



Dear Parent/Professional,

Please find below a summary of results of the 'PADIA – Parents and Professionals Attitudes towards Dietary Interventions in ASD' survey, which you kindly completed in 2009/2010. The PADIA study was led by Professor Ann Le Couteur from Newcastle University, collaborating with Edinburgh University and Guys and St Thomas Trust in London.

We are pleased to report that a research paper about PADIA is currently underway which we hope to submit for publication at the end of the summer, 2010.

The PADIA team would like to take this opportunity to thank all those who completed the survey. If you have any queries please contact our research assistant, Jenna Charlton by telephoning 0191 2821379, or email jenna.charlton@ncl.ac.uk.

Best wishes from the PADIA research team.

PADIA: Parents and Professionals Attitudes towards Dietary Interventions in Autism Spectrum Disorders (ASD): Summary of findings for all parents and professionals July 2010

We would like to thank all parents and professionals who took part in PADIA.
We are very grateful for the time and effort you put in to complete the surveys.

Introduction

Parents of children with ASD are implementing biomedical interventions such as special diets and dietary supplements, despite a lack of robust independent evaluation of these treatments. In a recent US survey, parents reported that they have tried 7-9 treatments for their child, and are using at least 4-6 treatments at the same time (Goin-Kochel et al, 2007). Indeed these interventions are being used by parents with or without professional support. Parents also report that professionals are unable to provide advice about many of these interventions (Rhoades et al, 2007) and so parents need to look to other parents, the media and internet for such information (Mackintosh et al, 2005).

The most commonly used special diet for ASD is the **gluten-free casein-free (GFCF) diet**. The use of this GFCF diet, as with other exclusion diets is not without risk for both the child and family (Arnold et al, 2003).

What was the purpose of our PADIA study?

In this study parents of children with an ASD (up to age 11 years) and child health professionals who work with young children with ASD were invited to complete online questionnaires. These questionnaires were developed to survey:

- (i) Parents and key professionals experience with ASD interventions and their attitudes to biomedical interventions such as the GFCF diet
- (ii) Their current research priorities, and previous and current experiences of research
- (iii) And their attitudes about a proposed large-scale randomised controlled trial (RCT) of the GFCF diet

This study was funded by a research grant from a US charity: AUTISM SPEAKS that funds autism research. Once we had designed the on-line questionnaires and had gained a favourable ethical opinion from Sunderland Research Ethics Committee (ref 09/H0904/7) recruitment took place from April 2009- February 2010. For all those who completed a questionnaire, there was the opportunity to win a laptop in our prize draw at the end of the study.

Findings:

258 **parents** (of the 361 who visited the website) completed the PADIA questionnaire. Responses came from all parts of the UK. Most were white British mothers (87%) and 3/4 had successfully completed higher education qualifications.

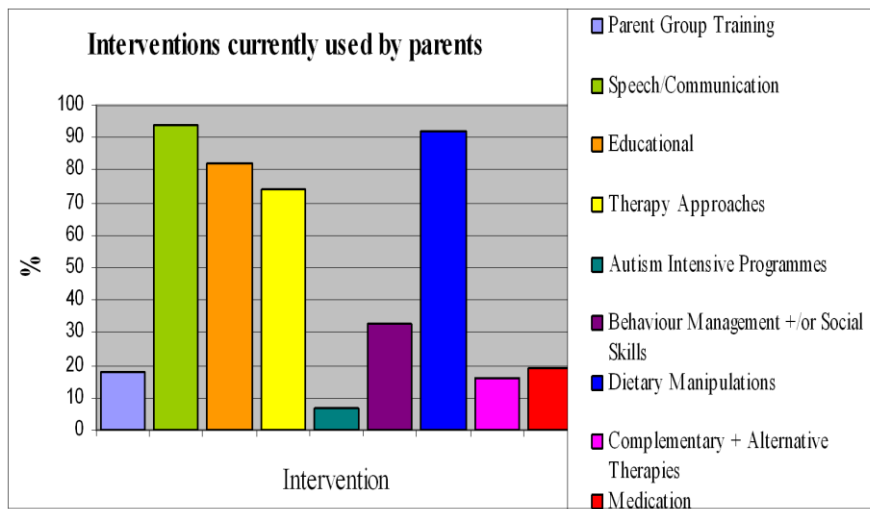
Of the **children** about whom parents answered their survey about, 84% were male and the majority (77%) were aged between 6-11 years old. Children had received a diagnosis of either Autism/Asperger's Syndrome (47%) or ASD/Atypical Autism/Pervasive Development Disorder-Not Otherwise Specified (52%), and most had been diagnosed between the age of 3 years and 5 years 11 months. The majority of children had some useful speech (79%) and the most common co-morbidities were Food Allergies (19%), Non Food Allergies (13%), Asthma (13%), ADHD (11%) and Dyspraxia (10%). The most common problem behaviours were sensory reactions, selective eating, temper tantrums, hyper periods and sleep problems.

244 **professionals** (of the 320 who visited the website) completed the PADIA questionnaire. Responses were mainly from Paediatricians (32%) and Child and Adolescent Psychiatrists (32%). Dietitians accounted for 17% of responses, Paediatric Neurodisability Specialists 10%, and 9% were 'other' professionals. Professionals were from all parts of the UK. Nearly all consultants (43%), had been practicing at their specific grade for more than 10 years, with 23% practicing for 5-10 years, and 33% for less than 5 years

(i) Parents and key professionals experience with ASD interventions and their attitudes to biomedical interventions such as the GFCF diet.

Parents reported using a wide range of interventions (see Figure 1). The use of Dietary manipulations (including special diets and dietary supplements) are amongst the most popular interventions.

Figure 1.



Attitudes towards biomedical interventions including the GFCF diet.

60% of parents had previously implemented a biomedical/Complementary or Alternative Medicine (CAM), most commonly special diets and dietary supplements. 86% of parents reported that they were aware of the GFCF diet, and 29% were currently implementing the diet. Of these, over 50% of parents reported significant benefits for their child, with most noticeable improvements in the areas of gastrointestinal symptoms, concentration/attention and communication.

75% of professionals reported that they had been asked by parents for advice about the GFCF diet although most were seeing less than 10% of their ASD caseload currently on the diet. 73% of professionals reported that there was insufficient evidence about the benefits or otherwise of the GFCF diet. The majority would not explicitly recommend the GFCF diet but *would support* parents who intended to use it, with only 19% of professionals directly advising *against* the use of the GFCF diet.

(ii) Current research priorities, and previous and current experiences of research.

When asked about previous experiences of research, 24% of parents had participated in autism research and 31% of professionals had referred to autism trials in the past. Parents reported 'causes' of autism and 'communication/early intervention' strategies as their high research priorities, placing 'dietary/behavioural interventions' next (see Figure 2). Professionals placed 'dietary interventions' as their second top research priority (see Figure 3).

Figure 2.

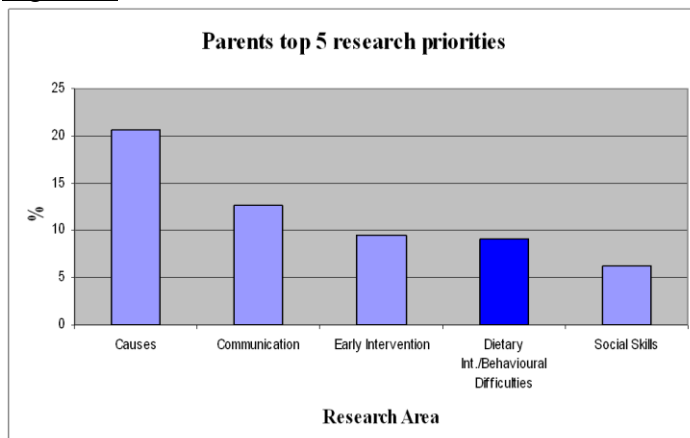
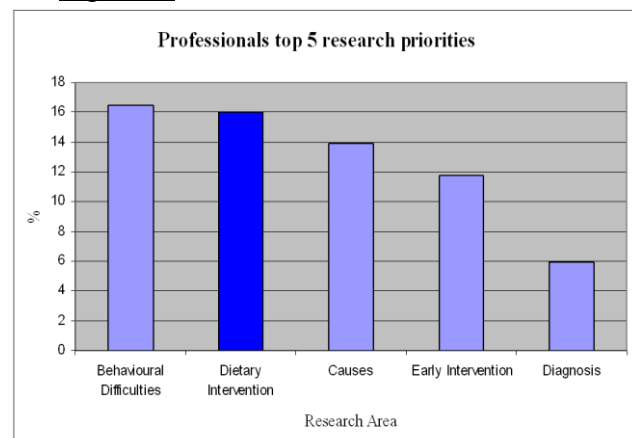


Figure 3.



When asked about other future research, 69% of parents & 43% of professionals agreed with the statement that 'Complementary and Alternative Medicines should be systematically evaluated'. Almost all of professional responders (97%) were willing to refer families to research projects in the future and this correlated well with the number of professionals who would be prepared to refer to a GFCF diet trial (95%).

(iii) Attitudes about a proposed large-scale randomised controlled trial (RCT) of the GFCF diet.

Most parents (78%) would be prepared to take part in the proposed GFCF trial. Almost all (94%) professionals supported the need for such a trial and 75% were prepared to refer children into the trial. Both parents and professionals indicated the need for increased paediatric and dietetic support throughout such a trial. This reflects the likely burden that would be placed on families taking part in research that involves complex lifestyle interventions such as the GFCF diet. Both groups felt the main barrier to involvement would be if a child's diet was already very limited, which may result in a trial being more likely to recruit children with less restricted diets.

What are our main conclusions?

The PADIA survey highlighted that many parents are currently using dietary interventions, and they would like to see diets and dietary supplements further evaluated. Many professionals have been asked for advice about the GFCF diet but feel that the evidence is too limited to be able to advise families properly. However, most professionals would support parents wishing to try this diet for their child. Both parents and professionals indicated their support for further evaluation of the GFCF diet within a randomised controlled trial (RCT). This survey has certainly given us some helpful insights for the trial design such as the need for specific paediatric and dietetic support within our proposed trial.

Limitations to the study.

Although the PADIA study was a success, there were some limitations with the survey. For example, most parents had further education qualifications. However, we did receive responses from across the UK and there was no evidence of any particular bias amongst parents or professionals. Also we know that occasionally some responders had problems using the electronic survey which could have affected access to the questionnaires.

Our next steps...

So far, articles about the PADIA survey have been published in 'Food Matters' Magazine (October 2009), National Autistic Society 'Communication' Magazine (Winter 2009) and 'Network Health Dietitians (NHD)' Magazine (August/September 2009).

Presentations have been made at York University, Newcastle University, the Royal College of Paediatrics and Child Health Conference 2010 (Warwick), and the International Meeting for Autism Research 2010 (Philadelphia, US).

We plan to submit an article about the PADIA survey for publication to a major peer-reviewed journal in summer 2010. We will also be presenting the findings from PADIA at the Faculty of Child and Adolescent Psychiatry Conference in September 2010 (Oxford). Unfortunately as we go to press we have recently been turned down from a major funder to carry out a randomised controlled trial of the GFCF diet in pre-school children with ASD. We will continue to pursue other funding to carry such a trial. In the meantime, we are confident that the PADIA findings will be useful for other research groups.

Finally, the laptop prize draw for those who completed the survey has now been drawn and the winners have been notified.

References

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2. Goin-Kochel, R. P., Mackintosh, V. H., and Myers, B. J. (2007). Parental reports on the use of treatments and therapies for children with autism spectrum disorders. *Res Autism Spect Dis.*, 1; 3:195-209
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4. Rhoades, R., Scarpa, A., Salley, B. (2007). The importance of physician knowledge of autism spectrum disorder: results of a parent survey. *BMC Pediatrics*, 7:37.

Once again, we would like to **thank you for your support for the PADIA survey, and thank you to AUTISM SPEAKS** for funding the PADIA study. If you have any questions or would like to discuss the results further, please contact Jenna Charlton, Research Associate, Newcastle University: jenna.charlton@ncl.ac.uk or telephone 0191 2821379.

Ann Le Couteur, Professor of Child and Adolescent Psychiatry, Institute of Health and Society, Newcastle University