“There are no services”: Gloucestershire parent carers’ experiences accessing support for restrictive eating and swallowing difficulties.

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Parent & Carer
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Report into accessing support for restrictive eating & swallowing difficulties.

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1. Executive summary

Background: The Alliance heard from families that they were unhappy with the support their children with restrictive eating or swallowing difficulties were receiving from health services in Gloucestershire. The Parent and Carer Alliance asked an independent researcher to undertake a survey to understand the experiences of families living with eating or swallowing difficulties, the impact of these difficulties on them and how they have experienced accessing health services.

Method: The survey questions were a mix of fixed choice, Likert scale and free-text responses and explored demographics, the impact of difficulties on the individual and carer, the risk of harm, support received from professionals, the ease of accessing services and transitions to adult services. Fifty people consented and 48 people answered the survey.

Finding 1: High number with autism diagnosis, few with ARFID diagnosis.
The majority of participants focused on restrictive eating in this survey. A large proportion (83%) of children were considered to have a disability related to neurodivergence, with 50% of children having a diagnosis of autism. The low number of those diagnosed with ARFID might be expected given the context of difficulties accessing health services for assessment and treatment.

Finding 2: Difficulties associated with significant health needs and risk.
Participants described frequent experiences of anxiety around swallowing and restrictive eating. Additionally, two in five children or young people had not put on adequate weight with a third not growing sufficiently. Given the potential and actual risk to both physical and mental health, it is highly concerning that there is a lack of an ARFID pathway or service in Gloucestershire to meet the needs of its population.

Finding 3: Distress, isolation and carer burden
Participants described how their loved one's difficulties had a pervasive impact. Individuals and their families experienced social isolation. Eating can cause huge levels of anxiety as well as impacting the physical health of children and young people. Carers worked hard with planning and organisation to ensure that their young person could be sufficiently fed and access the community. The additional cost of caring for their loved one was found to be on average £2850 per year. There is a clear psychosocial impact on both the young person and their carers which commissioners need to address.

Finding 4: Service offer in Gloucestershire is barely minimal
Participants experienced a lack of understanding from health professionals which at times, bordered on ignorance and uncaring. Participants experienced referrals being rejected, long waits, professionals with little clinical experience managing the presenting difficulties and fighting to get support. Parent carers in this survey were left with the impression there is nothing available in the NHS to support them and their loved one. Noting the risk to health alone, the lack of a clear service or pathway in Gloucestershire is of substantial concern.

Conclusion: Our survey offers useful insights into the experiences of parent carers supporting children and young people with restrictive eating and swallowing difficulties. We have found parent carers have been left without a clear clinical service they can access, whilst managing the physical and mental health of their young loved ones alongside the risk of harm. When parent carers have sought support, they have been excluded from services and dismissed by health professionals. Commissioners must listen to the experience of parent carers in Gloucestershire and urgently work towards creating a service that parent carers and young people can access. This must provide them with support in managing their difficulties alongside the psychological impact these difficulties can give rise to.

2. Background

The Parent and Carer Alliance C.I.C. supports families whose children have additional needs across Gloucestershire. The Alliance heard from families that they were unhappy with the support their children with eating or swallowing difficulties were receiving from health services in Gloucestershire. In this context, difficulties with eating primarily refers to children with a presentation of Avoidant-Restrictive Food Intake Disorder (ARFID). Those with ARFID may avoid or restrict eating certain types of food. This may be because of sensory aspects of the eating, anxiety about the consequences of eating or a lack of interest in eating[1].

The Parent and Carer Alliance asked an independent researcher, Benjamin Newton, to undertake a survey of families it works with. The purpose of this survey was to understand the experiences of families living with eating or swallowing difficulties, the impact of these difficulties on them and how they have experienced accessing health services.

3. Method

The researcher has over ten years research and evaluation experience working in the NHS. He has a psychology degree and a PhD and is a Chartered Psychologist. He has lived experience as a parent carer managing ARFID. A survey was designed and delivered on a secure platform. The survey questions were a mix of fixed choice, Likert scale and free-text responses and explored:

- Demographics;
- Impact of difficulties on the individual;
- Impact of difficulties on the carer;
- Risk of harm;
- Support received from professionals;
- Ease of accessing services;
- Transitions to adult services.

The survey was advertised using the Parent and Carer Alliance's Facebook group. The first response was received 28th July 2025 and the last response was received 26th August 2025. A total of 1097 visits were recorded to the survey and 57 people proceeded to the survey. Of these, 50 people completed the consent statement for the survey and two of these did not answer any further questions. All respondents indicated they had a Gloucestershire postcode.

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[1] See Beat Eating Disorders.

Prior to completing the survey, respondents were asked to read information about the survey and how their data would be used. To proceed, respondents gave their consent to complete the survey.

The researcher drew on thematic analysis principles to analyse free-text data, reading and re-reading responses before identifying commonly occurring themes. Participant quotes are offered to support the emerging themes.

4. Findings: Who completed the survey?

All respondents (n=48) indicated they were parents or carers of a young person under 26 years with an eating or swallowing difficulty. The majority of respondents were female (97%, n=35) with one respondent identifying as ‘other’; 50% (n=18) were in the age bracket 41-50 years; a high proportion (53%, n=19) identified as disabled themselves.

Table 1. Age of children

Age range	%	n
0-4	11.1%	4
5-11	58.3%	21
12-17	25.0%	9
18-21	5.6%	2
22-25	0.0%	0
26+	0.0%	0

Regarding the demographics of the children being reported on, 81% (n=29) were male; 19% (n=7) were female. Table 1 shows the age range of children, with most aged 5-11 years.

All children were considered disabled, with 83% (n=30) identifying the disability as related to neurodivergence and 11% (n=4) relating it to physical health.

Most respondents reported their young person had a difficulty with restrictive eating (n=35). Eleven respondents said their young person had both restrictive eating and swallowing difficulties, with just two respondents choosing to focus on swallowing difficulties in the survey. See Figure 1. Nearly 70% (n=33) of respondents indicated difficulties with swallowing or restrictive eating had been going on over two years, with 44% (n=21) of respondents stating that the difficulty had lasted over five years. See Figure 2.

Figure 1. Frequency of respondents with swallowing and restrictive eating challenges.

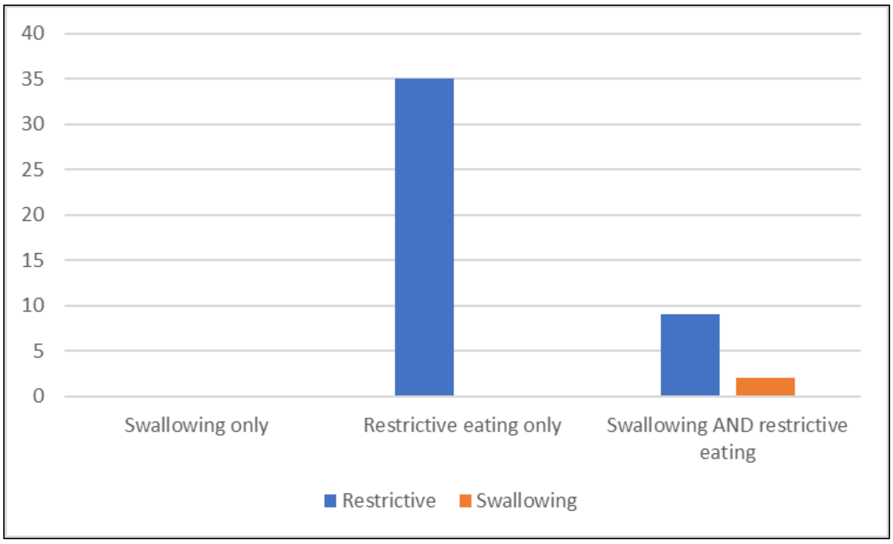
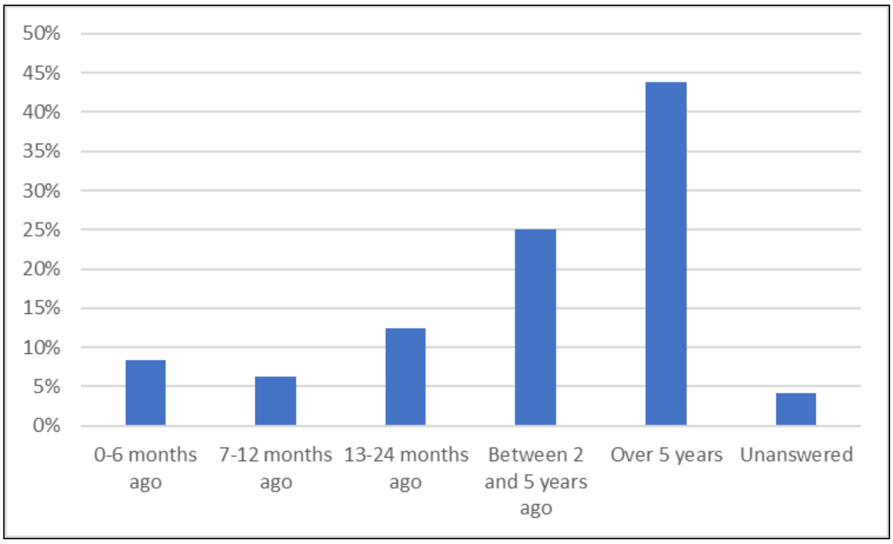


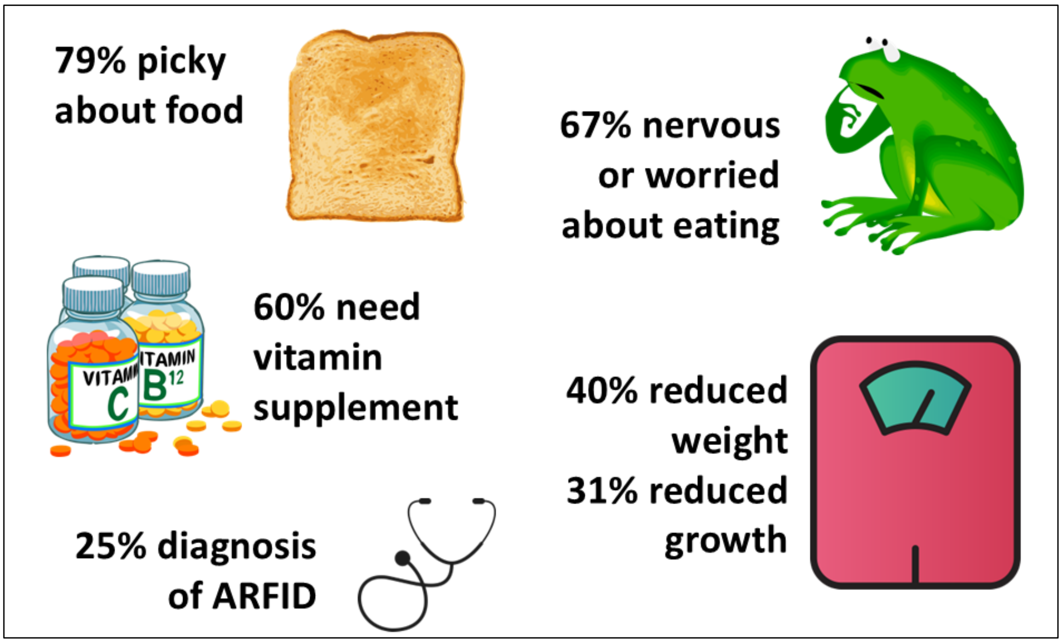
Figure 2. Percentage of respondents indicating when the difficulty started.



We asked respondents to describe some of the difficulties their loved one had experienced in the previous two years. Figure 3 offers an infographic to describe some of these.

The most prominent difficulties were appearing picky around foods (79%), appearing worried or nervous around eating (67%), requiring a vitamin supplement (60%). Many respondents indicated their loved one had not put on enough weight (40%) or grown enough (31%). Whilst over a quarter reported swallowing difficulties (27%). A small number required tube feeding (13%).

Figure 3. Difficulties experienced in the previous two years.



Respondents were asked about whether their loved one had another condition or diagnosis in a free-text response. These have been sorted and are shown in Table 2 below. Half of respondents indicated their loved one had a diagnosis of Autism (n=24), with a further 8% (n=4) awaiting assessment for suspected Autism. Fifteen percent (n=7) had a sensory processing disorder or difficulties. Thirteen percent (n=6) had a diagnosis of ADHD with a further one individual awaiting assessment.

Table 2. Additional conditions or diagnoses.

Diagnosis / Condition	n	%
ADHD	6	13%
Autism	24	50%
Sensory Processing Difficulties	7	15%

5. Findings: Impact of difficulties

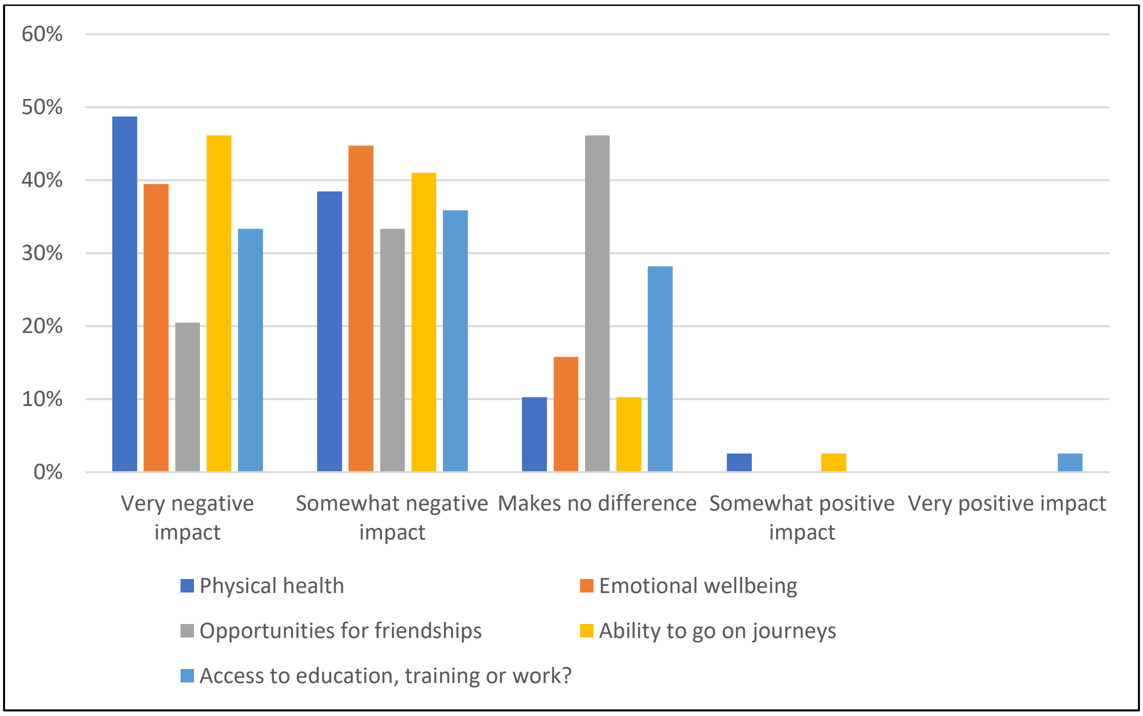
We asked participants about the impact of their loved one's swallowing or restrictive eating, on the following life domains:

- Physical and mental health.
- Opportunities for friendships.
- Ability to go on journeys.
- Access to education, training or work.

The data indicates swallowing and eating difficulties have a pervasive impact across all life domains. The domains where higher numbers of participants reported the impact was very negative or negative, were physical health (87.2%, total n=39), ability to go on journeys (87.2%, total n=39) and emotional wellbeing (84.2%, total n=38). See Figure 4.

We asked participants in a free-text box, to tell us more about the impact on their loved one. Twenty-seven individuals left comments which have been analysed using a thematic approach.

Figure 4. Chart showing the impact of their difficulties across life domains.



Impact on social inclusion

The largest impact of eating and swallowing difficulties was around taking part in ordinary life, resulting in individual and families experiencing social exclusion. This ranged from participating in education, holidays or travel, and social opportunities. Participants talked about how their loved one's difficulties restricted their lives.

- ***"Can't join in with family dinner".***
- ***"They miss out on a lot of opportunities due to the restrictions of their diet".***
- ***"They cannot live a normal life".***
- ***"Can't access food options in the community restricting activities or being able to travel".***

Families found it was hard to eat out together or go on holiday because of the limited food their child would eat. For young people, this would mean their ability to participate or access school was impacted. It could be difficult for young people to eat at their school. One young person was bullied regarding their restricted ‘safe’ foods. Another could not do Food Technology lessons.

- ***“School competitions and Easter Egg Hunts are often rewarded with sweets or chocolate (my child doesn’t eat these). He always feel sad about this. It hurts him”.***

Expanding effort with organisation
It was evident that the restrictive eating and swallowing difficulties would require carers to be organised so that their child could have access to their ‘safe’ foods, which inevitably carers had to ensure was taken with them:

- ***“We always have to take foods with us and I have to supply foods for events like scout camps etc”***
- ***“We take our own where possible and don’t go any where new.***

Participants told us about the significant amount of planning they had to do in order to support their child.

- ***“Eating requires forward planning for any trip out. His foods are so restricted that we can sometimes struggle to access safe foods away from home.”***
- ***“Absolutely everything has to be supplemented, costing money, time and requiring incredible dedication from us to ensure he actually consumes any supplements.”***
- ***“Have to plan events ahead and if events are catered I have to sort food as he won’t eat”.***

It was striking that participants had sought medical help only for this to be rejected.

- ***“Food issues were his first autism signs and ive had nurses laugh on the phone when I've expressed concern.”***
- ***“I've worked so hard on my own (4 dietician referrals from consultant/GP refused) to ensure he gets the support he needs.”***

Anxiety and food
Participants described the presence of anxiety. Food and associated sensory experiences, such as smell, could be anxiety-inducing. Experiences ranged from discomfort to severe anxiety.

- ***"They are terrified of being sick."***
- ***"The anxiety my son displays is the most heartbreaking impact.***
- ***"He also struggles with smells so being at school has been an issue due to the smell of cooked school dinners."***

One carer talked about the severe anxiety associated with supporting their child with tube-feeding:

- ***"Changing the tube, or even the plaster is traumatic. Distress lasts for hours. Sensory processing disorder means constant awareness of the tube in nose and throat"***

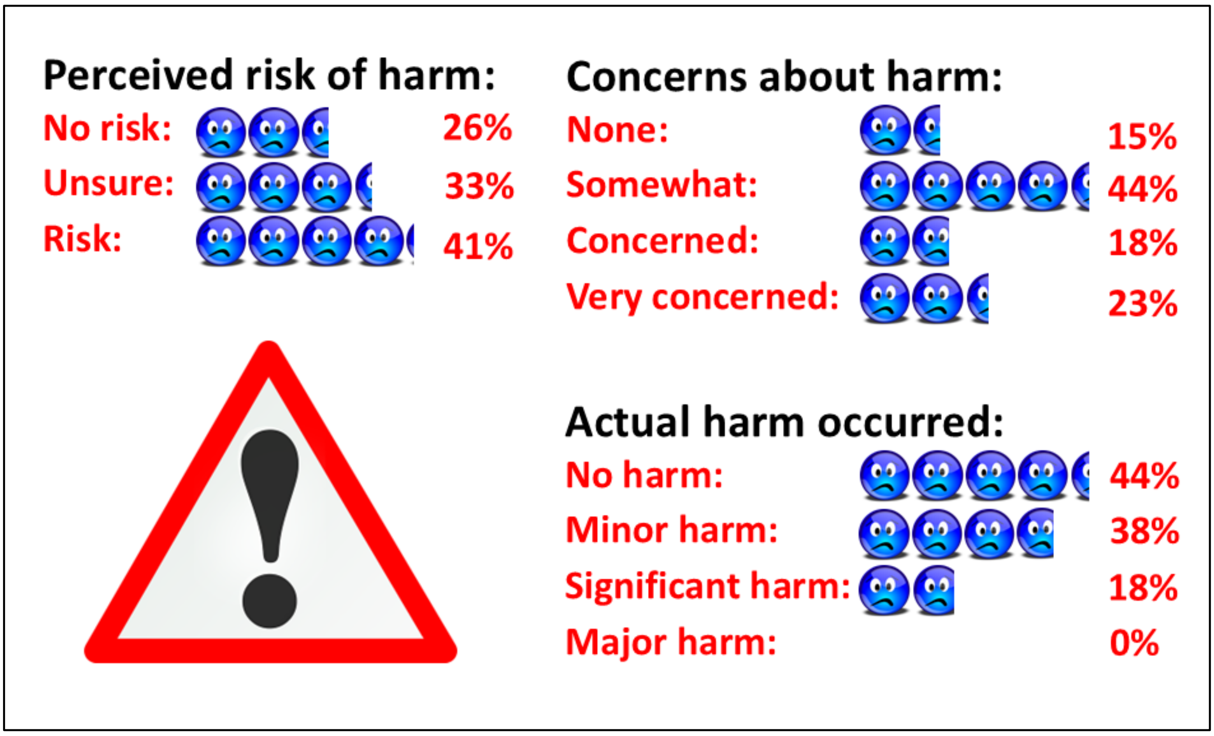
Physical health
Finally, it was clear there was an impact on the physical health of children. This included, low energy, vomiting, low weight, constipation and pain .

- ***"We have to think carefully about where we take him as we don't want him to lose any more weight if he can't eat or we have to take lots of food with us."***

6. Findings: Risk of Harm

We wanted to explore the perceived risks associated with the child or young person's difficulties with swallowing and restrictive eating. We asked respondents whether there was a risk of harm due to their difficulties and 41% (n=16) believed there was, whilst 33% (n=13) were unsure. Over four in five respondents (84%, n=33) held concerns about a risk of harm occurring due to their loved one's difficulties. Over half of participants (56%, n=22) reported that some form of harm had occurred due to a swallowing difficulty or restrictive eating.

Figure 5. Infographic showing experiences around risk and harm.



7. Findings: Carer Impact

Respondents were asked about how the swallowing or restrictive eating difficulties impacted the main carer. We asked them to rate the impact across four domains:

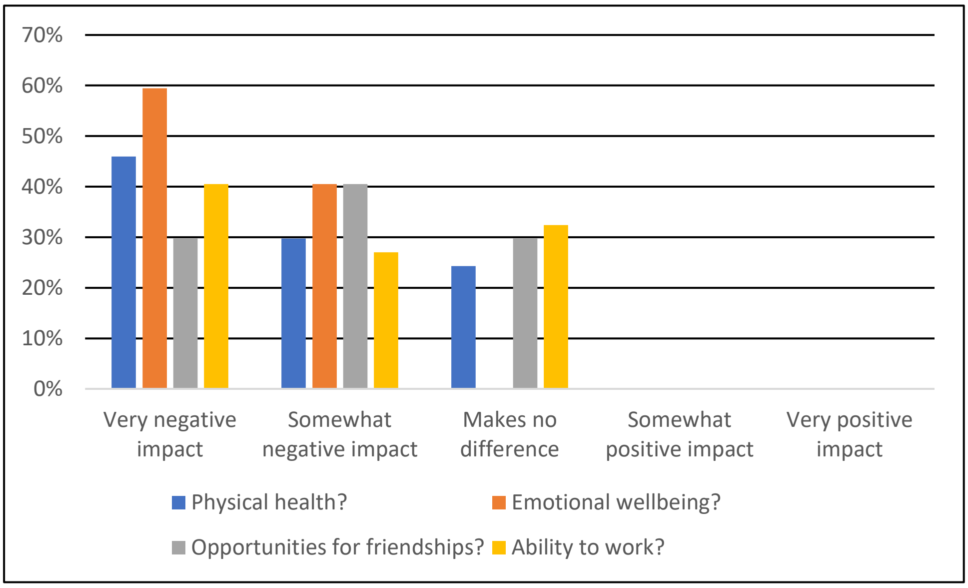
- Physical health;
- Emotional wellbeing;
- Opportunities for friendships;
- Ability to work.

The biggest impact was on carer's emotional wellbeing with all respondents saying it negatively impacted this (total n=37): For 3 in 5 carers the difficulties with swallowing or restricted eating has a 'very negative' impact on their emotional wellbeing (n=22), and for 2 in 5 carers it has a 'somewhat negative' impact (n=15).

For physical health, 75% of respondents reported swallowing and restrictive eating difficulties had a somewhat or very negative impact (n=28). This negative impact was echoed in opportunities for friendships (70%, n=26) and ability to work (68%, n=25).

We invited carers to tell us more about the impact on them. Their responses were reviewed thematically and grouped into similar responses.

Figure 6. Clustered bar chart showing the impact on carers.



Incredibly Stressful
The most recurring theme was around the emotional impact on carers and this was raised by twelve participants. Carers talked about the huge levels of stress, uncertainty and anxiety they experienced. This could come from worries about their child's health, the extra work needed to meet their child's needs, the lack of support or breaks and even from the medical indifference they encountered.

- ***"My life is on hold whilst I try and care for them…I literally haven't had a day to myself in 3 years let alone a break."***
- ***"The constant fighting for having the impact of this need recognised is taking its toll."***
- ***"The arguing & gaslighting from GRH over years was extremely stressful."***
- ***"I…spend my life trying to explain the impact to people and I'm tired. To sum it up, imagine the stress if your dog stops eating and will only eat crisps. We take it to the vet, they get care, love, support, tests and no one just says "oh well their height is fine"."***

The Extra Work
Looking after a child with a swallowing or restrictive eating difficulty entailed a lot of work. This was raised by ten respondents. Their child can require substantial supervision; specific foods and approaches to preparation are required; carers may need to go to multiple shops to get safe foods.

- ***“We…spend a lot of time making sure our son has the foods he'll eat often going to several shops in one evening.”***
- ***“Constant supervision needed especially at meal times. Cooking from scratch usually.”***
- ***“Everyday has to be planned down to the last detail…I need to shop at three different supermarkets for brand specific items…there’s the preparation - ensuring the carrots are sliced the right way…making sure foods don’t share the same space on a plate.”***

No help available
The lack of support available to carers and children was evident in seven respondents’ data. Participants described the lack of healthcare provision, including experiencing dismissive attitudes from health professionals, whilst some described the lack of support in more general terms.

- ***“The dismissive attitude of doctors and other healthcare providers. The lack of medical intervention…The fact that drs don’t care when your child has low ferritin even when on multi vitamins with iron.”***
- ***“I gave up work to learn from international professionals about restrictive eating…I had no choice as there was no help available and my child was unable to eat any food since weaning.”***
- ***“She was constantly in a failure to thrive state and getting ill and no one at GRH would take it seriously.”***
- ***“No provision for treatment - centres of excellence…can't be accessed as there is no lead professional to liaise with and they don't accept referrals from Gloucestershire. Eating disorders team don't recognise or treat/support children with ARFID.”***

Participants raised other issues, including the impact on them being exhausting; the uncertainty around their child’s health; the socially limiting nature of their child’s difficulties leading to isolation; and the financial impact on them.

Costs of Caring

We asked carers to specifically tell us how much extra per week they spend to manage their child’s difficulty with restrictive eating or swallowing. A total of 30 participants responded. The minimum spend was £10 per week and the maximum spend was £300, which appeared to be an outlier. The mean spend was therefore calculated without this outlier and was found to be £54.76 per week. Over the course of a year this extra spend equals £2,848.

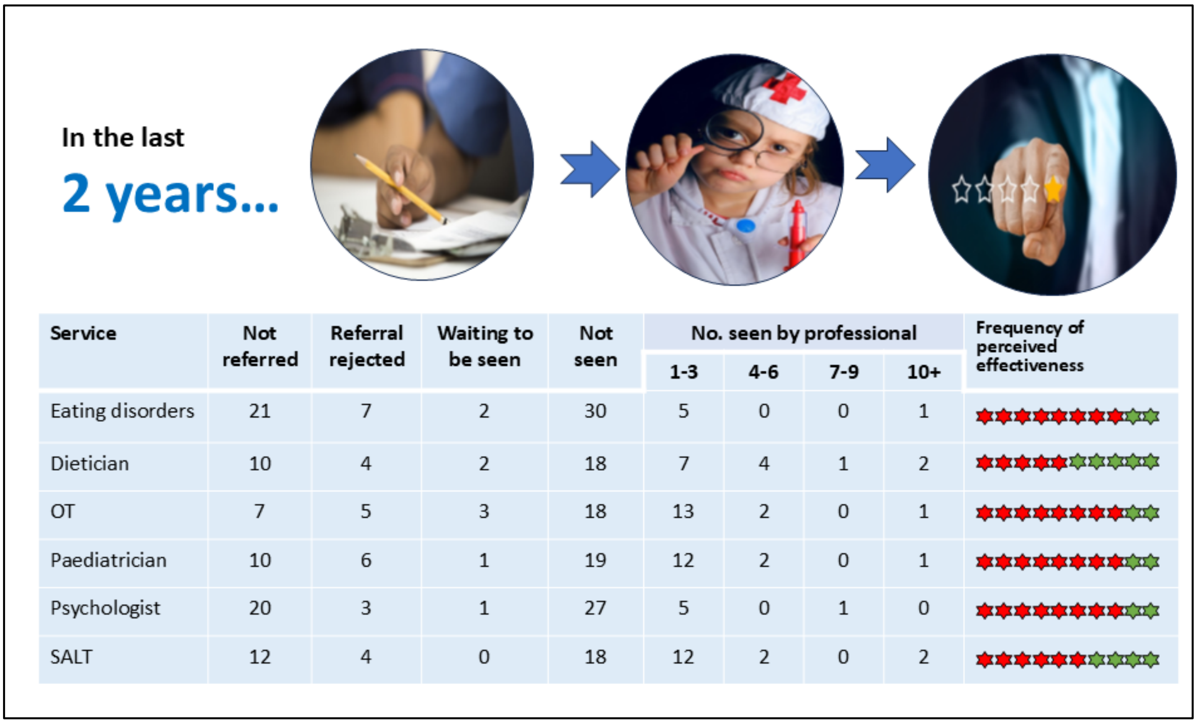
8. Findings: Service Access by Type

We asked participants about their experiences of seeking help for their loved one's difficulties in the last two years. See Figure 7. We questioned them about their referral to services, the number of times they had seen specific professionals and their perception of how effective these professionals were.

Given the variable number of individuals answering these questions, we have presented actual numbers of respondents rather than calculating percentages.[2] Services with a lower frequency of access are eating disorders and psychology. The SALT service was the most frequently accessed. For those accessing the eating disorder service, 5 of the 6 accessed the service for assessment, with only 1 respondent's loved one receiving any treatment.

We asked participants to rate the effectiveness of services using a four-point Likert scale (highly ineffective, ineffective, effective, highly effective). These were grouped together (red stars being ineffective, green stars being effective). The services with higher ratings of perceived effectiveness are SALT and dietetics. No services were perceived effective by more than 50 percent of individuals.

Figure 7. Numbers of individuals accessing services and their perceived effectiveness.



Service	Not referred	Referral rejected	Waiting to be seen	Not seen	No. seen by professional				Frequency of perceived effectiveness
					1-3	4-6	7-9	10+	
Eating disorders	21	7	2	30	5	0	0	1	🟥🟥🟥🟥🟥🟥🟥🟥🟩🟩
Dietician	10	4	2	18	7	4	1	2	🟥🟥🟥🟥🟥🟩🟩🟩🟩🟩
OT	7	5	3	18	13	2	0	1	🟥🟥🟥🟥🟥🟥🟥🟥🟩🟩
Paediatrician	10	6	1	19	12	2	0	1	🟥🟥🟥🟥🟥🟥🟥🟥🟩🟩
Psychologist	20	3	1	27	5	0	1	0	🟥🟥🟥🟥🟥🟥🟥🟥🟩🟩
SALT	12	4	0	18	12	2	0	2	🟥🟥🟥🟥🟥🟥🟩🟩🟩🟩

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[2] The total number of people not seen will not always be the sum of those not referred, rejected or waiting to be seen, as not all answers were compulsory.

We asked participants about other professionals involved with their loved one. Participants described a range of roles including:

- Birmingham Feeding clinic
- CAMHS
- GOSH feeding clinic
- Physiotherapists
- Respiratory Consultant
- School Nurse

We were concerned by the comments participants expressed about professionals:

- ***[Regarding referral to GOSH] “consultant keeps fouling the process and referral ‘some people with autism are just like this ‘ - he’s dangerously underweight”.***
- ***“He was discharged from all services despite us asking for dietician and speech and language.”***
- ***“One paediatrician admitted child to hospital for immediate NG tube as severely malnourished in spite of over a year of pleasing for help. The next paediatrician was dismissive”***
- ***“Phone call with eating disorder. Couldn’t offer anything further as AFRID not recognised in Gloucester”***

94% (n=34) reported it being either very difficult or difficult to get the right support for their loved one’s difficulties, though only 19% (n=7) complained about accessing services and 28% (n=10) had used private services. Unsurprisingly perhaps, only 11% (n=4) of respondents were satisfied that the right professionals were supporting their loved one’s difficulties.

9. Findings: Narrative accounts of accessing and receiving services

Accessing services

We invited respondents to tell us about their experiences of accessing services (n=27). See Figure 8. Participants articulated there were a lack of services in Gloucestershire. They described accounts of long wait lists, referrals being rejected and ARFID not being recognised.

- ***“There are no services to access”***
- ***“There’s nothing available”***
- ***"His height and weight is ok so you can't have any support"***
- ***“Wait list are too long, and little advice or support is offered, leaving you left alone to deal with it”***

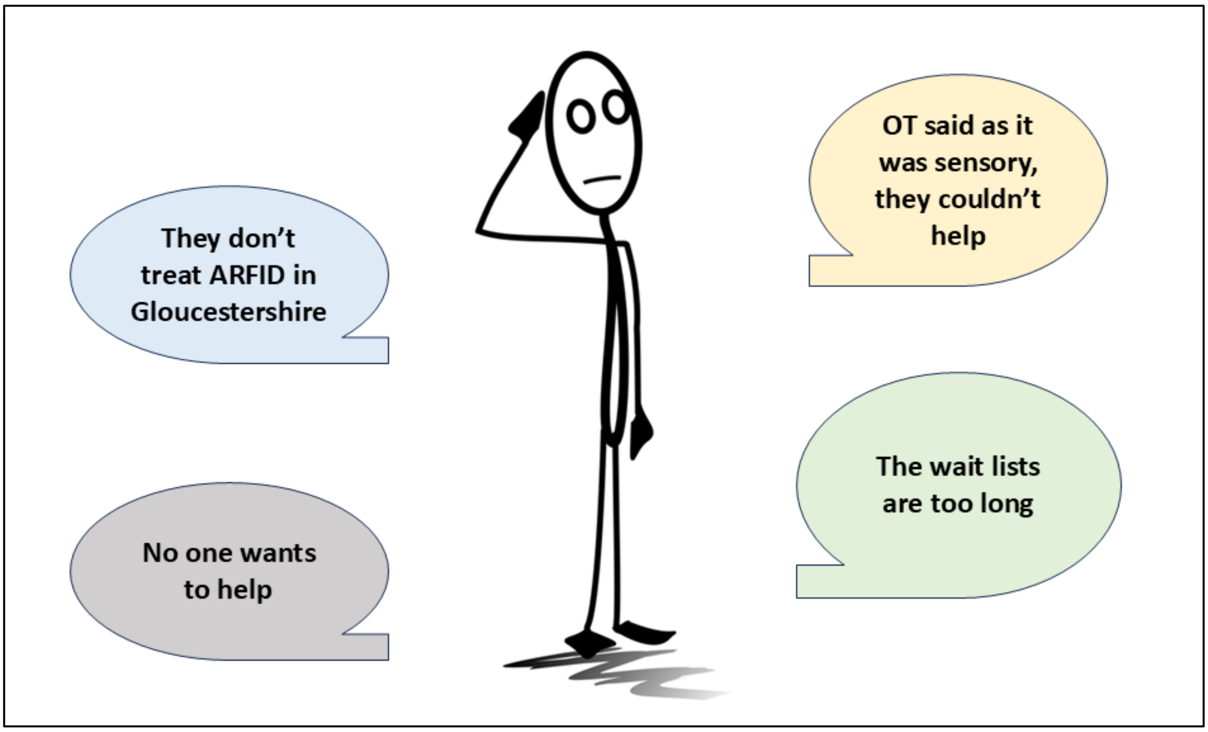
Families described an absence of support from services and in some instances a lack of clinical experience.

- ***"I was told by GP it was a phase, he was a picky eater"***
- ***"GP said they couldn't do anything for Arfid."***
- ***"When I have finally got to see anyone they don't have any experience of the problem and don't know how to support or what to suggest"***

Respondents described being passed from pillar to post, fighting to get support. Participants reported experiences such as not being listened to, and being gaslit.

- ***"Nobody wants to listen and nobody is telling me where to access the right support."***
- ***"No one knows who should be helping. Professionals all pass the buck"***
- ***"You get passed around to different people and so it goes on"***

Figure 8. Key quotes regarding accessing services



Receiving services

We asked participants to describe the treatment they had received and 21 participants answered. Twelve participants reported a lack of services available to support or treat their loved one, with requests for referrals rejected.

- ***“Nothing. He's received nothing other than an ASD diagnosis and a leaflet explaining ASD.”***
- ***“None get palmed off”***
- ***“Nothing specific to support restricted eating”***
- ***“Lack of treatment. We have not found any doctor or school nurse interested in listening to our concerns around his foods.”***

Of the handful of individuals who managed to get access to a clinician, their experiences were largely negative. Participants described their requests for support being rejected; two were told their child was not ill enough to be supported; participants described working with professionals who did not understand their child’s needs and who did not have the skills or experience to provide adequate support.

- ***“There has been none, they all just say they don’t have any experience of the condition and don’t know how to support him”***
- ***“As soon as he shows signs of dysregulation they end the appointment. They clearly have no idea about his needs so it loses any faith I have in them being able to support us.”***
- ***“Our daughter didn't fit neatly into anyone's boxes so no one wanted to take responsibility for her care.”***

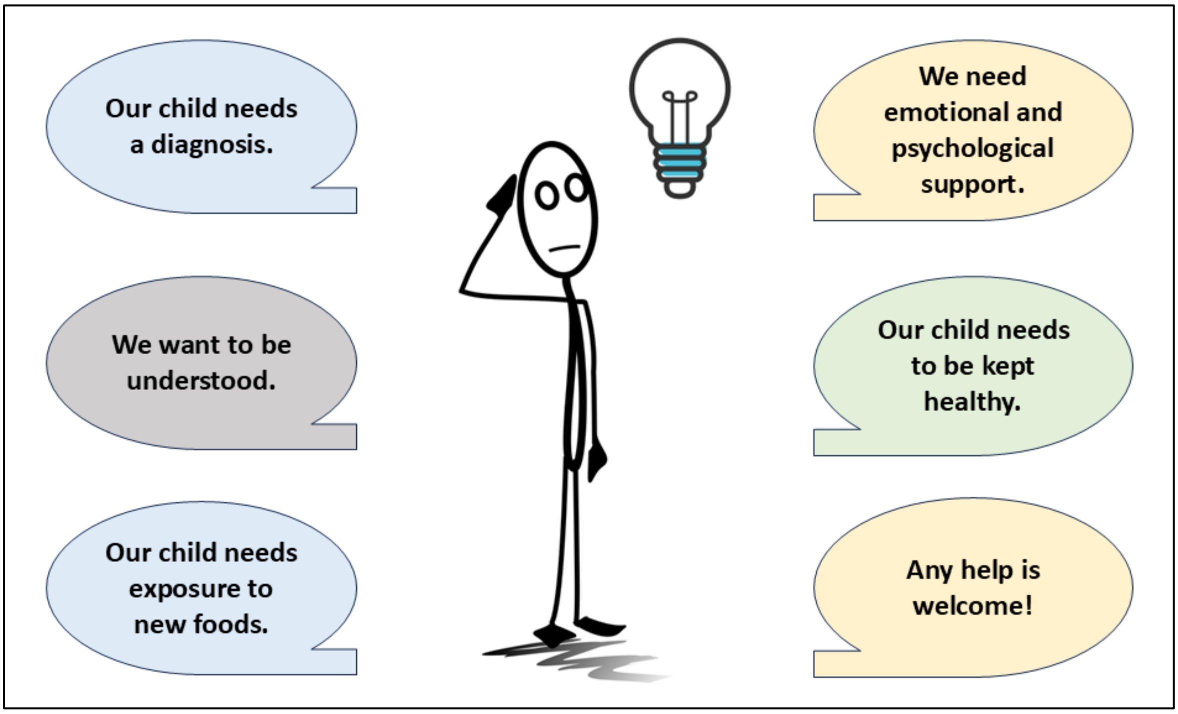
Only two individuals described positive experiences and even these were qualified:

- ***“Whilst I have said I am satisfied, I suppose that is because I don’t know if there are other professionals that can help him beyond the dietician.”***
- ***“The community dieticians and nurses have been great. Previously the in house dieticians we saw at GRH were abysmal- dismissive and judgmental.”***

10. Findings: What treatment and support is needed?

Participants were asked about the treatment or support their loved one needs for swallowing or restrictive eating difficulties. A total of 26 participants responded. Some participants were unsure what support was needed, whilst others had very clear ideas. Given the lack of support people currently received, some participants were open to anything. It was evident from the responses people gave, that their expectations were not high; they were open to any support that could be provided.

Figure 9. Key ideas around what support is needed.



Participants sought therapeutic work, typically psychological, that would support exposure to new foods, manage the sensory challenges and support emotional difficulties. Individuals wanted support from Occupational Therapists and Dieticians too.

Two individuals wanted access to a diagnosis, with one of these explicitly linking this to a need to be understood. Other participants also mentioned the need for understanding from professionals.

- ***"A correct diagnosis so people can understand better.***
- ***An understanding dietician linked with a therapist/counsellor to support the emotional side of it."***

Additionally, participants described the need for support to ensure their young person stayed healthy:

- ***"Health monitoring specifically and to be taken seriously."***
- ***"We are willing to try anything as he is getting so underweight and we don't want him to need a tube/peg."***
- ***"Some guidance on how to ensure he's getting enough nutrition to grow and develop."***

11. Transitions into adult services

We asked participants about their experiences of accessing adult services for difficulties with restrictive eating and swallowing. Only three people responded to our question on the challenges they have faced. These responses highlighted the lack of support and advice available from services. Given only three responded, these responses are listed in full below:

- ***“Very hard. Not much information. Told to go through to GP. Most of the time, GP is busy, not enough appointments available and clueless.”***
- ***“Have not been adviced of any?? I got told no service between 16 - 18 years”***
- ***“There’s even less help for adults than children”***

We also asked how the experience of services transition has been. Only two responded, again highlighting the very challenging nature of accessing support:

- ***“Haven’t had any support or advice”***
- ***“Impossible”***

12. Discussion of Finding 1:
High number with autism diagnosis, few with ARFID diagnosis.

Although this survey covered both swallowing and restrictive eating difficulties, the majority of participants focused on restrictive eating. Whilst a quarter of participants reported their child had a diagnosis of ARFID, a large proportion (83%) of children were considered to have a disability related to neurodivergence, with 50% of children having a diagnosis of autism: this is unsurprising given research indicates there is a relationship between ARFID and autism[3]. The low number of those diagnosed with ARFID might be expected given the context of difficulties accessing health services for assessment and treatment.

13. Discussion of Finding 2:
Difficulties associated with significant health needs and risk.

Participants described frequent experiences of anxiety around swallowing and restrictive eating. Additionally, two in five children or young people had not put on adequate weight with a third not growing sufficiently. Families were concerned about the risk of harm these difficulties could cause and worryingly, over one in two children or young people had experienced actual harm.

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[3] See ARFID Awareness UK.

Given the potential and actual risk to both physical and mental health, it is highly concerning that there is a lack of an ARFID pathway or service in Gloucestershire to meet the needs of its population (see Finding 4).

14. Discussion of Finding 3:
Distress, isolation and carer burden

Participants described how their loved one's difficulties had a pervasive impact. Individuals and their families experienced social isolation. Eating can cause huge levels of anxiety as well as impacting the physical health of children and young people. Carers worked hard with planning and organisation to ensure that their young person could be sufficiently fed and access the community. Unsurprisingly, this places an intolerable amount of stress on carers. Moreover, carers must find an average £2850 per year to fund the costs of managing their loved one's restrictive eating or swallowing difficulties. This figure does not capture the costs of other disabilities their loved ones may experience.

These findings demonstrate how the difficulties faced by young people go beyond receiving adequate nutrition. There is a clear psychosocial impact on both the young person and their carers. Given that many carers are not in paid employment[4] there is likely to be an additional financial stress on families of meeting the nutritional needs of their young person. Commissioners of services must consider how individuals and parent carers can receive psychological support as part of managing swallowing and restrictive eating difficulties. The provision of psychological support is in line with the views participants in this survey expressed was needed.

15. Discussion of Finding 4:
Service offer in Gloucestershire is barely minimal

Participants experienced a lack of understanding from health professionals which at times, bordered on ignorance and uncaring. Over 90% of individuals found it difficult to get the right support. Participants experienced referrals being rejected, long waits, professionals with little clinical experience managing the presenting difficulties and fighting to get support. Parent carers in this survey were left with the impression there is nothing available in the NHS to support them and their loved one.

Our survey highlights the risk to health that ARFID and swallowing difficulties cause alongside the huge impact on both individuals and their parent carers.

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[4] See Carers UK.

We know from anecdotal reports[5] that ARFID is a very serious condition; academic research[6] notes how ARFID can cause complications with physical health, including low weight and nutritional deficiencies, whilst dysphagia (swallowing difficulties) is associated with serious health complications[7]. We also know from mental health research that early intervention is key to better long-term outcomes[8].

Considering the above, a recent Freedom of Information request[9] confirmed that Gloucestershire ICB has not commissioned an ARFID pathway or service, nor do they collate data on ARFID referrals that were rejected, accepted or placed on waiting lists. The lack of a service chimes with participant experiences of a complete lack of support and a lack of joined up thinking across professionals working with young people with these difficulties. Noting the risk to health alone, the lack of a clear service or pathway available is of substantial concern.

16. Conclusion

Our survey offers useful insights into the experiences of parent carers supporting children and young people with restrictive eating and swallowing difficulties. We have found parent carers have been left without a clear clinical service they can access, whilst managing the physical and mental health of their young loved ones alongside the risk of harm. When parent carers have sought support, they have been excluded from services and dismissed by health professionals.

The lack of assessment and diagnostic services can contribute to a lack of shared understanding of the child's difficulties and in the experience of the Parent and Carer Alliance, can contribute to parental blame. Commissioners must listen to the experience of parent carers in Gloucestershire and urgently work towards creating a service that parent carers and young people can access. Commissioned services must provide families with support in managing their difficulties alongside the psychological impact these difficulties can give rise to. In addition, service managers of healthcare must ensure their colleagues deliver front line services in an empathetic manner, appreciating the challenging contexts in which families care for their loved ones.

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[5] https://www.bbc.co.uk/news/health-49551337

[6] e.g. James RM et al. Physical health complications in children and young people with avoidant restrictive food intake disorder (ARFID): a systematic review and meta-analysis. BMJ Paediatr Open. 2024 Jul 8;8(1):e002595. https://doi.org/10.1136/bmjpo-2024-002595

[7] Robertson, J et al. People with intellectual disabilities and dysphagia. Disabili Rehabil, 2018. 40(11), 1345–1360. https://doi.org/10.1080/09638288.2017.1297497

[8] McGorry PD, Mei C. Early intervention in youth mental health: progress and future directions. Evid Based Ment Health. 2018 Nov;21(4):182-184. https://doi.org/10.1136/ebmental-2018-300060

[9] FOI on ARFID Services for Children & Young People, reference: FOI 51928 GLO QR1