

Looking After Us Too

Health Inequalities for Parents of Autistic Children & Young People

A report by The SEND Dynamic C.I.C.

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Author: Victoria Wright, Manager & Director, **The SEND Dynamic C.I.C.**

Reviewed by: Anjali Taylor, Psychotherapist and Clinical Lead Talking Mental Health Derbyshire

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1. Foreword

The **SEND Dynamic C.I.C.** wishes to thank the parents of autistic children and young people in **Derby** and **Derbyshire**, and beyond, who worked with us to achieve this report. Some participated in the survey and shared their experiences with us that way, others attended in person or online groups or spoke with us on a one to one via Teams about their health and parenting experiences.

There are too many individuals to mention by name, and the survey was anonymous but thank you to every one of you for taking time to get involved. It has been our privilege to connect with you and we hope that you will feel recognised and validated as you read on.

Thanks also to the **Derby Health Inequality Partnership (DHIP)**, firstly for recognising that people within the autistic community experience health inequalities, and secondly for supporting **The SEND Dynamic C.I.C.** by awarding us a grant to deliver the **Looking After You Too** project.

It is our hope that all who read this report will gain a deeper understanding of the health inequalities faced by parents of autistic children and young people, and that those in positions of influence consider the lived experiences of the parent participants and seek to change the status quo.

Vicky Wright

Manager & Director

The SEND Dynamic C.I.C.

2. Executive Summary

2.1 The survey shows that parents of autistic children living in **Derby** and **Derbyshire** are experiencing excessive, sometimes traumatic levels of stress, that is having an adverse impact on their physical and mental health. Many feel isolated and broken.

Parents have multiple mental and physical health conditions that are exacerbated and/or caused by stress.

There are layers of complex factors that impact parents of autistic children. Given that autism is now widely accepted to be a genetic condition[i], it is not surprising that some parents we surveyed are already diagnosed or are discovering after their child's diagnosis that they are autistic themselves. Becoming a parent is a time of huge transition for an autistic person with lots of change, and sensory overwhelm, including sleep deprivation.

Coping with uncertainty is especially challenging for autistic people. This can make navigating the diagnostic pathway for their child intolerable. Children are waiting longer, sometimes several years longer than they should wait for diagnostic assessments.

There is a lack of early intervention for autistic children and young people. Parents are relying on schools to help them to spot the signs of autism and seek the right help, but the help is not always there. Parents are turning to their GP's who make referrals, but children suspected of autism are lost in a black hole waiting to be assessed whilst their needs go unmet, and their mental health deteriorates.

For those who finally do get a diagnosis for their children there is the challenge of helping the child to process their diagnosis in a positive way. Parents are struggling alone trying to make sense of autism diagnoses for their child and to help them to understand and accept their autistic identities.

The assumption that the diagnosis will unlock support trips parents up too. Many are shocked to find that their child's official diagnosis results in discharge from service with no support, help or guidance. They are increasingly needing to turn to independent professionals to identify support measures and interventions to assist their children and young people.

Then there is the arduous experience of fathoming the route to securing an Education, Health and Care Plan. Contending with the injustice of the unlawful decisions of local authorities, the misinformation, the lack of accountability and the delays in adhering to the statutory timescales, whilst parenting children with complex needs all creates significant stress and anxiety for parents. The research base indicates that parents are often disbelieved or blamed when advocating for their child, when resources are tight, and schools are trying to ration scarce resources.

To achieve equality will require change. Services must be able to **differentiate** for parents of autistic children and young people. There cannot be a one size fits all approach. Despite best intentions, there is inadequate personalisation of pathways for autistic people because there is inadequate understanding of their needs. In addition, the nature of those needs means that services perceive them as "hard to reach" so do insufficient co-production with them in designing care pathways to reduce barriers to access and improve efficacy of treatment.



2.2 Purpose and Scope

This is intended to be a meaningful report bringing validation for parents of autistic children and young people, an evidence base which should be considered by all professionals working in the education, health and care sector in **Derby** and **Derbyshire.**

The SEND Dynamic C.I.C. wanted to connect with parents to give them an opportunity to be heard, to share their lived experience of parenting and how this impacts on their own physical and mental health.

The reason for doing this is to help parents to have improved health and mental well-being. **The SEND Dynamic C.I.C.** wants parents to:

- Feel better supported.
- Experience reduced feelings of isolation.
- Feel listened to.
- Be more likely to access treatment/support for their physical health conditions.
- Have reduced stress and anxiety.
- Have improved awareness of the support already available locally and be more likely to seek help.
- Have a peer support network of others with lived experience.

Parents came forward to form a peer support group facilitated by **The SEND Dynamic C.I.C.** The group offered in person opportunities for parents to talk with each other and helped them to feel less isolated. For those parents unable to access in person groups an online group was formed, meeting on different days and at different times in the day to increase participation.

In addition to identifying needs in relation to both physical and mental health, the aims were to provide a voice for parents to highlight gaps in services and to raise awareness of and access to the range of services already available for parents locally in **Derby** and **Derbyshire**.

In presenting the collective viewpoint of parents it is hoped that decision makers would better understand what is needed to address health inequalities and to improve the experiences, health, and well-being of parents of autistic children and young people.

This work has been user led from the outset. An anonymous survey questionnaire was targeted at parents of autistic children and young people living in **Derby** and **Derbyshire**. The questions for the survey were developed by parents and tested with a small focus group of parents.

The survey was created using google forms and was distributed via social media and by email to reach parents of autistic children and young people.

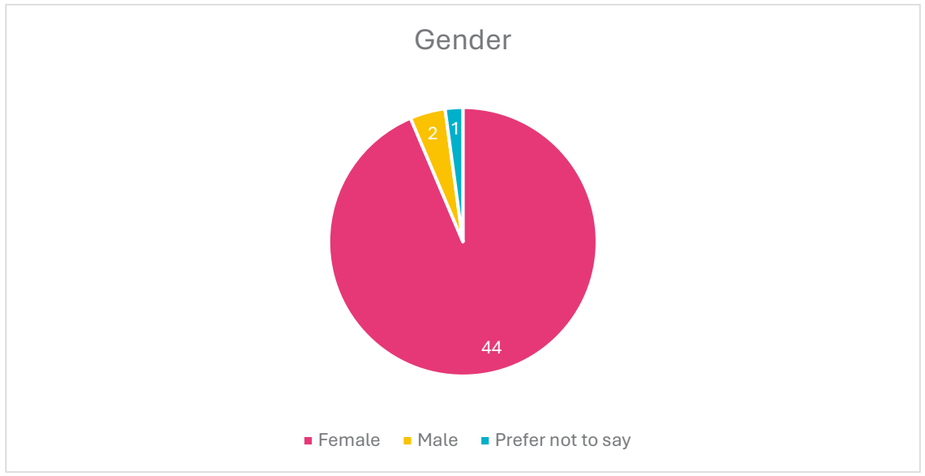
Despite the scale of the responses this report is not intended to be considered a piece of academic research. There is existing academic research investigating parental stress in parents of autistic children and young people and health comorbidities for autistic individuals. Some of these studies are referenced at the end of the report.

3. Findings Part One: Derby City

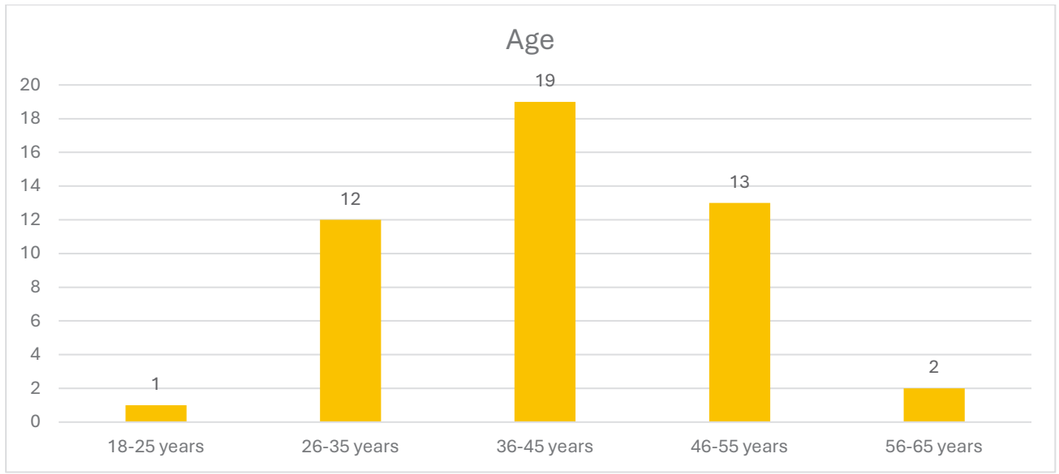
3.1 Gender, Age, Ethnicity & Work

A total of **47** parents who completed the survey came under the **Derby** city local authority for services.

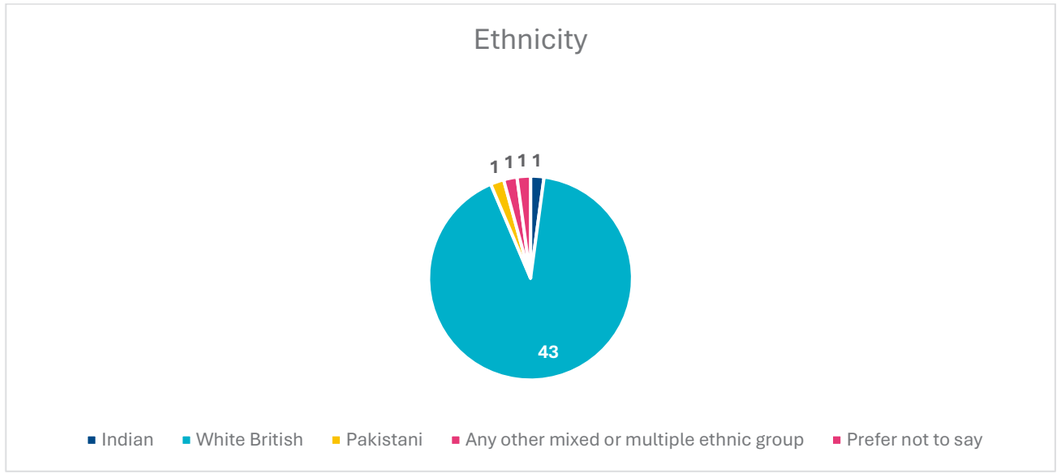
Most of these are female parents which is unsurprising given that mums are often the primary care givers[ii] for children and young people generally, and our parent service users are predominantly mums. The survey did not look at marital status or marriage breakdown, but it is important context to note that autism in the family can either drive a marriage apart or hold it together[iii].



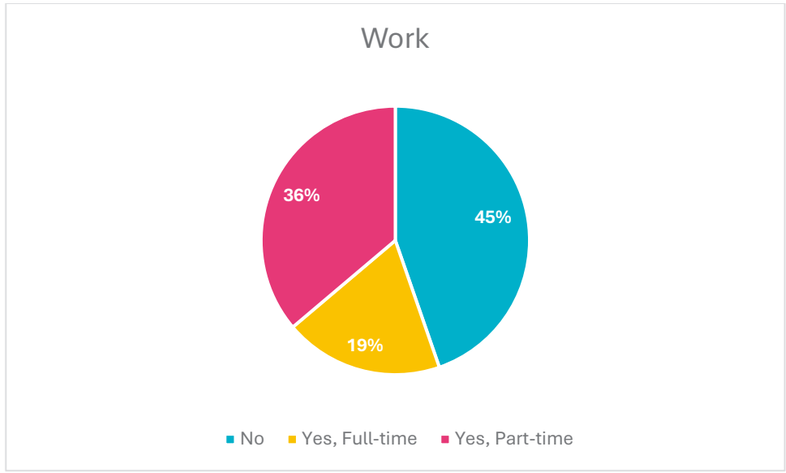
Most **Derby** city parents completing the survey are in the 36-45 years age category **(45%)**, followed by 46-55 years **(31%)** and 26-35 years **(29%)**.



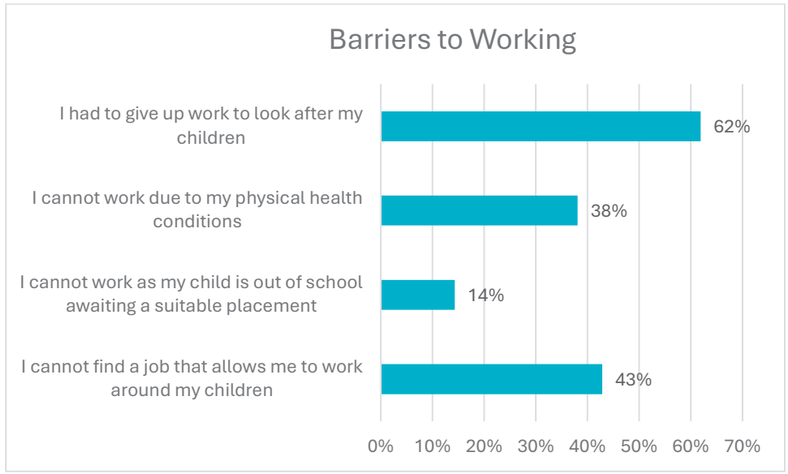
43 (91%) of parents who completed the survey from **Derby** city are white British.



We asked parents about work because we know that parenting autistic children and young people can impact significantly on a parent's ability to access and sustain employment. Of the **Derby** city parents who participated in the survey **45%** reported they are not in work.

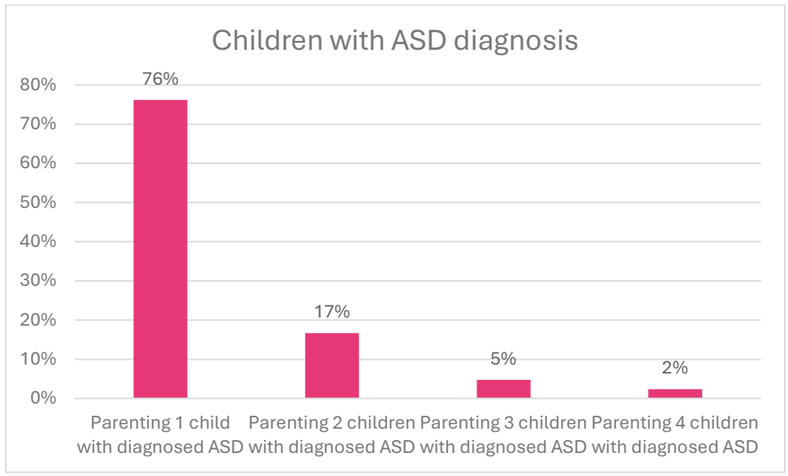


Parents shared with us the barriers they experienced in accessing work as parents of autistic children and young people. Of the **21** parents who are not in work, a significant number **(62%)** have been required to give up work to look after their children. There are multiple barriers facing parents **43%** reported not being able to find a suitable job that allowed them to work around their children, **38%** of parents cannot work due to their own health conditions and **14%** of parents are not able to take up employment because their children are out of school awaiting a suitable school placement.

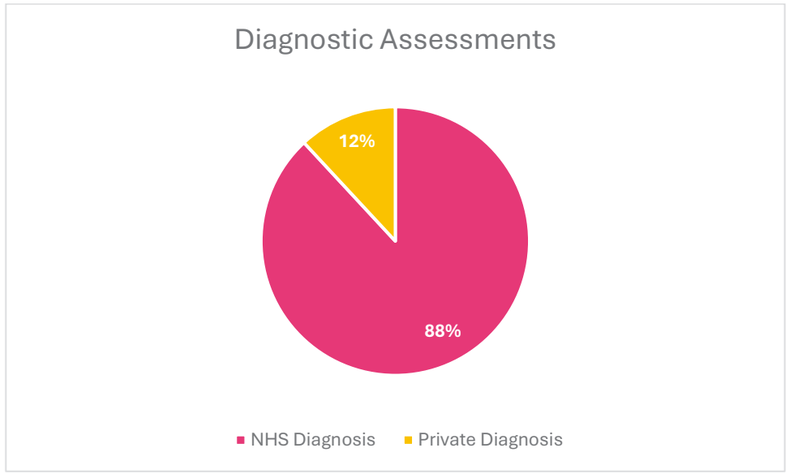


3.2 Children and young people with ASD diagnosis

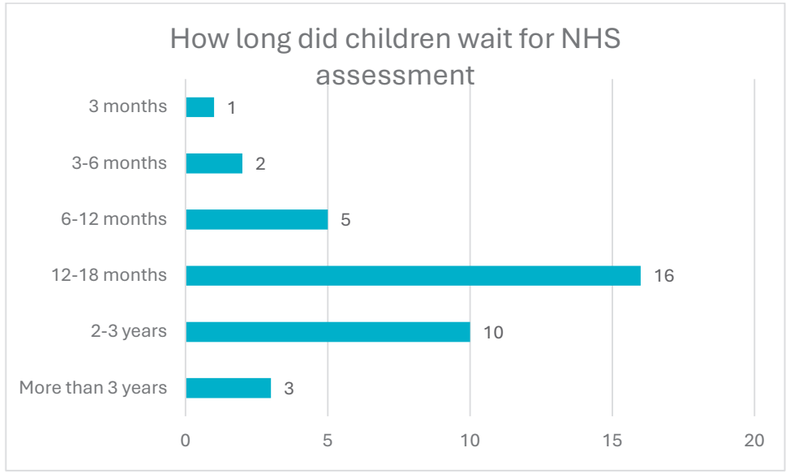
Of the **47 Derby** city parents who responded to the survey **42 (89%)** are parents of children with a formal diagnosis of ASD (Autism Spectrum Disorder). Of those **76%** are parenting one child with a formal diagnosis and **17%** are parenting two children.



The majority **(88%)** of children with formal diagnosis of ASD were assessed within the NHS and **12%** were diagnosed via private assessment.

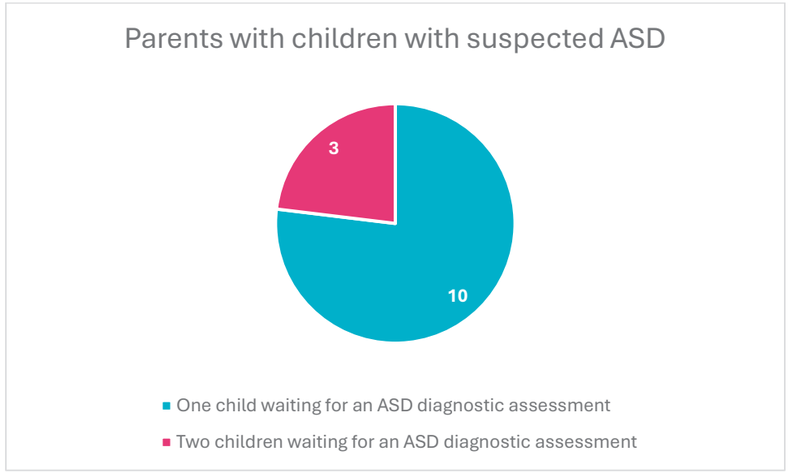


3 parents reported their child waiting for over 3 years for an ASD assessment, **10** parents reported waiting 2 to 3 years for their child to be assessed and **16** reported waiting a year to 18 months for the diagnostic assessment appointment. The NICE (National Institute for Health and Care Excellence) Guidelines state that if a child is referred for an autism assessment this should happen within 3 months. The current delays in the NHS system do not comply with the NICE guidelines[iv].

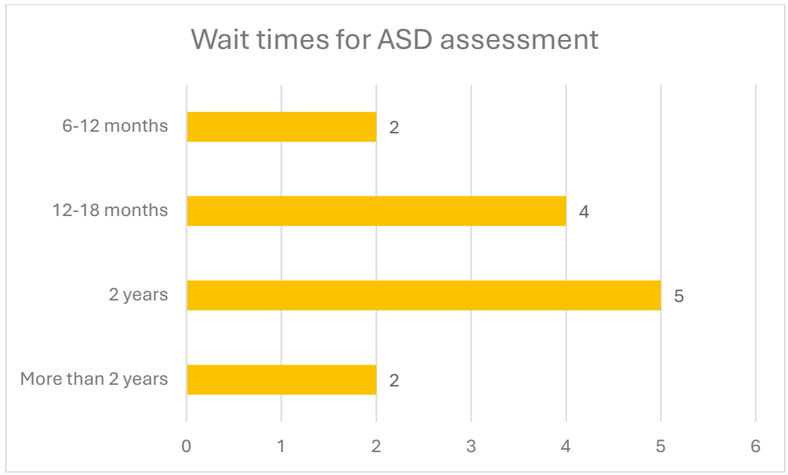


3.3 Children and young people waiting for an ASD assessment

Of the **Derby** city parents who completed the survey **13** are waiting for their children with suspected ASD to be seen for an assessment. **3** of those parents have two children on the waiting list.

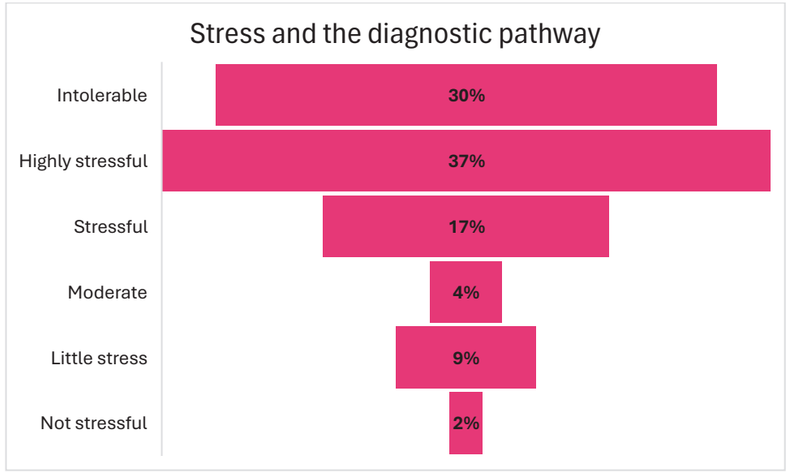


Of the **13** parents who are currently waiting for their children suspected of ASD to be assessed, **7** have been waiting for 2 years or more. All the children have been waiting for longer than the statutory timescales for assessment according to the NICE Guidelines. **92%** of these children are compulsory school age.



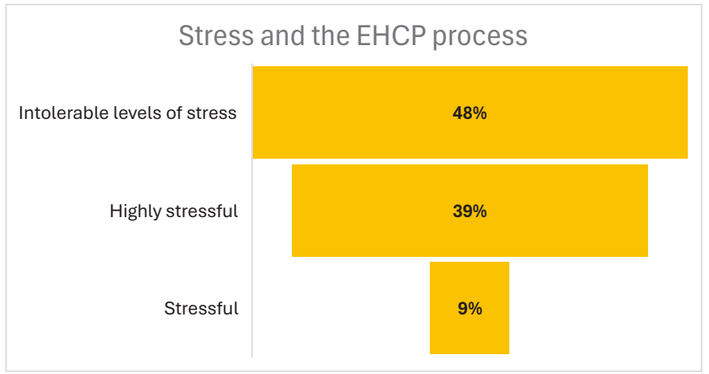
3.4 Stress and experiences of the Diagnostic Pathway for Parents of Autistic Children

30% of parents from **Derby** city described the ASD diagnostic pathway for their children as intolerable in terms of the stress they experienced. A further **37%** said the pathway was highly stressful and **17%** described it as stressful. Just **11%** of parents felt they experienced little to no stress.



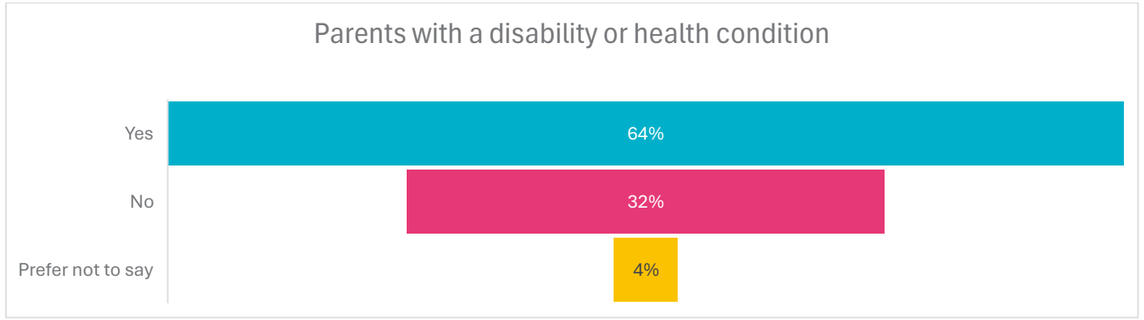
3.5 Experiences of the Education Health and Care Plan Process for Parents of Autistic Children

When asked about their experiences of navigating the education health and care plan process for their autistic children **48%** of **Derby** city parents described this as causing them intolerable levels of stress. A further **39%** shared that they found the process highly stressful and **9%** felt it was stressful. Significantly no **Derby** city parent respondents described the process as causing them little to no stress, everyone felt stressed to differing extremes.

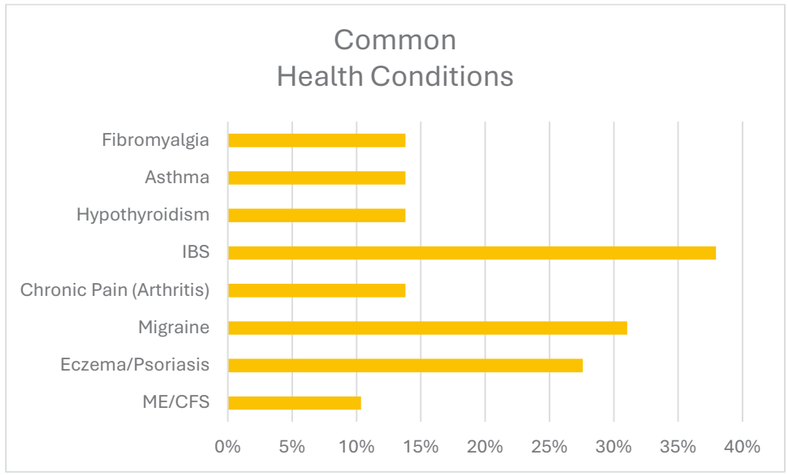


3.6 Disability and Health Conditions

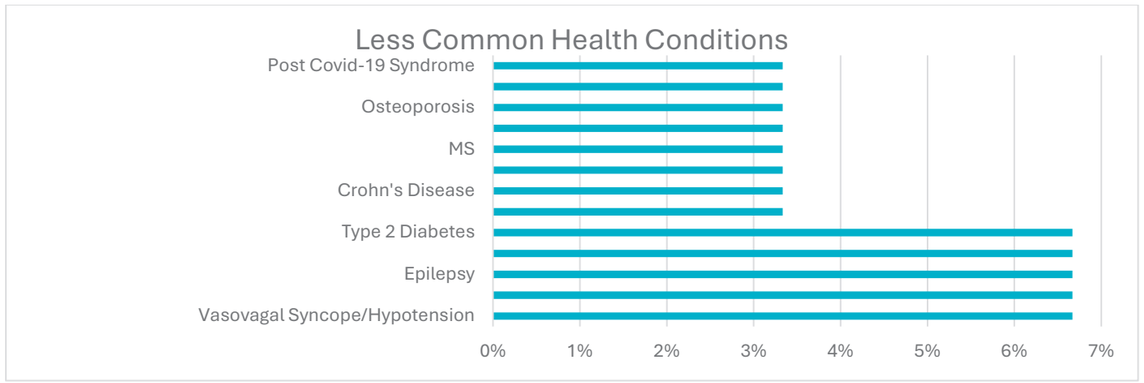
64% of parent respondents living in **Derby** city are disabled or have a health condition themselves. **38%** of parents shared with us that they have a neurological condition (ASD, ADHD (Attention Deficit Hyperactivity Disorder) and **15%** are physically disabled. **17** parents **(59%)** with a health condition reported living with multiple (3 or more) chronic health conditions.



The most common health condition is irritable bowel syndrome (IBS) with **40%** of parents with a health condition experiencing this. **33%** of parents have migraines and **27%** live with chronic eczema or psoriasis. **14%** are living with Fibromyalgia.



The less common debilitating conditions experienced by parents included Interstitial Cystitis, Crohn's Disease and Postural Orthostatic Tachycardia Syndrome (POTS) **(3%),** Functional Neurological Disorder (FND), Vasovagal Syncope and epilepsy **(7%).**

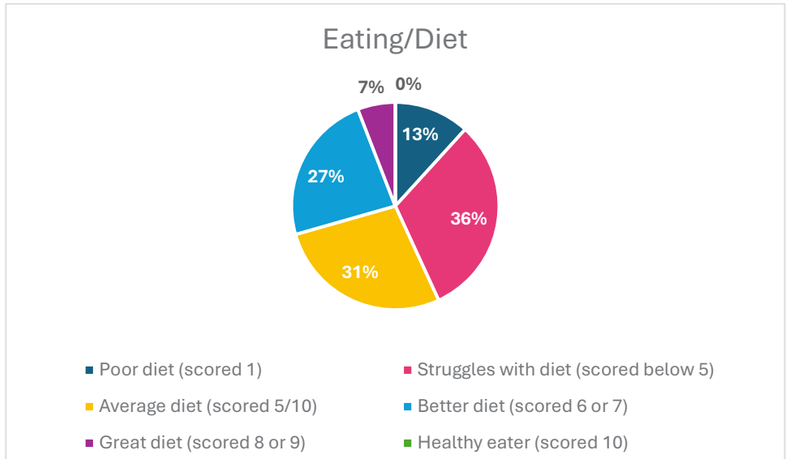


3.7 Diet

We asked parents about their diet and eating habits. We asked them to rate their diet on a scale of 1 to 10 where 1 is struggling to eat a healthy diet and 10 is a healthy eater.

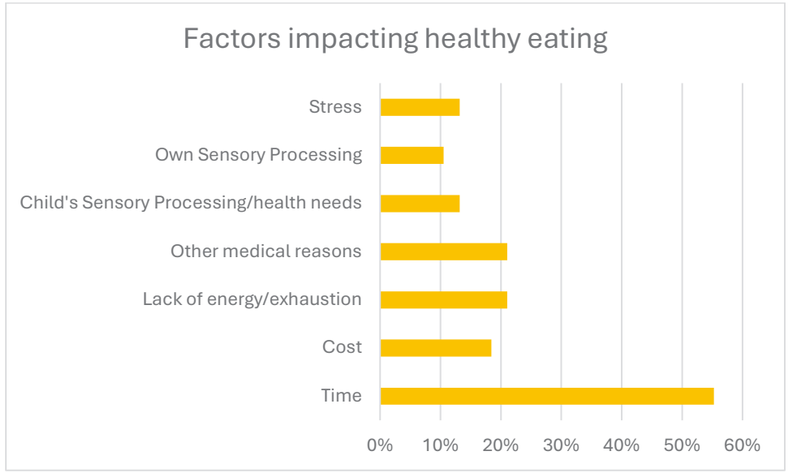
13% of **Derby** city parents shared that they are struggling to eat a healthy diet and rated it 1 out of 10 indicating poor diet. **49%** of parents scored below 5 for diet.

0% of parents reported being a healthy eater, and just **7%** rated their diet 8 or 9 indicating a healthier diet than most.



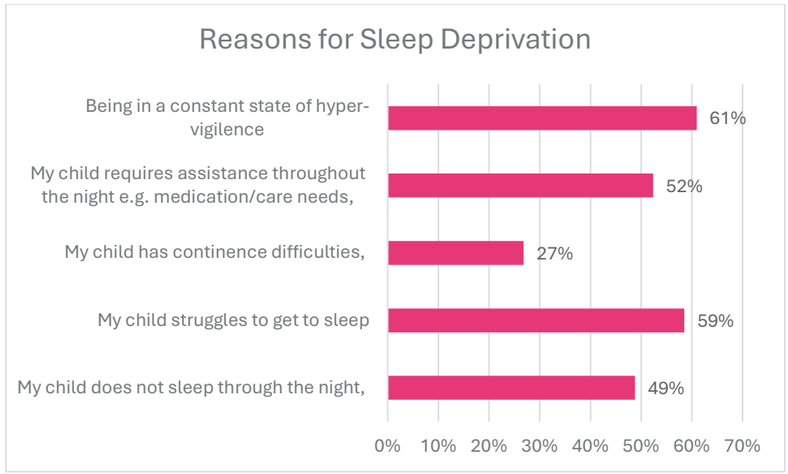
3.8 Factors for struggling with diet

Of those **Derby** city parents who reported struggling with eating a healthy diet a variety of factors were at play including lack of time **55%, 24%** of parents reported sensory processing difficulties either their child's or their own resulted in struggles to achieve a healthy diet, lack of energy/exhaustion and other medical reasons **21%** respectively, cost of food **18%,** and stress was reported as a factor for **13%** of parents.



3.9 Lack of Sleep

89% of parents of autistic children and young people from Derby city shared that they experience sleep deprivation on a regular basis. Parents experience a multitude of problems which impacts their ability to sleep. 61% felt that this was due to their heightened sense of hypervigilance to the needs of their child or young person throughout the night. 59% of parents were unable to sleep themselves due to the impact of their children's sleep difficulties being unable to fall to sleep and 49% shared that their autistic children do not sleep through the night. 52% of parents shared that they provided assistance throughout the night to attend to the medication/care needs of their child/ren. 27% of parents were managing their child/ren's continence difficulties throughout the night.



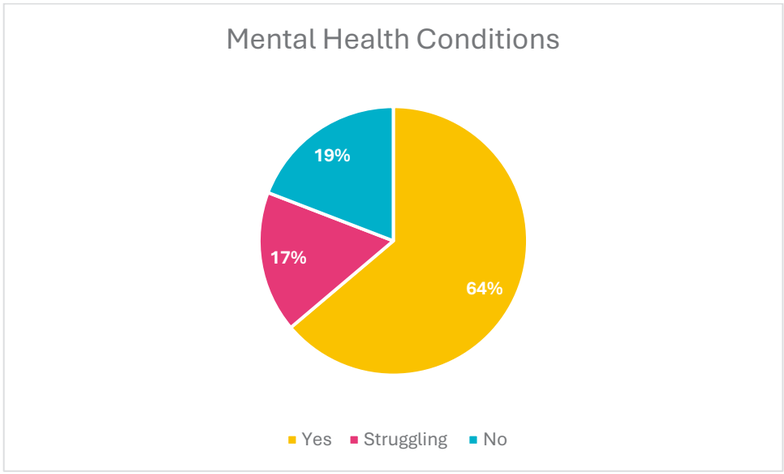
Parents shared other reasons for sleep deprivation including:

- Their own anxiety, stress, and worry.
- Their own ADHD, autism, and sensory processing challenges.

- Health reasons such as sleep apnoea, sleep pattern disorder, chronic pain, and menopause.
- Sleeping arrangements including co-sleeping due to their child being unable to sleep on their own.

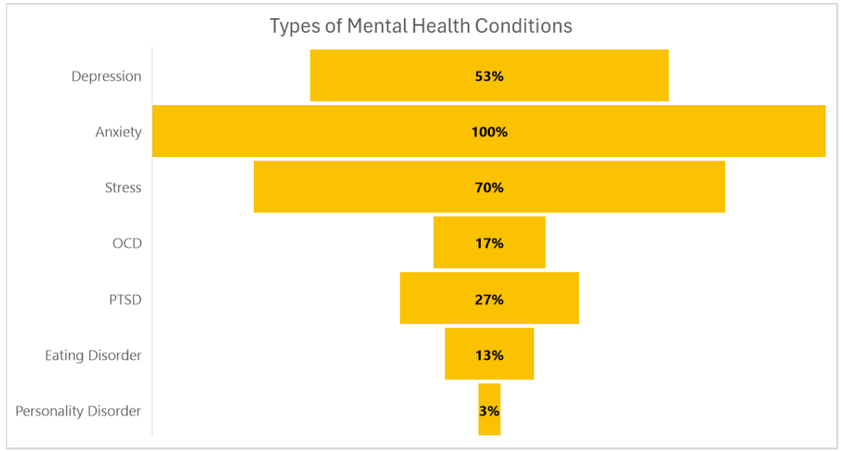
3.10 Mental Health

Of the 47 Derby city parents 30 (64%) reported having a diagnosed mental health condition. 8 parents (17%) reported struggling with their mental health but without diagnosis and 9 parents (19%) reported they did not have a mental health condition.



Of those parents who reported having a mental health condition, 100% reported suffering with anxiety, whilst 70% experienced stress and 53% reported having depression.

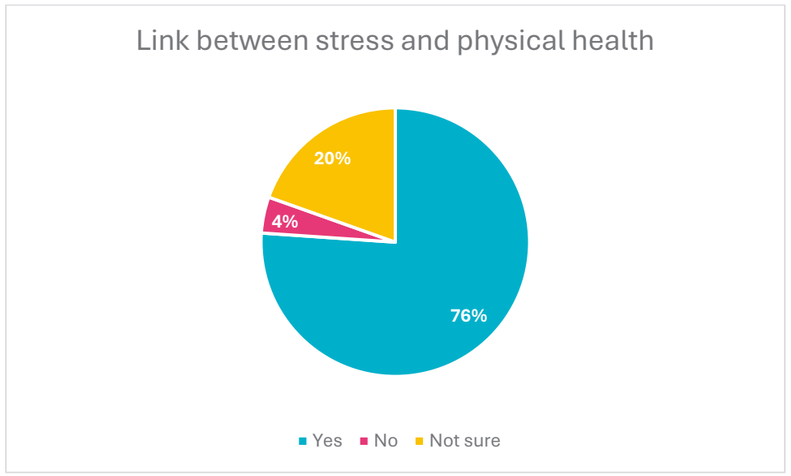
A significant number of parents (77%) reported living with multiple mental health conditions. 27% of parents were experiencing Post Traumatic Stress Disorder (PTSD) and 17% were diagnosed with obsessive compulsive disorder (OCD).



3.11 Is there are link between stress and physical health?

We asked parents if they believed there was a direct link between the stress they experienced and their physical health. **76%** of parents believed there was a link and that the stress they experienced caused them to be physically unwell. **51%** of **Derby** city parents are living with a diagnosed mental health condition alongside multiple physical health conditions. A further **9%** of **Derby** city parents reported they have diagnosed physical health conditions and are struggling with their mental health.

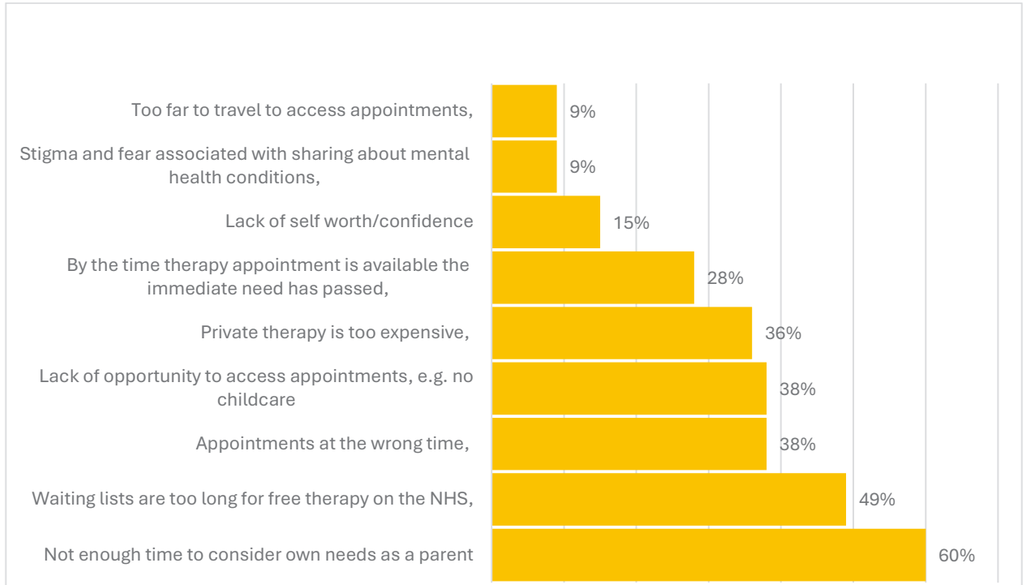
Significantly **75%** of parents of autistic children and young people in **Derby** city with diagnosed physical conditions **and** diagnosed mental health conditions are experiencing **STRESS.**



We explored the topic of mental health further with parents:

- **70%** of **Derby** city parents reported it was difficult to access treatment and support for their mental health.
- **21%** of parents were unaware that they could access and self-refer for NHS Talking Therapies

Parents were asked what would prevent them from accessing therapy and support for mental health conditions. The findings confirmed anecdotal reports, **60%** of parents said there was not enough time to consider their own needs as a parent and **49%** said the waiting lists were too long on the NHS. Lack of access **(38%)** and timing of appointments **(38%)** were also significant barriers to parents seeking help for their mental health.



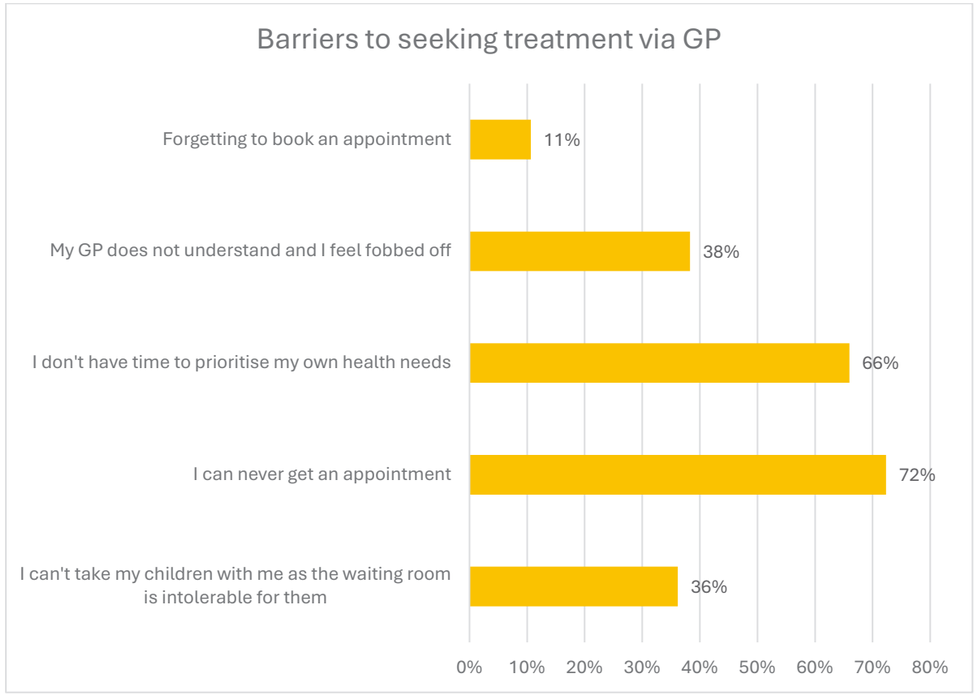
Parents also shared difficult experiences of accessing NHS Talking Therapy:

- "Absolutely no help at all. I saw a therapist who discharged me after 3 sessions because there was nothing, he could do to alleviate the situation I was in".
- "Therapies are not intersectional; the NHS offer CBT which is typically harmful for Autistic patients (I found it harmful and was treated really badly). A lot of things for Autistic people over 18, we need art, drama, music, sensory, movement therapies".
- One parent told us accessing NHS therapy was impossible as they are "housebound due to severe ill health".

3.12 Experiences of NHS Treatment

The GP Surgery

59% of parents in Derby city shared that they experienced their GP to be unsupportive. Parents shared with us the challenges they face when seeking treatment via the GP surgery. 72% of parents felt that they could never get an appointment. 66% said that they did not have the time to prioritise their own health needs. 38% of parents felt that their GP does not understand and fobs them off.

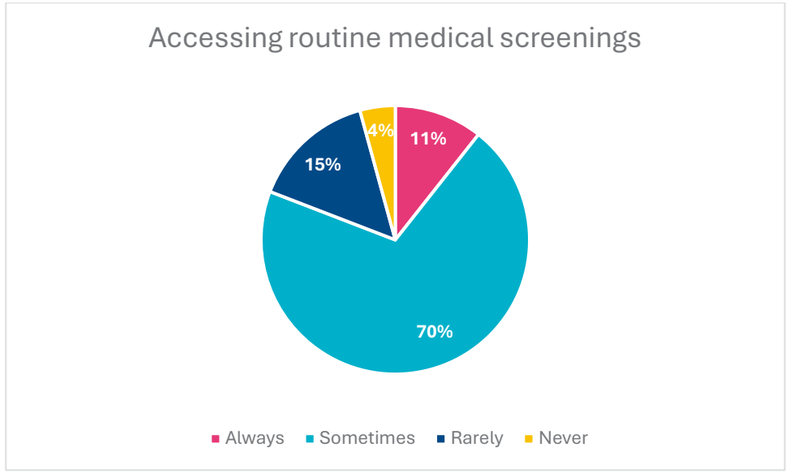


Parents who are also autistic themselves shared additional barriers including;

- *"Medication for stress has further side effects like sickness, nausea, headaches".*
- *"Phone appointment unsuitable for me as an autistic person due to audio processing".*
- *"Just feel too misunderstood and GP and many professionals discuss autism as a deficit, and I don't have the energy to explain and fight for myself as my daughter comes first".*
- *"I find phone calls extremely hard but am just told to call at 8am, when I am also trying to get my Autistic kids ready for school. I have a big list of things that I need help with, but I am both seen as able and treated like I am stupid during an appointment*".

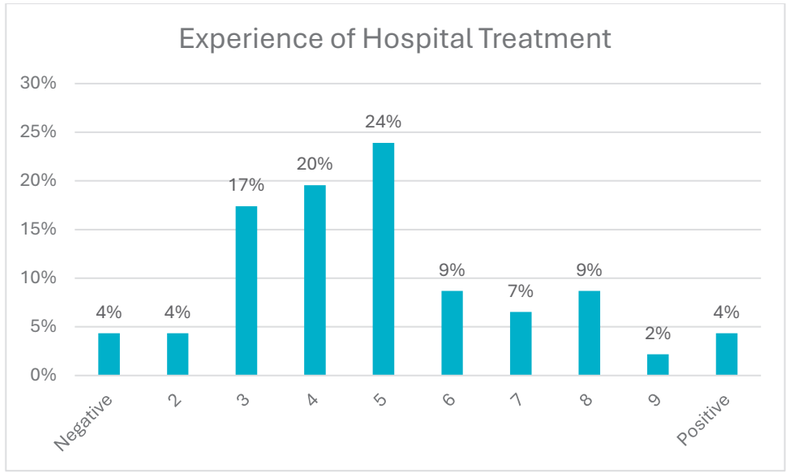
One parent shared *"Changes to my own needs and health effects my autistic child's needs. I'm not allowed to have illness or struggle as it affects my daughter's needs. I need surgery, but I can't risk not being able to recover as my child needs are a priority because I'm all she's got helping her".*

We asked parents to share their experiences of accessing routine medical screenings. 19% of parents in Derby city rarely or never attended these.



Hospital

Experiences of hospital treatment varied amongst parents in Derby city. 45% rated their experience 4 and below and only 6% rated it 9 or 10, where 10 is positive.



Parents shared their views on accessing hospital treatment:

- "Occasionally, staff are amazing. Other times I have had keys rattled at me to get my attention because I wasn't looking at the doctor in the face (I was rocking and looking at the floor but fully engaging in the conversation. I had a sunflower lanyard on and an Autism card). This is one of the tamer experiences I have had".
- "Each different department acts individually; nobody seems to see the whole picture".

- “Very, very long waiting lists to just be fobbed off and gas lighted as too many do not know or are limited in awareness of my conditions”.
- “I've had to push repeatedly to be taken seriously”.
- “GPs are reluctant to refer”.
- “I have had frequent emergency treatment via ambulance, and they have saved my life 4 times”.
- “I have had some emergency admissions and the hospital / ambulance have been amazing”.

3.13 Financial Factors Parenting Autistic Children

Research shows that there are every day costs associated with caring for autistic children that place additional financial pressures on families[v]. We asked parents to share their views on financial barriers associated with parenting children with special educational needs and disabilities that impact on physical and mental health. This issue was also discussed in our online focus group discussions. Common issues included:

- Issues with accessing welfare rights and benefits.
- Inability to work full time due to lack of wrap around care.
- Cost of sensory equipment.
- Cost of dietary requirements for children with eating differences/disorders.
- Cost of differentiation for a disabled child.

Parents shared:

“Only one income so everything is restricted or limited. I find that you need to pay extra for disabled services especially on holiday locations or transport”.

“Employment lacks understanding with being parent, a female and having health needs and needs of a child. Have been told to seek social services to take my child so I can work my hours”.

“Money I receive is a blessing while no longer able to work due to failing health and all the meetings, appointments and constant high alert in dealing with my child basic needs; which is not being met consistently within school”.

“Having the threat of school fines because my child cannot physically handle school”.

“The constant information needed about the child to receive help is an extremely hard and upsetting process”.

“Special equipment for the child's needs is very over inflated”.

“Only able to take child out in certain environments and factors means you risk constantly losing out or experience fines from school for quieter times”.

“Unable to work - unable to afford legal assistance actually in Tribunal - living on benefits”.

“Short term (lower pay) and long term (lower pension) from needing to provide 3.5 hours driving per school day as the LA wouldn’t provide anything suitable”.

“There is no childcare options when you have a child with ASD as they don’t accommodate them. So, holiday times are difficult, and you rely on family”.

“Everything is means tested”.

“The worry of applying/ renewing DLA and changing over to PIP”.

“Benefit system has been horrendous struggled to understand it so got in a huge mess with it with no support”.

“Had to reduce to part time work and I am single parent”.

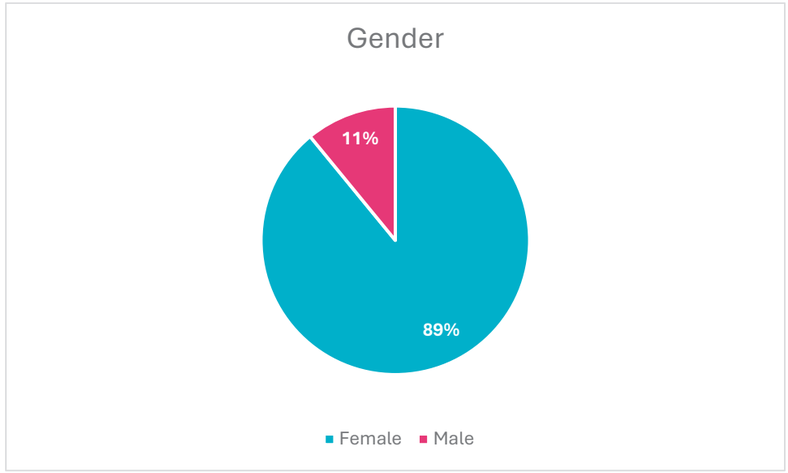
“Constantly fighting with providers to get equal treatment, e.g. swimming lessons, they keep on saying he should only have 1-2-1 more expensive lessons not the lessons available to other children”.

“My work has discriminated against me and am fighting all the time to keep my job and my child who has no school as LA FAILED us and an autistic school practiced APA. I am in debt for trying to meet my child’s needs paying for private assessments and just living”.

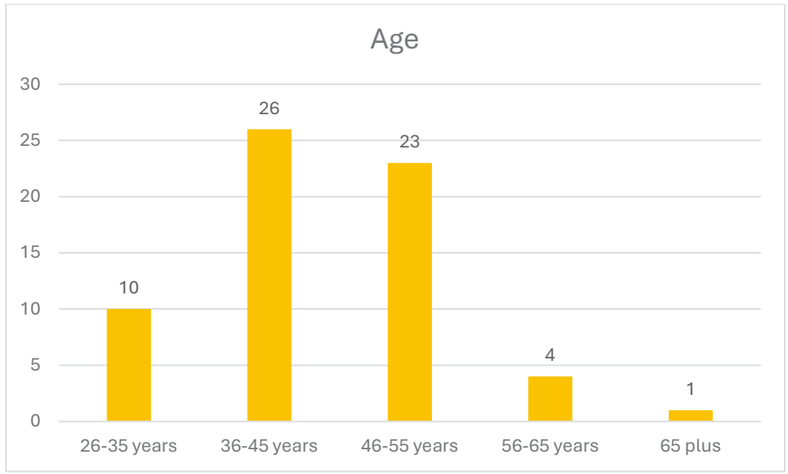
4. Findings Part Two: Derbyshire

4.1 Gender, Age, Ethnicity & Work

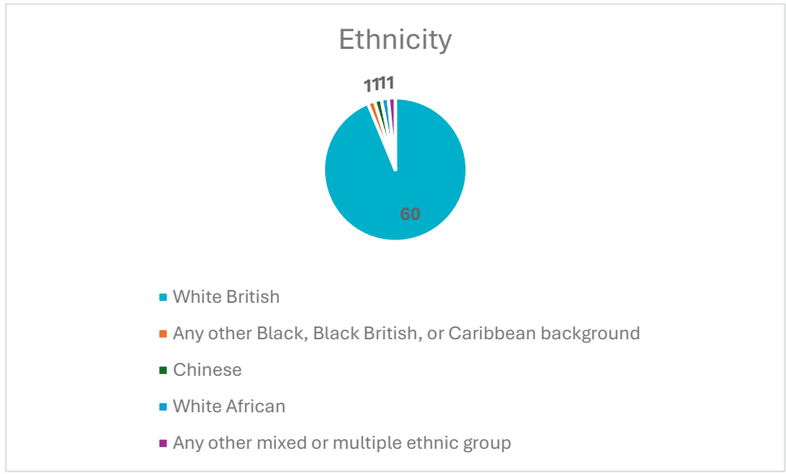
A total of **64** parents who completed the survey came under the **Derbyshire** local authority for services. **89%** of parents were female and **11%** were male.



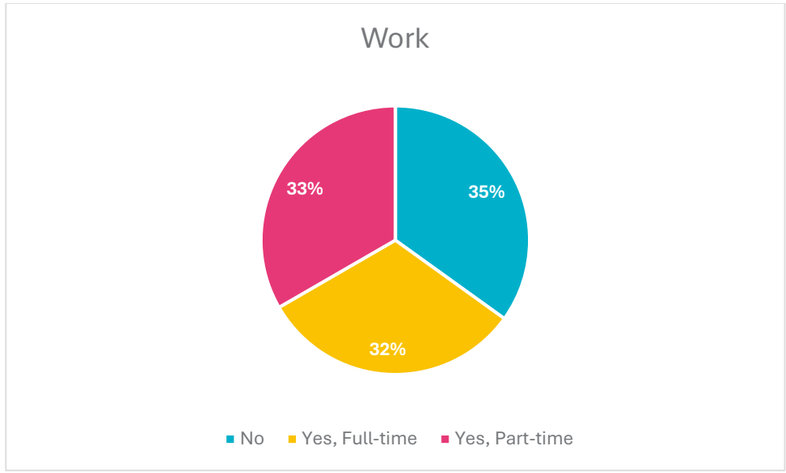
41% of parents were aged 26-45 years and **36%** were aged 46-55 years.



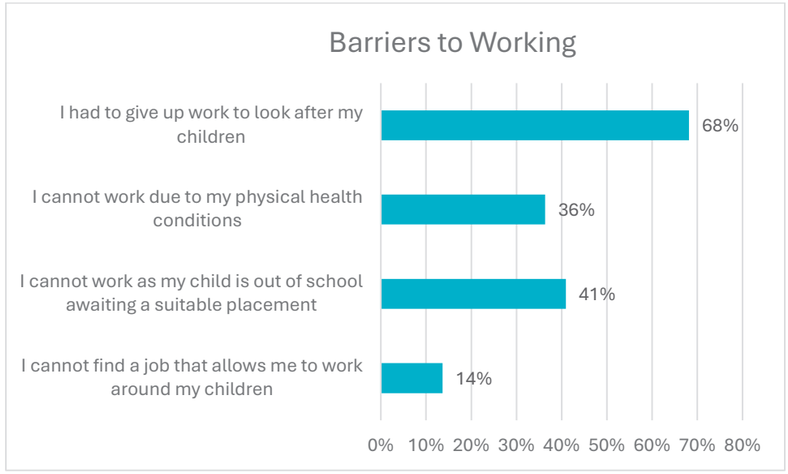
94% of parents who completed the survey from **Derbyshire** were white British.



Of the **Derbyshire** parents who participated in the survey **35% (22)** reported they are not in work.

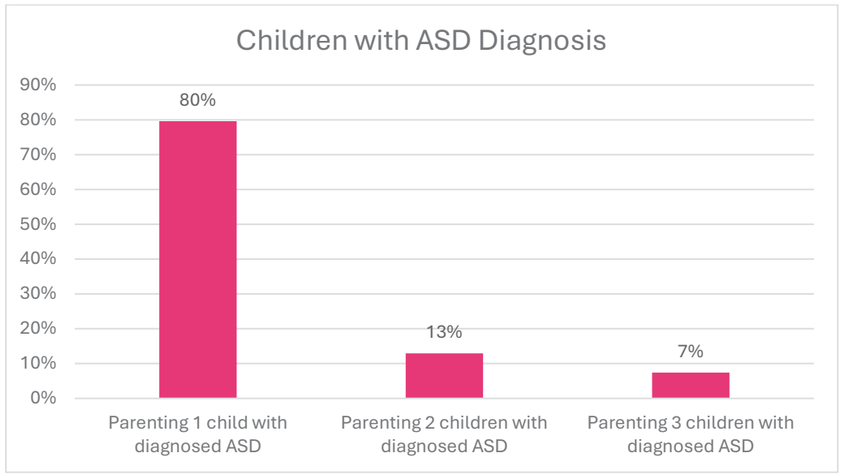


Parents shared with us the barriers they experienced in accessing work as parents of autistic children and young people. Of the **22** parents who are not in work a significant number **(68%)** had been required to give up work to look after their children. There are multiple barriers facing parents**:** **36%** of parents could not work due to their own health conditions and **41%** of parents were not able to take up employment because their children are out of school awaiting a suitable school placement.

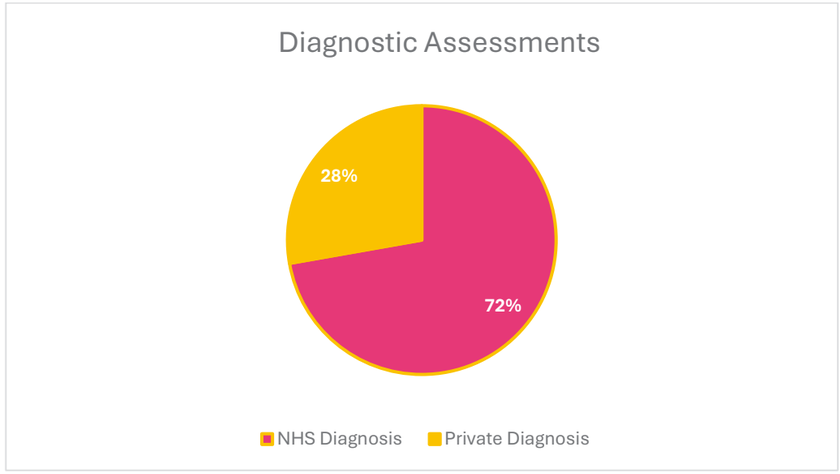


4.2 Children and young people with ASD diagnosis

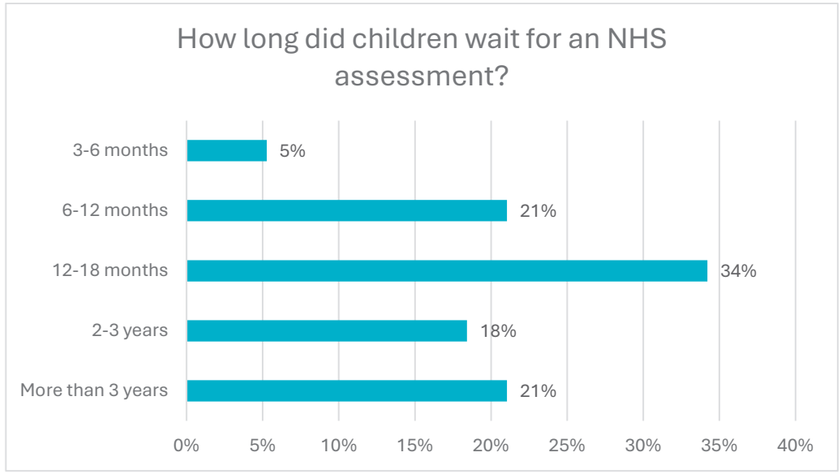
Of the **64 Derbyshire** parents who responded to the survey **54 (84%)** were parents of children with a formal diagnosis of ASD. Of those **80%** were parenting one child with a formal diagnosis and **13%** were parenting two children.



72% of children with formal diagnosis of ASD were assessed within the NHS and **28%** were diagnosed via private assessment.

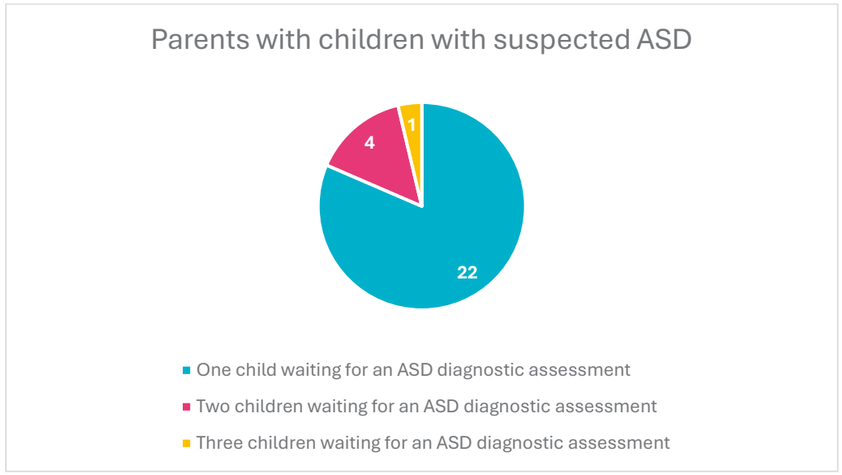


8 parents reported their child waiting for over 3 years for an ASD assessment, **7** parents reported waiting 2 to 3 years for their child to be assessed and **13** parents reported waiting a year to 18 months for the diagnostic assessment appointment. As previously stated in Part One, the NICE Guidelines are clear that all children suspected of being autistic should be assessed within 3 months.

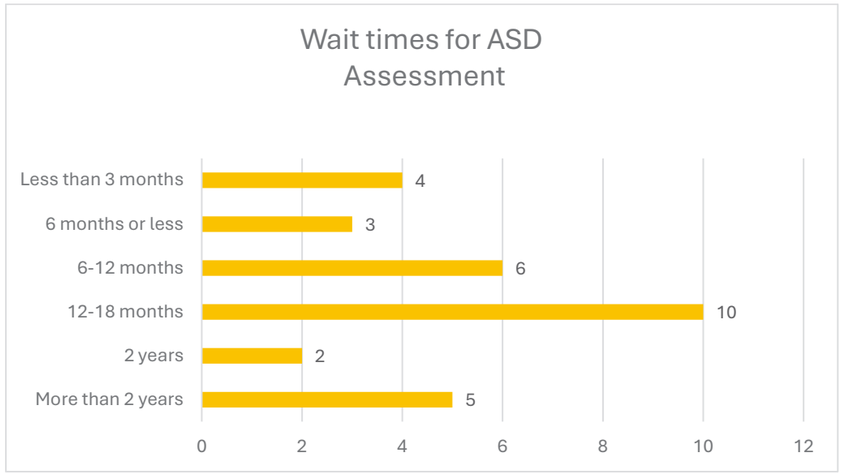


4.3 Children and young people waiting for an ASD assessment

Of the **Derbyshire** parents who completed the survey **27** are waiting for their children with suspected ASD to be seen for an assessment. **4** of those parents have two children on the waiting list, and **1** parent has 3 children waiting to be assessed.

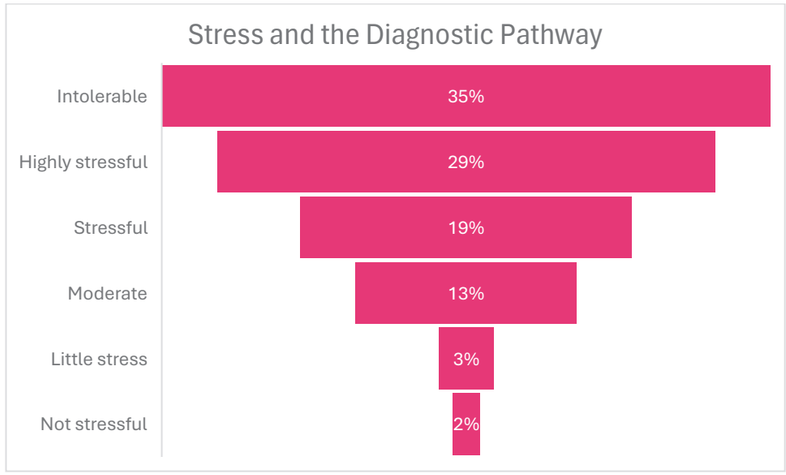


Of the **27** parents who are currently waiting for their children suspected of ASD to be assessed, **5** have been waiting for 2 years or more. **85%** of the children have been waiting for longer than the statutory timescales for assessment according to the NICE Guidelines. **70%** of the children waiting for ASD assessment are compulsory school age.



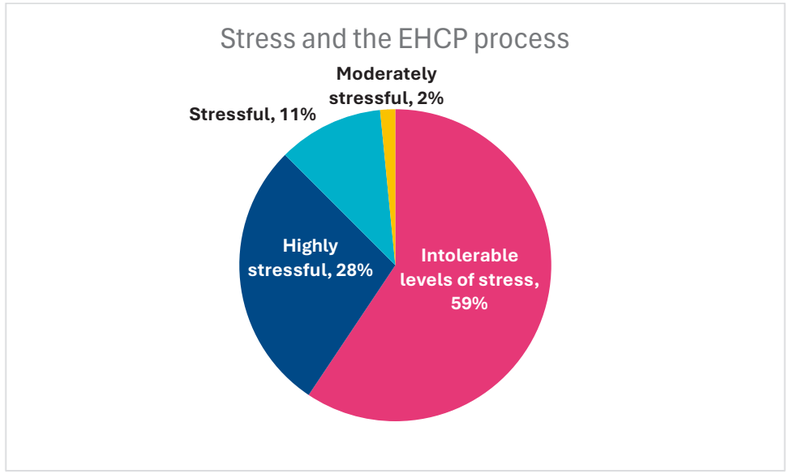
4.4 Stress and experiences of the Diagnostic Pathway for Parents of Autistic Children

35% of parents from **Derbyshire** described the ASD diagnostic pathway for their children as intolerable in terms of the stress they experienced. A further **29%** said the pathway was highly stressful and **19%** described it as stressful. Just **5%** of parents felt they experienced little to no stress.



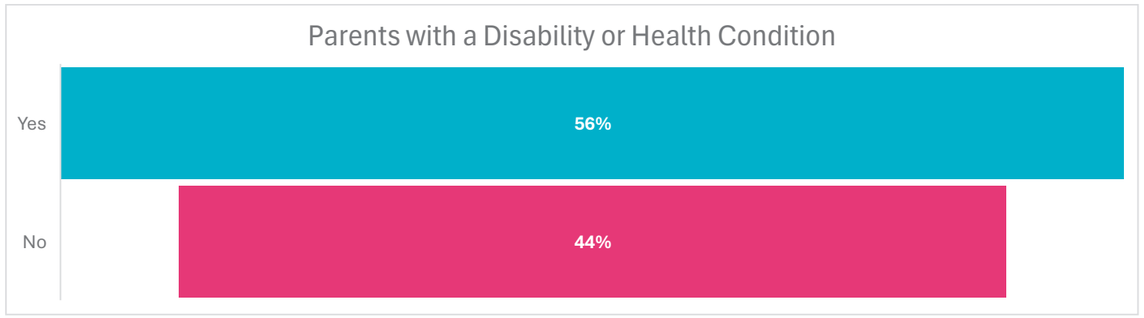
4.5 Experiences of the Education Health and Care Plan Process for Parents of Autistic Children

When asked about their experiences of navigating the education health and care plan process for their autistic children **59%** of **Derbyshire** parents described this as causing them intolerable levels of stress. A further **28%** shared that they found the process highly stressful and **11%** felt it was stressful. **Not one** **Derbyshire** parent respondent described the process as causing them little to no stress, **all parents felt stressed** to differing extremes.

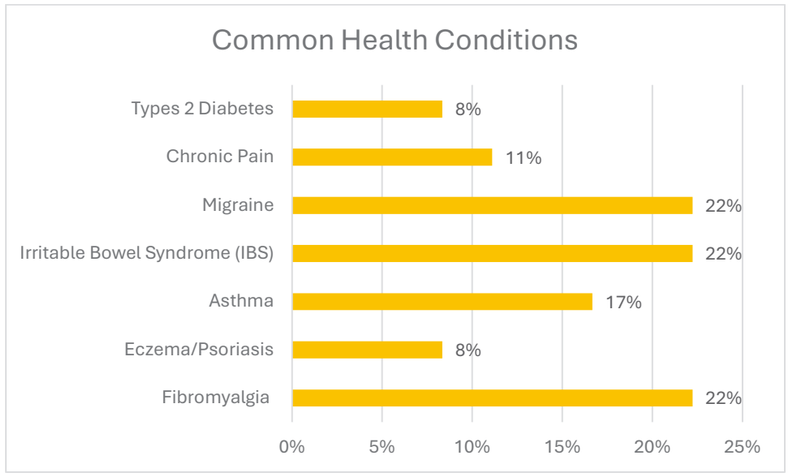


4.6 Disability and Health Conditions

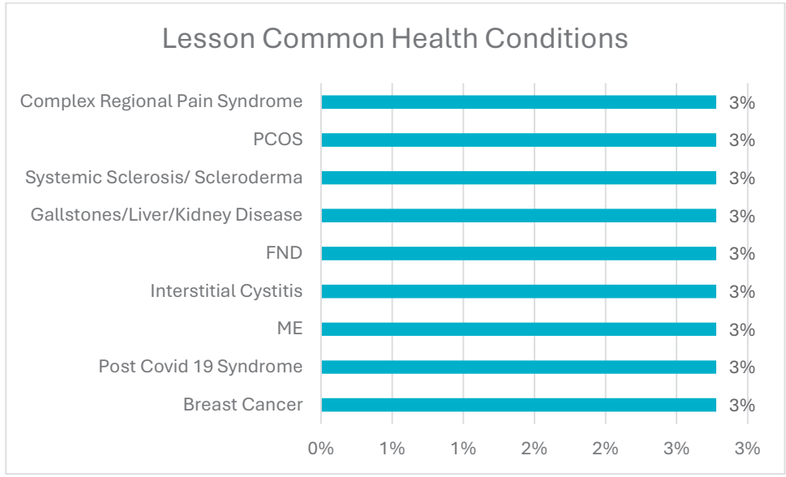
36 parents (56% of respondents living in **Derbyshire)** are disabled or have a health condition themselves. Of those parents **53%** shared with us that they have a neurological condition (ASD, ADHD) and **31%** are physically disabled. **17** parents **(47%)** with a health condition reported living with multiple (3 or more) chronic health conditions.



The most common health conditions are irritable bowel syndrome (IBS), migraines and Fibromyalgia **(22%)** and Asthma **(17%).**



The less common debilitating conditions experienced by individual parents included a range of conditions as highlighted in the chart below Systemic Sclerosis, Functional Neurological Disorder (FND), ME and Breast Cancer, **(3%).**

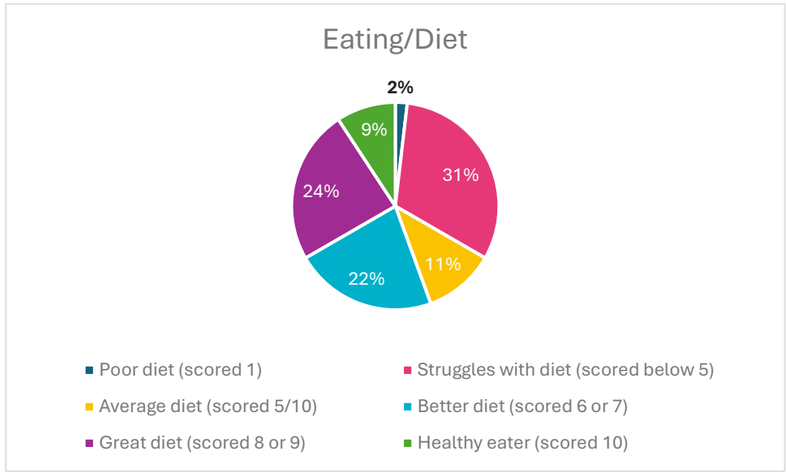


4.7 Diet

We asked parents about their diet and eating habits. We asked them to rate their diet on a scale of 1 to 10 where 1 is struggling to eat a healthy diet and 10 is a healthy eater.

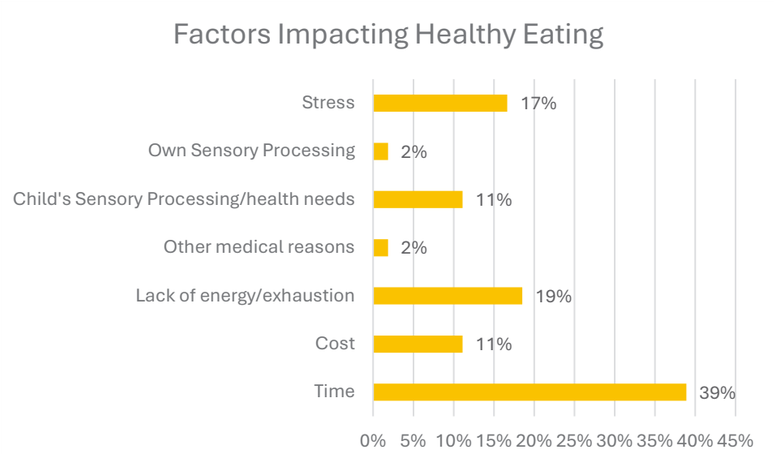
2% of **Derbyshire** parents shared that they are struggling to eat a healthy diet and rated it 1 out of 10 indicating poor diet. **31%** of parents scored below 5 for diet. **11%** of parents described their diet as average (scoring 5/10).

24% rated their diet 8 or 9 indicating a healthier diet than most and just **9%** of parents reported being a healthy eater.



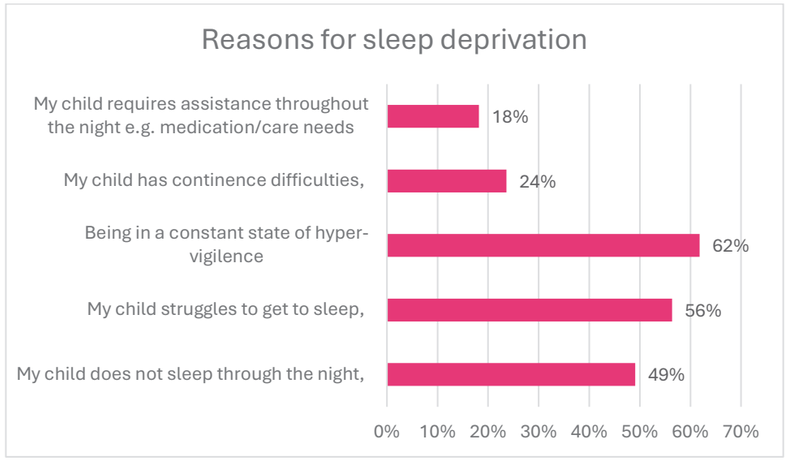
4.8 Factors for struggling with diet

Of those **Derbyshire** parents who reported struggling with eating a healthy diet a variety of factors were at play including lack of time **39%, 13%** of parents reported sensory processing difficulties either their child's or their own resulted in struggles to achieve a healthy diet, lack of energy/exhaustion **(19%),** cost of food **11%,** and stress was reported as a factor for **17%** of parents.



4.9 Lack of Sleep

86% of parents of autistic children and young people from **Derbyshire** shared that they experience sleep deprivation on a regular basis. There were a variety of factors at play. **62%** felt that this was due to their heightened sense of hypervigilance to the needs of their child or young person throughout the night. **56%** of parents were unable to sleep themselves due to the impact of their children's sleep difficulties being unable to fall to sleep and **49%** shared that their autistic children do not sleep through the night. **18%** of parents shared that they provided assistance throughout the night to attend to the medication/care needs of their child/ren. **24%** of parents were managing their child/ren's continence difficulties throughout the night.

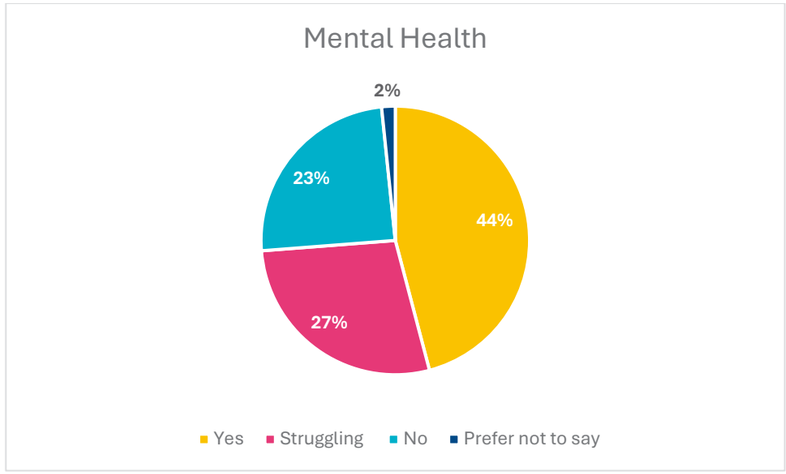


Parents shared other reasons for sleep deprivation including:

- Sleep procrastination
- Their own anxiety, stress, and worry.
- Their own ADHD.
- Child pacing at night.
- Anxiety based nightmares.
- Menopause.

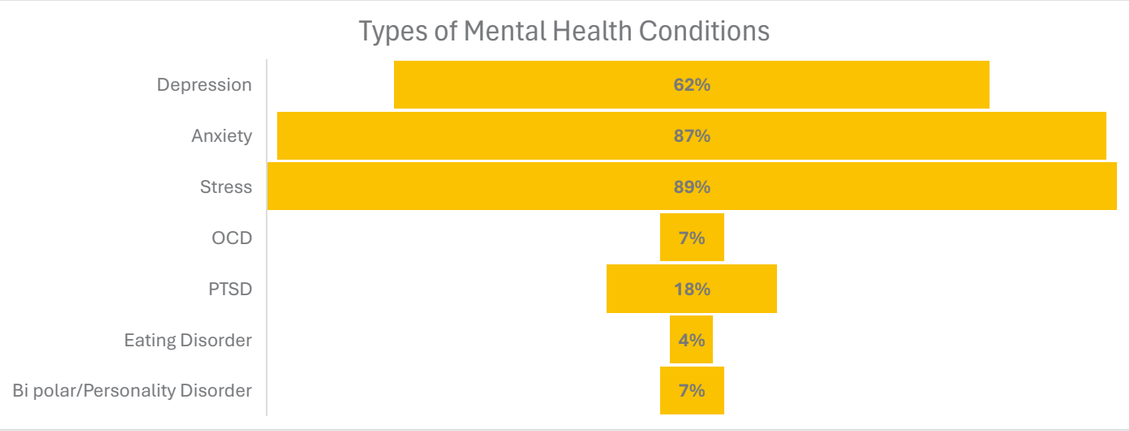
4.10 Mental Health

Of the **64 Derbyshire** parents 28 **(44%)** reported having a diagnosed mental health condition. **17** parents **(27%)** reported struggling with their mental health but without diagnosis and **15** parents **(23%)** reported they did not have a mental health condition. **2%** (**1** parent) preferred not to share about their mental health diagnosis.



Parents are living with multiple mental health conditions. Of those parents who reported having a mental health condition, a high percentage **(89%)** reported suffering with stress, whilst **87%** experienced anxiety and **62%** reported having depression.

18% of parents were experiencing Post Traumatic Stress Disorder (PTSD) and **7%** were diagnosed with obsessive compulsive disorder (OCD) and bi-polar/personality disorder respectively. **2 (4%)** parents were living with an eating disorder.

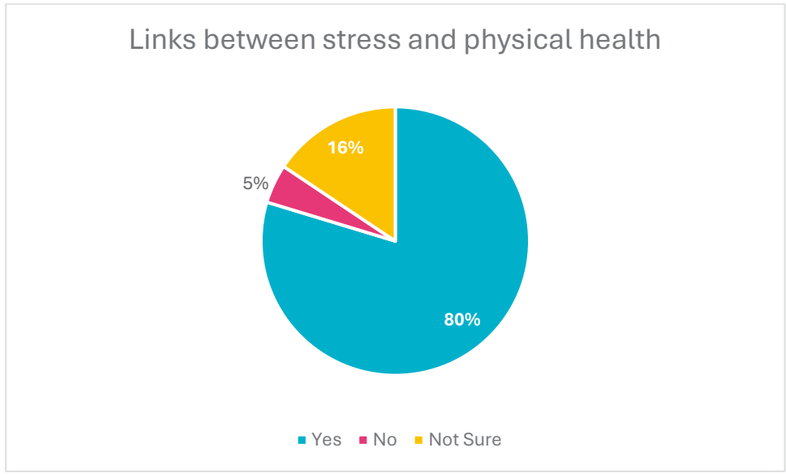


4.11 Is there are link between stress and physical health?

We asked **Derbyshire** local authority parents if they believed there was a direct link between the stress they experienced and their physical health. **80%** of parents believed there was a link and that the stress they experienced caused them to be physically unwell. **16%** of parents were not sure and only **5%** felt there was no link between the stress they experienced and their physical health.

34% of Derbyshire parents are living with a diagnosed mental health condition **alongside** multiple physical health conditions. A further **14%** of Derbyshire parents reported they have diagnosed physical health conditions and are struggling with their mental health but were undiagnosed.

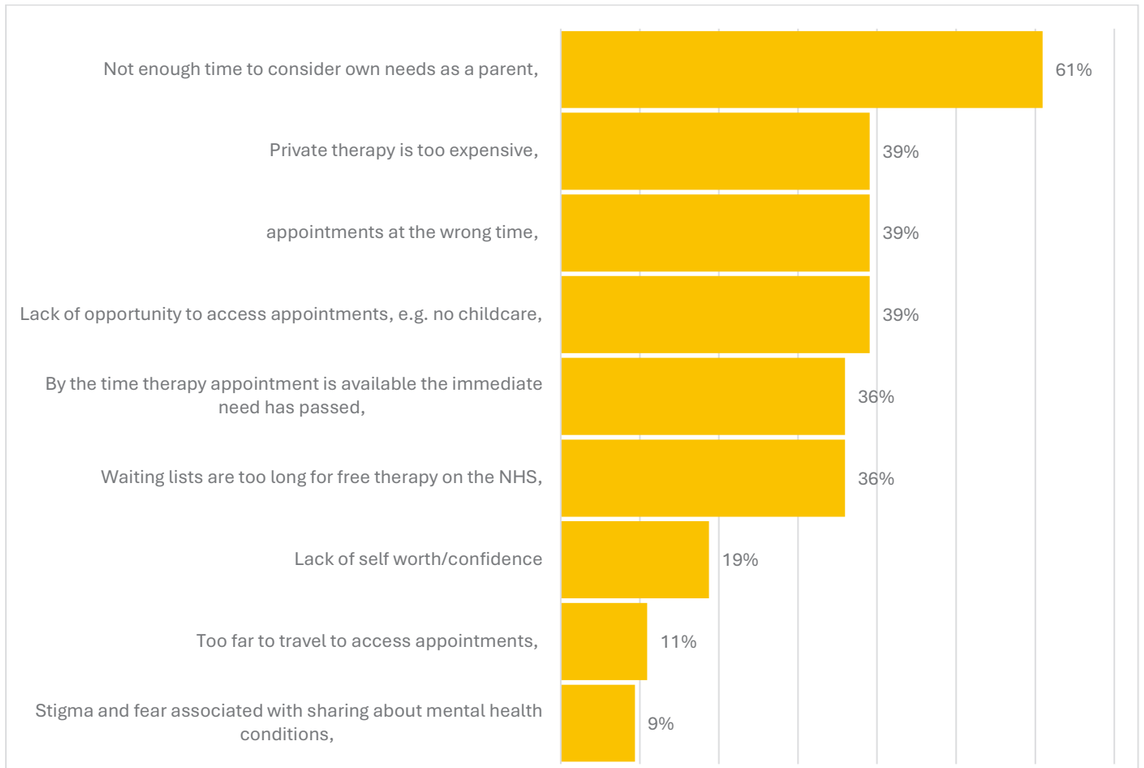
Significantly **86%** of parents of autistic children and young people in **Derbyshire** with diagnosed physical conditions and diagnosed mental health conditions are experiencing **STRESS.**



We explored the topic of mental health further with parents:

- **66%** of **Derbyshire** parents reported it was difficult to access treatment and support for their mental health.
- **25%** of parents were unaware that they could access and self-refer for NHS Talking Therapies
- **58%** of parents have accessed NHS talking therapy.
- Of those parents who have accessed the service **41%** felt that NHS talking therapy was unhelpful.

Parents were asked what would prevent them from accessing therapy and support for mental health conditions. The findings confirmed what we already knew anecdotally to be the case **61%** of parents said there was not enough time to consider their own needs as a parent and **36%** said the waiting lists were too long on the NHS. Lack of access **(39%)** and timing of appointments **(39%)** were also significant barriers to parents seeking help for their mental health. **19%** shared that lack of self-worth and confidence was a barrier to them seeking help for their mental health.



Parents also shared views on the limitations of NHS Talking Therapy in terms of understanding autism and parenting autistic children and young people:

- “NHS therapy isn’t specific or well informed enough about the needs of ND people or parents. It is short term, (unrealistic for ND) goal oriented and not ND affirmative”.

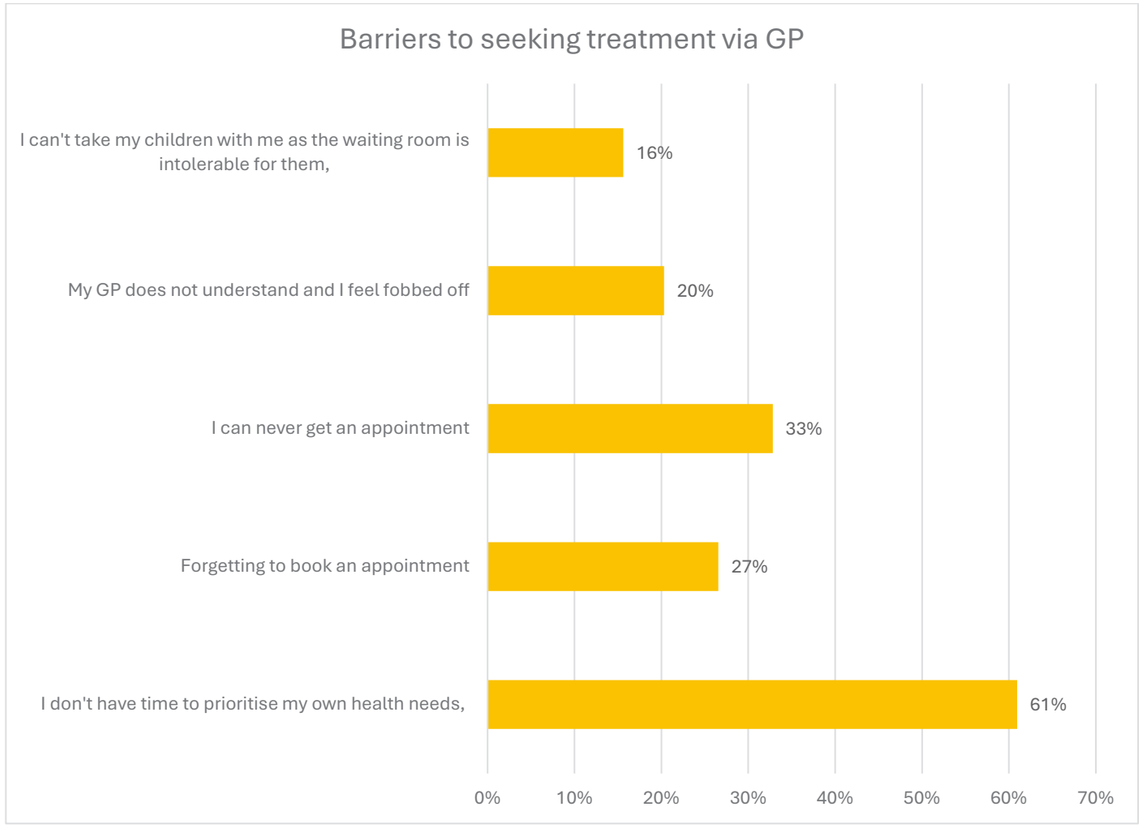
There is also for some parents a sense of despair, that the challenges of parenting are relentless, and that therapy will not work:

- “Feelings are difficult to explain/ would they understand?”
- “I have been having talking therapy but the stress of a child with anxiety especially around school is so out of your control. You cannot do anything but support your child and you are dealing with the day-to-day issues which you cannot control”.
- “Nothing else can be done for me”.

4.12 Experiences of NHS Treatment

The GP Surgery

33% of parents in **Derbyshire** shared that they experienced their GP to be unsupportive. Parents shared with us the challenges they face when seeking treatment via the GP surgery. **61%** said that they did not have the time to prioritise their own health needs. **33%** of parents felt that they could never get an appointment. **27%** shared that they forgot to book an appointment for themselves. **20%** of parents felt that their GP does not understand and fobs them off.



Other reasons for not seeking treatment:

“I don't think GPs have an understanding of the difficulties of raising children with autism”.

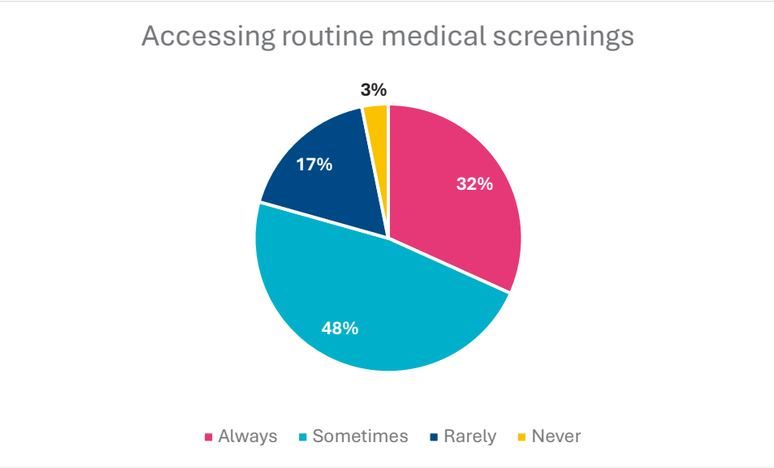
“Feel GP can’t really suggest anything specific to stresses of living as the only NT in a household. Talking therapy not specific to autism. Just used to living like this now. Don’t feel like I have any needs of my own anymore”.

“Already on the highest medication so what else can be done”.

“Time off work, I have enough time off dealing with my child”.

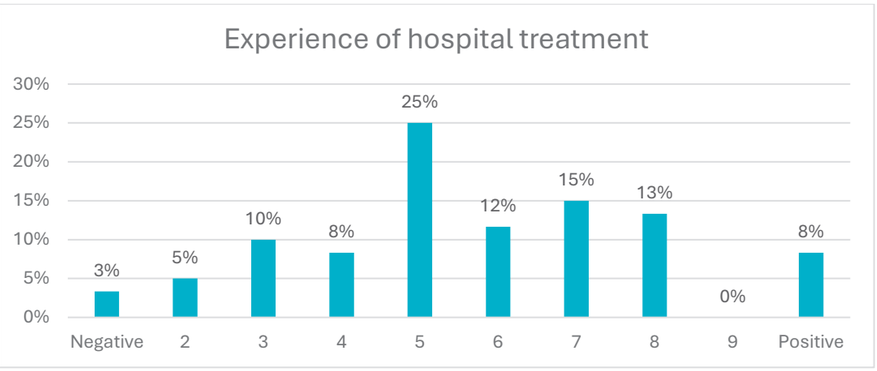
“Forgetting appointments altogether. Chronic fatigue that puts me off even making appointments”.

We asked parents to share their experiences of accessing routine medical screenings. **20%** of parents in Derbyshire rarely or never attended these.



Hospital

Experiences of hospital treatment varied amongst parents in **Derbyshire**. **26%** rated their experience 4 and below, **25%** rated their experience 5 out of 10 and only **8%** rated it 9 or 10, where 10 is positive.



Parents shared their views on accessing hospital treatment:

- “I have had appointments so have been looked after but the waiting times have been stressfully long”.
- “They did recently allow me to swap an appointment time as it was during the school run. I wouldn't have been allowed to swap it again without being discharged”.

- “Grateful I can still access them at all, but some referrals not processed, waiting lists too long, and although there is some good care, there is equally some appalling and failing care provision”.
- “I've had some good experiences and some less good. Sometimes I'm referred on and get help, but sometimes I'm just fobbed off”.
- “Appointments get cancelled or changed making it difficult to rearrange childcare”.
- “I find that I am with my child all the time as he is not accessing school so difficult to organise appointments”.
- “Never any appointments or the appointment times are impossible as a single parent with no help or support. Or the doctors don’t care. Also being signed off while waiting for an appointment without being told”!
- “My biggest treatment was in 2014 when I had treatment for Breast Cancer, and I cannot fault them. when it comes to the treatment and waiting times for my daughter, that leaves a lot to be desired”.
- “Planned or even urgent care has been good, but accessing A & E is impossible as an autistic person. With 3 boys I’ve often had to attend and have ended up waiting outside in the dark and cold under an ambulance blanket in the early hours, with the smokers being aggressive, both parent and child in tears and overstimulated. The waiting areas are impossible and even the ‘quiet’ space is not at all quiet or safe”.
- “Too busy and difficult to navigate”.
- “It can be a long wait and a long journey with trying to get the referral first through GP as so hard to get an appointment”.

In addition to the parents from Derby and Derbyshire, 4 parents from **other Local Authority areas** also completed the survey. Their experiences mirror those of parents living in Derby and Derbyshire.

- **3 (75%)** parents who completed the survey from other LA’s were female, and **1** was male **(25%).**
- **3** were aged 46-55 years, and **1** was 56-65.
- **50%** had a disability or health condition.
- **50%** described themselves as struggling with their mental health, **25%** had a diagnosed mental health condition (anxiety).
- All parents had children that were already diagnosed with ASD. **3 (75%)** were assessed on the NHS and **1 (25%)** privately.
- The children who had been assessed and diagnosed on the NHS were assessed within 6-12 months **(67%)** and 12-18 months **(33%).**

5. Discussion

Our survey provides evidence that parents of autistic children and young people in **Derby** and **Derbyshire** are experiencing health inequalities. They are experiencing multiple mental and physical health conditions and barriers to accessing treatment and support for these conditions. They report that services are not accessible and fail to differentiate for their needs as parents of autistic children and young people.

Parents are experiencing layers of trauma and stress caused by a multitude of factors. These factors are not exclusive or exhaustive.

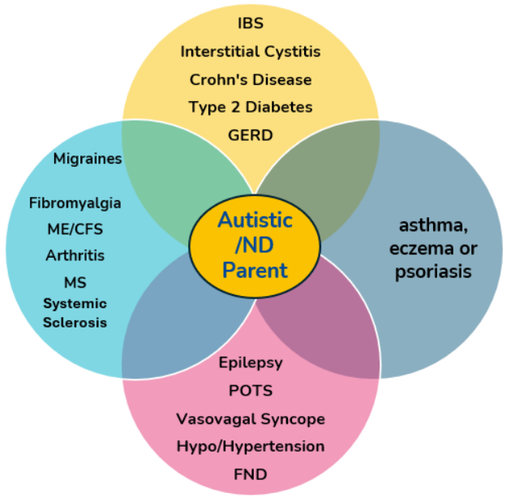
- A parent may be coping with navigating the ASD diagnostic pathway for their child or young person, they may be attempting that for more than one child and simultaneously.
- They may be trying to secure an Education, Health and Care Needs Assessment for their child or young person, again they may be seeking to achieve that for more than one child, and at the same time.
- They may be needing to appeal at the SEND Tribunal for one or more children, because the Local Authority has refused a needs assessment, refused to issue an Education, Health and Care Plan, or the EHC plan that has been issued is not fit for purpose, or the educational placement is unsuitable.
- The parent may be coping with an autistic child or young person whose educational placement has broken down and they are out of education awaiting placement.
- Their child or young person may have experienced autistic burnout, and have significant mental health issues including anxiety, OCD, an eating disorder and/or PTSD.
- The parent may be managing all of this on their own as a single parent.
- They may have been forced to give up their job to look after the child or young person who is out of school.
- They may have not been able to work because they can't find a job that allows them to work between school hours.
- They may be experiencing ongoing and extreme levels of sleep deprivation.

All these factors are causing stress for parents which is resulting in deterioration in both their mental and physical health.

We know that some of these parents are diagnosed autistic/ND (**30%** of **Derby** and **31%** of **Derbyshire** respectively). These parents told us they are experiencing multiple mental health conditions including OCD and PTSD, as well as multiple chronic physical health conditions. Of the known autistic/ND parents **79%** and **85%** (**Derby** and **Derbyshire**) experienced multiple health conditions. **86%** and **70%** had diagnosed mental health conditions. Further to this **14%** and **20%** of those that are undiagnosed with a mental health condition are struggling with their mental health.

Autism and mental health is a well-researched topic. Thinking about physical health in the context of autism, however, is a relatively new concept. The first UK study to indicate that autistic people experience multiple comorbid physical health conditions was published in 2023 by researchers at Cambridge University[vi]. A previous American study in 2020 highlighted that **"physical health comorbidities occur significantly more frequently in individuals with ASD than in the wider general population"**[vii]. The range of physical health comorbidities associated with ASD found in that study included motor dysfunction, metabolic disorders, immune system, HPA dysfunction, GI impairment, seizure disorders and sensory dysfunction.

Our findings also showed a similar range of types of health comorbidities for parents of autistic children and young people to the UK and US studies. The infographic below illustrates the types of health conditions that autistic/ND **Derby** and **Derbyshire** parents are living with.



The significance of alexithymia and anxiety is also important. Studies have shown that there is a high prevalence of alexithymia in autistic individuals with anxiety. We did not explore alexithymia with parents but this is something that those reading this report may wish to consider. Parents with an autism diagnosis and those who are yet to discover this about themselves may be struggling to identify their own emotions. In a GP surgery or hospital consultation this would be helpful for health professionals to consider.

An important link also is that between autism, alexithymia and Functional Neurological Disorder. Very recent studies have shown that there are a high proportion of autistic and alexithymia traits in adults who have a diagnosis of Functional Neurological Disorder[viii]. There are indications that autistic people with FND are experiencing differing levels of interoception difficulties (sensory processing). Our survey confirmed this and found that there were several parents living with

multiple health conditions including FND who were also diagnosed autistic. Importantly there were parents who were undiagnosed autistic but had diagnosis of FND.

An autistic Parent's Story

"I am autistic. I was diagnosed late in life like a lot of parents of autistic children are. I also live with multiple chronic physical and neurological health conditions. Some I have lived with for several decades. I have Interstitial Cystitis, Irritable Bowel Syndrome, Vasovagal Syncope, Hypotension, and Functional Neurological Disorder. Until my children were diagnosed, I was not aware that I had significant sensory processing difficulties particularly with recognising the needs of my own body. I struggle to know when I am thirsty, when I am hungry, when I need to go to the toilet, and I process pain differently. As a child and young adult, I had several kidney infections and UTI's due to dehydration. As an adult I was eventually diagnosed with Interstitial Cystitis also known as bladder pain syndrome and I have lived with this condition for over 20 years.

My daughter is autistic, and she had recurrent UTI's and an impacted colon prior to her ASD diagnosis at age 5. Once we understood that her UTI's and impaction were due to her interoception difficulties and not registering thirst, hunger, or when to empty her bladder/bowels we were able to monitor her fluid intake, provide regular prompts and she was prescribed permanent medication to prevent impaction in future.

My hope is that my daughter will not have problems later in life and will not develop IBS and IC and that the early intervention will prevent her from struggling with a debilitating condition in adulthood. If I had never had children, I possibly would never have understood my own identity as an autistic person, I would never have known that much of my health problems were associated with neurological differences, with being autistic.

I have struggled for many years seeking answers for why I was having random symptoms and unexplained pain, experiencing dismissive and invalidating comments from medical professionals, which caused me to doubt my own sanity at times".

There are parents who completed the survey who reported multiple physical conditions and mental health conditions that are comorbid conditions with autism but who did not report to be autistic.

Some parents who had experienced parent blame shared that they felt scared to self-identify or seek an ASD diagnosis for fear of further blame. Some parents who completed the survey possibly had not made a connection between their own physical and mental health conditions and possible autism. There is a need for parents to feel safe to explore their own identities to gain understanding and self-acceptance.

If more medical professionals had a greater understanding of autism and comorbid conditions and asked the right questions at the right time this would lead to reduced health inequalities for parents of autistic children, some of whom may also be autistic themselves. Improved awareness

of the links between physical health and autism would inevitably lead to better health outcomes for autistic parents of autistic children and young people.

Our survey shows that health services are missing opportunities to support the physical and mental health needs of parents of autistic children and young people. There is a lack of joined up thinking. Nobody is joining the dots when parents present at the GP surgery or are referred to hospital specialists. Health professionals simply do not consider the wider context, there is no curious concern. If professionals had a greater awareness of comorbidities and used this knowledge when parents of autistic children presented with health difficulties it could lead to significantly improved health outcomes for autistic people.

Equality would be if patients who are presenting with multiple health conditions had their needs considered holistically rather than being treated in silo's or being dismissed as psychological. It would be improving diagnostic procedures to factor in the genetic aspect of autism including screening siblings and parents so that families can get the right help sooner. There is arguably an urgent need for support for parents exploring their own autistic identity later in life especially in the context of improving physical and mental health outcomes.

The impact of sleep deprivation is hugely significant for parents of autistic children in **Derby** and **Derbyshire**. Studies show that there are associations between stress, sleep and functioning in parents of non-autistic children who are coping with the typical challenges of parenting. "Not getting enough sleep or poor-quality sleep can increase risk for mental health disorders. While insomnia can be a symptom of psychiatric disorders, like anxiety and depression, it is now recognized that **sleep problems can also contribute to the onset and worsening of different mental health problems**, including depression, anxiety, and even suicidal ideation"[ix].

Parents of autistic children and young people are dealing with sleep deprivation in addition to a multitude of other challenges. In this context and considering that The United Nations Convention Against Torture (UNCAT)[x] states that **"sleep deprivation is a form of torture when it is prolonged"**, it is not surprising that many of the parents who participated in our survey are beyond breaking point.

All parents struggle when their children are distressed, parents of autistic children experience that vicarious distress more frequently as autistic children are emotionally delayed and prone to dysregulation and meltdowns. Autistic children are 28 times more likely to think about or try suicide. Autistic children and young people are operating outside of their window of tolerance and parents are in a state of hypervigilance much of the time. Parents not only have the pressure of attempting to help their children regulate their emotions and anxiety levels to stay inside the window of tolerance, but they must find ways to manage their own anxiety and worry to be able to effectively co-regulate with their children. Psycho-educational courses such as **The SEND Dynamic C.I.C**. **Looking After You Too** peer support programme can be invaluable in terms of helping parents to focus on their own mental health needs to be better able to support their child

or young person. Parents need validation of their experiences and shared understanding from those with lived experience.

It is important to recognise that autism is a lifelong condition, the challenges are ongoing, children do not grow up and grow out of these difficulties. Instead in terms of executive functioning, the gap widens for autistic children as they get older. So where neurotypical children going into secondary school are becoming more independent and doing more for themselves, with parents doing less for them, autistic children with executive functioning differences are not able to meet the expectations school and wider society has of them. Jodie Smitten says **"A person with executive functioning difficulties can sometimes be deemed lazy or disorganised. Sadly, many are made to feel this way, as those around them don't realise this is actually due to executive functioning challenges and it not a choice. Executive functioning can be impacted by anxiety, stress, autism and ADHD, so if you have a child with one or a combination of these the impact on them day to day can be significant"**[xi].

Dr Tony Atwood refers to the mother of an autistic child as the "executive secretary"[xii] scaffolding the autistic child to achieve those executive functioning tasks to help them to achieve their full potential. Managing executive functioning differences compounds the challenges of daily life for the parent of the autistic child, and more so if that parent is also autistic with their own executive functioning difficulties.

Our survey shows that opportunities for early intervention are being missed. The ASD diagnostic pathway is not fit for purpose. Identifying autism in children sooner leads to better outcomes in the long term and improved mental health for the child and the parent, the whole family. With the right support in place the child is more likely to achieve their full potential instead of burning out, and crashing out of education, with long term mental health problems and an inability to achieve independence.

There is an urgent need to address the failings in the education system also, not only to meet the needs of children but to reduce stress on parents which will in turn improve their physical and mental health outcomes. If the special educational needs of autistic children are identified early on, if the child has the right support and educational setting, they will not only be more likely to stay in school, achieve their potential and have improved mental health and well-being, they will be more likely to contribute to society as an adult. This was evidenced in a recent report[xiii] Reaching My Potential – A Study of the Value of SEND Provision by NASS (the National Association of Special Schools). **"This study used mixed methods to track the impact to learners and society when children and young people with SEND have their needs met effectively. The report makes a persuasive case for investing in specialist support for learners who need it most, demonstrating an average net impact of £380k across an individual's lifetime".**

Most children waiting for ASD assessments in our survey are of compulsory school age, if their needs were identified in early years, and parents were aware and understood their child's needs in the context of autism, and Education Health and Care Plans were issued that were fit for purpose, children would be more likely to achieve their full potential, remain in education, and become independent adults. This positive outcome for the child translates into improved health and well-being for parents, due to the reduction in stress and anxiety.

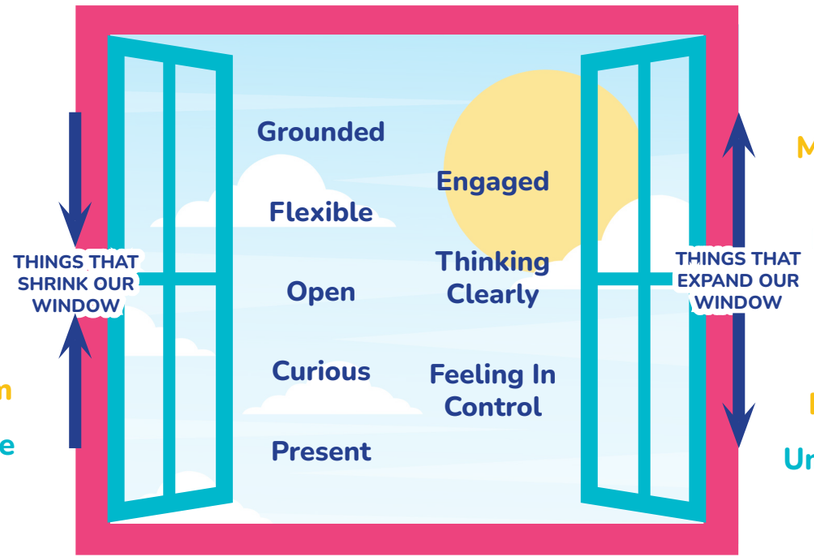
It is important to recognise the significant financial impact on parents of autistic children too. There are many different scenarios for parents, including not being able to work due to their own ill health, or needing to be at home to care for a child who is out of school, or a child not being able to access wrap around care making it impossible to find work that fits between the school runs, or an employer who understands the demands of parenting an autistic child. There are parents with PTSD or needing to give up work to avoid burnout after years of fighting the system.

The Window of Tolerance

HYPER-AROUSAL

High Energy, Anxiety, Anger, Feeling Overwhelmed, Hyper-vigilance, Fight, Flight, Hyperventilating, Shaking

Poor Sleep
Poor Diet
Stress
Anxiety
Trauma
Pain/ Illness
Sensory Overwhelm
Battling the System
Isolation
Rejection



Self-care
Physical Exercise
Mindfulness
Deep Breathing
Therapy
Nature
Friendship
Understanding
Support
Music

HYPO-AROUSAL

Shutdown, Feeling Disconnected, Depressed, Passive, Withdrawn, Unable To Move, Low Energy, Tired

© The Window of Tolerance is a term coined by Daniel J. Siegel, a clinical professor of psychiatry at the UCLA School of Medicine, to describe the optimal emotional "zone" we can exist in, to best function and thrive in everyday life.

6. Conclusion

We have found that the experience of navigating the diagnostic pathway for their children, combined with seeking an education, health and care plan, causes high levels of stress over extended periods of time which is resulting in the deterioration of mental and physical health for parents.

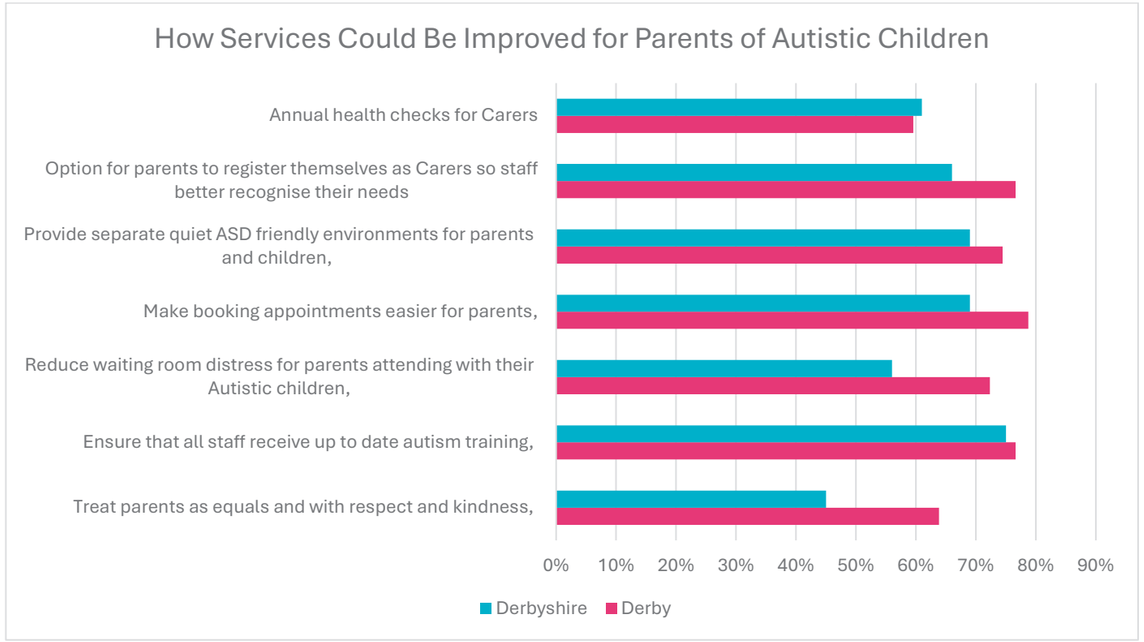
Opportunities are being missed to identify health conditions and provide treatment for parents of autistic children, and there is a real need to shape health services to better support autistic parents who are at a higher risk of ill health than their neurotypical counterparts.

It is vital that there is improved early intervention in terms of early identification of needs for children and young people with autism to prevent children from experiencing significant health inequalities as adults and to give them the best opportunities to thrive in education and work. We did not ask parents in this survey whether they had contemplated or attempted suicide, but we are aware of parents who have reached that level of crisis. Recent research[xiv] indicates that the risk of death by suicide amongst autistic people is 8 times higher than for neurotypical people and that autistic women are 13 times more likely to die by suicide than neurotypical women[xv]. This highlights the cumulative tragic effects of unmet need and untreated poor mental health and evidences the urgent need to improve services to autistic people and their families **to save lives.**

7. Recommendations

7.1 The parents who participated in the survey recommended specific ways that health services could be improved to reduce health inequalities for them as parents of autistic children and young people.

1. The overwhelming request from parents was for it to be made **easier for parents to book a medical appointment**. This request relates to all types of appointment including GP, hospital, and routine medical screenings. The concept of introducing a priority booking system for autistic people was also suggested. The ICB (Integrated Care Board) should consider commissioning support for developing neurodiverse led access pathways and help to develop personalised communication passports for use in healthcare settings.
2. Ensure that all staff have regular and up to date **autism training** is considered a high priority for parents. The training must be delivered by autistic people. **The SEND Dynamic C.I.C.** recognises the aim to roll out the Oliver McGowan[xvi] mandatory training as part of the NHS Long Term Workforce Plan training within the NHS. The Oliver McGowan training is designed to be delivered and co-produced with autistic people. This is essential so that health workers develop an understanding of the health inequalities, needs and barriers faced by autistic people and those that care for them, many of whom are also autistic. There is an urgent need to supplement e-learning with more experiential autistic led training.
3. Parents recommend that **separate, quiet ASD friendly environments** are provided for parents and children.
4. Related to recommendation 3 is efforts to find ways to **reduce waiting room distress** for parents attending with their autistic children.
5. Give parents the option to **register themselves as Carers** so that health staff can better recognise their needs.
6. Treat parents as equals and with **kindness and respect**. This costs nothing.
7. Introduce **annual health checks specifically for Carers**.



7.2 **The SEND Dynamic C.I.C.** offers the following key recommendations to reduce health inequalities for parents of autistic children given our unique position as an advice and support organisation with some understanding of the commissioning process.

1. The ICB should ensure that they adhere to the NICE guidelines for ASD assessment and introduce improvements to the diagnostic pathway to reduce the intolerable stress caused by wait times.
2. Health professionals should offer automatic screening for biological parents and siblings when they diagnose children with ASD.
3. All frontline health professionals should access training on comorbidities with autism in terms of both physical and mental health conditions. Priority for GP's.
4. Patients presenting with multiple health conditions which are known comorbidities of ASD should be offered screening for ASD.
5. Local Authorities should adhere to the Children and Families Act 2014 and the SEND Regulations 2014.
6. All public bodies should adopt trauma informed approaches to assist recovery of PTSD in children and their parents.
7. The new clinical trials for NHS Talking Therapies to be tailored to autistic people are welcomed.
8. Retaining and recruiting more autistic and neurodivergent therapists withing the NHS Talking Therapy services would also be a significant step forward.

9. There is an urgent need for the ICB to commission a health equality audit of their services in relation to access and effectiveness of services for neurodiverse populations including: GP services, NHS Talking Therapy services, Living Well and Community services, Urgent care mental and physical health services.
10. The ICB should add routine collection and analysis of equality monitoring information in relation to neurodiversity into local service specifications and performance monitoring arrangements.
11. Services should be asked for evidence of coproduction of care pathway design with local and national organisations which advocate for neurodiverse populations.
12. Derbyshire should volunteer to be a pilot site for the forthcoming national research project in adaptations of care pathways in NHS Talking Therapy services to meet the needs of neurodiverse populations.

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info@theSENDdynamic.co.uk
www.theSENDdynamic.co.uk

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Registered Office: 20 Royal Scot Road, Pride Park, Derby, DE24 8AJ

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