Queen Mary
University of London

# Health and service provision for people with Autism Spectrum Disorder:

## A survey of parents in the United Kingdom, 2014

Jane Wills and Yara Evans
Queen Mary University of London, E1 4NS, UK

March 2016

**2016**

ISBN: 978-1-910195-17-8

Corresponding author: Professor Jane Wills, Queen Mary, University of London, UK.

With special thanks to Treating Autism (UK Registered Charity: No. 1113628) for collecting and providing the survey data.

We are grateful for financial support from the Life Sciences Initiative, Queen Mary, University of London, UK and the project leadership provided by Dr Ute-Christiane Meier.

## Introduction

There are more than 600,000 people living with autism in the UK today. Autism Spectrum Disorder (ASD) is recognised to bring life-changing challenges to all those directly affected. It is also reckoned to cost the UK something like £32 billion every year in lost earnings, care and support for all those involved (Buescher et al, 2014).

There are a growing number of charities dedicated to aspects of the affected community including the National Autistic Society (NAS) that provides a range of services including its own schools and parent help-lines as well as campaigning and advocacy work; Ambitious about Autism that focuses on educational support and access to training; Resources for Autism that provides activities for people with ASD; Child Autism UK that provides support for Applied Behaviour Analysis (ABA) therapy; and Autistica that raises funds for research and potential treatments. Treating Autism is a registered charity, established in 2005, that provides information and events with a particular focus on potential therapies and treatments for autism. In this regard, the charity works to keep abreast of the developments in research and clinical experience in order to share information with parents, people with ASD and professionals in the field (see for example the document on medical co-morbidities produced in 2014 (Treating Autism, 2014)). Regular events and conferences are organised to facilitate information sharing and the exchange of personal experiences. The charity also advocates for more research to be done to understand the underlying biological causes, and to develop better medical care for those affected by the condition. To this end, the charity undertakes regular surveys of its membership in order to find out more about the experiences of those living with autism and their families in the UK.

This report documents the findings from one of these surveys that was conducted in 2014. The survey was designed and completed online in order to capture parents' experiences of the main health challenges facing their children with ASD, their efforts to access services, and their experiences with the various treatments on offer. The survey was sent, with a request for completion, via an e-mail to all members of the charity in 2014. It was also publicised on the Facebook page managed by the charity, with a further request for completion. By the closing date, 264 parents and carers had submitted data about their experiences of caring for children with ASD and this is the data presented in this report.[1] The data was collected via survey monkey and exported into SPSS for analysis.

The data analysis and completion of this report have been facilitated by funding from the Life Sciences Initiative at Queen Mary, University of London. The survey analysis forms part of a larger project entitled *Autism and Inflammation*, led by Dr Ute-Christiane Meier, that is designed to combine basic science – looking at the relationships between immune inflammation and ASD – with social science, looking at the experiences of parents and carers of children with ASD. The latter has involved a partnership with Treating Autism in order to analyse the data collected from their members. The hope is that this small pilot project can then be used to make the case for larger-scale research funding and support in this field in the future.

The number of respondents included in this survey is relatively high in comparison with other published studies. In their recent review of qualitative research into the experiences of parents who care for a child with ASD, De Pape and Lindsay (2015) identified 31 published studies that allowed a consistent comparative analysis across studies. In total, these studies had engaged 160 fathers and 425 mothers who were caring for a child with ASD. The average number of respondents per study was just 26, and as such, the survey reported here should be a strong addition to the field. In addition, there are very few published accounts of parent and carer experiences of using NHS services to support their children with ASD, and this forms a major part of the material that is included in this report. As such, it augments the growing number of reports focusing on the experiences of particular groups who have struggled to secure the support they need from the NHS in the UK (Mencap, 2007; Mazars, 2015; Mental Health Taskforce to the NHS, 2016).

[1] Two cases were completed by individuals with ASD and these have been looked at separately. In addition, all those cases with large amounts of incomplete data were also excluded in order to reduce the impact of non-response rates on the figures presented.

In what follows the findings of the survey are presented by outlining the problems faced by those with the condition. The report then looks at parent and carers' experiences of trying to access support for these problems, their experiences of working with a range of professionals, and their use and experiences of a range of treatments and therapies. The report ends with a short conclusion that summarises the data collected and highlights the most important issues being raised.

**Table 1: Challenges faced and severity of issues**

| Effects | Very Significant (VS) | | Significant (S) | | Slight (SL) | | Not a problem | | Responses[2] | VS + S % of N=264 |
|---|---|---|---|---|---|---|---|---|---|---|
| | *N* | *%* | *N* | *%* | *N* | *%* | *N* | *%* | *N* | *%* |
| Anxiety/fearfulness/avoidance behaviours | *150* | 57 | *74* | 28 | *29* | 11 | *9* | 3 | 262 | 85 |
| Irritability (low mood/oppositional behaviours/tantrums/lack of flexibility) | *155* | 59 | *70* | 27 | *33* | 13 | *4* | 2 | 262 | 85 |
| Sensory sensitivity (light/sound/touch/ abnormal pain sensitivity) | *144* | 55 | *81* | 31 | *23* | 9 | *15* | 6 | 263 | 85 |
| Agitation/stimming behaviours | *141* | 54 | *78* | 30 | *32* | 12 | *9* | 3 | 260 | 83 |
| Sudden negative changes in behaviour | *140* | 54 | *76* | 29 | *27* | 10 | *17* | 7 | 260 | 82 |
| Diarrhoea/constipation/highly abnormal bowel movements | *142* | 54 | *64* | 24 | *27* | 10 | *29* | 11 | 262 | 78 |
| Lethargy/hyperactivity | *118* | 45 | *87* | 33 | *41* | 16 | *14* | 5 | 260 | 78 |
| Repetitive behaviours (spinning/flapping hands/obsessive speech) | *128* | 48 | *79* | 30 | *35* | 13 | *22* | 8 | 264 | 78 |
| Dietary problems (eats too little/too much/non-food items/extremely limited diet) | *137* | 52 | *64* | 24 | *37* | 14 | *25* | 10 | 263 | 76 |
| Sleep problems | *138* | 53 | *60* | 23 | *33* | 13 | *29* | 11 | 260 | 75 |
| Gastrointestinal symptoms (flatulence/ bloating/posturing/seeking pressure on stomach) | *133* | 51 | *57* | 22 | *41* | 16 | *31* | 12 | 262 | 72 |
| Fine or gross motor skills issues | *106* | 40 | *80* | 31 | *44* | 17 | *29* | 11 | 259 | 70 |
| Mouthing behaviours (chewing clothes/ teeth grinding) | *108* | 41 | *62* | 24 | *45* | 17 | *46* | 18 | 261 | 64 |
| Unexplained unhappiness/crying for no reason/shouting/screaming | *98* | 37 | *70* | 26 | *59* | 22 | *39* | 15 | 266 | 64 |
| Odd vocalizations (squealing/moaning/ sighing) | *101* | 39 | *65* | 25 | *54* | 21 | *39* | 15 | 259 | 63 |
| Aggressive towards self or others/ destructive behaviours/damages objects | *95* | 36 | *52* | 20 | *69* | 26 | *46* | 18 | 262 | 56 |
| Loss of previously acquired skills | *111* | 43 | *50* | 19 | *51* | 20 | *49* | 19 | 261 | 61 |
| Incontinence (urinary/bowel) | *92* | 35 | *59* | 22 | *43* | 16 | *69* | 26 | 263 | 57 |
| Facial grimacing/tics/wincing | *67* | 26 | *51* | 20 | *77* | 30 | *65* | 25 | 260 | 45 |
| Acid reflux (tapping on throat/frequent throat clearing or swallowing/night waking) | *65* | 25 | *42* | 16 | *58* | 22 | *93* | 36 | 258 | 41 |
| Difficulty swallowing | *20* | 8 | *29* | 11 | *50* | 19 | *158* | 61 | 257 | 19 |
| Seizures/epilepsy/erratic electrical brain activity | *28* | 11 | *17* | 7 | *38* | 15 | *174* | 68 | 257 | 17 |

[2] The % figures given relate to all those who provided data for each particular challenge whereas the final column shows the proportion of the whole sample (264) that reported a significant or very significant challenge in relation to the problem.

## The problems encountered

Survey participants were asked about a number of the challenges likely to be faced by their children, and the significance of these. Respondents were given a list of problems that were developed on the basis of the shared experiences of members of the charity and a review of the published literature on ASD and its associated co-morbidities, and they were asked about the significance of each problem on a four-point scale, ranging from 'not a problem' to 'slight', 'significant' and 'very significant'. As indicated in Table 1, almost all respondents reported problems with behavioural challenges such as irritability, agitation, anxiety, lethargy and/or hyperactivity, erratic behaviour and repetitive behaviours such as spinning, flapping hands and obsessive speech. For the majority, these problems were reported to be significant. Almost all reported a significant challenge in relation to sensory sensitivity and more than half had a significant problem with aggression. The majority reported significant problems with eating, diarrhoea or constipation as well as other gastrointestinal problems, incontinence, acid reflux, mouthing behaviours (chewing clothes/teeth-grinding) and challenges with sleep. Fine or gross motor skills were a significant problem for the majority. A third had some problems with seizures and half of these cases were reported to be significant.

The number of problems faced ranged from a low of 5 to as many as 22 (the full list) and as many as 73% of respondents selected 16 or more of the options listed (Table 2). When then asked to provide further information about these concerns, respondents often wrote very long responses that documented both the severity of the problems they faced, and the way that the combination of symptoms made life especially difficult for their child and those who cared for them. Examples of the comments given include:

*"Hand biting, arm flapping, hitting things and people, posturing after meals, defiance, aggression, oppositional behaviour."*

*"Spinning round objects has moved on to smacking one hand on top of the other and biting his hand or fingers to the point where his skin is now leathery as it hasn't had a chance to heal."*

*"Reflux and diarrhoea from 2-3 weeks old with frequent night waking. A weighted blanket has made a big difference but will still wake 1-7 times at times when feeling anxious."*

*"Will not chew or swallow solid foods at the age of almost 5 years, has to be liquidised but will chew anything wooden, metal or plastic."*

*"Complete loss of speech at age 2 1/4 coincided with onset of diarrhoea. Sleep problems can mean waking at 3am and not getting back to sleep again."*

*"Sensory seeking - all plastic items. As got older - will wet tissue and put in mouth for lengthy periods of time. Will go to sleep with item in mouth."*

Many of the comments also highlighted things that had improved the situation somewhat, and anticipating material presented later on in this report, changes in diet were often reported to have made a very significant difference in relation to bowel problems and behaviour. The following comments are good examples of parent experience in this regard:

*"Aged 26 months he weighed 0.5lbs more than he had weighed aged 20 months. He looked like a white famine victim: pale faced, black circles around eyes, blood red lips. At this point he was already dairy-free but still*

**Table 2: Number of challenges faced by each respondent**

| | N | % |
|---|---|---|
| 1-10 | 7 | 3 |
| 11-15 | 63 | 24 |
| 16-20 | 157 | 59 |
| 21+ | 37 | 14 |
| Total | 264 | 100 |

*having gluten. Multiple doses of diarrhoea per day (some exploding out of nappy and needing a shower to hose down …). Multiple doses of sickness per day. Sickness resolved upon becoming gluten and dairy-free, aspartame-free, MSG-free and olive oil-free, whereupon speech came at the rate of 2 or 3 words a day for the first 2 weeks. He had probably only had 4 spoken words before this time."*

*"My son had chronic diarrhoea for 8 years and was told children with autism have problems like that. The fourth gastroenterologist I saw suspected food allergies and put him on an elimination diet. Two days on plain boiled rice and he had a formed stool!"*

*"My son used to experience periods of significant agitation, distress, self-harming, which would occur without any obvious trigger. As he was non-verbal, he could not explain why this was happening. Once we realised that he was in pain due to chronic constipation and bowel loading, he was given treatment and we changed his diet. His bowel function is now much improved, and he is a very happy child, and never gets upset or self-harms. Other issues such as sleep also improved once his bowel problems were addressed."*

More than half of those who completed the survey reported that their child had lost previously acquired skills (61%), indicating that regressive autism was a problem for many of those taking part in the survey. As one respondent put it: *"At 18 months our child had hit and exceeded every milestone, by 36 months he was non-verbal and diagnosed with severe autism, global development delay, ADHD etc."* Another similarly reported that their child regressed: *"Between 18 months and 2 years when we had total loss of language and eye contact. He went from a happy boy to a stressed out boy locked in his own world."* And another reported a similar process at a much later age:

*"Went from a normal … 5.5 year old who could read and write and was in the top quartile of his class to being a whimpering wreck, screaming that everything hurt, couldn't cope with sound, light or touch and lost motor skills, the ability to write, look in others eyes etc. the list goes on."*

## Access to support from the NHS and other publicly-funded provision

Respondents were asked about their access to treatment for the identified problems via the National Health Service (NHS) and/or other publicly funded organisations. A minority had not sought help from the NHS (23 people, or 9% of all respondents) but the rest had sought help for a variety of problems (Table 3).

The data revealed that a significant number of respondents had sought access to a number of services without success. As indicated in Table 4, the largest group (48 people or 24% of those trying to use the NHS) had been unsuccessful in getting support for diet and nutritional support, even though this is the area that most parents reported having the greatest success in helping their children. Similar numbers had been unsuccessful in accessing services for the challenges associated with gastrointestinal and bowel complaints (22%), as well as for support with problem behaviour (20%).

In addition, however, many of those who had been able to see health professionals via the NHS or other official channels reported that the service provided was only 'somewhat' or 'not at all helpful' for their child. As indicated in Table 5, only 1% of those who were able to access services for diet and nutritional issues had their problem resolved in contrast to 77% who did not. Similar patterns were found in relation to services for gut problems, behavioural challenges, sleep difficulties

**Table 3: Have you sought help from the NHS for services and health care practitioners for the person with ASD?**

| | N | % | % whole sample |
|---|---|---|---|
| Yes | 234 | 91 | 87 |
| No | 23 | 9 | 9 |
| Total | 257 | 100 | |
| No answer | 7 | | 3 |
| Total | 264 | | 100 |

and toileting issues. The survey data suggests that more appropriate help was provided in relation to children suffering with seizures whereby 13% of those who accessed treatment had their problem resolved, and a further 37% had some useful help from the service. However, even in this case, half of all respondents were left disappointed. The data indicate that services appear to be failing families across the board, even in areas that are well-established in relation to treating children, such as in cases of epilepsy and seizures. In relation to important everyday challenges such as toileting, sleep, behaviour, bowel complaints and diet/nutrition, the majority of respondents reported that the service did not resolve their concerns.

**Table 4: Treatment sought from NHS or public funded organisations but not provided**

| | Sought help but not provided | % all who sought help and answered the question (N=203) |
|---|---|---|
| | N | % |
| Dietary/nutritional issues | 48 | 24 |
| Gut issues | 45 | 22 |
| Behavioural issues | 40 | 20 |
| Sleep | 31 | 15 |
| Toileting issues | 28 | 14 |
| Seizures | 6 | 3 |
| Other | 12 | 6 |
| | N | **%** |
| All respondents | 203 | 77 |
| Did not use NHS | 23 | 9 |
| No response | 38 | 14 |
| Whole Sample | 264 | 100 |

**Table 5: Outcome of the service received from the NHS or publicly-funded organisations**

| | Issue resolved | | Somewhat helpful | | Not helpful | | All who sought help and received | |
|---|---|---|---|---|---|---|---|---|
| | *N* | *%* | *N* | % | *N* | % | N | |
| Dietary/ nutritional issues | *1* | 1 | *24* | 22 | *83* | 77 | 108 | |
| Gut issues | *3* | 3 | *31* | 31 | *65* | 66 | 99 | |
| Behavioural issues | *2* | 2 | *34* | 34 | *64* | 64 | 100 | |
| Sleep | *7* | 8 | *33* | 39 | *45* | 53 | 85 | |
| Toileting issues | *4* | 6 | *26* | 36 | *42* | 58 | 72 | |
| Seizures | *5* | 13 | *14* | 37 | *19* | 50 | 38 | |
| Other | *4* | 18 | *7* | 32 | *11* | 50 | 22 | |
| | | | N | | | | % | |
| All respondents | | | 203 | | | | 77 | |
| Did not use the NHS | | | 23 | | | | 9 | |
| No response | | | 38 | | | | 14 | |
| Whole sample | | | 264 | | | | 100 | |

When asked for further comment about their experiences of trying to access treatment from NHS services, respondents provided a wide range of comments, both positive but largely negative. Examples of the comments given in relation to negative experiences – particularly concerning efforts to improve bowel function – included the following:

*"Had horrendous diarrhoea for years, constantly told it is 'toddler diarrhoea' which is nonsense as he is no longer a toddler … he has severe eating disorder … unable to swallow solid foods without choking or vomiting but no help given. The attitude is very much get on with it."*

*"Gut issues – we spoke to our GP and paediatrician several times asking about chronic diarrhoea and was told it was 'toddler's diarrhoea' and it would clear up by the time he was 5."*

*"We spoke to paediatricians regarding gut issues, dietary and sleep issues essentially since birth and none provided any help whatsoever and implied that we were being led by 'fads'."*

*"Our experience was blatant discrimination and dismissal of medical problems ... The NHS practitioners who were seeing our son were very ignorant and dismissive of health problems he had when he was a toddler and later. This was especially bad in regards to his gastrointestinal problems, with our paediatrician being reluctant to refer and the gastroenterologist being openly hostile towards investigating our son's problems. We had to seek help elsewhere, and pay for it ourselves."*

*"The NHS seem bewildered – especially the GPs. They assume his gut issues are 'in his mind' and 'part of his autism'."*

"*He/she was sent to NHS constipation specialist at age 2.5 years. He just recommended keeping him on Movicol, and Senna (as had already been for a year) and he did not endorse any dietary changes. We paid privately to see a NHS paediatric gastroenterologist whose first suggestion was take out dairy completely."*

*"Generally, NHS services are stuck in an outdated model of autism which is skewed towards the Aspergers model of autism. The NHS believes autism to be genetic and life-long and therefore does not support the concept of recovery or it being a medical condition."*

*"I have felt like it has been a constant battle to get any treatment from the NHS. It has been completely exhausting and when treatment is finally offered (rarely), turns out it's very poor with a serious lack of understanding behind my son's conditions."*

*"I do not think they have autism specialists on the NHS. If they do, I'd love to meet one!"*

*"My son has had multiple physical problems: chronic constipation, self-harming, food intolerances, epilepsy. Yet it is only the epilepsy which has been taken seriously (although the treatment has been ineffective to date). All his other issues have been dismissed as 'just autism' and there has been a reluctance to offer any kind of investigation or treatment."*

There were many comments in keeping with these: parents reported feeling that their concerns were not taken seriously and there was a particular concern about the way in which gastrointestinal and diet-related problems were often dismissed.

A number of the respondents who had something more positive to report often focused on their success in getting access to material resources, such as nappies, or accessing information, such as workshops for parents. However, a number did mention that the latter tended to be more about coping with the challenges and deploying common sense than actually relieving the symptoms associated with the condition, as this respondent suggested: *"Behavioural issues have been covered in the Early Bird course I attended although the help is a bit basic, along the lines of 'child-proof your house', or 'make sure you prepare your child for changes in routine', 'use visuals', etc. It is helpful but nothing that isn't common sense."*

A number of respondents also reported positive experiences in relation to their encounters with particular professionals. As one person put it: *"Paediatricians have varied from dreadful and a waste of time to our current one who is excellent. I wish all paediatricians were like her!"* Others reported finding professionals who were willing to try and help them as best they could. In one case, a parent was able to work with a supportive GP who was willing to find them to a nutritionist who was similarly able and willing to support them rather than simply telling them what (not) to do:

*"The NHS dietician was very helpful when I first tried the GF/CF diet[3] when my son was 6. She said she knew nothing but it was worth a try and she checked to make sure his nutrition was adequate. When my son was aged 19, a different NHS dietician was adamant that there was no evidence that the dietary changes I had made for my son were beneficial and was scathing when I said the evidence was in front of my eyes. Fortunately, my GP just referred me to a different dietician who again checked that the levels of nutrients were adequate."*

Another parent similarly found a helpful paediatrician, and in this case, the professional took the initiative in helping the child to get treatment that would otherwise not have been available:

*"Our son has recently been seen by a paediatrician at secondary school and was referred for an endoscopy, which lead to a diagnosis of H-pylori infection in stomach and colitis of the stomach - which was very helpful to know and was dealt with using antibiotics. This is, however, the first useful intervention from NHS and was largely due to an understanding and observant paediatrician - this has not been our experience before."*

When they were asked to rate their experiences of services from the NHS or other publicly funded organisations, only a minority of respondents reported that they were satisfied with the service received (Table 6). Indeed, as many as 88% of people were not satisfied with the service from immunologists, 68% were dissatisfied with gastroenterology, 61% with neurology and 57% with speech and language. As many as half found GPs and paediatricians to be unsatisfactory too.

Given these findings it is perhaps not surprising that the majority of respondents (61%) reported that the NHS professionals did not understand their concerns about the behaviour and healthcare issues facing their child, with just 11% confirming that they did understand (as many as 18% saying that they understood their concerns only to a degree) (Table 7). In this regard, a majority of respondents (70%) reported that they had been told that physical symptoms were due to the autism and as such, the implication was that they did not warrant further investigation or treatment (Table 8).

**Table 6: How satisfied are you with the treatment provided by the NHS or publicly funded services?**

| | Not satisfied (NS) | | Mildly satisfied (MS) | | Very satisfied (VS) | | Total (NS+MS+VS) |
|---|---|---|---|---|---|---|---|
| | *N* | % | *N* | % | *N* | % | N |
| GP | *107* | 54 | *70* | 36 | *20* | 10 | 197 |
| Paediatrician | *96* | 49 | *77* | 40 | *21* | 11 | 194 |
| Speech and Language | *111* | 57 | *58* | 30 | *26* | 13 | 195 |
| Occupational Therapist | *86* | 51 | *63* | 38 | *18* | 11 | 167 |
| Gastroenterologist | *63* | 68 | *18* | 20 | *11* | 12 | 92 |
| Autism Specialist | *68* | 63 | *31* | 29 | *9* | 8 | 108 |
| Neurologist | *36* | 61 | *15* | 25 | *8* | 14 | 59 |
| Immunologist | *29* | 88 | *3* | 9 | *1* | 3 | 33 |
| Epilepsy expert | *17* | 53 | *13* | 41 | *2* | 6 | 32 |
| Other | *15* | 79 | *4* | 21 | *0* | 0 | 19 |

| | N | % |
|---|---|---|
| All respondents | 211 | 80 |
| Did not use the NHS | 23 | 9 |
| No response | 30 | 11 |
| Whole sample | 264 | 100 |

[3] The GF/CF diet refers to the exclusion of gluten and casein (dairy) from the diet. A full list of acronyms is provided in the appendices at the end of this report.

**Table 7. Did the NHS healthcare professionals you approach understand your concerns about the behaviour and healthcare issues of the person with ASD?**

| | N | % | % of whole sample |
|---|---|---|---|
| Yes | 22 | 11 | 8 |
| No | 126 | 61 | 48 |
| Only to a degree | 37 | 18 | 14 |
| All respondents | 185 | 100 | |
| Did not use the NHS | 23 | | 9 |
| No response | 56 | | 21 |
| Whole Sample | 264 | | 100 |

**Table 8: Have any NHS professionals told you that the person with ASD's physical symptoms are due to their autism?**

| | N | % | % whole Sample |
|---|---|---|---|
| Yes | 133 | 70 | 50 |
| No | 56 | 30 | 21 |
| Total | 189 | 100 | |
| Did not use the NHS | 23 | | 9 |
| No response | 52 | | 20 |
| Whole Sample | 264 | | 100 |

When asked to further elaborate on their response, one parent reported that *"as soon as we received our diagnosis it seemed the greatest excuse to ignore the other symptoms."* Another respondent reported being told *"they do these things"* in relation to their child's toe-walking and that *"all these children have gut issues"* in relation to the bowel complaints. Whereas another child might have had these problems investigated, the diagnosis of autism seemed to 'normalise' the concerns. Indeed, one parent *"was told that my son has loose stool and is not sleeping at night because he is autistic*." Another parent was similarly *"told by a paediatric gastroenterologist that our son's gut problems were due to his autism. He said he wasn't curious as to why or how this could be, and he advised us to stop thinking about it or trying to solve it."* Another parent reported that: *"I've been told the head-banging, sleeplessness, hand flapping, chewing, tantrums, bad bowels – all his symptoms – are because of his autism and that's just the way it is."* Respondents gave similar accounts in relation to the whole range of problems all of which could potentially be investigated and treated.[4]

Without some official acknowledgment that children with ASD are more likely to have a range of co-morbidities that can be treated, it seems that many professionals are attributing these symptoms to autism which then makes it less likely for follow-up with investigations or additional support. From the parent's point of view, this often seemed like a lack of concern and even neglect. As one parent put it: *"The NHS is simply not set up to deal with children at the severe end of the spectrum. Non-verbal children are dismissed because they can't explain anything about their symptoms. They don't listen to the parents, or provide an environment suitable for treating the child."*

Another respondent reported that:

*"When my daughter was small, whatever symptom my daughter was troubled by her paediatrician would*

[4] Problems identified in this part of the survey included eating challenges, pica, biting, tooth-grinding, toe-walking, anxiety, sleep problems, sound-sensitivity, constipation, diarrhoea, acid reflux, self-harm, aggression, fine-motor problems, slow growth, regular illness, tantrums, hyperactivity, night sweats and lack of speech.

*say that it was autism. My husband and I felt like if my daughter was having a heart attack the paediatrician would say 'that's autism'. We gave up seeing her and tried to help our daughter ourselves."*

In some cases the professionals left children in severe distress even though they might have been helped in some way. As one parent put it: *"Yes everything is due to autism. He's autistic and that's why he punches his head and head butts the floor and wails aloud and bites his finger, and I should just let him! That's what I'm told by the so called professionals!"* Another respondent reported that *"screaming in pain has been dismissed as 'just his way of expressing himself' rather than an indication of pain."* For another parent, the contrast with the way siblings might be treated was marked: *"our GP said exactly this when I went to him about my son's gut issues. I was horrified and burst into tears. If I had gone to him with the same concerns about either of my girls I am certain he would have suggested a treatment plan. This was my first taste of discrimination against my son."*

A number of respondents pointed to evidence that the pain caused by constipation or the discomfort of acid reflux was the underlying reason for at least some of the odd and aggressive behaviour, screaming and head-banging, and once the pain was reduced, the behaviours sub-sided. As one person reported: *"we have had many run-ins with NHS professionals telling us our son's screaming … was just his autism. Absolute nonsense! We proved this after an x-ray showed that his bowel was about to burst … it really is shameful."* Similarly, another parent reported that: *"My son used to vomit a lot and I approached my GP about the problem. I was told straight away that it is due to his autism. I tried a private doctor and he found that he had a digestion issue."* Still another that: *"my son has now been scoped and has eosinophilic oesophagitis. I knew he had problems as his eating was terrible as were his bowel movements but the NHS doctor told me he was just constipated due to his autism."*

In the main, professionals were not able or willing to explain why children with ASD presented with these particular sets of concern but in a few cases respondents were given explanations that made little sense to the parent. Examples included one parent being told *"that his constipation is due to his weak muscle tone which is a symptom of his autism and can be found throughout his body. Also that he has persistent cold sores because he suffers more anxiety than a neuro-typical child and this causes all his cold sores."* Another was told that *"our son's bowel problems were because of his autism ... his brain couldn't 'talk to' his bowel in order to open them and get rid of the constipation."*

## Using private professional services to access support

Given the challenges faced in accessing adequate treatment options from the NHS, outlined above, it is perhaps not surprising that a very large number of respondents (80%) reported that they had consulted professionals privately in order to get more support (Table 9). Many respondents had consulted more than one private professional with more than half paying up to 5 different professionals (Table 10). When those who had seen professionals privately were asked to indicate which professionals they had contacted and why, more than half indicated that they had consulted a nutritionist, a doctor and/or a homeopath, with very significant numbers also accessing speech and language therapists (SALT) and occupational therapists (OT) (Table 11). In each case, the main reason given was because they couldn't access these services via the NHS although in the case of SALT, it was that the private service was

**Table 9: Have you used private care professionals for the person with ASD?**

| | N | % | % of whole sample |
|---|---|---|---|
| Yes | 210 | 80 | 80 |
| No | 52 | 20 | 19 |
| All respondents | 262 | 100 | |
| No response | 2 | | 1 |
| Whole Sample | 264 | | 100 |

**Table 10: Number of Private Health Care Professionals Used**

| | N | % | % of whole sample |
|---|---|---|---|
| 1-5 | 148 | 71 | 56 |
| 6-10 | 49 | 24 | 19 |
| 11-15 | 8 | 4 | 3 |
| 16-20 | 2 | 1 | 1 |
| Total | 207 | 100 | |
| No Response | 57 | | 22 |
| Whole Sample | 264 | | 100 |

**Table 11: Which private health professionals have you used and why have you chosen to use them?**

| Practitioners | Couldn't access via NHS | | Not available on NHS | | Better Service | | Other | | Respondents | % respondents (N=207) |
|---|---|---|---|---|---|---|---|---|---|---|
| | *N* | % | *N* | % | *N* | % | *N* | % | N | % |
| Nutritionist | *72* | 39 | *50* | 27 | *58* | 31 | *5* | 3 | 185 | 89 |
| Private Doctor | *73* | 40 | *56* | 31 | *47* | 26 | *6* | 3 | 182 | 88 |
| Homeopath | *60* | 42 | *51* | 35 | *27* | 19 | *6* | 4 | 144 | 70 |
| Speech and language | *36* | 32 | *11* | 10 | *57* | 50 | *10* | 9 | 114 | 55 |
| Occupational therapist | *41* | 46 | *8* | 9 | *33* | 37 | *8* | 9 | 90 | 43 |
| Osteopath | *30* | 41 | *27* | 37 | *12* | 16 | *4* | 5 | 73 | 35 |
| Herbalist | *26* | 53 | *14* | 29 | *7* | 14 | *2* | 4 | 49 | 24 |
| Gastroenterologist | *24* | 56 | *2* | 5 | *12* | 28 | *5* | 12 | 43 | 21 |
| HBOT | *18* | 47 | *14* | 37 | *2* | 5 | *4* | 11 | 38 | 18 |
| Neurologist | *15* | 54 | *3* | 11 | *7* | 25 | *3* | 11 | 28 | 14 |
| Immunologist | *6* | 43 | *4* | 29 | *2* | 14 | *2* | 14 | 14 | 7 |
| Epilepsy expert | *2* | 29 | *1* | 14 | *1* | 14 | *3* | 43 | 7 | 3 |
| Other | *20* | 44 | *14* | 31 | *7* | 16 | *4* | 9 | 45 | 22 |

| | N | % |
|---|---|---|
| All respondents | 207 | 78 |
| Did not use private health professionals | 52 | 20 |
| No response | 5 | 2 |
| Whole sample | 264 | 100 |

better than the one provided by the NHS. A small number had paid to see gastroenterologists, neurologists and allergists privately, even though these services are generally available on the NHS and in each case, the main reason given was an inability to access the service through the NHS, echoing the findings outlined in Table 4 and the previous section.

Parents listed a range of additional specialists they had seen (categorised in the 'other' category in Table 11) including experts in Applied Behaviour Analysis (ABA), chiropractors, continence therapists, educational psychologists, endocrinologists, equine therapists, dentists, massage therapists, optometrists, osteopaths, physiotherapists, psychiatrists, psychologists and sensory integration specialists. Echoing the findings outlined earlier, a number of respondents had sought this private help after trying – and failing – to get adequate help from the NHS. For one respondent, this included access to a timely diagnosis without facing years of delay: *"We saw a private doctor when we were getting nowhere*

*with diagnosis (my son is severely autistic, he is still non-verbal as a teenager) - we were told there was a 2 year waiting list for diagnosis."* Similar comments were made by another respondent: *"Wait times are far too long for conventional therapy when early intervention is so critical."*

A shortage of SALT and OT was often reported to be a particular problem and as this respondent indicated: *"We were never able to get access to Occupational Therapist in our area. If you were lucky, you could get a phone assessment but we were never even offered this but did not think it was of any value anyway. How can you check motor skills over the phone?"* A number of people also reported that the SALT was useful but insufficient in relation to the scale of the problems faced by their children. As this respondent put it: *"I felt the SALT and OT were excellent; the problem was barely getting any actual support. The resources were so limited we only got a few sessions (18) over two years for SALT and none for OT."* Others sought help privately in order to get a more thorough service and ongoing support, as in relation to OT services in the following case: *"The NHS was merely a taster session and a report and that was it. Private OT was much more intensive with far superior knowledge and information provided. The reports we received from the private OT were much more detailed and they had the time to listen and come to your home which made such a difference to us."*

A number of respondents reported that private nutritionists had been particularly helpful in supporting their children with making positive changes in diet:

*"We were given no useful advice at all on the NHS regarding diet and nutrition, yet change in diet and supplementation have brought about the most positive changes in my son's general health and behaviour of any interventions that we have tried. The private nutritionists I have consulted have given excellent advice which has led to a significant improvement in my son's quality and enjoyment of life. It is a pity that this kind of advice is not available on the NHS - as things stand, only those children whose parents can afford to pay for private advice can benefit."*

## Using diet to help their children

Almost all the respondents (90%) reported that they had used dietary interventions or modifications to try and help the person with ASD (Table 12). When asked to elaborate on these interventions, respondents reported on a number of different dietary changes, the most prevalent being to exclude gluten and casein (Table 13). Half of those reporting changes had removed processed sugar from the diet and just under half had reduced other carbohydrate intake substantially. When asked to report on the changes associated with these alterations in diet, three-quarters of the respondents reported some kinds of improvement, many of them reporting significant change, and almost a third reporting 'life changing improvement' in the symptoms associated with the condition (Table 14). Remarkably, no-one said that the condition had worsened, although a minority (20%) reported only minor improvements, and a further minority were unsure about the outcomes of dietary change (3%) or reported that no change had occurred (5%).

Many respondents provided powerful testimony about their experiences of changing the diet of their child and most reported that the change in diet helped to reduce at least some of the symptoms associated with autism such as hyperactivity, lack of sleep, eating difficulties, bowel problems, anxiety, communication and odd behaviours. For many families these changes were life-changing and they reduced the distress faced by their child as well as the stress faced by the whole family. A flavour of the comments made in relation to removing gluten and/or dairy are presented below:

**Table 12: Have you used dietary interventions or modifications for the person with ASD?**

| | N | % |
|---|---|---|
| Yes | 229 | 90 |
| No | 27 | 10 |
| Total | 264 | 100 |

**Table 13: Dietary Interventions Used**

| | Responses | Responses | Respondents |
|---|---|---|---|
| | N | % (N=785) | % (N=234) |
| Gluten Free | 219 | 28 | 94 |
| Casein Free | 210 | 27 | 90 |
| Low sugar | 122 | 15 | 52 |
| GAPS/SCD/Paleo[5] | 99 | 13 | 44 |
| Low carb | 51 | 6 | 22 |
| Low oxalate | 39 | 5 | 17 |
| WAP | 8 | 1 | 3 |
| Other | 37 | 5 | 16 |
| All responses | 785 | 100 | |
| | N | | % |
| All respondents | 234 | | 89 |
| Did not use dietary interventions | 27 | | 10 |
| No response | 3 | | 1 |
| Whole sample | 264 | | 100 |

**Table 14: What changes did you see with dietary interventions?**

| | N | % (n=237) | % whole sample |
|---|---|---|---|
| Significant improvement | 101 | 43 | 38 |
| Life changing improvement | 69 | 29 | 26 |
| Slight improvement | 48 | 20 | 18 |
| No change | 12 | 5 | 5 |
| Don't know | 7 | 3 | 3 |
| All respondents | 237 | 100 | 90 |
| Did not use dietary interventions | 27 | | 10 |
| Whole sample | 264 | | 100 |

*"After implementing a gluten and dairy free diet, he slept for the first time in months. He stopped being as aggressive and only becomes aggressive when he has gluten or dairy. He stopped stimming and gave us a chance at some kind of life. Without the diet we would not have come this far and we would not be able to function as a family."*

*"After taking our son off dairy products, at age three and a half, nearly three days exactly to the hour he started naming letters and numbers!! We didn't even know if he knew them or not although we suspected he did. We didn't believe in the diet but thought it was worth 'giving it a go'. Diet and supplements have played a huge part in his life ever since."*

*"As soon as I removed gluten and casein from my son's diet he changed significantly - almost overnight. He went from oppositional, irritable, extremely hyperactive and spacey to much more compliant. School noticed the change instantly. Before removing casein and gluten I was frightened he would run into the road. I used to grab him by the hand to keep him next to me but he used to pull away saying it hurt. He would never ever hold my hand. He said it hurt but I thought he was being difficult! He would either be running ahead of me or lagging way*

[5] GAPS is shorthand for the diet advocated by Natasha Campbell-McBride in her book Gut and Psychology Syndrome hence GAPS for short. This diet is based on the specific carbohydrate diet (SCD) developed by Dr Haas and publicised by Elaine Gottschall (1994). The diet eliminates all complex sugars, removing grains and processed sugar from the diet.

*behind complaining he was exhausted and demanding to be carried to school. I kept him in a buggy way past his peers because I was afraid of where he would end up if I let him out. A couple of weeks after removing gluten and casein he was walking to school next to me and then he quietly slipped his hand into mine and held my hand. What more can I say!!"*

*"By 2 and a half years had regressed to the point of nothing there at all, constant head banging, headshaking, self-harming, very violent would hit, bite, scratch, head-butt, no eye contact and unresponsive to anything. Would not cope with going outside or shops, or crowded rooms, would vomit everywhere also could not cope with being at the top of stairs, certainly couldn't climb up or down....in short we had lost them. Put on gluten and casein diet and within three days the violence, the head-banging and shaking, the vomiting disappeared and eye contact returned, it was a miracle. Within 2 months language returned and within 6 months, his formal diagnosis of 'severe autism with sensory processing disorder and learning disabilities' was changed to 'classic autism and sensory processing disorder'."*

*"Changing to a dairy free diet brought back eye contact within three weeks. It was amazing. Removing processed sugar from the diet stopped the incontinence completely."*

*"The GF/CF diet brought him back into our world and cured his all over body eczema and helped reduce seizures."*

For some respondents, removing gluten and/or casein did not make a significant difference but this changed when they made additional changes to diet. As this respondent reported: *"GF/CF didn't make much difference, but when we totally cleaned up diet and removed, soy, sugar, MSG, aspartame, fruit juice, and only drank filtered water, then a difference could be seen within days."* Similarly, another respondent said that they did not *notice "much noticeable improvement [with GF/CF but] then tried GAPS and saw a huge difference cutting out sugar and grains. Wish we had done this in the first place."*

Thus a number of parents started by eliminating gluten and casein from the diet and then extended this to remove sugar, additives and in some cases, grains. As this respondent reported: *"I have used GF/CF, sugar free, diet. There was an immediate improvement in behaviour, connection and reduction of discomfort. Also GAPS diet, with even more progress in development, loads of pain reduction, and almost total elimination of aggression."* For many, changes in the bowel were particularly associated with the SCD or GAPS diet, as this respondent suggests: *"He had his first normal (fully formed and not foul smelling) bowel movement the day after we introduced Specific Carbohydrate Diet, shortly before his 2nd birthday."* Others reported particular improvements in speech: "*When following the SCD diet, my son went from using 3 word utterances to talking in full sentences. This happened overnight, at a time when no other new interventions took place. Other improvements happened and continued and after 2 years on the diet he now eats a completely normal diet with no noticeable intolerances."* For another parent, the changes from the GAPS diet were more focused on sensory toleration as well as bowel movements and levels of aggression:

*"My daughter started on the GAPS diet and within 2 days we saw major improvements in sensory issues (much less agitated by sound and touch which had totally taken over her life as well as ours), and much improved bowel movements - much more regular and normal as opposed to once every 3 days and rocky and hard. She almost immediately stopped being aggressive towards her brother."*

Some parents reported making additional changes in diet, such as the removal of oxalates in one particular case: *"We noticed improvement in speech and happiness once we implemented GF/CF and noticed better bowel movements with low oxalate."* Some parents also identified particular foods that were problematic for their children, and this person reported about a problem with peanuts: *"We used a gluten free diet - this produced a rapid change in behaviours (less compulsive behaviour). We also reduced peanuts after finding that when eating lots of ground organic peanut butter (nothing else added) my son started to head-butt concrete and pavements hard enough to bruise himself very badly. This behaviour disappeared rapidly on removing the peanut butter from his diet."*

In summary, many respondents reported that their child was calmer, with better eye contact, greater focus, increased compliance, improved sociability and better communicative skills as a result of changing their diet. In relation to health, people highlighted reduced problems with allergies including eczema and asthma, fewer problems with digestive problems, including picky eating and reflux, and healthier stool consistency and bowel movements. Remarkably, a number of respondents reported that changes in diet had stopped or reduced the seizures experienced by their child, making a dramatic difference to their overall health. One respondent said that *"eliminating full fat milk reduced her daily seizures and in my opinion having a sugar free diet including the elimination of fruit, stopped her seizures altogether."* For another, the changes facilitated an *"improved control of complex partial seizures allowing withdraw of anti-epileptic drugs and courses of high dose steroids."*

For many parents, the change in diet was associated with improvements in sleep, which in turn, helped the overall well-being of both child and family:

*"Dietary intervention was key in relieving my son's significant chronic constipation, which we now realise was causing his outbursts of agitation, aggression and self-harming. These became much fewer and further between as a result of dietary intervention, and eventually disappeared altogether. His sleep also improved vastly on the diet, from falling asleep late and waking several times per night, to sleeping eight to nine hours almost every night."*

In some cases, the changes associated with diet seemed to alter almost everything that a child was able to do, and their ability to interact with the world around them, as illustrated in this long and detailed response:

*"Now talks - previously whole days without speech and then any speech was echolalia. Now plays WITH other children - previously ran off when any child came near, asks to go to their houses after school etc. Now is happy - previously screamed a lot of the time. Now talks about his experiences, brings things and asks for things, all appropriate. Previously sat in a room alone and screamed if anyone came near except Mum. Now gets self-dressed most of the time with help, previously had to be forced. Now gets in and out of the car most of the time and is mostly ok going places that are busy, previously had meltdowns going anywhere and had to be forced into car seat/pushchair. Will now be persuaded to brush teeth, previously had to be forced. Now eats a very healthy diet, previously refused and was a very picky eater. Now will wash hands and face with help/ encouragement, previously refused and screamed. Now plays with toys, previously lined them up. Now holds pen and writes with support, previously refused holding anything like crayons, paint etc. Has stopped running round with hands on ears. Now sits on toilet, previously refused, still in nappies but will sit on toilet. Previously spent hours banging doors/staring at lights - now stopped. Now knows his name, his age and his family and previously did not answer to his name nor understand who he was."*

However, a minority of respondents did report some negative changes associated with a new kind of diet. For one respondent changing the diet was associated with a sharp rise in the incidence of viral problems, as though the alterations in diet had prompted a different response from the body's immune system in this particular case: "*Taking the dairy out of his diet at age of 4 was like turning on a light and the difference was rapid. Teachers at school noticed within 2 or 3 days and we had not told them about diet. We gradually removed gluten over the next 3 months. However he went from hardly ever having minor illnesses to having only about 3 weeks in that first 6 months when he did not have a cold or flu. He also caught chicken pox in that first 6 months, which he had not caught when his sister had it previously, despite drinking from her lipped cup. It was as if he was catching up on 4 years of colds and flu in that 6 months.*"

Another small group also reported very little obvious change from making changes in diet: *"Did the GF/CF diet for one year. No significant improvements and on balance the restrictions of the diet on a 'normal' lifestyle outweighed the benefits."* For another, they had *"tried gluten and dairy free diets with no effect; now trying organic fruit and veg."*

## Using non-prescription supplements to treat co-morbid conditions

In addition to changes in diet, the survey asked respondents about their use and experiences with a range of nutritional supplements. The majority of respondents (90%) had used a variety of nutritional supplements, such as vitamins, minerals, fish oils and probiotics to try and help their child (Table 15). When asked to indicate the type of supplements being used from a pre-structured list, respondents were most likely to report using fish oil/fatty acids, vitamins, minerals and probiotics (Table 16). As indicated, as many as 29 people also ticked the box for 'other' supplements, and when prompted, people reported these as including adrenal support, aloe vera and glutathione.

More than half of the respondents were able to report on more than six different supplements although it was not known if they were still being used, or administered at the same time (Table 17). More than three-quarters of respondents reported an improvement as a result of this treatment with 18% saying these changes were 'life-changing'. Only two people reported a worsening of the condition with this form of treatment and a larger number saw no change (7%) or were not sure about any changes (6%) (Table 18).

**Table 15: Have you used nutritional supplements for the person with ASD?**

| | N | % | % whole sample |
|---|---|---|---|
| Yes | 235 | 90 | 89 |
| No | 28 | 10 | 10 |
| Respondents | 263 | 100 | |
| No response | 1 | | 1 |
| Whole sample | 264 | | 100 |

**Table 16: Nutritional supplements used**

| | Responses N | Responses % (N=1571) | Respondents % (N=233) |
|---|---|---|---|
| Fish oils/Essential Fatty Acids | 214 | 14 | 92 |
| Vitamins | 212 | 13 | 91 |
| Digestive/gut support | 208 | 13 | 89 |
| Minerals | 197 | 13 | 84 |
| Amino acids | 108 | 7 | 46 |
| Anti-microbials | 100 | 6 | 43 |
| CoQ10 and other mitochondrial support | 97 | 6 | 42 |
| Detoxification | 85 | 5 | 36 |
| Anti-inflammatories | 78 | 5 | 33 |
| Anti-parasitical treatments | 64 | 4 | 27 |
| Immune support | 62 | 4 | 27 |
| Anti-virals | 59 | 4 | 26 |
| Sleep support | 58 | 4 | 25 |
| Other | 29 | 2 | 13 |
| Total | 1571 | 100 | |
| | N | | % |
| All respondents | 233 | | 88 |
| Did not use nutritional supplements | 28 | | 11 |
| No response | 3 | | 1 |
| Whole sample | 264 | | 100 |

**Table 17: Number of Nutritional Supplements Used**

| | N | % (N=233) | % whole sample |
|---|---|---|---|
| Up to 2 | 17 | 7 | 6 |
| 3-5 | 75 | 32 | 28 |
| 6-10 | 114 | 49 | 43 |
| 11+ | 27 | 12 | 10 |
| Total | 233 | 100 | |
| Did not use supplements | 28 | | 11 |
| No Response | 3 | | 1 |
| Whole Sample | 264 | | 100 |

**Table 18: What changes did you see from nutritional supplements?**

| | N | % (n=235) | % whole sample |
|---|---|---|---|
| Significant improvement | 106 | 45 | 40 |
| Slight improvement | 56 | 24 | 21 |
| Life changing improvement | 42 | 18 | 16 |
| Worsening | 2 | 1 | 1 |
| No change | 16 | 7 | 6 |
| Don't know | 13 | 6 | 5 |
| All respondents | 235 | 100 | |
| Did not use nutritional supplements | 28 | | 10 |
| No response | 1 | | 1 |
| Whole sample | 264 | | 100 |

When asked to provide more information, a number of respondents linked the use of fish oil to improved eye contact from their children. As one person put it: *"fish oil stopped his side glancing."* Another reported that the fish oil had changed the texture of their child's hair from *"fibreglass to lush".* Another thought the fish oil had helped with language and cognition. Other comments highlighted positive experiences using curcumin to reduce inflammation, magnesium to help the bowel, zinc to improve appetite, concentration, teeth-grinding and behaviour, and P5P (the active form of vitamin B6) to reduce seizures. Another respondent reported that vitamin B6 helped their child to look where they were pointing.

One respondent particularly highlighted the impact of supplementing vitamin B, magnesium and zinc in helping their son: "*He used to be lethargic and would often only walk even short distances by being dragged down the road wailing about how his legs hurt. Now he runs and scoots and jumps. He has developed empathy for others, better speech, emotional self-control, tantrums have stopped and night-waking has stopped. He has started pretend play, and is generally pleasant to be with now. B1, B6, magnesium and zinc have given the biggest improvements though all the B vitamins have been very helpful."*

Another respondent highlighted the impact of iron supplementation on their child: *"Paediatrician put him on iron supplements for 3 months and the mouthing objects stopped immediately, otherwise slight improvement noted (and slight worsening/regression once stopped plus the mouthing objects started again)."*

A number of respondents also mentioned the positive benefits of using probiotics to help with bowel function and eating. As this example attests: *"Probiotics solved the major constipation issues we had (resulting in several hospital visits), within days of starting the probiotics we noticed significant deflation of his distended tummy and then we got real poos and he has been fine for 6 months now."*

For another, *"Supplements resulted in the following: 1)*

*Huge reduction of sound sensitivity; 2) Improvement in language skills; 3) Increased ability to show affection/ express love; 4) Deeper understanding of language."* Similarly, another respondent reported a range of improvements following the use of nutritional supplements saying: *"Within a month of our son being on supplements, he noticed people in the room, responded to his name, stopped spinning, stopped stumbling around like a drunk man. He became more aware of his environment and stopped tripping over toys. He would walk around obstacles rather than right into them."*

Respondents were often using these supplements alongside changes in the diet and as one person put it, this made it *"difficult to separate dietary interventions and supplements as we started to use both at the same time and keep doing it. We saw improvements along the way but can't say what had contributed more, diet, particular supplements, or a combination of both."* Likewise for another respondent, the combination of diet and supplements were helping their child: *"My son is taking a range of different supplements under the guidance of a doctor. He is doing really well. He is much improved in a wide range of areas - eye contact, less hyperactive, better concentration, less spacey/more with it, more able to carry out a conversation, more compliant - the list goes on. He is nowhere near where he could/should be but he's moving in the right direction and I believe this is down to the supplements/dietary interventions."*

## Using prescription medicines to treat co-morbid conditions

More than half of those surveyed reported using prescription medicines to treat one or more of the problems they faced (62% of the 260 people who answered the question) (Table 19). In this regard, respondents were most likely to have used antibiotics and anti-fungals, but drugs such as steroids and anti-seizure medication were also used by a minority of those who had experience of using prescription medicines to try and help their child (Table 20). Most of those surveyed had only used one or two of these drugs, and only 3% had used more than 5 medications, reflecting the experience of parents with older children and very complex sets of concerns (Table 21).

Respondents were asked about the outcome of this treatment and as shown in Table 22, the majority (72%) reported some kind of improvement, and for almost half (47%), this was described as significant or life changing.

When asked to comment on their experiences, respondents provided a wide range of comments. In regard to antibiotics, a number reported benefits including one person who said that they were *"very helpful in the short-term"* and another that they: *"Completely stopped stomach pains which were so severe they caused him to constantly seek pressure for his stomach and bang his head and scream."* For another, antibiotics had caused a *"significant improvement in behaviour and cognitive function."* Another respondent noted that anti-fungals had brought *"notable behavioural change"* and another that they "*produced rapid results during early stages of treatment".* One respondent reported that anti-histamines were *"life-changing"* and another that they had *"helped".* Melatonin had helped with sleep in a number of cases.

While many reported positive effects, the data also suggested more mixed experiences with a number of these medications; they were positive for some and negative for others. This was particularly true in relation to Methylphenidate or Ritalin, a drug which is licensed for children with ADHD: one respondent reported that it lessened *"hyperactivity and improved focus and*

**Table 19: Has the person with ASD used any prescription medication**

| | N | % | % whole sample |
|---|---|---|---|
| Yes | 161 | 62 | 61 |
| No | 99 | 38 | 38 |
| All respondents | 260 | 100 | 2 |
| No response | 4 | | |
| Whole Sample | 264 | | 100 |

**Table 20: Prescription medication used[6]**

| | Responses N | Responses % (N=324) | Respondents % (N=156) |
|---|---|---|---|
| Antibiotics | 95 | 27 | 61 |
| Anti-fungal | 80 | 22 | 51 |
| Anti-viral | 50 | 14 | 32 |
| Anti-inflammatories | 26 | 7 | 17 |
| Anti-epileptics | 25 | 7 | 16 |
| Steroids | 18 | 6 | 11 |
| Risperidone (brand Risperdal) | 14 | 4 | 9 |
| Methylphenidate (brand Ritalin) | 10 | 3 | 7 |
| Carbamazepine (brand Tegretol) | 6 | 2 | 4 |
| Other | 30 | 9 | 20 |
| Total | 324 | 100 | |
| | N | | % |
| All respondents | 156 | | 59 |
| Did not use prescription medication | 99 | | 38 |
| No response | 9 | | 3 |
| Whole sample | 264 | | 100 |

**Table 21: Number of Prescription Medications Used**

| | N | % (N=152) | % whole sample |
|---|---|---|---|
| Up to 2 | 96 | 62 | 36 |
| >2-5 | 56 | 36 | 21 |
| >5-7 | 4 | 3 | 2 |
| Total | 156 | 100 | |
| Did not use prescription medication | 99 | | 38 |
| No Response | 9 | | 3 |
| Whole Sample | 264 | | 100 |

**Table 22: What changes have you seen from using prescription medication?**

| | N | % (N=157) | % whole sample |
|---|---|---|---|
| Significant improvement | 60 | 38 | 23 |
| Slight improvement | 39 | 25 | 15 |
| Worsening | 25 | 16 | 9 |
| Life changing improvement | 14 | 9 | 5 |
| No change | 13 | 8 | 5 |
| Don't know | 6 | 4 | 2 |
| All respondents | 157 | 100 | |
| Did not use prescription medication | 99 | | 38 |
| No response | 8 | | 3 |
| Whole sample | 264 | | 100 |

[6] A full list of the medications identified by name, is provided in the appendices to this report.

*attention"* while another reported that "*he was calm for a few hours but then behaviour deteriorated."* Likewise, in relation to Risperidone/Risperdal that is licensed for psychosis and anxiety, some parents reported improvements in sleep and behaviour but others reported major problems with weight-gain and drooling.

## Using alternative treatments and therapies

As many as 72% of respondents reported that they had used one or more alternative treatments or therapies, other than dietary and nutritional supplementation, to try and help their child (Table 23).

There were a wide range of alternative treatments and therapies reported - unprompted - in this part of the survey and the most prevalent were homeopathy, Applied Behavioural Therapy (ABA), Craniosacral therapy (CST) and Hyperbaric Oxygen Treatment (HBOT) (Table 24).

**Table 23: Has the person with ASD received any alternative treatments other than dietary changes and supplementation?**

| | N | % (N=261) | % whole sample |
|---|---|---|---|
| Yes | 187 | 72 | 71 |
| No | 74 | 28 | 28 |
| All respondents | 261 | 100 | 99 |
| No response | 3 | | 1 |
| Whole Sample | 264 | | 100 |

**Table 24: Alternative therapies used (88 respondents)[7]**

| Therapy | N | | Therapy | N |
|---|---|---|---|---|
| Homeopathy/CEASE | 32 | | Eye therapy | 1 |
| ABA | 10 | | Herbal medicine | 1 |
| CST | 16 | | Acupuncture | 1 |
| HBOT | 14 | | Atypical antipsychotics | 1 |
| Chiropractic therapy | 7 | | Drama group | 1 |
| Scotson technique | 6 | | Exercises | 1 |
| AIT | 5 | | Eye contact and speech | 1 |
| HANDLE | 4 | | Bowen | 1 |
| SIT | 4 | | Immunotherapy | 1 |
| Epsom Salts | 3 | | Infra-red sauna detox | 1 |
| SonRise | 3 | | LDN | 1 |
| Massage | 2 | | NAET | 1 |
| Reflexology | 2 | | Osteopath | 1 |
| RDI | 2 | | Sally Goddard Blythe | 1 |
| Talk Tools | 2 | | Table work | 1 |
| TLP | 2 | | Vibrating plate | 1 |
| | | | Other | 7 |

7 A full list of the names of these therapies is provided in the table of acronyms in the appendices to this report.

**Table 25: What changes have you seen from using alternative treatments?**

| | N | % (N=185) | % whole sample |
|---|---|---|---|
| Significant improvement | 72 | 39 | 27 |
| Slight improvement | 62 | 34 | 23 |
| Life changing improvement | 25 | 14 | 9 |
| No change | 12 | 6 | 5 |
| Don't know | 12 | 6 | 5 |
| Worsening | 2 | 1 | 1 |
| All respondents | 185 | 100 | 70 |
| Did not use alternative treatments | 74 | | 28 |
| No response | 5 | | 2 |
| Whole sample | 264 | | 100 |

When asked about the impact of this range of alternative treatments and therapies, a majority (87%) reported improvements or some kind with 53% identifying significant or life-changing improvements (Table 25). A small minority of the respondents reported no change or being unsure about change, and just 1% reported a worsening of the condition (and there were no comments provided to illuminate this).

The comments made in this section of the survey ranged across the therapies being reported but many were convinced of the benefits of one or more of these treatments. Examples from across the range of experience include: *"ABA [Applied Behavioural Analysis] has helped his learning." "SonRise therapy*[8] *helped with language, sociability, flexibility, imagination." "Sensory Integration Therapy (SIT) has shown good results"* and for another respondent: *"Sensory Integration Therapy has been life changing- a complete game changer in day to day life."* Similarly *"Auditory integration training (AIT) has provided a great improvement in sensitivity to noise."* Another respondent reported a *"Great improvement in balance from seeing a chiropractor."*

Acupuncture was reported to have reduced anxiety and a number of respondents were very positive about the impact of cranial osteopathy, as these comments attest: *"Cranial osteopathy, helps with head tightness and need to seek pressure for head."*

*"We took him to a cranial osteopath at the age of 4 - by a fluke as we were advised to take his sister by a dentist. The osteopath had her hands on him for about 5 minutes at most. He improved more in the month following that (during school holidays) than he had done in a whole 3 terms of 5 mornings a week special needs preschool! The first change happened that very day and then 3 more firsts happened approximately weekly before our second appointment. Subsequent appointments did not result in such marked changes but we kept going until she felt she could do no more for him - maybe 4 or 5 appointments."*

A number of people had also had positive experiences using homeopathy: *"CEASE homeopathy has brought great change to my son's life. His language has improved, he is less stimmy and has relaxed greatly."* Similarly, another person said that *"Homeopathy sorted sleep issues rapidly and significantly."* For another, there had been an *"Excellent improvement on homeopathy especially using the CEASE protocol. Reduced anxiety and more affectionate."* And another similarly reported that *"CEASE therapy, homeopathy has been amazing as for us all as a family not just for our son as has equine facilitated therapy. Both therapies address the whole family holistically."*

Other therapies that received positive comments included experience with Hyperbaric Oxygen Therapy (HBOT) that had been *"great for improving bowels but the effect doesn't last if you don't keep up."* Even relatively minor interventions were reported to have useful effects for some children and a number of people

[8] SonRise is a program of therapy whereby parents are trained to work with their child in order to aid their development see: http://www.autismtreatmentcenter.org/

mentioned that Epsom salt baths helped to reduce anxiety and hyperactivity. As one parent put it: *"Epsom salt baths really calm him down."*

## Ideas for improvements in service provision and support for children and families in future

At the end of the survey respondents were asked 'what changes would you like to see in the NHS in order to provide better care for the person with ASD?' and even though this was an open question, requiring respondents to type in the words to respond, as many as 213 people (81% of the sample) gave a response. These comments were subsequently categorized in relation to those who were looking for an improved relationship with professionals, those who wanted the professionals to change their understanding of the condition, and those who wanted improved access to better quality services. In regard to the latter, parents were particularly focused on doing a thorough investigation of the problems faced by their child, and then identifying areas for possible treatment. Some of the clearest expressions of these desires are presented in Table 26.

**Table 26: Desired changes in the NHS and publicly-funded services, by broad category**

| | |
|---|---|
| Improved relationships between parents and professionals | I would like the NHS to listen to parents.<br>That the professionals LISTEN to the parents!<br>A willingness to listen to a parent who usually knows best.<br>A non-judgemental attitude towards parents who are forced to go down the private route as they cannot bear seeing their child in constant pain.<br>Listen to parents more, they should always be the top of the list when seeking information about their children.<br>To listen to the parent when they know something is seriously wrong.<br>For all medical staff to listen to parents. We watch our children daily and know when they are in pain. Just because they have a tantrum this does not mean it is always behavioural. Our children are non-verbal and this is how they communicate pain. |
| An end to discrimination in service provision | As simple as ASD children having the same care as all other children, and not being stereotyped autistic. They are human too … A child that is very sick should be treated by doctors and the public as a sick child that needs love instead of just a strange autistic boy.<br>Treat an ASD child as they would any other child and deal with any symptoms of pain and bowel problems as they would any other child.<br>We feel that attitudes of a large majority of NHS staff are downright discriminatory towards children (and adults?) with autism. As soon as autism is mentioned it is used to dismiss health concerns as 'normal' (whereas they would not be considered 'normal' in typical children) and to refuse medical investigation or referral.<br>Recognition of the medical and educational needs of people with ASD, as opposed to drugging them to control them and shorten their lives.<br>It seems as if people with ASD and other incurable immune disorders are part of a huge nasty eugenics social experiment! |

| | |
|---|---|
| A better understanding of the condition | A complete reform in understanding and treatment of ASD and mental illness.<br><br>A more holistic approach to autism which encompasses gut and immune system.<br><br>A recognition that our children have health issues outside of the autism diagnosis and their pain be recognized and treated as it would were they a child without this condition.<br><br>Acceptance that some symptoms in relation to autism can be relieved, thus preventing suffering.<br><br>Start acknowledging the co morbidities as a minimum.<br><br>Treat the physical symptoms and not write it off as autism.<br><br>The recognition that ASD is a medical problem. The recognition that appropriate treatments from a wide variety of professionals can make a huge difference in quality of life for people with ASD.<br><br>At the very least that people on the autistic spectrum have a number of comorbidities which can be treated and should be treated.<br><br>I would love if they could acknowledge that some of the physical symptoms of children with autism are due to their autism and represent a great deal of their challenges for them and cause lots of behaviours that they want to modify or change and provide help accordingly.<br><br>Negative behaviour should be investigated for possible physical roots not just brushed aside as a symptom of autism. The diagnosis of ASD in purely psychological terms is ludicrous and should be reassessed to include physical symptoms as well.<br><br>I would like the NHS to forget about the label of autism and treat the symptoms of each individual. |
| Better education and training for professional staff | Better education of all medical personnel about autism, its possible causes and the range of treatments available.<br><br>Every doctor to understand autism.<br><br>They need to be completely retrained and spend some time with those who have autism as they do not seem to understand it at all.<br><br>The NHS professionals should be educated about treating autism. They should be open to change and to explore more about the world of ASD. The NHS professionals are still in the dark ages compared to other health care professionals around the world.<br><br>For all health professionals to be given extensive training in current trends in thinking/ research about autism and the health implications that accompany it.<br><br>It has to start with education so people begin to understand that health issues should be investigated and that behaviour is often the only way of communicating pain and discomfort. Also that just because a person cannot speak or look at you. It does not mean they cannot hear or think or understand and be hurt by their low expectations.<br><br>Improve the training and knowledge of GP's and nurses, paediatricians, nutritionists, everyone who will have contact with our kids.<br><br>Acknowledgement and understanding of dietary interventions and that they really do help for whatever reason. |

| | |
|---|---|
| More thorough investigations of the problems involved | Investigate the causes not just go by superficial presentation of behaviours.<br><br>More exploration into why certain behaviours might be happening.<br><br>A comprehensive physical examination of the child's body - what's going on inside.<br><br>A full health screen of all children and adults with a diagnosis to make sure they have no underlying health conditions. This should be a regular thing as communication is hard and they often cannot say they are in pain.<br><br>As they agree that the gut issues are common for children with autism (both diarrhoea and constipation), I would like to have a proper testing done regularly for the people with these symptoms (including for allergies and intolerance) and the treatment given if required.<br><br>I would like to see all children with autism given a thorough physical investigation shortly after diagnosis, including gut health, possible allergies, and blood tests to screen for deficiencies. There should be proper nutritional advice available, including help with elimination diets if appropriate. |
| New services including autism-specialist teams | I would love to be able to see an autism specialist who has up to date knowledge of the condition.<br><br>I would like to see an autism health specialist - who will treat the symptoms – gut, bowel, sleep and to test for abnormalities, to treat, heal and support.<br><br>I would like to see … a medical doctor who understands the comorbidities of autism and is willing to treat them. There is a complete lack of understanding or knowledge of this on the NHS.<br><br>The breaking down of services into specialists is a nightmare for adults with ASD. What we need is a core of medics to develop skills that relate specifically to ASD. By this I mean neurologists, gastroenterologists, bacteriologists and virologists, immunologists, toxicologists etc.<br><br>The only acceptable model for me is a network of specialist autism teams in tertiary centres such as GSTT. Anything on a local level is never going to be able to deliver anything in the NICE Quality Standard. The professionals seeing children with autism have to be specialists in autism, and not be generalised paediatricians or GPs.<br><br>We need much better services for our children. We need specialist centres with doctors and clinicians who understand autism and what can be done about it ... but I realise we are a long way off this.<br><br>We now have specialist ASD teams for diagnosis, but they focus on psychological and educational interventions. I think ASD teams should include specialists in medical problems associated with ASD, so that on diagnosis, screening for gut / bowel / immune / mitochondrial etc. problems can be done, and treatment can start early.<br><br>When a child receives a diagnosis then there should be a range of services automatically offered to help identify the child's issues and solutions found.<br><br>When the child is diagnosed there should be a referral to a centre of excellence where thorough testing is done to look for any underlying issues that might have either caused or be contributing to the autism.<br><br>I would like to see a well-informed GP in every medical centre in the country. With so many children with autism in this country there should be no excuse. At least one person in each centre should have at least the basic knowledge so that a child being brought in for whatever reason can at least be seen by a doctor who knows how to treat them and can ask the right questions. It should not just be a case of passing things along to the hospital.<br><br>Full investigation for every ASD child with a tailored health plan and full educational support. |

| | |
|---|---|
| More appropriate health and medical services | A recognition of the issues that people with autism face and alternative arrangements for appointments, somewhere they feel safe and don't have to wait.<br><br>Better quality of service, more accountable, more user-friendly, more able to work in collaboration with parents and other practitioners. |
| More ongoing health and medical care | The child's GP should regularly see the child to see if anything is being overlooked (and GPs will have to be more knowledgeable about all the co-morbidity so as to do this).<br><br>A thorough periodic review of the condition to view whether it has worsened, improved, or is same, and if any help can be provided. |
| More care in vaccination and keeping records of adverse effects | A change in the vaccine schedule to be tailored to each child rather than one size fits all.<br><br>Many report their concerns following deterioration after vaccination. At no point this is being recorded in any way. It is dismissed as if it had never been said, or heard.<br><br>Look at the vaccine issue again. |
| Improved access to services | More funding to provide more access to SALT and OT for children in mainstream schools.<br><br>Earlier diagnosis & assessment. |
| Other | I would like to see the autism community pooling its efforts into providing research to convince NHS practitioners that tax payers' money is well spent trying to address the medical problems associated with autism because unless there is credibility nothing will change. |

## Conclusion

This report has highlighted the scale of the challenges faced by parents and children with ASD both in relation to the behaviours and health problems encountered but also in relation to accessing adequate services for support. The survey data indicated that a minority of respondents were struggling to access services from the NHS for basic support with challenges such as diet, nutrition, gut problems and sleep difficulties. In addition, even those who had managed to access the professional services available did not have their problems resolved. Only 11% of respondents felt that the NHS professionals they encountered understood their concerns about the behaviour and healthcare issues of their child, and the majority (70%) felt that their child's symptoms were attributed to ASD, rather than being worthy of investigation with the potential for treatment. Indeed, having a label of autism seemed to get in the way of accessing services and potential treatments that would ordinarily be available on the NHS. This diagnostic overshadowing meant that children's symptoms were often left untreated and when parents sought help privately, they were often able to get at least some of these problems resolved.

Many of the comments exposed what might best be called a 'perception gap' between parents' experiences of looking after their children– and trying to deal with the wide range of health and behavioural problems they face - and the official health system that still classifies autism as a developmental disability. The official diagnosis is based upon the observation of cognitive, social and other behavioural and communication problems (the so-called 'triad of impairments') rather than any recognition of the wide range of co-morbid conditions that are commonly associated with the condition, many of which can be treated. As a result, parents struggled to access treatment, and what was provided was often inadequate.

Given this, it is hardly surprising that almost all respondents (80%) had sought help privately. Parents had paid to see a range of health professionals that included doctors, nutritionists, speech and language and occupational therapists. In addition, however, and often in consultation with privately-accessed professionals, parents were experimenting with diet, nutritional supplementation and safe alternative therapies to see if they could help relieve some of the challenging problems faced by their children. In the vast majority of cases, these experiences had been positive, and for a sizeable number, the changes were reported to be life-changing.

The collective experiences of these parents are a reservoir of valuable testimony about the impact of

relatively easy, low-cost, interventions that can improve the lives of children with ASD and their families, sometimes dramatically. Much more could be done to document these experiences and develop a more helpful dialogue between parents and clinical practitioners. It would also be possible to foster wider debate and education about these possibilities amongst NHS staff and thereby help many more families to improve the well-being of their children.

In this regard, many respondents argued that they would like to see improved relationships with NHS staff, along with a new approach to training and service provision. There were also calls for specialist teams to be set up, including a range of professionals, who could then fully investigate the range of challenges faced by children with ASD and identify possible areas for treatment and support. This has the potential to be life-changing for children with ASD and their families, and in the long-run, it could also save the wider community from at least some of the financial and emotional costs associated with the condition. New forms of best practice that incorporate routine medical checks for treatable co-morbid conditions are now being developed for people with ASD in other parts of the world, and there is scope for extending this learning to the UK. As Perrin (2016, 1; see also McElhanon et al 2014) and his co-authors from the Autism Intervention Network on Physical Health and the Autism Speaks Autism Treatment Network (AIR-P/ATN) explain: "*Whereas, until recently, medical complaints (eg, abdominal pain, poor sleep, or disruptive behaviors) were typically considered part of the disorder and therefore not requiring specific attention, today clinicians throughout the country directly assess and treat these associated conditions. The combined AIR-P/ATN network has developed systematic ways to assess and treat coexisting conditions, focusing on those for which management was previously highly variable or sporadic and has shared those methods broadly with the larger parent and professional communities. The active involvement of families and young people with ASD has helped the network identify key issues for individuals and families and focus its attention accordingly. Although clinicians may have limited new, evidence-based options for treating autism directly, they now have systematic ways to evaluate and manage coexisting conditions. In turn, families have learned about new ways to help their children and improve their functioning and outcomes*."

This approach would greatly improve the lives of the families who took part in the survey reported here, as well as many thousands of others across the UK. In addition, the survey highlights the need for more scientific research into the causes and possible treatments of ASD and the range of co-morbid conditions associated with the condition. Parental experiences highlight the way in which diet and nutritional supplements can make a significant difference to the lives of children with ASD, and this is a vital area for further research.

In summary, this research report has highlighted the scale of the challenges faced by children with ASD and their families, the inadequacy of the current services provided by the NHS, the experiences of parents who are using changes in diet, nutritional supplements and a range of therapies to support their children, and the need for new thinking by those who are training health professionals and designing services for the twenty-first century.

**Appendices**

| Table A1: Acronyms | |
|---|---|
| ABA | Applied Behaviour Analysis |
| ABA/ VB | Applied Behaviour Analysis/Verbal Behaviour |
| ADHD | Attention deficit hyperactivity disorder |
| ADOS | Autism Diagnostic Observation Schedule |
| AED | Antiepileptic drugs |
| AIT | Auditory Integration Therapy |
| ASD | Autism Spectrum Disorder |
| ATEC | Autism Treatment Evaluation Checklist |
| CAMHS | Child and Adolescent Mental Health Services |
| CEASE | Complete Elimination of Autistic Spectrum Expression (Homeopathy) |
| CST | Craniosacral Therapy |
| DLA | Disability Living Allowance |
| EEG | Electroencephalogram |
| EP | Emotional Processing |
| FODMAP | Fermentable Oligo-, Di-, Mono-saccharides And Polyols |
| GAPS | Gut and Psychology Syndrome |
| GERD | Gastroesophageal Reflux Disease |
| GF/CF | Gluten Free Casein Free |
| GI | Gastro-Intestinal |
| GMO | Genetically Modified Organism |
| GOSH | Great Ormond Street Hospital |
| GP | General Practitioner |
| HANDLE | Holistic Approach to Neuro Development and Learning Efficiency |
| HBOT | Hyperbaric Oxygen Treatment |
| IDN | Interdisciplinary Developmental Neuroscience |
| LEA | Local Education Authority |
| LDN | Low Dose Naltrexone |
| MAD | Modified Atkins Diet |
| MRI | Magnetic Resonance Imaging |
| MSG | Monosodium Glutamate |
| MTD | Mitochondrial Dysfunction |
| NAET | Nambudripad's Allergy Elimination Techniques |
| NHS | National Health Service |
| NAS | National Autistic Society |
| NICE | National Institute for Health and Care Excellence |
| OCD | Obsessive-Compulsive Disorder |
| ODD | Oppositional Defiant Disorder |
| OT | Occupational Therapist |
| Paleo diet | Linked to GAPs above; removal of complex carbohydrate as well as dairy |
| PCT | Primary Care Trust |
| PDDNOS | Pervasive Developmental Disorder Not Otherwise Specified |
| PEACH | [now] Child Autism UK |
| PECS | Picture Exchange Communication System |
| RDI | Relationship Development Intervention |
| S&L/ SLT /SALT | Speech and Language Therapy |

| | |
|---|---|
| SCD | Specific Carbohydrate Diet |
| SEN | Special Education Needs |
| SENCO | Special Education Needs Coordinator |
| SENDIS | Special educational needs and disabilities |
| SIB | Self-Injurious Behaviour |
| SIT | Sensory Integration Therapy |
| SUDEP | Sudden unexpected death in epilepsy |
| TA | Teaching Assistant |
| TLP | The Listening Program |
| WAP | Work Activity Program |

**Table A2: Prescription medicines identified in the research, by type**

| ***Medication Type*** | ***Medication Name*** | ***Brand Names*** |
|---|---|---|
| Antibiotic | Amoxicilin | |
| | Azythromycin | Zythromaz |
| | Metronidazole | Flagyl |
| | Vancomycin | Vancocin |
| Anti-fungal | Clotrimazole | Canesten, Lotrimin |
| | Fluconazole | Diflucan |
| | Nystatin | |
| Anti-depressant | Aripiprazole | Abilify |
| | Citalopram | Celexa, Cipramil, Paxoran, |
| | Escitalopram | Lexapro |
| | Fluoxetine | Prozac, Serafam |
| | Methylphenidate hydrochloride | Ritalin |
| | Paroxetine | Seroxat |
| | Quotiepine | Seroquel, Xeroquel, Ketipinor |
| | Sertraline | Zolofot |
| Anti-viral | Isoprinosine | Immunovir |
| | Valtrex | Valacyclovir |
| Anti-inflammatory | Low Dose Naltrexone | |
| | Prednisalone | |
| Anti-histamine | Cetirizine | Zirtec, Zyrtec, Reactine |
| | Hydroxyzine | Atarax |
| | Ketotifen | Nalcrom |
| | Sodium Cromoglicate | |
| Anti-epileptics | Benzodiazepine | Clobazam |
| | Carbamazepine | Tegretol |
| | Clonazepam | Klonopin |
| | Cortexin | |
| | Lamotrigine | Lamictal |
| | Levetiracetam | Keppra |
| | Sodium valproate | Epilim |
| Anti-anxiety | Clonidine | Catapres, Kapvay, Nexiclon, Clophelin |
| | Diazepam | |
| | Escitalopram | Lexapro |
| | Hydroxyzine | Atarax |
| | Lorazepam | Ativan |
| | Rispiridone | Risperdal |

## References


Buescher, A. Cidav, Z, Knapp, M. and Mandell, D. (2014) Costs of autism spectrum disorders in the United Kingdom and the United States of America. *JAMA Pediatriacs,* 168(8):721-728.

DePape, A M. and Lindsay, S (2015) Parents Experiences of Caring for a Child With Autism Spectrum Disorder. *Qualitative Health Res*earch, 25(4):569-583.

Gottschall, E. (1994) *Breaking the vicious cycle: Intestinal health through diet*. Ontario, Canada: The Kirkton Press Ltd.

Mazars (2015) *Independent review of deaths of people with a learning disability or mental health problem in contact with Southern Health NHS Foundation Trust, April 2011- March 2015*. Available from: https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2015/12/mazars-rep.pdf

Mencap (2007) *Death by indifference: Following up the Treat me right! report*. Available from: https://www.mencap.org.uk/sites/default/files/documents/2008-03/DBIreport.pdf

Mental Health Taskforce to the NHS (2016) *The five year forward view for mental health*. Available from: https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf

McElhanon, B. McCraken, C. Karpen, S. and Sharp, W G. (2014) GI symptoms in ASD: A meta-analysis. *Peadiatrics*, 133, 872-833.

Perrin, J. M., Coury, D. L. Klatka, K. Winklosky, B and Wolfe, A (2016) The Autism Intervention Network on Physical Health and the Autism Speaks Autism Treatment Network. *Pediatrics*, 137 (S2/S67), early download: e201528 1D

Treating Autism (2014) *Medical co-morbidities in Autism Spectrum Disorders: A primer for health care professionals and policy makers* (second edition). Treating Autism, available from: https://issuu.com/treatingautism/docs/medical_comorbidities_in_autism_spectrum_disorders