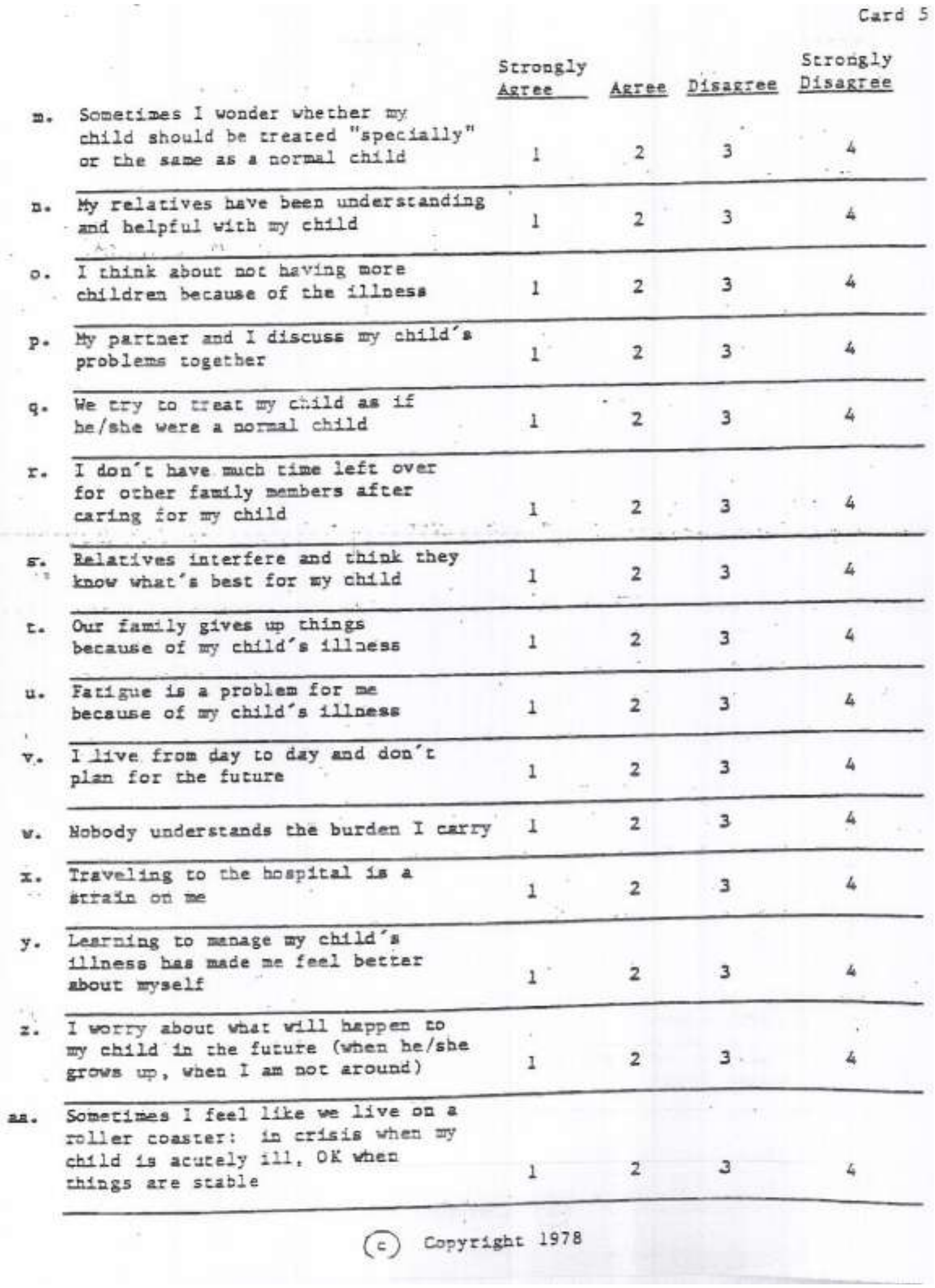
IMPACT ON FAMILY (ENGLISH)

40. I am going to read some statements that people have made about living with an ill child. For each statement I read, please tell me whether at the present time you would strongly agree, agree, disagree, or strongly disagree with the statement.

(HAND RESPONDENT CARD C)

		Strongly Agree	Agree	Disagree	Strongly Disagree	
a.	The illness is causing financial problems for the family	1	2	3	4	50/
b.	Time is lost from work because of hospital appointments	1	2	3	4	51/
c.	I am cutting down the hours I work to care for my child	1	2	3	4	52/
d.	Additional income is needed in order to cover medical expenses	1	2	3	4	53/
e.	I stopped working because of my child's illness	1	2	3	4	54/
f.	Because of the illness, we are not able to travel out of the city	1	2	3	4	55/
g.	People in the neighborhood treat us specially because of my child's illness	1	2	3	4	56/
h.	We have little desire to go out because of my child's illness	1	2	3	4	57/
i.	It is hard to find a reliable person to take care of my child	1	2	3	4	58/
j.	Sometimes we have to change plans about going out at the last minute because of my child's state	1	2	3	4	59/
k.	We see family and friends less because of the illness	1	2	3	4	60/
l.	Because of what we have shared we are a closer family	1	2	3	4	61/

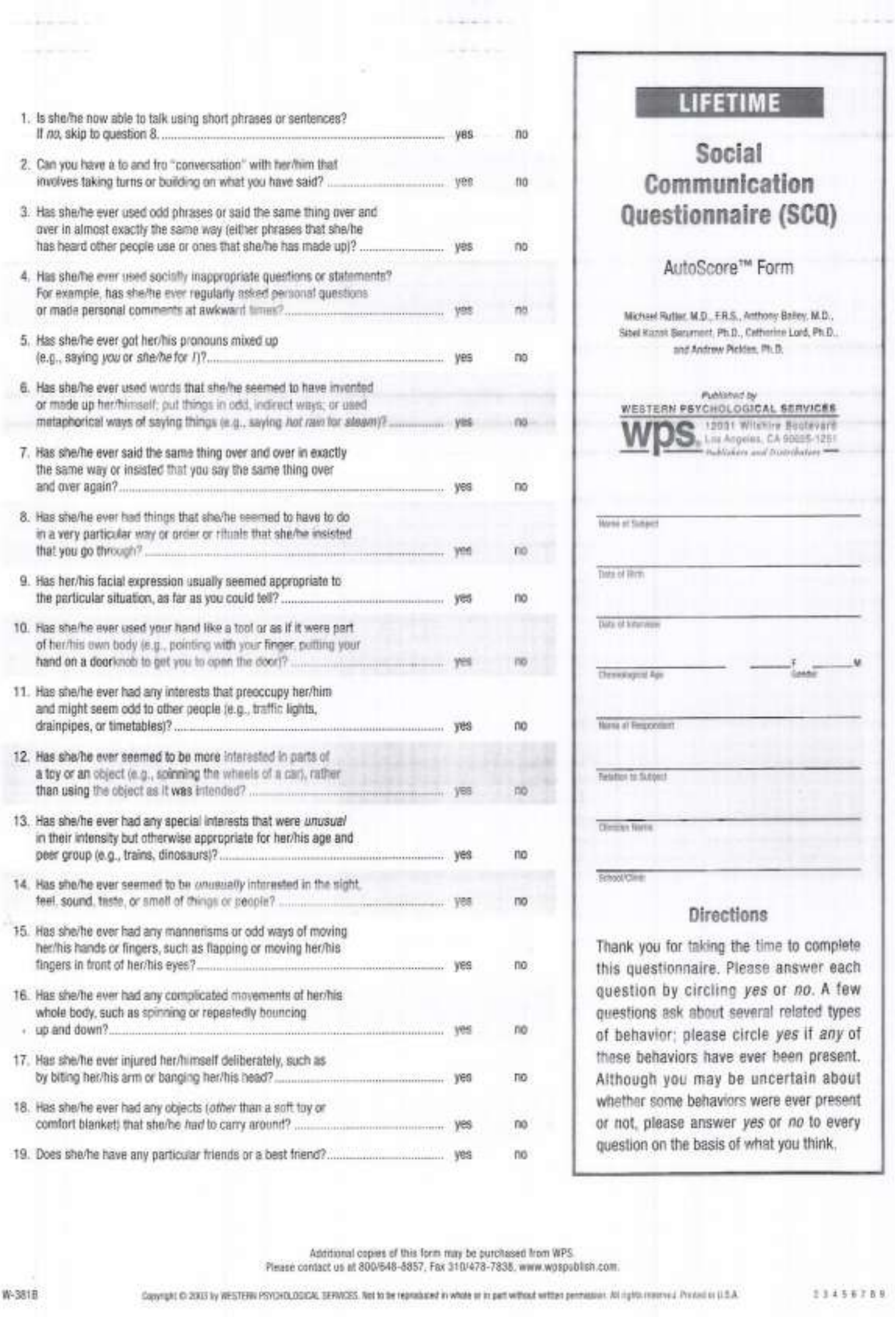
Appendix 11. Impact on Family Scale (IFS)



Card 5

		Strongly Agree	Agree	Disagree	Strongly Disagree
m.	Sometimes I wonder whether my child should be treated "specially" or the same as a normal child	1	2	3	4
n.	My relatives have been understanding and helpful with my child	1	2	3	4
o.	I think about not having more children because of the illness	1	2	3	4
p.	My partner and I discuss my child's problems together	1	2	3	4
q.	We try to treat my child as if he/she were a normal child	1	2	3	4
r.	I don't have much time left over for other family members after caring for my child	1	2	3	4
s.	Relatives interfere and think they know what's best for my child	1	2	3	4
t.	Our family gives up things because of my child's illness	1	2	3	4
u.	Fatigue is a problem for me because of my child's illness	1	2	3	4
v.	I live from day to day and don't plan for the future	1	2	3	4
w.	Nobody understands the burden I carry	1	2	3	4
x.	Traveling to the hospital is a strain on me	1	2	3	4
y.	Learning to manage my child's illness has made me feel better about myself	1	2	3	4
z.	I worry about what will happen to my child in the future (when he/she grows up, when I am not around)	1	2	3	4
aa.	Sometimes I feel like we live on a roller coaster: in crisis when my child is acutely ill, OK when things are stable	1	2	3	4

Appendix 12. Social Communication Questionnaire (SCQ)



1. Is she/he now able to talk using short phrases or sentences? If *no*, skip to question 8. .... yes no
2. Can you have a to and fro "conversation" with her/him that involves taking turns or building on what you have said? .... yes no
3. Has she/he ever used odd phrases or said the same thing over and over in almost exactly the same way (either phrases that she/he has heard other people use or ones that she/he has made up)? .... yes no
4. Has she/he ever used socially inappropriate questions or statements? For example, has she/he ever regularly asked personal questions or made personal comments at awkward times? .... yes no
5. Has she/he ever got her/his pronouns mixed up (e.g., saying *you* or *she/he* for *I*)? .... yes no
6. Has she/he ever used words that she/he seemed to have invented or made up her/himself; put things in odd, indirect ways; or used metaphorical ways of saying things (e.g., saying *hot rain* for *steam*)? .... yes no
7. Has she/he ever said the same thing over and over in exactly the same way or insisted that you say the same thing over and over again? .... yes no
8. Has she/he ever had things that she/he seemed to have to do in a very particular way or order or rituals that she/he insisted that you go through? .... yes no
9. Has her/his facial expression usually seemed appropriate to the particular situation, as far as you could tell? .... yes no
10. Has she/he ever used your hand like a tool or as if it were part of her/his own body (e.g., pointing with your finger, putting your hand on a doorknob to get you to open the door)? .... yes no
11. Has she/he ever had any interests that preoccupy her/him and might seem odd to other people (e.g., traffic lights, drainpipes, or timetables)? .... yes no
12. Has she/he ever seemed to be more interested in parts of a toy or an object (e.g., spinning the wheels of a car), rather than using the object as it was intended? .... yes no
13. Has she/he ever had any special interests that were *unusual* in their intensity but otherwise appropriate for her/his age and peer group (e.g., trains, dinosaurs)? .... yes no
14. Has she/he ever seemed to be *unusually* interested in the sight, feel, sound, taste, or smell of things or people? .... yes no
15. Has she/he ever had any mannerisms or odd ways of moving her/his hands or fingers, such as flapping or moving her/his fingers in front of her/his eyes? .... yes no
16. Has she/he ever had any complicated movements of her/his whole body, such as spinning or repeatedly bouncing up and down? .... yes no
17. Has she/he ever injured her/himself deliberately, such as by biting her/his arm or banging her/his head? .... yes no
18. Has she/he ever had any objects (*other* than a soft toy or comfort blanket) that she/he *had* to carry around? .... yes no
19. Does she/he have any particular friends or a best friend? .... yes no

LIFETIME

Social Communication Questionnaire (SCQ)

AutoScore™ Form

Michael Rutter, M.D., F.R.S., Anthony Bailey, M.D.,
Sibel Kazak Berument, Ph.D., Catherine Lord, Ph.D.,
and Andrew Pickles, Ph.D.

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Name of Subject

Date of Birth

Date of Interview

Chronological Age

____ F ____ M
Gender

Name of Respondent

Relation to Subject

Clinician Name

School/Clinic

Directions

Thank you for taking the time to complete this questionnaire. Please answer each question by circling *yes* or *no*. A few questions ask about several related types of behavior; please circle *yes* if *any* of these behaviors have ever been present. Although you may be uncertain about whether some behaviors were ever present or not, please answer *yes* or *no* to every question on the basis of what you think.

Additional copies of this form may be purchased from WPS.
Please contact us at 800/648-8857, Fax 310/478-7838, www.wpspublish.com.

W-381B

2 3 4 5 6 7 8 9

Appendix 12. Social Communication Questionnaire (SCQ)

For the following behaviors, please focus on the time period between the child's fourth and fifth birthdays. You may find it easier to remember how things were at that time by focusing on key events, such as starting school, moving house, Christmastime, or other specific events that are particularly memorable for you as a family. If your child is not yet 4 years old, please consider her or his behavior in the past 12 months.

20. When she/he was 4 to 5, did she/he ever talk with you just to be friendly (rather than to get something)? .... yes no

21. When she/he was 4 to 5, did she/he ever *spontaneously* copy you (or other people) or what you were doing (such as vacuuming, gardening, or mending things)? .... yes no

22. When she/he was 4 to 5, did she/he ever spontaneously point at things around her/him just to show you things (not because she/he wanted them)? .... yes no

23. When she/he was 4 to 5, did she/he ever use gestures, other than pointing or pulling your hand, to let you know what she/he wanted? .... yes no

24. When she/he was 4 to 5, did she/he nod her/his head to mean *yes*? .... yes no

25. When she/he was 4 to 5, did she/he shake her/his head to mean *no*? .... yes no

26. When she/he was 4 to 5, did she/he usually look at you directly in the face when doing things with you or talking with you? .... yes no

27. When she/he was 4 to 5, did she/he smile back if someone smiled at her/him? .... yes no

28. When she/he was 4 to 5, did she/he ever show you things that interested her/him to engage your attention? .... yes no

29. When she/he was 4 to 5, did she/he ever offer to share things other than food with you? .... yes no

30. When she/he was 4 to 5, did she/he ever seem to want you to join in her/his enjoyment of something? .... yes no

31. When she/he was 4 to 5, did she/he ever try to comfort you if you were sad or hurt? .... yes no

32. When she/he was 4 to 5, when she/he wanted something or wanted help, did she/he look at you and use gestures with sounds or words to get your attention? .... yes no

33. When she/he was 4 to 5, did she/he show a normal range of facial expressions? .... yes no

34. When she/he was 4 to 5, did she/he ever spontaneously join in and try to copy the actions in social games, such as *The Mulberry Bush* or *London Bridge Is Falling Down*? .... yes no

35. When she/he was 4 to 5, did she/he play any pretend or make-believe games? .... yes no

36. When she/he was 4 to 5, did she/he seem interested in other children of approximately the same age whom she/he did not know? .... yes no

37. When she/he was 4 to 5, did she/he respond positively when another child approached her/him? .... yes no

38. When she/he was 4 to 5, if you came into a room and started talking to her/him without calling her/his name, did she/he usually look up and pay attention to you? .... yes no

39. When she/he was 4 to 5, did she/he ever play imaginative games with another child in such a way that you could tell that they each understood what the other was pretending? .... yes no

40. When she/he was 4 to 5, did she/he play cooperatively in games that required joining in with a group of other children, such as hide-and-seek or ball games? .... yes no

Appendix 13. Telephone interview questionnaire

TELEPHONE INTERVIEW QUESTIONNAIRE

FEEDBACK FROM PROFESSIONALS ON

THE BEFG-ASD AND INFORMATION PACK

ID Number ☐☐☐☐☐☐☐
[for office use only]

Name (Professional) :..

Job Title :..

Date of Interview :..

July 2011

Appendix 13. Telephone interview questionnaire

For this question, please indicate your answer whether yes

General Instruction to the interviewer

***Please tick* √ for each answer**

Before we start, do you have a copy of the BEFG-ASD questionnaire with you?

☐ Yes ☐ No (make a note if the professional didn't have the questionnaire)

1. How did you choose the parent?...

2. Did you specifically choose a parent whose child had any feeding or gut problems?

☐ Yes ☐ No

3. In general, was the questionnaire easy to use?

☐ Yes ☐ No

If **NO**, could you please expand the reason and why?...

……

Appendix 13. Telephone interview questionnaire

For the next few questions, I will be asking you some questions in a standard format. There are four choice of answer : <u>very useful</u>, <u>useful</u>, <u>somewhat useful</u> or <u>not useful</u>. Please indicate your choice.

No	**Question**	**Very Useful**	**Useful**	**Somewhat Useful**	**Not Useful**
4.	Overall, would the questionnaire be useful for your current practice?				
5.	Was the questionnaire useful in helping you to <u>identify feeding problems</u> in the child with ASD in a systematic way?				
6.	Was the questionnaire useful in helping you to <u>identify gastrointestinal</u> (GI) <u>symptoms</u> in the child with ASD in a systematic way?				
7.	Was the questionnaire useful in helping you to <u>identify the impact of feeding problems</u> in the child with ASD in a systematic way?				
8.	Was the questionnaire useful in helping you to <u>identify the impact of GI symptoms</u> in the child with ASD in a systematic way?				

For the next section of questions, can you please indicate your answer whether it is 'Yes' or 'No'. For each answer, please tell me why.

No	**Question**	**Yes**	**No**	**Tell us why?**
9.	Did you find the questionnaire useful in <u>increasing your awareness</u> of feeding problems in children with ASD?			
10.	Did you find the questionnaire useful in <u>increasing your awareness</u> of gastrointestinal (GI) symptoms in children with ASD?	**Yes**	**No**	**Tell us why?**

Appendix 13. Telephone interview questionnaire

11.	Did you find the questionnaire useful in increasing your awareness of : • the impact of feeding problems in children with ASD on their family life?			
	• the impact of GI symptoms in children with ASD on their family life?			

For the last section, could you please choose one of the four options whether strongly agree, agree, disagree or strongly disagree?

No	**Question**	**Strongly agree**	**Agree**	**Disagree**	**Strongly disagree**
12.	The questionnaire offers something unique to support professionals working in the community with children with ASD and their families				
13.	The questionnaire should be used for training of professionals in the early identification of feeding problems and GI symptoms in children with ASD.				
14.	The professionals could use the questionnaire as part of their overall management for children with ASD to help parent to talk about their concerns on feeding problems or GI symptoms.				

15. What did you find MOST useful about the questionnaire?

....
....

16. What did you like LEAST about the questionnaire?

…..
....

Appendix 13. Telephone interview questionnaire

17. Was there anything that you would have liked to be included to improve the questionnaire?

☐ Yes ☐ No

If yes, could you please give the details of it **(please probe in which section of the BEFG-ASD)**

....

....

Thank you for your answer about the BEFG-ASD questionnaire. Now I would like to ask about the information pack.

For the following questions, can you please indicate your answer whether it is 'Yes' or 'No'.

18. Did you give the information pack to the parent?

☐ Yes ☐ No

19. Do you think the information pack is easy to use?

☐ Yes ☐ No

For the next section, could you please choose one of the four options about the information pack whether: very useful, useful, somewhat useful or not useful

No	Question	Very Useful	Useful	Somewhat Useful	Not Useful
20.	Overall, would the information pack be useful for your current practice?				
21.	Would the information pack be useful for you to support parent's concern about feeding problems?				

22. What did you find MOST useful about the information pack?

…..

23. What did you like LEAST about the information pack?

…..

Appendix 13. Telephone interview questionnaire

24.Was there anything that you would have liked to be included to improve the information pack?

....
....

Lastly,

25. How long did you take to complete each interview using the BEFG-ASD?

…………………..minutes

26.How many schoolchildren with ASD aged 4-11 years have you seen over the past one year?

....

27. Do you have any other comments related to your experience in this study?

☐ Yes, give detail ☐ No

....
....

The interview is finish and thank you very much for your time. Goodbye.

Appendix 14. The BEFG-ASD (Version 1)

PART A- FEEDING PROBLEMS

General instruction

- **Circle/tick** the answer as you ask the question to parent/caregiver.
- **Please read this statement to parent/caregiver of the particular child**

Can we start by talking about your child's eating ***over the past 3 months?***

FOOD SELECTIVITY			
1.	**(In the last 3 months)** which of these food groups or foods does your child usually eat or drink **at least once a week**? ***(please read one by one to parent)***		
	• Bread/rice/potato and other staple foods (eg: pasta/noodle/cereal)	Yes	No
	• Milk and dairy products (e.g: cheese/yogurt)	Yes	No
	• Meat /chicken	Yes	No
	• Fish/seafood	Yes	No
	• Eggs (eg: omelette, pancakes)	Yes	No
	• Beans (including baked beans) or other non-dairy sources of protein (e.g: tofu, nuts, grains, lentils)	Yes	No
	• Fruit (eg: apple, orange, banana, grapes)	Yes	No
	• Fruit juice (fresh fruit juice but not squash/cordial)	Yes	No
	• Vegetables (e.g: broccoli, carrot, cabbage, spinach, salad)	Yes	No
	• Food and drinks that high in sugar and fat (eg: carbonated drinks, crisps, sweets, chocolate,cakes)	Yes	No``

2.	Are there any food that your child refuses to eat?	Yes	No
	If yes, please give details ……………………………………………………………………………………… ……………………………………………………………………………………… ………………………………………………………………………………………		
3.	Does your child insist on the same foods at most meals ?	Yes	No
	If yes, please give details …………………………………………………………………………………… …………………………………………………………………………………… …………………………………………………………………………………………		
4.	Do you have to prepare any special foods for your child (compared with other family members)?	Yes	No
	If yes, please give details ………………………………………………………………………………………… ……………………………………………………………………………………………		
FOOD PHYSICAL CHARACTERISTICS			
5.	**(In the last 3 months)** has your child insisted on most foods having any particular characteristics such as food with a certain: ***(please read one by one to parent)***		
	• Smell?	Yes	No
	• Shape?	Yes	No
	• Colour?	Yes	No
	• Temperature?	Yes	No
	• Brand?	Yes	No
	• Type of packaging?	Yes	No

	If yes to any of the above, please give details and describe the special characteristics? ………………………………………………………………………………………… ………………………………………………………………………………………… …………………………………………………………………………………………		
6.	Does your child have a strong preference for foods with **specific textures**? (eg: soft/ hard/ lumpy/ crunchy foods)	Yes	No
	If yes, please give details and example of foods ………………………………………………………………………………………… ………………………………………………………………………………………… …………………………………………………………………………………………		
7.	Does your child have a strong preference for foods with **specific flavours**? (e.g: salty/ spicy/ sweet/ sour foods)	Yes	No
	If yes to any of the above, please give details and examples of foods ? ……………………………………………………………………………………… …………………………………………………………………………………… …………………………………………………………………………………………		
8.	**(In the last 3 months)** has your child ever insisted that: ***(please read one by one to parent)***		
	• his/her food is served in a particular way?	Yes	No
	• he uses specific utensils or crockery for eating or drinking?	Yes	No
	• his/her food is cooked by a certain person?	Yes	No
	If yes to any of the above, please give details ………………………………………………………………………………………… …………………………………………………………………………………………		

MEALTIME BEHAVIOUR			
9.	**(In the last 3 months)**, has your child shown any of these behaviours **at least once a week**? ***(please read one by one to parent)***		
	• aggressive during mealtimes (e.g. kicking, hitting, shouting, scratching others)	Yes	No
	• spitting out food ?	Yes	No
	• any self injurious behaviour during mealtimes? (e.g. biting self, hitting self)	Yes	No
	• insisted on eating his/her meals in the same place?	Yes	No
	• refused to eat at family mealtimes?	Yes	No
	• had disruptive behaviour during mealtimes? (e.g. pushing/throwing utensils/food)	Yes	No
	• cried or screamed during mealtimes?	Yes	No
	If yes to any of the above, please give details ………………………………………………………………………………… …………………………………………………………………………………… ……………………………………………………………………………………		
PARENTAL DIETARY RESTRICTIONS			
10.	**(In the last 3 months)**, have you used any special diet as part of your child’s treatment? (e.g.gluten free casein free diet, yeast free diet,allergy)	Yes	No
	If yes, please give details and examples of diet …………………………………………………………………………………		

11.	Do you give any vitamin, mineral or other supplements to your child?	Yes	No
	If yes, please give details ……………………………………………………………………………………		
12.	Do you avoid giving your child any particular foods?	Yes	No
	If yes, please give details ……………………………………………………………………………………		
FOOD NEOPHOBIA AND FOOD PICA			
13.	**(In the last 3 months)** has your child ever appeared frightened/ fearful of trying to eat any foods that are new or unfamiliar to him/her?(eg: child seems fearful of swallowing food or shows signs of choking)	Yes	No
	If yes, please give details and examples of foods. ………………………………………………………………………………………		
14.	Does your child show specific craving for any non-food items? (e.g. paper, wood, plastic)	Yes	No
	If yes, please give details and example of the non-food items ……………………………………………………………………………………… ……………………………………………………………………………………… ………………………………………………………………………………………		

PART B - GASTROINTESTINAL SYMPTOMS

General instruction

- **Circle/tick** the answer as you ask the question to parent/caregiver.
- **Read this statement to parent/caregiver about their child**

*"Now can we talk about any gut/bowel problems your child might have experienced over **the past 3 months?"***

In the last 3 months, has your child shown or complained about any of the following problems? ***(please read one by one to parent)***

1.	Constipation **(bowel actions/movements less than 2 times a week)?**	Yes	No **(Go to Q2)**
	1.2. If yes, does he/she say its hurt?	Yes	No
	Please describe what you noticed about his/her poo. (e.g. hard poo, pellet-like poo, bloody poo) …………………………………………………………………………………………………		
	1.2. Does your child ever have 'accidents' (in opening his/her bowels)?	Yes	No
	1.3. Do you use any laxatives to treat his/her constipation?	Yes	No
2.	Diarrhoea **(bowel motion of 2 - 5 times per day)**?	Yes	No **(Go to Q3)**
	If yes, please describe what you noticed about his/her poo. (e.g. loose poo, mucousy poo, bloody poo) …………………………………………………………………………………………………		
	2.1. Do you use any medication to treat his/her diarrhoea?	Yes	No

3.	Abdominal pain **(more than 3 times a week)?**	Yes	No **(Go to Q4)**
	3.1 Does the pain disrupt daily activity of your child? (eg: stopping child from playing, sleeping or going to school)	Yes	No
4	Vomiting **(at least once week)?**	Yes	No **(Go to Q5)**
	4.1. If yes, is it related to meals?	Yes	No
	4.2. How much does she/he vomits? ………………………………………….		
	4.3. What does` the vomits look like ?(eg: green, brown or red colour)...........		
5.	Has your child lost weight for over the past 3 months ago?	Yes	No
	If yes, did you worry about his/her weight loss?	Yes	No

PART C- IMPACT OF FEEDING PROBLEMS AND GASTROINTESTINAL SYMPTOMS

General instruction

Please **Circle/tick** the answer as you ask the question to parent/caregiver.

Read this statement to parent/caregiver of the particular child

*Finally, I would like to ask you about what impact, if any, your child's feeding or gut problem(s) have had on you and your family **over the last 3 months***

*For each question please base your answer on these four (4) categories: **'a great deal, quite a lot, only a bit or not at all'**.*

IMPACT OF FEEDING PROBLEMS ON FAMILY LIFE				
1.	Do your child's feeding problems have an impact on the financial aspects of the family?			
	A great deal *	***Quite a lot ****	***Only a bit***	***Not at all***
2.	Do you think that the feeding problems restrict your social life in any way?			
	A great deal *	***Quite a lot ****	***Only a bit***	***Not at all***
3.	Do you think that the demands of managing feeding problems of your child have placed any stress on you?			
	A great deal *	***Quite a lot ****	***Only a bit***	***Not at all***
IMPACT OF GASTROINTESTINAL SYMPTOMS ON FAMILY LIFE				
4.	Do your child's gut problems have an impact on the financial aspects of the family?			
	A great deal *	***Quite a lot ****	***Only a bit***	***Not at all***
5.	Do you think that the gut problems restrict your social life in any way?			
	A great deal *	***Quite a lot ****	***Only a bit***	***Not at all***
6.	Do you think that the demands of managing gut problems of your child have placed any stress on you?			
	A great deal *	***Quite a lot ****	***Only a bit***	***Not at all***

Appendix 15. The BEFG-ASD (Version 2)

BRIEF STRUCTURED QUESTIONNAIRE

A standardised instrument identify feeding problems, gastrointestinal symptoms of school children with Autism Spectrum Disorders (ASD) and the impact of these problems to family.

For health and educational professionals only

Draft 2010

GENERAL INSTRUCTION

- This is a brief structured questionnaire to identify feeding problems, gastrointestinal symptoms of school children with **Autism Spectrum Disorders (ASDs)** and the impact of these problems to family.

- The new questionnaire is designed for professionals (in clinics and schools) to use with parents/caregivers of **children with ASDs aged 4 -11 years** when there are concerns about feeding problems or gastrointestinal (GI) symptoms.

- The questionnaire has three components:
    - **Part A: Feeding problems**
    - **Part B: GI symptoms**
    - **Part C: Impact on family life**

- Before you use the questionnaire, please fill up general information about the child and parent. Read and understand the general instruction in Part A, Part B and Part C.

- All questions need to be asked to parent/caregiver. Please familiarise yourself with the questionnaire before you conduct the interview.

- If you have any enquiries on the instrument, please e-mail Professor Ann Le-Couteur (a.s.le-couteur@newcastle.ac.uk) or Ms Noor Safiza (n.s.mohamad-nor@newcastle.ac.uk)

Part A: FEEDING PROBLEMS

General instruction for professionals

- **Circle/tick** the answer as you ask the question to parent/caregiver.
- **Please read this statement to parent/caregiver of the particular child**

Can we start by talking about your child's eating and feeding ***over the past 3 months?***

1.	In the last 3 months, is there any food that your family regular eats that your child refuses to eat?	Yes No
	If yes, give examples :………………………………………………..	
2	Does your child **insist similar foods at most meals** in the last 3 months?	Yes No
	If yes, give examples:………………………………………………	
3.	Do you have to **prepare special foods** for your child (compared with other family members) in the last 3 months?	Yes No
4.	Has your child insist on most foods to have **particular physical characteristics** in the last 3 months ?(e.g.:smell, certain shape, colour, temperature, brand or packaging)	Yes No
	If yes, give examples:………………………………………………	
5	Does your child have a strong preference for foods with **particular textures**? (e.g.: soft/ hard/ lumpy/ crunchy foods)	Yes No
	If yes, give examples:………………………………………………	
6.	Does your child have a strong preference for foods with **particular flavours**? (e.g.: salty/ spicy/ sweet/ sour foods)	Yes No
	If yes, give examples:……………………………………………………..	
7.	Has your child insisted that his/her food is **served in a particular way**?	Yes No
8.	Has your child insisted that he/she uses **specific utensils or crockery for eating or drinking?**	Yes No
9.	Has your child insisted that his/her **food is cooked by a certain person**?	Yes No

10.	Has your child insisted on eating his/her **meals in the same place**?	Yes No
11	Has your child refused to eat at family mealtimes **at least once a week**?	Yes No
12.	Has your child shown any of these **behaviours during mealtimes at least once a week**?e.g.: kicking, hitting, shouting, scratching others, spitting out food)	Yes No
	If yes, give examples:…………………………………………………	
13	Has your child shown any of these **self- injurious behaviours during mealtimes at least once a week**? (e.g. biting self, hitting self)	Yes No
	If yes, give examples:…………………………………………………	
14	Has your child had disruptive behaviour during mealtimes **at least once a week**? (e.g. pushing/throwing utensils/ throwing food)	Yes No
	If yes, give examples:…………………………………………………	
15	Has your child ever appeared **frightened/ fearful of trying to eat any foods that are new or unfamiliar** to him/her?(eg:child seems fearful of swallowing food or shows signs of choking)	Yes No
	If yes, give examples:…………………………………………………	
16	Does your child show any specific craving for any **non-food items**? (e.g. paper, wood, plastic)	Yes No
17.	Have you used any **medically prescribed special diet** as part of your child's treatment in the last 3 months? (e.g. gluten free casein free diet, yeast free diet, diet for allergy)	Yes No
	If yes, give examples:……………………………………………….	
18.	Do you give any vitamin, mineral or other supplements to your child in the last 3 months?	
	If yes, give examples:………………………………………………	
19.	Do you avoid giving your child any particular foods?	
	If yes, give examples:………………………………………………	
20.	Have you received any **advice from health professionals** on managing feeding or diet of your child?	
	If yes, who?:……………………………………………………………	

PART B - GASTROINTESTINAL SYMPTOMS

General instruction for professionals

- **Circle/tick** the answer as you ask the question to parent/caregiver.
- **Read this statement to parent/caregiver about their child**

“Now can we talk about any gut/bowel problems your child might have experienced over ***the past 3 months?”***

1.	**In the last 3 months**, has your child shown or complained about constipation **(which is bowel motion/passage less than 2 times a week)?**	Yes	No **(Go to Q2)**
	1.1. If yes, does he/she say its hurt?	Yes	No
	1.2. Please describe what you noticed about his/her poo (e.g. hard poo, pellet-like poo, bloody poo) …………………………………………………………………………………………………		
	1.3. Does your child ever have ‘accidents’ (in opening his/her bowels) in the last 3 months?	Yes	No
	1.4. In the last 3 months, do you use any laxatives to treat his/her constipation?	Yes	No
2.	**In the last 3 months**, has your child shown or complained about diarrhoea **(which is bowel motion /passage of 2-5 times per day)**?	Yes	No **(Go to Q3)**
	2.1. If yes, please describe what you noticed about his/her poo.(e.g. loose poo, mucousy poo, bloody poo) …………………………………………………………………………………………………		
	2.2. Do you use any medication to treat his/her diarrhoea?	Yes	No
3.	**In the last 3 months**, has your child shown or complained about abdominal pain **(more than 3 times a week)?**	Yes	No **(Go to Q4)**
	3.1. Does the pain disrupt daily activity of your child? (eg: stopping child from playing, sleeping or going to school)	Yes	No
	3.2. Do you use any medication to treat his/her pain?	Yes	No
4	**In the last 3 months**, has your child shown or complained about vomiting **(at least once week)?**	Yes	No **(Go to Q5)**
	4.1. If yes, is it related to meals?	Yes	No
	4.2. How much does she/he vomits? …………………………………………		
	4.3. What does` the vomits look like? (e.g.: green, brown or red colour)........................		
5.	**In the last 3 months**, has your child unintentionally lost weight?	Yes	No
	5.1. If yes, how much is the weight loss?...........................		
	5.2 Did you worry about his/her weight loss?	Yes	No

PART C- IMPACT OF FEEDING PROBLEMS AND GASTROINTESTINAL SYMPTOMS

General instruction for professionals

For parents who do not have any feeding problems or GI symptoms (**if all answers are no)**, please mark **‘not applicable’** .Please **Circle/tick** the answer as you ask the question to parent/caregiver.

Read this statement

Finally, I would like to ask you about what impact, if any, your child’s feeding or gut problem(s) have had on you and your family. Impact refers to any restriction experienced ***over the last 3 months*** *by you and your family as a result of these problems*

For each question please tell me your answer based on these four (4) categories: ***‘a great deal, quite a lot, only a bit or not at all”****.*

1.	Has your child’s feeding problems affected the financial aspects of the family?				
	A great deal *	***Quite a lot*** *	***Only a bit***	***Not at all/No***	***Not Applicable***
2.	Do you think that the feeding problems restrict your social life in any way?				
	A great deal *	***Quite a lot*** *	***Only a bit***	***Not at all/No***	***Not Applicable***
3.	Do you think that the demands of managing feeding problems of your child have placed any stress on you?				
	A great deal *	***Quite a lot*** *	***Only a bit***	***Not at all/No***	***Not Applicable***
4.	Has your child’s gut problems affected the financial aspects of the family?				
	A great deal *	***Quite a lot*** *	***Only a bit***	***Not at all/No***	***Not Applicable***
5.	Do you think that the gut problems restrict your social life in any way?				
	A great deal *	***Quite a lot*** *	***Only a bit***	***Not at all/No***	***Not Applicable***
6.	Do you think that the demands of managing gut problems of your child have placed any stress on you?				
	A great deal *	***Quite a lot*** *	***Only a bit***	***Not at all/No***	***Not Applicable***

Appendix 16

REVIEW SUMMARY (FIRST ROUND)

Expert Group: Professional

Date of review: 7th July -23th July

1. **Number of experts**

   In this review, twenty (20) professionals from various backgrounds were invited to take part. Ten (10) members have expressed their interest and in this first round of the review, 9 out of 10 members (90%) have returned their review format and comments.

2. **Score of opinion on section A – Feeding problems**

   Members have reviewed 20 questions. On average, members have rated all questions as **important to very important questions** (details as below)

QUESTION	AVERAGE SCORE	QUESTION	AVERAGE SCORE
Q1	2.1	Q11	2.0
Q2	1.7	Q12	2.1
Q3	1.9	Q13	2.1
Q4	1.4	Q14	2.0
Q5	1.3	Q15	1.6
Q6	1.4	Q16	2.2
Q7	1.1	Q17	1.9
Q8	2.4	Q18	2.1
Q9	2.4	Q19	1.9
Q10	2.0	Q20	2.1

Average score: **1.9** **(close to important questions)**. Therefore, all questions in Section A will be remained in the questionnaire.

Note: ***Question with score of 3.0 and below (which means 'less important to not important') need further opinion by members, whether the question should be retained or removed from the questionnaire.***

Comments for section A

There were 14 comments from members (details as below). There were suggestions **<u>to improve the current questions and also to add new questions (highlighted in yellow)</u>**

No	**Question Number**	**Comments**
1.	General instruction/ statement for professionals	• Take out reference to last 3 months in all questions , this does not anything and confuses the question (because questionnaire for early identification) • Take out all examples - If professionals is not able to use them as part of advice package, this will add extra time and possibly distress to the process • Would be better " on most days" rather than '3 months' • 3 months seems like a long time. If the questionnaire meant for early identification, professional should ask 'now'/ recent problems • 3 months is a long time .Better to ask problems in the last week or regularly
2.	Q1	‘Regularly’ rather than regular
3.	Q2	Seems quite not specific
4.	Q3	Should be “have you had to......”
5.	Q4	Should be “has your child insisted.......”
6.	Q12	• Need rewording. • Might be better to say something like ‘has your child reacted in an aggressive or violent way during mealtimes’ as examples might not catch all such behaviours
7.	Q14	• To change ‘at least once a week’ to ‘more than once a week’ • To change ‘disruptive behaviour’ to ‘non- aggressive’ • Some families don’t have ‘mealtimes’ • Where would we include the not siting/fidgeting/continual getting up from the table type of behaviours?
8.	Q15	• Need re wording, examples might be too specific. Parents might think the child is frightened without evidence of fear or swallowing or choking • Suggestion – ‘Is your child ever frightened to trying new food? • Does this need an example of reaction that could be observed before food reaches mouth?
10.	Q17	• Need rewording • Word ‘medically prescribed’ need to be omitted to avoid false negative response

		• Many will do this without prescription • Rarely medically prescribed. Most children on special therapeutic diet have not had it medically prescribed, use term ‘special diet’ and then list examples • Q17 is telling us about parents suspicions of ASD, not the child’s behaviour
11.	Q18	• How often, regularly? Daily? Once? Need to know which ones • Q17 is telling us about parents suspicions of ASD, not the child’s behaviour
12.	Q19	• Does this question need to go before Q17? • This could be because they think the child does not like it or because they think there might be intolerance. Perhaps should be more specific • Q17 is telling us about parents suspicions of ASD, not the child’s behaviour
13.	Q20	• 2 different things in one questions • Maybe would want to ask " An NHS health professional, and a separate question asking about private practitioners? • Ask for details • Q17 is telling us about parents suspicions of ASD, not the child’s behaviour •
14.	General comments on part A	In section A, have you thought asking about the following:- • Regression of eating- many children that I seem to have often had a normal diet with a good variety until approximately 2-5 years • Sensitivity to food smells • Complete intolerance of disliked foods on their plate- foods have to be separated

Note : New questions have been added to section A. Members need to review again these questions in the second round of the review

3. Score of opinion on section B – GI symptoms

Members have reviewed 18 questions. On average, members have rated all questions as **important to very important questions** (details as below)

QUESTION	AVERAGE SCORE	QUESTION	AVERAGE SCORE
Q1	1.6	Q3.2	2.0
Q1.1	2.0	Q4	1.9
Q1.2	2.1	Q4.1	1.9

Q1.3	2.2	Q4.2	2.1
Q1.4	1.8	Q4.3	2.3
Q2	1.4	Q5	1.3
Q2.1	1.3	Q5.1	1.9
Q2.2	2.0	Q5.2	1.8
Q3	1.4		
Q3.1	1.8		

Average score: **1.8(close to important questions).** Therefore, all questions in Section B will be remained in the questionnaire.

Note: ***Question with score of 3.0 and below (which means less Important to not important) need further opinion by members, whether the question should be retained or removed from the questionnaire.***

Comments for section B
There were 13 comments from members (details as below). There were suggestions **to improve the current questions and also to add new questions (highlighted in yellow)**

No	**Question Number**	**Comments**
1.	General instruction/ statement for professionals	Time frame ' 3 months' is too high, suggestion : last month
2.	Q1	• Check official definition • Definition constipation less than 3 times per week- as per NICE Guidance CG99
3.	Q1.1	• 'Indicate to you that 'it hurts' might be better given that there will be some non-verbal children • Suggestion: Does he/she show or appear in pain while opening his/her bowel?
4.	Q1.2	• Why ask this question unless your are a dietitian or doctor who might have some idea what it means? • Might need to add 'what, if anything you noticed…' • Too detailed
5.	Q1.3	• Might not tell much about GI symptoms as such accidents may be for psychological or developmental reasons.
6.	Q2	• Add consistency of stool - definition of diarrhoea • Suggestion:'…shown symptoms of, or complained about….'
7.	Q2.1	• Why ask this question unless you are a dietitian or

		doctor who might have some idea what it means - Suggestion:'what , if anything….
9.	Q4	If vomiting, should investigate to send to GP (although not a symptom of autism?)
10.	Q4.1	- What does it mean by related to? Caused by what they ate (allergy or intolerance) - Reword to ' Is it related to eating or drinking'?
11.	Q4.2	- Too vague - He/She
12.	Q4.3	- Billious vomits suggest obstruction and should lead to a medical referral for assessment
13.	Q5	- What about overweight children with planned weight loss? - Child should gain weight. If no weight gain over past one year, it would also cause for concern - Does this mean unintentional weight loss?should this be clarified in question? - What is the child's height and age?

Note : New questions have been added to section B. Members need to review again these questions in the second round of the review

Score of opinion on section C – The Impact

Members have reviewed 6 questions. On average, members have rated all questions as **important to very important questions** (details as below)

QUESTION	AVERAGE SCORE
Q1	2.4
Q2	2.3
Q3	1.8
Q4	2.3
Q5	2.4
Q6	1.0

Average score: **2.1(important question).** Therefore, all questions in Section C will be remained in the questionnaire.

Note: ***Question with score of 3.0 and below (which means less important to not important) need further opinion by members, whether the question should be retained or removed from the questionnaire.***

Comments for section C

There were 5 comments from members (details as below). There were suggestions **to improve the current questions and also to add new questions (highlighted in yellow)**

No	Question Number	Comments
1.	Q1	• Suggestion to change to'…feeding problems had a significant impact on your finances' • Depends on secondary outcomes for the study , not clear in accompanying text
2.	Q2	• Make this more general 'family' rather than 'social life'
3.	Q2 and Q1	• Swap sequence
4.	Q4 and Q5	• Swap sequence
5	General	• Section C: Having a child with autism will invariably cause stress and limit your social life so not sure how useful asking these questions would be.

Overall comments

- As a whole, the questions are demonstrating typical autistic approaches to diet, rather than predicting a future feeding problems
- This questionnaire would be a useful tool to help identify and recognise these problems to enable appropriate support to be given to address these problems at an early stage

Specific comments

- It is essential that there is a clear pathway to help for these parents and children if they need it-otherwise the questionnaire is asking a lot of difficult and possibly distressing questions with no benefit to parent or child
- At the end of the interview, it could end up with a distressed parent, if they have answered yes to several of these questions.
- The professional administering the questionnaire needs a clear pathway for dealing with this- they cannot having uncovered problems by just say ‘thanks very much-goodbye'.
- Professionals not trained to give correct advice to these parents should be referring them to professional who can give advice and know about the 'whole' person (eg the GP or Health service professional involved in the case)

Suggestions for new questions: **At the end of section C , if the parents answer ‘yes' to many of the questions and particularly if the family life is affected**

Q7 -Do you feel that you are getting the help you need with these problems?
Q7.1- If no, what would you ideally like?

4. Score of opinion on the Information pack

Members have reviewed 5 information sheets. On average, members have rated all sheets as **important to very important** (details as below)

INFORMATION	AVERAGE SCORE
S1	1.9
S2	1.6
S3	2.9
S4	1.4
S5	1.6

Average score: **1.9(close to important information).**

Comments for information pack

No	Information Pack	Comments
1.	S1 (Food Plate)	• Need a bit more information provided • Needs additional information on basics of a healthy diet (as on the diet, behaviour and learning sheet)
2.	S2	• Useful, due to be updated
3.	S3 (Food and Mood)	• Might confuse parent. It is not specific enough
4.	S5 (List of resources)	• Needs editing but useful to those with access
5	General	• resource pack will need to be regularly updated • S5 -To add website www.brainand body.co.uk as it has lots of free information available on diet and ASD • New info sheet on Diet on Autism (updated version)

Appendix 17

REVIEW SUMMARY (FIRST ROUND)

Expert Group: <u>Parent</u>

Date of review: <u>5TH July -16th July</u>

1. Number of experts

In this review, fifthteen (15) members of the parents' support group were invited. Twelve (12) members have expressed their interest and given their consent. In this first round of the review, 11 out of 12 members (92%) have returned their review format and comments. Three members have also answered the questions from the BEFG-ASD and returned the questionnaire.

2. Score of opinion on section A – Feeding problems

Members have reviewed 20 questions. On average, members have rated all questions as **<u>important to very important questions</u>** (details as below)

QUESTION	AVERAGE SCORE	QUESTION	AVERAGE SCORE
Q1	1.4	Q11	2.4
Q2	1.2	Q12	1.4
Q3	1.4	Q13	1.4
Q4	1.5	Q14	1.8
Q5	1.3	Q15	1.8
Q6	1.9	Q16	1.3
Q7	1.6	Q17	1.3
Q8	2.2	Q18	1.8
Q9	2.5	Q19	1.3
Q10	2.3	Q20	1.4

Average score: **<u>1.7</u> (between very important questions to important questions)**. Therefore, all questions in Section A will be remained in the questionnaire.

Note: ***Question with score of 3.0 for and below (which means less important to not important) need further opinion by members, whether the question should be retained or removed from the questionnaire.***

Comments for section A

There were 20 comments from members on specific questions (detail as below). There were suggestions to **add new questions (highlighted in yellow)**

No	Question Number	Comments
1.	Q1 and Q11	Very important question to be asked because it has impact on family life. The impact of Q11 can be very distressing.
2.	Q2	This question relates to behavioural management, which involve psychologist not dietitian.
3.	Q3	Want professional ask examples of food
4.	Q3 to Q6	These questions relate to sensory issues which involve occupational therapy
5.	Q4	This question may indicate rigidity of thought and might help to determine sensory pattern for chain of food
6.	Q7	1) This question may indicate rigidity of thought and might help to determine sensory pattern for chain of food 2) This question may involve behavioural management (child psychologist)
7.	Q8	1) Question on repetitive behaviour 2) Suggestion for other question – control of cutlery
9.	Q9	Add a separate question 'served' by particular person.
10.	Q13	Behavioural issue
11.	Q12, Q13 , Q14	Very important question to distinguish behaviour and control from the food used (role of psychologist and dietitian)
12.	Q15	Fearful /frightened is too strong, suggestion of wording : 'reluctant'
13.	Q16	Could be harmful to child if identified by professionals
14.	Q17	Needs indication on how to proceed (whether by dietitian advice or anybody)
15.	Q18	Need questions what type of vitamin given to the child
16.	Q18	Is the parent trying to manage the child's diet or do they have correct information on vitamin and supplements
17.	Q19	Add question on 'why' to establish reason avoid child any particular food
18.	Q20	Add questions on what advice and who give it
19.	Q20	General comments: parent feels that she is not getting the help she needs because professionals/nobody seems interested. She has to search the information on the American website.

Note : New questions have been added to section A. Members need to review again these questions in the second round of the review

3. **Score of opinion on section B – GI symptoms**

Members have reviewed 18 questions. On average, members have rated all questions as **very important questions** (details as below)

QUESTION	AVERAGE SCORE	QUESTION	AVERAGE SCORE
Q1	1.1	Q11	1.7
Q2	1.3	Q12	1.3
Q3	1.2	Q13	1.3
Q4	1.1	Q14	1.6
Q5	1.4	Q15	1.6
Q6	1.2	Q16	1.2
Q7	1.3	Q17	1.5
Q8	1.5	Q18	1.4
Q9	1.2		
Q10	1.4		

Average score: **1.2(very important questions).** Therefore, all questions in Section B will be remained in the questionnaire.

Note: ***Question with score of 3.0 for and below (which means less Important to not important) need further opinion by members, whether the question should be retained or removed from the questionnaire.***

Comments for section B

There were 9 comments from members on specific questions (detail as below). There were suggestions to **add new questions (highlighted in yellow)**

No	Question Number	Comments
1.	Q1 to Q 2.2.	Professionals needs this information to decide if there are any problemQ1.2.and Q2.1Parent not sure what professional can tell by stools
2.	Q1.1	Children with SD may not be able to give this information
3.	Q1.4	Add question on what type of laxative given
4.	Q2.1	Parents may find it hard to answer for older children
5.	Q2.2	Add question on what type of medication given
6.	Q4.2 and 4.3	Parents may find these questions are hard to answer
7.	Q5 t0 Q5.3	Parents may want to know how quickly is the referral or need to know if problem is urgent
9.	General	More detail required about child's behaviour (refuse to go to toilet) Example of behaviour : lying on floor, sweating, gripping with pain

Note : New questions have been added to section B. Members need to review again these questions in the second round of the review

4. Score of opinion on section C – The Impact

Members have reviewed 6 questions. On average, members have rated all questions as **important to very important questions** (details as below)

QUESTION	AVERAGE SCORE
Q1	1.8
Q2	1.7
Q3	1.3
Q4	1.8
Q5	1.8
Q6	1.2

Average score: **1.5(close to important question).** Therefore, all questions in Section C will be remained in the questionnaire.

Note: ***Question with score of 3.0 for and below (which means less important to not important) need further opinion by members, whether the question should be retained or removed from the questionnaire.***

Comments for section C

1)The questions of a direct impact on the health of parent/carer due to stress and coping with difficulties related to having children on the spectrum is something else to consider, not just financial impact.

5. Score of opinion on the Information pack

Members have reviewed 5 information sheets. On average, members have rated all sheets as **important to very important** (details as below)

INFORMATION	AVERAGE SCORE
S1	2.2
S2	1.3
S3	1.9
S4	1.6
S5	1.3

Average score: **1.7(close to important information).**

S1 – (Food plate) members need to give further opinion (see below comment)

Comments for information pack

S1 – food plate is patronising. Everybody knows this. This put pressure to as parent already at having a difficulty. Setting them to eat anything that makes them ill is a bomb. The food plate is very idealistic. Most parents know what their children should be eating. It is an autistic child nature to be very picky but they are more likely to be intolerance to certain foods. When a child has a very limited diet and was struggling to eat, general advice can be stressful because parent knows that he/she cannot achieve it. ASD children can become very obsessive (e.g. my plate needs to look like that)

S2 – very useful information. A lot of parents seem to promote faddy diets and use ASD as an excuse

S5 – very important as it direct parents away from unscientific advice.

General comment :
1)very good sheet, easy to follow and answer all questions.
2) information pack was excellent, it helps parents to decide what choices they can make for their children or family.

Appendix 18

Summary of review from the Delphi technique (Round 1 and 2)

	Section A – Feeding problems (20 Qs)	Review (Parents)	Review (professionals)	My personal opinion/judgement	Final decision
***	Can we start by talking about your child's feeding and eating problems over the past 3 months?	-	Can we start by talking about your child's eating and feeding on most days/one months?	**One month** **(we can tap longstanding problems)**	Can we start by talking about your child's eating and feeding over the past month?
1.	In the last 3 months, is there any food that your family regular eats that your child refuses to eat?	In the last 3 months, is there any food that your family regularly eats that your child refuses to eat? 3/11	1) Is there any food that your family regularly eats that your child refuses to eat? 2) Are there several foods that your child refuses to eat?	Are there several foods that your child refuses to eat? **(we can directly detect many types of food, can distinguish typically selective and the very selective child)**	Are there several foods that your family regular eats that your child refuses to eat?
2	Does your child **insist on eating similar foods for most meals**?	Does your child insist on eating similar foods for most meals?	Does your child insist on eating the same types of foods for every meal or most meals?	Does your child insist on eating the same types of foods for every meal or most meals?	Does your child insist on eating the same types of foods for every meal or most meals?
3.	Do you have to **prepare special foods** for your child (compared with other family members) in the last 3 months?	Do you have to **prepare special foods** for your child (compared with other family members) in the last 3 months?	Have you had to **prepare special foods** for your child (compared with other family members)?	Have you had to **prepare special foods** for your child (compared with other family members)?	Have you had to prepare special foods for your child (compared with other family members)?
4.	Does your child insist that most of his/her foods has **particular physical characteristics** in the last 3 months ?(such as smell/ certain shape/ colour/temperature,/brand or packaging)	Does your child insist that most of his/her foods has **particular physical characteristics** in the last 3 months ?(such as smell/ certain shape/ colour/temperature/ brand /packaging)	Has your child insisted that most of his/her foods have **particular physical characteristics**?(such as smell /certain shape/ colour/ temperature/ brand or packaging)	Has your child insisted that most of his/her foods have **particular physical characteristics**?(such as smell /certain shape/ colour/ temperature/ brand or packaging)	Has your child insisted that most of his/her foods have particular characteristics?(such as smell /certain shape/ colour/ temperature/ brand or packaging)

5	Does your child have a strong preference for foods with **particular textures**? (such as soft/ hard/ lumpy/ crunchy foods)	Does your child have a strong preference for foods with **particular textures**? (such as soft/ hard/ lumpy/ crunchy foods)	Does your child have a strong preference for foods with **particular textures**? (such as soft/ hard/ lumpy/ crunchy foods)	As it is	As it is
6.	Does your child have a strong preference for foods with **particular flavours**? (such as salty/ spicy/ sweet/ sour foods)	Does your child have a strong preference for foods with **particular flavours**? (such as salty/ spicy/ sweet/ sour foods)	Does your child have a strong preference for foods with **particular flavours**? (such as salty/ spicy/ sweet/ sour foods)	As it is	As it is
7.	Does your child insist that his/her food is **served in a particular way**?	Does your child insist that his/her food is **served in a particular way**?	Does your child insist that his/her food is **served in a particular way**?	As it is	As it is
8.	Does your child insist that he/she uses **specific utensils or crockery for eating or drinking?**	Does your child insist that he/she uses specific utensils or cutlery for eating or drinking?	Does your child insist that he/she uses **specific utensils or crockery** for eating or drinking?	**Cutlery and crockery** Does your child insist that he/she uses **specific cutlery or crockery** for eating or drinking?	Does your child insist that he/she uses specific cutlery or crockery for eating or drinking? (such as spoon/fork/cups/bowl/knife)
*	New items: Cutlery control	Does your child have problems with cutlery control while eating or drinking?(such as holding knife/fork/spoon)		**I'm not sure about this. However it could contribute to inadequate intake of food**	Does your child have problems with cutlery control while eating or drinking?

***	New Item: Sensitive to smell	Does your child dislike the smell of other foods taken by family members during mealtimes?	Is your child **sensitive to food smells**?	Is your child **sensitive to food smells**? **(Agree with item- significant)**	Is your child sensitive to food smells?
9.	Has your child insisted that his/her **food is cooked by a certain person**?	Has your child insisted that his/her food is cooked by a certain person?	Has your child insisted that his/her food is cooked by a certain person?	As it is	As it is
***	New Item: Food served by certain person	Has your child insisted that his/her food is served by a certain person?		Has your child insisted that his/her food is served by a certain person? **(Agree with item- significant)**	Has your child insisted that his/her food is served by a certain person?
***	New Item: Foods not touching with each other	Does your child insist different foods not touching with each other on the plate?	1) Does your child insist on their different **foods not touching each other on the plate?** 2) Does your child insist that **different foods are not touching………?**	Does your child insist that different foods are not touching each other on plate? **(Agree with item- significant)**	Does your child insist that different foods are not touching each other on plate?
10.	Has your child insisted on eating his/her **meals in the same place**?	Has your child insisted on eating his/her meals in the same place?	Has your child insisted on eating his/her meals in the same place?	As it is	As it is
11	Has your child refused to **eat with family members during mealtimes**?	Has your child refused to eat with family members during mealtimes?	Has your child refused to eat with family members during mealtimes?	As it is	As it is
12.	Has your child shown any of the following **behaviours**	Has your child shown any behaviour during mealtimes at	1)Has your child shown an **aggressive or violent**	Has your child frequently shown an aggressive or violent behaviour	Has your child frequently shown aggressive or violent

	during mealtimes at least once a week in the last 3 months? (Such as kicking/ hitting/ shouting/scratching others or spitting out food)	least once a week in the last 3 months? Such as kicking/ hitting/ shouting/ scratching others/spitting out food)	**behaviour** during mealtimes more than once a week? (such as kicking/ hitting/shouting/ scratching others/ spitting out food) 2) Has your child frequently reacted in aggressive or violent way…………… 3) Does your child react in an aggressive or violent way…………………………….………..	during mealtimes more than once a week? **I feel that the word behavior is better to be used to relate with problematic mealtimes behaviour**	behaviour during mealtimes? (such as kicking/ hitting/shouting/scratching others/ spitting out food) ***[by ‘frequently I mean more than once a week]*** (to re-arrange the sequence of Q12,13 and 14) (to add note for the interviewer)
13	Has your child shown any **self- injurious behaviour during mealtimes at least once a week**? (such as. biting self/ hitting self)	Has your child shown any self- injurious behaviour during mealtimes at least once a week? (such as. biting self/ hitting self)	Has your child shown any **self-injurious behaviour** during mealtimes more than once a week? (such as. biting self/ hitting self)	Has your child frequently shown any **self- injurious behaviour** during mealtimes more than once a week?	Has your child frequently shown any self- injurious behaviour during mealtimes? (such as biting self/ hitting self) ***[by ‘frequently I mean more than once a week]***
14 ***	Has your child had any disruptive behaviours during mealtimes **at least once a week**? (such as pushing/throwing utensils/ throwing food)	Has your child had any disruptive behaviour during mealtimes at least once a week? (such as pushing/throwing utensils/ throwing food)	1) Has your child had any disruptive but **non-aggressive behaviour** during mealtimes more than once a week? (such as pushing/throwing utensils/ throwing food/ fidgeting/not sitting) 2) Has your child shown any difficulty to manage his/her behavior during	Has your child frequently shown any disruptive behaviour during mealtimes more than once a week? (such as pushing/throwing utensils/ throwing food **(word disruptive is much clearer, I add word ‘frequently shown’)**	Has your child frequently shown any disruptive behaviour during mealtimes? (such as pushing/throwing utensils/ throwing food) ***[by ‘frequently I mean more than once a week]***

			mealtimes……….. 3) Does your child show……………….. 4) Has your child frequently shown any disruptive behavior……….		
15 ***	Has your child ever appeared **frightened/ fearful of trying to eat new or unfamiliar foods** ?(such as child seems fearful of swallowing food or shows signs of choking)	Has your child ever appeared reluctant of trying to eat new or unfamiliar foods ?(such as child seems fearful of swallowing food or shows signs of choking)	1) Is your child ever **frightened** of trying new food?(such as child seems fearful of swallowing food or shows signs of choking) 2) Is your child **seems fearful** of swallowing foods or shows signs of choking? New question	**I agree to split this into 2 Qs (double barrel question)** 1) Has your child appeared reluctant of trying to eat new food? 2) Has your child seems fearful of swallowing food or shows signs of choking	Has your child appeared reluctant to eat new food? Has your child seemed fearful of swallowing food or shows signs of choking?
16	Does your child show craving for any **non-food items**? (such as paper/ wood/ plastic)	Does your child show craving for any non-food items? (such as paper/ wood/plastic/ playdough)	Does your child try to eat or lick any non-food items? (such as paper/ wood/plastic/ playdough)	Does your child eat or lick any non-food items? (such as paper/wood/plastic/playdough)	Does your child eat or lick any non-food items? (such as paper/wood/plastic/playdough/ wet wipes)
17. *****	Have you used any **medically prescribed special diet** as part of your child's treatment in the last 3 months? (such as gluten free casein free diet/ yeast free diet/ diet for allergy)	Have you used any medically prescribed special diet as part of your child's treatment in the last 3 months? (such as gluten free diet /casein free diet/ yeast free diet/ diet for allergy)	Have you used any special diet as part of your child's ASD treatment? (such as gluten free /casein free diet/yeast free diet/diet for allergy)	**I agree medically prescribed diet is not appropriate** Have you used any special diet as part of your child's ASD treatment? (such as gluten free /casein free diet/yeast free diet/diet for allergy)	Have you changed your child's diet as part of your child's ASD treatment?(such as excluding certain foods) The question has been reworded. Earlier question will lead to misunderstanding about special diet for ASD
			If yes, who gave the advice on how to proceed with the special diet? (such as dietitian/ paediatrician/other health professionals)	**Not agree – redundant with Q20**	If yes, give examples …..(qualifier question)

18.	Do you give any vitamin, mineral or other supplements to your child in the last 3 months?	Do you give any vitamin to your child in the last 3 months?	Do you give any vitamin supplement to your child?	**Agree to split questions (double barrel question) but disagree on the frequency given to the child**	Do you give any dietary supplements to your child? (such as vitamin/mineral/other supplement)
*		If yes, what type of vitamin?	If yes, what type of vitamin? How often you give the vitamin?	Do you give any vitamin supplement to your child? If yes, give example	If yes, give examples…….
*		Do you give any mineral or other supplement to your child in the last 3 months?	Do you give any mineral supplement to your child?	Do you give any mineral supplement to your child? If yes, give example	
*		If yes, what type of mineral or supplement?	If yes, what type of mineral? How often you give the mineral?	Do you give any other supplement? If yes, give example	
			Do you give any other supplement?		
19.	Do you avoid giving your child any particular foods?	Do you avoid giving your child any particular foods?	Do you avoid giving your child any particular foods?	As it is	As it is
*** *		If yes, why you avoid that particular food?		**I agree (to tap reason or underlying problems)**	If yes, why you avoid that particular food?

20.	Have you received any **advice from health professionals** on managing feeding or any aspect of your child’s diet?	Have you received any **advice from health professionals** on managing feeding or any aspect of your child’s diet?	1)Have you received any advice on managing feeding or any aspect of your child’s diet? 2) Have you received any advice about any aspect of your child’s diet?	**I agree with suggestions to make it general, followed by qualifier questions** Have you received any advice on managing feeding or any aspect of your child’s diet?	In the last 12 months, have you received any advice on managing feeding or any aspect of your child’s diet? (one month is too short and didn’t have any implication)
*		If yes, who give the advice?	1)If yes, who gave the advice? (such as NHS professionals or private practitioners) 2)If yes, who gave the advice?	If yes, who gave the advice?	If yes, who gave the advice?
*		What type of advice given by the professional?	What type of advice was given by the professional?	**Disagree, too specific.**	What type of advice was given by the professional? (important to know type of advice for planning any intervention)
					25 main questions

SECTION B - GI SYMPTOMS

	Section B – GI Symptoms	**Review (Parents)**	**Review (professionals)**	**My personal opinion/judgement**	**Final decision**
*******	*“NOW CAN WE TALK ABOUT ANY GUT/BOWEL PROBLEMS YOUR CHILD MIGHT HAVE EXPERIENCED **OVER THE PAST 3 MONTHS**?”*	**-**	Now can we talk about any gut/bowel problems your child might have experienced over the past one month?	**It is better to standardise the period** Now can we talk about any gut/bowel problems your child might have experienced over the past one month?	Now can we talk about any gut/bowel problems your child might have experienced over the past month?
Q1	In the last 3 months, has your child suffered from constipation (defined as bowel motion/passage less than 2 times a week)?	In the last 3 months, has your child suffered from constipation (defined as bowel motion/passage less than 2 times a week)?	In the last month, has your child suffered from constipation (defined as bowel motion/passage less than 3 times a week)?	In the last month, has your child suffered from constipation (defined as bowel motion/passage less than 3 times a week)?	In the last month, has your child suffered from constipation (defined as bowel motion/passage less than 3 times a week)?
Q1.1	If yes, does he/she say it hurts to open his bowels?	If yes, does he/she say it hurts to open his bowels?	If yes, does he/she show or appear in pain while opening his/her bowels?	If yes, does he/she say it hurts or appear in pain while opening his/her bowels?	If yes, does he/she say it hurts or appear in pain while opening his/her bowels? (qualifier)
Q1.2	Please describe what you noticed about his/her stool/ faeces/poo (e.g. hard poo, pellet-like poo, bloody poo)	Please describe what you noticed about his/her stool/ faeces/poo (e.g. hard poo, pellet-like poo, bloody poo)	1)What, if anything you noticed about his/her stool/ faeces/poo ?(such as hard poo /pellet-like poo/ bloody poo) 2)What, if anything, have you noticed……………. 3) Can you describe his/her stool?	What, if anything you noticed about his/her stool/ faeces/poo ?(such as hard poo /pellet-like poo/ bloody poo)	What, if anything have you noticed about his/her stool/ faeces/poo ?(such as hard poo /pellet-like poo/ bloody poo) ***[show picture of stools using the Bristol Stool Scale]***

Q1.3	Has your child had any ‘accidents’ with his/her bowels(in opening his/her bowels) in the last 3 months?	Has your child had any ‘accidents’ with his/her bowels (in opening his/her bowels) in the last 3 months?	Has your child had any ‘accidents’ with his/her bowels (in opening his/her bowels) in the last month?	In the last month, has your child had any ‘accidents’ with his/her bowels (in opening his/her bowels)	In the last month, has your child had any ‘accidents’ with his/her bowels (in opening his/her bowels)
Q1.4	In the last 3 months, have you used any laxatives to treat his/her constipation?	In the last 3 months, have you used any laxatives to treat his/her constipation?	Have you used any laxatives to treat his/her constipation?		Have you used any medication to treat his/her constipation?
		If yes, what type of laxative that you used to treat his/her constipation?		**This is significant** If yes, what type of laxative that you used to treat his/her constipation?	If yes, what type of medication that you used to treat his/her constipation? (qualifier)
		Was it prescribed? By whom?		**I disagree – not significant**	
Q2	In the last 3 months, has your child shown or complained about diarrhoea (which is bowel motion /passage of 2-5 times per day)?	In the last 3 months, has your child shown or complained about diarrhoea (which is bowel motion /passage of 2-5 times per day)?	In the last month, has your child shown symptoms of, or complained about diarrhoea (which is bowel motion /passage of 2-5 times per day)?to check	In the last month, has your child shown symptoms of, or complained about diarrhoea (which is bowel motion /passage of 2-5 times per day)	In the last month, has your child shown symptoms of, or complained about diarrhoea (which is bowel motion /passage of more than 3 times per day) Definition of Diarrhoea : more than 3 times a day

Q2.1	If yes, please describe what you noticed about his/her stool/ faeces/ poo.(e.g. loose poo, mucousy poo, bloody poo)	If yes, please describe what you noticed about his/her stool/ faeces/ poo.(e.g. loose poo, mucousy poo, bloody poo)	1)What if anything you noticed about his/her stool/ faeces/ poo.(such as loose poo, mucousy poo, bloody poo) 2)What, if anything, have you noticed……………. 3) Can you describe his/her stool?	1)What if anything you noticed about his/her stool/ faeces/ poo.(such as loose poo, mucousy poo, bloody poo)	What, if anything have you noticed about his/her stool/ faeces/poo ?(such as hard poo /pellet-like poo/ bloody poo) ***[show picture of stools using the Bristol Stool Scale]***
Q2.2	Do you use any medication to treat his/her diarrhoea?	Do you use any medication to treat his/her diarrhoea?	Have you used any medication to treat his/her diarrhoea?		Have you used any medication to treat his/her diarrhoea?
		If yes, what type of medication that you used to treat his/her diarrhoea?		**This is significant** If yes, what type of medication that you used to treat his/her diarrhoea?	If yes, what type of medication that you used to treat his/her diarrhoea?
		Was it prescribed? By whom?		**I disagree – not significant**	
Q3	In the last 3 months, has your child shown or complained about abdominal pain (more than 3 times a week)?	In the last 3 months, has your child shown or complained about abdominal pain (more than 3 times a week)?	In the last month, has your child shown or complained about abdominal pain (more than 3 times a week)?	In the last month, has your child shown or complained about abdominal pain (more than 3 times a week)?	Do you think that your child has regular pain at the abdominal? If yes, why? *(qualifier)*
***		Do you think that your child has regular pain at the abdominal? (more than 3 times a week) If yes, why?		Do you think that your child has regular pain at the abdominal? (more than 3 times a week) If yes, why? **This is significant**	In the last month, has your child shown or complained about abdominal pain (which is more than 3 times a week)?

Q3.1	Does the abdominal pain disrupt daily activity of your child? (eg: stopping child from playing, sleeping or going to school)	Does the abdominal pain disrupt daily activity of your child? (eg: stopping child from playing, sleeping or going to school)	Does the abdominal pain disrupt daily activity of your child? (such as stopping child from playing/sleeping/going to school)	Does the abdominal pain disrupt daily activity of your child? (such as stopping child from playing/sleeping/going to school)	Does the abdominal pain disrupt daily activity of your child? (such as stopping child from playing/sleeping/going to school)
Q3.2	Do you use any medication to treat his/her abdominal pain?	Do you use any medication to treat his/her abdominal pain?	Have you used any medication to treat his/her abdominal pain?	Have you used any medication to treat his/her abdominal pain?	Have you used any medication to treat his/her abdominal pain?
Q4	In the last 3 months, has your child shown or complained about vomiting (at least once week)?	In the last 3 months, has your child shown or complained about vomiting (at least once week)?	In the last month, has your child shown or complained about vomiting (at least once week)?	In the last month, has your child shown or complained about vomiting (at least once week)?	In the last month, has your child frequently vomited? ***[by 'frequently I mean more than once a week]***
Q4.1	If yes, is it related to meals?	If yes, have you any idea what may caused it?	If yes, is it related to eating or drinking?	If yes, is it related to eating or drinking?	If yes, is it related to eating or drinking? *(qualifier)*
Q4.2	How much does she/he vomits?(e.g. great amount/quite a lot/a bit)	How much does she/he vomits?(e.g. great amount/quite a lot/a bit)	How much does he/she vomit?(such as great amount/quite a lot/a bit) …………………………………………….	How much does he/she vomit?(such as great amount/quite a lot/a bit) ……………………………………………	How much does he/she vomit?(such as great amount/quite a lot/a bit) *(qualifier)*

Q4.3	What does` the vomits look like? (e.g.: green, brown or red colour(with blood)	What does` the vomits look like? (e.g.: green, brown or red colour(with blood)	What does` the vomit look like? (such as green, brown or red colour(with blood)	What does` the vomit look like? (such as green, brown or red colour(with blood)	What does` the vomit look like? (such as green, brown or red colour(with blood) *(qualifier)*
***	New item : Toileting Issue	In the last 3 months, has your child refused to go to the toilet?		Significant- related to abdominal pain In the last 3 months, has your child refused to go to the toilet?	In the last month, has your child refused to go to the toilet?
		If yes, has she/he shown any of this behaviour? (e.g. lying on floor, sweating or gripping with pain?)			If yes, has she/he shown any behaviour? (such as lying on floor, sweating or gripping with pain?) *Question need to be added earlier (before questions on weight)*
					New question Do you worry about any aspects of your child's growth? If yes, what is your concern? *(qualifier)*

Q5	In the last 3 months, has your child lost weight?	In the last 3 months, has your child lost weight?	In the last month, has your child unintentionally lost weight?	In the last month, has your child unintentionally lost weight?	In the last month, has your child unintentionally lost weight?
Q5.1	If yes, how much is the weight loss?	If yes, how much is the weight loss?	If yes, how much is the weight loss?	As it is	If yes, how much? ?(such as great amount/quite a lot/a bit) *(qualifier)*
Q5.3	Did you worry about his/her weight loss?	Did you worry about his/her weight loss?	Do you worry about your child's weight loss?	Do you worry about your child's weight loss?	Do you worry about your child's weight loss?
***	New Item: Weight Gain		In the last one month, has your child gained weight?	In the last one month, has your child gained weight?	In the last one month, has your child gained weight?
			If yes, how much is the weight gain?	If yes, how much is the weight gain?	If yes, how much? ?(such as great amount/quite a lot/a bit) *(qualifier)*
			Do you worry about your child's weight gain?	Do you worry about your child's weight gain?	Do you worry about your child's weight gain?
					15 main questions

Suggestion to use Bristol Stool Scale (BSS)

SECTION C: IMPACT ON FAMILY LIFE

	Section B – GI Symptoms	**Review (Parents)**	**Review (professionals)**	**My personal opinion/judgement**	**Final decision with supervisors**
***	Finally I would like to ask you about what impact, if any, your child's feeding or gut problem(s) has had on you and your family? Impact refers to any restriction experienced over the last 3 months by you as a result of these problems.		Finally, I would like to ask you about what impact, if any, your child's feeding or gut problems(s) has had on you? Impact refers to any restriction experienced by you as a result of these problems.	**I standardised with FP and GI – 1 month** Finally, I would like to ask you about what impact, if any, your child's feeding or gut problems(s) has had on you? Impact refers to any restriction experienced over the past one(1) month by you as a result of these problems.	Finally, I would like to ask you about what impact, if any, your child's feeding or gut problems(s) has had on you? Impact refers to any restriction experienced over the past month by you as a result of these problems.
Q1	Has your child's feeding problems affected the financial aspects of the family?	Has your child's feeding problems affected the financial aspects of the family?	1)Has your child's feeding problems had a significant impact on your finances? 2) Has your child's feeding problems have a significant impact on your finances?	Has your child's feeding problems have a significant impact on your finances?	Have your child's feeding problems had a significant impact on your finances?
Q2	Do you think that the feeding problems restrict your social life in any way?	Do you think that the feeding problems restrict your social life in any way?(such as going out, working, attending functions)	1)Do you think that the feeding problems restrict your social life in any way? (such as going out/ working/ attending functions) 2)Do you think that the feeding problems restrict your family life in any way? 3) Do you think that the feeding problems make your social life more difficult?	Do you think that the feeding problems restrict your social life in any way? (such as going out/ working/ attending functions	Do you think that the feeding problems restrict your life in any way? (such as going out/ working/ attending functions

Q3	Do you think that the demands of managing feeding problems of your child have placed any extra stress on you?	Do you think that the demands of managing feeding problems of your child have placed any extra stress on you?	Do you think that the demands of managing feeding problems of your child have placed any extra stress on you?	As it is	As it is
	New item: Overall Impact on family	How has the feeding problems affected your family life?		**Significant item** How has the feeding problems affected your family life?	How has the feeding problems affected your family life?
Q4	Has your child's gut problems affected the financial aspects of the family?	Has your child's gut problems affected the financial aspects of the family?	Has your child's gut problems had a significant impact on your finances? 2) Has your child's feeding problems have a significant impact on your finances?	Has your child's gut problems have a significant impact on your finances?	Have your gut problems had a significant impact on your finances?
Q5	Do you think that the gut problems restrict your social life in any way?	Do you think that the gut problems restrict your social life in any way?(such as going out, working, attending functions)	1)Do you think that the gut problems restrict your social life in any way? (such as going out/ working/ attending functions) 2)Do you think that the gut problems restrict your family life in any way?		Do you think that the gut problems restrict your life in any way? (such as going out/ working/ attending functions
Q6	Do you think that the gut problems of your child have placed any extra stress on you?	Do you think that the demands of managing gut problems of your child have placed any extra stress on you?	Do you think that the demands of managing the gut problems of your child have placed any extra stress on you?		Do you think that the demands of managing the gut problems of your child have placed any extra stress on you?

	New item: Overall Impact on family	How has the gut problems affected your family life?			How has the gut problems affected your family life?
	New Item: Coping with ASD difficulties	Do you think that coping with difficulties of having a child with ASD have placed any extra stress on you?			Do you think that coping with difficulties of having a child with ASD have placed any extra stress on you?
***	New Item: Getting help/Support	Do you feel that you are getting the help you need with these problems?	Do you feel that you are getting the help you need with these problems? Yes No	**Very significant** Do you feel that you are getting the help you need with these problems?	Do you feel that you are getting the help you need with these problems?
		If No, what help would you ideally like?		If No, what help would you ideally like?	If No, what help would you ideally like?
					8 main questions

The information pack

	Section B – GI Symptoms	Review (Parents)	Review (professionals)	Final decision
S1	Food plate –eat well picture	Not important – parents would be stressful/feel guilty if been told to follow the general guideline (40% have rated this)	-	Removed
S2	Diet and Autism Spectrum Disorder	Very important information	Very important information	Retained
S3	Food and Mood	important information	Not Specific enough/Not important (20% have rated this)	Retained
S4	Diet, behaviour and learning difficulties	important information	Not Specific enough/Not important (20% have rated this)	Retained
S5	List of useful websites about ASD (content has been updated)	Very important information	important information	Retained

Appendix 19. The BEFG-ASD (Version 3)

THE BEFG -ASD

The Brief Structured Questionnaire for the Early Identification of Feeding Problems and Gastrointestinal Symptoms in Primary School Children with Autism Spectrum Disorders (ASD)

ID Number P ☐ ☐ PR ☐ ☐ ☐

Name (Interviewer) :..

Name (Parent/Carer):..

For health and education practitioners

Version 3 (2010)

GENERAL INSTRUCTION

- The **BEFG-ASD** is a **B**rief structured questionnaire for the **E**arly identification of **F**eeding problems and **G**astrointestinal symptoms in primary school children with **Autism Spectrum Disorders (ASD)** and the impact of these problems on family life.

- The new instrument is designed for professionals to use with parents/caregivers of **children with ASDs aged 4 -11 years** when there are concerns about feeding problems or gastrointestinal (GI) symptoms.

- The BEFG has three sections:

  - **Section A: Feeding problems**
  - **Section B: GI symptoms**
  - **Section C: Impact on family life**

- Before you use the BEFG, please read and understand the general instruction in **Section A (Feeding Problems), Section B (GI symptoms) and Section C (Impact on family life).**

- Please familiarise yourself with the questionnaire before you conduct the interview. **Please follow the instruction given in each section**.

SECTION A: FEEDING PROBLEMS

General instruction for professional

- **Circle the response given by parent/caregiver**

CAN WE START BY TALKING ABOUT YOUR CHILD'S EATING AND FEEDING ***OVER THE PAST MONTH?***

1.	Are there several foods that your family regularly eat that your child refuses to eat?	Yes	No
	If yes, give examples:…………………………………………		
2	Does your child insist on eating the same types of foods for every meal or most meals?	Yes	No
	If yes, give examples:……………………………………………		
3.	Have you had to prepare special foods for your child (compared with other family members)?	Yes	No
4.	Has your child insisted that most of his/her foods have particular characteristics?(such as smell /certain shape/ colour/ temperature/ brand or packaging)	Yes	No
	If yes, give examples:……………………………………………		
5	Does your child have a strong preference for foods with particular textures? (such as soft/ hard/ lumpy/ crunchy foods)	Yes	No
	If yes, give examples:……………………………………………		
6.	Does your child have a strong preference for foods with particular flavours? (such as salty/ spicy/ sweet/ sour foods)	Yes	No
	If yes, give examples:……………………………………………		
7.	Is your child sensitive to food smells?	Yes	No
8.	Does your child insist that his/her food is served in a particular way?	Yes	No
9.	Does your child insist that he/she uses specific cutlery or crockery for eating or drinking? (such as spoon/fork/cups/bowl/knife)	Yes	No
10.	Does your child have problems with cutlery control while eating or drinking?	Yes	No

11.	Has your child insisted that his/her food is cooked by a certain person?	Yes	No
12.	Has your child insisted that his/her food is served by a certain person?	Yes	No
13.	Does your child insist that different foods are not touching each other on plate?	Yes	No
14.	Has your child insisted on eating his/her meals in the same place?	Yes	No
15.	Has your child refused to eat with family members during mealtimes?	Yes	No
16.	Has your child frequently shown any disruptive behaviour during mealtimes more than once a week? (such as pushing/throwing utensils/ throwing food) ***[by 'frequently' I mean more than once a week]***	Yes	No
	If yes, give examples:………………………………………………		
17.	Has your child frequently shown aggressive or violent behaviour during mealtimes? (Such as kicking/ hitting/ shouting/scratching others or spitting out food) ***[by 'frequently' I mean more than once a week]***	Yes	No
	If yes, give examples:………………………………………………		
18.	Has your child frequently shown any self- injurious behaviour during mealtimes? (such as. biting self/ hitting self) ***[by 'frequently' I mean more than once a week]***	Yes	No
	If yes, give examples:………………………………………………		
19.	Has your child appeared reluctant to eat new food?	Yes	No
20.	Has your child seems fearful of swallowing food or shows signs of choking		
	If yes, give examples:………………………………………………		
21.	Does your child eat or lick any non-food items? (such as paper/wood/plastic/play dough/wet wipes)	Yes	No

22.	Have you changed your child's diet as part of your child's ASD treatment? (such as excluding certain foods)	Yes No
	If yes, give examples:……………………………………………	
23.	Do you give any dietary supplements to your child? (such as vitamin/mineral/other supplement)	Yes No
	If yes, give examples:……………………………………………	
24.	Do you avoid giving your child any particular foods?	Yes No
	If yes, why you avoid that particular food? ………………………………………	
25.	In the last 12 months, have you received any advice on managing feeding or any aspect of your child's diet?	Yes No
	If yes, who gave the advice?:………………………………………	
	What type of advice?..	

SECTION B - GASTROINTESTINAL SYMPTOMS

General instruction for professional

- **Please circle the response given by parent/caregiver.**

"NOW CAN WE TALK ABOUT ANY GUT/BOWEL PROBLEMS YOUR CHILD MIGHT HAVE EXPERIENCED ***OVER THE PAST MONTH****?"*

1.	In the last month, has your child suffered from constipation (defined as bowel motion/passage less than 3 times a week)?	Yes	No **(Go to Q3)**
	If yes, does he/she say it hurts or appear in pain while opening his/her bowels?	Yes	No
	What, if anything have you noticed about his/her stool/ faeces/poo ?(such as hard poo /pellet-like poo/ bloody poo) ***[show picture of stools using the Bristol Stool Scale]*** …………………………………………………………………………………		
2.	Have you used any medication or therapy to treat his/her constipation?	Yes	No
	If yes, what type of medication that you used to treat his/her constipation? ………………………………………………………		
3.	In the last month, has your child had any 'accidents' with his/her bowels (in opening his/her bowels)	Yes	No
4.	In the last month, has your child shown symptoms of, or complained about diarrhoea (which is bowel motion /passage of 2-5 times per day)	Yes	No **(Go to Q7)**
5.	What, if anything have you noticed about his/her stool/ faeces/ poo?(such as loose poo/ mucousy poo/ bloody poo) ***[show picture of stools using the Bristol Stool Scale]*** …………………………………………………………………………………		
6.	Have you used any medication or therapy to treat his/her diarrhoea?	Yes	No
	If yes, what type of medication that you used to treat his/her diarrhoea?		

7.	Do you think that your child has regular pain at the abdominal?	Yes	No **(Go to Q11)**
	If yes, why? …………………………………………………………….		
8.	In the last month, has your child shown or complained about abdominal pain (which is more than 3 times a week)?	Yes	No
9.	Does the abdominal pain disrupt daily activity of your child? (such as stopping child from playing/sleeping/going to school)	Yes	No
10.	Do you use any medication or therapy to treat his/her abdominal pain?	Yes	No
	If yes, what type of medication that you used to treat his/her abdominal pain? ……………………………………………………………		
11.	In the last 3 months, has your child refused to go to the toilet?	Yes	No
	If yes, has he/she shown any behaviour? (such as lying on floor/sweating / gripping with pain?) ……………………………………………………………	Yes	No
12.	In the last month, has your child frequently vomited? ***[by 'frequently' I mean at least once a week]***	Yes	No **(Go to Q13)**
	If yes, is it related to eating or drinking?	Yes	No
	How much does he/she vomit? (such as great amount/quite a lot/a bit) ……………………………………………………………………………..		
	What does` the vomit look like? (such as green, brown or red colour(with blood) ……………………………………………………………………………..		
13.	Do you worry about any aspects of your child's growth?	Yes	No
	If yes, what is your concern?..		
14.	In the last month, has your child unintentionally lost weight?	Yes	No
	If yes, how much? (such as a bit/quite a lot/great amount) ……………………………………………………………………………..		
15.	Do you worry about your child's weight loss?	Yes	No
16.	In the last month, has your child gained weight?	Yes	No
	If yes, how much? (such as a bit/quite a lot/great amount) ……………………………………………………………		
17.	Do you worry about your child's weight gain?	Yes	No

SECTION C- IMPACT OF FEEDING PROBLEMS AND GASTROINTESTINAL SYMPTOMS

General instruction for professional

For parents who do not have any feeding problems or GI symptoms (**if all answers are no),** please mark **'not applicable'**.

Please circle the response given by parent/caregiver.

"*FINALLY, I WOULD LIKE TO ASK YOU ABOUT WHAT IMPACT, IF ANY, YOUR CHILD'S FEEDING OR GUT PROBLEM(S) HAS HAD ON YOU AND YOUR FAMILY?IMPACT REFERS TO ANY RESTRICTION EXPERIENCED* ***OVER THE LAST MONTH*** *BY YOU AND YOUR FAMILY AS A RESULT OF THESE PROBLEMS".*

For each question please tell me your answer based on these four (4) categories: ***'a great deal, quite a lot, only a bit or not at all"****.*

1. Do you think that the feeding problems restrict your life in any way? (such as going out/ working/ attending functions)

   A great deal** *   **Quite a lot** *   **Only a bit**   **Not at all/No**   **Not Applicable

2. Do you think that the demands of managing the feeding problems of your child have placed any extra stress on you?

   A great deal** *   **Quite a lot** *   **Only a bit**   **Not at all/No**   **Not Applicable

3. Have your child's feeding problems have a significant impact on your finances?

   A great deal** *   **Quite a lot** *   **Only a bit**   **Not at all/No**   **Not Applicable

4. How has the feeding problems affected your family life?

   A great deal** *   **Quite a lot** *   **Only a bit**   **Not at all/No**   **Not Applicable

5. Do you think that the gut problems restrict your life in any way? (such as going out/ working/ attending functions)

   A great deal** *   **Quite a lot** *   **Only a bit**   **Not at all/No**   **Not Applicable

6. Do you think that the demands of managing the gut problems of your child have placed any extra stress on you?

   A great deal** *   **Quite a lot** *   **Only a bit**   **Not at all/No**   **Not Applicable

7. Have your child's gut problems have a significant impact on your finances?

   A great deal** *   **Quite a lot** *   **Only a bit**   **Not at all/No**   **Not Applicable

8 How has the gut problems affected your family life?

   A great deal** *   **Quite a lot** *   **Only a bit**   **Not at all/No**   **Not Applicable

If answer a great deal/quite a lot to any of these questions, please get details (if necessary):

……………………………………………………………………………………

……………………………………………………………………………………

……………………………………………………………………………………

9.	Do you feel that you are getting the help you need with these problems?	Yes	No
	[by 'problems' I mean feeding problems or gut problems]		

If No, what help would you ideally like?

....
……………………………………………………………………….

[Thank you to parent]

THANK YOU VERY MUCH FOR GIVING THE INFORMATIONS".

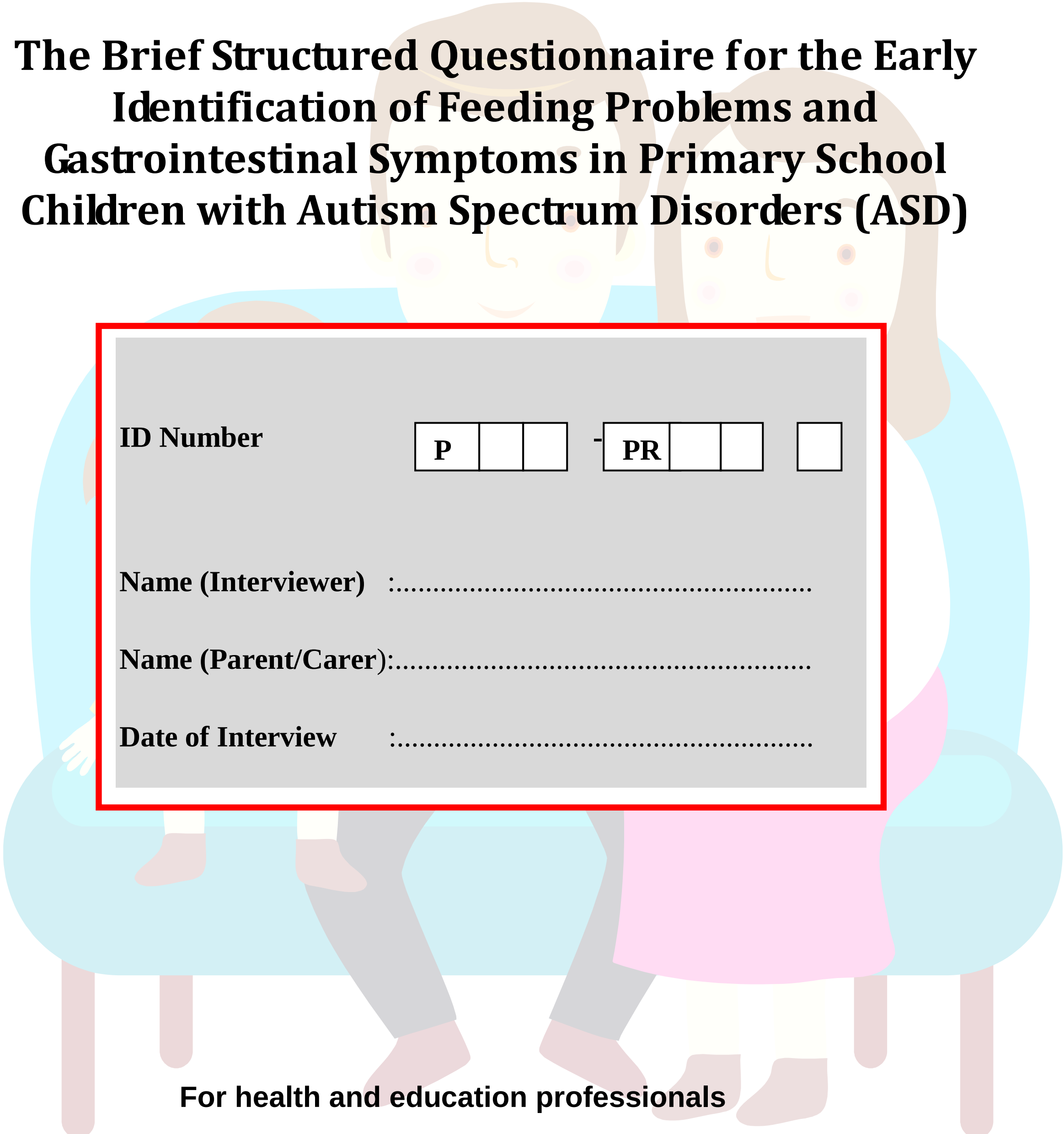
Further instruction for professional

Towards the end of the interview, give the information pack to parent.

END OF INTERVIEW

Appendix 20. The BEFG-ASD (Version 3.1)

THE BEFG -ASD



The Brief Structured Questionnaire for the Early Identification of Feeding Problems and Gastrointestinal Symptoms in Primary School Children with Autism Spectrum Disorders (ASD)

ID Number P☐☐ - PR☐☐ ☐

Name (Interviewer) :..

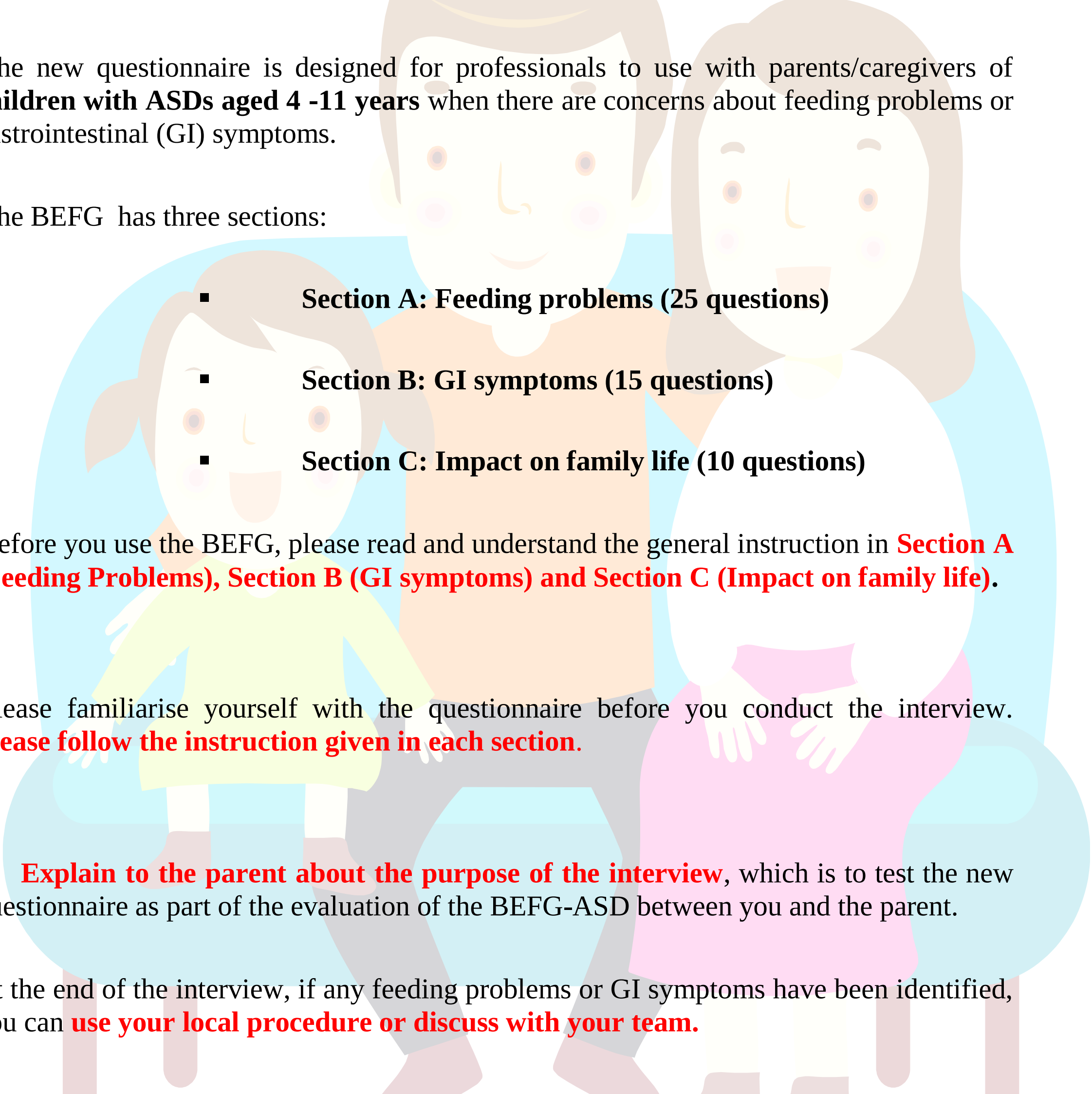
Name (Parent/Carer):..

Date of Interview :..

For health and education professionals

Version 3.1 (2010)

GENERAL INSTRUCTION FOR PROFESSIONAL



- The **BEFG-ASD** is a **B**rief structured questionnaire for the **E**arly identification of **F**eeding problems and **G**astrointestinal symptoms in primary school children with **Autism Spectrum Disorders (ASD)** and the impact of these problems on family life.

- The new questionnaire is designed for professionals to use with parents/caregivers of **children with ASDs aged 4 -11 years** when there are concerns about feeding problems or gastrointestinal (GI) symptoms.

- The BEFG has three sections:
  - **Section A: Feeding problems (25 questions)**
  - **Section B: GI symptoms (15 questions)**
  - **Section C: Impact on family life (10 questions)**

- Before you use the BEFG, please read and understand the general instruction in **Section A (Feeding Problems), Section B (GI symptoms) and Section C (Impact on family life).**

- Please familiarise yourself with the questionnaire before you conduct the interview. **Please follow the instruction given in each section**.

- **Explain to the parent about the purpose of the interview**, which is to test the new questionnaire as part of the evaluation of the BEFG-ASD between you and the parent.

- At the end of the interview, if any feeding problems or GI symptoms have been identified, you can **use your local procedure or discuss with your team.**

- If the parent wants to seek further referral or assessment, you should ask **permission from the parent** before you forward any concern to the research team. The research team will then write a formal letter to the child's GP and give the parent a copy of the letter.

SECTION A: FEEDING PROBLEMS

General instruction for professional

- **Circle or tick the response given by parent/caregiver**

CAN WE START BY TALKING ABOUT YOUR CHILD'S EATING AND FEEDING ***OVER THE LAST FOUR (4) WEEKS?***

1	Are there several foods that your family regularly eat that your child refuses to eat?	Yes	No
	If yes, give examples:……………………………		
2	Does your child insist on eating the same types of foods for every meal or most meals?	Yes	No
	If yes, give examples:……………………………		
3	Have you had to prepare special foods for your child (compared with other family members)?	Yes	No
	If yes, give examples:…………………………		
4	Has your child insisted that most of his/her foods have particular characteristics?(such as smell /certain shape/ colour/ temperature/ brand or packaging)	Yes	No
	If yes, give examples:…………………………		
5	Does your child have a strong preference for foods with particular textures? (such as soft/ hard/ lumpy/ crunchy foods)	Yes	No
	If yes, give examples:…………………………		
6	Does your child have a strong preference for foods with particular flavours? (such as salty/ spicy/ sweet/ sour foods)	Yes	No
	If yes, give examples:………………………		
7	Is your child sensitive to food smells?	Yes	No
	If yes, give examples:…………………………		
8	Does your child insist that his/her food is served in a particular way?	Yes	No
	If yes, give examples:…………………………		

9.	Does your child insist that he/she uses specific cutlery or crockery for eating or drinking? (such as spoon/fork/cups/bowl/knife)	Yes	No
	If yes, give examples:……………………….		
10.	Does your child have problems with cutlery control while eating or drinking?	Yes	No
	If yes, give examples:………………………		
11.	Has your child insisted that his/her food is cooked by a certain person?	Yes	No
	If yes, give examples:………………………		
12.	Has your child insisted that his/her food is served by a certain person?	Yes	No
	If yes, give examples:………………………		
13.	Does your child insist that different foods are not touching each other on plate?	Yes	No
	If yes, give examples:……………………		
14.	Has your child insisted on eating his/her meals in the same place?	Yes	No
	If yes, give examples:……………………		
15.	Has your child refused to eat with family members during mealtimes?	Yes	No
	If yes, give examples:……………………		
16.	Has your child frequently shown any disruptive behaviour during mealtimes? (such as pushing/throwing utensils/ throwing food) ***[by ‘frequently’ I mean more than once a week]***	Yes	No
	If yes, give examples:………………………		
17.	Has your child frequently shown aggressive or violent behaviour during mealtimes? (Such as kicking/ hitting/ shouting/scratching others or spitting out food) ***[by ‘frequently’ I mean more than once a week]***	Yes	No
	If yes, give examples:…………………………		

18. Has your child frequently shown any self-injurious behaviour during mealtimes? (such as. biting self/ hitting self) Yes No

[by ‘frequently’ I mean more than once a week]

If yes, give examples:………………………

19. Has your child appeared reluctant to eat new food? Yes No

If yes, give examples:………………………

20. Has your child seemed fearful of swallowing food or shows signs of choking? Yes No

If yes, give examples:………………………

21. Does your child eat or lick any non-food items? (such as paper/wood/plastic/play dough/wet wipes) Yes No

If yes, give examples:………………………

22. Have you changed your child’s diet as part of your child’s ASD treatment? (such as excluding certain foods) Yes No

If yes, give examples:………………………

23. Do you give any dietary supplements to your child? (such as vitamin/mineral/other supplement) Yes No

If yes, give examples:……………………….

24. Do you avoid giving your child any particular foods? Yes No

If yes, why you avoid that particular food?
………………………………………

25. In the last 12 months, have you received any advice on managing feeding or any aspect of your child’s diet? Yes No

If yes, who gave the advice?:………………………………………

What type of advice?..

SECTION B - GASTROINTESTINAL SYMPTOMS

General instruction for professional

- **Please circle or tick the response given by parent/caregiver.**

"NOW CAN WE TALK ABOUT ANY GUT/BOWEL PROBLEMS YOUR CHILD MIGHT HAVE EXPERIENCED ***OVER THE LAST FOUR (4) WEEKS?***

1	In the last month, has your child suffered from constipation (defined as bowel motion/passage less than 3 times a week)?	Yes	No **(Go to Q3)**
	If yes, does he/she say it hurts or appear in pain while opening his/her bowels?	Yes	No
	What, if anything have you noticed about his/her stool/ faeces/poo ?(such as hard poo /pellet-like poo/ bloody poo) ***[show picture of stools using the Bristol Stool Scale]*** …………………………………………………………………………………		
2	Have you used any medication or therapy to treat his/her constipation?	Yes	No
	If yes, what type of medication that you used to treat his/her constipation?…………………………………		
3	In the last month, has your child had any 'accidents' with his/her bowels /gut (in opening his/her bowels)	Yes	No
4	In the last month, has your child shown symptoms of, or complained about diarrhoea (which is bowel motion /passage more than 3 times per day)	Yes	No **(Go to Q7)**
5	What, if anything have you noticed about his/her stool/ faeces/ poo?(such as loose poo/ mucousy poo/ bloody poo) ***[show picture of stools using the Bristol Stool Scale]*** …………………………………………………………		
6	Have you used any medication or therapy to treat his/her diarrhoea?	Yes	No
	If yes, what type of medication that you used to treat his/her diarrhoea? ……………………………………………………		
7	Do you think that your child has regular abdominal pain?	Yes	No **(Go to Q11)**
	If yes, why?...		
8	In the last month, has your child shown or complained about abdominal pain (which is more than 3 times a week)?	Yes	No

9.	Does the abdominal pain disrupt daily activity of your child? (such as stopping child from playing/sleeping/going to school)	Yes	No
	If yes, give examples:……………………		
10	Do you use any medication or therapy to treat his/her abdominal pain?	Yes	No
	If yes, what type of medication that you used to treat his/her abdominal pain? ………………………………………………		
11.	In the last month, has your child refused to go to the toilet?	Yes	No
	If yes, has he/she shown any behaviour? (such as lying on floor/sweating / gripping with pain?) ……………………………………………	Yes	No
12.	In the last month, has your child frequently vomited? ***[by 'frequently' I mean at least once a week]***	Yes	No **(Go to Q13)**
	If yes, is it related to eating or drinking?	Yes	No
	How much does he/she vomit? (such as great amount/quite a lot/a bit) …………………………………………………………………………		
	What does` the vomit look like? (such as green, brown or red colour(with blood)…………………………………………………………..		
13.	Do you worry about any aspects of your child's growth?	Yes	No
	If yes, what is your concern?..		
14.	In the last month, has your child lost weight?	Yes	No **(Go to Q15)**
	If yes, were you trying to reduce his/her weight?	Yes	No
	How much? (such as a bit/quite a lot/great amount) …………………………………………………………………………		
	Do you worry about your child's weight loss?	Yes	No
15.	In the last month, has your child gained weight?	Yes	No **(Go to section C)**
	If yes, how much? (such as a bit/quite a lot/great amount)…………………………….		
	Do you worry about your child's weight gain?	Yes	No

SECTION C- IMPACT OF FEEDING PROBLEMS AND GASTROINTESTINAL SYMPTOMS

General instruction for professional

For parents whose child do not have any feeding problems or GI symptoms (**if all answers are no),** please mark **‘not applicable’**.

Please circle or tick the response given by parent/caregiver.

“FINALLY, I WOULD LIKE TO ASK YOU ABOUT WHAT IMPACT, IF ANY, YOUR CHILD’S FEEDING OR GUT PROBLEM(S) HAS HAD ON YOU AND YOUR FAMILY?

IMPACT REFERS TO ANY RESTRICTION EXPERIENCED ***OVER THE PAST FOUR (4) WEEKS*** *BY YOU AND YOUR FAMILY AS A RESULT OF THESE PROBLEMS”.*

For each question please tell me your answer based on these four (4) categories: ***‘a great deal, quite a lot, only a bit or not at all”****.*

1	Do you think that the feeding problems restrict your life in any way? (such as going out/ working/ attending functions)				
	A great deal *	***Quite a lot ****	***Only a bit***	***Not at all/No***	***Not Applicable***
2	Do you think that the demands of managing the feeding problems of your child have placed any extra stress on you?				
	A great deal *	***Quite a lot ****	***Only a bit***	***Not at all/No***	***Not Applicable***
3	Has your child’s feeding problems had a significant impact on your finances?				
	A great deal *	***Quite a lot ****	***Only a bit***	***Not at all/No***	***Not Applicable***
4	How have the feeding problems affected your family life?				
	A great deal *	***Quite a lot ****	***Only a bit***	***Not at all/No***	***Not Applicable***
5	Do you think that the gut/bowel problems restrict your life in any way? (such as going out/ working/ attending functions)				
	A great deal *	***Quite a lot ****	***Only a bit***	***Not at all/No***	***Not Applicable***
6	Do you think that the demands of managing the gut/bowel problems of your child have placed any extra stress on you?				
	A great deal *	***Quite a lot ****	***Only a bit***	***Not at all/No***	***Not Applicable***
7	Have your child’s gut/bowel problems have a significant impact on your finances?				
	A great deal *	***Quite a lot ****	***Only a bit***	***Not at all/No***	***Not Applicable***
8	How have the gut/bowel problems affected your family life?				
	A great deal *	***Quite a lot ****	***Only a bit***	***Not at all/No***	***Not Applicable***

If answer a great deal/quite a lot* to any of these questions, please get details (if necessary):

……………………………………………………………………………………………

……………………………………………………………………………………………

……………………………………………………………………………………………

……………………………………………………………………………………………

9	Do you feel that you are getting the help you need with these problems? ***[by 'problems' I mean feeding problems or gut/bowel problems]***	Yes	No
	If No, what help would you ideally like? …………………………………………………………………… …………………………………………………		
10.	Do you think that coping with difficulties of having a child with ASD have placed any extra stress on you?	Yes	No

THANK YOU VERY MUCH FOR COMPLETING THE QUESTIONNAIRE".

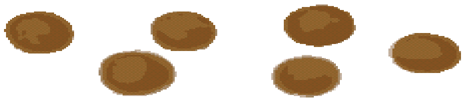
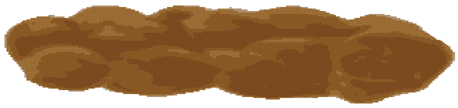
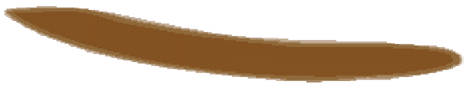
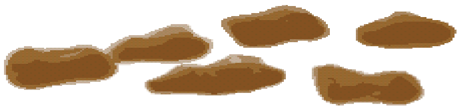
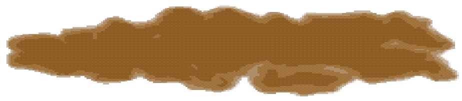
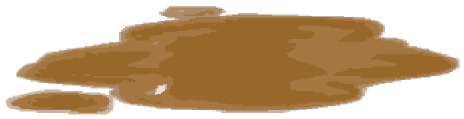
Further instruction for professional

Towards the end of the interview:

- give the information pack to parent.
- if any feeding problems or gut problems have been identified, you can **discuss with your team/ colleague or use your local procedure**
- if the parent wants to seek further referral or assessment , you should ask **permission from the parent** to forward the concern to the research team. The research team will then write a formal letter to inform the child's GP and give the copy of the letter to the parent and the professional.

Appendix 21- Bristol Stool Chart

Bristol Stool Chart

Type 1		**Seperate hard lumps, like nuts (hard to pass)**
Type 2		**Sausage-shaped but lumpy**
Type 3		**Like a sausage but with cracks on its surface**
Type 4		**Like a sausage or snake, smooth and soft**
Type 5		**Soft blobs with clear-cut edges (passed easily)**
Type 6		**Fluffy pieces with ragged edges, a mushy stool**
Type 7		**Watery, no solid pieces. Entirely liquid**

Type 1and 2: Constipation

Type 3 and 4: Normal stool patterns

Type 4, 5 and 6: Diarrhoea