ARFID

Understanding People's Experiences of Avoidant Restricted Food Intake Disorder

Services and Support

healthwatch
Blackburn with Darwen

Contents

About Healthwatch Blackburn with Darwen

Healthwatch was established under the Health and Social Care Act 2012 as an independent consumer champion to understand the needs, experiences and concerns of people who use health and social care services and to speak out on their behalf.

There are over 150 local Healthwatch across England. The role of a local Healthwatch is to:

- Listen to people, especially those who are most vulnerable, to understand their experiences and what matters most to them.
- Influence those who have the power to change services so that they better meet people's needs now and into the future.
- Empower and inform people to get the most from their health and social care services and encourage other organisations to do the same.

Find out more at: www.healthwatchblackburnwithdarwen.co.uk

Background to our Engagement

What is ARFID?

ARFID Awareness UK.org describe Avoidant Restrictive Food Intake Disorder (ARFID) as: -

'ARFID is characterised by a pattern of eating that avoids certain foods or food groups entirely and/or is restricted in quantity (eating small amounts). Avoidant and restrictive eating cannot be due to lack of available food, or cultural norms (e.g. someone who is fasting or chooses not to eat certain foods for religious or cultural reasons alone).

ARFID is different to other restrictive eating disorders in that:

- ARFID is not affected by a person's beliefs about the size and shape of their body.
- Someone with ARFID does not restrict their food intake for the specific purpose of losing weight.
- ARFID does not feature some of the other behaviours that can be associated with anorexia, bulimia, or OSFED, such as over-exercising.'

Our Engagement

The focus of our engagement is to understand parents' experiences of accessing diagnosis, services and support for their children. We hope to acquire a deeper understanding of the current provision available for children and young people living with ARFID. The aim of the study is to identify any gaps in resources, care delivery and treatment approaches within Lancashire and South Cumbria and to identify what services parents and care givers would like to see implemented. Healthwatch Blackburn with Darwen is a member of the Lancashire and South Cumbria Arfid Pathway Steering Group, led by the Integrated Care Board and we hope to inform the development of this pathway with the experiences of parents and young people and related recommendations detailed in this report.

Methodology

Healthwatch BwD gathered information and experiences from parents of children and young people living with ARFID and/or receiving treatment within Lancashire via an online survey, individual case studies collated through interviews and focus groups.

We engaged with forty parents and carers of children and young people living with ARFID via an online survey, six of these parents engaged in the focus group and eight participated in case studies.

Healthwatch Blackburn with Darwen would like to thank all of the parents who participated for their time and being so open about their views and experiences of a sensitive topic.

Feedback from our Online Survey

Forty parents and carers of children and young people living with ARFID within Lancashire completed the survey. Whilst all of the parents believed their child had ARFID only 30% had an official diagnosis.

ARFID presentation in cohort

The majority of children experienced symptoms before they were 4 years old. 22.5% experienced difficulties from the onset of weaning with some parents noting that their child experienced difficulties with formula/ breast feeding prior to weaning.

Age at presentation of symptoms	
Under 12 months	22.5%
1 year – 4 years	60%
5 – 10 years	12.5%
11 years+	0

‘Safe foods’ is the term used to describe food items that the child will tolerate eating. None of the children in the survey had more than twenty safe foods, with the majority if children having less than 10 items.

Number of safe foods	
Less than 5 items	32.5%
Less than 10 items	25%
Less than 20 items	17.5%
More than 20 items	0

92% of parents stated that they believed that their child was neurodivergent or had a neurodivergent diagnosis.

Of those parents that believed their child to be neurodivergent 87.5% suspected that their child has autism spectrum disorder. Other conditions reported were: -

Attention Deficit Hyperactivity Disorder and Attention Deficit Disorder

Dyspraxia

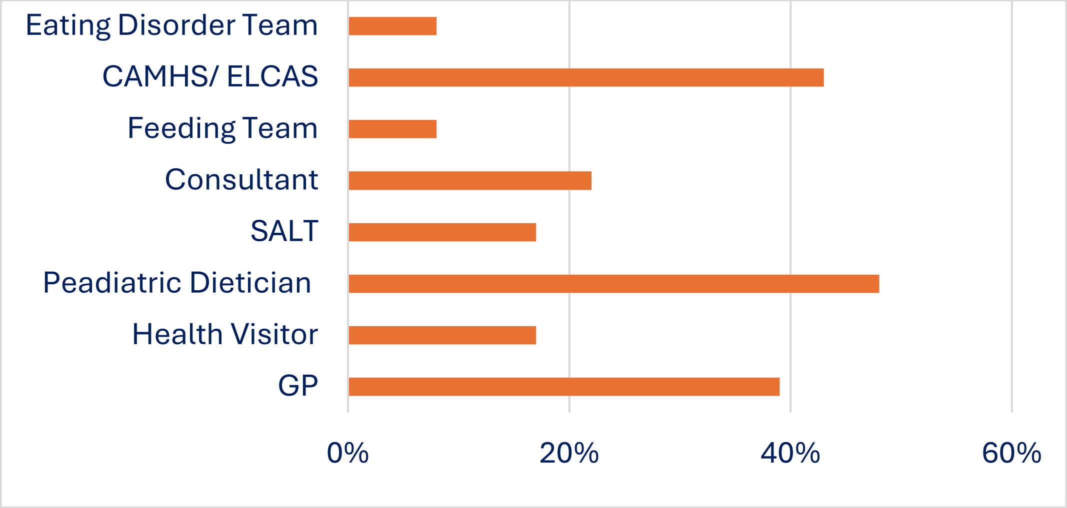
FOXP2 syndrome (a rare genetic chromosome condition)

Obsessive Compulsive Disorder

Demand Avoidance

Auditory processing disorder

72% of respondents stated that they have been successful in obtaining some form of support for their child. This has come from the following services:



Children have received different support in a variety of forms. The most common support parents had been able to obtain was advice from their GP, CAMHS and paediatric dieticians. Many of the parents had paid privately for services.

Other services that families had accessed included:

Private talking therapy

ICB commissioning

Occupational therapist

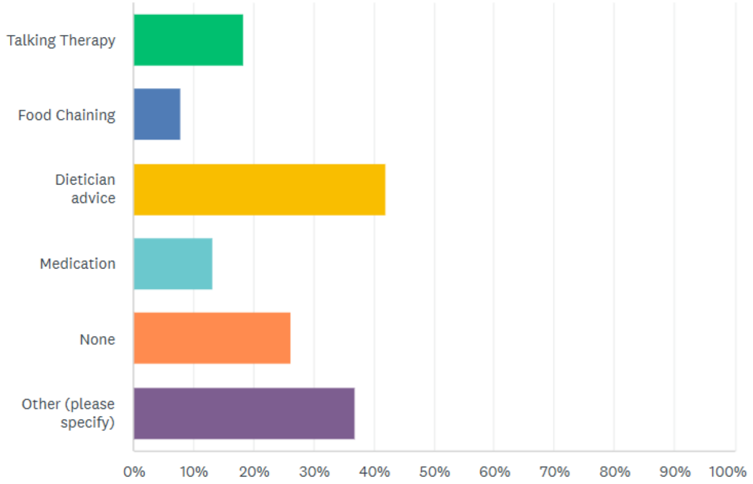
Physiotherapy

Advanced nurse practitioner

The Mosley clinic in London

Occupational Therapy

The types of support they were able to access are as detailed below, with 26% reporting ‘none’.



Other forms of help received: -

Weaning advice

Weekly BP/ECG, weight monitoring

Private Dietitian

Supplement drinks

EMDR therapy

NG feeding tube

CBT family therapy and play therapy

All participants stated that they found help and support difficult to obtain.

> *“Seeing a dietician was easy enough but finding one with enough knowledge of ARFID, particularly early on was difficult and seeking further support other than regular weighing's and Frebini prescriptions is impossible.”*

> *‘No extremely difficult. I have had to chase everything and request everything, even the blood test that showed low enough iron levels to need iron infusion.’*

> *‘No, we had years of being told by a previous dietitian at RLI that my daughter was a ‘fussy eater.’ I was given leaflets. taken years and lots of failed attempts to get different support.’*

> *‘No, no one will provide support for ARFID. Diagnosis was private.’*

> *‘No extremely difficult. I have had to chase everything and request everything, even the blood test that showed low enough iron levels to need iron infusion.’*

> *‘No, we have had to pay privately for counselling because there are no services available to us.*

Participants were asked how helpful they rated these services, 32% found them to be helpful, however the majority stated that they were ether not so helpful or not helpful at all.

How helpful have you found the support?	
Extremely helpful	0%
Very helpful	7%
Somewhat helpful	25%
Not very helpful	36%
Not helpful at all	32%

We asked parents what services they would like to see available for children with ARFID. Many parents stated that they would like to see a multidisciplinary approach to treatment with monitoring of the child’s physical health as well as access to therapies such as talking therapies and food therapies. Parents also emphasised the importance of being able to obtain a diagnosis and the correct advice for parents from professionals who are knowledgeable about ARFID.

‘Access to diagnosis’

‘Food desensitisation sessions/food therapy/play.’

‘More education for health professionals.’

‘Early help and to be taken seriously at the onset.’

‘Services that provide support in home environment.’

‘CBT’

‘Talking Therapy’

‘Food chaining’

‘Monitoring of medical aspects as a result of low intake and appropriate concern for results.’

‘A group education session like the HENRY session’

‘Specific help with diet etc with regard to nutrients and recognition by Paediatricians earlier’

‘Younger services for children who are under 5’.

‘Referral to assessment like Maudsley offered with lots of pre assessment diaries and questionnaires to fill out online.

‘More education for health professionals as suggesting withholding safe foods and child will then eat is not helpful. A website where we can go to get the do's and don'ts as I caused more trauma trying to force and persuade him to eat and I wish I could have avoided that scenario.’

‘Joined up services that help parents and work together for the child. Funding for it in Lancashire so you do not have to pay private dieticians and get hospital treatment locally.’

‘Early diagnosis. specialist consultants both mental health and physical health, psychologist, dietician, OT and educational support.’

‘Proactive support, not waiting until they're losing weight and dropped most of their foods before being taken seriously’.

Talking therapy, food chaining, regular check-ups in terms of monitoring children physically as well as emotional wellbeing. Support for parents. A dedicated ARFID team and referral pathway.

A fully integrated Multidisciplinary service specialising in ARFID that is all ages - not just until age 18. also, parental support group/ peer support for the child as it is very isolating and debilitating condition. Has to be focused on needs as well. also, services that provide support in home environment if that is what a child needs. Early diagnosis. specialist consultants both mental health and physical health, psychologist, dietician, OT and educational support. EHCP refused. Also, more family support and definitely one person who oversees everything- like a support worker or key worker... Also, a way for the arfid sufferer to improve social life and activities as it is the most socially isolating condition. Food is everywhere in society. the impact is massive in terms of dealing with food outside the home. An 8-week maximum wait from referral to assessment

95% of the parents who responded to the survey stated that they had not been offered support as a parent of a child with Arfid.

“Our only lifeline has been an online support group where I try to educate myself about it and learned how to remove demands around food and I'm doing my best to lower his stress around food and eating.”

“It is just the lack of services and support, and it seems to depend on area. Very sad that my child’s paediatrician has referred him to three different services that have all said no due to our postcode and even put on the letter to try local services... there is none! Which is why we were willing to travel so far for some expert support.”

“We have had both children assessed by learning disabilities nursing team, which confirmed arfid. They could not diagnose and neither can dietician, however both fought our corner to paediatrician with evidence, but it was still refused due to them being autistic. We were told if they were not autistic, they would diagnose them but because they are a lot of autistic people are sensory eaters, so it was due to their autism.”

Case studies

Eight parents participated in case study interviews. The children's initials and genders have been removed for confidentiality purposes.

Case study A

Background:	A started having difficulties at the weaning stage which gradually became worse. A has been diagnosed with ASD.
Age at presentation of symptoms:	6 months – (current age 8)
Presentation of Symptoms:	Began having difficulties at the weaning stage which gradually became worse.
Initial Diagnosis:	"A has been assessed by a learning disability nurse who has had training in ARFID and how to assess for it and has provided results clearly showing ARFID, alongside dieticians who also confirm this, however they cannot diagnose. These results (and many conversations) have been shared with our paediatrician however they refuse to diagnose because they are autistic. It was last stated to me that if they were not, they would give the diagnosis."
Treatment/ advice received timeline:	Clinicians seen: Disability Nurse Paediatric Dietician Treatments/ support offered: "Food chaining which only had negative consequences and resulted in the loss of more safe foods. A began having difficulties at the weaning stage which gradually became worse. They were refusing anything with lumps in when trying to move up to stage 2 food, we also tried baby led weaning. At this stage they would eat a wide variety of foods but only firm foods and nothing in a sauce. Their diet gradually became more restricted to the point where they preferred only a handful of foods refusing many that they had previously eaten. I suspected this to be typical 'fussy eating' and carried on offering their usual foods alongside 'preferred' foods however they would push them away/ ignore them/ throw them on the floor. By the age of two they were eating the same meals and snacks every day. At 2 they were put on a pathway for an ASD diagnosis and it was thought that the issues were surrounding sensory issues too so we as parents followed the dietician's advice of food chaining and they were offered foods similar to those that they accepted in terms of bland/ crunchy etc. unfortunately this only restricted them further.

	(for example: at the time one of the snacks, they ate everyday was yoghurt coated raisins, we offered them another fruit coated in yoghurt, but they refused this along with the raisins they had previously tolerated). Their safe foods have become increasingly restricted over time and now has very few foods now.”
Current support being received:	Under the disability nurse for ASD

Case Study B

Background:	B was born at full-term at 40 weeks, had 5 days gestation, normal delivery and required no specialist interventions. In their first few months of life, they experienced multiple episodes of bronchiolitis. B had a tongue tie; however, this was originally by dismissed professionals. They also struggled with social interaction and had sensory aversions to noise, smells, certain textures, flashing lights on toys as well as a huge aversion to wet textures and bath times remain challenging. They have global developmental delay.
Age at presentation of symptoms:	6 months
Presentation of Symptoms:	"At weaning (baby led weaning) B gagged and vomited, despite being so interested in food. The Health Visitor was contacted, and B was referred to Speech and Language Therapy (SALT) for a swallowing assessment. It was deemed that B had a safe swallow and their issues were sensory. Due to the gagging and vomiting, B would not accept anything coming near their mouth such as a spoon. They would accept some fruit puree (2 tablespoons) in which we could disguise vitamin powder. We were given T shaped chewy tubes to encourage chewing, but by this point at 11 months old, they would not accept anything near his mouth and stopped mouthing toys. They were referred to a dietician who prescribed Fortini shakes to disguise in his formula that were neutral flavoured. B detected 5mls in an 8oz bottle and subsequently did not feed for 17 hours. As a result, B would only accept formula on a specific bean bag and would not feed elsewhere including nursery and their grandparents' house. They also dropped eating his puree."
Initial Diagnosis:	"The paediatrician has diagnosed them with severe oral aversion due to sensory needs. I was advised that they had previously been able to refer to Evalina in London for an official ARFID diagnosis, however they were no longer accepting referrals. The dieticians have recorded ARFID in their clinical notes. They also have a diagnosis of autism, sensory processing disorder, constipation, sleep difficulties, complex motor stereotypies disorder."
Treatment/ advice received timeline:	• October 2021 – aged 6 months old could not wean on to solids. • March 2022 – seen by SALT for swallowing assessment – safe swallow identified; sensory issues were the cause of their restricted feeding. Discharged from service September as they cannot help with sensory issues around feeding or food aversion. • September 2022 – referral made to dieticians. • October 2022 – referred to ENT regarding tongue tie.

	• April 2023 – sensory assessment completed and sensory diet in place. • October 2023 – referred to dietician. Prescribed Fortini drinks to disguise in formula. B detected 5mls in an 8oz bottle and subsequently did not feed for 17hrs. As a result, we lost feeding of formula at nursery and grandma’s house and B would only accept formula on a beanbag in the living room at home. • November 2023 – B has tongue tie revision surgery at Royal Manchester Children’s Hospital. • January 2024 – MDT appointment with dietician, paediatrician, health visitor and parents. B’s growth was static for 4 months and no improvements to his oral intake. Referred to surgeons at Royal Manchester Children’s Hospital to discuss a gastrostomy. • May 2024 – seen by surgeons and listed for an urgent gastrostomy. Due to B’s sensory needs, he could not tolerate an NG tube. • October 2024 – gastrostomy inserted and commenced on Paediasure Plus feeds. • B is now solely tube fed.
Current support being received:	Under the care of the dieticians and Children’s Community Nursing Team to manage his gastrostomy and feeds. A sensory diet in place to expose them to different textures. B has food play throughout the day, and this is included in their EHCP.

Case study C

Background:	C began losing foods around the age of two
Age at presentation of symptoms:	2 years old
Presentation of Symptoms:	“C began losing foods around the age of two, making clear to us that they did not like what was being offered and visibly gagging when they tried something. This escalated to not being able to try new food items.”
Initial Diagnosis:	‘Fussy eating’ until ARFID was diagnosed at age of ten
Treatment/ advice received timeline:	“At the age of two, difficulties with eating began and we were advised that they were ‘just a fussy eater’ and that they would grow out of it. The food aversions continued to escalate, and they lost foods daily. By 9 years old, C’s diet was restricted to just pasta and cheese. We discussed the situation with a Health Visitor who was visiting a sibling, and they referred C to hospital who referred to CAMHS where they received an ARFID diagnosis and were under their care for 2 years.”
Current support being received:	Once diagnosis was made the support stopped. There has been no improvement in C’s symptoms.

Case Study D

Background:	“D had always struggled with bottle feeding as a baby, then again at weaning. This became progressively worse at around 6 years old, and the number of foods and liquids D would consume also reduced. D would gag on foods and have severe reflux pains.”
Age at presentation of symptoms:	“We noticed difficulties with feeding when D was an infant, this became more pronounced when D was 2 years old.”
Presentation of Symptoms:	“D would limit their food and liquid intake. They have severe reflux and would not tolerate taking medication. D would gag on foods and smells around them. They started to decline rapidly and could not stand the smells in the house. They struggled to enter shops, restaurants and eat around others. They would take their accepted foods with them when going to their grandparents’ house. D’s aversions became so severe they could not pass someone eating in the street. They would freeze and need to be carried past them, or they would go into flight mode and run away. D has opened the car door and jumped out the car for example if food was picked up on the way home.”
Initial Diagnosis:	Private ARFID diagnosis- March 2002
Treatment/ advice received timeline	“When D was 6 years old, we raised concerns and D was admitted into the Royal Lancaster Hospital for an observation of their eating, where they were not allowed to take their accepted foods in. A wide range of food was offered at every mealtime, however this caused D severe distress. Food was placed in front of them; however, they were not observed eating once. We contacted Dr Gillian Harris who advised us that this was not the way to treat ARFID and gave us advice. We raised several complaints, and we just felt that there was no awareness of ARFID, and that the hospital stay caused D significant trauma. They have no trust in medical professionals now and will not attend any medical appointments. We feel that we have had to fight for support for D and are still fighting with the ICB regarding D’s lack of treatment.”
Current support being received:	Private support via Dr Gillian Harris

Case Study E

Background:	"E is very restrictive with what types of food they will eat, likes the same types of food, very beige in colour and texture. E refuses food and drinks often and cannot spend lots of time thinking about food and drink or becomes to stressed by it and will then have nothing at all. E can vomit in the morning from anxiety and stress and often regurgitates tablets and food when struggling to swallow. E has lost weight and is already classed as underweight. They will sometimes pass out from dehydration and anxiety. E is very anaemic and has lots of nutritional deficiencies."
Age at presentation of symptoms:	7/8 years old but became much more difficult to manage at 11/12
Presentation of Symptoms:	"It started at primary school with E refusing most meats and would only have the same packed lunch at school every day. After 5 to 6 months, they changed back to something they had previously. Things got worse when their anxiety increased with the start of high school. E will not eat or drink at all at school and is too anxious most mornings to manage food and often throws up before school."
Initial Diagnosis:	Anxiety
Treatment/ advice received timeline	"We had to fight to see CAMHS and specifically a psychiatrist. We eventually got a generalised anxiety diagnosis and E was given medication which helps anxiety and therefore helps some anxieties around food. We went privately, due to wait times, for an ASD diagnosis at 13. We subsequently also got private diagnoses of sensory processing disorder and ARFID diagnosis due to there being no support locally. No one will support with ARFID, they just touch on it and work around the edges including the Hospital Paediatrician consultant, dietician, GP, CAMHS and psychiatrist. It's felt a constant battle with the NHS to get help. Having a child who is underweight and losing weight has pushed a little more action from people last year but with ARFID it is not always about weight loss. E needs intensive Cognitive Behavioural Therapy. In the past E has seized due to lack of food and hydration and ended up in A&E but was sent away and we were just told that it was anxiety. The psychiatrist tried to reduce their anxiety medication but then refused to re-increase the dose when their eating got much worse until E was safeguarded."
Current support being received:	CAMHS mental health nurse, Psychiatrist, Dietician, Paediatrician consultant & Paediatric Gynae consultant

Case Study F

Background:	“F had no issues with breast feeding and formula. They began having difficulties when they were around 12 months old following an incident of choking. The range of foods F would eat gradually declined over the years and was at its worse around the age of 7/8 when their weight dramatically decreased, and they only had around five safe foods.”
Age at presentation of symptoms:	12 months
Presentation of Symptoms:	“F started refusing foods and gagging at the sight, touch and even thoughts of certain food. On the advice of the GP and Health Visitor to withhold their safe foods and only offer alternatives they still would not try foods despite visible distress that they were hungry.”
Initial Diagnosis:	Fussy eating
Treatment/ advice received timeline	“Between the ages of 1 to 6 years we had numerous visits to the GP where we were told it was just fussy eating and a phase they would grow out of. We were told to withhold safe foods and offer alternatives. This just resulted in weight loss and distress. At 7 years old we got a referral to CAMHS, but this was rejected due to the issues with food not being body image related. At 8 years old we got a referral to a paediatrician; however, they could only offer nutrition shakes and juices which F would not drink. We then paid privately and travelled to see a professional that specialises in ARFID in London. At age 11 we chose to pay privately for talking therapy.”
Current support being received:	Private talking therapy

Case Study G

Background:	“G has a cow’s milk protein allergy, which caused significant health problems with feeding in infancy. G showed no interest in food from the onset of weaning. This was sustained despite multiple approaches and requests for help from the Health Visitor and GP.”
Age at presentation of symptoms:	From birth
Presentation of Symptoms:	Food refusal from weaning onset
Initial Diagnosis:	Allergies/ Failure to thrive
Treatment/ advice received timeline:	“Between the ages of 0-6 months, G had a cow’s milk protein allergy which resulted in failure to thrive, and G was extremely underweight. We got no support from our existing GP so moved GP surgeries. The new GP realised there was a problem and helped manage their allergy. At 6 months- G began weaning but showed no interest in food and we just faced clear refusal despite trying multiple approaches. We had little support from the Health Visitor and G was not gaining weight. The GP could not make a referral due to G’s age. Between 6 and 18 months, we made numerous attempts to get support but were faced with none being available and G was still not gaining weight. At 18 months, G was now losing weight and was lethargic and physically unwell. We were referred to a dietician made but the referral bounced back due to G’s age. At 19 months the GP was concerned again and made another referral to both a dietician and paediatrician, but both were refused due to age and percentile. We had weekly appointments with the nurse practitioner at our GP surgery. G’s physical health problems increased so a referral to the Rapid Access Team was made. We had a consultation with a paediatrician who discussed G’s health concerns but referred back to a dietician for ARFID diagnosis, which was again rejected. The GP and nurse practitioner repeatedly emailed their concerns, and G was eventually invited to be admitted in hospital for 48 hours. They remained an inpatient for nearly 2 weeks and were fitted with an NG tube. We paid privately for a consultation with Gillian Harris who expressed concerns about the restricted calories in G’s feeds and advised that they should be getting a full calorie intake. At the age of two, G had a PEG fitted.”
Current support being received:	Support for the PEG, however no support for ARFID still

Focus Group

Six parents of children and young people with ARFID participated in our focus group. The focus group discussions centred around which services parents feel would have been or would be beneficial for treating and managing ARFID. We spoke particularly about which professionals parents would like to see involved in care at the various stages of a child's ARFID journey.

Early Intervention

The focus group discussed the need for early intervention to provide help and guidance at the onset of symptoms. The majority of children began presenting with symptoms whilst they were toddlers and so support and correct advice should be made available at this early stage, and which supports improved intake of foods. Many parents had been given ill-advised and sometimes harmful advice from health professionals who are not aware of ARFID. Advice such as withholding safe foods and being advised that their child is just 'fussy 'and will 'grow out of it' is not helpful for families.

Weight measurement

It was agreed amongst the group that referrals and assessments should not be based on weight alone. Children with ARFID may remain on an acceptable percentile but their restricted diet is still having a serious detrimental effect on their health. Parents felt that they were not taken seriously due to their child not being significantly underweight. Parents stated that their child was experiencing medical issues such as high blood pressure and severe anaemia however because their weight was deemed to be within a normal range professionals took no action.

Physical health checks

Parents felt that they should be respected as the expert in their child and that if and when a child's food intake becomes seriously restricted and parents feel that their diet is having a detrimental effect on their physical health then physical examinations should be carried out as a matter of course (e.g. physical examination, bloods, a urine sample, ECG, BP). Consequently, this should result in appropriate medical treatment based on the results of these tests. Due to other neurological conditions which are frequently present with children with ARFID, parents felt that physicians should be prepared to carry out the physical examination of the child appropriately and in a way that is not distressing. One parent gave the example that children who have autism spectrum disorder and/or sensory processing issues may find procedures such as blood tests more difficult. It is also important that they have the correct equipment, another parent gave the example of the correct size small blood pressure cuff not being available.

Treatment

Dependent on the needs of the individual child, parents felt that children would benefit from play therapy, sensory food play and talking therapy. The consensus was that parents felt this would be extremely beneficial although they had not had access to any of these services.

Professionals

Parents would like their children to have access to a multidisciplinary approach to supporting their child and mentioned specifically dieticians, occupational therapists, paediatric consultants, and therapy workers. They would also like to see increased education for professionals around ARFID, with some parents saying that their GP did not know what ARFID was. They also felt that having a key worker would help them navigate a multidisciplinary team approach better and with targeted support.

Severe ARFID

Parents felt that children whose food and drink intake has become severe and who require medical intervention should have a specific point of contact with professionals who understand ARFID and access to medical services within Lancashire and South Cumbria. Parents who have had to travel significant distances outside of Lancashire for inpatient stays and procedures such at PEG tubes expressed that they faced the added implications of financial hardship, logistical challenges and children being separated from their families due to having to remain out of area.

Recommendations

Below is a summary of recommendations for healthcare professionals within Lancashire to best support children and young people living with Arfid and their families and carers.

Education for all professionals who may come into contact with children with ARFID

A key message from parents was that they felt that the professionals they had come into contact with had little or no knowledge surrounding ARFID. As a result, incorrect advice has sometimes been given which can exacerbate the symptoms and have a detrimental impact on the child's health. Professionals in primary care, secondary care and mental health should be provided with training surrounding ARFID.

Role of primary care practitioners such as GP's and Health visitors

The majority of parents first point of contact with professionals concerning ARFID is their GP or Health Visitor, but these have often been unsure of what course of action should be taken and where referrals need to be directed. This often results in referrals being rejected and repeating the same process. We recommend that the ICB develop a clear pathway which is shared widely so that timely support can be obtained.

Education and support for parents of children with ARFID

Parents felt strongly that there was a lack of support for them in terms of helping to manage their child's ARFID. Available information is scarce and conflicting advice often given. We recommend that an early intervention service which can provide accessible information surrounding ARFID, provide advice on supporting a child with ARFID and nutritional advise is imperative.

Importance of a multi-disciplinary approach

We recommend that the management of ARFID should delivered through a multi-disciplinary approach, bringing together services that provide medical treatment and holistic care. Services such as paediatric consultants, dieticians, Speech and Language Therapy and Occupational Therapy should run alongside more holistic approaches for example food and play therapy. Therapies such as Cognitive Behavioural Therapy and talking therapies should also be accessible. Services and treatment should be appropriate according to the needs of the child and where they are in the ARFID severity index.

Importance of single place of contact

We recommend a single point of contact such as a key worker for parents in order to manage the multidisciplinary approach.

Importance of diagnosis

Parents noted the struggles their child may face in a nursery or educational setting fitting in with their policies and practices around food and eating. This can have a serious impact on the child's education and can create social barriers. Parents stated that education settings are often reluctant to make exceptions and alternative provisions for a child without an official diagnosis. We recommend that appropriate diagnosis should be available and factored into Education and Health Care Plans.

Accessible services within Lancashire and South Cumbria

Travelling out of area to receive treatment and care for ARFID causes a significant impact to families logistically and financially. Having to travel a significant distance for lengthy in-patient stays affects the child, parents and siblings and family life. We recommend that children should be able to obtain treatment and care within Lancashire.