Needs assessment

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Notes on this report

Three key audiences were included in this research: Derian House service users, commissioners and palliative and end of life service providers.

Service user methodology

- A telephone survey took place with 100 Derian House service users.
- A segmentation analysis was carried out using the survey results.
- In-depth interviews were carried out with 10 service users as a follow up from the survey.

Unmet need methodology

- Desk research was carried out to understand the broader context of palliative and end of life care needs and provision in the UK and North West of England.
- Freedom of information requests were sent to 19 CCGs in the North West. 16 CCGs responded and the responses are included in this report.
- 30 minute in depth interviews were conducted with 10 stakeholders, including commissioners and end of life or palliative care providers.

- DJS Research managed the survey, conducted interviews, analysed the data and produced this report, which outlines the findings and recommendations.
- Without the appropriate involvement of a social worker or equivalent sitting in on interviews and requirement for Ethical approval, this research did not include bereaved families, and so any interpretation of the findings should consider the absence of any bereaved families' experiences.
- Families with a child under one year living with a life-limiting condition are also not accounted for in this research. This is due to a small service user sample for this age group.
- The findings detailed in this report should be read and interpreted in the context of the Covid-19 pandemic, which has limited what Derian House has been able to do for its service users over the past 10 months.

Headline Summary

Derian House wanted to understand the needs of children, young people and families living with a life-limiting condition. The needs assessment covers the needs of families currently using the Derian House services, as well as any unmet needs, explored through desk research, freedom of information requests and stakeholder interviews.

The aim was to understand where there are gaps in end of life and palliative care provision, which Derian House could fill.

This report should be situated in the context of the Covid-19 pandemic, which has limited funding and the ability of the NHS, hospices and other palliative and end of life care services to operate in the usual way.

The diversity of needs indicated by a segment analysis of Derian House service users reflects a key finding from this research: that families most need options when they are on the palliative or end of life journey with their child. Needs vary enormously from family to family, between children, parents and siblings, often changing throughout the journey of living with a life-limiting condition.

Current service users overwhelmingly highlight respite as a key area of need, with some families feeling they don't access enough days of respite each year to take a full break. In contrast, palliative and end of life care providers highlight end of life, out of hours care as an area that needs more resource, along with services such as bereavement care and transition. This disparity can be explained by the priorities of these two very different audiences: service users and service providers.

End of life, out of hours care is the top limitation in palliative care for children in England as a whole, and this research indicates that end of life care is not sufficiently resourced across the North West. The research highlights the question: what is the minimum standard we should expect to see for any child and their family on an end of life pathway?

Derian House is meeting end of life and palliative needs, where otherwise they would not be met, and have done so throughout the Covid-19 pandemic. Whether or not Derian House can continue to do so is a concern among stakeholders across the North West.

Recommendations I

A set of recommendations are outlined, based on the needs indicated by service users and service providers in the North West of England:

- Raise awareness of the full range of services Derian House offers among service users, who don't always know of other services being offered. There are also palliative and end of life care providers across the North West who aren't aware of all the services Derian House can offer. Providers heavily rely on their networks and can refer a family to Derian House if needed.
- Continue to form partnerships with children's community nursing teams across the North West. This partnership approach between community nursing and children's hospices is considered the gold standard of children's end of life and palliative care.
- Offer out of hours, end of life care in the areas where this is most needed, particularly overnight and at weekends: Wigan, Bury, Salford, Warrington, Chorley and South Ribble, Greater Preston and South Cumbria.
- Review how Derian House can step in to provide a level 4 paediatric palliative care consultant across CCGs. The need for this is tied to a need for specialist palliative and end of life training and education, particularly in the areas where consultants and nurses without palliative training are providing this care.
- There is a big gap in transition services. This is partly down to current service users not being aware of transition services, but at a broader level providers are uncertain how to formalise this process. Discussions need to be had about what this care should look like and who can provide the appropriate facilities.

Recommendations II

- A rapid transfer process between hospital and home, or to the hospice is highlighted as a key area of need in several areas of the North West, including Chorley and South Ribble, Greater Preston, North Cumbria, Southport and Formby, Warrington, Bury, Salford and Wigan. Derian House could look at the provision of transport options to fill this need.
  - Transport to and from Derian House is also an area of need among service users
- Although respite is not highlighted as a key need outside of Derian's service users, it does meet some of the most basic needs of families. There is a perception that some families receive more respite allowance than others, with some feeling they don't get enough days to take a longer break. Derian House may need to explore what is driving this perception and offer more communication around how respite is allocated.
- Derian House can do more to increase awareness of the sibling support service, or to expand this service offering. Stakeholders indicate a lack of support in this area across the North West, which may be tied to a lack of awareness of the services that do exist. Sibling support was the only service mentioned as missing from Derian House's services among service users.
- Finally, more can be done to understand the needs of families with a child aged under one, who is living with a life-limiting condition. Prevalence rates are notably higher for this age group and it is likely that families with a child under one year have a very different experience to families with a child over one year. Derian House may need to consider a separate piece of targeted research to understand the specific needs of these families and the provision of neonatal or perinatal care in this context.

Part I: Current needs

Key insights

Key insights: I

Service users share some common ground in the unique set of challenges they face, but their profile and support needs are diverse.

It is clear that over and above everything else, families need respite. Whether this means day or overnight respite, parents and guardians use this to meet some of their most basic needs – sleep, time with their family and the ability to attend various appointments.

Respite isn't just for parents; one of the most important forms of support for children and young people is having opportunities to take part in activities during the day so they can spend time away from their family, gain some independence and socialise with other children. This research indicates that Derian House could offer more respite opportunities for children and young people.

In general, most service users express a need for more allocated days or nights of respite. There is a perception that respite is unevenly distributed across families and longer-term service users in particular express some frustration with a perceived reduction in allocated respite days/nights.

Crisis support is a key element of the respite service and is very important to service users; the findings suggest that this is an area for Derian House to improve.

Key insights: II

The need for respite is also tied to the need for Derian House to meet the health needs of their child; parents cannot take a break if they can’t trust Derian House staff to care for their child appropriately.

This means that continuity of care – getting to know each individual child’s specific needs and ensuring the safety of children when they are under the care of Derian House – is paramount. Parents need to know that Derian House staff offer emotional support to their children at all times; this could mean recognising when a child is uncomfortable (socially or physically) and doing what is needed to support them or ensuring that children get the rest they need.

Emotional or psychological support is a key need among parents too. The provision of counselling and other wellbeing services are important, but parents also value the everyday conversations with nurses and other Derian House staff who understand what they are dealing with. Again, there is a need for continuity, as parents and children alike benefit from seeing staff they are familiar with.

Access to hydrotherapy and physiotherapy is a high priority for families, particularly recent joiners and those who sit in the Life Enhancement segment.

The findings suggest that children would benefit from having more access to the hydrotherapy pool, with the perception that there is not enough staff for everyone to use it when they need to.

BAME and C2DE SEG families tend to be less positive about the hydrotherapy and physiotherapy service, with some high neutral scores, suggesting ambiguity around what this involves.

Key insights: III

Around half of the service users interviewed expressed a need for transport provision. These families are faced with the challenge of either being unable to drive or unable to travel while attending to their child's health needs. Those whose partner or spouse is the driver can miss out on some services, as they can only visit around their partner's work schedule.

That said, some of the service users who mention distance as a barrier feel they live too far away (over 1 hour) for it to be worth visiting Derian House for some of the services (such as the hydrotherapy pool or cinema). The physical difficulties of travelling with a sick child plays a part in forming this view.

Some families indicate a need for Derian House to proactively check in with them if they haven't used the services for a while.

While this doesn't stand out as being as essential as some of the core services, parents appreciate Derian phoning to see if there is anything the family needs, especially as parents can be too busy to reach out for support.

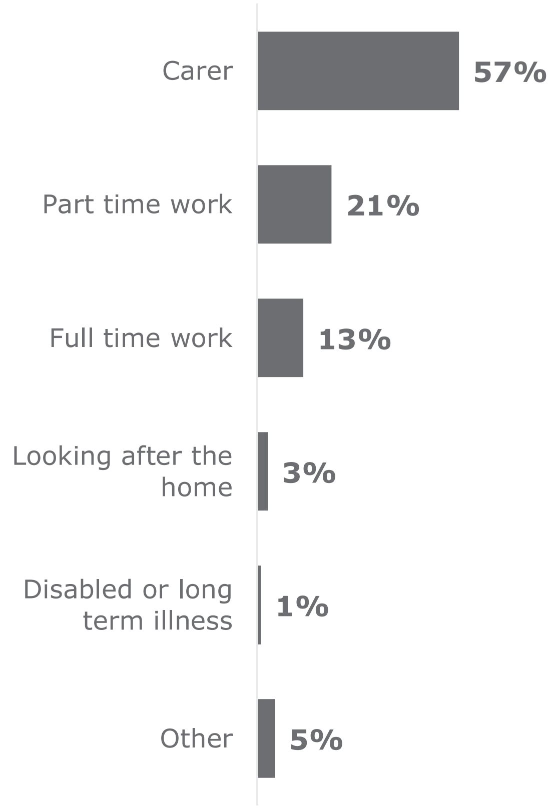
Derian's telephone check-ins during the Covid-19 pandemic have been very well received.

Finally, service users express a great deal of positivity towards Derian House, with high performance ratings across the board, strong likelihood to recommend and also high awareness before referral.

Service user profile

Service user profile

Work status of parent



Gender of CYP

58%
Male

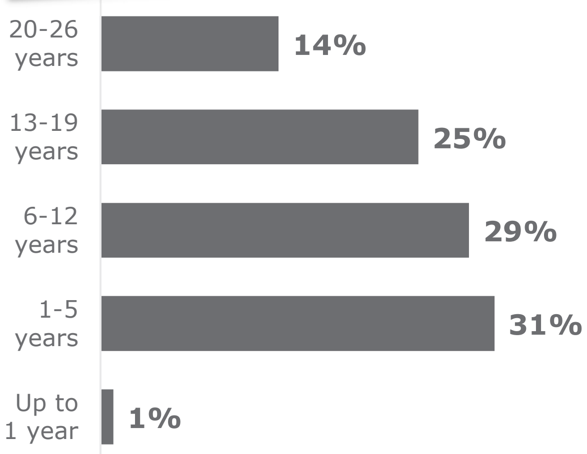
42%
Female

Ethnicity of family

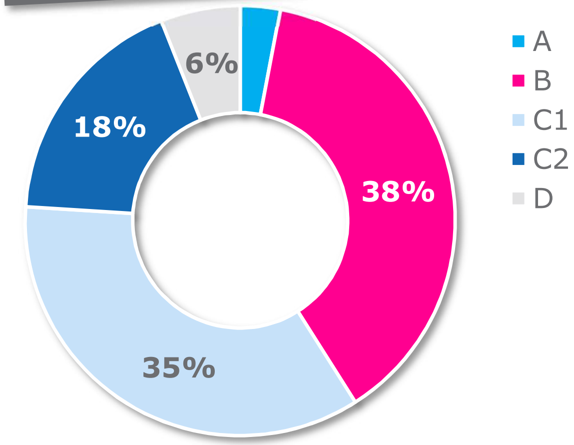
22% BAME

78% non-BAME

Age of CYP



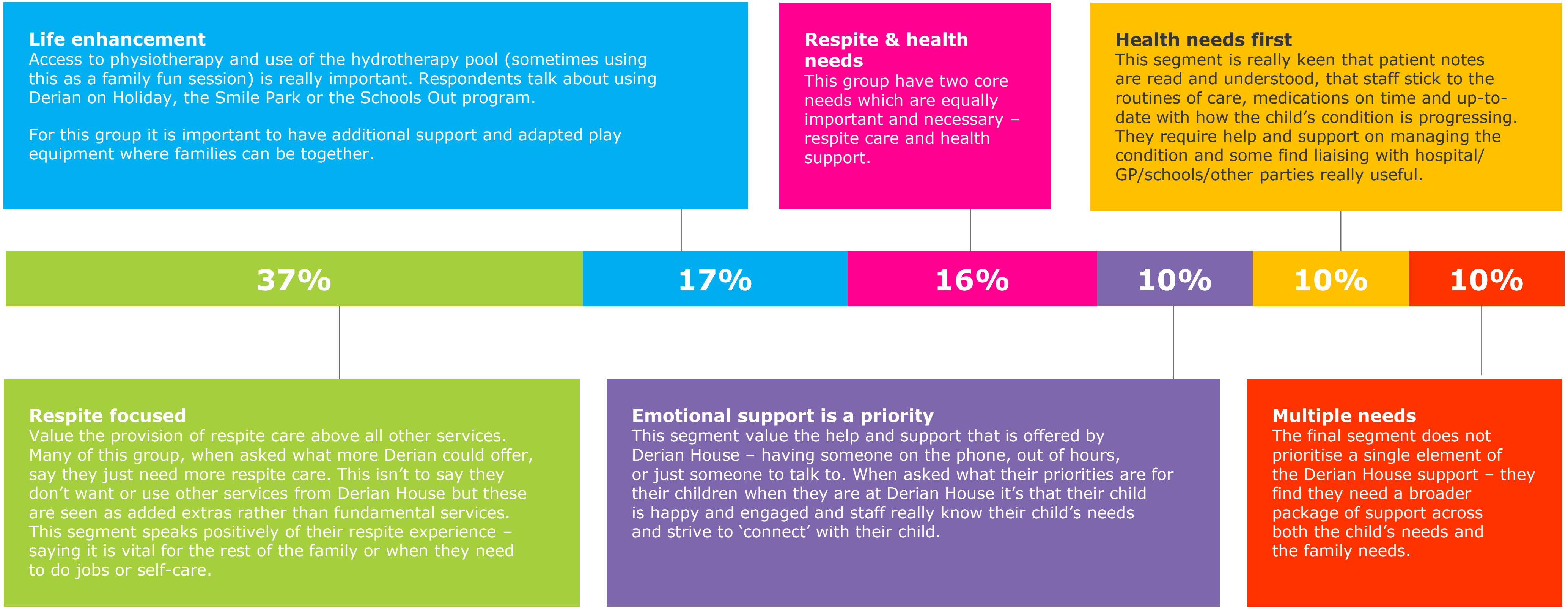
SEG of family



Segmentation profile

To make sense of the diverse needs of families, we have carried out a 'needs based segmentation' analysis. A high-level summary of the segments we identified is provided.

Please note: Bereaved families were not included in the sample, therefore end of life and bereavement care needs are underrepresented in this research.



Life enhancement
Access to physiotherapy and use of the hydrotherapy pool (sometimes using this as a family fun session) is really important. Respondents talk about using Derian on Holiday, the Smile Park or the Schools Out program.

For this group it is important to have additional support and adapted play equipment where families can be together.

Respite & health needs
This group have two core needs which are equally important and necessary – respite care and health support.

Health needs first
This segment is really keen that patient notes are read and understood, that staff stick to the routines of care, medications on time and up-to-date with how the child's condition is progressing. They require help and support on managing the condition and some find liaising with hospital/ GP/schools/other parties really useful.

Respite focused
Value the provision of respite care above all other services. Many of this group, when asked what more Derian could offer, say they just need more respite care. This isn't to say they don't want or use other services from Derian House but these are seen as added extras rather than fundamental services. This segment speaks positively of their respite experience – saying it is vital for the rest of the family or when they need to do jobs or self-care.

Emotional support is a priority
This segment value the help and support that is offered by Derian House – having someone on the phone, out of hours, or just someone to talk to. When asked what their priorities are for their children when they are at Derian House it's that their child is happy and engaged and staff really know their child's needs and strive to 'connect' with their child.

Multiple needs
The final segment does not prioritise a single element of the Derian House support – they find they need a broader package of support across both the child's needs and the family needs.

Needs based segmentation analysis

About the segmentation…

Factor analysis

Factor analysis looks at the patterns in the data and is used to identify core themes. For this analysis we are concentrating on support needs.

Cluster analysis

Cluster analysis is a statistical technique that can be applied to data which exhibits ‘natural’ groupings. It sorts through the raw data and groups participants into ‘clusters’. Each cluster is a group of relatively homogeneous participants who share common characteristics. They are dissimilar to those outside the cluster.

We completed n=100 interviews with parents/carers of children referred to Derian House 1

We incorporated data across different questions – looking at priority needs, which services are important for themselves as carers and their child, and services mentioned in the open text when asked to think of services they need most. 2

We identified four key service areas and derived a score for each area. We then employed a cluster analysis using those scores. 3

Factor analysis reveals four key service areas which form the key themes...

Four key services areas identified

Respite
Including at home, day respite, day care planned overnight or crisis respite.

Emotional support
Including sibling support, counselling, our of hours/crisis support, having someone to talk to, staff knowledge and support and care for their child.

Therapeutic/life enhancement
Including use of hydrotherapy pool, physiotherapy, family fun sessions, Derian on Holiday, Smile Park, adapted cinema, School's Out, and so on...

Health
Including symptom management, health care needs, liaising with hospitals on their behalf, help with step down from hospital.

Introducing the segments

Respite focused

37%

"They are doing an amazing job to be honest. However, as parents we probably want a bit more respite. At the moment we get so many days a year and you don't always get the dates you want as it's a busy place."

Attitudes towards respite services

Agree Derian provide the respite support parents need.	82%
Agree Derian enable parents to focus on the rest of the family.	76%
Agree Derian provide the respite support their child needs.	66%

We are less likely to recommend Derian House in comparison to the other segments, but the majority of us (83%) still say we are extremely likely to recommend the Derian House services.

The provision of **transport** to and from Derian House would make it easier to use the services.

Awareness

76% were aware of Derian House before they were referred.

This group tend not to use wellbeing services and are less likely to agree Derian House meets their child’s emotional needs, with some uncertainty around this.

About us & our families...

Age of child

Our children tend to be a mix of ages, but we have more aged 9+ compared to other segments:

1-5 years: **27%**

6-12 years: **27%**

13-19 years: **30%**

20-26 years: **16%**

Gender of child

68% of our children are male

32% of our children are are female

We have more male children than the average.

Ethnicity

81% of us are non-BAME

19% of us are BAME

Most of us are non-BAME.

Work situation

54% of us are carers

27% are part-time workers

8% are full-time workers

SEG

69% of us are SEG B (38% avg.)

23% of us are SEG C1

8% of us are SEG C2

Life enhancement

17%

“More access to hydrotherapy would be beneficial for us, and hydrotherapy with a physiotherapist would be really useful. I also hope they will start the Boys Out club again where both my boys can mingle with kids in the same situation.”

Services used

Hydrotherapy pool	81%
Derian on Holiday	38%
Wellbeing services	25%
Stay & Play	25%
Smile Park	19%
Schools Out	19%

We are the least likely group to use planned overnight respite services.

Many of the children in this group have siblings who also attend Derian House.

We tend to be **more likely to agree** that Derian House provide respite opportunities for our children.

We also **tend to agree** that Derian House meets our children's needs for hydrotherapy access.

We tend not to agree that Derian House provide access to a specialised palliative care team.

About us & our families...

Age of child

Our children tend to be younger...

Under 1 year: **6%**

1-5 years: **35%**

6-12 years: **29%**

13-19 years: **24%**

20-26 years: **6%**

Gender of child

59% of our children are male

41% of our children are are female

This is similar to the average.

Ethnicity

65% of us are non-BAME

35% of us are BAME

We are the group with the biggest BAME population.

Work situation

53% of us are carers

29% are part-time workers

18% are full-time workers

SEG

38% of us are SEG C1

25% of us are SEG C2

13% A
13% B
13% D

Respite & health needs

16%

“He needs 24-hour care, mainly night time, feeds, medication, and he’s fully incontinent. I need more regular respite care, just so I can take holidays and have a break.”

Attitudes towards Derian House services…

Agree that Derian House is meeting their child's needs by managing symptoms.	**79%**
Agree that Derian House meets their child's needs by providing out of hours support.	**91%**
Agree that Derian House meets their child's health needs.	**85%**
Agree that Derian House meets their respite opportunity needs.	**80%**

We are very **positive** about the respite care we have received and the way that Derian House support and manage our children's health needs. ✓

We are less likely to recommend Derian House in comparison to the other segments, but the majority of us (81%) still say we are extremely likely to recommend the Derian House services.

About us & our families...

Age of child

Our children tend to be a mix of ages, but we have more aged 9+ compared to other segments.

1-5 years: **25%**

6-12 years: **19%**

13-19 years: **38%**

20-26 years: **19%**

Gender of child

56% of our children are female

44% of our children are are male

We have slightly more females than males.

Ethnicity

94% of us are non-BAME

6% of us are BAME

Very few BAME families compared to the average.

Work situation

69% of us are full-time carers

19% are full-time workers

SEG

67% of us are SEG C1

33% of us are SEG B

Emotional support is a priority

10%

"Having someone there to talk to is very important for me. Just being there for my son and also providing access to my other son to use the sibling support services has been massive for us."

Attitudes towards Derian House services…

Of parents agree that Derian House is improving their emotional health. **100%**

Agree that Derian House meets their families needs by providing brothers and sisters with a chance to talk about their feelings. **89%**

Agree that Derian House meets their families needs by providing counselling. **80%**

Agree that Derian House meets their families needs by providing out of hours support. **100%**

Awareness

We had high levels of awareness of Derian House before we were referred (70%).

Referral

We are more likely to have been referred via ‘other’ routes, such as another respite facility, a charitable Trust or a complex needs team.

About us & our families…

Age of child

Our children tend to be a mix of ages…

1-5 years:
30%

6-12 years:
40%

13-19 years:
0%

20-26 years:
30%

Gender of child

70% of our children are are male

30% of our children are female

We have the highest proportion of male children.

Ethnicity

70%
of us are non-BAME

30%
of us are BAME

Work situation

60% of us are full-time carers

30% are part-time workers

10% look after the home.

SEG

67% of us are SEG C1

33%
of us are SEG C2

Health needs first

10%

"The main thing is knowing that he is safe there as he such high care needs. I can relax because I know his needs are being met. I don't worry when he's there, compared to when he is in hospital. Being able to trust them and knowing he's safe is vital."

Attitudes towards Derian House services…

Agree that Derian House is meeting their families needs by providing brothers and sisters with a chance to talk about their feelings.

100%

Agree that Derian House meets their child's needs by providing respite opportunities

29%

…this segment has high levels of uncertainty about Derian's provision of respite for children, with 71% giving a neutral score.

The provision of **transport** to and from Derian House would make it easier to use the services.

We tend to have started using the services more recently than other segments (in the past five years) (except Multiple Needs)

We are the least likely segment to use the hydrotherapy pool.

About us & our families...

Age of child

Our children tend to be younger...

1-5 years: **40%**

6-12 years: **40%**

13-19 years: **10%**

20-26 years: **10%**

Gender of child

60% of our children are are male

40% of our children are female

These figures are in line with the average.

Ethnicity

80% of us are non-BAME

20% of us are BAME

Work situation

60% full-time carers

30% are full-time workers

10% are part-time workers

SEG

50% of us are SEG B

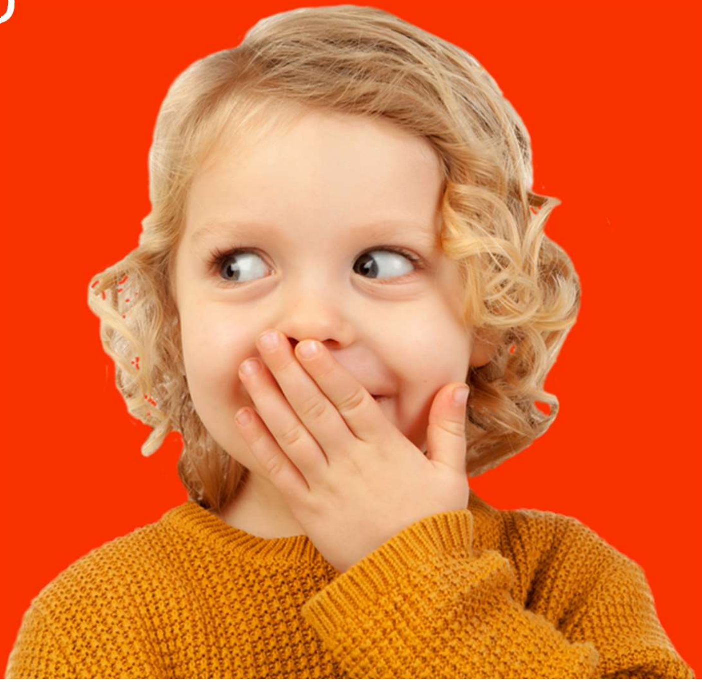
25% of us are SEG C1

25% of us are SEG C2

Multiple needs

10%

“We have access to the respite side of things. It's not just the medical care we need help with, she can be demanding at times and we need help and support with our mental health.”



Attitudes towards Derian House services…

Agree that Derian House meets their families needs by providing counselling services.

88%

Agree that Derian House meets their families needs by providing out of hours advice.

50%

Agree that Derian House meets their child's needs by providing community support.

50%

Agree that Derian House meets their child's needs by providing someone to talk to about their illness/condition.

50%

We are more **positive** about the counselling services offered, but **less positive** about the out of hours advice, community support for children and providing someone for children to talk to.

We tend to have started using the services more recently than other segments (in the past five years) (except Health Needs First)

About us & our families…

Age of child

Our children are a mix of ages, but on the younger end…

1-5 years:
40%

6-12 years:
30%

13-19 years:
30%

Gender of child

70% of our children are male

30% of our children are female

We have a much larger proportion of males.

Ethnicity

70% of us are non-BAME

30% of us are BAME

Work situation

50% full-time carers

20% are part-time workers

10% look after the home

10% maternity leave

SEG

33% of us are SEG C1

33% of us are SEG C2

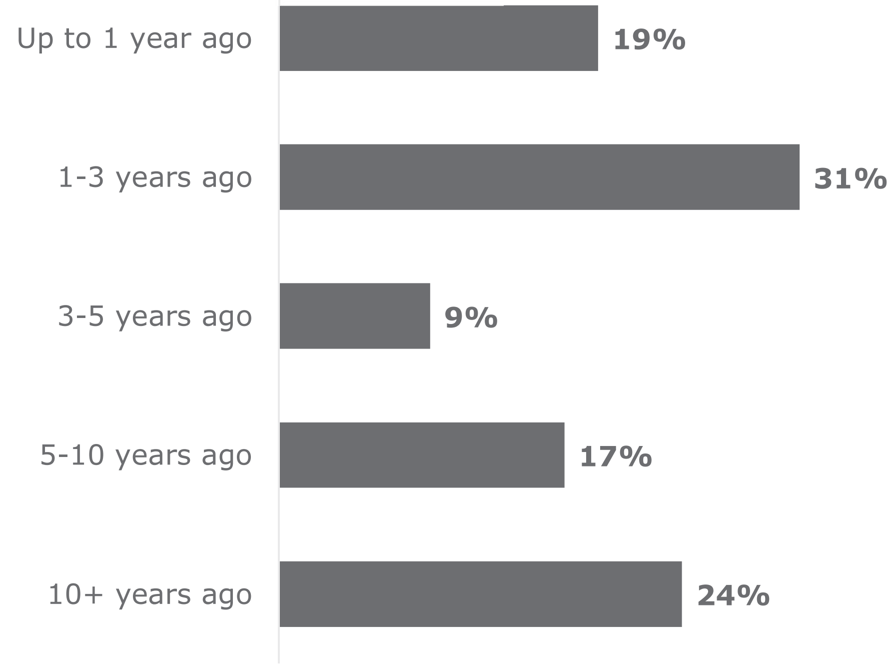
33% of us are SEG D

1. Access

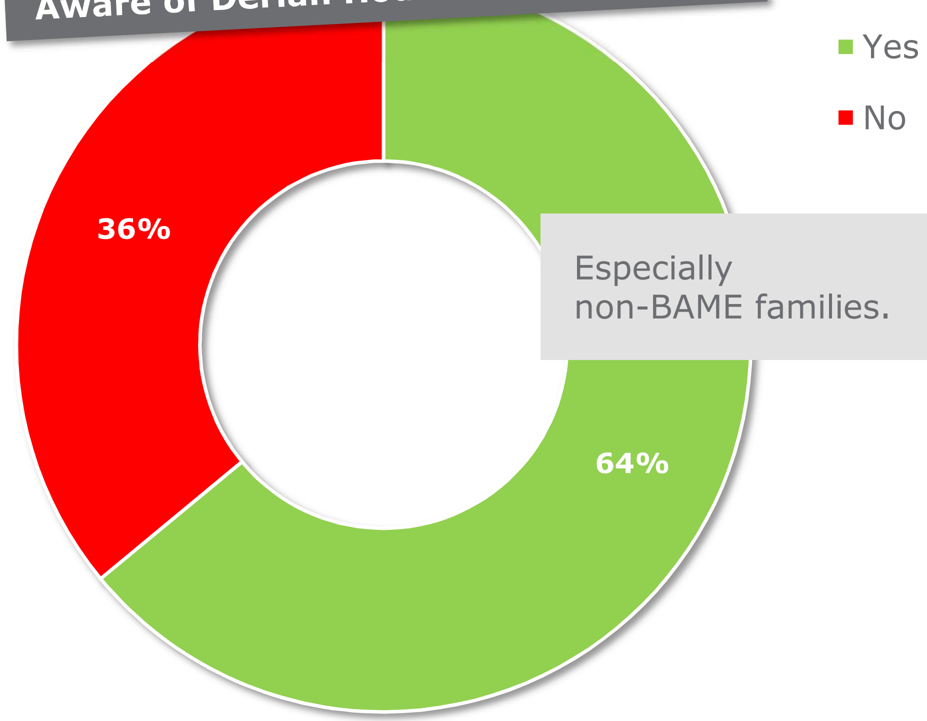
Awareness of Derian House is high

Six in ten families first accessed the services at Derian House in the past five years.
Before getting the referral, a large proportion had already heard of Derian House

First accessed services



Aware of Derian House before referral



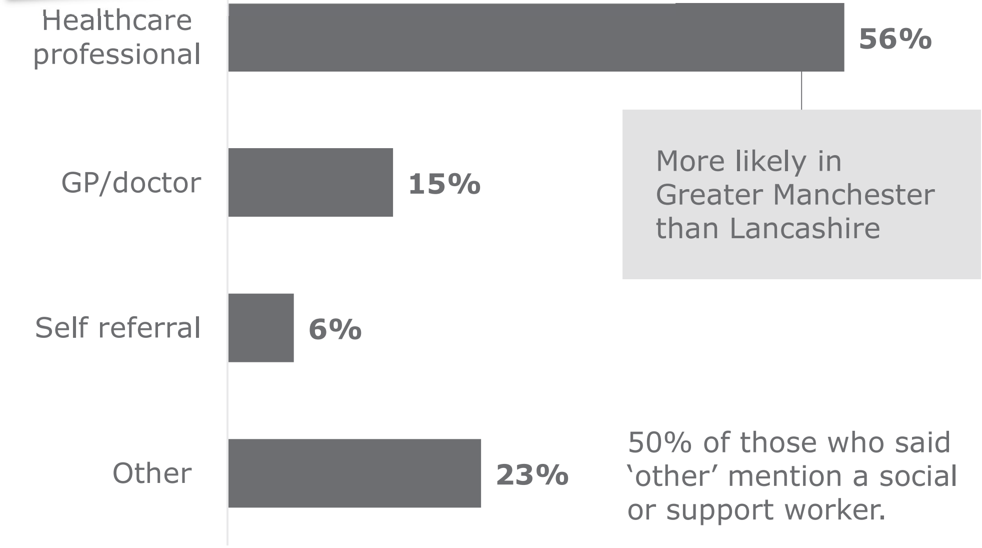
Especially
non-BAME families.

Q2. When did you first access the services at Derian House? (all excl. D/K: 100). **Q3.** Had you heard of Derian House before you were referred? (all excl. D/K: 99).

Referrals typically come from healthcare professionals

In most instances, referrals are straightforward, quick and easy.

How service users were referred



More likely in Greater Manchester than Lancashire

50% of those who said ‘other’ mention a social or support worker.

Families who were referred by a healthcare professional are generally very positive about the referral process. The process is described as quick, straightforward and handled well, meaning the family did not need to get involved. The story is similar for those who were referred by their GP/ doctor or who self-referred.

> “They took care of the entire process. I didn't have to do anything.”
>
> **Family of male, 6 years**

> “It was very easy. I self referred and a nurse came to visit me from Derian and the next day confirmed that my daughter could attend.”
>
> **Family of female, 26 years**

Q4. How were you and your family referred to Derian House? (all excl. D/K: 97). **Q5.** Are there any ways that the referral process could have been easier?

The referral process can be too long for some

Among the handful who say this, longer waiting times are caused by the health or social care professional, but there is also some ambiguity around who Derian House can support.

A small proportion of families say the referral process took around six months, which is deemed lengthy. The health or social professionals making the referral are sometimes behind the delays.

However, a small number of families mention that due to Derian's strict application criteria, their child was initially rejected because of their specific diagnosis (described as a rare condition), but then later accepted. These instances suggest a need for Derian House to be well informed about all types of conditions at the outset to avoid delaying care for those with a less known diagnosis.

"Nothing that Derian House could have done to make it easier but my consultant took a long time to send a supporting letter to Derian House after my self referral."

Family of male, 12 years

"The first time we were referred he was declined (…) we seemed to be asked more questions second time around and they spoke to Ed at this point as well, which I don't remember them doing the first time we applied."

Family of male, 14 years

"They said they wouldn't take him if he was having a specific gastric procedure. They then came back and said they would take him, I don't know who spoke to them or who changed their minds."

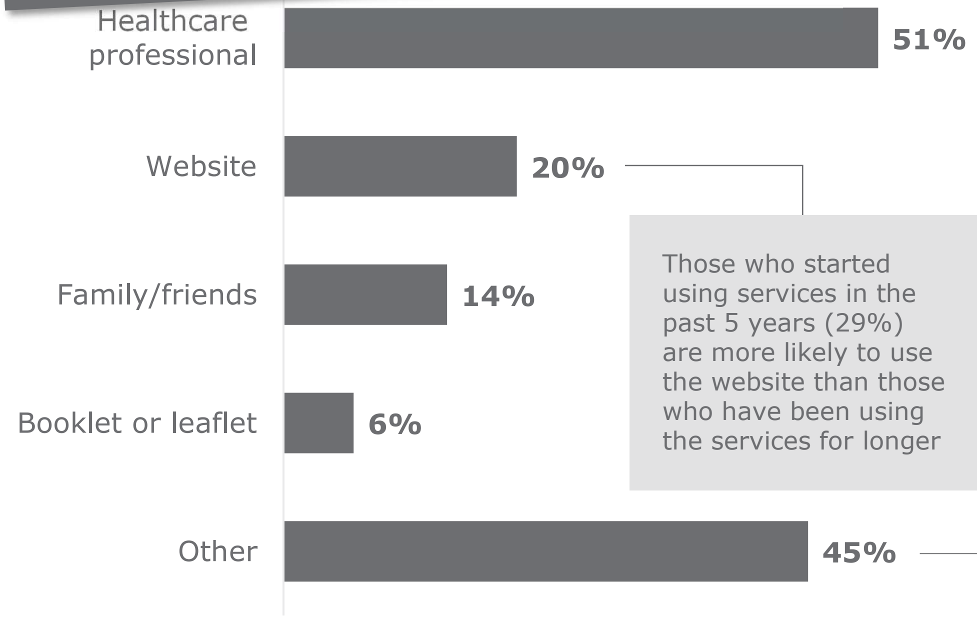
Family of male, 18 years

Q5. Are there any ways that the referral process could have been easier?

Half of families hear about Derian House through a healthcare professional

In addition to the website and family/friends, families also source their information from the local community. A small proportion don't access any information until they speak to Derian staff.

Where most information was sourced from



Those who started using services in the past 5 years (29%) are more likely to use the website than those who have been using the services for longer

> "We didn't get any [information]. They came out to see my daughter and assess her needs."
>
> **Family of female, 3 years**

> "Word of mouth, and I knew it existed through their fundraising efforts."
>
> **Family of female, 13 years**

Other families mostly hear about Derian House through word of mouth or hearing the name in the local area, especially through the Derian House fundraising activities. In some cases families don't receive any information until they speak to a member of staff at Derian House. This tends to be when a staff member initially visits the family at their home.

Q6. Where did you get most of your information about the services at Derian House before you were referred? (all excl. D/K: 93).

Information received is largely clear & straightforward

A handful of families suggest ways the information could be clearer, particularly details about the home service, overnight respite and the availability of facilities during the day.

Quality of information about Derian House

The majority of families feel the information they received before the referral was clear and straightforward. Only a handful of families mention that some of the services became known to them via other people or Derian staff once they had been referred.

"It was fairly straightforward as I was specifically interested in the Derian at Home service, I do think that they could have included more detailed information on the Derian at Home service. I learnt more about this service when they came to visit me and explain what was involved."

Family of female, 4 years

"If I hadn't known from other people that parents were allowed to stay over I wouldn't have known by just reading the leaflet. It didn't make it clear I could stay with my son so they need to mention the option of staying over in their leaflet."

Family of male, 14 years

"Information on how you can just go in and stay and do activities not just respite. Sometimes I hear about things after they had happened, and I would have like to have gone along and taken part."

Family of male, 17 years

"Seeing the website an image of a ventilator on their website made me feel "hugged" and reassured that they would be able to cater for my sons needs. It is an excellent website."

Family of male, 5 years

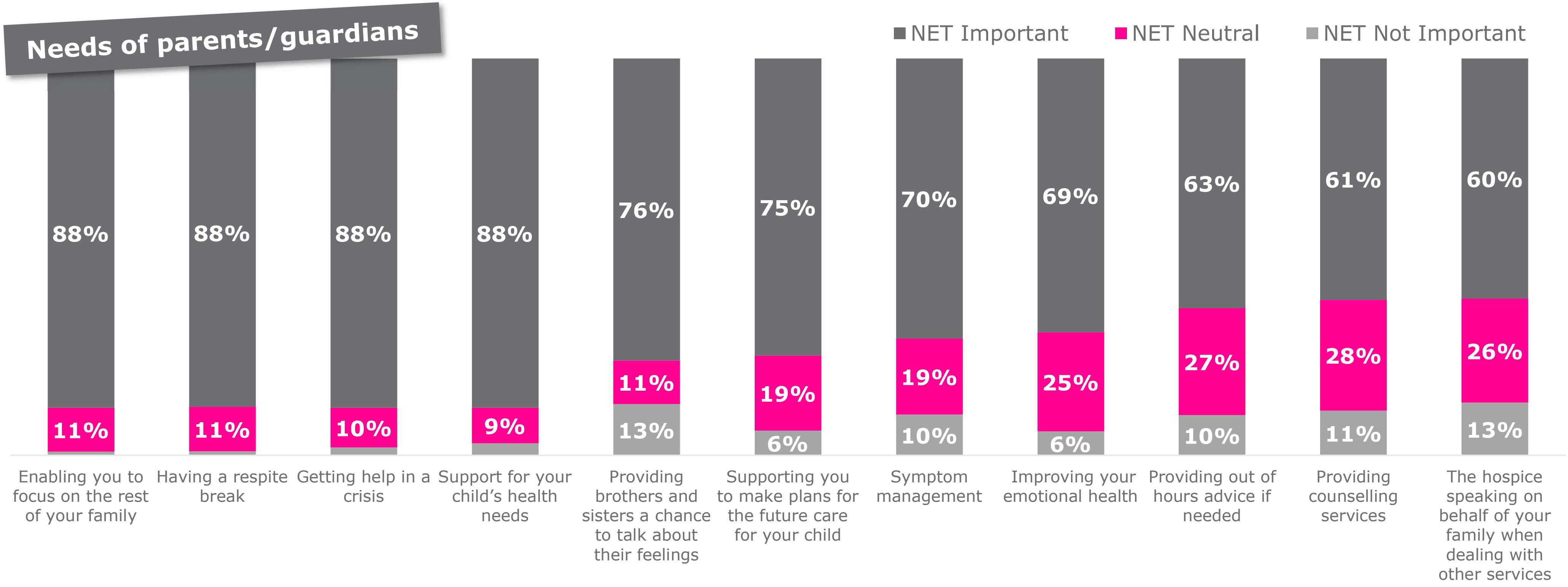
Q7. Are there any ways the information in the website, booklet or leaflet could have been easier to understand. **Q8.** Was there anything missing from the information? If so, please give details.

2. Support

Respite to focus on the rest of the family is rated most important to parents

Crisis support and meeting the child's health needs are also highly important.

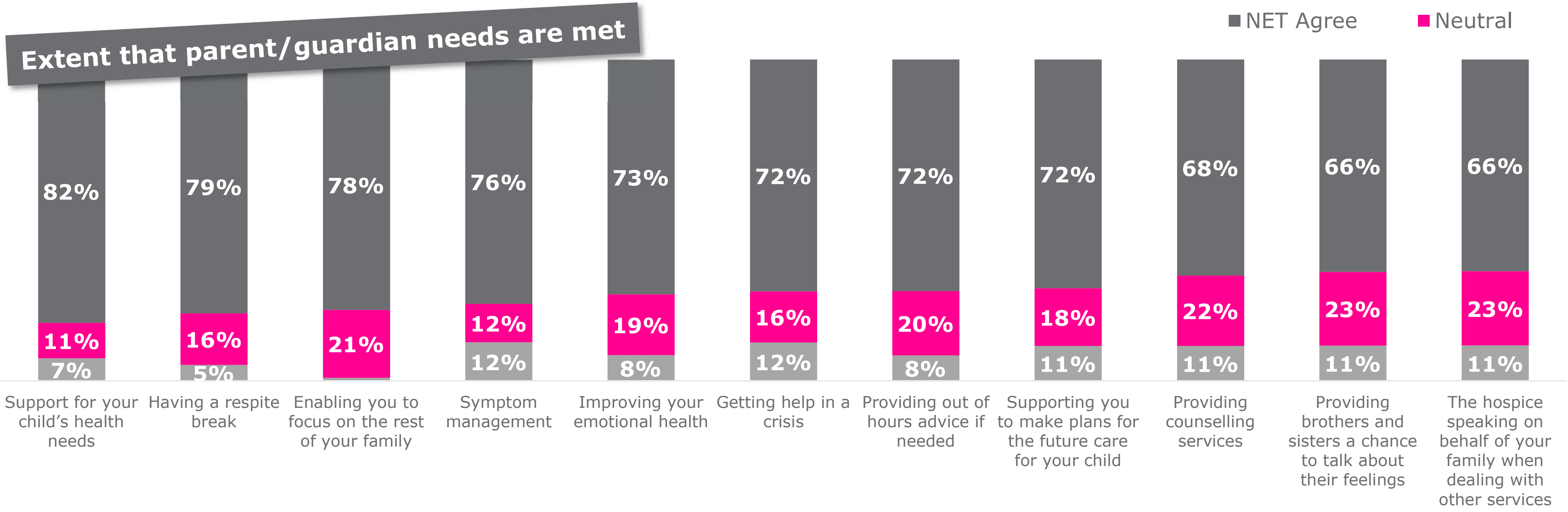
Needs of parents/guardians



Q11. Please rate the extent to which the following are important to you as a parent or guardian? (all excl. D/K: sizes vary).

Derian are meeting the essential needs of parents

The highest performing areas are ‘support for your child’s health needs’,
‘having a respite break’ and ‘enabling you to focus on the rest of your family’.

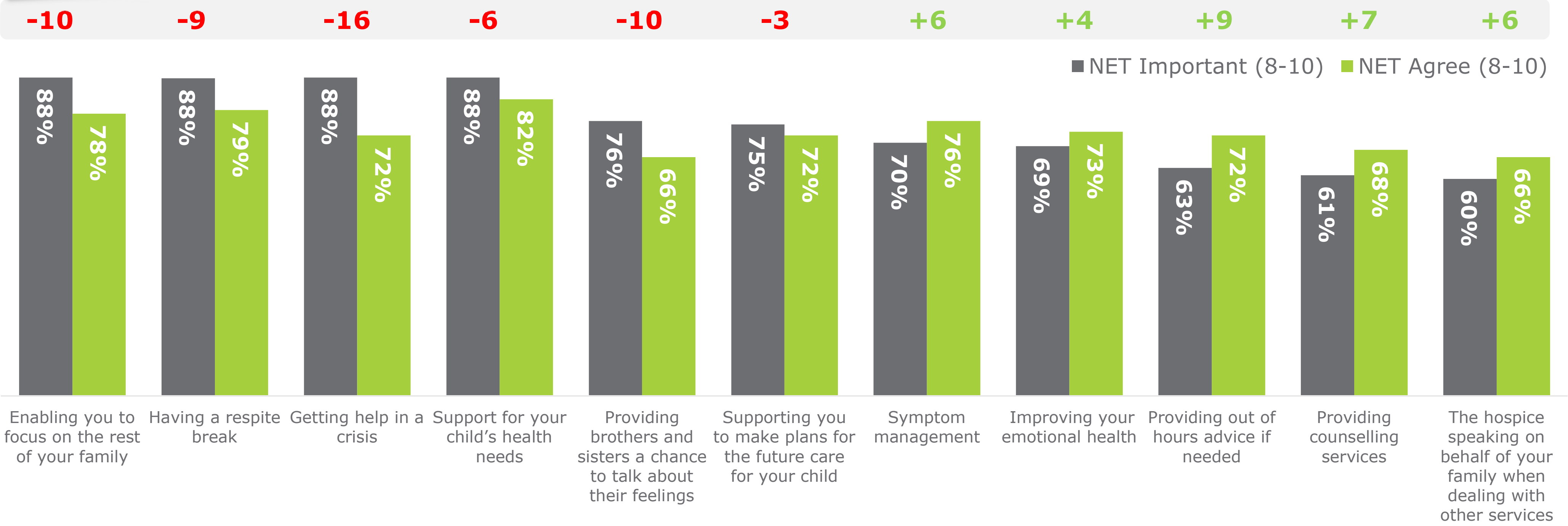

Extent that parent/guardian needs are met

Q12. Please rate the extent to which you agree or disagree that Derian House provided the support that you needed? (all excl. D/K: sizes vary).

Getting help in a crisis could be improved

While Derian House performs well across most of the essential services, crisis support and providing siblings a chance to talk about their feelings may be areas for improvement.

Extent that parent/guardian needs are met



Q11. Please rate the extent to which the following are important to you as a parent or guardian? (all excl. D/K: sizes vary).
Q12. Please rate the extent to which you agree or disagree that Derian House provided the support that you needed? (all excl. D/K: sizes vary).

Significant differences between age groups are indicated

Families with younger children tend to be more positive about certain services (especially if the child is aged 1-5 years).

Needs of parents/guardians: significant differences

Improving parent's emotional health
Those with children aged 6-12 (86%) are more likely to say this is important compared to other ages.

Providing brothers and sisters a chance to talk about their feelings
This service is more important for those with children not aged 13-19 years (36%).

Extent that parent/guardian needs are met: significant differences

Getting help in a crisis
Those with children aged 1-5 years (89%) are more positive than those with children aged 6-12 years.

Supporting parents to make plans for the future care of their child
This service is more important for those with children not aged 13-19 years (30%).

Providing out of hours advice if needed
Those with children aged 1-5 years (90%) are more positive than those with children aged 6-19 years.

Providing counselling services
Those with younger children (1-5 years: 90%/ 6-12 years: 75%) are more positive than those with older children.

Q11. Please rate the extent to which the following are important to you as a parent or guardian? (all excl. D/K: sizes vary).
Q12. Please rate the extent to which you agree or disagree that Derian House provided the support that you needed? (all excl. D/K: sizes vary).

Respite meets parents’ basic needs

When asked what support they need, a large proportion of parents and guardians mention respite, as this enables them to spend time with their other children, have a break and a full night of sleep.

Support most needed for parents/guardians

1. **Respite** (60 mentions)
2. **Psychological/emotional support** (24 mentions)
3. **Safe pair of hands** (22 mentions)
4. **Home visits** (9 mentions)

“It’s an extra pair of hands for me, so I can have a break and some me time. It's more the respite really, even if it's just for three hours a couple of times a week. This is so helpful to me.”

Family of female, 4 years

Respite: An overwhelming majority of parents and guardians say that respite is the most important form of support. Respite allows busy parents and guardians to have a break, spend time with the rest of their family, get a decent night’s sleep and have time to themselves.

“The fact we are not dealing with things on our own. Being able to go out and be a normal family and not have the burden of being mum, carer, doctor. It's great.”

Family of female, 3 years

“Just being able to be mummy and do the hugely important outdoors-y stuff with my other daughter would be great but as things stand, I can’t, and I feel like I am letting her down (…) I just want to be me sometimes, and sometimes I feel like I’ve lost my identity.”

Family of female, 14 years

Q10. What support do you need as a parent to care for your child? (all).

Emotional support can be formal or informal

Parents and guardians seek psychological and emotional support and often find this in the conversations they have with staff and other families who understand what they are going through.

Psychological & emotional support: The counselling and wellbeing services are important forms of support. However, emotional and psychological support can often occur informally outside of specific services, particularly when parents frequently talk to the same nurse or other families when they visit Derian. Parents need to talk to someone who understands what it is like to be in their position. The telephone support from Derian during the Covid-19 pandemic is also a highly valued form of support.

"The verbal support is key (…) since coronavirus I have had a call from them every week, it's been amazing. Their telephone support has got me through coronavirus."

Family of female, 5 years

"We have already accessed the counselling support and wellbeing services, sibling support and have been allocated day and night care as well. This is the support I will continue to need when she comes out of hospital."

Family of female, less than 1 year

"When I first started there, I had the same named person (nurse/play specialist) who I could talk to and tell them about my feelings. This was so important for me. I can only open up to someone I've known for a while."

Family of male, 9 years

"She can be demanding at times and we need help and support with our mental health. Support for the parent is just as important; having someone to talk things through with is key."

Family of female, 12 years

Q10. What support do you need as a parent to care for your child? (all).

Parents need to feel reassured their child is safe

Ensuring staff are qualified and trustworthy are key to ensuring parents feel reassured.
A smaller proportion of parents' value getting help at home when doing everyday chores.

Safe pair of hands: parents and guardians need to feel reassured that they can go away knowing their child is in safe hands. It's important they can trust the staff to ensure their child is physically, emotionally and socially safe while under the care of Derian House.

"We need to know that our daughter is being well looked after and her needs are being met. That was our biggest concern. As long as we knew her needs were being met, that made us feel supported."

Family of female, 25 years

"Knowing that my child is in a safe environment Knowing that their personal care and hygiene is taken care off General well-being and health and safety are paramount."

Family of male, 20 years

Home visits: some parents feel they most need support at home, to help with chores and watch the children if they need to go out. A few parents also mention needing help with transporting children back and forth to Derian House, particularly if the child's health needs make travelling difficult.

"I have three children. I need support daily getting them ready. I can't leave the house with all three children."

Family of female, 4 years

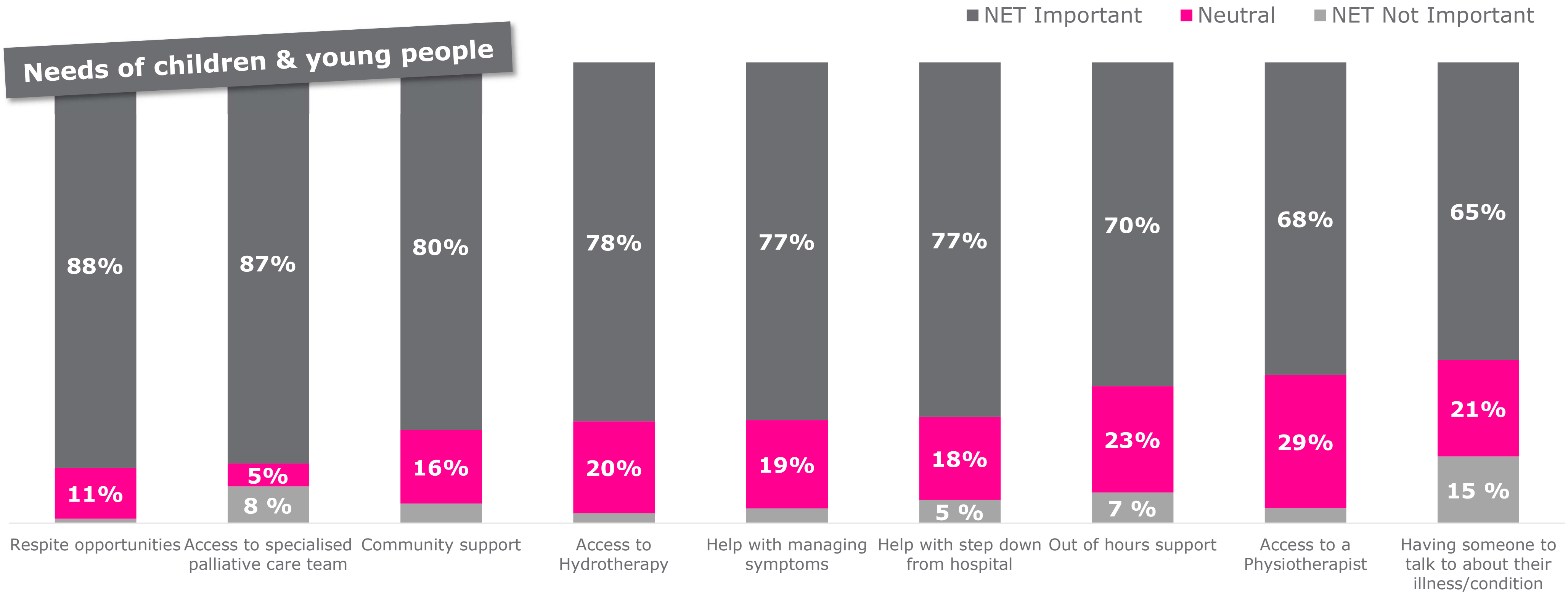
"Support with help at home, when my child is at home and a HDA coming in for a few hours a week. More help with both children, so I could to the gym, go for a swim, go to the hairdresser. I have no one to look after him within the family."

Family of male, 1 year

Q10. What support do you need as a parent to care for your child? (all).

Children & young people also need respite

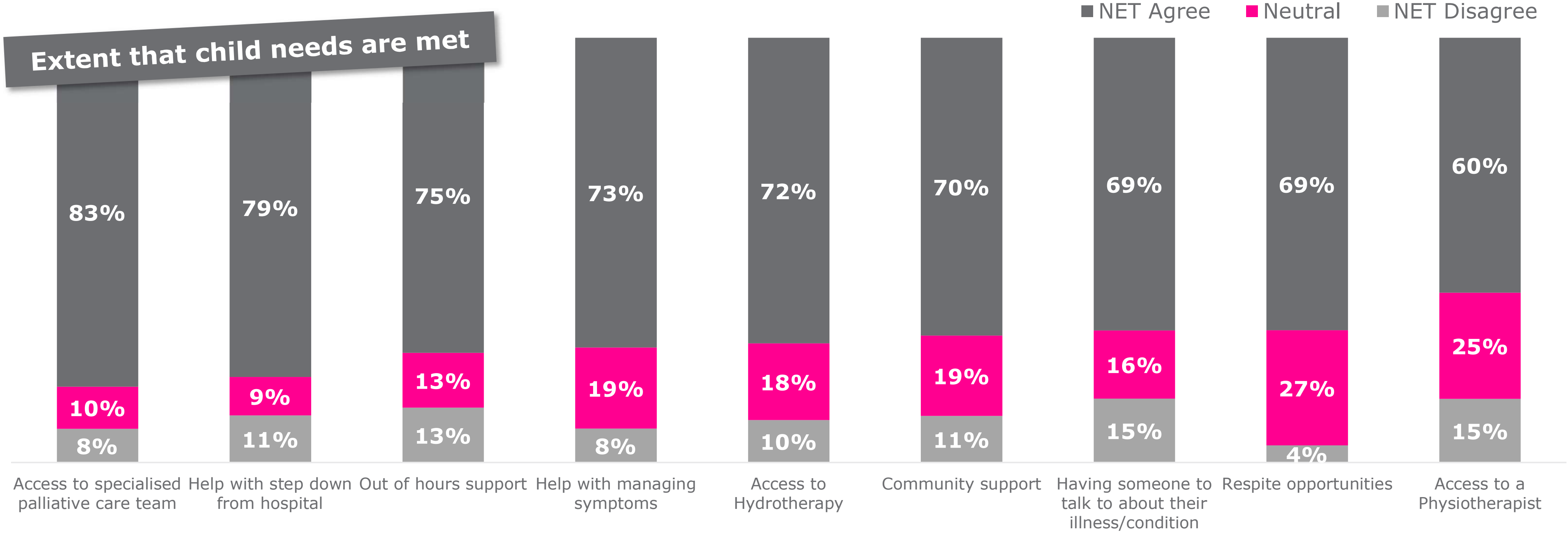
Access to specialised care and community support are also among the most important support services for children and young people.



Q15. Please rate the extent to which the following are important to your child? (all excl. D/K: sizes vary).

Derian perform well in 'providing children access to specialised care'

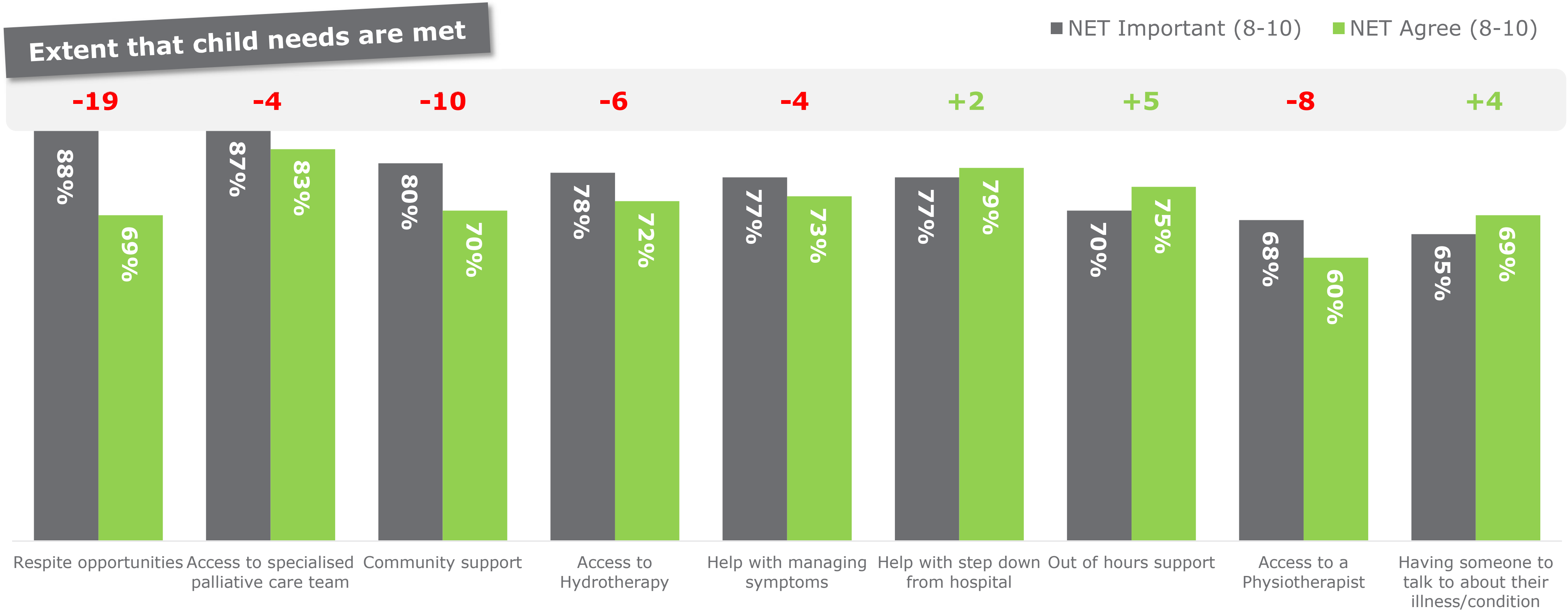
Strengths also lie in helping children and young people with step down from hospital and out of hours support. However, 'respite opportunities' is one of the lower scoring areas



Q16. Please rate the extent to which you agree or disagree that Derian House provided the support that your child needed? (all excl. D/K: sizes vary)

Focus on respite for children & young people

While respite for children and young people is considered most important, Derian may not be providing sufficient respite opportunities



Q15. Please rate the extent to which the following are important to your child? (all excl. D/K: sizes vary)
Q16. Please rate the extent to which you agree or disagree that Derian House provided the support that your child needed? (all excl. D/K: sizes vary)

Perceptions differ between ethnicity, socio-economic & work status

When families are asked to rate the services most important to them, there are some differences among demographic groups.

Parents who are not working (i.e. full time carers or who look after the house) tend to say that access to specialised palliative care and help with step down from hospital are very important (in comparison to parents who are working).

BAME families and those in a lower SEG tend not to prioritise getting access to hydrotherapy, when compared to non-BAME and higher SEG's.

Needs of children and young people: significant differences

Help with step down from hospital
Those who are not working (68%) are more likely to say this is vitally important compared to those who are working.

Access to Hydrotherapy

- BAME families (35%) are significantly more neutral than non-BAME, suggesting some uncertainty about this service
- Those in a higher SEG (ABC1) (64%) are more likely to say this service is 'vitally important' than those in a lower SEG (C2DE)

Access to specialised palliative care team
This service is more important to those who are not working (94%) compared to those who are working.

Q15. Please rate the extent to which the following are important to your child? (all excl. D/K: sizes vary).
Q16. Please rate the extent to which you agree or disagree that Derian House provided the support that your child needed? (all excl. D/K: sizes vary).

Differences in views also exist between locations

BAME families and those in Greater Manchester are less positive about some of Derian's support services & care.

Extent that child needs are met: significant differences

Help with managing symptoms: Those with a female child (16%) are more likely to agree this services meets their needs.

Help with step down from hospital: Those with children aged 1-5 years (89%) are more likely to agree this service meets their needs, than those with children aged 6-12 years.

Access to a Physiotherapist
BAME families (31%) are less positive about this service compared to non-BAME.

Access to specialised palliative care team
Those in a lower SEG (C2DE) (50%) are more neutral about this service than those in a higher SEG (ABC1).

Community support

- Those with a child aged 1-5 years (84%) are more positive about this service than those aged 6-12 years.
- Those in Greater Manchester (21%) are less positive about this service than those in Lancashire.

Having someone to talk to about their illness/condition

- BAME families (30%) are less positive about this service than non-BAME.
- Families in Greater Manchester (30%) are less positive about this service than families in Lancashire.

Q15. Please rate the extent to which the following are important to your child? (all excl. D/K: sizes vary).
Q16. Please rate the extent to which you agree or disagree that Derian House provided the support that your child needed? (all excl. D/K: sizes vary).

Longer term service users can be less positive about Derian's care

Comments suggest that some of those families who have been using the services for longer have seen their respite allowance reduced, despite their need remaining the same.

Families who started using the services at Derian House more than five years ago are significantly less positive about some of Derian's services.

These families are less likely to agree that Derian House provides the support they need for the following services:

- Support for their child's health needs (13%)
- The hospice speaking on behalf of the family (21%)
- Supporting you to make plans for the future care of the child (24%)
- Providing out of hours advice (16%)
- Providing counselling services (19%)

"In the early days we always felt we did have their support and they could always manage to get my child in for respite even if it was for a night or a couple of days. It doesn't feel like that now."

Family of male, 24 years

"We used to get fourteen nights, they cut it down to just seven. They said the decision was based on them re-evaluating their resources. Personally, I think that it's because my child doesn't have too many medical needs, despite being severely and mentally disabled."

Family of male, 14 years

"Some families at Derian (including me) have had a 50% reduction in our overnight respite. I understand that this may be because our kids are not palliative, but my child still requires 24-hour care and I need the respite."

Family of male, 16 years

Continuity of care is a key priority when supporting children

When asked for their main priority in terms of support needed for their child, most families say Derian staff should know the specific needs of their child and provide an appropriate, high standard of care.

Support most needed for children

1. **Continuity of care** (55 mentions)
2. **Safety** (24 mentions)
3. **Feel comfortable and happy** (21 mentions)
4. **Fully trained staff** (18 mentions)
5. **Emotional support** (13 mentions)
6. **Access to services/hydrotherapy** (12 mentions)
7. **Having fun** (7 mentions)

Continuity of care: a key priority with regards to support provided to children is that Derian staff understand each child's individual needs so their specific health needs are carefully attended to. In other words, families need to know Derian House will care for their child as they would be cared for at home.

> "That they know his routine and don't get things wrong when it comes to his medicines and care. It's also important that the staff caring for him get to know him well so that they can read his symptoms and know when he's in pain. It all comes back to continuity of care."
>
> **Family of male, 12 years**

Q14. Thinking now about your child receiving hospice care, what is your priority in terms of support needed for your child? (all).

Families frequently mention 'safety' as a priority

Ensuring the safety of children involves professional health care, protection from any kind of physical or emotional danger, but also instilling a sense of security in the families and children receiving the care.

Continuity of care involves knowing the specific clinical needs, but also the personality and social or emotional needs of each child.

"He needs a member of staff he knows. He doesn't have a learning disability and his condition doesn't affect his cognitive abilities. He is very bright and out going, so if he is quiet, it is not because he is a shy lad, there is something wrong."

Family of male, 12 years

"I want people that know Joseph. He's non-verbal, and lacks basic communication skills so I need to rely on people who know what his needs and wants are."

Family of male, 14 years

Safety: a key priority is that the children of families are in a place of safety. 'Safety' encompasses both the need for trained and experienced professionals to provide appropriate care but also a sense of safety that children need to feel when they are being cared for by Derian House.

"That he is safe and happy. To be looked after well and free of tension, needs a lot of attention, makes sure his needs are met and he is kept entertained."

Family of male, 7 years

"Safety - knowing how to deliver medications. New staff are properly trained and monitored."

Family of female, 11 years

Q14. Thinking now about your child receiving hospice care, What is your priority in terms of support needed for your child? (all)

Families want to ensure children are happy in care

Equally as important is the provision of fully qualified and experienced staff who are experienced in dealing with all health needs.

Feel comfortable and happy: in addition to meeting the health needs of children, its important that every child feels included, comfortable and happy while they receive care. It's not always *what* service is being provided, but *how* the care is provided that can make a difference to a child's experience.

"That he is happy when we leave him there. Things were not great at our last hospice and he was often distressed when we came to pick him up. It is totally the opposite when we pick him up from Derian as he is always very happy (…) we can leave him there in the knowledge that he is being well looked after."

Family of male, 7 years

"The main thing is that they manage his medication; his physical and mental health; his happiness, that they play and talk with him and make sure he's safe."

Family of male, 10 years

Fully trained staff: often the children and young people needing end of life care exhibit a wide range of complex health conditions, so families need to know Derian House have staff who are available, fully trained and capable of dealing with all clinical needs.

"They must be trained, to meet his health needs, his seizures, his tubes, dealing with his colostomy bag."

Family of male, 4 years

"Her needs are very complex so she needs intensive care. I will need to be confident that they are able to administer her meds, oxygen and tubes as necessary and whenever she has a medical episode, which happens three or four times a day."

Family of female, less than 1 year

Q14. Thinking now about your child receiving hospice care, What is your priority in terms of support needed for your child? (all).

Understanding individual emotional needs is key

Access to services, particularly hydrotherapy is also regarded as important, although less so than some of the core needs

Emotional support: in addition to providing the formal emotional support services, families also need their child's emotional wellbeing to be considered and cared for at all times.

"They also need to keep him well supported and reassure him as sometimes he does not like being away from home."

Family of male, 17 years

"Emotional well being - she is guarded child, and has autistic traits, managing that and keeping that a consistent relationship, it is the difference between her learning or not learning, she will just sit there and not join in, she needs to have things explained to her and encouragement to take part."

Family of female, 3 years

Access to services/hydrotherapy: there are many health benefits to accessing the playground, sensory room and other services at Derian House, so these are important to families. The hydrotherapy pool stands out as a key service needed by children.

"Once he has left school he won't be able to use the schools hydrotherapy pool, he really enjoys it, and it is good for him to move about in the water. He will want to come to Derian House for that."

Family of male, 14 years

"The accessibility of the playground, lets him be free without restrictions. The hydrotherapy is good for his muscles and the theatre is just for fun. All these things are good for his mental health and provide him with a change of scenery."

Family of male, 6 years

Q14. Thinking now about your child receiving hospice care, What is your priority in terms of support needed for your child? (all)

Parents & children need more respite

When asked how support from Derian could be improved, an overwhelming majority of parents said the family needs more access to respite – overnight and daytime.

What are the gaps in support?

Respite availability: a large proportion of parents feel they are unable to access enough respite days or nights. Parents feel there is an unequal distribution of respite allowance across families (particularly overnight respite), with some only receiving up to 1-2 weeks a year, while others receive more than this. Some of those with a lower respite allowance feel its not worth booking a holiday with this allowance, especially because check-in times can take several hours in some instances. Parents feel more day respite and daytime activities are also needed for their child; some need a day respite centre closer to where they live while others need more activities to be available during the week (9am-4pm).

"Things like planned respite care tend to get booked up very fast, so it's a gamble if you book a holiday as you probably wouldn't get the respite on the dates you want (…) we would like to be able to have two weeks holiday allowance (at Derian) to go abroad but it's not possible. Any less than two weeks wouldn't be worth it as by the time we have booked our son in (a process which can take five or more hours) that could be one less day for our holiday."

Family of male, 6 years

"By providing more respite care and more community-based activities like a 10am - 4pm community club for instance."

Family of male, 17 years

"My son only qualifies for seven nights a year and has been for the last two years. We have asked on several occasions, for more nights and have been refused. I know families who have 14 or 21 nights a year which doesn't seem fair."

Family of male, 9 years

Q13. Are there any gaps in the support Derian House provided to the families of children and young people, or ways the support could be improved? (all)
Q17. How else do you think that Derian House could support your child? (all)

Check in with parents more

Adopt more of a consistent approach to telephone check-ins with parents, particularly those who have stopped using services, as some feel they have been forgotten.

Ways of improving parent/guardian support

More telephone check-ins (8 mentions)**:** some families feel Derian House could be more consistent when they telephone to check in with them to see how things are progressing and if the family needs any support. There is the perception that when families stop using services Derian will stop making check-in calls.

Having said that, during the Covid-19 pandemic, Derian is praised for proactively telephoning families to see how they are doing. Parents would like to see more of this during normal circumstances.

> "They could be in contact a bit more. Sometimes you don't hear from them for a while, then they'll contact you several times in a short space of time . Since Covid they've been in contact quite consistently, which has been nice. They should have done this before."
>
> **Family of male, 22 years**

> "They could contact you now and then to see if you need any help. Maybe a phone call now and then to check on you and see if you require extra support."
>
> **Family of female, 5 years**

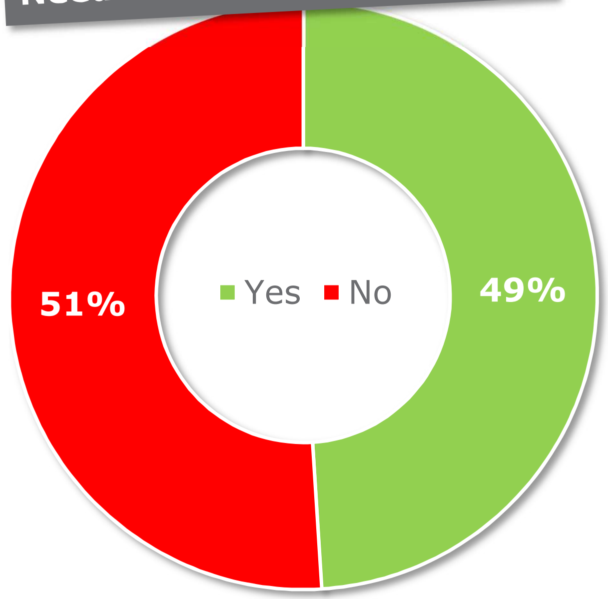
> "They used to contact me every two weeks when my daughter was a baby and receiving at home respite, but that phone contact has stopped now and I'm too busy looking after my daughter to call them. I think that if you aren't using their services you are forgotten, which is wrong."
>
> **Family of female, 5 years**

Q13. Are there any gaps in the support Derian House provided to the families of children and young people, or ways the support could be improved? (all).
Q17. How else do you think that Derian House could support your child? (all).

Around half of families need transport provision

Transport would help those who cannot drive with their child. However, in a few cases it is felt the distance is simply too far for it to be worth the journey to Derian.

Need for transport provision



Transport provision (6 mentions)**:** families who need transport either have to wait for another family member to drive them after work which can mean missing out on respite time or daytime activities, or they need to use medical equipment while travelling with their child. Others feel the journey is too far to use the facilities.

"More support for day care - transport to take children to Derian House - I can't drive and provide suction at the same time."

Family of male, 5 years

"I don't drive myself. When I book him in I have to do it for when my partner has finished work. They [Derian] normally go at 12 pm and we go at 6 pm when my partner finishes work. We are missing 6 hours respite."

Family of male, 4 years

"We are about an hour to an hour and a half away. That has caused difficulties for us in the past as we can't just pop down to use the hydro pool or the cinema."

Family of male, 17 years

Q9. Would the provision of transport to and from Derian House make it easier to use the services? (all excl. D/K: 99).
Q13. Are there any gaps in the support Derian House provided to the families of children and young people, or ways the support could be improved? (all)

Physiotherapy & one-to-one care for children

Some families mention a difficulty with accessing physiotherapy or the hydrotherapy pool, while others indicate a need for staff to be more familiar with their child.

Ways of improving support for children

Physiotherapy (6 mentions)**:** some families occasionally receive physiotherapy through the NHS and would like to receive this at Derian. Others struggle to access the hydrotherapy pool so cannot use it as much as they would like to.

One-to-one care (5 mentions)**:** continuity is very important to families. If a member of staff could be assigned to a child, there is less risk of that child feeling uncomfortable socially or not receiving the right kind of care.

"Maybe physio sessions would help. We have an NHS physio who does not come that often, so it would be filling a gap if they could provide physio services."

Family of female, 5 years

"They don't access the pool enough, the children don't get as much use out of the pool as they could. I have asked if she could use the pool, and been told that the pool is closed. All staff should be able to access the pool to give the children the most out of the experience."

Family of male, 17 years

"Some of the less experienced staff won't understand (…) the subtleties of her condition and that she needs to rest frequently. My daughter won't tell them she needs a rest and will just keep going. But this can have catastrophic consequences for her health."

Family of female, 9 years

"He finds it difficult to make relationships (…) he doesn't get the chance to go enough to get used to the surroundings and the staff, and where possible it would be good for him to have the same members of staff, someone to form a relationship with."

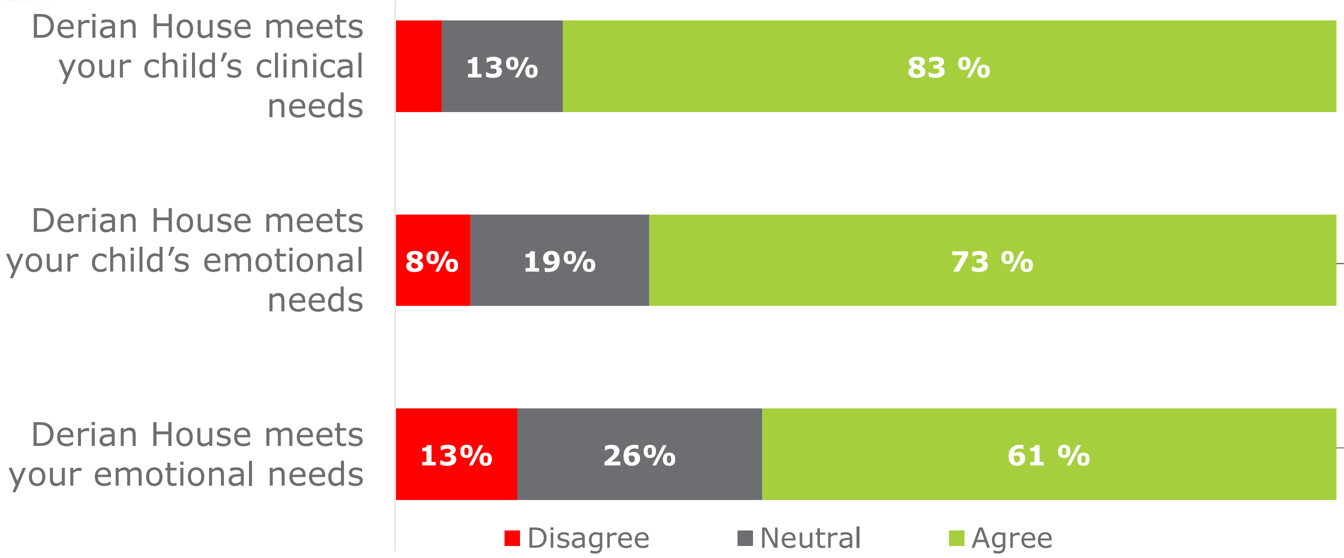
Family of male, 9 years

Q13. Are there any gaps in the support Derian House provided to the families of children and young people, or ways the support could be improved? (all)
Q17. How else do you think that Derian House could support your child? (all)

Derian are rated highly for meeting both clinical & emotional needs

However, families are more likely to agree that Derian meets the clinical and emotional needs of their child over their own emotional needs.

Meeting clinical & emotional needs



Most likely to agree:
Child aged 1-5 years or 20-26 years

Most likely to agree:

- Child aged 1-5 years
- Working parents

Q18. Please rate the extent to which you agree or disagree that Derian House provided the support that your child needed? (all excl. D/K: sizes vary).

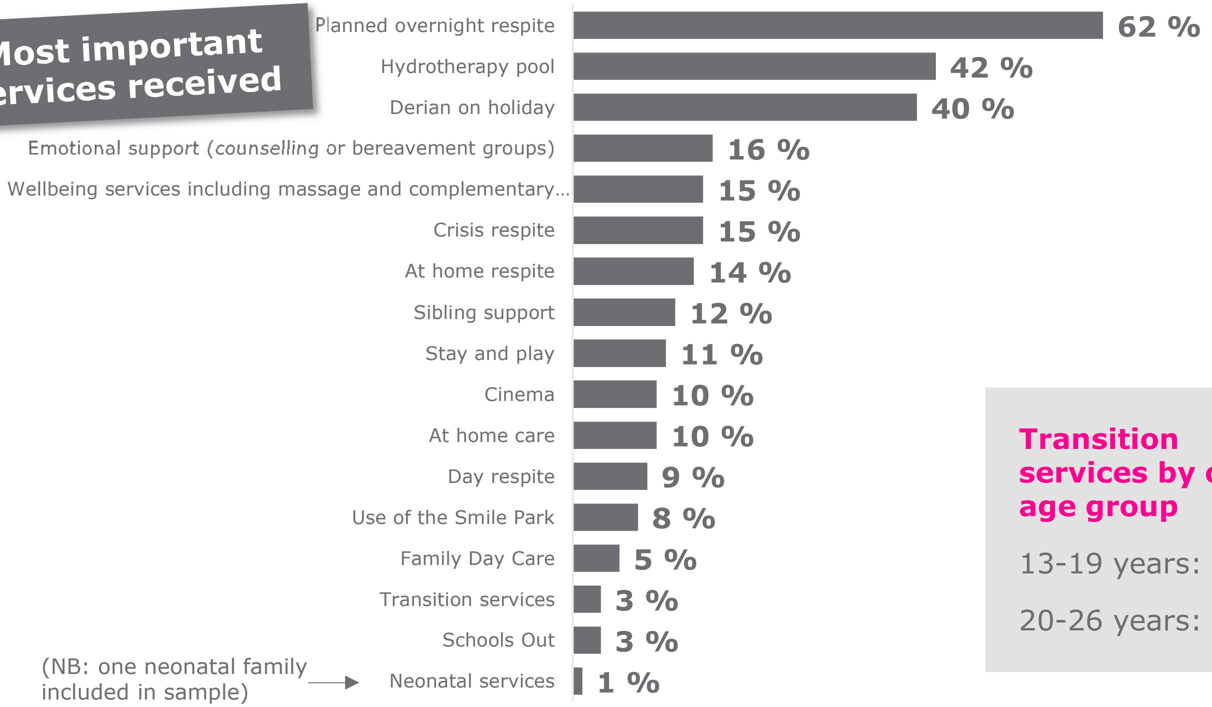
3. Specific services

Almost two thirds consider planned overnight respite as one of the most important services

Please note: Bereaved families were not included in the sample, therefore end of life and bereavement care needs are underrepresented in this research.

One in four families also rank the hydrotherapy pool and Derian on Holiday in the top three most important services.

Most important services received



(NB: one neonatal family included in sample)

Q19. What are the top three most important services you receive from Derian House? (all excl. D/K: 92).

Planned overnight respite

Most likely groups:

- Aged over 5 years (6-12 years 73%, 13-19 years 79%, 20-26 years 79%)
- Started using Derian’s services over 5 years ago (79%)

Least likely groups:
Life enhancement segment (13%)

Transition services by older age group

13-19 years: 4%

20-26 years: 14%

Hydrotherapy Pool

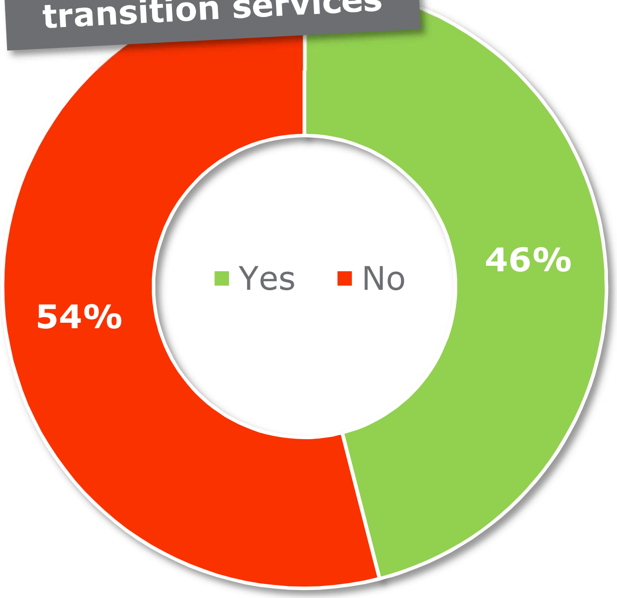
Most likely groups:

- Started using Derian’s services less than 5 years ago (53%)
- Life enhancement segment (81%)

Just under half of families are aware of transition services

Those who are aware generally feel the information came at the right time and was helpful.

Awareness of transition services



Information about transition services

> "The information provided was good and they have been doing all the searches for us. I think the information came at the right time as it's given us 18 months to two years to search for alternatives to Derian."
>
> **Family of male, 25 years**

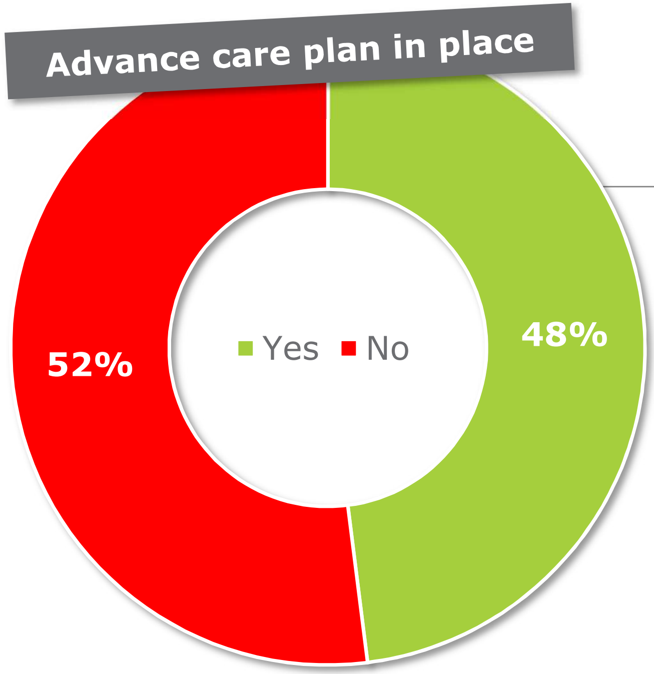
> "I don't think I've received anything. The social worker just attends the transition meetings to say her bit and that is it."
>
> **Family of male, 19 years**

> "Nothing was missing. And I feel the information was provided at the right time as she is coming towards the end of her usage at Derian House."
>
> **Family of female, 25 years**

Q20. Are you aware of the transition services Derian House provide? (all aged 13+ years: 39). **Q21.** If you have received information about transition services, was there anything missing (i.e. was the information of interest to you or provided at the right time)? (all aware of transition services).

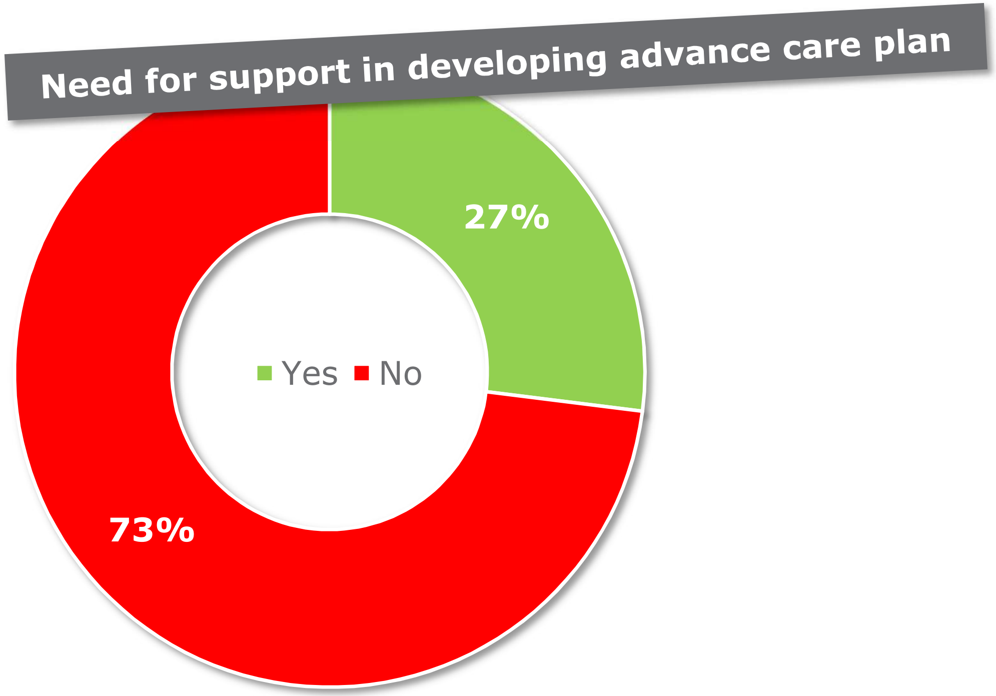
Just under half of families have an advance care plan

Among those who don’t have an advance care plan, a quarter say they would like support in developing one.


Advance care plan in place

Most likely to have a care plan in place:

- Those in Greater Manchester (compared to those in Lancashire)
- SEG C2DE


Need for support in developing advance care plan

Q22. Does your child have an advance care plan? (all excl. D/K: 96). **Q23.** Would you like support in developing an advance care plan? (all without an advance care plan: 49).

Derian’s services are perceived to be extensive

When asked whether there are any services or activities families could benefit from that are not being offered, the majority feel the offering is extensive enough. However, a handful say they would benefit from more sibling support, while others feel they are not aware of all the services on offer

New services

No suggestions: 35 mentions

Sibling support: 3 mentions

Not aware of other services: 5 mentions

“When the Sibling Support service is up and running again that would be a useful service to access.”

Family of male, 7 years

“I didn't know some of these services you mentioned were even offered at Derian.”

Family of male, 9 years

“Half of the things on the list you read out I didn’t know about. Such as respite at home and Schools Out. I would have made use of them if I'd known about them.”

Family of female, 13 years

“I didn't know about the day care. It would have been really useful to know about this service.”

Family of female, 14 years

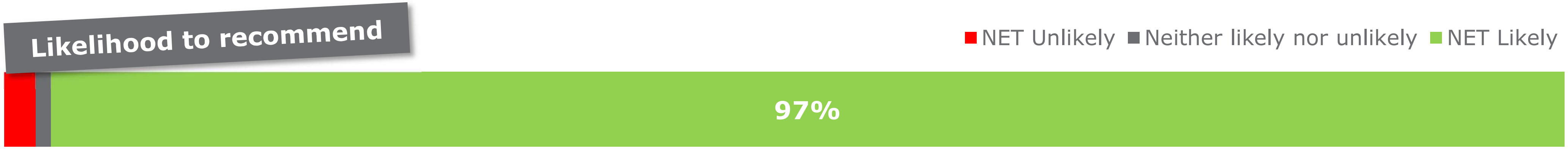
“When things are on offer or you are going through a difficult time, Derian inform you regarding how they can help – though sometimes the support can come a bit late. We would like to know earlier about things in place we could access. For instance - advanced and palliative care.”

Family of male, 24 years

Q25. Are there any services or activities you feel you or your family could have benefitted from, that are not currently being offered?

Almost all families would recommend Derian House

Families praise Derian House for its ability to meet the needs of families in such a way that parents trust their child will be safe; they also feel accepted, understood and well-informed in the process.



"When you have a child with a disability people often give you pitying looks. But at Derian, all the kids are celebrated for who they are. They are all capable as far as Derian are concerned. It's a fun place to go."

Family of female, 4 years

"They are kind, caring, a good bunch of people. We are a family. Everyone looks out for everyone else. The staff are never in a rush and they always make time for us. They know their stuff so well so I am happy leaving my son there as I know he will be well looked after."

Family of male, 22 years

"Because they've been amazing throughout the process and made it easier for us to understand the diagnosis and come to terms with many things. They've talked us through issues relating to end of life care. They've been so supportive."

Family of female, less than 1 year

Q26. How likely are you to recommend Derian House to other people if they needed similar care or support?? (all excl. D/K: 99).

Part II: Unmet needs

Key insights: I

Overall prevalence of children or young people living with a life-limiting condition in the North West of England is higher compared to England as a whole. These prevalence rates are relatively low when compared to adults living with a life-limiting condition. That said, in the North West there has been a steady increase of cases among children and young people since 2001, and prevalence is rising.

Prevalence is notably higher among children aged under one year and this age group also sees the highest number of hospital admissions and deaths per year. However, there is little spontaneous mention of a need for neonatal or perinatal care among palliative and end of life care providers. This discrepancy may require further research to identify any gaps and barriers to provision of care for families with a child under one month and under one year.

End of life care for children and young people differs from adult end of life care. Providing support means attending to the entire family in addition to the child who is living with the life-limiting condition.

The needs of families can be unpredictable, as members grapple with the emotional and physical impact of losing a child or sibling, and children experience the longer term psychological impact of grief and death in the family.

The needs of families vary depending on their circumstances, and they change over time. As a result, families most need options, so they can make the decision for their child to die at home rather than in hospital, or for their child to receive hospice care. Providing options can be a challenge with limited staff and resource. At present, charitable hospices provide this end of life, out of hours care without being commissioned to do so.

Local end of life and palliative care providers say that Derian House are important players in ensuring that end of life care, out of hours is provided across the North West, and particularly in areas which have limited or no funds for end of life care. There is concern among providers about the ability of Derian House to continue providing in the future without necessary funds. In areas such as Wigan and Oldham, work is being done to formalise the partnership with Derian House to ensure this provision is not lost.

Key insights: II

Derian House has been asked to take a leading role in actively shaping plans for local end of life and palliative care provision. However, more support is needed to make sure the hospice can continue, particularly during the Covid-19 pandemic.

Almost all CCGs out of those spoken to in this research do not have a level 4 paediatric palliative care consultant, and palliative and end of life care is limited as a result. Linked to this is a need for specialised training and education of the children's care providers who often step in to provide palliative services, despite this not being their usual remit.

There are also large gaps in provision, particularly around emotional, psychological and bereavement care. Sibling support specifically is an area lacking in provision. The NHS often does not provide this range of services, so hospices are often relied on to offer these, and often out of goodwill.

Transition services and rapid transfer services from hospital to home, or hospices are key limitations across CCGs. Providers admit there is some uncertainty around the former, particularly around how to transition a child into appropriate adult care, and what this care should look like.

Need for services

Who we could help...

'A Together for Short Lives' report details the prevalence of children and young people aged between 0–19 years who are living with a life-limiting or life-threatening condition in the North West of England.

Overall prevalence

in 2017

72.5

North West of England

Prevalence by gender

Males aged 0–19 are more likely to live with a life-limiting condition than females.

Prevalence by ethnic group

Highest among those of Pakistani origin. Lowest among Chinese origin.

Prevalence by deprivation group

Prevalence is highest among those with higher rates of deprivation.

Prevalence by age

221.9	Age <1
85.7	Age 1–5
58.9	Age 6–10
57.0	Age 11–15
53.3	Age 16–19

Prevalence by diagnosis

Ordered highest to lowest.

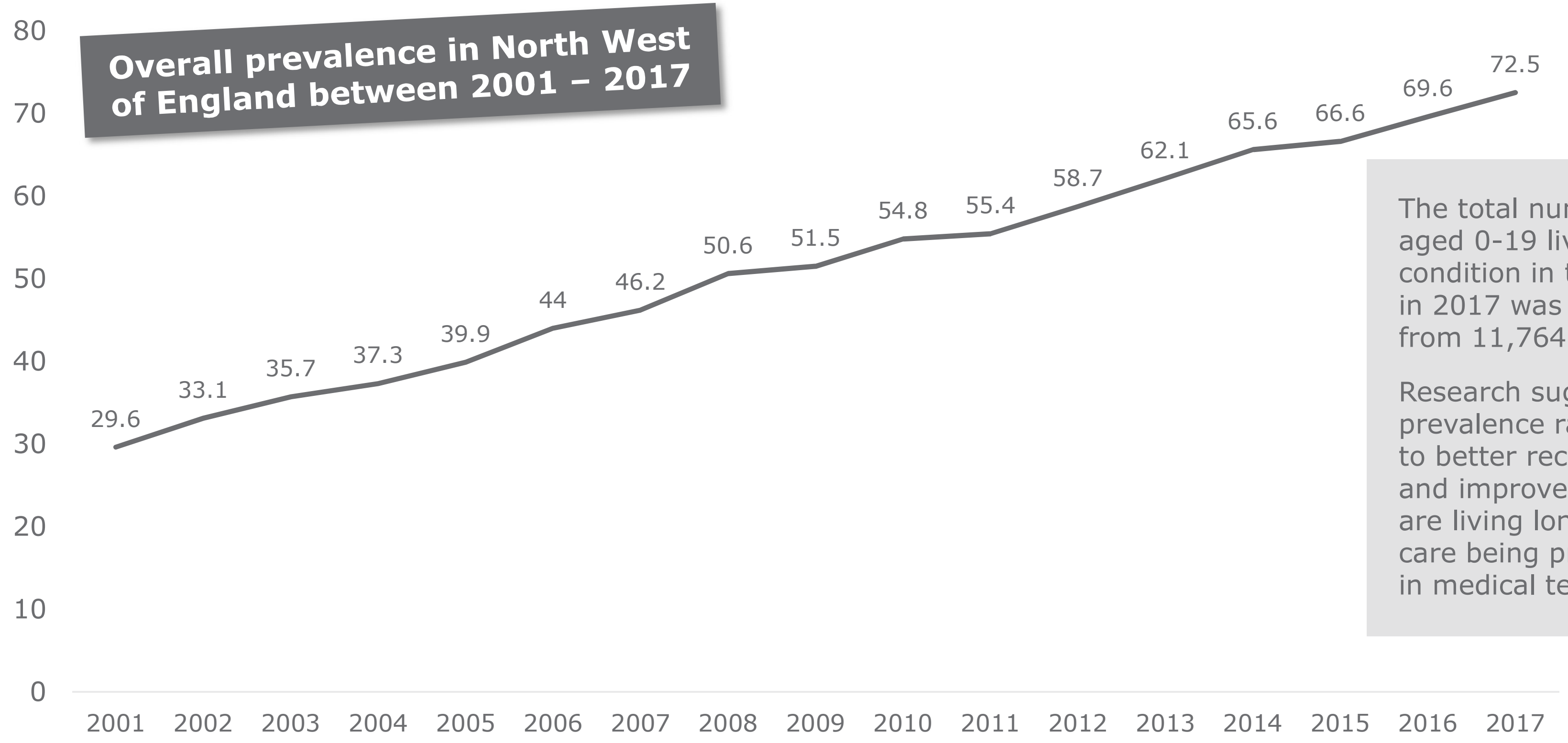
1. Congenital
2. Perinatal
3. Neurology
4. Respiratory
5. Haematology
6. Oncology
7. Genitourinary
8. Metabolic
9. Gastrointestinal
10. Circulatory
11. Other

Prevalence by local authority per 10,000

Data sources: Fraser et al, 'Make Every Child Count' (2020). Figures taken from North West Government Office Region, 2017. Prevalence per 10,000 population.

Prevalence rates are increasing in the North West

The prevalence of children and young people (aged 0-19 years) living with a life-limiting condition in the North West of England saw an upward trend between 2001 – 2017


Overall prevalence in North West of England between 2001 – 2017

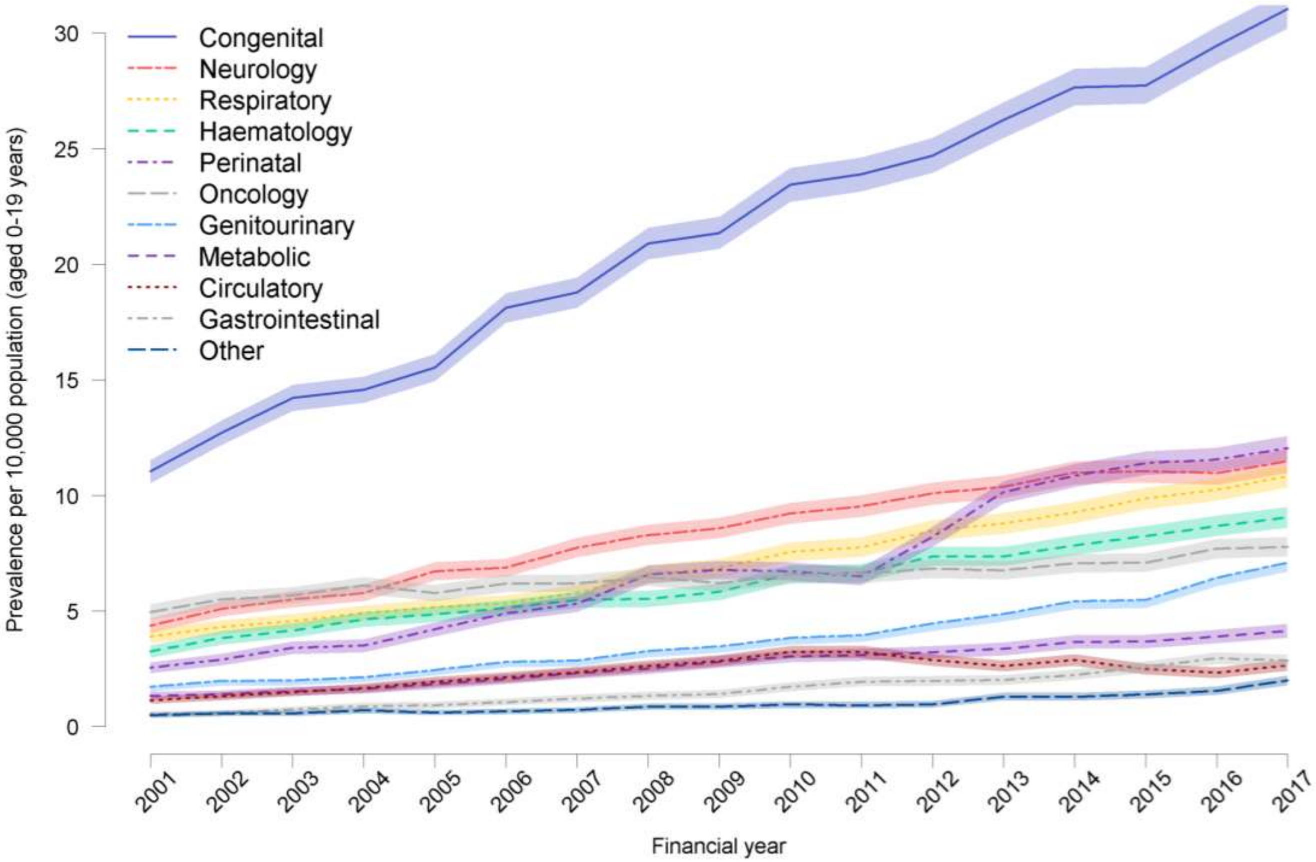
The total number of cases of children aged 0-19 living with a life-limiting condition in the North West England in 2017 was 12,278. This figure rose from 11,764 in 2016.[1]

Research suggests that this rise in prevalence rates may be partly down to better recording of hospital data and improved diagnosis. Also children are living longer as a result of better care being provided and advances in medical technology.[2]

[1] Fraser et al. 2020. 'Make Every Child Count: Estimating current and future prevalence of children and young people with life-limiting conditions in the United Kingdom'.

[2] The Children's Trust 2020: https://www.thechildrenstrust.org.uk/brain-injury-information/latest/more-children-than-ever-living-with-life-limiting-conditions

The rise in prevalence is seen across diagnosis types



Prevalence by diagnosis in North West England between 2001-2017

A steep rise in prevalence is seen among children and young people living with a congenital condition between 2015 – 2017.

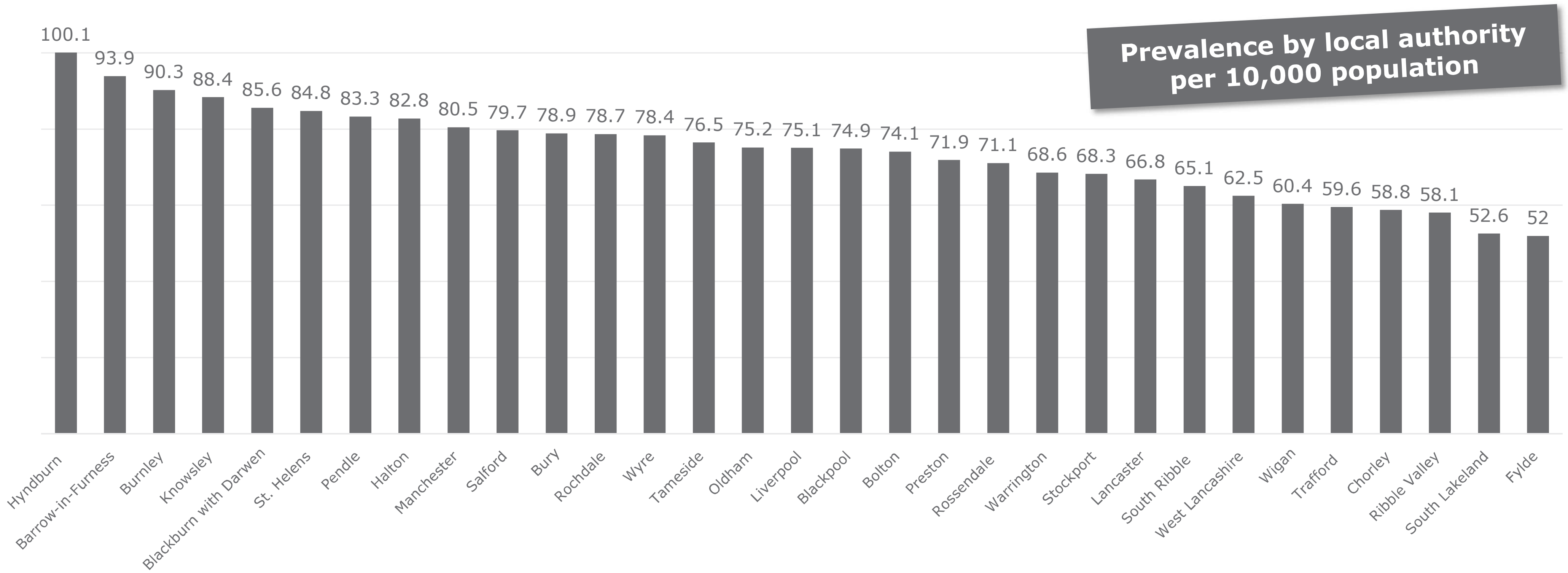
In the North West of England, prevalence per 10,000 population has increased across all diagnosis types.

Prevalence rates are particularly high for children and young people living with congenital conditions. The rates of those living with this condition saw a steep rise between 2015 and 2017.[3]

[3] Fraser et al. 2020. 'Make Every Child Count: Estimating current and future prevalence of children and young people with life-limiting conditions in the United Kingdom'.

Prevalence by local authority in North West England

The prevalence of children and young people aged 0-19 years living with a life-limiting condition is highest in Hyndburn, Barrow-in-Furness and Burnley.

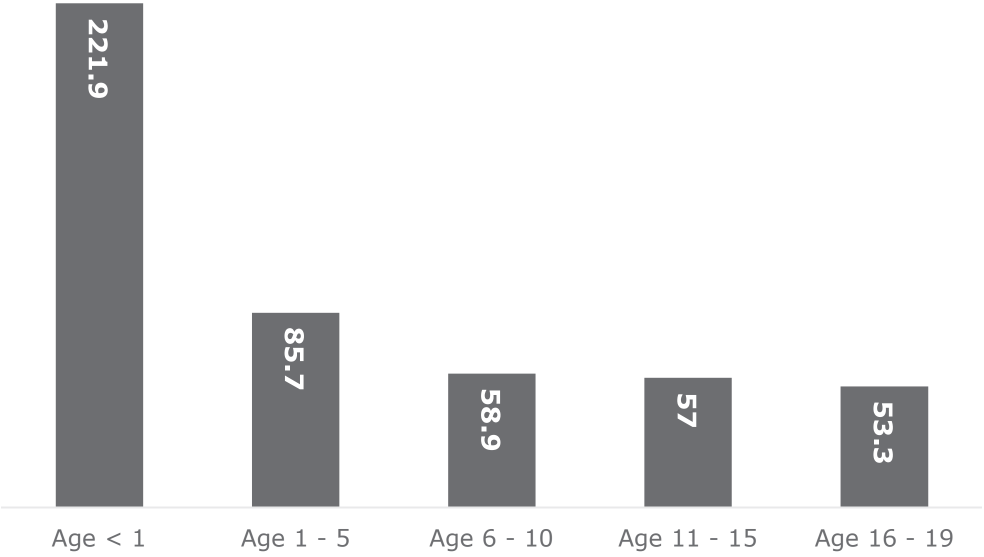


Fraser et al. 2020. ‘Make Every Child Count: Estimating current and future prevalence of children and young people with life-limiting conditions in the United Kingdom’.

Prevalence is highest among children aged under one

Prevalence of children and young people living with a life-limiting condition is highest among children under 1 year. Figures take from hospital admissions indicate that Royal Manchester has around half the number of PICU patients under 1 year of age compared to Alder Hey

Prevalence by age in North West



Admissions by age 2017-2018

	<1	1-4	5-10	11-15
2017				
Alder Hey Children's Hospital, Liverpool	556	227	114	88
Royal Manchester Children's Hospital	216	161	96	106
2018				
Alder Hey Children's Hospital, Liverpool	600	186	100	65
Royal Manchester Children's Hospital	323	337	216	257

Data taken from paediatric intensive care units in Alder Hey and Royal Manchester Children's Hospital 4.

Fraser et al. 2020. 'Make Every Child Count: Estimating current and future prevalence of children and young people with life-limiting conditions in the United Kingdom'.
4 PICANet 2019 Annual Report: https://www.picanet.org.uk/annual-reporting-and-publications/

Child deaths also occur more frequently among children aged under 1

Number of child deaths by local authority

Local Authority	**No. of child deaths 2018-19** (0-18 years)
Bolton Metropolitan Borough Council	**10**
Bury Metropolitan Borough Council	**10**
Manchester City Council	**15**
Oldham Metropolitan Borough Council	-
Rochdale Metropolitan Borough Council	**10**
Salford City Council	**10**
Stockport Metropolitan Borough Council	**10**

Local Authority	**No. of child deaths 2018-19** (0-18 years)
Tameside Metropolitan Borough Council	-
Trafford Metropolitan Borough Council	-
Wigan Metropolitan Borough Council	**5**
Liverpool City Council	**35**
Lancashire County Council	**40**
Blackburn With Darwen Borough Council	**10**
Blackpool Borough Council	**10**

NHS Digital Child Death Reviews. 2018-2019. 5. The Manchester Safeguarding Children Board. Manchester Child Death Overview Panel: 2017-2018 Annual Report 6 Blackburn Health and Wellbeing Board. 2019. 7. Merseyside CDOP Annual Report 2018/19. 8. Cumbria Child Death Overview Panel 2015-2016.

In 2018/2019 Lancashire and Liverpool County Councils saw the highest number of child deaths. These mainly occur during the neonatal/perinatal period

Lancashire and Liverpool saw the highest number of child deaths between 2018-2019.

Figures from The Manchester Safeguarding Children Board indicate there were 274 child deaths in Greater Manchester between 2017-2018. Of those, the largest number were categorised as a perinatal or neonatal event (37%) and chromosomal, genetic or congenital anomalies (24%). [5]

These findings are similar in Lancashire, with the most common category of death for cases reviewed in 2017/2018 classed as a perinatal/neonatal event (29%) and chromosomal, genetic and congenital anomalies (24%).[6]

These categories are also the most common cause of child deaths in Merseyside. [7]

There are few child deaths in Cumbria and these mainly occur in the neonatal or perinatal period. [8]

Despite a high prevalence, there are few mentions of neonatal or perinatal needs among stakeholders

Interviews with stakeholders who provide or commission end of life or palliative care were carried out to understand where the gaps are in provision for the North West of England. Despite the evidence that life-limiting conditions are most prevalent among children under 1 year, there was almost no mention of a need for neonatal or perinatal end of life care.

Stakeholders mention that end of life or palliative care for this age group mostly takes place in hospital, although some may be referred to a children's community nursing team or hospice. The reason for families spending more time in hospital with a new-born or a child aged under one year may be partly due to the high levels of diagnostic uncertainty common among this age group and the shorter lives that babies with a life-limiting condition often have. [9]

The absence of commentary on neonatal or perinatal end of life care among stakeholders, in conjunction with the high prevalence of children under one living with a life-limiting condition, suggests some uncertainty in relation to how families on this pathway can best be supported by children's palliative services.

"There are definitely gaps at neonatal and transition."

Chorley and South Ribble and Greater Preston CCGs

"I wouldn't know perinatal because we don't get them. In oncology we identify tumours in babies sometimes, we only pick them up from when they have an absolute diagnosis."

Royal Manchester Children's Hospital NHS Foundation Trust

"They have a large in-patient unit [for neonatal care], some will be referred to the children's community nursing team and hospice for joint care."

Oldham Northern Care Alliance

"If I had a mum and a child on my case load with leukaemia who was doing well and in school but mum was having a baby, I would contact my counterpart in St Mary's and make sure I'd caught mum."

Royal Manchester Children's Hospital NHS Foundation Trust

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[9] https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/01/ProRes-Perinatal-Pathway-for-Babies-With-Palliative-Care-Needs.pdf

End of life and palliative care for children and young people differs to adult care

Needs are dependent on the wider family context, the age of the child and the clinical or emotional stage of the child and their individual family members who are on the end of life/palliative care journey.

A series of interviews took place with stakeholders who provide palliative and end of life care for children and young people in the North West. The interviews explored the needs of families on end of life pathways…

A clear finding from these discussions is that the needs of children and their families varies considerably, depending on whether the child has siblings, their parent's work status, living situation, ethnicity, proximity to local services and stage of the palliative journey.

End of life care differs from adult end of life care. The needs of a teenager who develops a life-limiting condition are remarkably different from the needs of a family who's child is born with a condition, making the provision of end of life care more unpredictable.

On top of that, the needs of families can change overnight. Provision cannot focus solely on the needs of the child, because that child is emotionally, psychologically, physically and even financially tied to his or her parents, siblings or grandparents.

Therefore, **the priority is to be able to provide a range of options** to those children and their families who are on the palliative and end of life journey.

> "Not try to fit that child in to a process, but the support is around that child, and [is] individual to them. The needs can vary from family to family. Some families are very resilient and have a lot of support, but of course, that can 'turn on a pin-head'."
>
> **Lancashire Care**

> "Finding out a healthy child has got a condition or having a child born with a condition, again is very different set of approaches and intervention that are needed with the family and child."
>
> **Wigan Borough CCG**

Families most need different end of life care options to be accessible to them

The provision of options requires sufficient resource. However, at present this often involves dependence on or informal partnerships with children’s hospices.

The provision of end of life care for children and young people is described by stakeholders as a ‘postcode lottery’. In many areas of the North West, there is either partial or complete dependency on hospices to deliver this care, often through joint working. Particularly where out of hours support is sparse or non-existent, the involvement of hospices ensures that families have a choice about how they receive their end of life care.

Capacity is key to being able to offer a family with end of life options. However, at present, one of the biggest challenges faced is insufficient resource to be able to deliver day-to-day end of life care for children and their families.

A lead children’s community nurse in Oldham describes how not every family has the resilience or practical set-up to remain at home while their child receives end of life care, whereas some families would rather spend their last moments with their child at home. Therefore, the ‘gold standard’ is for a partnership to exist between community nurses and a children’s hospice to ensure a family has options, with a sense of familiarity with nurses from their community.

“The ideal and gold standard for me is that we would do that in partnership with a children’s hospice. With Children’s Community Nursing Team being the lead because we know the children, we know the locality, we have a relationship with the parents, but also the hospices’ have the specialist knowledge.”

Oldham Northern Care Alliance

“Insufficient resources…just not enough people to deliver the care and not enough day to day support for these families.”

Manchester Foundation Trust

Families need their emotional needs to be attended to

Hospices play a key role in providing options for each family's specific needs, but also in using their specialist palliative knowledge to appropriately attend to the emotional and psychological needs of parents and children.

NHS services cannot always provide the emotional and psychological support specific to end of life or palliative care, with bereavement care specifically named as an area lacking coordination. Hospices are often relied on to meet these specific needs and to offer stability and comfort that the family may struggle to find elsewhere.

As well as meeting the specific clinical needs of the child or young person, many families need emotional and psychological support from the moment they first receive a diagnosis.

Children may need more literal support, such as helping them to understand death and how the condition may impact them. Parents may have different requirements, depending on whether they have other children or other issues they may be facing. A sibling may need help coming to terms with losing their brother or sister.

"There may be conversations that the child or young person needs to have in confidence with a professional as oppose to a family member who is struggling to understand or cope with the situation themselves."

Lancashire Teaching Hospitals

"Having to hold together a family unit after sadly one of the children passes away. Again, that needs a family dynamic approach to it as well as support for individual parents as well as maybe separate support for any siblings."

Wigan Borough CCG

"It all depends as well on how long, maybe, there is in relation to coming to terms with whatever the condition may be."

Manchester Foundation Trust

Current provision

Provision of palliative services by CCG

Clinical Commissioning Groups (CCGs) across the North West of England were asked to specify which services are being commissioned and provided in their geographic area.

The FOI responses indicated areas of need that Derian House could meet.

Freedom of Information requests show that the approach to palliative care for children and young people is patchy across the region.

Very few have published strategies for the care of Children and Young People with life limiting conditions, however they have recognised this and are working towards developing strategies either on a CCG basis or they are working collectively with other CCGs to develop a more system wide approach.

Spending on palliative care is patchy across the region. Many CCGs are aware that they “need” to invest in palliative care but need a steer on to how to do this. This included:

- Perinatal care
- Transition
- Reaching hard to reach communities
- Emotional support

Freedom of Information requests sent to 19 CCGs in the North West. In some cases the CCG didn't hold the information or were unable to provide a response.
Three CCGs did not reply with the requested information.

Services not currently provided

Clinical Commissioning Groups (CCGs) across the North West of England were asked to specify which services are being commissioned and provided in their geographic area.

Outlined below are the end of life and palliative services **not** currently being provided in each of the relevant CCGs. These are indicated as areas of need that Derian House could meet.

Lancashire

- A rapid transfer process for children and young people with life-limiting conditions to allow urgent transfer from the ICU to home, or to a hospice
- Transition services
- A level 4 paediatric palliative consultant
- Voluntary sector children's palliative care services
- Bereavement care before and after a child or young person has died

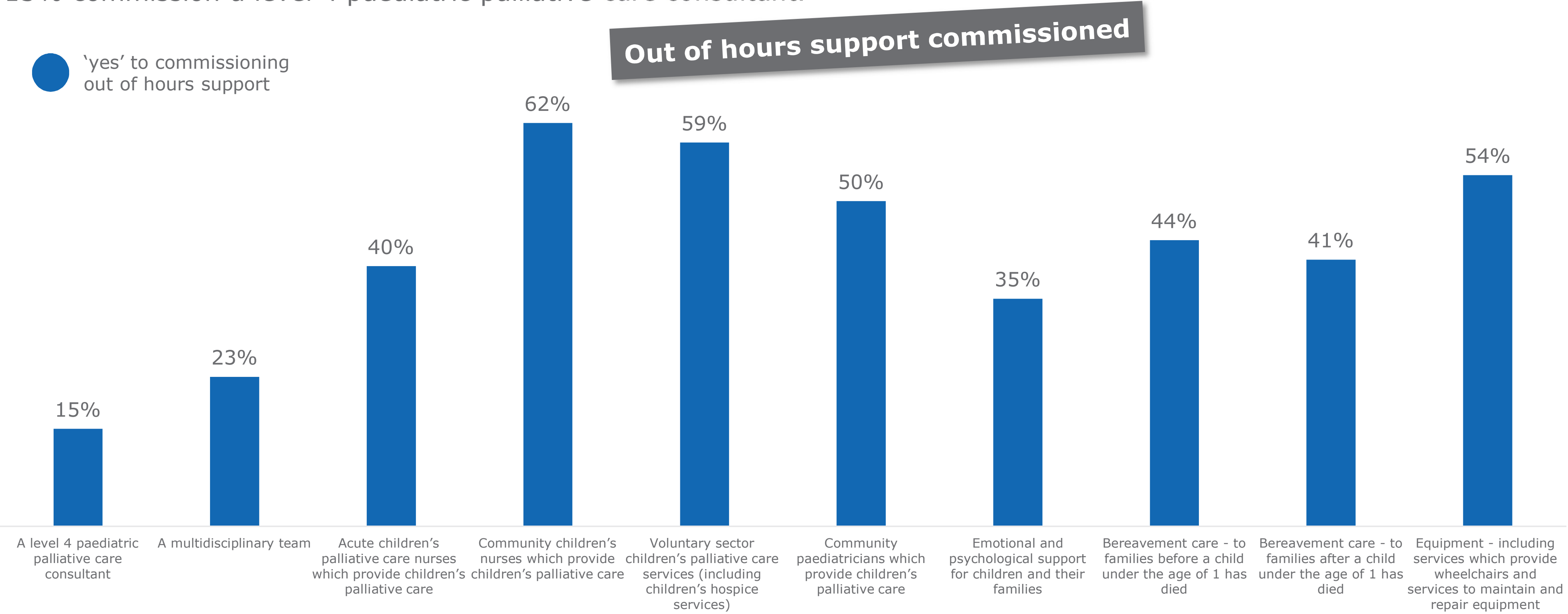
Freedom of Information requests sent to 19 CCGs in the North West.

Greater Manchester

- Acute children's palliative care nurses, which provide children's palliative care
- Palliative care for children and young people with a life-limiting or threatening condition
- Rapid transfer process for children and young people with life-limiting conditions to allow urgent transfer from the ICU to home, or to a hospice
- Transition services
- Voluntary sector children's palliative care services
- Step down care
- End of life care

Some out of hours services receive notably less funding than others

20 CCGs in the North West were asked whether they commission a range of out of hours services. Most commissions go towards community children's nurses and voluntary sector palliative care services, whereas only 15% commission a level 4 paediatric palliative care consultant.



End of life care

Funding is 'patchy' & often non-contractual

Within the areas where specialist end of life or palliative care is sparse, the care is not always family-centric.

End of life or palliative care provision is often described as 'patchy' across the North West of England. Children's Community Nursing Team models differ between areas, with some adopting more of a case management model (a model of continuity) whereas others are task oriented (dealing with families on a case by case basis).

With a low volume of children and young people needing end of life or palliative care, service provision tends to be funded via grant agreements, rather than contracts. This often means a dedicated specialist palliative care team is not commissioned, but other local services (such as charitable organisations or hospices) receive grants to care for children and young people on palliative pathways; in some cases end of life care is provided out of goodwill.

Collaboration between providers across regions is how most families receive end of life or palliative care. This process is described as a 'cobbled together' approach. While this does mean the care is provided to all families who need it, it doesn't mean the services are always family-centred. For example, if a family wishes for their child to die at home rather than in hospital, this may not be possible if 24-hour care and supervision is not available.

"If parent has mental health issues, you find the person who can deal with it in the area and make a call. That's what we do. You find it if you need it."

MacMillan and Royal Manchester Children's Hospital NHS Foundation Trust

"While these are not palliative care services, they've got the ability to meet the needs of children and young people and their families who have care needs."

Chorley, South Ribble and Greater Preston CCG

There is limited resource for end of life, 24/7 care

Nurses are providing end of life, out of hours care out of goodwill, which is putting pressure on staff capacity. Palliative nurses feel the numbers of children dying at home may be higher than we think.

Interviews with stakeholders revealed that end of life, out of hours care is particularly patchy across the North West. In Greater Manchester there is no out of hours service commissioned for 24 hour end of life care at home. Children's community nurses, out of goodwill, make sure this is provided if and when families need it. However, nurses who are on call during the night are unable to work the next day so this leads to capacity issues.

In comparison to adults living with life-limiting conditions, the numbers are comparatively lower among children. However, stakeholders feel the numbers of children dying at home is high. A paediatric consultant in Salford noted the large proportion of children living with a neuro-disability, which isn't regressive and therefore isn't factored into the numbers of children needing palliative or end of life care. However, neuro-disability can be life-limiting and a 2012 Annual Report of the Chief Medical Officer finds that 6% of all children in the UK live with a neuro-disability, suggesting the proportion of children needing end of life care may be higher than we think.[10]

"There is no out of hours service commissioned anywhere across GM, for 24 hour end of life care at home. This is done out of goodwill and means the nurses who are up all night can't work the next day. A lot of children are still dying at home."

Manchester Foundation Trust

"What you don't want is a community team on their knees in two weeks-time because those girls have been on call and frightened to sleep because they are worried they might not hear the phone."

Royal Manchester Children's Hospital NHS Foundation Trust

"In Bury there is very little NHS provision there to be able to deliver out of hours end of life care."

Oldham Northern Care Alliance

"It's not that there isn't any provision for end of life or on call support in South Manchester, you just have to be careful the staff aren't tired."

Chorley, South Ribble and Greater Preston CCG

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[10] Annual Report of the Chief Medical Officer 2012, Our Children Deserve Better: Prevention Pays

Certain areas require evening & weekend cover

Although teams do cooperate to provide this when needed, resources can be sparse.

Areas affected include…

Across Greater Manchester (incl. Wigan and Bury), Chorley and South Ribble, Greater Preston

A palliative care lead nurse who previously operated in Wigan and has now moved to Oldham explained that since moving there has been nothing reinstated in Wigan, so palliative care for children and young people is sparse, including out of hours provision. It is a similar story in Bury.

In Chorley and South Ribble and Greater Preston there is no evening or weekend provision because outreach officers tend to be based in schools.

South Cumbria teams also cannot provide evening or weekend care. However, it is noted that Derian House are filling this gap.

It is also mentioned that bank holiday cover is missing from these areas. This type of provision is particularly important if a child requires on call care for a prolonged period of time.

An All Party Parliamentary Group report identifies out of hours, end of life care as the number one limitation in palliative care in England. [11]

"A lot of the outreach officers are based around a school, you know Monday to Friday type of function, so evenings and weekends there's a gap in provision."

Chorley, South Ribble & Greater Preston CCG

"Since I set this up in Wigan and left, there hasn't been anything reinstated. Areas like Wigan would be wholly dependant on a hospice to deliver that care."

Oldham Northern Care Alliance

[11] APPG 2018 'End of life care: strengthening choice'

Children’s hospices are filling the gaps out of goodwill

In some areas, hospices are wholly relied upon to provide end of life care for children and young people.

Certain areas, particularly where there is limited or no end of life provision, wholly rely on hospices to deliver this care. Derian House is described by stakeholders to be plugging the gap more often than is expected of them.

In West Lancashire, where there is no children’s community nursing team, Derian House provided district nurses every month because no one else could do this. In South Cumbria, Derian House have employed somebody to provide weekend end of life cover. A paediatric nurse notes that in the areas Derian House doesn’t cover, such as Derbyshire, a child may not be able to die at home because there is no 24 hour provision.

A consultant paediatrician in Salford says that she is often very focused on the child’s clinical needs, whereas a hospice complement the service by providing outreach for the entire family in their home. She notes that Derian provide this care in homes, but not all hospices do. However, most of this is achieved by Derian House and other children’s hospices with little or no funding.

“It’s better than it was but in terms of any service that can step up to 24/7 call for end of life care at home, the hospices are massively filling the gap…Derian are filling a massive gap.”

Alder Hey Children's Hospital

“Not all the hospices give what Derian give…we never presume that that care is available, even in the centre of Manchester we don’t have that.”

Royal Manchester Children's Hospital NHS Foundation Trust

“Derian were doing central line flushes every month because no other service could do it. It would have never been an expectation for Derian to do this because there would be other teams who would be commissioned to provide it.”

Lancashire Children’s Continuing Care and Assessment Team

Derian House is frequently named as a hospice that goes above and beyond

Palliative and paediatric nurses indicate a need to protect the sustainability of Derian House and involve them in leading local plans for end of life care for children.

In some areas, palliative and community nurses are working towards formalising their partnerships with Derian House, but also looking at how the hospice can be better supported. They highlight a need for establishing a 'minimum standard' in relation to end of life care for children.

A stakeholder from Wigan Borough CCG in particular says they want Derian House to actively lead on shaping local plans for end of life care for children. They also indicate a need to protect the future of Derian House so they don't lose an important provider.

"Thinking about Derian's future and being Covid weather-proof… Making sure we don't lose a provision that is clearly needed, so how do we do a sustainable resilience sort of supportive approach."

Wigan Borough CCG

"Recently we have instigated discussions with Derian House, we've now got a contract in place with specific funding that has been released through our CCG and our children's commissioner to formalise the optimal partnership work that we do with Derian. So, we are funded in that. However, I know hospices' get absolute minimal NHS funding, it's usually about 10% of their overall running costs "

Oldham Northern Care Alliance

"Somebody from a hospice that is coming and doing outreach with the family, they have that understanding and they have an understanding of what their service can offer."

Salford Royal Foundation NHS Trust

"We must ask, what is the minimum standard we would want to see in any area dealing with a family or individual on an end of life pathway?"

Wigan Borough CCG

"Getting them [Derian House] included in that discussion and not just participating but actively leading and developing and shaping some of the conversations"

Wigan Borough CCG

Gaps in provision

Staff need specialist knowledge & training

In the areas that do not have a specialist palliative consultant, the workforce need training and guidance on handling those difficult conversations with families.

Professionals working across a range of geographical areas mention a need for specialist palliative training and guidance.

There is a lack of confidence, particularly among staff who don’t often provide palliative or end of life care, about saying the wrong thing to families when discussing these matters. Training is provided there and then when the care is needed.

Families each handle these conversations differently, with some preferring to avoid the topic while others need a plan. Staff need training on palliative skills, but also the support of a palliative team or supervisor to speak to about how to handle each individual case.

One stakeholder shared their perception of an ‘ideal scenario’, which would be to recruit a specialist consultant who can supervise the workforce and provide training on how to speak to families about end of life or palliative care. They feel these ‘softer skills’ are not provided by the NHS and require support from elsewhere.

Chorley and South Ribble and Greater Preston are described as lacking a tertiary provider for more complex palliative cases. This means families needing this level of care have to go to Royal Manchester or Liverpool hospitals.

Areas affected include…

Salford, Chorley and South Ribble, Greater Preston, Liverpool, Manchester

"There is a whole raft of provision, but how confident and competent they are in managing end of life pathways is questionable.“

Chorley, South Ribble & Greater Preston CCG

“Different professionals have different levels of anxiety around talking about it.”

Alder Hey Children's Hospital

The need for palliative training is widely recognised

With a wide range of services providing end of life care to children, training on the lived experience of a life-limiting condition is needed

Research by Fraser et al (2020) finds that a large amount of children living with a life-limiting condition can lead full and happy lives on the basis that they get the care they need. This means that…

“all those working in paediatric services in all specialties and locations, need to be trained and equipped to provide the best possible care. The distinction between severe disability, complex health needs and palliative care is becoming increasingly less relevant, and children with life-limiting conditions are everyone’s business.”

This has big implications for planning and training of individuals who provide children’s services.

Training requires understanding and recognition of the stresses children, parents and siblings experience when living with a life-limited condition. [12]

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[12] Fraser et al. 2020. ‘Make Every Child Count: Estimating current and future prevalence of children and young people with life-limiting conditions in the United Kingdom’.

There are cultural & language barriers to care

Some families are not supported in the way they need because they hold different views about sickness and care.

In areas with a high BAME population, there is a need for cultural link workers. There are challenges associated with engaging BAME families in palliative and end of life care due to cultural and language barriers. Views about the management of sickness and death often differ across ethnic groups, as well as the role of women. Certain cultures fear hospice involvement or do not understand it because care tends to reside with the family for those groups. At the same time, some cultural groups may wish to use inpatient respite services in order to visit their family in a different country.

Given these differences in views across cultures, palliative care professionals feel there is a need to further help BAME families.

This can be done by understanding the natural mechanism for support in certain cultures and how these can best be supported.

In Oldham there is a specific need for Romanian link workers. There are a number of Romanian families that don’t always register with a GP and move house frequently with little spoken English. Help is needed to raise awareness among these cultural groups in the area.

In Greater Manchester a Muslim chaplain has worked to articulate Muslim attitudes towards caring for the sick, which has been helpful for both palliative professionals and families living with a life-limiting condition.

Areas affected include…

Greater Manchester (incl. Oldham) & Central Lancashire

> “These are quite fundamental challenges I don’t think we've been able to address as well as they could be.”
>
> **Alder Hey Children's Hospital**

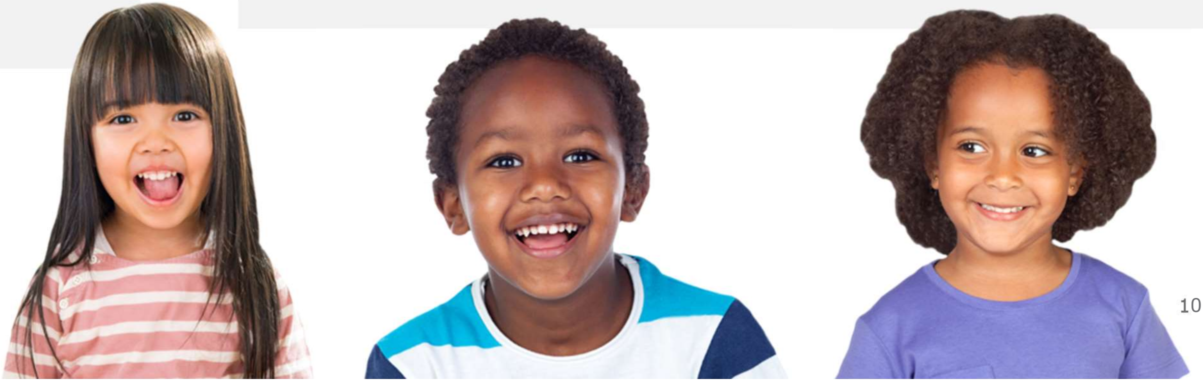
> “I'm not saying they’re [cultural link worker] not available in Oldham, but it can be very challenging.”
>
> **Oldham Northern Care Alliance**

Cultural barriers occur at a national & global level

A Marie Curie report indicates that cultural and language barriers occur at a national and global level, preventing BAME groups from receiving the care they may need

Low uptake of palliative and hospice care services amongst minority ethnic groups has been repeatedly and consistently reported across several countries, especially in the UK and the USA, across different healthcare settings (such as services in the community, in inpatient hospices and in care homes). The lack of information on relevant services in different languages and formats and across care settings/services is perceived as a barrier to knowledge/awareness, referral and consequently access to hospice care.

Lack of cultural equivalents for words such as ‘palliative’ and ’hospice’ (or negative connotation of equivalents) has been pointed out as a particular problem. Poor skills in written and spoken English may also influence low uptake. This lack of knowledge may help to generate mistrust about the services, and contribute to the thought that services (such as specific diets and space for their religious practices) are not available nor accessible to all, have low quality or inferior quality compared to aggressive care.[13]



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[13] Calanzi et al. 2013. Palliative and end of life care for black, Asian and minority ethnic groups in the UK: Marie Curie

Transition services are sparse in many areas

Often not commissioned, transition services are catered for by local hospices and hospitals; however gaps do still exist

Other areas lacking a commissioned transition service are Bury, Bolton, Wigan, North Cumbria, Salford and Warrington

There is a need for transition services in Chorley and South Ribble and Greater Preston. There is some uncertainty around who would be best placed to manage this for children and young people who are at the age of 25. There is also the question of whether adult care is appropriate for this age group. Having said that, the volume of children requiring these services are described as low.

Transition services are not specifically commissioned in Liverpool, but Alder Hey and Claire House cover this. However, there are some areas of provision where the two providers don’t have the same process. This includes the age at which transition services start; Alder Hey start this at 16 years, whereas Claire House start this at 23 years.

An All Party Parliamentary Group report describes the transition young people have to undergo as ‘daunting and often not joined up’, listing this as a limitation in care provided. [14]

Areas affected include…

Chorley, South Ribble, Greater Preston and Liverpool

> “Transition is something we need to address, probably your sixteen plus cohort and some understanding of who would be best placed to manage that, all the way up until twenty five years of age. There are some gaps around how child friendly the adult services are.”
>
> **Chorley, South Ribble and Greater Preston CCG**

> “Some of Alder Hey provisions Clare House doesn't always sit with. Clare House transition at twenty three, whereas Alder Hey start at sixteen.”
>
> **Alder Hey Children's Hospital**

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[14] APPG 2018 ‘End of life care: strengthening choice’

Other gaps in services across Greater Manchester were mentioned

These include a lack of suitable housing, sibling support and at home care

Palliative care professionals discussed the gaps in provision across Greater Manchester. These include:

- No palliative children's department in Manchester Royal Hospital
- Lack of suitable housing, with adaptations for some families
- Sibling bereavement support offered to families (rather than families seeking this out), particularly in Oldham and Salford
- Francis House don't offer at home end of life care, so this service can be sparse in South Manchester. The Trafford Community Team often step in to help with this

There is a lack of coordination of some services, including bereavement across Greater Manchester, which can mean children and young people and their families don't get the care they need.

"We don't get that in-reach (home) support from Francis House if a child needs additional support."

Salford Royal Foundation NHS Trust

"A service that we could pretty much guarantee across Greater Manchester that would allow children to die at home without staff having to drop everything and work all night - that's missing... like a lot of the country we depend on the hospices for that."

Manchester Foundation Trust

"Support for siblings and understanding that grief reaction in a sibling that's dying...there's nothing really, we'd need to access it through hospice provision really.."

Salford Royal Foundation NHS Trust

"The services are there but they're not coordinated. It meant that I couldn't be certain a family I was looking after was going to get those services...some are really good and some are scraping by and that's not equity."

Manchester Foundation Trust

Local context

In the absence of a national plan, local plans vary

Integrated Care Systems (ICS) have also been developed to form partnerships between regions

During the stakeholder interviews, a number of local plans were discussed.
As things stand, palliative care for children and young people lacks a national care strategy, which means services are patchy. A national plan would mean a minimum standard of care would be required across all regions. Although this isn't yet in place, end of life and palliative care for children and young people is very high on the agenda for some areas in the North West of England.

Wigan CCG in particular is prioritising these services and incorporating them into Deal 2030 and local transformation plans. Salford CCG is currently undertaking a big review to understand palliative care needs in the area. Areas they are interested in understanding include the need for paediatric beds, staff at consultant level, a bridge between a consultant and hospice care and what this would look like, as well as the need for counselling.

The development of Integrated Care Systems (ICS) are now in place to form partnerships between different organisations providing palliative care, including CCGs, hospices and charitable organisations. The aim is to develop a consistent approach to care in each region and palliative care is included in those conversations.

"It's very dependent on the individual leadership in that locality and place (…) we have local mobilisation in the absence of a national plan, but if you ask our neighbours they may have not done something similar because they may have not prioritised it."

Wigan Borough CCG

"In a sense anything is on the table...a lot of this stuff [gaps in services] is hidden from us, so anything additional we need to do, that quantified data will be key."

Salford CCG

There are limitations to the ICS plans

Stakeholders mention a few limitations to the ICS plans. These include too little focus on the emotional and psychological needs of children and families, as well as the lack of funding for child palliative services

Little mention of the wellbeing of children

Commissioners and health professionals feel that the ICS have a large focus on medical needs, with little attention paid to the emotional and psychological needs of families receiving end of life or palliative care. Wider research indicates the importance of attending to the emotional needs of families from the moment of diagnosis. Often hospice care is needed to fill some of the more holistic needs.

Funding

The volume of children or young people needing palliative care is low when compared to adults needing palliative care. This means child palliative services tend to be funded via grant agreements rather than contracts and often services are provided out of good will.

However, prevalence rates among children and young people are rising which puts into question the sustainability of charitable and hospice services.

"The plans, including ICS, focus too much on the medical needs of children and young people and there is not enough consideration of their wider needs, like emotional support."

Lancashire Teaching Hospitals NHS Foundation Trust

"The number of children that have a condition that is life limiting is very small compared to adults, so when it comes to providing services for them which can consume a lot of staff time...its not commissioned in anything except the block contracts, so technically we are commissioned but its a bit of an afterthought."

Manchester Foundation Trust

Public bodies don’t always adhere to duties

Local Authority	Implementing the NICE clinical guideline ‘End of Life Care for Infants, Children and Young People: Planning and Management’?	Implementing ‘Our Commitment to you for end of life care: The Government Response to the Review of Choice’ for children and young people with life-limiting and life-threatening condition?
Blackburn with Darwen CCG	**Yes**	**Yes**
Bolton CCG		
Bury CCG	**No**	**No**
Chorley and South Ribble & Gr. Preston CCG		
East Lancashire CCG	**Yes**	**Yes**
Knowsley CCG	**Yes**	**Yes**
Liverpool CCG	**No**	**No**
Manchester CCG		
Morecambe Bay CCG	**Yes**	**Yes**
North Cumbria CCG		
Salford CCG	**Yes**	**Yes**
Southport and Formby CCG		
St Helens CCG		
Warrington CCG		
West Lancashire CCG	**Yes**	**Yes**
Wigan Borough CCG	**Yes**	**Yes**

The Government and NICE guidelines set out for CCGs to implement, are not being met in every area of the North West

There are also some limitations of the ICS and STP, which relate to public bodies not always meeting statutory requirements. The 2017 Royal College of Paediatrics and Child Health report found that STP’s have not demonstrated they have met their statutory duties to engage with children, young people and their families, including vulnerable and hard to reach groups and those with complex needs.[15]

CCGs across the North West of England are fairly inconsistent in their implementation of the NICE and Government guidelines on providing end of life care for children and young people.

The data could not be gathered for a number of CCGs. However, the findings suggest that more could be done to drive a more consistent approach to end of life care across the North West regions.

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[15] Royal College of Paediatrics and Child Health. 2017. ‘State of Child Health’

Appendix

Service user case studies

About the qualitative research…

Tele-depth interviews

10 depth interviews conducted with families who took part in the CATI survey

Mix of segments, positive and negative stories

Participants were asked to **describe their experience** of using the services at Derian House, including:

- **Experience of access to services**: child’s health needs, initial access to services and general access to services
- **Support from Derian House**: how they have helped, best things about Derian House, what Derian House does well
- **Improvements**: how Derian House can improve, gaps in their service (if any)
- Opportunity to provide any **additional comments**

Respite family

Gender of child: Male

Condition:
Spinal muscular atrophy

Health needs: the child's health needs are mainly physical, given that he is mentally very capable. The mother feels that caring for her son is simply the norm and she doesn't focus too much on the challenging aspects. That said, she admits that when her son is having a bad day a simple task such as getting dressed can be very time consuming. The issue that causes most concern is the potential fatality of a chest infection, which has almost been fatal on two occasions.

Experience with Derian House:
although a Community Nurse regularly told the mother about Derian it took her a while to accept that her son needed the services and it was only when a doctor at the Children's Hospital explained the services in detail that she agreed to a referral.

The son normally goes for an overnight stay with Derian; this gives both the mother and son a break from one another, but it also allows him to spend time with other children his age and older. This helps the son to gain some perspective about his strong mental abilities, allowing him to shine when he takes part in certain activities.

The mother appreciates knowing 'there is someone on your side' who understands what she is dealing with. The respite supports her when she is struggling emotionally but also allows her to spend time with her other daughter.

"When he is at school he might be quite low down on that food chain, because he is quite unfortunate, but when he is playing wheelchair football he in on parr with everybody (…) he knows that the world is a big place and you can go up and down on that scale...it gives him a mature attitude and a caring attitude."

Respite family

Gender of child: Male

Condition: Cerebral palsy

Health needs: he needs 24-hour care and help with everything, getting up, being dressed, help with medication. He is unable to do anything for himself. He loves being sociable and being out and about, and a lot of what he used to do he can no longer do, so he benefits from interaction with others.

As he has got bigger it's been harder to find places that are accessible to him. A recently bought motorised powerpack has made it easier for him to get around.

Experience with Derian House
he has been accessing Derian following the recommendation of a social worker. The referral process took a few weeks and was "a bit chaotic to be honest." He was initially turned down, but after intervention he was eventually offered a place.

They have mainly accessed the overnight respite care. He was due to stay in April this year but this was cancelled due to COVID. They normally phone up well in advance to access services and normally Derian are able to accommodate him for the requested days.

The respite care is of value to them because it allows them to do things that they wouldn't otherwise be able to do.

"[It] gives us time to do non-wheelchair…or do things with his brother that we wouldn't be able to do with him. Or now that his brother's a bit older we can leave him on his own for the weekend if we want to go away, and have a bit of a break without having to clock watch with medicines or look after him all the time."

Issues: Communication could be better but day to day care is fine.

Life enhancement family

Gender of child: Male

Condition: Duchenne muscular dystrophy

Health needs: the child is in a wheelchair part time, requires constant monitoring and help with day-to-day living, as well as physio which the mother does herself. The hardest part about living with this condition for her son is the mental deterioration. The mother is struggling with the growing size of her son, as it becomes physically more demanding.

They are looking to move to a new house with adaptations and a downstairs bedroom.

Experience with Derian House
the family use respite services, as well as Schools Out and the hydrotherapy pool. The son has made friends when attending the services at Derian. The respite is important for him but also the mother who can spend that time with her other child. The mother has also used the counselling service when she was feeling upset, which helped her to talk through things. However, she doesn’t use these often because the time slots don’t fit with her schedule.

The mother is particularly grateful for the opportunity to use Ribby Hall for new year’s eve. What she had originally thought would be a lonely new year became a fun treat that the family are rarely able to enjoy. Derian have also provided the family with support at school, by attending a meeting to discuss an issue the son was facing.

> “The fact that there is a service there, at Derian, that provides this care, and gives us joy in the time that we have got, we make the most of the time we have got, because you don't know how long that is."

> “It [Ribby Hall] was beautiful and such a nice treat; we got to use the facilities, my daughter was in her element. It really changed things around for me.”

Life enhancement family

Gender of child: Male

Condition: Brain damage

Health needs: he is completely physically reliant on his mum. He has scoliosis of the spine, is partially blind, has daily seizures and is peg fed. He has no control over his body and gets tired easily.

Mentally he is fine and enjoys the company of other people. He enjoys swimming, baking and listening to music.

"I feel like if your face doesn't fit you don't get anywhere."

Experience with Derian House: his mum's main focus is that her son is comfortable and happy, and has everything he needs. She was told about Derian House by a Complex Needs Nurse who was focussed on the value of respite care.

Initially she was told that her son was not eligible for Derian but no explanation was given as to why this was the case; when she tried to apply for care again, he was accepted. She has had trouble accessing the services and despite frequent phone calls, feels that her son can only attend if there has been a cancellation. At first, her son was made very welcome, he enjoyed the activities, it allowed him to meet other people, and it gave her a break from being his primary caregiver.

However, she now feels that her son was treated as a lower priority than other children there, and the process of checking him in for an overnight stay was so laborious and lengthy that it made the respite night pointless.

She acknowledges that the facilities and service are very good but she feels let down that her son wasn't treated the same as other children, and that since she has withdrawn him, he's missing out on activities and she is missing out on respite help.

"He was accessing different things and seeing different people, and he loved it. He was getting a break from me."

Respite & health needs family

Gender of child: Male

Condition:
Early onset Parkinson’s

Health needs: he needs all-round care because of his various difficulties. He started suffering from the condition at 10 years, and has deteriorated since then. He has learning difficulties, very little speech, is mainly wheelchair bound and is pump-fed. The mother has found it hard seeing her son deteriorate.

“It’s been challenging seeing him go downhill.”

Experience with Derian House
her experience with Derian House, although fairly limited, has been positive. There were only two weeks between the initial visit from Derian House staff, and her son having his first visit, so the assessment turnaround was fast.

Her son enjoys going to Derian, and even though he is nervous upon leaving his house, he enjoys it once he is there. It benefits both her and her son because she gets a break, and it benefits him because it’s a change of scenery where he sees different people, he does different activities and it’s a safe environment where he is happy.

“The respite was really good, really helpful. [He] stayed with them for 2 nights. It was very welcoming and it was a good break.”

“"If I could have a bit longer it would really help....it's been a very long time since I had a long break."

Issues: She has had issues with transport to/from Derian because she has no transport of her own and so has to rely on public transport to get to/from Derian when she drops her son off or collects him. On that basis, she feels it would be beneficial if Derian provided transport. She would also appreciate longer breaks at Derian, say two weeks.

Multiple needs family

Gender of child: Female

Condition:
Chromosomal disorder, autism

Health needs: she is in a wheelchair, has learning disabilities & is non-communicative. Her father describes her as being "like a 6-month-old."

Main issues include: sleep disturbance (child waking during the night); child's distress when she is unable to communicate when something is wrong; cancellation of respite care due to COVID; caring more difficult now as child is growing.

Experience with Derian House
the main services used are respite care, hydrotherapy sessions and the Stay Days during holidays. In the past they accessed the Sibling Club.

The main benefit of Derian for them is that there are facilities and activities that their child case use and enjoy, when they find it hard to take her out because of her behaviour. The respite care allows them to spend time with their other children.

> "It gives you the opportunity to go without people looking and you know everything is there. If you go to Derian for the day to do an activity you know there's no issue…"

Issues: Issues: Communication can sometimes be an issue but that has become more of a problem during this year. The family prefer to communicate via email, but they find they sometimes have to chase for a response, or ask for confirmation that an email has been received. They would also appreciate home visits or contact calls just to 'check in' with the family.

That said, they appreciates the offer available at Derian, and it is superior to what is provided by the council.

Emotional support family

Gender of child: Male

Condition: Complex needs

Health needs: he has hyper-plastic lungs, and has suffered from multiple fractures, deformed limbs and subsequent surgeries. He has a tracheostomy, and was vented up until recently. He requires a lot of care for trache changes, moving/ handling care, suctioning, nebulisers, gastrostomy feeds, oxygen.

Experience with Derian House
the referral process was "smooth", with a Derian staff member spending time with them. They had found the process of discharge from hospital to be a confusing time and a struggle to get things in place, and "[nurse] was one of the first people that you felt he's on our side, he's an advocate for us."

Their son really likes Derian and enjoys his time there – there is a great nursing team, lots of activities, detailed handovers. A stay at Ribby Hall was a real bonus because it was so well set up, "that was really beneficial."

> "Derian is like a lifeline for parents like us. We can't leave [son] anywhere, with family members, if we want to go somewhere…"

> "So although we're allowed 21 nights in a year, we can't use that time how we want to use it, so we can only have a maximum of seven nights in a row. It limits us. We can't go anywhere as a family. Usually my husband has to stay behind and I'll go away with the girls."

Issues: she has been less sure with nursing care on the occasion that her son is left with a carer rather than a nurse, "having a nurse there is reassuring to us as parents to know that he's fine". Also, booking can be as issue, and they find that availability can be limited when they try to book nights they need. Going abroad is difficult because of the permitted length of stay, so 7 days of total respite is not quite enough for a break abroad.

Health needs family

Gender of child: Male

Condition: Duchenne muscular dystrophy

Health needs: it's a muscle wasting disease and he can't do anything for himself. He needs 24-hour support for all his physical and personal needs. He is on a ventilator.

Mum finds the emotional side of it the hardest to cope with – she finds it hard seeing him deteriorate.

"When he goes there, he does talk, he talks to certain people, other young men who go in there, that he meets up with…"

Experience with Derian House
her son benefits most from the respite care because he can talk to other boys his age, and he has friends up there. He also has a good relationship with two of the nursing staff who works with the older boys. Unfortunately he is unable to go to Derian at the moment because he is on a ventilator but they have video calls with Derian once a week which have been good, because since March they have only been out of the house for hospital visits.

"It's the way things have changed at Derian. Years ago it always felt like home from home. [Now] it feels more clinical up there…it's turned into a hospital, sort of."

Issues: She feels the care has changed over the years with it becoming more 'clinical' recently. She doesn't always feel that staff understand her circumstances and in the past has been turned down for help when she has asked for it.

Suggestions: transition services for those leaving Derian's care – there is no 'in-between' option for young adults. Nursing homes are too old and day centres don't cater for the intensity of their needs.

Summary: 1

Main benefits

Quick, easy, smooth referral process

Expert, professional and trusted staff

The feeling that someone is ‘on your side’; support

Range of services, respite care being the most valued amongst parents because it gives parents a break

Range of facilities that allow families to experience things with their children, e.g. the cinema, pool

Ribby Hall

Kids get to hang out with children who also have different/complex needs

“It just makes activities easier for us, like obviously swimming because we can’t take him to a local swimming pool.”

“It’s a chance for them to hang out and chat, and it gives me the chance, while he’s there, to go and do something with my daughter.”

“He was accessing different things and seeing different people…and he loved it. He was getting a break from me.”

“The fact that there is a service there, at Derian, that provides this care, and gives us joy in the time that we have got…because you don’t know how long that is.”

Summary: 2

Issues

Changes in the number of overnight respite days allowed in a consecutive run

Communication – lack of emails etc; lack of explanation if a help/respite request is refused; short notice cancellation of respite

Lengthy check in – while parents appreciate the care that is taken, check in can take a number of hours (and this can eat into the respite time)

> "I wasn't given a reason; it was just no, he can't come in…"

> "We've had swimming sessions cancelled due to unforeseen circumstances. We've had a couple of stays cancelled over time. They've had an emergency admission and they've had to cancel…very, very short [notice] on the ones we've had…[it left us with a] headache…"

Suggested improvements

Transport services, particularly for those who have to rely on public transport

Transition services for those who are too old for Derian/too young for nursing homes, but who have very complex needs

More flexibility in number of consecutive overnight respite days allowed

Improved communication, home visits, calls, explanations for when things change

Streamline/reduce check-in time

Attention to detail – nurse one-to-one care rather than a carer

> "Letting us stay for more than 7 nights. I think that would be the key thing for me…it would give us the freedom that normal people have."

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