# 'Marvellous Nurses'

# An independent evaluation of the role, impact and contribution of Roald Dahl Specialist Nurses

## Appendices to the Report to

## Roald Dahl's Marvellous Children's Charity

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## APPENDIX 1 NURSES AND MANAGERS: SEMI-STRUCTURED INTERVIEW FINDINGS

Twenty nurses and 15 managers took part in the study; all except one participant were female. The participants in the study sample were geographically diverse, representing 12 NHS Trusts in England, one in Wales and one Health Board in Northern Ireland. Seven out of the 12 English Trusts were based in Greater London and the South East. The nurses worked across eight different clinical specialties with the most commonly encountered roles related to epilepsy (n=5) and non-malignant haematology including sickle cell and thalassaemia (n=6). Nurses were also aligned to: rare diseases (n=3), neurology (neuro-disability=1; neuromuscular=2; neurosurgery=1), gastroenterology (n=1) and child to adult transition services (n=2).

All participants were forthcoming and felt comfortable sharing their views. The interviews were audio-recorded with permission, transcribed verbatim and anonymised. The duration of the interviews was 30-45 minutes. A total of 35 interviews were conducted; theoretical saturation was reached. Saturation was the point at which additional data did not yield new analytical insights or further elaborate on the properties of the developed categories.

Following the review of the Roald Dahl Specialist Nurse and manager transcripts, four main categories (themes) were identified, each with two or three sub-categories as shown in the Figure 1.1. Throughout the following sections, each element of the findings is supported by participant quotations from the interview data to provide evidence of the theoretical claims that have been made. Quotations were chosen to present the variations in participants' opinions and experiences. In certain circumstances, quotes were chosen for their representativeness of a specific theoretical claim. Alternatively, multiple excerpts were sometimes used to highlight some differences in participants' experiences regarding a particular construct.

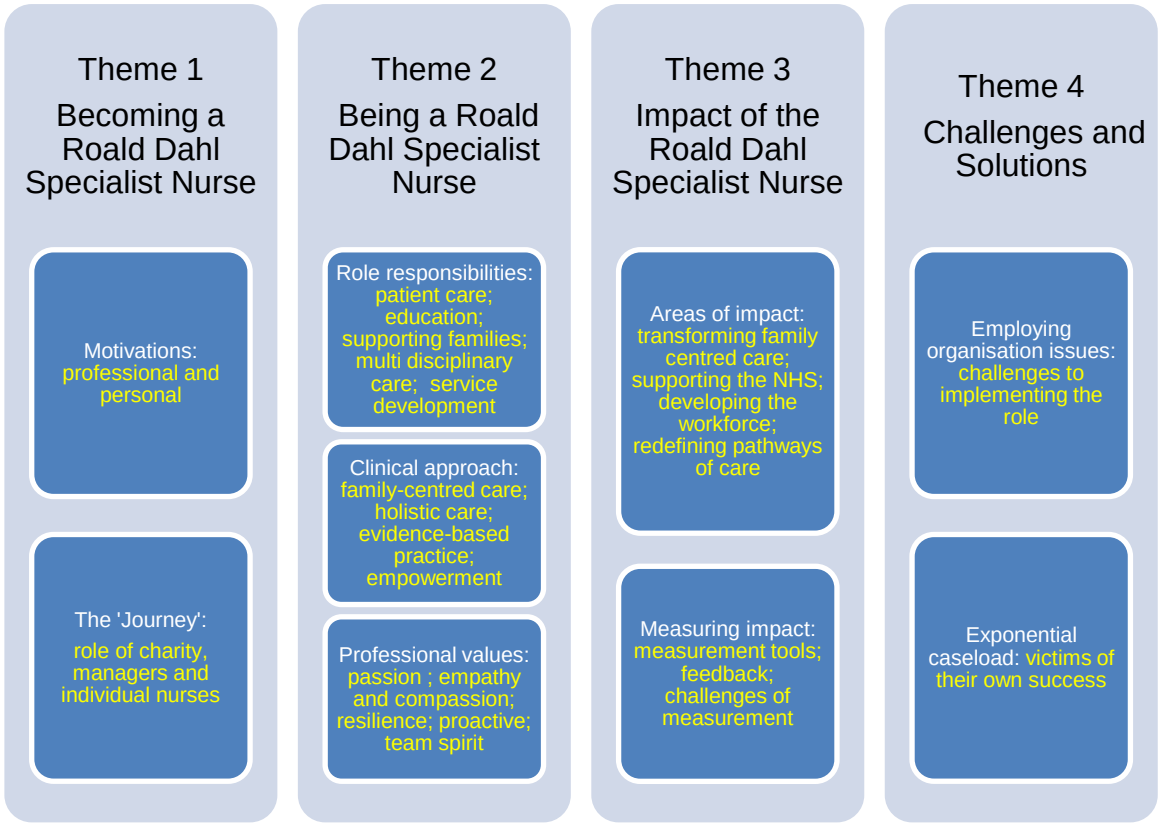


**Figure 1.1 Summary of the interview findings**

## 1.1 Theme 1: Becoming a Roald Dahl Specialist Nurse

This theme describes the reasons behind the nurses' decision to apply for the post, as well as the processes leading up to their recruitment and employment. It consists of two sub-categories namely 'Motivations to become a Roald Dahl Specialist Nurse' and 'The journey to become a Roald Dahl Specialist Nurse'.

### *1.1.1 Motivations to become a Roald Dahl Specialist Nurse*

The nurses elaborated on a wide range of professional motivations that encouraged them to apply for the position. Nearly all participants reported that their previous work experiences and interest in continuing to work closely with children, particularly those with rare and complex conditions, were the primary factors behind their desire to be Roald Dahl Specialist Nurses:

*"I've always had an interest in epilepsy... my neuro background and complex disabilities and things like that, so that's how I ended up going for it" (Nurse 17).*

Many participants highlighted that the shortage of NHS funding for transition-nursing roles created a substantial gap in young adult care. They explained that, by funding nurses, Roald Dahl's Marvellous Children's Charity was offering a great opportunity to bridge this gap which facilitated **the provision of holistic care**, which motivated participants to apply for the post:

*"What was advertised at the time to be a transition nurse and a team leader; and transition is an area that needs a lot of input" (Nurse 1).*

*"A lot of the medical side of things was being done, but not actually the holistic type focus that I think nurses bring to the role. So, there was felt the need that we needed to have an epilepsy nurse specialist and then we saw that Roald Dahl's [Marvellous Children's Charity] would potentially give us the opportunity to do that" (Manager 16).*

Several participants were also attracted to the **innovative nature of the role** that not only provided new and exciting professional challenges and career progression, but also the chance to improve existing services and set up new interventions. Many nurses cited the **availability of leadership opportunities and funding for life-long learning** as additional factors that sparked their interest in the role:

*"I'd been at the hospital for 20 years and in my job for 10 years. And I felt that I was at a point in my career where I just wanted a new challenge really" (Nurse 20).*

*"One of the things that also had me interested is the fact that they [ Roald Dahl's Marvellous Children's Charity] were willing to provide support for continuous learning, because within the NHS culture at the moment there's no financial assistance" (Nurse 1).*

Several participants noted multiple personal motivations to becoming Roald Dahl Specialist Nurses. These personal drivers revealed the participants' **immense passion for supporting young adults and families** by advocating for their best interests and improving the quality of care they receive:

*"I really wanted a job where I could build closer relationships with the families and help them more" (Nurse 12).*

*"I was interested in it because it's a role that's advocating and caring for all teenagers and young people across the whole Trust" (Nurse 13).*

Most nurses expressed great **enthusiasm towards working with the Charity** given the unique role the Charity played in supporting young people with long-term and underfunded conditions:

*"You read up about the Charity and about Roald Dahl himself and it's amazing... there aren't any other... So, it was just like a breath of fresh air" (Nurse 3).*

### *1.1.2 The journey to become a Roald Dahl Specialist Nurse*

Participants' initial awareness of the post and the work undertaken by the Charity seemed to vary. Some participants lacked prior knowledge about the nature of the role and the source of its funding, while others acquired relevant information from previous Roald Dahl Specialist Nurses within or outside their Trust. Some participants **acknowledged the promotional efforts used by the Charity** to advertise for the role on various platforms such as Twitter. Yet in most cases the creation of, and appointment to a Roald Dahl nursing position seemed to have **occurred via an element of luck**, as managers tended to learn about this vital funding opportunity through word of mouth. The following quotes highlight the need for a **systematic approach to advertisement** to increase the visibility of resources offered by the Charity:

*"He [manager] was en route to work and had the radio on and heard about Roald Dahl's [Marvellous Children's Charity] and the funding coming out... and he thought that sounded like a really good idea, so that's when he put in the bid for the first one" (Manager 5).*

*"I think I'd seen something on Twitter when it was first put out, and then I can't remember if someone sent it to me and said this sounds like it would be something that you might be interested in" (Manager 13).*

Despite the variations in participants' pre-existing knowledge of the role and the ways in which they had come to learn about the funding opportunity, almost all nurses reported having **positive recruitment experiences characterised by remarkable support from the Charity** and encouragement from their managers. The nurses valued the information offered by Charity representatives who were motivational and eager to answer individual's questions one-on-one and to provide access to additional online resources. Encouragement and access to information about the Charity and the nature of the role were considered important ways in which the Roald Dahl's Marvellous Children's Charity supported applicants at the beginning of their journey:

*"I met with [Charity representative], they were having a rare disease fun day over in the main building and I met up with [Charity representative] and had a chat with her and oh my gosh... and since then, I read up about the Charity and Roald Dahl himself and it was just amazing" (Nurse 3).*

A few initially unsuccessful participants emphasised the importance of the feedback they received during the interview process. This **feedback was deemed constructive and invaluable** in helping them develop the necessary skills and knowledge to reapply for the role. In such examples, the participant's commitment to reapply further highlighted their passion for this position:

*"I'd actually applied for a Roald Dahl nursing post and I didn't get it... the feedback was really good and I think I went along knowing that my knowledge of epilepsy wasn't as good as it could be, compared to some anyway, but the feedback was really good and so then this post came up and actually this is closer to me so I thought right OK, I'll go for it" (Nurse 17).*

Several nurses argued that having supportive managers was another factor that helped them succeed. The participants unanimously recognised the **critical role that managers played** in identifying and securing funding from the Charity, in promoting the role during formal nursing events and through word of mouth, and in encouraging their staff to apply. More importantly, it was considered **crucial that managers understood the need for holistic, family-centred care** so that Roald Dahl Specialist Nurses could succeed in their role. The excerpt below shows that the managers interviewed in this study had an in-depth understanding of the responsibilities of nurses and the impact they had on families of children with chronic health problems:

*"I [nurse manager] couldn't go to the home to tell the parents, which is really ideally what you would want, to see them in their own environment where they feel safest and go through the whole big discussion about having a baby who's been born with a chronic lifelong condition. And this is just very basic needs that these families have, which I couldn't address on my own. So, since X [Roald Dahl Specialist Nurse] she has been able to provide not just two dimensional but holistic care to these families" (Manager 18).*

The transcripts revealed that becoming a Roald Dahl Specialist Nurse required applicants to take ample initiative to research the post and seek information from professional contacts. Thus, it can be argued that **being proactive and zealous are core recruitment criteria** for this role:

*"I really liked looking after the children who had long-term chronic illness, and then I saw this job advertised and it just caught my attention and I just really investigated what it was all about" (Nurse 4).*

Once appointed, the nurses' journeys continued to vary substantially. Some nurses were the first of their kind within a Trust and were therefore required to design and implement services and policies from scratch. On the other hand, some nurses were able to draw upon existing structures and benefit from the experience of current and former Roald Dahl Specialist Nurses at their place of work, which highlighted the **great variability and challenges involved in this role**. However, all participants agreed that this role involved continuous service development, and in order to succeed nurses needed to possess **high levels of autonomy, motivation and creativity** to help them step into this new and often vaguely defined post:

*"I've spent a lot of time, because we set up the services from scratch, there was nothing, they had no policies. No processes, no paperwork, there was absolutely nothing, so I did it all" (Nurse 19).*

## 1.2 Theme 2: Being a Roald Dahl Specialist Nurse

This theme elaborates on the responsibilities undertaken by nurses and what their role entails. It also describes their approach to clinical practice and the professional values that guide them. It encompasses three subcategories as follows: “Role responsibilities’’, “Clinical approach’’ and “Professional values’’.

### *1.2.1 Role responsibilities*

Data analysis showed that the responsibilities falling within the scope of a Roald Dahl Specialist Nurse involved a mixed bag of professional duties that were grouped into three main areas of practice including: supporting families, organising multidisciplinary care and service development. **Providing families with information** about the nature, prognosis and treatment options related to their child’s condition is one of the main ways in which nurses supported families. They offered information and advice through different channels including in person, via email or over the phone. Family education and informing expectations were fundamental tools used by nurses to **empower parents to make the best decisions**. The participants demonstrated a high degree of empathy and great understanding of the stress associated with caring for children and young adults with long-term health problems. Accordingly, the nurses excelled at **offering emotional support to families** by making themselves available for consultations, facilitating sibling support and organising peer support events for families to share their experiences, in addition to arranging professional counselling. The comments below summarised how nurses approached the responsibility of supporting families:

*“My families can contact me by phone, email, text, whatever suits them. And prior I think to having a nurse they really had the secretary or the consultant, who is less accessible” (Nurse 19).*

*“It is definitely supportive and sometimes it is just a case of that emotional support in terms of just a phone call. I have one family that mum rings me every day actually that I am at work and it's just a two-minute phone call and it's just checking in and it's just what mum needs so that’s what we do’’ (Nurse 12).*

In addition to supporting families with aspects that directly related to healthcare, participants explained how they had to **work outside the traditional scope of nursing practice**. For example, the majority of participants explained that helping families get access to social services, financial aid or housing benefits was as crucial to the patient’s and their family’s wellbeing and quality of life as receiving good quality healthcare. Therefore, the role of nurses gradually expanded to include supporting families in every possible way. These nurses were the **primary care coordinators and the link between families and the resources they needed**:

*"We've got families who have very difficult social circumstances, where we've had to go and help and write letters to the council and support them from that perspective to try and get them a cleaner house, a better housing and safer housing for the children'' (Manager 18).*

**Organising multidisciplinary care** was another unique and major element of the role performed by nurses. They liaised and followed up with families and other health and social care professionals to ensure the continuity of care:

*"What I started doing was identifying, going to the consultants and saying look are you happy to be the lead for this? I will do everything. I'll do the liaison with the adults, I'll support families'' (Nurse 4).*

Roald Dahl Specialist Nurses aimed to **fill in the gap between hospital and community settings** to create cohesive care and smooth transition pathways for young adults:

*"Within her role [Roald Dahl Specialist Nurse] she can be contacted for advice or support, what should a good transition pathway look like, so more of an adviser and supporter for colleagues'' (Manager 14).*

Several nurses elaborated on the strategies they used to **embed their role within the service,** helping them raise awareness about their work, coordinate holistic care, and make their knowledge and skills available for families and colleagues:

*"I'll get a message on my phone, it's so-and-so in A&E please pop down and see this child... I work really closely with my consultant colleagues... I have written blurbs for rotation registrars and SHOs [junior doctors] and GP training, so I make sure that although there is regular turnover, they know me and know what I am offering. And I've put posters in different clinical areas as well as people have my number and they know what I am offering'' (Nurse 21).*

Many participants noted that **service development represented a significant aspect of their role**. It involved improving existing services by restructuring care pathways or facilitating access to available resources, in addition to designing and implementing new services by formulating business cases, putting in bids and drawing upon the expertise of different professionals from various fields:

*"We want to extend services but also create business cases, so internally people can start to think about how we look at young people's care in a slightly different way, which will be really positive'' (Manager 6).*

*"We have MDT [multidisciplinary team] meetings every month where we review where we are with different projects that we wanted to do and also who else we can tap into'' (Manager 15).*

Finally, some participants indicated that their role included **evaluating services and obtaining users' opinions** through formal (e.g., parent questionnaires) and informal (e.g., verbal feedback) measures. The quote below provides evidence that service users were highly satisfied with the standards of care provided by Roald Dahl Specialist Nurses:

*"We use questionnaires and we have got some good patient feedback, really good patient feedback'' (Manager 8).*

In conclusion, it is crucial to recognise that the responsibilities of Roald Dahl Specialist Nurses vary greatly. Their role is complex and cannot be reduced to the sum of its parts. It requires nurses to **work across professional boundaries in order to mobilise resources**. Thus, this role must remain highly flexible and autonomous so that nurses can get the right services involved at the right time. The **ability of nurses to (re)define their responsibilities** and work laterally and collaboratively in innovative ways is what has enabled them to remain responsive.

### *1.2.2 Clinical approach*

The analysis revealed four complementary philosophies which characterised and guided nurses' approaches to practice and therapeutic relationships. These clinical philosophies were family-centred care, holistic management, evidence-based practice and empowerment. They underpinned the work of nurses and defined their role-based responsibilities. All participants embraced a person-centred approach as they aimed to develop individualised care plans tailored for each patient based on their needs. Nevertheless, Roald Dahl Specialist Nurses **expanded the application of person-centred care to involve providing support for the entire family** of children and adolescents with lifelong conditions. The following comments showed how the participants' understanding of family-centred care underscored their approach:

*"For the families especially signposting and linking them with people who can help them over something that they can't do, and it's just giving that whole, it's not just the child, it's the whole family with it as well'' (Nurse 14).*

*"We have a philosophy that's very much around being person-centred. And I guess in a way our translation of that had always been about being family-centred'' (Manager 6).*

Providing holistic management was evident in the opinions and attitudes of all nurses interviewed in this study. The participants endeavoured to **facilitate inter-professional collaboration** to ensure the delivery of multidimensional care which addressed the various aspects of patient needs. These needs ranged from improving health outcomes to enhancing the patient's overall quality of life, as well as supporting the entire family. The following quote explained how nurses worked with colleagues to bridge the gap in current services to offer well-rounded management:

*"She [Roald Dahl Specialist Nurse] sometimes has to go to patient houses... She has done one or two and that was a joint visit with one of the consultants because they what to see what was going on exactly in the home and whether there were any factors that were affecting the child. So, it is bringing in together all of these factors that if we didn't have X [Roald Dahl Specialist Nurse] they just wouldn't be there" (Manager 18).*

Several participants explained that their approach to patient care was **founded upon evidence-based practice** which entailed that their clinical decisions were guided by the best and most recent research and guidelines both national and international. This knowledge was utilised to find the most effective treatment options that were discussed with the family before joint decisions were made:

*"We're also looking for speech and language help within the team... I think that would be the first time and would be really good and we do work with families because we know that from the research. I was involved in research in neurology a few years ago and looking at things, at impact outcomes, and extended family is a big thing, and how families cope with these problems, which is what they are, just the complexities of the whole thing" (Nurse 2).*

Some nurses explained how they consulted the literature and conducted research projects to inform service development and the implementation of new treatment approaches as described below:

*"It was actually Cannabidiol so the new cannabis, so we have got a trial of 10 children on that... collecting data, yeah, so it goes through the company X and it is just interesting to see what the side effects are because people thought it was the miracle drug and actually one person's come off it completely because it made her so much worse" (Nurse 17).*

The participants aimed to empower service users by providing and explaining medical information, teaching healthy strategies to cope with difficult emotions and ensuring access to social and financial support services. Thus, **empowerment emerged as a key clinical approach** that enabled nurses to deal with families and young adults as people, and avoided reducing the complexity of their experiences by looking at it strictly through a clinical lens. As such, the nurses succeeded in promoting high levels of active family participation in patient management and built **therapeutic relationships based on trust and joint autonomy**:

*"We've managed to educate them earlier and gave them more confidence and managed to get more services involved at an earlier point... we are giving them the best support and making sure the right people are in that" (Nurse 7).*

*"She [Roald Dahl Specialist Nurse] has a little business card that she gives out and she'll come in the morning and she'll have loads and loads of emails and messages to pick up. So, she's an absolutely fantastic asset... now they [family and Roald Dahl Specialist Nurse] have the conversations, they can*

*be pointed in the right direction, brought into clinic earlier. So, I think the whole patient experience is much more improved'' (Manager 16).*

### *1.2.3 Professional values*

All the nurses who took part in this study reported **great job satisfaction** which appeared to be linked to the caring values that underpinned their attitude towards the professional role. **Patient advocacy, being passionate, empathetic and motivational were core values** that informed the nurses' approach:

*"I love what I do. I don't think there's another specialty that has, you know. I don't know if I will be as passionate... to know that you are helping so many families, it's amazing'' (Nurse 1).*

*"It's all about coordinating care, being able to support families, encouraging research, to be empathetic and compassionate, all that... you've got to be multifaceted to do this role, really, it's unique'' (Nurse 4).*

*"It's advocating for our patients and going the extra mile and not giving up'' (Nurse 12*).

Several of the interviewed managers commended nurses for their **commitment to professional excellence and persistence in overcoming challenges**. They also described the nurses as highly proactive which resonated with the values of **enthusiasm, resilience and team spirit** that echoed throughout the nurses' narratives:

*"I think her [Roald Dahl Specialist Nurse] enthusiasm and drive are just, she's just full of life, that's the best way I can put it. And it rubs off on everybody else. You want to jump on the bus that she's on... she's very attentive and it's about getting it done. So, she comes with ideas and within the same day it's in your email box. It's already made, can we push through? So, she's not one to slow implementing things'' (Manager 15*).

## 1.3 Theme 3: Impact of Roald Dahl Specialist Nurses

This theme presents the different positive impacts that nurses accomplish through their role, together with how said impacts were evaluated. The findings related to this theme are summarised using the subcategories of 'Areas of impact' and 'Measuring impact'.

### *1.3.1 Areas of impact*

The data illustrated the substantial impacts that participants could evidence in terms of **saving time and financial resources for the NHS, taxpayers and service users**. Within their special role, this

group of dedicated nurses responded promptly to complex patient and family needs which **reduced waiting times, A&E visits, hospital admissions and duration of stay**:

*"I think our team manager and the MDT [multidisciplinary team] they can see the value, so if there's children and there's a lot of issues we can get out to them much quicker now. What would happen if I wasn't doing that is, they [family] would just constantly call or attend A&E, so to the wider Trust we are reducing hospital admission and less contact to the team that then can't be responded to... we will see patients on the ward, and we'll get them home as quickly as we can" (Nurse 7).*

Managers explained that Roald Dahl Specialist Nurses were excellent coordinators hence they arranged effective and efficient multidisciplinary care despite limited resources. Accordingly, managers attested that the **nurses were invaluable assets.** The following comment described how nurses built interdisciplinary teams and coordinated the work of different professionals to avoid duplication of efforts, which saved time and money:

*"Sometimes the diseases overlap, and endocrine [another speciality] have been a bit sometimes like we're not doing it. But we don't want to take your job... don't worry about that, we're not going to take your job in your clinic, we're just there to support the family, total family-orientated" (Nurse 3).*

The nurses excelled in performing tasks that were typically within the role of social workers or consultants, and thus they **patched up staff shortages**. Additionally, nurses indicated that they implemented multiple **novel interventions** and introduced new service developments which not only were cost-effective but also generated revenue for the hospital and Trust:

*"We earn our keep, so we provide with all the clinics we do, up to five a week, we bring in revenue and teaching we bring in revenue and we cover the consultants' workload basically, we are much cheaper than a consultant... consultants are doing a six-month [appointment], so we will see them [child and family] in between, we provide that contact, so that has a massive impact... I actually get to do service improvement, but also not only at our level, at Trust level and national level... I've been to Roald Dahl [Nurses'] conferences and networked with somebody and they've said they do this and I think that's fantastic, I'm going to take that back, this can save us money" (Manager 6).*

Nurses participating in this study shouldered **huge managerial and administrative burdens**. They strived to develop and implement effective policies and processes to reduce the amount of time wasted on paperwork. Moreover, Roald Dahl Specialist Nurses relied on evidence-based guidelines that ensured optimal timing for healthcare interventions, facilitated the best therapy outcomes and spared resources that could have been wasted on non-tested, and thereby potentially less effective, interventions:

*"They might say well this is my experience, but this isn't necessarily evidence-based, whereas we will only practice evidence-based, all of our advice is based on national and international guidelines" (Manager 5).*

The powerful impact of Roald Dahl Specialist Nurses extended beyond their immediate workplace. This encompassed the **development of the healthcare workforce** within the field of childcare for long-term and rare conditions. It was evident throughout transcripts that the nurses actively worked to produce and share research knowledge with fellow child specialists including physicians, community and school nurses. They offered teaching and training to colleagues within and outside the Trust and **built communities of practice** that served to educate families, students and professionals. The nurses also provided teaching on creative, time and cost-effective measures to optimise services as shown below:

*"They [Roald Dahl Specialist Nurses] have spent such a lot of time teaching and training others and the feedback often I get is about, oh it's been amazing, we never knew that, we never thought of it, now we've put this in place. And actually, a lot of the stuff is not at a cost, it's only about behavioural differences" (Manager 6).*

*"There's a lot that we have developed since having X [Roald Dahl Specialist Nurse], in terms of we can arrange family days, education days" (Manager 18).*

*"I'm involved in teaching of nurses. Again, I'm thinking of innovative ways to make as good use of my time as possible. So, I am trying to make online resources and things like that. I'm part of nurse induction... when the nurses start, they come to spend a little bit of time with me. I am able to explain my role and I might do a little bit about epilepsy if they've got any questions. So, there's a teaching element and in fact I am part of the doctors' sim in the morning, we did the simulation this morning, and I did some teaching in that alongside the consultant. I'm a part of policy writing and putting things together and communicating via email. So, at the moment we're looking at standardising some care plans" (Nurse 21).*

The above comment emphasised the significant contributions of nurses to policymaking and setting benchmarks, that ensured the delivery of standardised, good quality care across the NHS. Therefore, it was through arranging holistic and multi-site management, service improvements, family and peer education and the introduction of better policies, that the nurses **promoted positive changes in the organisational culture**. One of the most profound changes that Roald Dahl Specialist Nurses were committed to achieving involved the **reshaping of the transition pathways of young people from children to adult services**. The nurses spoke at length about the pitfalls of some of the current transition procedures that involved a mere referral from paediatric to adult specialists. It was explained that such a simplistic procedure overlooked the complex biopsychosocial requirements of young people with chronic conditions. The nurses endeavoured to replace the outdated 'transfer of care' model with the more apt 'transition pathways' approach. They defined transition pathways as well-rounded, interdisciplinary care processes tailored to address the specific requirements of young people and family in order to successfully guide their way from child to adult services in a smooth, step-by-step manner. This approach guaranteed the continuity of care and empowered patients to cope with the change. The nurses were changing how transition was understood and dealt with by professionals, and thereby promoting best practice for the benefit of service users:

*"We're looking at the pathways across sites, how can we make it so it's a standardised pathway because we know that in some areas there's really good examples of transition, but in others not so great or it's just not really happening, it's more of a transfer of care. And it's also looking at, so not just standardising it, how can we make it more equitable across Trusts as well because we know that different services can look so different, even if they are from the same specialty from site-to-site" (Manager 13).*

*"The roles [of Roald Dahl Specialist Nurses] are more about influencing and encouraging and engaging our clinical staff to think differently about how they support young people... the idea is that X [Roald Dahl Specialist Nurse] can either personally liaise with that clinical team or phone the ward or drop an email to say I noticed that Y [patient] has been admitted to the ward, and Y has a background of [condition] and has anybody thought about beginning the transition pathway... it's about planting that seed to say actually 13 is an ideal time to start having those conversations" (Nurse 14).*

The participants had a marked influence as **active change agents.** This also manifested in the form of **increasing public awareness** about rare conditions. They informed societal perceptions and raised the profile of different health problems in an attempt to correct misconceptions and secure more funds from the charities and the NHS:

*"Roald Dahl has been fantastic with putting me at the forefront of events and stuff so that people could recognize what [condition] is. We've had the opportunity to go to Buckingham palace with a [condition] patient. And things like even lifeline, just lots of people contacted me and said, oh you know [condition] and so that was really good" (Nurse 1).*

*"Mum was crying in the corridor and X [Roald Dahl nurse] stopped and spoke to them... and we [two Roald Dahl nurses] got involved and the patient's development was getting worse and we found a charity … And we took him and his mum and dad and raised £3000 and [the charity] put up £3000 and he had nine months of intense physiotherapy... They got him in a standing frame and that little boy is three now and he runs around like any other little boy... that was looking through charities and seeing what could be done for him and making lots of different phone calls... so we have an impact, he's developed from having no movement to being able to walk" (Nurse 3).*

The words of participant three were amongst countless success stories that demonstrated the **massive effects that nurses had on therapy outcomes**. It was, therefore, the opinions of all managers that Roald Dahl Specialist Nurses were **indispensable for service users, the Trust, the medical team and community**:

*"I think if families didn't have that input [of Roald Dahl Specialist Nurse] it would be a disadvantage to families. I feel like they were being cheated because they need it in order for their child to get the best care and for families to get support" (Manager 15).*

*"To me X [Roald Dahl Specialist Nurse] performs an absolutely invaluable role that would not be possible if we hadn't had the Roald Dahl funds [Roald Dahl's Marvellous Children's Charity's support]... I think the value that she brought to the service, to the patients, to the staff on the ward, obviously also decreasing the workload of consultants... it's been a much more holistic approach" (Manager 16).*

### *1.3.2 Measuring impact*

Many participants enumerated the methods used to evaluate the nurses' practice. Some of the measurement tools served to quantify the **impacts that Roald Dahl Specialist Nurses had on health-related outcomes, while others measured the nurses' productivity**. The effectiveness of care provided or organised by nurses was quantified using evidence-based tests that evaluated the patient's condition, such as movement or functional assessment. Although these tests were sometimes conducted by other specialists, improvements reflected the effectiveness of treatments coordinated by Roald Dahl Specialist Nurses. Reductions in the number of missed appointments, number of A&E visits, number of hospital admissions and duration of hospital stay were also recorded by some nurses and reflected the time and resources saved by nurses as well as the positive effects that they had on the child's health:

*"We're looking at things like Was Not Brought [non-attendance] rates to the adult clinic... other ways that I could evaluate my role is the amount of phone calls that I get for advice, the number of emails that I get for support and advice" (Nurse 9).*

*"She [mother] was there and I said why don't you just come and see me, or call me, and then I can see you and then reassure you... what I am doing is keeping her out of A&E actually" (Nurse 20).*

Examples of **quantitative tools that measured productivity and efficacy** included detailed call logs in which nurses registered the number and duration of calls with families seeking help, also the number of families on each nurses' caseload, number of teaching sessions for families, students and peers together with the number of attendees. Additionally, surveys were conducted to evaluate the extent to which nurse-led teaching informed learners and/or resulted in positive changes in practice:

*"Calls that we've made, or we've received, and the patient Excel sheet we've got, we write on there what the conversation was, what's been done, how long it took and about the phone calls as well" (Nurse 3*).

*"One of the measurements is how many education sessions that we deliver across the Trust and the number of professionals and the variety of professionals that we target. And embedded in the evaluation we are revisiting the professionals that have attended the sessions and say 'so following the education session, what changes have been made within your team? Has it had a positive impact, have you taken something away from it and have you improved?" (Manager 13).*

Typically, the more calls, cases and teaching a nurse had been able to manage, the more productive they considered themselves to have been. However, several of the duties performed by the nurses were complex, time-consuming and required cooperation from families, healthcare professionals and social workers in various organisations. Consequently, managers acknowledged that **the work of**

**Roald Dahl Specialist Nurses cannot always be measured in numbers** and should not be reduced to ticking tasks off a checklist. In other words, responding to less calls or emails was not equated with lower efficiency. Instead, the quality of advice and support that families received were more accurate measures. Therefore, several nurses used **qualitative measures such as parent and patient reported questionnaires** and informal verbal feedback to evaluate the extent to which the services offered had been impactful and satisfactory:

*"I think there are really good cases where we have got fantastic patient experience, where professionals as well talk a lot about how great it is" (Manager 8).*

*"Patients tell me time and time again that they're so thankful for that because that's been a big impact on patients, that they've now got somebody to contact, somebody that will answer their questions that helped with alleviating stress and patient experience and reduced complaints or issues that the service experienced. I get good feedback from families as a whole..." (Nurse 12).*

Feedback from managers and colleagues was sought, regular audits were undertaken, and the participants were keen on producing and disseminating reports detailing the nature and impact of their work:

*"We produce a six-monthly report to the Charity... we are part of a quality improvement methodology for this work, so we are looking at things like, how many staff have come to our awareness training; we're looking at patient experience questionnaires and feedback for young people who are in adult clinics" (Nurse 10).*

The findings signified **overwhelmingly positive service user, peer and managerial feedback**. Most feedback was subjective which is better suited for the nature of the nurses' role. However, this **subjectivity made it challenging for nurses to estimate their impact in exact figures**. It was also reported that obtaining quantitative feedback from already overwhelmed and busy families was a lengthy process, resulting into poor response rates to surveys. Moreover, it was imperative to note that Roald Dahl Specialist Nurses were employed in different settings and performed various tasks, and therefore it was **difficult to systematically quantify and compare their collective impact**:

*"It is so subjective what we do, it's difficult to measure what we do, but we have put things in place since I've started just trying to document how many phone calls we received in a day. And out of hours as well, we have our mobiles and although we don't work weekends, we keep our mobiles on and I say to my families if it's an emergency, if you need me then I am available, so we are evaluating and then also I developed a questionnaire that we send out to a number of patients in a month. It is difficult to getting, we're asking a lot of families, they've got a lot to do so it's been very slow to get feedback" (Nurse 12).*

## 1.4. Theme 4: Challenges and solutions

This theme describes the challenges that Roald Dahl Specialist Nurses faced and the strategies they adopted to overcome said challenges. They have been grouped into two subcategories: 'Trust issues' and 'Exponential caseload'.

### *1.4.1 Employing organisation issues*

The first challenge that many nurses encountered when they stepped into the post was to establish the service. This task was particularly demanding if the new nurse could not draw on the expertise of existing or previous Roald Dahl Specialist Nurses. Tackling this challenge was often complicated by several **issues related to systems and processes within the employing organisation** (NHS Trust or Health Board). These issues included the lack of processes to get services up and running, poor infrastructure and limited technological resources, staff shortages, financial constraints and bureaucracy. Therefore, **creating a sustainable, smooth and seamless service was a time-consuming and frustrating process** that was described by one participant as *"treading water just trying to make everything work" (Nurse 4).* The excerpt below elaborated on some of the reported Trust issues:

*"I suppose all the services aren't there that you would want, out in the community as well. So, you ring colleagues and whatever, or you've children in here who have been here for weeks and they need discharging, and they need discharge plans and packages put in place, and it's not there and whatever. That is all very frustrating…" (Nurse 2).*

The nurses addressed the challenges associated with setting up services by developing and implementing the policies, procedures and paperwork required to map out a clear pathway for families to access resources. Throughout this process the nurses had to make their role and the new service known to families and colleagues. This was not considered an obstacle hence the nurses endeavoured to inform key stakeholders using different methods including business cards and posters. The following comment showed how nurses explained their role and **defined their identity in inter-professional settings** to ensure collaboration. The comment also demonstrated how nurses persevered to **create communication channels** with medical professionals to coordinate patient care:

*"When I first started, I think people were a lot more 'what are you doing? Well, why have you come to see that patient?' We were like well we're here to support the family. So, it wasn't a barrier as in don't come, but it was a bit like well what are you doing? Well, it's a new service. And explain to them about the service and what we're doing and we're here for the family. And then the other barriers; the difficulty is getting people to answer their, doctors in particular, their emails. You email them and email them" (Nurse 3).*

Some nurses reported encountering resistance to the changes they proposed. **Overcoming inertia and reshaping the organisational culture** were other challenges that some nurses overcame through effective communication and promoting best practice:

*"You've also got the issue with consultants and we use the culture of 'this is what we do' and trying to get them on board with actually 'this is what's best' and this is what's going to provide the best care for the patient …and changing their culture and their mind-set on board with your thinking" (Manager 15).*

The data indicated that Roald Dahl Specialist Nurses performed a vital role and contributed to the multidisciplinary team through their unique expertise which was heavily relied upon by consultants. This reflected the nurses' invaluable input, but it highlighted the unreasonable workload that was sometimes required of them. Several nurses explained how they managed their time and prioritised vulnerable families. They **tactfully negotiated with medical colleagues to set realistic expectations** through which the nurses were able to regain control over their workload:

*"They (consultants) are quite a challenging group to work for… Like one of them does the spasticity clinic and the spina bifida clinic, and he wants me in that one. And then the other one wants me to run my hydrocephalus clinic, and the other ones wants me to do a head injury clinic, and there's only one of me" (Nurse 20).*

Many nurses shared their experiences of **working in sub-par conditions that hindered their ability to perform their role**. They identified several problems including insufficient amount of digital equipment such as laptops and tablets and limited IT support, office space and storage. The nurses' experiences were corroborated by managers who acknowledged the need for better infrastructure. There were also concerns for patient wellbeing as a result of being treated in a poor environment with inadequate lighting and ventilation:

*"The infrastructure around supporting these patients in really challenging environmental settings… So, I don't know if you've seen our outpatient area, you know, it's not nice. It's oppressive; there's no natural light, it's always overcrowded" (Nurse 10).*

Despite these problems, the nurses construed a positive attitude that reflected their work ethic and understanding of the financial constraints existing within the NHS. They shared equipment and offices whenever possible and **collaborated with managers on business cases** to improve conditions in their department. However, most of the nurses and managers expressed concerns that financial decisions impacting on the Trust could mean that they may not continue to fund the nurse's post once the initial five-year commitment between the Charity and the NHS Trusts had concluded. Both groups of participants agreed that defunding the post would disrupt services, compromise quality, disempower families and cut off their support:

*"Unfortunately, a lot of their [NHS Trust] decisions are based on money. It doesn't matter about quality, unfortunately that's not something which is prioritised for them, but I would hope when you appoint somebody you appoint them knowing that the Trust is going to take that on after that funding's finished" (Manager 18).*

### *1.4.2 Exponential caseload*

*"I know that X (Roald Dahl Specialist Nurse) has a caseload of about 800 patients. There are challenges, as I said, with managing the team, managing the patient caseload" (Nurse 10).*

The above quote was one of numerous comments that documented the massive caseload that nurses handled individually. It was a significant challenge as **the caseload continuously increased** due to referrals and word of mouth. In that sense, Roald Dahl Specialist Nurses were **victims of their own success**. It was often difficult to reduce caseload, because some families tended to become reliant on the assistance they received from nurses in the absence of alternative services:

*"The conditions have just increased tenfold, and the dependency of patients… I'm seeing patients that I discharged off neonatal, and you sort of discharge them and you know that they're going to have problems" (Nurse 3).*

Several nurses explained that cases piled up because it was **difficult to transition existing patients** to adult services that were not prepared to address the intricate demands of young people with rare conditions:

*"We don't actually transition that many compared to the ones that we get in. So, we have about eight referrals, eight to ten referrals every month and then maybe four to five of those will be epilepsy patients that we actually diagnose. So, I think we're getting more in than we are transitioning" (Nurse 17).*

The data suggested that Roald Dahl Specialist Nurses did not always receive sufficient cooperation from adult specialists. Specifically, the nurses sought to create holistic transition routes, while **the clinical philosophy that dominated adult services reduced this complex process to a mere transfer or referral procedure**. The responsibility of building better bridges to adult services as well as educating and encouraging other specialists to participate in the process fell on nurses. Tackling these challenges was time consuming and led to a growing caseload:

*"I think it's also about that it's an enormous task and this is not one person's role, it's a bit like transition is everybody's business, so what are people, what are they also doing about it? And to think about when they're talking about transition, are they actually talking about transition or are they talking about transfer of care?" (Nurse 9).*

Moreover, nurses **struggled to turn families away** which added to their duties, especially in acute settings where new patients were admitted daily. Yet, several strategies were employed to handle caseloads as **nurses rationalised appointments, prioritised vulnerable families and selected cases based on accurate assessment**:

*"The job gets bigger and bigger and bigger the more cards you give out, but I am selective. You know, I have to be, because it's such a massive caseload or workload. But I know who might need that kind of support" (Nurse 20).*

Finally, empowering families by offering information and building a support network of peers and professionals around them was a fundamental strategy deployed by nurses to promote independence and, as a result, manage their workload:

*"When these children actually start getting older, start having to think about their condition, and having to become empowered, then that is a long process. Not something that you can just do in one clinic session, you have to do an education over several years, and then having that familiar face then in the adult environment when you're handing them over is also really important as well, to have that proper continuation" (Manager 18).*

# APPENDIX 2

# NURSES:

## FOCUS GROUP FINDINGS

## Appendix 2 Nurses: Focus group findings

### 2.1 Exploratory Theme 1 - An insight into caseload management of the Roald Dahl Specialist Nurses

The focus group questions explored how caseloads were defined initially, how they have changed over time, and how the nurses and teams have responded to these changes. The findings can be seen in Table 2.1.

With the exception of some transition-focused roles, the Roald Dahl Specialist Nurses all **managed their own caseload** although in some cases this was defined by the lead clinician. While the nature of the caseloads differed from one nurse to the next (e.g., size and condition), the majority of nurses experienced a **very similar pattern of how caseloads evolved over time**. Key phases related to caseload management, from the establishment of the post to embedding of the role are shown in Figure 2.1.

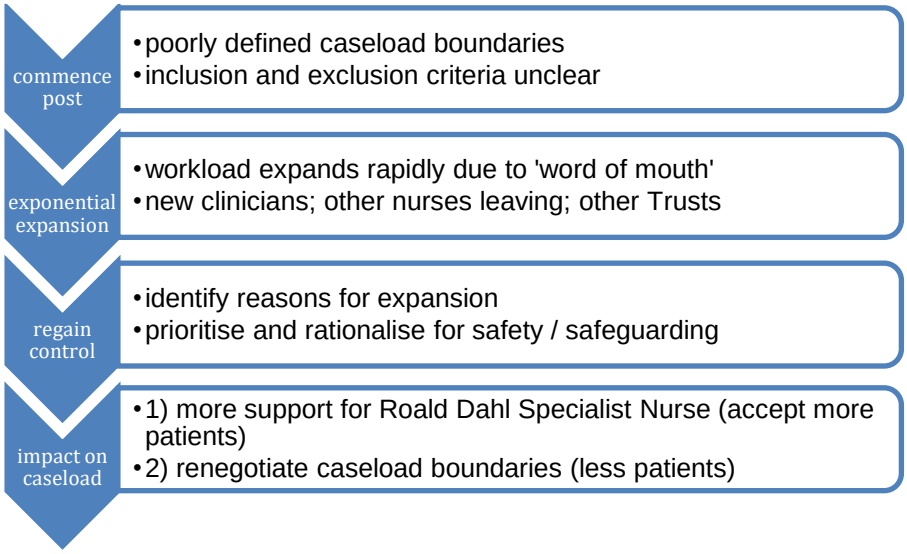


**Figure 2.1 How Roald Dahl Specialist Nurses' caseloads evolve over time**

**At the commencement of the role, the caseload was often not well defined** and this led to uncertainty and frustration for the nurse and the clinical team within which they worked. A lot of time and effort were devoted to **defining the caseload boundaries** (inclusion and exclusion criteria) and this sometimes put the nurses into conflict with clinicians and other team members. **Caseloads were noted to have grown 'exponentially'** with nurses feeling they were **'victims of their own success'**. The more mature services had put strategies in place to **regain control over their workloads** and this had been successful to varying degrees. However, this meant that uncomfortable decisions had to be made, such as removing some children from the caseload when they were improving in the management of their health and were no longer priority patients. Some nurses expressed concern that they could now only see the sickest of their patients, or only

those in acute care rather than in the community, and felt they were neglecting other children and families who would still benefit from their care. Nevertheless, safety was paramount, and **caseload restrictions were justified by undertaking risk-benefit analysis**.

Nurses argued that much of their time was taken up by undertaking tasks that did not require their skills and knowledge, and that **access to an administrator or support worker role** would vastly improve the efficiency of their role and enable them to provide more front-line care. Additionally, better access to psychologists, interpreters, youth workers and social workers would be welcomed as **much of their workload crossed the boundaries of health and social care**. In particular, they believed a **large proportion of their role was focused on safeguarding**, filling in many of the service gaps by liaising with housing, welfare and education services.

In summary, carefully defining the boundaries for caseloads before or at the commencement of the role is vital for an effective and harmonious service. The caseloads are expected to grow, so should be monitored carefully and the boundaries revisited periodically by the nurses and their wider clinical team. Innovative strategies should be considered to facilitate expansion of the service to enable as many children as possible to benefit from the Roald Dahl Specialist Nurse, while at the same time safeguarding the health and wellbeing of the post-holder.

**Table 2.1 Topics discussed by Roald Dahl Specialist Nurses related to their caseloads**

| Topic | Specific points | Comments |
|---|---|---|
| Responsibility for a caseload | • Majority of post-holders manage their own caseload though some are defined by their consultant | Some transition roles do not have own caseload (work across sites, large numbers). |
| Definition of caseload at commencement of post | • Most caseloads are not well-defined at commencement of role<br>• Some 'dysfunctional' services - significant effort to define roles and boundaries ('jigsaw puzzle with no picture')<br>• One or two very new services have had to actively seek patients (rare diseases) - this also requires time for networking | No legacy or footprint and therefore time-consuming to define once in post: caseloads should be worked up before appointment. Danger is they say yes to all at first, even if not directly in scope - they pay for this later as it is harder to remove a client than add one. |
| 'Exponential' caseload expansion | • 'Victims of their own success' - word of mouth referrals<br>• Safeguarding requirements take precedence<br>• New clinicians bringing additional patients with them<br>• Local barriers to transitioning mean increased caseload<br>• Local factors (e.g., asylum/refugee settlements in area)<br>• Other nurses leaving and passing on their caseload | Nearly all nurses reported large increases to their initial caseloads (snowballing). Transitioning issues can be a barrier to older patients moving off their caseload, yet new ones continue to be added. |
| Re-gaining control over caseloads | • Require strict referral criteria<br>• Requires buy-in from matrons, managers, clinicians, MDT, community colleagues (supported to say 'no')<br>• New systems and processes: regular review, capped lists, notice periods for new referrals, specialist clinics to reduce 1:1s; training to empower other staff (e.g., health visitors) | Strict criteria are particularly important as Roald Dahl Specialist Nurses do not have the normal 'ward based' support structures in place - e.g., when on leave nobody else does their work and this work accrues. |
| Impact of revised referral criteria | • Criteria are tightened over time<br>• For large client groups (e.g., epilepsy) they can only see the sickest children - adverse impact on others who would benefit<br>• Removal of some 'well' patients to facilitate new referrals<br>• signposting of 'care coordination' to more appropriate services<br>• community referrals 'out of scope' | Some Roald Dahl Specialist Nurses report their consultants 'hold on' to patients who should be moved on. |

| Topic | Specific points | Comments |
|---|---|---|
| Safety is paramount in caseload decisions | • New referrals suspended until safe levels (isolated cases)<br>• Referrals only accepted from hospital-based clinicians (as community/hospital systems don't link up and risk is too high)<br>• Some do accept community referrals but work closely with a community-based nurse specialist | Community patients may be losing out due to incompatible technology and work practices. |
| How could Roald Dahl Specialist Nurses be facilitated to manage their caseloads more effectively? | • Many had underestimated the psychological input required for many of their patients: ideal model is a Roald Dahl Specialist Nurse, administrator and psychologist working together<br>• Admin or support worker support would make a significant difference for most Roald Dahl Specialist Nurses (but longer-term substantive, not short-term agency)<br>• Support should be expected at the same level as that offered to consultants (e.g., support for clinics, letter writing etc.)<br>• Inter-connectivity of different systems (time-consuming re-entering data multiple times)<br>• Access to hospital-based interpreters rather than telephone services (parent trust)<br>• Better access to youth workers and psychiatry/psychology services (poor for 16-18-year-olds) | Better support will increase front-line patient care and introduce or protect important services such as nurse-led clinics.<br><br>It is not time or cost-effective for a Roald Dahl Specialist Nurse to undertake tasks that could be done by a lower salaried colleague or other professional. |
| Are Roald Dahl Specialist Nurses undertaking roles beyond healthcare? | • Roald Dahl Specialist Nurse role characterised by high volumes of safeguarding and non-healthcare liaison and sign-posting - welfare, child protection, housing officer, social worker<br>• Safeguarding work reduces the amount of healthcare that they can provide and ultimately reduces the numbers on their list | If the Roald Dahl Specialist Nurse doesn't undertake safeguarding, they believe there will be nobody else to do this - the child falls through the cracks.<br>Safeguarding requirements have increased with austerity / social care cut-backs. |
| Additional training required since appointment to manage the caseload | • Medicines management – nurse-prescribing training is challenging, intense and complex for practitioners, but ultimately saves a lot of time chasing clinicians and speeds up care pathway<br>• subject knowledge (e.g., transition, epilepsy, genetics)<br>• training the trainer courses<br>• clinical skills courses such as cannulation; communication / counselling / motivational interviewing<br>• quality improvement | Two nurses expressed frustrations because the way their NHS Trusts had interpreted role demarcations had prevented them from prescribing after completing the training (they were informed that only Advanced Clinical Practitioners could prescribe).<br><br>All of these that the nurses recognised as vital training are pointing towards advanced clinical practice. |

## 2.2 Exploratory Theme 2 - An insight into the role and working relationships of the Roald Dahl Specialist Nurses

The focus group questions explored how nurses perceived their role in terms of the skillset required, and how they made the transition to 'novice' Roald Dahl Specialist Nurse, through to an experienced and established post-holder. Working relationships with clinicians were also explored. The key topics and findings are discussed in Table 2.2.

The nurses described a number of routes through to their Roald Dahl nursing post, with some already being employed in the organisation and often the service, and others entering the role as a new member of staff. However, their **transition journeys through the early stages of the role, i**n terms of exploration of role boundaries, priorities and support networks, were similar. In particular, the now experienced Roald Dahl Specialist Nurses were able to articulate what they felt **the required skillset** is for the role to work well; interestingly **few mentioned clinical skills as they felt these were often a pre-requisite for the role**. Their required skillset was clearly defined by both focus groups as **excellent communication, innovation, efficiency and knowledge, with many examples given that aligned clearly to the leadership element of advanced clinical practice**. The transition journey from novice Roald Dahl Specialist Nurse to established, embedded practitioner is shown in Figure 2.2.

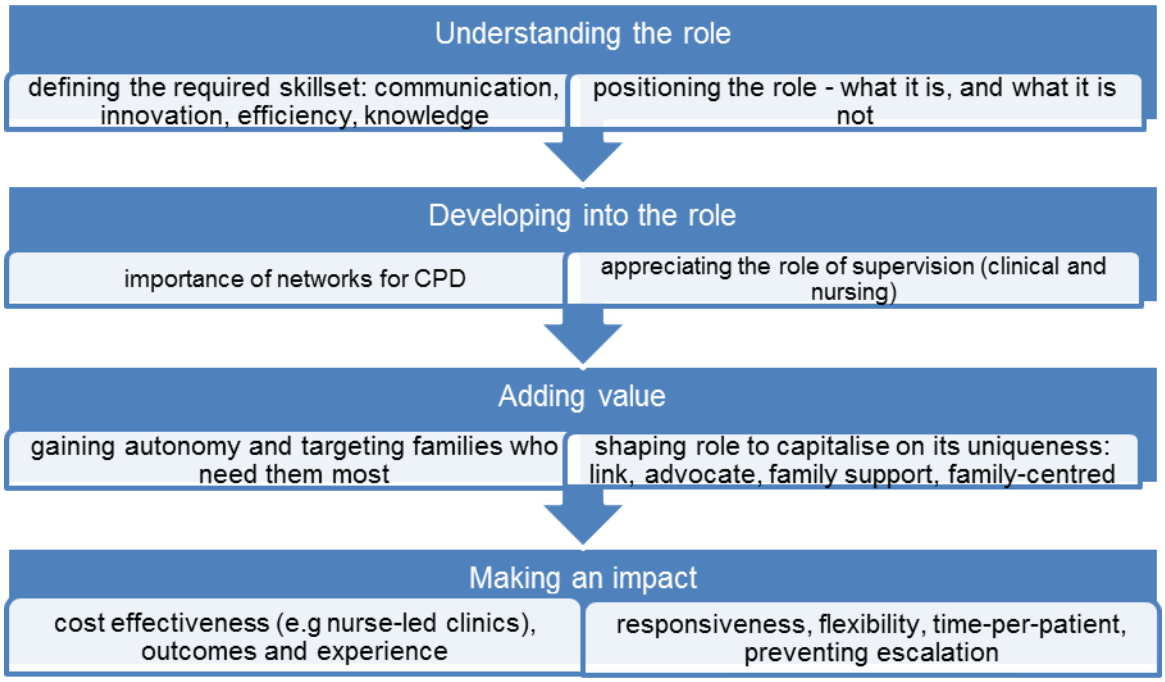


**Figure 2.2 How Roald Dahl Specialist Nurses evolve from novice to established roles**

**Table 2.2 Topics discussed by Roald Dahl Specialist Nurses related to their role**

| Topic | Specific points | Comments |
|---|---|---|
| How would you describe the role? | *Role titles:* Most were a 'specialist nurse' or 'clinical nurse specialist' and one or two 'advanced nurse specialists'. *"I celebrate being a Roald Dahl Nurse and a crocodile nurse - carrying the title, tell people that I am funded by the Charity, wear the badges etc."*<br>• *"a graceful duck":* head above water but paddling hard<br>• *jack of all trades:* caseload manager, social worker, admin staff, support worker, educator, advocate, spokesperson<br>• *"the link between families and the rest of the world":* a lot of politics to negotiate between different trusts and services within and outside the hospital, and between people and technology which don't talk to each other<br>• *"Carrying this burden":* on my own | There was some confusion between role titles such as specialist and advanced nurse, but all were proud of the 'Roald Dahl Nurse' status.<br><br>Some nurses had experienced difficult mental health issues, and they acknowledged that they had regularly practiced 'crisis management' for everyone else while neglecting themselves. It was very difficult to 'say no' and so they had little time to do the core job. Some emotional blackmail to take more patients "just one more patient - I am really worried about them". |
| Required skillset | • *Communication*: good communicator, cooperative, empathetic, patience, intuition (sixth sense), emotional intelligence, networking, educator (other professionals and patients, teachers, students), negotiator<br>• *Innovation*: adaptable, flexible, ability to think outside the box, innovator and new ways of working<br>• *Efficiency*: ability to prioritise, good organisation skills, tenacity, resilience, autonomous, delegation, seeking advice<br>• *Knowledge*: of speciality, change management and leadership skills, healthcare management skills, writing policies and pathways, setting up business meetings and writing business cases | When asked about the skillset of a Roald Dahl Specialist Nurse, the participants responded collectively with a high degree of insight into their role which stretched beyond the clinical care elements (which they perceived as a given when applying for the role). The Roald Dahl Specialist Nurses (all with at least 18 months experience in the role) recognised that in order to be effective they required an advanced level of leadership and management expertise more aligned to 'advanced clinical practitioner' role descriptions rather than a 'clinical nurse specialist' role. |

| Topic | Specific points | Comments |
|---|---|---|
| How do you learn these skills? | • *Learn on the job*: need experience and time, as you "*don't know what you don't know*" at first<br>• *Asking for help*: from managers, from Roald Dahl's Marvellous Children's Charity, from parents who often become experts. Be honest, say you don't know and sign-post to others - parents appreciate this<br>• *Research online*: can be difficult to find info on some conditions as children are living longer with some conditions so evidence is patchy<br>• *Make 'friends' in every department*: (e.g., social services, wards, housing) and tap into specialist nursing knowledge<br>• *Supervision from clinicians/ MDT*: required to discuss decisions, provide support and education<br>• *Importance of CPD*: rapidly changing specialities so need to be part of local/national SIGs and networks. Acknowledge always something to learn, but say if out of scope of practice | The post-holder may be very experienced coming into the post but needs time to embed and make new contacts. The nurses all agree that they can never be 'all knowing' and to understand when they reach the limits of their scope of practice. CPD was seen as essential in their rapidly changing specialties although opportunities for external funding were limited. |
| Transitioning into a Roald Dahl nursing post | • *Existing employee, new Roald Dahl nursing post*: often insufficient induction "Here is your desk and computer, off you go". The transition to the new role needs support even for existing staff<br>• *Existing Roald Dahl nursing post, new employee*: having a new Roald Dahl Specialist Nurse come into established team can be challenging for the existing nurses, "the old way is not necessarily the right way"<br>• *Transition period too short:* particularly for those not used to managing their own caseload "After day 5 was given 250 patients". "I was supernumerary for 2 weeks then given 500 patients to manage"<br>• *Pressure comes from within:* being perfect is unachievable, manage own, patients' and staff expectations. Management training helps: go for a few quick wins, *"which 3 things would not have happened if you had not turned up for work today?"*<br>• *Succession-planning*: following on from difficult transition experiences, some had initiated 'link' roles who can support future post-holders or e prepared for the role themselves<br>• | The transition to a new post was often described as stressful, both for existing employees and those new to an organisation. While a good training and support package was offered in some cases, this was an exception rather than the norm. Existing employees find it very difficult to move away from their old role to concentrate on the Roald Dahl nursing role.<br><br>Many of the nurses self-identify as 'perfectionists'. Management training helps to provide strategies to put the role into perspective, reduce stress and enhance motivation. |

| Topic | Specific points | Comments |
|---|---|---|
| Relationships with clinicians | • *The 'missing' link:* the nurses often adopt a role between patient and doctor - translating what medical teams want to communicate. Parents appreciate this one point of contact, as do the doctors. Senior medical staff see them as an asset, filling in a gap that improves their service<br>• *'Not a doctor':* Often need to explain the complexity of the role. Challenging to educate consultants in difference between a CNS role and a junior doctor- what does and does not come into remit. Nurse role focuses more on families and support, rather than clinical intervention<br>• *Understanding medical hierarchies:* need to work hard on relationships, very different to a nurse hierarchy<br>• *Shaping your own role:* often role is defined initially by service managers or consultants; nurse managers/matrons not working in the specialism day to day. Only the Roald Dahl Specialist Nurse will see the gaps in the service over time, though this can put them in conflict with those who initially defined it. Most nurses have managed the development of their role effectively | On the whole, Roald Dahl Specialist Nurses relationships with clinicians are very positive, but the relationship needs constant attention as new medical staff join the team (e.g., rotational training posts). In particular, they need to differentiate between their role and that of junior doctors. The nurses also need to get used to the fact that you are not 'managed' by clinicians in the same way as nurse managers.<br><br>While clinicians are seen as a safety net to capture children who need urgent care, the Roald Dahl Specialist Nurse role has enabled service to follow families up a lot better. Many Roald Dahl Specialist Nurses can see patients at home and this is really valued by the clinicians. Most Roald Dahl Specialist Nurses are very autonomous and manage their own caseload, and feel an equal part of the team. They feel they can target families who need support the most. |
| Impact of the Roald Dahl nursing role on the service | • *Cost-effectiveness:* Can see children in clinic for a lot less cost than a consultant, and free up clinicians to see the more complex cases<br>• *Responsiveness:* More flexible than clinicians and can see patients more quickly, provide reassurance. Non-medical prescribing provides responsiveness for medication requests<br>• *Flexibility:* May see patients at home if needed, providing a different service to clinicians. In homes get a much different picture and understand the challenges they face and the adaptations they might need<br>• *Time-per-patient:* More time with patients, e.g., explore medicines adherence with teenagers, easier in a home setting than a formal clinic with parents present<br>• *Preventing escalation:* Can prevent a major event requiring admission e.g., by seeing a complex child for an early appointment | Nurses can be really responsive in terms of reassurance to parents and answering 'quick' questions that otherwise would build up their anxiety – *"small things make a massive difference"*. Nurses are more able to provide this than clinicians.<br><br>One nurse articulated the impact as follows: *"Fundamentals of being a paediatric nurse is the holistic family-centred care that our consultant colleagues do not have the capacity to deliver".*<br><br>All noted how difficult it is to prove their impact (such as preventing admissions) and recognised the need to gather qualitative data such as parent feedback. |

| Topic | Specific points | Comments |
|---|---|---|
| What would make the job more manageable? | • *Administrative support:* essential to free up nurse for other roles<br>• *Technology and systems:* that 'talk to each other' - patient information is spread across many different applications<br>• *Family support worker:* to help with referrals to social care<br>• *Psychologist:* attached to the service to support mental health needs<br>• *Safeguarding:* role is huge so any support in this area would be beneficial to all | All nurses mentioned the extensive administrative elements of the role that take them away from clinical care. Most also recognised the value that specific professionals or support workers could bring to their service. |

# APPENDIX 3

# LEAD CLINICIANS:

# QUESTIONNAIRE SURVEY RESULTS

## APPENDIX 3 LEAD CLINICIANS: QUESTIONNAIRE SURVEY RESULTS

*"We were delighted to receive Roald Dahl ['s Marvellous Children's Charity's] support to appoint a specialist NM [neuromuscular] transition nurse…" (Clinician).*

### 3.1 Section 1: Basic demographic details

In all there were 17 responses received from clinicians from a wide variety of different clinical environments. All of the respondents were designated *consultant* and had all been in their post for at least three years.

Their clinical specialisms included epilepsy, non-malignant haematology, neurology and gastroenterology (Figure 3.1).

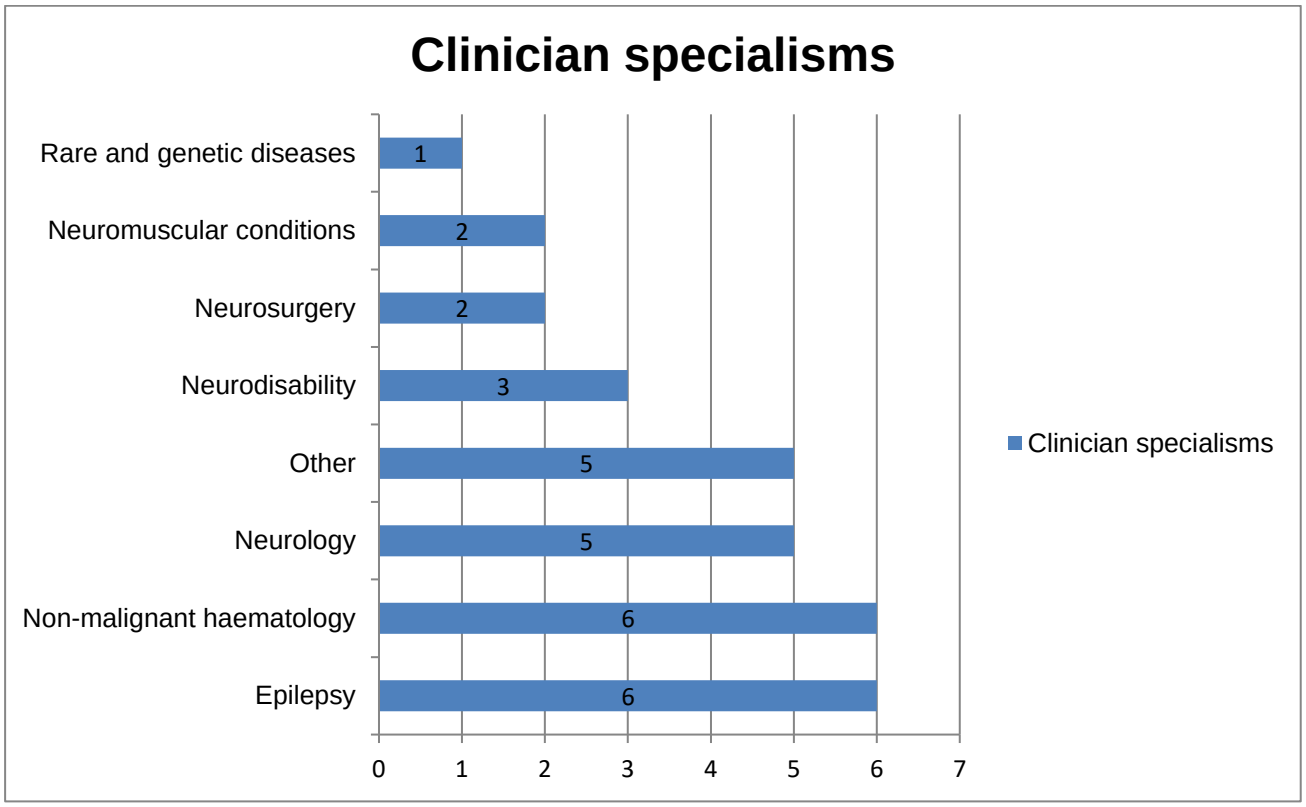


**Figure 3.1 Area of expertise of the participating clinicians** *(clinicians could indicate more than one area). 'Other' included renal, hepatology, oncology and adolescent health and transition.*

### 3.2 Section 2: The business case for the Roald Dahl Specialist Nurse

We wanted to know if the clinicians had been involved in the business case and their views on this. In all, 75% (n=13) of the respondents were involved in developing the business case.

*"Without the RD nurse [Roald Dahl Specialist Nurse], these families would have nothing…" (Clinician).*

We asked the clinicians for the rationale that they had presented to Roald Dahl's Marvellous Children's Charity for establishing the Roald Dahl Specialist Nurse role. There were a number of themes that emerged from the data. At the most basic level, the overriding rationale for the Roald Dahl nursing posts was that there was clear evidence of widespread unmet clinical need for CYP and their families living with conditions that did not attract either much kudos or popular charitable funding. Other issues such as the transition from child to adult services were emerging as important issues (but also unrecognised by management) requiring specialist support.

*"Transition is a huge step for any young adult with a rare disease that has been under paediatric services and there is often so much to coordinate and even create to allow successful transition to adult services, hence the business case for this post…"*

As another pertinent example, there was a recognised need for dedicated specialist nursing support for CYP with complex gastrointestinal diseases (inflammatory bowel disease and intestinal failure requiring home parenteral nutrition). These sorts of less 'glamorous' long-term conditions were driving the agenda as the funding for these services was not seen as a priority.

*"We were developing the first Paediatric Rare Disease Centre in the UK and we quickly realised that families affected by rare and undiagnosed genetic conditions needed help and support in accessing the available resources and also coordination of care. That was the business case for the first two Roald Dahl Rare Disease Specialist Nurses."*

#### *3.2.1 Plugging a gap…*

There did not always seem to be a coherent long-term strategy for the business cases. The most common reason identified for the role was to 'plug a gap' in care delivery. The quotes below illustrate the scale and nature of the problem:

*"We were unable to meet the service specification which helped with the business case... and allowed us to be compliant with the standards for haemoglobinopathy."*

*"We had no nursing provision at all for children with non-malignant haematology conditions except for haemophilia. We have a large population of children with sickle cell disease, but also many others with long-term, significant blood disorders. We were not able to give the children the care that they deserved or meet their needs with only consultant level staffing."*

*"We needed nursing input to be able to properly support children, families, and schools, who are scattered over a large geographical area… To support the growing number of children with non-malignant haematology conditions who did not have access to a CNS."*

The scale of the problem was apparent. One consultant described dealing with a large caseload of 650+ patients with epilepsy with no Epilepsy Specialist Nurse (ESN) support:
*"We desperately needed a specialist nurse to fill the huge gaps in care not covered by other allied specialists such as physiotherapists or occupational therapists."*

### *3.2.2 Coordination and development of CYP services*

At a more sophisticated level, we wanted to understand in more detail what that unmet need actually looked like and therefore how it might be addressed. The clinicians appeared to want a nurse to fill the gap, but they were not always clear at the time of writing the business case what they actually wanted them to do:

*"As it is the first of its kind in our department it was challenging defining the exact role as there was no similar service to compare with…"*

It was interesting to note that whilst the role is always seen as a nursing one, it was equally apparent that the Roald Dahl Specialist Nurse role was envisaged as much more than a straightforward nursing role. Part of the issue relates to the ability of the team to 'ring fence' the boundaries of the Roald Dahl Specialist Nurse role and to identify how their skills may be best used. There are not enough specialist practitioners in relation to the increasing number of new referrals:

*"There was a significant need to bridge community, outpatient, and inpatient services…"*

One post was established in order to take a pivotal role in the development and implementation of an integrated pathway of care for CYP with epilepsy. The rationale for the business case presented by the lead clinician was that there was a clearly identified need for a senior nurse to play a key role across the entire pathway, helping to ensure continuity between settings (both primary and secondary care) and being a main source of epilepsy expertise for the CYP and their families. There was also a perceived need to support and educate other clinical staff including community children's nurses, school nurses, teachers, learning disability nurses and medical colleagues.

*“In our setting, the post extends to children who have complex needs with other neurological diagnoses (including epilepsy). For these children, the RD nurse [Roald Dahl Specialist Nurse] oversees and coordinates all of the care planning, school and respite care liaison, rescue medication training and telephone triage and advice for the families on the books.”*

There was also a perceived need for the Roald Dahl Specialist Nurse to act as a single point of access or contact for the team; filtering access to the team including the triaging of calls from families, carers, A&E, and primary care. Examples given included taking on follow-up outpatient clinics as an example of ways to increase service capacity. Another clinician describes a perceived need for a senior clinician to coordinate the development and delivery of new disease modifying treatments for neuromuscular conditions such as spinal muscular atrophy and Duchenne muscular dystrophy, leaving a gap in standard care that the Roald Dahl Specialist Nurse might fill:

*“To support and oversee in conjunction with the wider team… We had no nurse and the nurse needed to fill a huge gap…”*

*“…confining the post-holder to duties and responsibilities which required her specialist nursing experience and expertise, rather than being expected to perform all nursing duties for the patients with the index conditions.”*

One clinician said… *“there is a lot of work to be done and knowing where to start / what to prioritise. We have had our Roald Dahl Specialist Nurse in post for almost 18 months and they have been developing the post from scratch. The families have high levels of need and social deprivation so there is a lot of work to be done.”*

Clinicians identified that the Roald Dahl Specialist Nurse would be required to provide *“Cover for the [clinician] post-holder when not working e.g., for annual leave, sickness etc.,”* but few had considered the need for cover for the nurse's work when they were away from work, or for succession planning in the role. This appeared to be an issue for many nurses whose work piled up whilst they were away during annual leave or sickness absence.

## 3.3 Section 3: The perceived challenges

### *3.3.1 A successful business case*

A challenge highlighted by a number of respondents was a lack of experience and support in creating a viable business case. Some clinicians were clearly prepared for the challenge following acceptance of the business case although others were daunted by the task. The barriers to a successful business case included financial issues. A number of the respondents referred to a freeze on all new posts, and the perceived 'dire financial status' of a number of the organisations prevented the approval of business cases:

*"Failure to persuade NHS Health Board management of this being a priority, and so funding not available…"*

One consultant referred to the challenges of funding 'Cinderella services' with a long history of under-investment:

*"From my experience of being a consultant with 21+ years of experience, paediatric epilepsy service in most DGHs is a Cinderella service with a lack of investment, unlike other services such as paediatric oncology or diabetes service. Hence, to convince the management of need for an epilepsy nurse specialist is an uphill task."*

In addition, consultants had to challenge conventional wisdom with senior management:

*"First of all is the acceptance of the roles by the Hospital Management and Nursing Team given the novelty of the idea and also commitment to continue funding the post after the initial two years."*

### *3.3.2 Setting up the service*

Finding the 'right' person for the post was clearly very important and required rigorous selection processes:

*"Selecting a competent, dynamic individual was going to be tricky, I knew. I needed to appoint the best candidate (I am happy to provide information on the interview style I devised) … In developing and planning the role, I was quite particular with selecting a candidate who is ready and capable of evolving, not afraid of taking on initiatives and who genuinely loves working with people. The nurse in question has risen to the challenge in a very impressive way. This reflects her own personal abilities, but I am aware that the support she receives from the Roald Dahl network [of nurses] has also been vital."*

However, several clinicians noted previous failed attempts to appoint the right person for this unusual role. Some earlier appointments had resulted in the nurse being moved on to other clinical roles more suited to their experience and abilities, whilst some highly suitable appointees had not felt the role was appropriate for them, and had moved on to other posts.

Initial challenges to setting up a new service included logistical issues such as getting to know people in the hospital and the surrounding teams and networks, the geographical challenges of a large catchment area. Other bureaucratic issues such as IT support and the lack of existing infrastructure were cited as important.

*"I set up the service from scratch but had a huge amount of support in doing so. The difficulties were therefore manageable because of this."*

### *Figure 3.3.3 Integrating into an existing team*

While the Roald Dahl nursing service may have been new, the newly appointed nurse had to 'bed in' to an existing multi-disciplinary team. In some cases this included other nursing colleagues, but in others they were the only team member inputting nursing expertise as well as a nursing philosophical approach to the care of the patients. Networking with other health professionals and across healthcare boundaries was recognised by the clinicians as highly valuable and requiring higher level skills and attributes:

*"Coming into a new role, dealing with a group of rare disorders, and joining a well-established team can be challenging. As the only nurse on the team, it took time to build up links across our regional network and these have been very effective in supporting local care and monitoring."*

*"She has 'upskilled' a number of community and school nurses and involved them actively in patient care. She has developed her confidence and undertaken a prescribing course and now runs a number of nurse-led clinics, providing more regular access to expert clinical assessment and advice."*

*"She has forged links with other organisations and services to develop 'alert' systems for our patients and with other specialty teams across the region to develop evidence-based emergency care plans for all patients… She is balancing many competing needs… the safeguarding of an individual child against the importance of dealing with a teenager having a myasthenia crisis against a planned clinic and this requires levels of competence, leadership and initiative that can be daunting."*

## 3.4 Section 4: Roald Dahl Specialist Nurses and their caseloads

### *3.4.1 Size of the caseload*

Thirteen of the services (81%) had employed one Roald Dahl Specialist Nurse. Two services had employed two nurses, and one clinical team had four Roald Dahl Specialist Nurses working within their service (Figure 3.2).

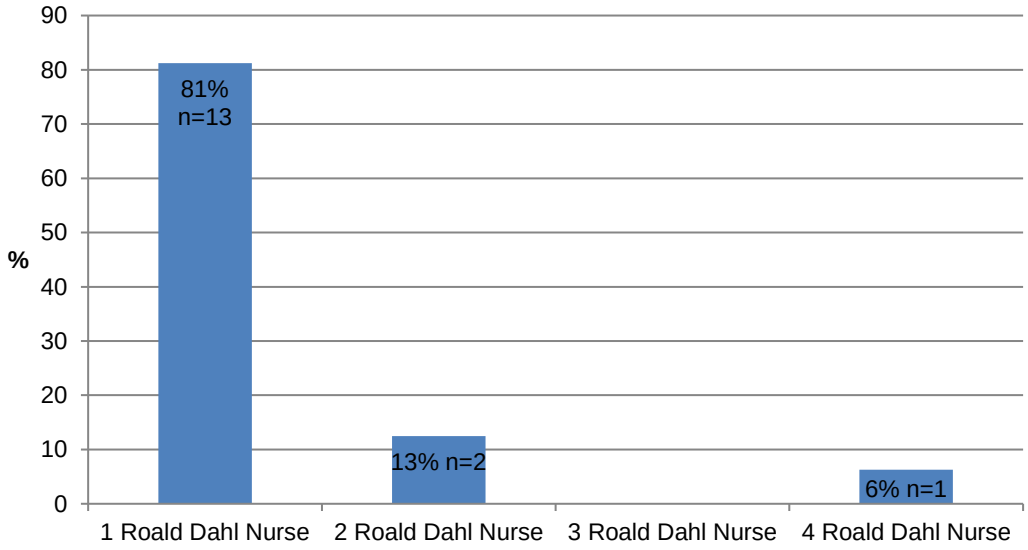


**Figure 3.2 The number of Roald Dahl Specialist Nurses in the clinician's clinical service** *(16 responses)*

We were interested in the lead clinicians' views of the Roald Dahl Specialist Nurses' caseloads. One of the key issues that emerged from the interviews and focus groups was the size of the caseload and the challenges in managing caseload numbers and complexity. In terms of caseload, we wanted to understand the factors that affected the size of the caseload. Four nurses in one clinical centre (three FTE) had a caseload of less than 20 patients each, although this small caseload number accounted for some of the most complex children with rare and genetic diseases. For the remainder of the NHS Trusts, clinicians indicated that nine of the Roald Dahl Specialist Nurses in the survey had a caseload in excess of 300 Children and Young People, with four of these nurses having a caseload in excess of 400 (Figure 3.3).

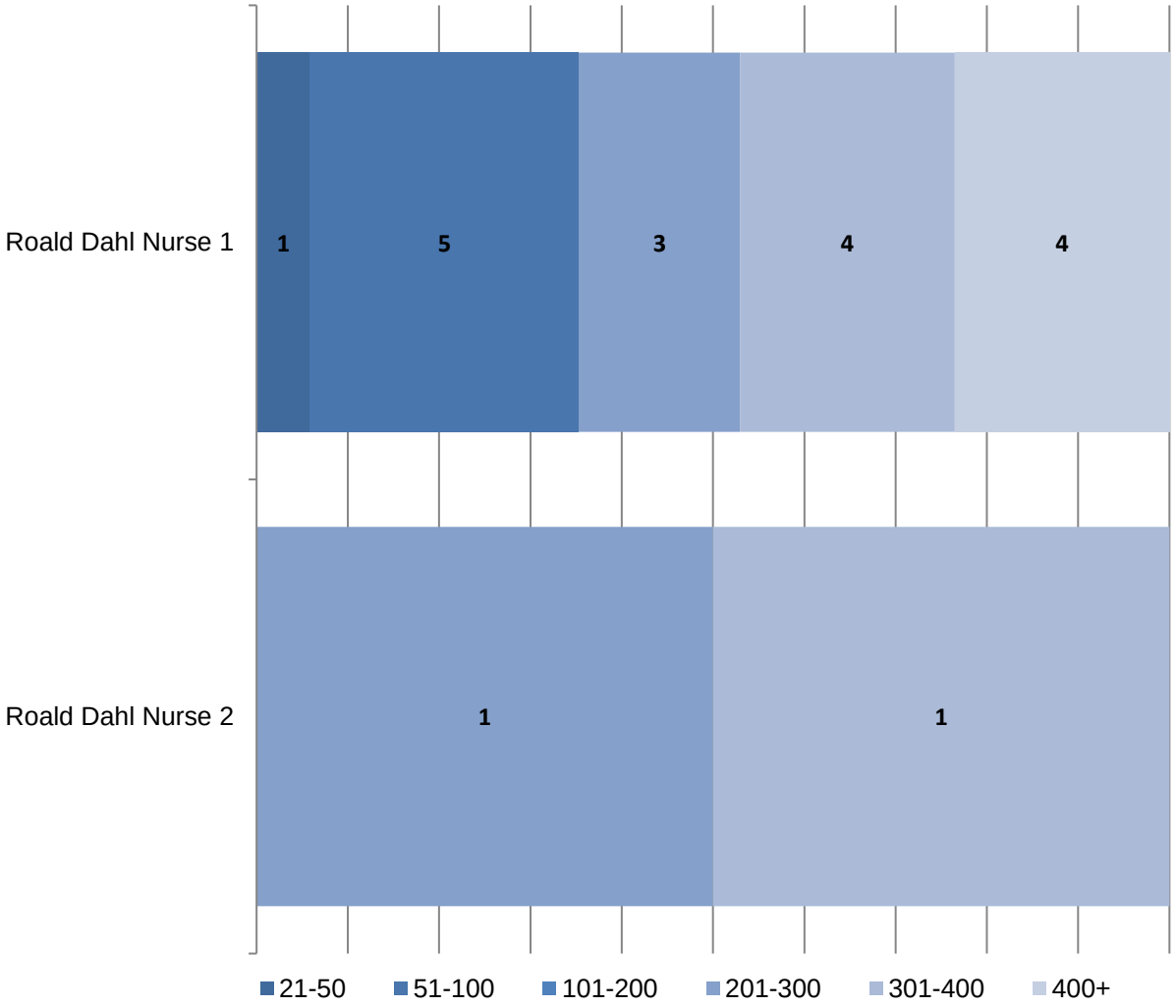


**Figure 3.3 Current size of the caseload of the Roald Dahl Specialist Nurses working within the clinical service.** *The four nurses working in a single clinical service were excluded from this figure. The numbers of nurses are shown against each caseload size (represented by different colours).*

### *3.4.2 Case complexity and prevalence of the condition*

Many of the services described by the clinicians are tertiary referral services and therefore have a regional or national caseload; one of the teams serves a population of about four million people, including one million children. Not all patients require specific input from the specialist nurse but benefit from the work they can/have done in relation to educating other HCPs in the region, drafting regional guidelines and standards of care and signposting families and other professionals. Nevertheless, the clinicians recognise that caseloads are often too high and that there is a need to keep caseloads in check:

*"The Rare Disease Team now triage all referrals, so they can keep the numbers manageable. Ideally, they would like to offer help to more families but have had to set limits to be able to manage each case properly."*

One of the challenges for the clinicians when setting up the service is to identify which of the patients would benefit most from the services of the Roald Dahl Specialist Nurse. As an example, the team at one hospital look after roughly 600 CYP and their families with neuromuscular conditions. The clinician noted that not all of the CYP need input from the specialist nurse. It is more appropriate for the neuromuscular nurse specialist to get involved with the more complex problems, for example if an inpatient stay is required or disease modifying treatment is necessary. This view on the complexity of the caseload was echoed by another clinician working in the epilepsy field:

*"The complex epilepsy service and the size of the caseload depends on the number of referrals received and the number of CYP that transition to adult services each year. This caseload is part of the [regional] Epilepsy Network and is very complex containing children who have had epilepsy surgery or are on ketogenic diet."*

Clinicians explained that the size of the caseload is less important than the complexity of the patients, and tertiary centres often receive more complex caseloads:

*"We have a single Epilepsy Nurse Specialist for a paediatric epilepsy caseload of 650+ patients with a significant higher percentage of CYP with complex epilepsy."*

*"Our caseload is skewed more towards that of a central London hospital offering tertiary epilepsy services rather than a stand-alone non-London DGH (which is what we are) … which makes life interesting."*

The complexity of the condition and the complexity of the population background are inextricably linked. For example, sickle cell patients' families tend to have a high proportion of challenging circumstances in addition to the healthcare challenges that they face. These wider challenges include, for some families, being asylum seekers, having high levels of poverty and cultural and language barriers. For many of the families English is not their first language. The need of these families, that might be supported by a Roald Dahl Specialist Nurse, is often greater than their healthcare needs alone. Additionally, some conditions may affect more than one child in a family, which adds to the complexity of these challenging circumstances, with many children requiring specific support from social services and education services:

*"Underlying condition and how much the child is affected…The family set up, e.g., socioeconomic, extended support, if just one affected child or multiple, housing, geographical location and what other support is available locally… Language barriers."*

*"The complexities of the condition, the social and psychological issues involved and whether patients need or have social services involvement, whether they require help with Educational Health Care Plan and the number of specialists involved."*

Geographical location was also flagged by some clinicians as influencing the size and complexity of caseloads:

*"Our hospital covers an area with an increased population of CYP as a percentage of whole population and there is also significant deprivation and migration into the borough with CYP with complex epilepsy. Hence the need for support from a Paediatric ESN [Epilepsy Specialist Nurse]."*

### *3.4.3 Sustainability of the caseload*

Clinicians were asked if they felt the caseload was appropriate for the Roald Dahl Specialist Nurse to handle. While the majority of clinicians felt caseloads were probably or definitely within acceptable limits (Figure 3.4), one third (n=7) of the caseloads handled by the Roald Dahl Specialist Nurses were not felt to be sustainable in the longer term:

*"This is a huge caseload for one person. In our setting, the RD nurse [Roald Dahl Specialist Nurse] also covers neurology (and in this regard, the clinical complexity of the patients can be quite high)."*

*"I think it [the caseload] is quite high and very complex, so I would definitely call it unreasonable. It would be great to have more epilepsy specialist nurses, especially experienced ones…"*

One clinician noted their previous experience:

*"In the past the nurse made clear that she felt overwhelmed and we reduced it accordingly."*

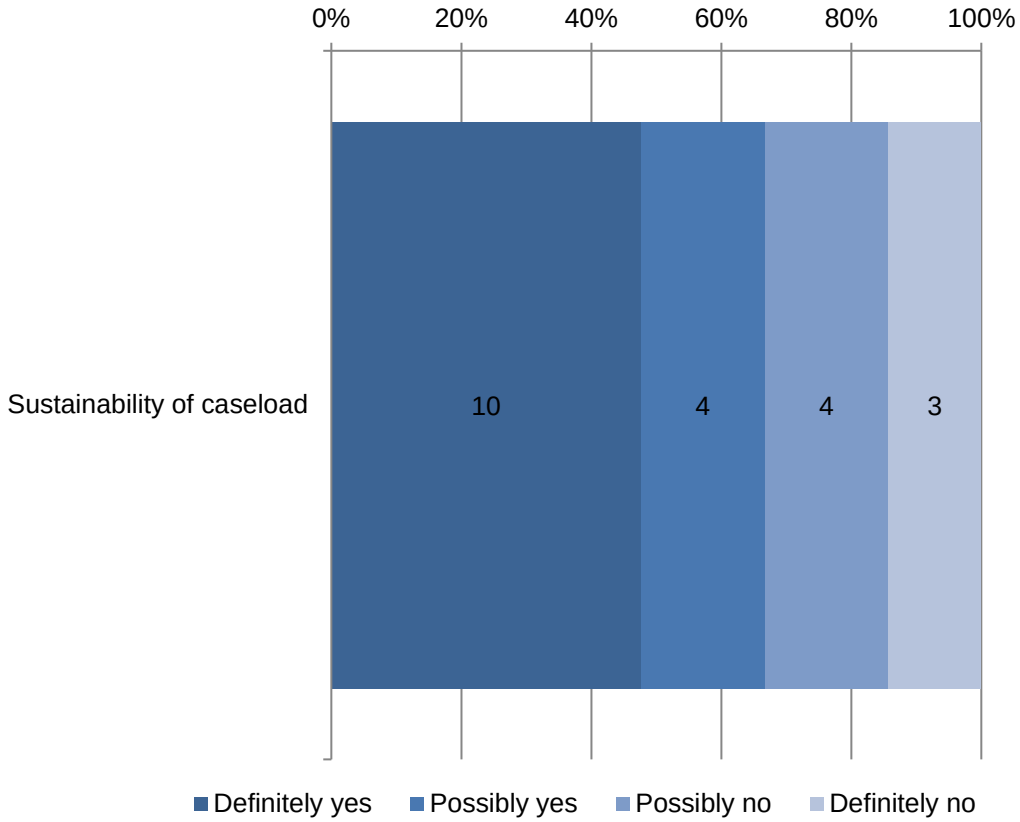


**Figure 3.4 Clinician assessment of the sustainability of the size and complexity of the caseload (n=21 services)**

Many clinicians recognised that caseloads had grown since the initial inception of the Roald Dahl nursing role. Clinicians stated that 12 of the 21 nurses' caseloads (57%) had increased over the last one to two years, although several were unsure of current caseload numbers (Figure 3.5).

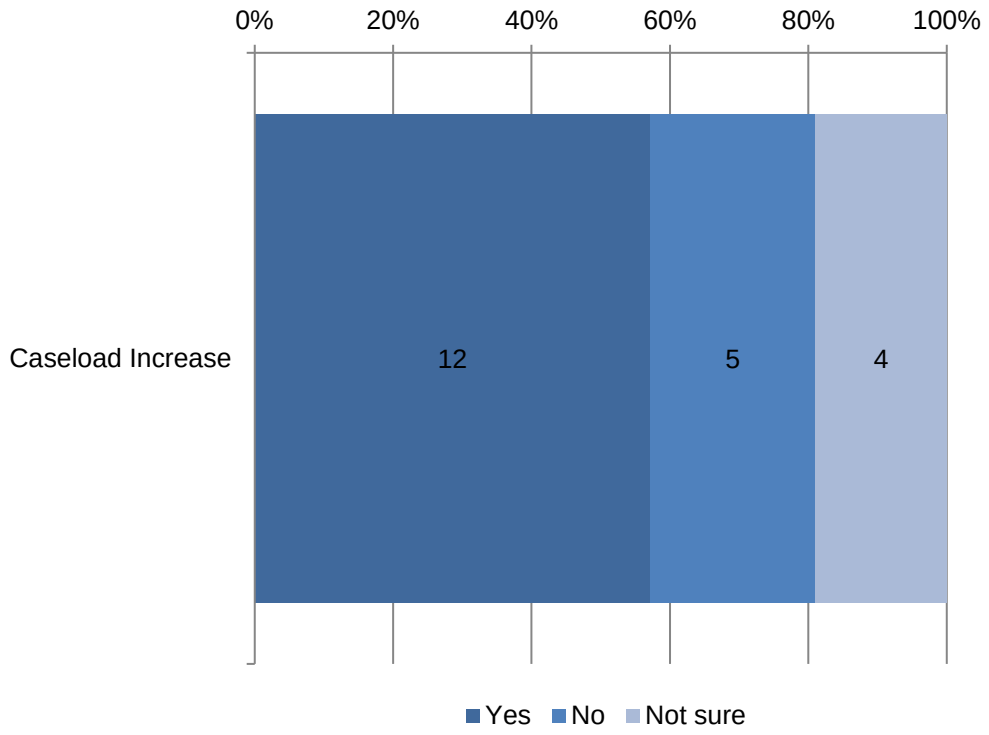


**Figure 3.5 Has the caseload increased since the role first started? (n=21 services)**

Increasingly, there are fewer discharges from long-term condition services, as CYP are living longer and surviving conditions which previously would have proved terminal; this contributes to an exponential increase in the workload. As one consultant noted:

*"The caseload is increasing, and the complexity is as well... I foresee that sooner rather than later additional specialist nurses will be required to enable us to provide the quality (and equity) of care throughout the region… Our team had always been designed to deal with complex epilepsy, but our caseload is increasing as the service is maturing and as we take over more children from other paediatric services across the region."*

One of the clinicians discussed the effect of the COVID-19 pandemic on the caseload. The team see approximately 500 CYP and their families face to face each year, though this model has had to change owing to the pandemic. The recent move to virtual and more phone support may be adopted as normal practice for the service moving forwards. This technology-supported practice may enable services to cope with some increase in caseload numbers.

Clinicians identified certain key areas where there are gaps in their service that cannot be filled by the Roald Dahl Specialist Nurse in a sustainable way, recognising the need for either an additional Roald Dahl Specialist Nurse, or other healthcare input to support them:

*"…in providing emotional and behavioural support to families who may be facing complex lifelong disability and/or life limiting disease we believe that we need dedicated mental health support for many of our patients and are hoping to pilot a NM [neuromuscular] mental health nurse with external funding from [company] to support our RD NM nurses [Roald Dahl Neuromuscular Specialist Nurses]. We also feel that the adult NM patients would benefit form a dedicated NM nurse. Therefore, while the caseload may be similar in total numbers, having more input has allowed us to identify the needs of our patients more comprehensively and this in turn creates greater pressure for existing team."*

One clinician, however, issues a note of caution regarding the longer-term sustainability of the role:

*"We have been extremely happy with our current Roald-Dahl Paeds ENS [Roald Dahl Epilepsy Specialist Nurse]. She has added significant value to the patient management pathway. However, I worry that this is a right recipe for burnout and job dissatisfaction for her, due to the humongous caseload and a higher complexity of the caseload. Unless our Trust recruits another ESN to support the current one (either Trust funded or Charity supported) - then I fear that in due course of time we will end up losing the current one as well."*

One clinician had also recognised very early that the caseload would not be sustainable for the Roald Dahl Specialist Nurse, and had campaigned for additional nursing support which was a successful addition to their team:

*"The very high workload and large/ increasing patient numbers and complexities, and lack of cover for this important role during time of absence (for example annual leave)…In recognition of this, [our] hospital agreed within three months in principle to the post of a junior neuromuscular specialist nurse - this post has been successfully recruited to and has made a significant difference."*

### 3.5 Section 5: The impact of the Roald Dahl Specialist Nurse upon different aspects of the care of the CYP and their families

Clinicians were asked whether the Roald Dahl nursing role had a positive or negative impact on various aspects of clinical care within their service. Figure 3.6 shows that the clinicians recognised positive or extremely positive impacts on a wide range of service provision, including psychological and practical support for families, multi-disciplinary team working, improving access to services, coordination of care and navigating the healthcare system.

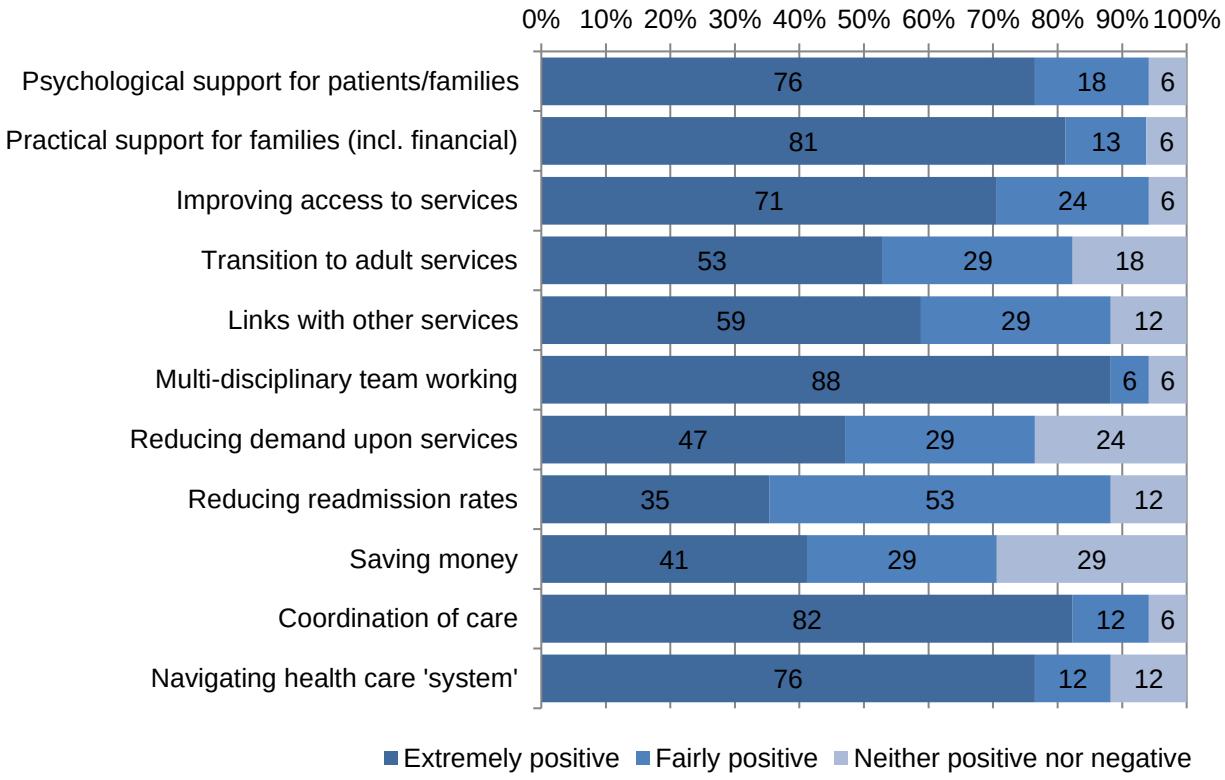


**Figure 3.6 The perceived impact of the Roald Dahl Specialist Nurse on various aspects of the clinical service**

While no negative impacts were highlighted, some clinicians felt that in some aspects of care it was more challenging to identify any positive impacts including saving money (n=5/17; 29%) and reducing demand on services (n=4/17, 24%). In fact, demand appears to increase in some services as word-of-mouth referrals become more commonplace. Clinicians were divided in their opinions on whether the Roald Dahl Specialist Nurses had an impact on reducing readmission rates, with two thirds identifying either no effect or a fairly positive effect (n=11/17, 65%).

Some clinicians commented that it would take time for any impacts of the Roald Dahl Specialist Nurses to be measurable; it is also challenging to confidently state cause and effect as the nurse does not work in isolation. This made it difficult to provide substantive evidence to senior managers for the on-going funding of the role:

*"…it is difficult to be certain in the NHS with Managers that do not understand why the service is needed.... unfortunately, there are still many such managers in the NHS that are not patient-focused and instead, fixed on numbers and payments..."*

However, the clinicians gave many tangible examples of where they recognised the impact of their Roald Dahl Specialist Nurses:

*"The Roald Dahl Nurses have been fantastic and many families would not have been able to manage without them. As a Consultant, it is very reassuring to know that the Rare Disease Nurse Specialist will be able to help in the management of a complex patient and to have the treatment that I intend them to have."*

*"… the addition of a [Roald Dahl] Specialist Nurse has greatly improved the quality of service we offer to our patients and their families, and feedback from these families has all been extremely positive."*

*"The Roald Dahl Nurse has been a very useful addition to the team providing a more holistic approach and assisting with coordination of care. We deliver a lot of day case work and this would not be possible without nursing pre-assessment and support. The advantages for children and families are very clear with a child-centred approach to care and treatment. The nurse provides additional support regarding medication queries and service queries which is very useful for families."*

### *3.5.1 Potential expansion*

The majority of clinicians (n=13, 76%) recognised the value of the Roald Dahl Specialist Nurses and answered ‘definitely yes’ to whether there are other areas in their organisation which could benefit from a similar service (Figure 3.7).

These areas included some clinical specialities already associated with Roald Dahl nursing, including: non-malignant haematology; children’s epilepsy; complex neurological disorders and neurodisability, and sickle cell disease. Transition of CYP to adult services in some of these conditions was also mentioned. However, clinicians also mentioned some additional areas suitable for Roald Dahl Specialist Nurses which had not been addressed within this current study cohort. These included: nephrotic syndrome and chronic kidney disease; children's rheumatology; oncology; spina bifida; diabetes, and allergy nursing.

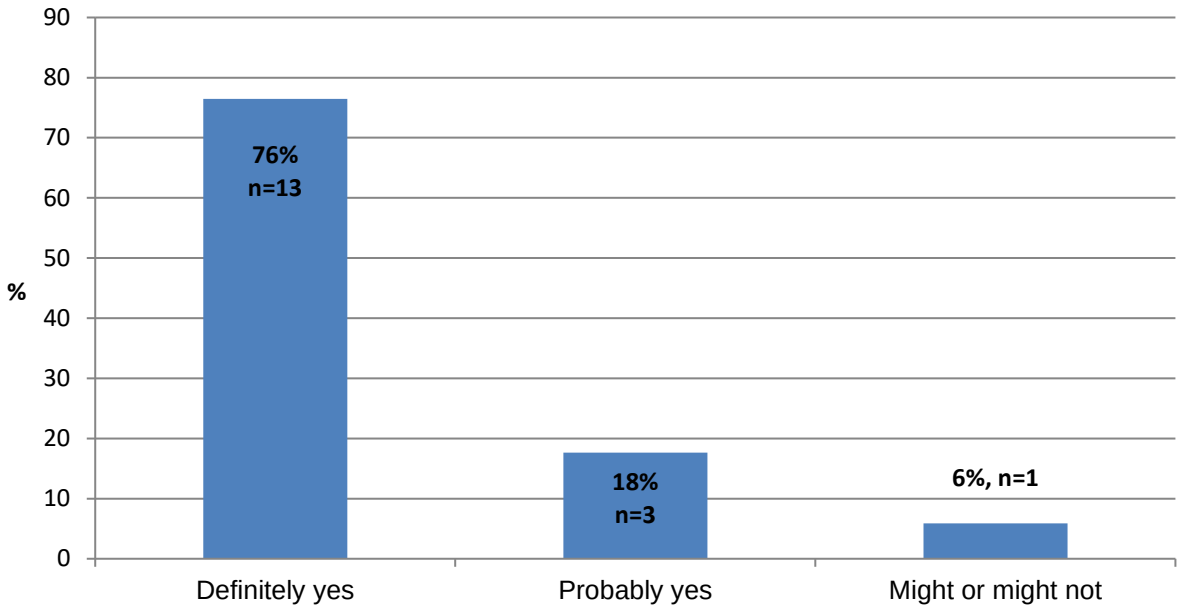


**Figure 3.7 Other areas in the clinician's organisation that would benefit from a Roald Dahl Specialist Nurse**

Having a Roald Dahl Specialist Nurse in one specialty had demonstrated, to some clinicians, the inequity of care for children and young people in some similar specialties that they oversaw:

*“At present we do not have any support for children with other severe and complex neurological disorders, which feels very difficult at times, especially when contrasting the support and care children with NM [neuromuscular] disorders and in particular those with cancer can access. A neurology specialist nurse would help us support and care for these families in a much more holistic and comprehensive way.”*

They also identified aspects of their own specialism that would mean a business case for an additional Roald Dahl Specialist Nurse would be sensible:

*"There are also novel therapies and strategies coming online for what were previously incurable NM disorders meaning that individual patient care is becoming increasingly complex."*

### *3.5.2 The future for the role*

Clinicians were asked whether they believed the role would be likely to continue after the 5-year partnership with the Roald Dahl's Marvellous Children's Charity comes to an end. All clinicians stated that it would definitely or probably continue (Figure 3.8), which the quotations below fully support:

*"This is a central role in our service and I have every confidence that it will be sustained."*

*"We could not run our service without the role and I would not be willing to continue to look after these children without any nursing support."*

*"The Trust has committed to this being a permanent post."*

*"The work of the NM nurse is vital and the Trust recognise this so can see the benefits of continued funding."*

*"There is a clear need for this role."*

*"We could not do our jobs without this post."*

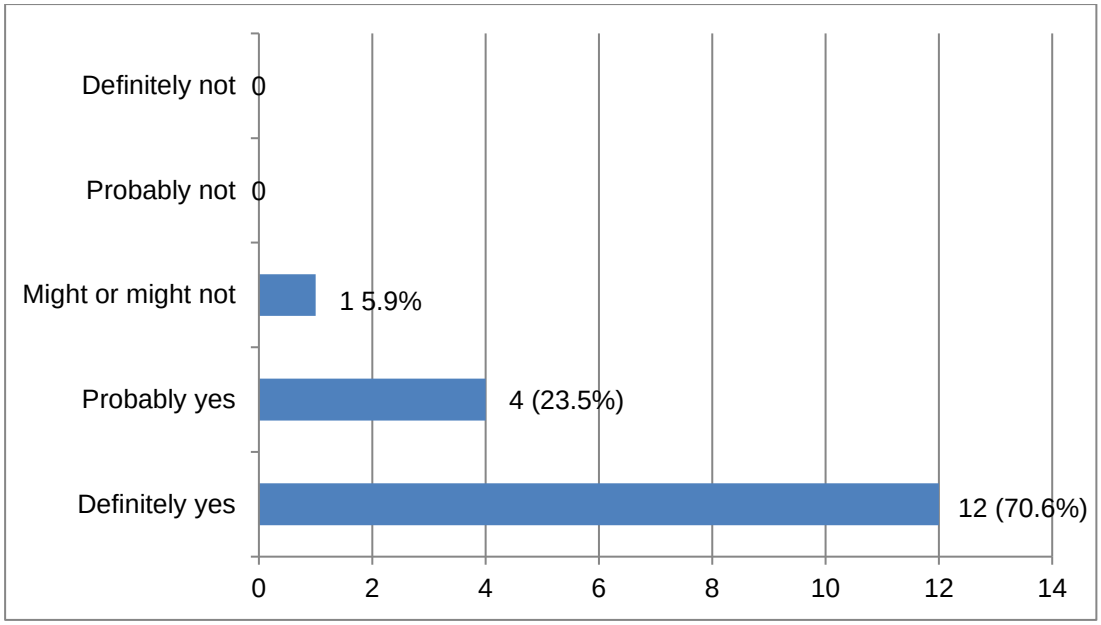


**Figure 3.8 Clinicians' views on whether the role will continue to exist after the 5-year agreement period with the Roald Dahl's Marvellous Children's Charity comes to an end (n=17)**

Those who expressed some doubt did so because of the uncertainty of NHS finances, rather than because of doubts about the impact of the role:

*"I will certainly be advocating for the post to continue, but uncertainty about financial circumstances at that time."*

*"I can't be any more definitive as everything depends upon the financial situation of the Trust and whether they will continue to fund the position."*

*"We hope this will be supported with ongoing funding but given the pressures on healthcare this may not be assured."*

Several clinicians commented on the positive relationship with Roald Dahl's Marvellous Children's Charity:

*"This provision by the Charity is invaluable and is making a significant impact in improving the care of children with disease. Thank you so much!"*

*"We feel that the collaboration with RDMCC [Roald Dahl's Marvellous Children's Charity] has been very productive and beneficial for our patients We have valued the support and input we have received from Sophie and the RD [Roald Dahl's Marvellous Children's Charity] team throughout the recruitment and appointment of our successful candidates and the ongoing support the individual nurses have received, in terms of education, networking and of course practical support."*

*“I am very grateful to the Roald Dahl Charity [Roald Dahl’s Marvellous Children’s Charity] for providing us with a specialist nurse; it is now hard to imagine the service without her.”*

Finally, one clinician summed up the recognition and gratitude for the continuing Charity involvement in these roles:

*“I do not think that there is any way the neuromuscular service at [hospital] will be able to function effectively without the Roald Dahl Specialist Neuromuscular Nurse. If anything, my opinion would be that we need more than one or two of them. They are highly appreciated. I don't think that, considering the current situation in the NHS, service provision can be sustained without the immensely appreciated support from charitable organisations such as the Roald Dahl’s Marvellous Children's Charity. I am very pleased that [hospital] has recognized this need and has agreed, as far as I am aware, to continue to fund this post after charitable funding has ceased.”*

# APPENDIX 4

# PARENTS:

# RESULTS OF PARENTAL SURVEY

## APPENDIX 4 PARENTS: RESULTS OF PARENTAL SURVEY

*"Without our amazing Nurse, I would feel isolated, lost in the medical system and unsupported" [Parent].*

This chapter reports the results of an online survey of parents in the caseload of the Roald Dahl Specialist Nurses. At the closing date (7th April 2021), 159 parents had consented to take part. Not all participants completed every question, so the results are reported against the number completing each question rather than the total number completing the survey.

### 4.1 Participant Demographics

Initial questions ascertained information regarding the person who was completing the questionnaire. The participants were asked what their relationship was to the child (or children) under the care of the Roald Dahl Specialist Nurse, and **86.8% (n=138/159) indicated they were the child's mother**. Sixteen indicated they were the father (10.06%), two were carers, and three indicated other (relationship not specified). For the purposes of this report, the participants will be referred to herein as 'parents'.

The majority of parent participants indicated ages between 25 and 54 years, with just under **50% (n=78/159) in the 35-44 age bracket** (Figure 4.1). Two respondents were under 18 years of age; one indicated they were a young person (patient) and one a sibling of a patient. Only one participant indicated that they were 65 or over.

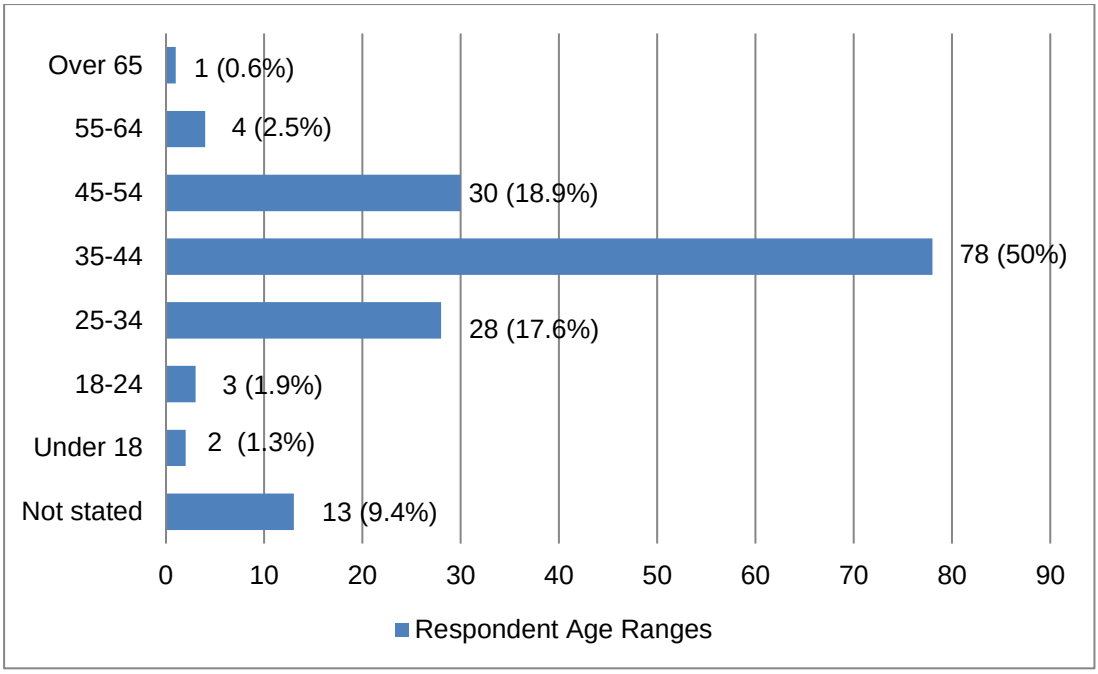


**Figure 4.1 Number of parent participants in each age group (n=159)**

The ethnicity of the parent participants can be seen in Figure 4.2, with **the majority of parents indicating white ethnicity** (n=100/159, 62.89%). Twenty-seven parents (16.98%) indicated Black / African / Caribbean / Black British, and 25 (15.72%) indicated Asian / Asian British.

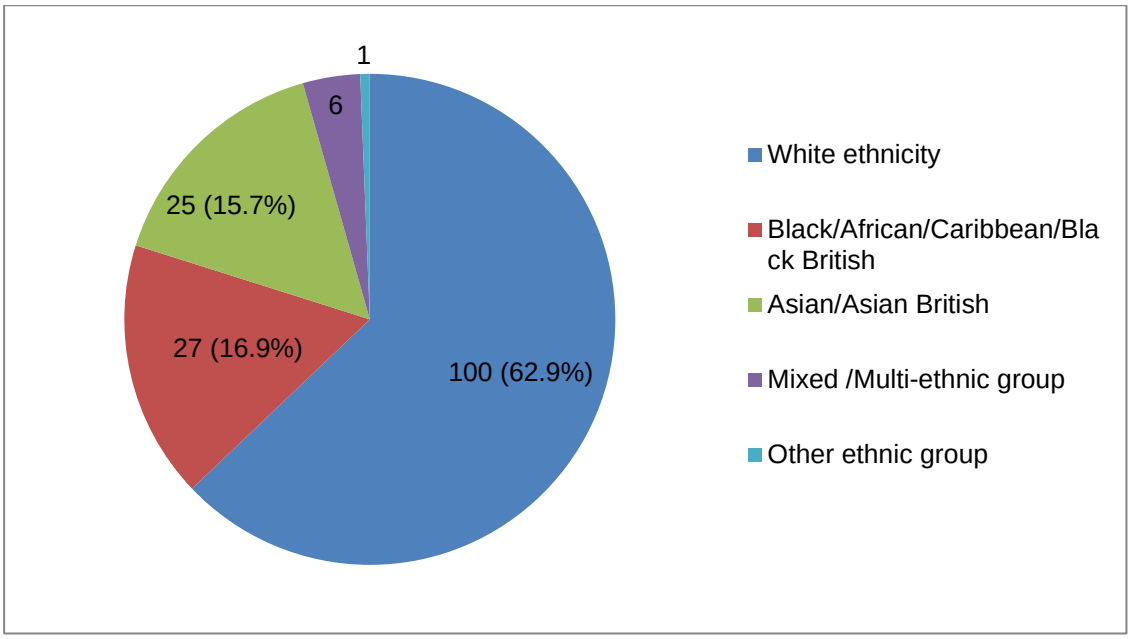


**Figure 4.2 Ethnicity of the parent participants** *(n=159)*

Twelve (8%) of the parent participants noted that they lived in Northern Ireland, eight (5.33%) in Wales, with the remaining 130 parents (86.67%) living in nine different regions of England (see Figure 4.3). The majority were living in Greater London (n=44/150, 29.33%) and the South East (n=38, 25.33%).

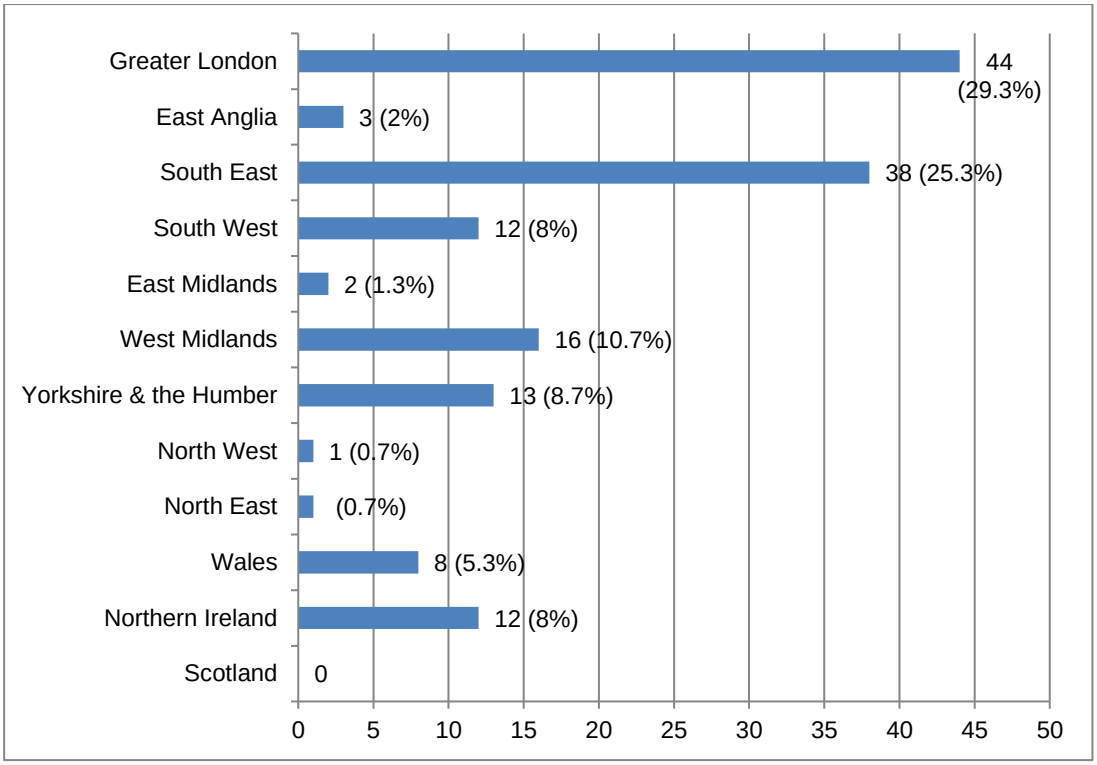


**Figure 4.3 Region of the UK in which the parent participants live** ***(n=150)***

## 4.2 The Participant's Household

**Two thirds of parents (65.41%, n=104/159) indicated that they were either married or in a civil partnership**, with a further nine parents stating that they were in a stable relationship (co-habiting or living with a partner). Fifteen parents indicated that they were separated, divorced or widowed, and a further 21 (13.21%) indicated they were single parents (Figure 4.4). The support networks available to the parents included other family members living in the same household, and family members living elsewhere who were providing regular or occasional support (Figure 4.5). However, 18.59% (n=29/156) indicated 'other' support, including support groups, friends, care workers and respite care. Nine of these participants had no support from relatives, friends or care agencies.

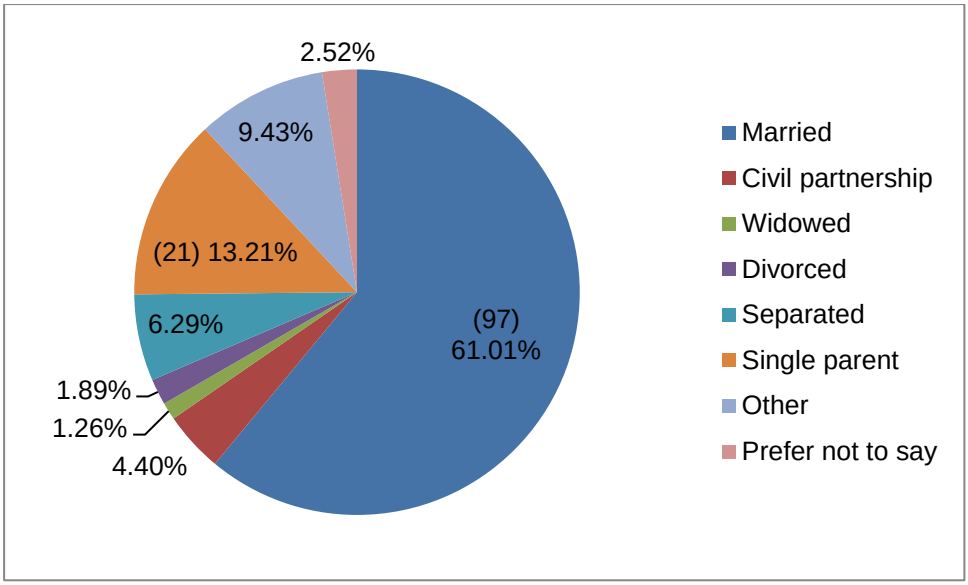


**Figure 4.4 Marital status of the parent participants** (n=159)

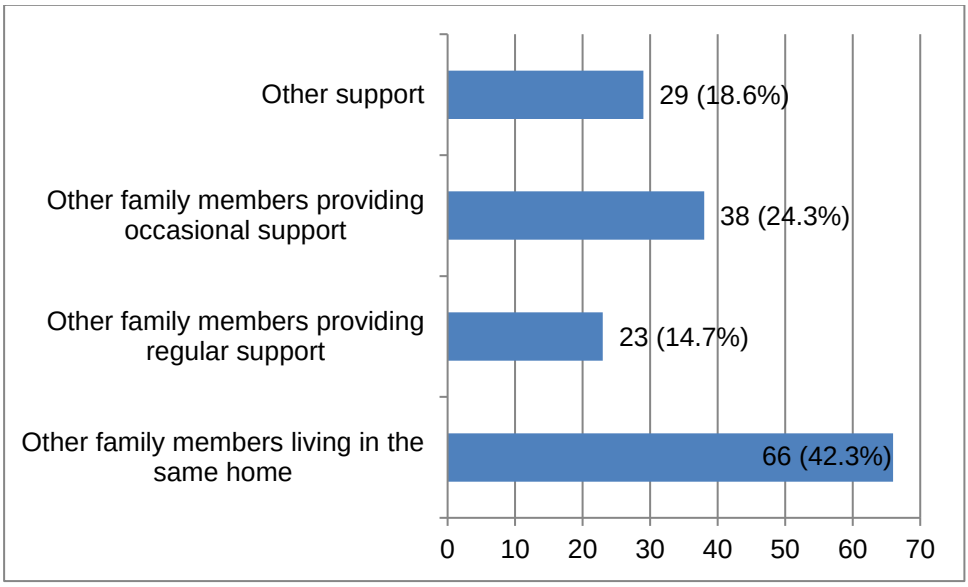


**Figure 4.5 Support networks of the parent participants**

The majority of participants completing the survey had one child under the care of a Roald Dahl Specialist Nurse (94.56%, n=139/147), with eight participants having two or more children under the care of the nurse (n=8/147, 5.44%). The participants indicating they had more than one child under the nurses' care were asked to complete the rest of the survey thinking about their child with the greatest need.

126/159 parents (79.25%) indicated that the child under the care of the Roald Dahl Specialist Nurse was not their only child. The children were mainly primary and secondary school ages, with 37 of the children five years old and under.

One third of the parent participants (n=48/150, 32.00%) indicated their **employment status as a 'stay at home parent/carer'**, with nearly two-thirds (n=91/150, 60.66%) **working either full or part time or self-employed** (Figure 4.6). Five were unemployed and five were in education at the time of completing the survey.

Where the participants had a partner, most of their partners were working full time and/or were self-employed (Figure 4.6). Only nine of the partners (7.63%) were identified as 'stay at home parent/carer' (compared to 32% of the parents completing the questionnaire); this suggests that **those completing the questionnaire are most likely to be the primary carer** for the child in the care of the Roald Dahl Specialist Nurse.

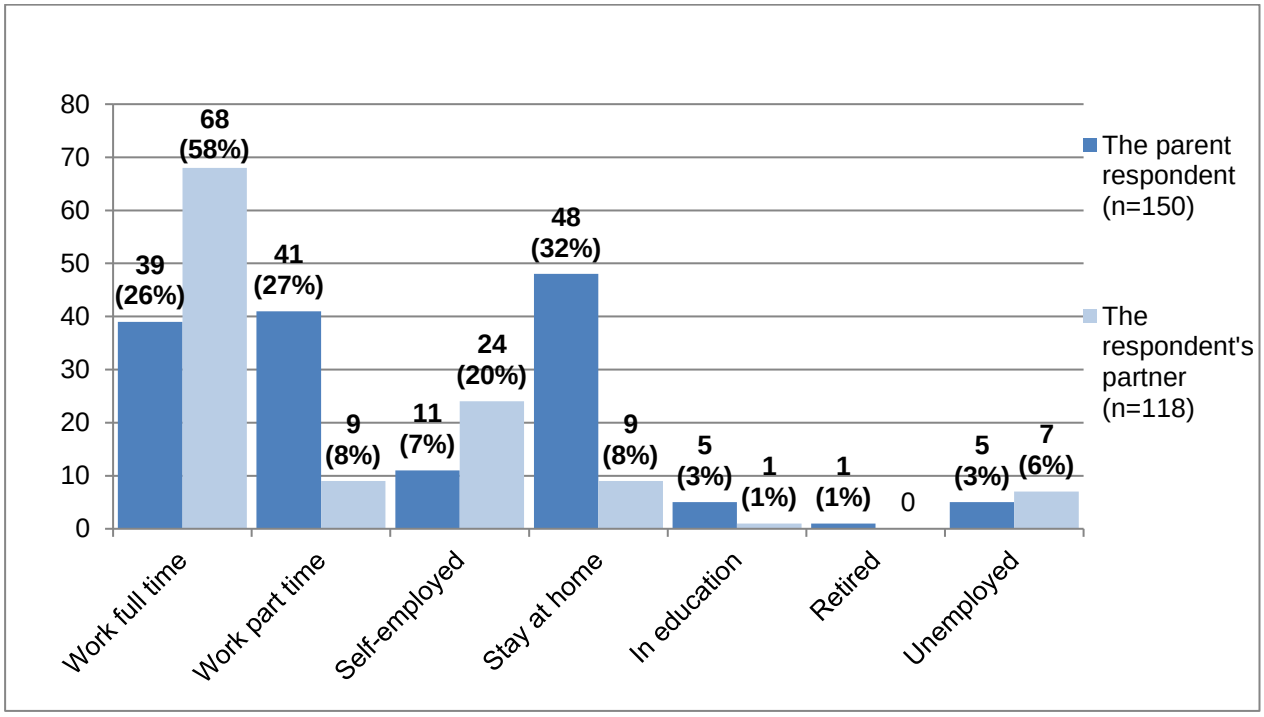


**Figure 4.6 Current employment status of the parent respondents and where relevant their partner's employment status**

Sixteen parents (10.7%) indicated that they were suffering a great deal of **financial hardship**, with one third of parents (n=55/149, 36.91%) occasionally experiencing hardship (Figure 4.7). When asked about the impact of their child's illness on the parent participant's financial or employment status (Figure 4.8), 40.2% (n=61/152) indicated that it had impacted significantly (a great deal or a lot).

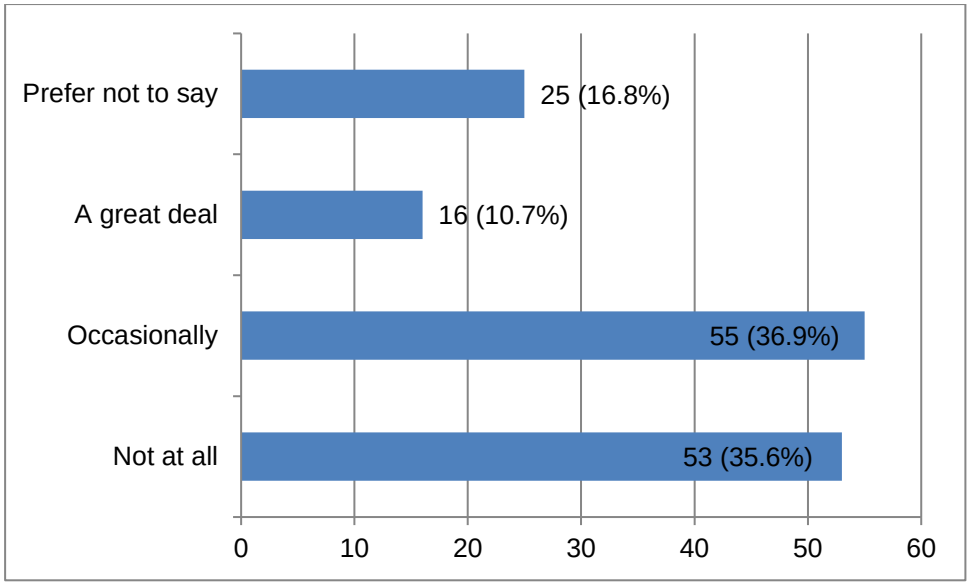


**Figure 4.7 Does the participant's family experience financial hardship?** ***(n=149)***

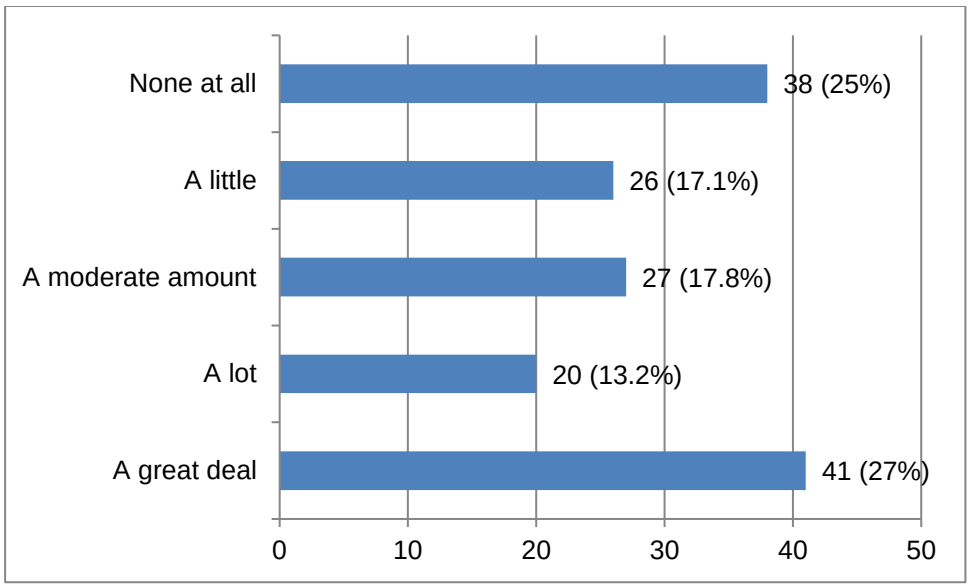


**Figure 4.8 Impact of the child's illness or condition upon the parent participant's financial or employment status** ***(n=152)***

### 4.3 The child under the care of the Roald Dahl Specialist Nurse

The children under the care of the Roald Dahl Specialist Nurse were spread across several age groups (Figure 4.9), with **the majority in the '5-10 years' theme** (n=61/140, 43.6%).

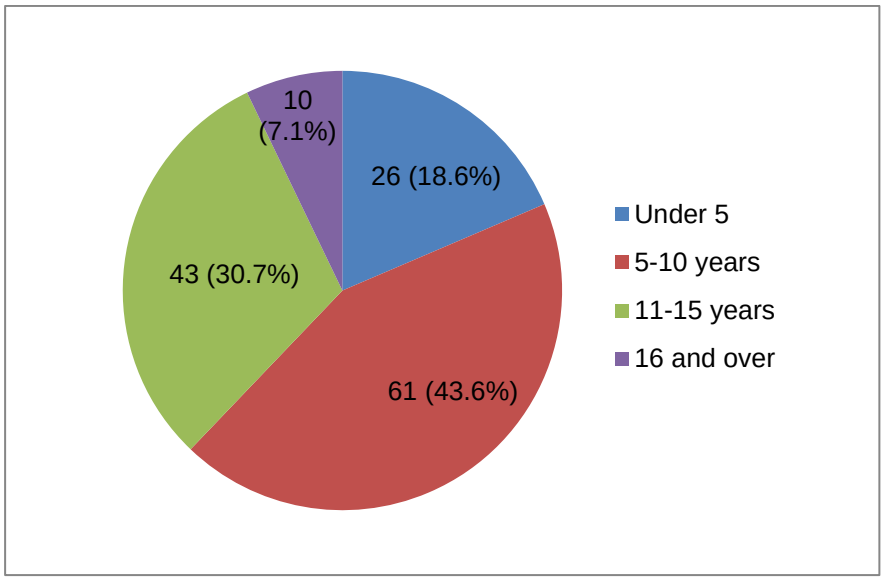


**Figure 4.9 Age of the child under the care of the Roald Dahl Specialist Nurse (For parents with more than one child cared for by the Roald Dahl Specialist Nurse, they were asked to consider the child with the greatest need).**

The children are attending a range of schools dependent upon their age groups (Figure 6.10), with one third (44/147, 29.93%) attending a school catering for special educational needs. Those indicating no schooling in Figure 4.10 correlate with pre-school children (under 5s in Figure 4.9 above), suggesting that **all the children beyond pre-school ages are attending a relevant educational establishment**. However, **44.5% (n=65/146) of children have missed at least 10 days of schooling** in the previous year due to their condition (Figure 4.11).

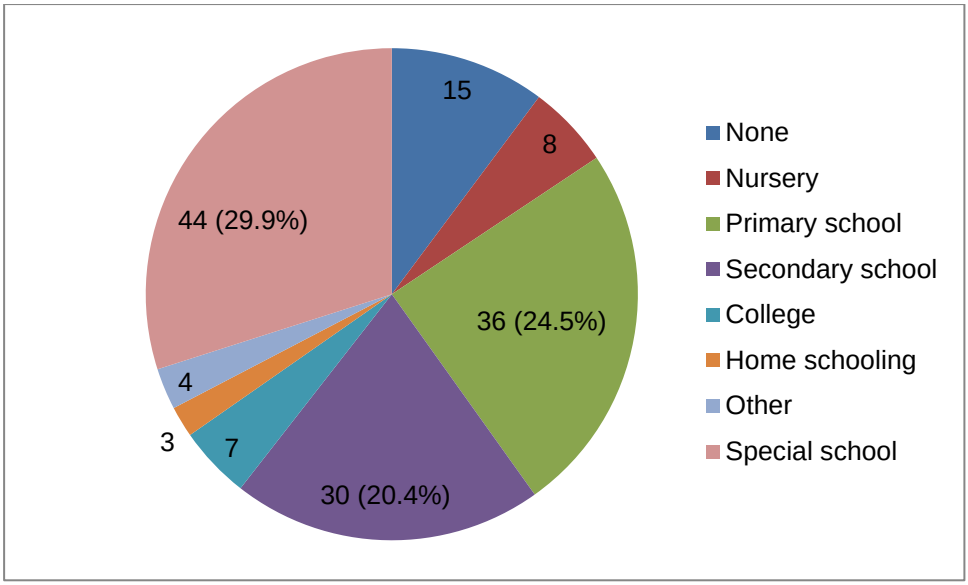


**Figure 4.10 Type of school attended by the child who is cared for by the Roald Dahl Specialist Nurse** ***(n=147)***

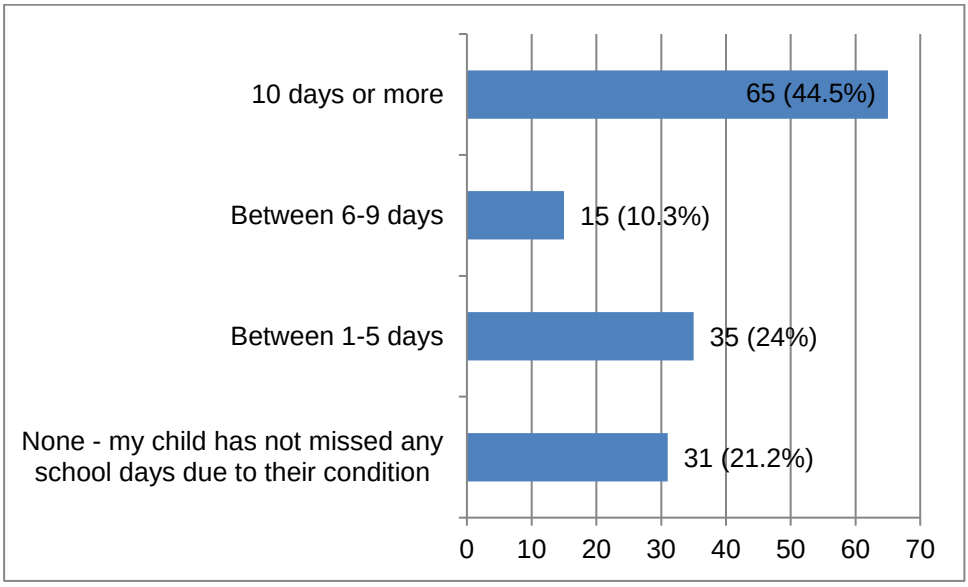


**Figure 4.11 Has the child had to miss any days of school due to their condition during the current school year (since Sept 2019)?** ***(n=146)***

The children experienced a range of medical conditions, as shown in Figure 4.12, with epilepsy, rare and genetic diseases, and blood disorders most commonly stated (n=93/147, 62.83%). Parents listed additional conditions including: autism; Duchenne muscular dystrophy; hydrocephalus; developmental delays; movement disorders; myotonic dystrophy; chromosome disorders, and they indicated that **some of these children had complex conditions exhibiting multiple organ system disorders**. Over half of the children's conditions were present at birth (n=81/147, 55.10%), though some parents indicated that the condition had developed later.

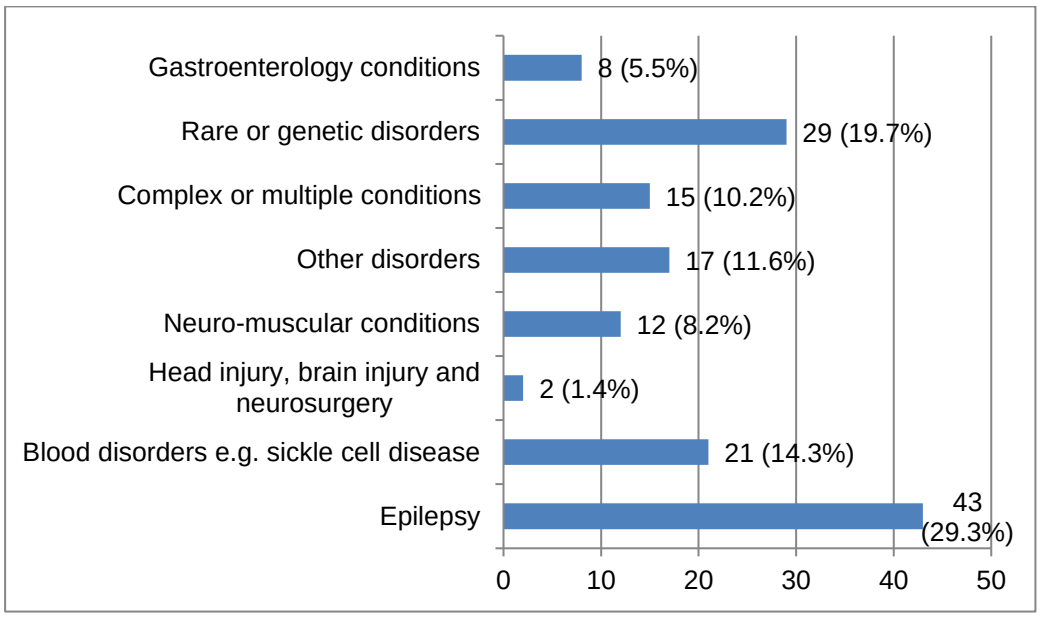


**Figure 4.12 The child's illness or condition** ***(n=147)***

38.8% (n=57/147) of parents indicated that their child's condition is stable and normally well-controlled, however **41 parents (27.9%) indicated that their child's condition is often unstable and requires round-the-clock care** (see Figure 4.13). **Some children required constant care as they needed support with 'activities of daily living'** including movement and positioning, washing and dressing, eating and drinking as well as their multiple clinical care needs. Several parents explained the complexity of their child's care needs:

*"My child has EDS vascular, chromosome deletion 2, 138 genes missing, cardio, gastro, neuro, and many more medical problems, she is very complex."*

*"Our son has severe face and brain abnormalities, having a very complex diagnosis."*

*"Care is now stable however has been unstable especially during winter months. Our child is currently under 24 teams between several Trusts."*

*"At the moment she is well controlled but in the past I've had to take a lot of time off work and I work for the NHS and we are always so short staffed, that I feel so bad."*

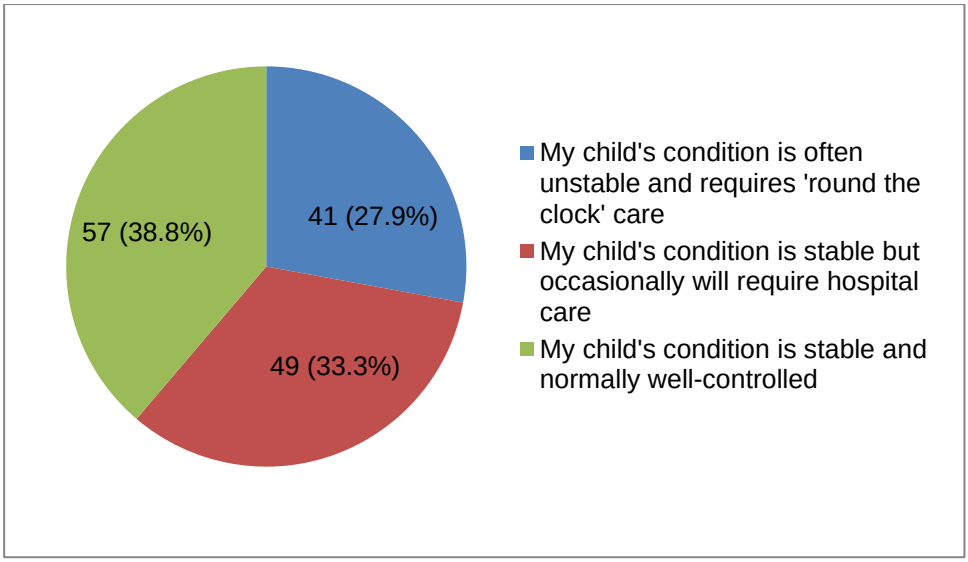


**Figure 4.13 An indication of the relative stability of the child's condition** ***(n=147)***

42.5% (n=62/146) of parents were concerned that their child's physical condition **also affected their mental health** (Figure 4.14).

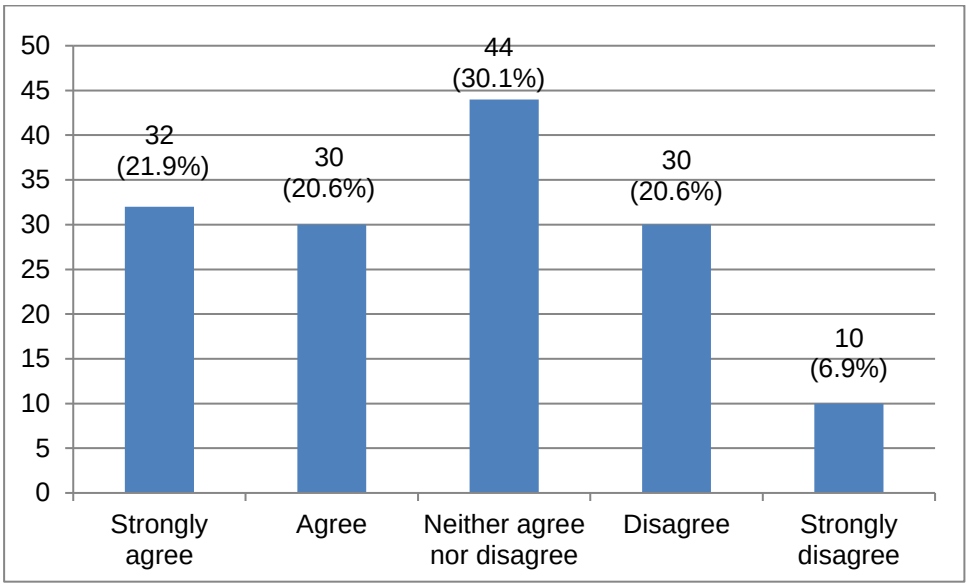


**Figure 4.14 Parent responses regarding the statement "I am worried that my child's mental health is affected because of their condition"** ***(n=146)***

Parents were asked how many routine hospital visits and GP appointments their child had to attend in the previous year, with **two thirds (n=95/148, 64.2%) indicating they had to attend five or more appointments** (Figure 4.15). For some parents these appointments were extremely challenging in terms of preparation, equipment and family support required for each visit. However, these scheduled appointments were helping to keep some children stable, with 38.8% (n=57/147) parents indicating that they had not needed to attend hospital for any unscheduled or emergency visits (Figure 4.15). However, some of the children's conditions were very unstable with **17 parents (11.6%) indicating they had to attend five or more emergency visits**.

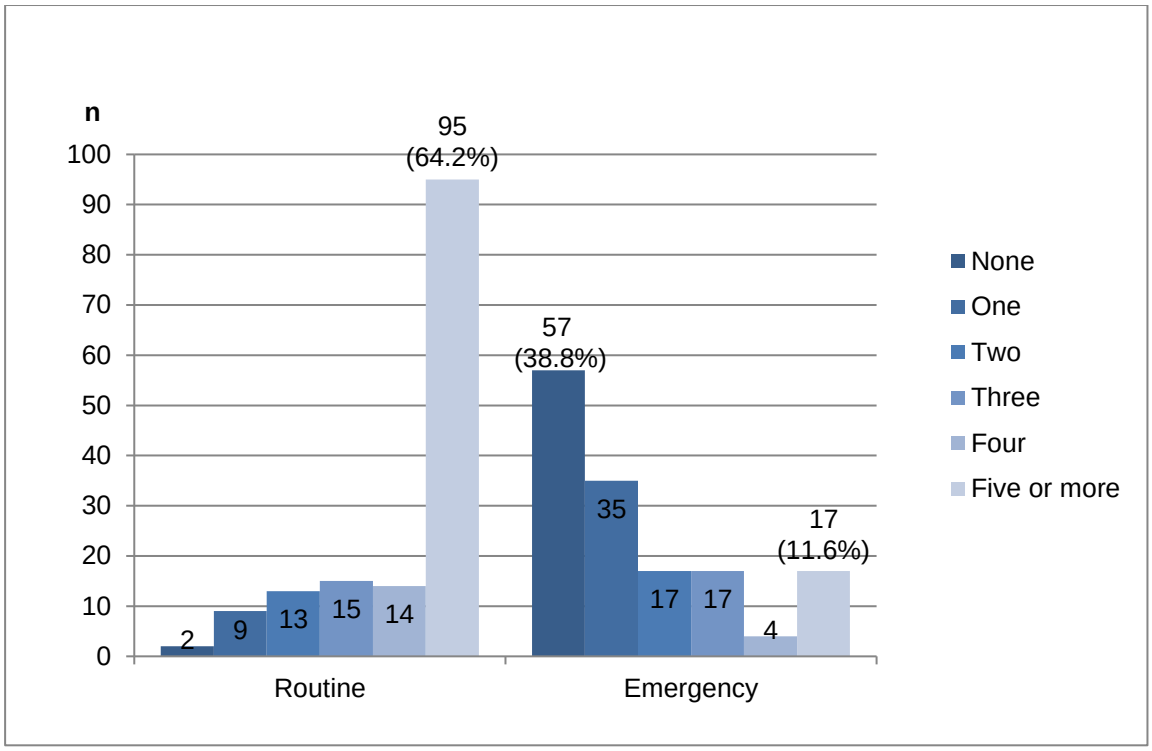


**Figure 4.15 Number of scheduled (routine) and unscheduled (emergency) appointments required specific to the child's condition.**

**Routine appointments included any pre-booked hospital and GP appointments.**

Three quarters of parents attended routine visits using their own transport (71.05%, n=108/152), with others using mainly taxis or ambulances. For the majority this journey took under one hour, but for 16 parents (10.81%) the journey was over one hour (Figure 4.16).

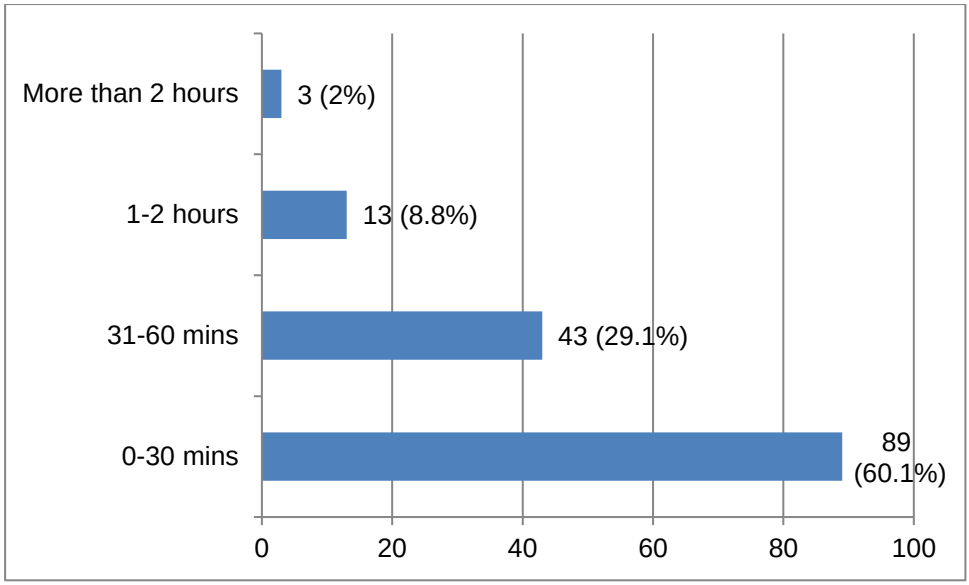


**Figure 4.16 How long does the journey to hospital take?**

### *6.3.4 The impact on the family of managing the child's condition*

Parent participants were asked a set of questions taken directly from the fully validated Impact-on-Family Scale which has been tested in different contexts around the world. The data (Figure 4.17) suggests that **there is a wider impact of the child's condition on parents and the wider family**. While there is a wide variation in answers, parents rate the answers more positively (agree or strongly agree) in seven out of 11 statements (less than a mean score of three in Table 4.1). The statement that parents most strongly disagreed with was: *"because of the illness, we are not able to travel out of the area"*, which reflects the earlier finding that the majority own their own transport.

Two of the statements provoked a more strongly positive response (agree or strongly agree selections): *"Our family gives up things because of my child's illness"* (mean 2.28), and *"Sometimes I feel like we are on a roller coaster: we are in crisis when my child is acutely ill, but coping well when things are stable"* (mean 2.19).

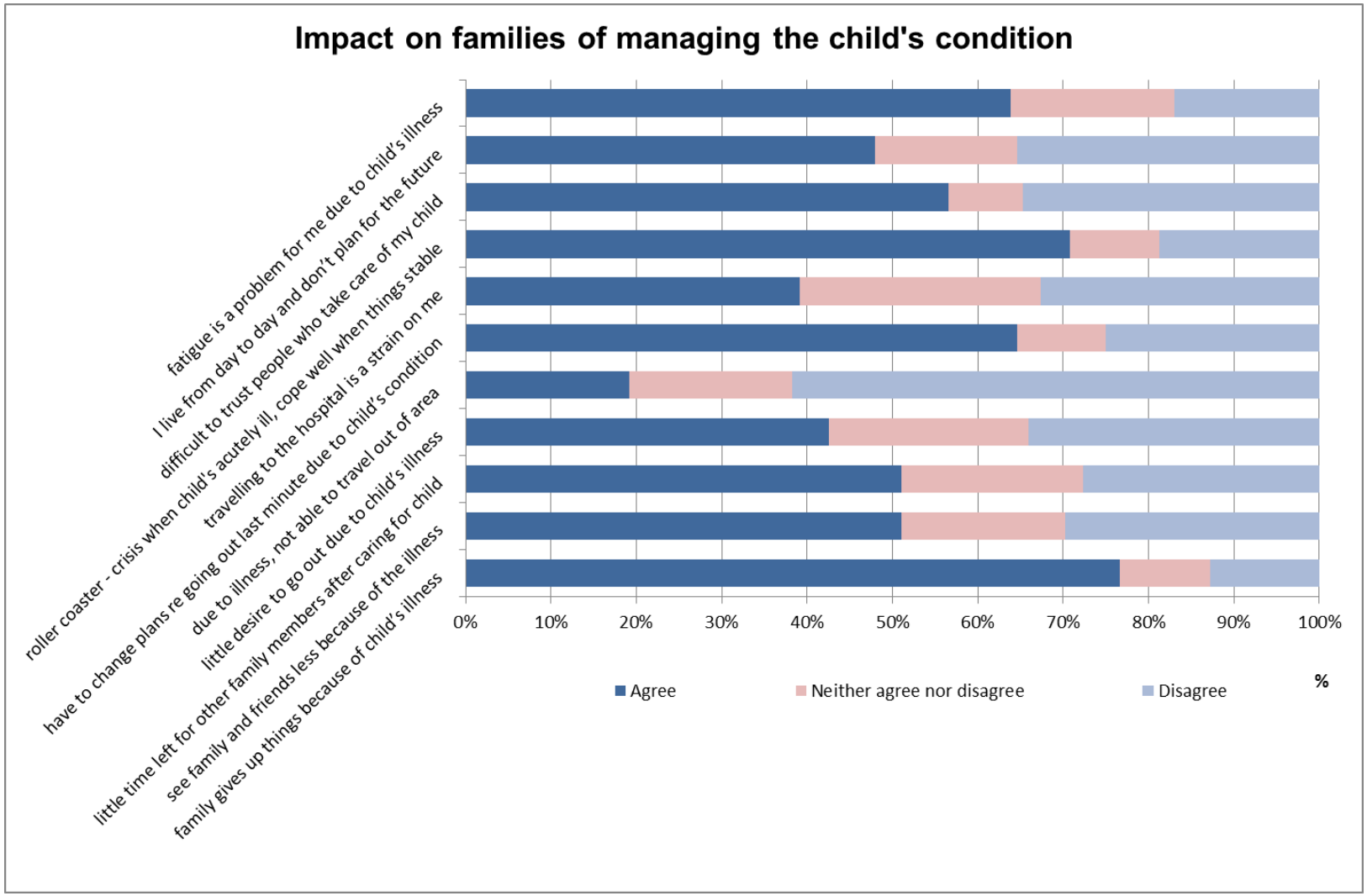


**Figure 4.17 Visual representation of parental responses to eleven statements in the Impact-on-Family Scale (IOFS-11).**

**Table 6.1 Mean and standard deviation responses to the pooled statements on the Impact-on-Family Scale (IOFS-11). Mean of <3.0 suggests a strong positive agreement (agree or strongly agree) for any particular statement (shaded).**

| # | Statement from Impact-on-Family Scale | Minimum | Maximum | Mean | Standard Deviation | Variance | Count |
|---|---|---|---|---|---|---|---|
| 1 | Our family gives up things because of my child's illness | 1.00 | 5.00 | 2.28 | 1.26 | 1.60 | 142 |
| 2 | We see family and friends less because of the illness | 1.00 | 5.00 | 2.80 | 1.40 | 1.97 | 142 |
| 3 | I don't have much time left over for other family members after caring for my child | 1.00 | 5.00 | 2.82 | 1.24 | 1.53 | 142 |
| 4 | We have little desire to go out because of my child's illness | 1.00 | 5.00 | 3.13 | 1.22 | 1.50 | 142 |
| 5 | Because of the illness, we are not able to travel out of the area | 1.00 | 5.00 | 3.56 | 1.21 | 1.45 | 141 |
| 6 | Sometimes we have to change plans about going out at the last minute because of my child's condition | 1.00 | 5.00 | 2.53 | 1.32 | 1.73 | 143 |
| 7 | Travelling to the hospital is a strain on me | 1.00 | 5.00 | 3.15 | 1.18 | 1.40 | 141 |
| 8 | Sometimes I feel like we live on a roller coaster: we are in crisis when my child is acutely ill, but coping well when things are stable | 1.00 | 5.00 | 2.19 | 1.20 | 1.44 | 143 |
| 9 | It is difficult to place my trust in the people who take care of my child | 1.00 | 5.00 | 3.10 | 1.40 | 1.96 | 141 |
| 10 | I live from day to day and don't plan for the future | 1.00 | 5.00 | 2.92 | 1.28 | 1.64 | 142 |
| 11 | Fatigue is a problem for me because of my child's illness | 1.00 | 5.00 | 2.49 | 1.29 | 1.66 | 140 |

### 4.4 Interactions with the Roald Dahl Specialist Nurse

Parents were asked how long a Roald Dahl Specialist Nurse had been involved in their child's care (Figure 4.18); three quarters indicated they had worked with the Roald Dahl Specialist Nurse for at least one year (76.09%, n=105/138). The majority were scheduled to visit the Roald Dahl Specialist Nurse for **routine appointments once or twice per year** (57.69%, n=75/130), but over a quarter of the children had more than three routine appointments scheduled per year (27.69%, n=36/130). The majority of parents stated that these routine appointments were sufficient for their needs, but 15.33% (n=21/137) stated that they were unsure and nine (6.57%) confirmed that they were insufficient for their needs.

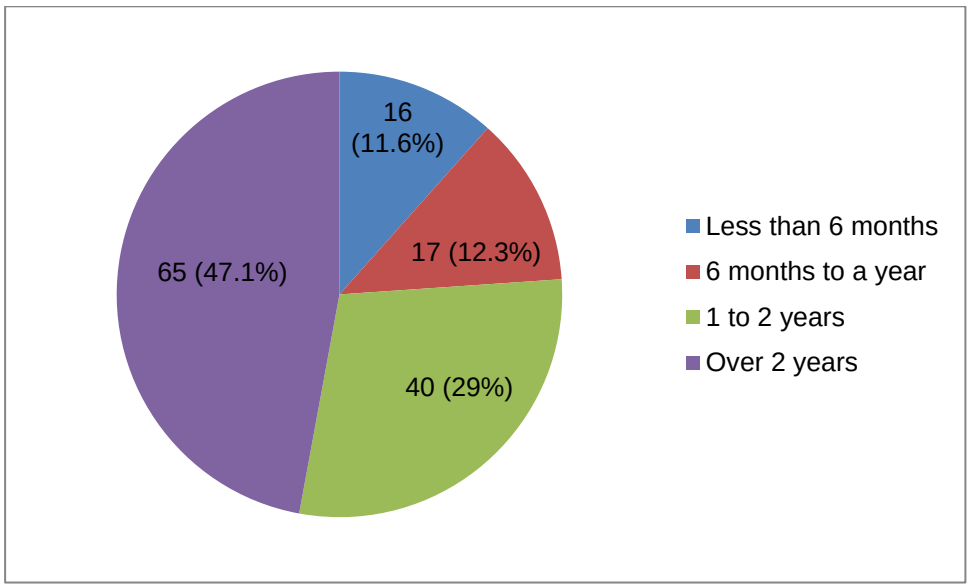


**Figure 4.18 How long have you had a Roald Dahl Specialist Nurse involved in your child's care?** ***(n=138)***

The majority of parents indicated that **they had needed to contact the Roald Dahl Specialist Nurse between routine appointments**, with nearly three quarters of parents (n=102/140, 72.86%) needing to contact them at least three times in the last year. **The main methods of contacting the Roald Dahl Specialist Nurse are by telephone (41.30%, n=57/138) or email (38.41%, n=53/138)**, with some using texts and voicemail contact methods.

*"Our Roald Dahl Nurse is always available at the end of a phone call to answer any questions and if unable to help there and then, will always come back to us."*

*"I am very impressed at how promptly [Roald Dahl Nurse] replied to text / phone calls and the advice and help given, I cannot praise them enough for their advice, care and support…they are doing a fantastic job."*

The consequences of the Roald Dahl Specialist Nurse not being available when they contact them can be seen in Figure 4.19; most parents would contact the hospital or the medical consultant directly. Parents appreciated the comparative availability of the Roald Dahl Specialist Nurse, and the willingness to 'go the extra mile':

*"I find the nurses very helpful especially as they are more accessible and available to respond to our day-to-day needs which a consultant may be unavailable to do."*

*"It's great to have a point of contact without having to ask the consultant."*

*"Having a home visit before Covid was really nice to build up relationship."*

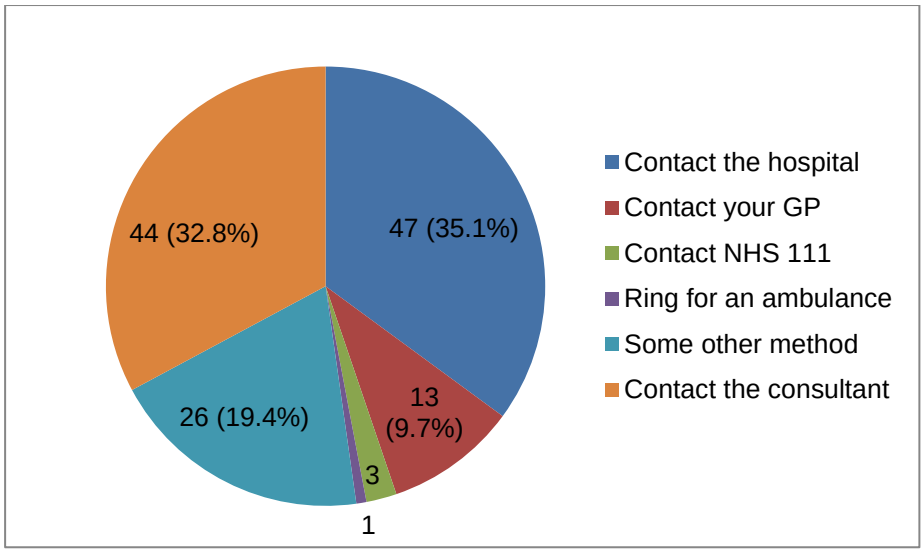


**Figure 4.19 What do you do if your Roald Dahl Specialist Nurse is not available?** ***(n=134)***

42.3% (n=55/130) of parents acknowledged that timely contact with the Roald Dahl Specialist Nurse had **prevented visits to A&E on at least one occasion, with at least one emergency admission to hospital prevented for 37.5% (n=48/128) of parents** (Figure 4.20). Forty percent (n=54/135) of parents stated that **this contact had prevented urgent GP appointments on more than one occasion,** with over half of parents (52.7%, n=68/129) indicating that **consultant appointments had also been prevented on at least one occasion**.

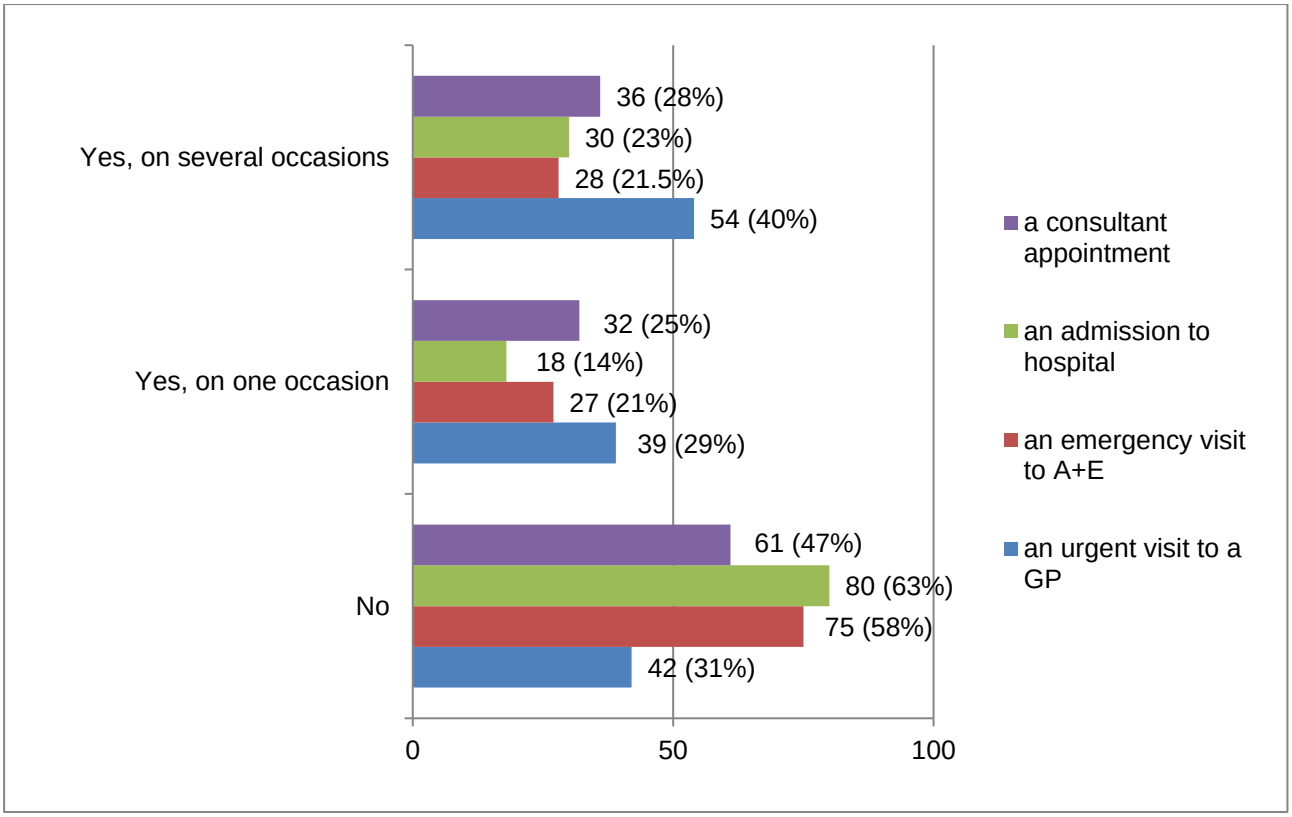


**Figure 4.20 Has contact with your Roald Dahl Specialist Nurse helped you to avoid having to access the following services for your child?**

Parents were asked what clinical care support provided by the Roald Dahl Specialist Nurse is important to them (Figure 4.21), although parents' needs differ widely. This figure shows that the **clinical nursing support most highly valued by parents** includes *"being a point of contact and coordinating my child's care across hospital services"*:

*"She coordinated three appointments so that they were on the same day instead of us traveling nearly a four hour round trip to hospital over three days."*

*"They are a friendly face and impartial which is great when battling a number of departments at the same time."*

*"Being the go-between for my son's services over three hospitals."*

*"She has helped to follow up appts or bring appts forwards when necessary."*

*"She's always there when required, she's always in coordination with the consultant, the school and other nurses and people involved in my daughter's care."*

*"They are worth their weight in gold …our recent MRI appointment was the best ever due to [Roald Dahl Specialist Nurse] writing emails to inform ward staff and MRI staff all about my son, his needs, his triggers, his autism. It was amazing to have people who just "get it" so, so, grateful for them."*

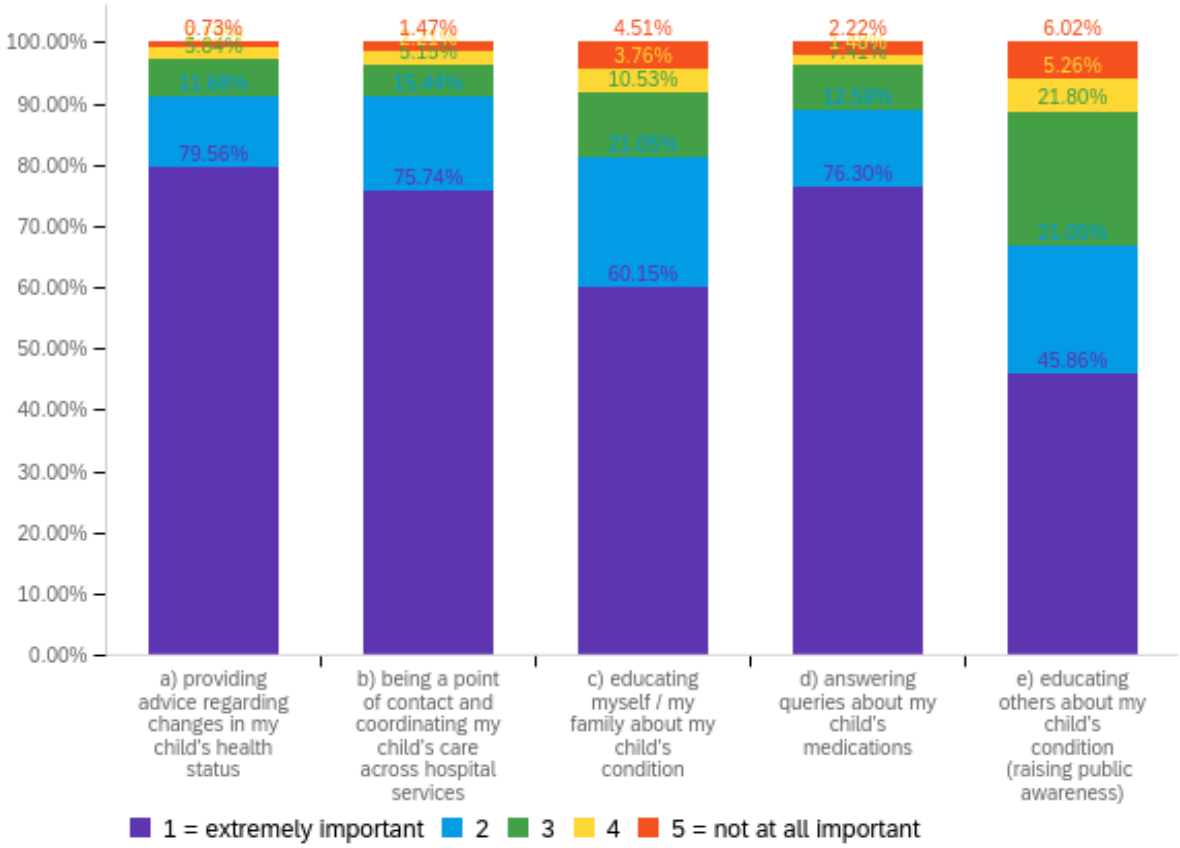


**Figure 4.21 What nursing support provided by the Roald Dahl Specialist Nurse is the most important for you?**

**(Parents were asked to rank each of the statements from 1= extremely important to 5= not important)**

*"Liaising between our local hospital and the specialist hospital has been fantastic."*

*"She has been an amazing support to my family and our little boy, he is extremely complex so therefore has a lot of doctors involved in his care. She has been great at helping them to all work and communicate together… it is hard when so many professionals are involved."*

*"Lots of emotional support, liaison between specialists, sorting out paper work, a 'fixer'!"*

*"She came to visit us in the hospital. Wonderful. We were scared in these uncertain times. Having a knowledgeable friendly face was so very much welcome at that time. She followed up, was in the know and generally there for us. Invaluable."*

*“With so many medical professionals involved in our daughter's care, it has been great to have a person whom we can turn to, to liaise between them when we are not sure who to contact. It has been MUCH appreciated!”*

Also highly valued in terms of clinical support is *"providing advice regarding changes in my child's health status"*, and *"answering queries about my child's medication"* as demonstrated by the following parent comments:

*“Being available to ask questions about any worries we have.”*

*“She's reliable, efficient and always providing nursing advice. She goes beyond and above with anything involving my daughter's health in ensuring that she gets the support she deserves.”*

*“Never makes me feel like I'm being demanding or asking stupid questions. If they don't know the answer, they will find someone who does.”*

*“She has answered questions in relation to medications, has helped us identify and rank pain and then proceed with new medication for our son. She has helped advocate for new medication. He is currently so much more settled in terms of health; he's sleeping better and is generally much more contented as a result of liaising with the Roald Dahl nurse.”*

*“When the first medication didn't work, she provided me information on the new medication and explained the transition to the new medication specifically the gradual increase in dose. I was very comfortable adding the second medication.”*

Parents were also asked about other **non-clinical forms of support** provided by their Roald Dahl Specialist Nurse. Figure 4.22 demonstrates parent responses regarding which forms of support are important to them.

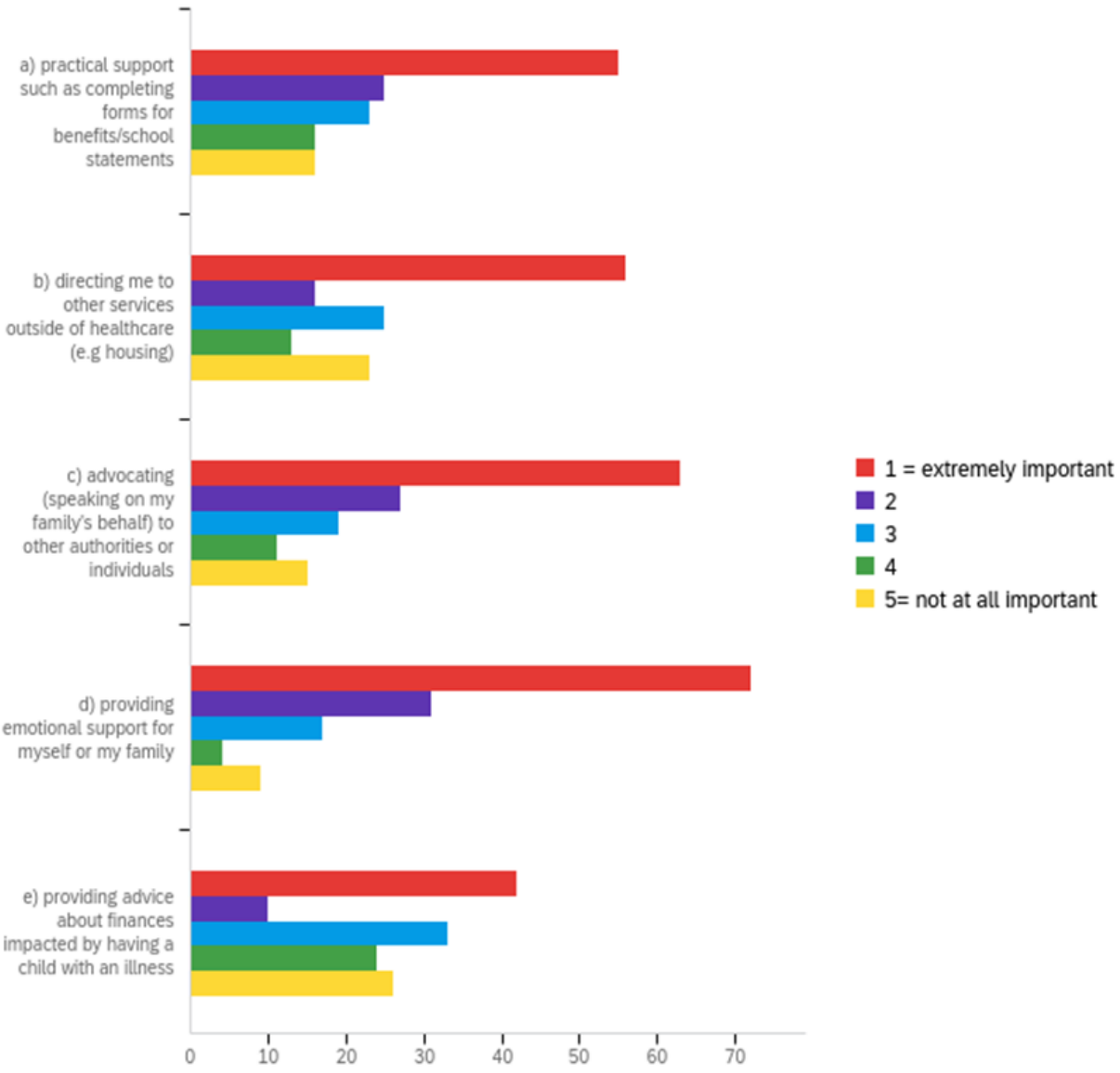


**Figure 4.22 What other types of support provided by the Roald Dahl Specialist Nurse are the most important for you? (Parents were asked to rank each of the statements from 1= extremely important to 5= not important)**

One of the most highly valued forms of non-clinical support is *"providing emotional support for myself or my family"*:

*"From diagnoses till now our Roald Dahl Nurse has been a great help and support for me and my family. She's there when we have a question or just need advice. Showed us compassion and she cares about our family and most of all our son's needs."*

*"[Roald Dahl Nurse] is the most brilliant nurse in every aspect of her job, a helpful professional but also caring, she listens which is brilliant when you need a good moan about things… don't know what I would have done without her help and advice…A credit to her profession."*

*“They have been brilliant in every way, I don't know what I would do without them, really helps with my mental health to know that someone is there for me, for support for my ill child and family.”*

*“Our amazing nurse is a compassionate, knowledgeable voice, who is pretty much always available, this has massively reduced family anxiety, bridged a huge gap and reduced lengthy waiting times trying to contact consultants, and been a regular (sometimes weekly) proactive guide through medication and condition concerns and changes. She has made a dramatic impact on our lives, and we really don’t know how we would get through so many days without her support and dedication.”*

*“Our nurse has helped with emergency medication, arranging blood transfusions to accommodate my family's needs and has provided emotional support at times it has been needed most.”*

*“When I went to see the nurse about the seizures my son has been having and the worries that I have due to his profound communication difficulties I was overwhelmed by her understanding and sympathetic nature. I left feeling extremely well supported.”*

*“Amazing support she has given myself and my daughter is exceptional with nothing too much trouble at all. Could not have coped without her.”*

*“She provides us with emotional and practical support when no one else is available. It’s really a lifeline sometimes when you feel lost and confused and sad.”*

*“Advocating (speaking on my family's behalf) to other authorities or individuals"* was also flagged by parents as extremely important to them. This included **liaising with external organisations and authorities,** including local councils, charities and other services:

*“Coordinating appointments, and sorting medication when it becomes unavailable in the community. Direct access to consultants for advice and help to keep my daughter out of hospital unless an absolute last resort. Knowing my child and what will work for her, liaising with hospital professionals and community to get what my daughter needs and always being at there for a chat and advice when I need it.”*

*“Emotional support and assistance with getting access to respite services by completing referrals and attending meetings to advocate for my child to be eligible for additional services.”*

**Liaison with schools** was cited frequently by parents as a great assistance to them. The Roald Dahl Specialist Nurses assisted parents with completion of educational forms, and worked with teachers to help them to better understand the child's condition and their capabilities:

*“She has liaised with school who were being unsupportive.”*

*“My nurse has recently supported me when I was trying to move my son's education setting. She provided valuable information that helped my case.”*

*“She has contacted and provided my son's school with information about his condition to enable them to create a health care plan.”*

*“…offering to speak to the pre-school about my child's condition.”*

*“Our nurse has written letters to school to advise them on how best to support our child.”*

*“She has been invaluable at school meetings when we needed to push for certain measures.”*

*“She played a huge role in helping us to win our sons appeal to get him into his school where he can be safe and get the care he absolutely needs.”*

This support often included visits to schools to observe the child in the classroom environment, providing the most appropriate advice to teachers, and supporting the preparation of an Education Health and Care (EHC) Plan. An EHC plan is a legal document that describes a child or young person's special educational, health and social care needs, explains the extra help that will be given to meet those needs, and how that help will support the child or young person to achieve what they want to in their life. These complex documents are drawn up by local authorities, and appear to cause a lot of stress to parents, who appreciate the support given by the Roald Dahl Specialist Nurse:

*“My child’s school has been difficult on some occasions and [Roald Dahl Specialist Nurse] has helped enormously by contacting school and updating his care plan and advising me on how best to deal with them.”*

*“She called school to set up a care plan for my child with them.”*

*“Recently our son's school has lost the care package that he received from our local council and our nurse has been giving us as much help as she can about whom to contact etc.”*

*“[She assisted with] the preparation of the Education Health and Care Plan.”*

*“We live in another local authority outside London and the LA and School have different ways of doing health care plans for the school. Our nurse has been pivotal in helping with the coordination and making sure that the healthcare plan is done and arranging meetings with the local epilepsy nurses. Without her, it would have been impossible and we would have to have left the NHS Trust that provides the care.”*

The nurses also liaised with other organisations and charities, including the Roald Dahl's Marvellous Children's Charity, to **assist families to access basic necessities** to support the care of their child:

*"She supported me by helping me get a very much needed freezer for my family."*

*"Financial in terms of provided a fridge for me to store my son's medicines."*

*"Our epilepsy nurse has been a huge support to my family. My daughter has severe epilepsy and spends long periods in intensive care. She has attended meetings on my behalf when I am unable to attend. She has helped with getting us rehoused, accessed lots of specialist equipment for us. And got us grants and trips away from different charities. She is amazing we would be lost without her!"*

*"I was helped to get a household appliance I needed for my child."*

*"Helping in many ways and getting in touch with other charities for support with equipment and other stuff, their service is very important and helpful for me and my family."*

In addition, the nurses appear to be a **source of education for the families**, not only about their child's condition but also about ensuring the child remains stable and well:

*"Mainly providing resource materials for education."*

*"Giving advice about travelling abroad."*

*"I met the Roald Dahl nurse last September when my daughter was hospitalized and since then she has been getting in touch with us and guiding us … because we just moved to the UK from Nigeria in seeking good healthcare for my daughters who are both sickle cell patients age 15 and two."*

*"…very supportive with regard to recent findings in genetics and further investigations required … always there when I need her and will always find answer to my questions!! She is fantastic...huge help to us as a family!"*

One or two comments from parents highlighted that their **engagement with their Roald Dahl Specialist Nurse had not always been positive**. One of the participants raised concerns about discrimination of single fathers in hospitals, and one parent highlighted that they had little previous engagement with their nurse, and that the questions in the survey had prompted them to question the service they had received thus far:

*"Not supported myself at all, more so for child's mother. Very disappointing but still massive discrimination within hospitals and single fathers."*

*"… we have received v little care from Roald Dahl nurses despite our numerous requests for them to be involved in our child's care. The nurses are quite often not available at the times we have tried to contact them, nor do action matters which are required e.g., coordinating care. It is only as a result of this survey that we fully understand the objectives of the nurses as none of this has been provided during our child's diagnosis or treatment. They have not eased any burden of the healthcare process which was promised to us at the initial meeting with the consultant… We have stopped asking for their care as they are not reliable or responsive."*

While these parents have clearly experienced some gaps in care provision, an interesting perspective can be gained from one parent who had recently been transferred from one hospital Trust to another. The parent expressed her experience of having a Roald Dahl Specialist Nurse as "a breath of fresh air":

*"Up until recently we were at a different hospital where they did not provide us with any liaison nurse. This meant we had no support or help within the hospital so the help we now get is like a breath of fresh air. [Roald Dahl Specialist Nurse] is incredibly supportive, willing to listen and empathize as well as give any practical support she can think of."*

### 6.5 Parents' summary comments

Parents were invited to add any additional points regarding the role of the Roald Dahl Specialist Nurses. Many commented that their nurse was "**amazing", "appreciated", "a god- send", "invaluable", "incredible", "inspirational" and "worth their weight in gold".**

*"Without our amazing nurse, I would feel isolated, lost in the medical system and unsupported."*

*"Absolutely amazing stars, before Roald Dahl nurses I spent hours upon hours, days upon days chasing appointments, medication, explaining my daughter's condition, waiting for a call-back. Roald Dahl nurses have relieved the stress of some of my daughter's care. I feel like I have so much support and advice from them they are absolutely invaluable and worth their weight in gold!"*

*"She is amazing and has been an absolute rock of support to us."*

*"These nurses are great as they offer the best support and understanding of your child, they truly are inspirational."*

*"They are a real godsend. I leave them to sort out appointments, medication etc. and I can concentrate on being mummy."*

They reiterated **the huge difference that the nurses made to their own, their child's and their family's lives**, taking away a little of the stress that they would otherwise encounter as they traverse clinical, educational and social care services.

*“[Roald Dahl Specialist Nurse] is very easily accessible which is great when you’re full of worries so I thank her for all her help”.*

*“Our nurse is able to prevent many a disaster. Promptly responding to emails. Calling back. Even visiting when admitted to hospital to check everything ok and all medication is in place and correct. She is amazing.”*

*“Our nurse always makes us feel like she will make life easier for us in any way she can”.*

*“When my son first developed Epilepsy, I was in a state and not coping. I had a newborn baby as well. [Roald Dahl Specialist Nurse] was incredible. She always had time to speak on the phone. Nothing was too much for her. She was always there for support and we would not have got through it without her”.*

*“Our child has been transformed since our initial visit with the Roald Dahl nurse and consultant; we were in a state of crisis, unable to manage pain, sleepless nights etc., and now our life has been so settled and that is 100% down to the service we received from the Roald Dahl nurse and the [clinical team].”*

*“Our nurse has been essential in maintaining complicated medical supports and interventions for our child, as well as keeping us together as a family. I have never met someone with so much dedication to their work and passion for seeing the whole family, not just a condition.”*

*“Our [Roald Dahl Specialist Nurse] has been a godsend to us at some of the lowest points in my life. I honestly don’t think I would mentally be where I am now without her.”*

*“Couldn’t even begin to imagine this journey without her - utterly vital and so appreciated! Thank you.”*

*“Having a Roald Dahl nurse has made coming to terms with my child's condition so much easier to bear.”*

*“She has been a light in our darkest times.”*

Many parents stated how fortunate they were to have their child under the care of a Roald Dahl Specialist Nurse, and **they advocated for the service to be expanded** to include other families:

*"They are vital to supporting families through their child's medical conditions."*

*"They are a lifeline for many families struggling. Such a fantastic support for tired and emotional parents."*

*"Roald Dahl nurses are invaluable and provide so much support not only to the patient but to the family as well."*

*"This is such a valuable service for families like ours who have children with complex health and multiple health issues."*

*"There should be more Roald Dahl nurses employed, they make a big difference to peoples' lives."*

*"They do an amazing job from all aspects… more need to be employed as they make big differences."*

*"It is absolutely vital to have this support, without it, I don't know what resources we would have - and would probably be bounced around 111 and others with no consistent care plan. It's is absolutely crucial to us."*

*"They need recognition for the excellent work they do and other services should learn from them."*

*"They often say you don't know what you have until you lose it…"*

At the end of the survey, parents were asked to assess **their overall satisfaction with the care received via the Roald Dahl Specialist Nurse** for themselves and their families (Figure 4.23).

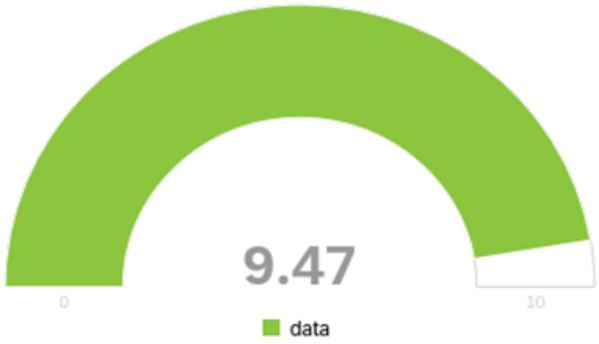


**Figure 4.23 The overall satisfaction with the care received from the Roald Dahl Specialist Nurse**

On a sliding scale from 0=not important to 10=very important Figure 4.23 shows the mean value selected by parents was 9.47 (standard deviation of 1.49) which demonstrates how highly parents appreciate the impact of the Roald Dahl Specialist Nurse on their families. While the parents' quotations provided are only a snapshot of the total comments provided in the survey, two quotations sum up the feelings of many parents:

*"Having a Roald Dahl nurse has made coming to terms with my child's condition so much easier to bear."*

*"We would be lost and more fatigued without them. A MASSIVE thankyou to them all."*

# APPENDIX 5

# Children and young people:

# Results of children and young people's survey

## APPENDIX 5 CHILDREN: RESULTS OF CHILDREN AND YOUNG PEOPLE'S SURVEY

### 5.1 Demographics

Thirty-six children and young people completed the online survey, including 20 boys (55.56%) and 16 girls (44.44%). Just over half of the children were between ages 11-16 years (52.8%, n=19/36) as seen in Figure 5.1.

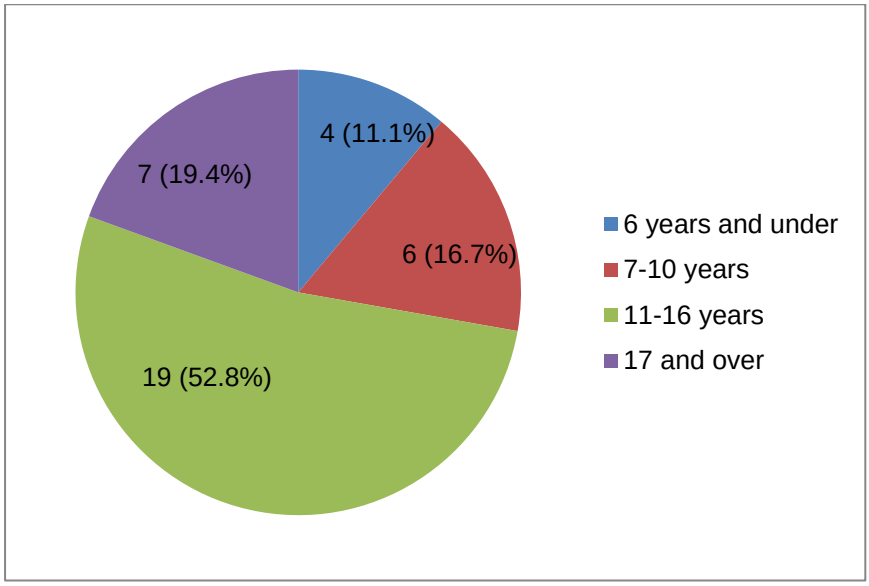


**Figure 5.1 Ages of the children and young people responding to the survey (n=36)**

### 5.2 Experiences with the Roald Dahl Specialist Nurse

The majority of respondents knew the name of their Roald Dahl Specialist Nurse (85.71%, n=24/28), although four children were unclear whether they had met the nurse. However, 46.43% (n=13/28) came into contact with their nurse two or three times a year (Figure 5.2).

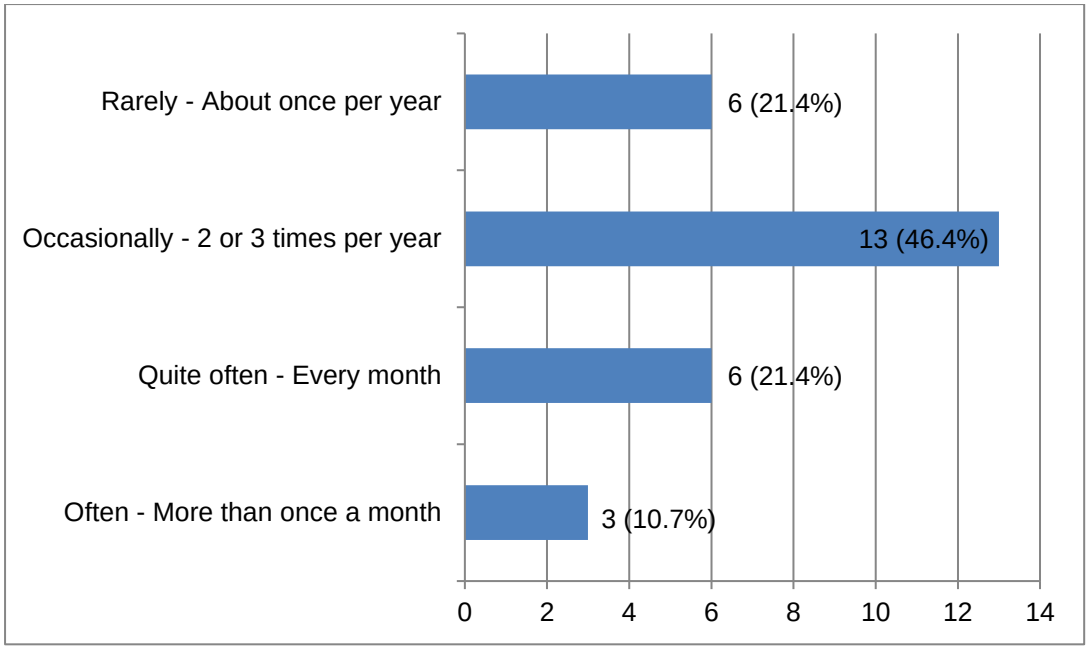


**Figure 5.2 How frequently the children and young people visit their Roald Dahl Specialist Nurse (n=28)**

The children and young people were asked what activities they did with the Roald Dahl Specialist Nurse, and for younger children this was largely centred around play and distraction activities to enable the parents to interact with clinicians.

"Play cars and with other toys and makes sure I'm OK."

"We play while my dad speaks with the other doctors."

Older children, whilst acknowledging that the nurse might mention clinical symptom checks and practical measures, recognised that the majority of their interactions with the Roald Dahl Specialist Nurses focused upon their emotional wellbeing:

*"Chat about how I'm feeling and arrange next appointments."*

*"Talk a lot about my meds and how I feel and how things are at school and home."*

*"We talk about my difficulties and ways of managing them as well as having a giggle about all sorts of other stuff, she's fab!"*

*"I talk to her about my health and well-being, and she makes sure I have everything I need."*

*"Talk about my medication. Answers any questions I have. Always asks me how I have been or if I am worried about anything."*

*"Talk about how I am feeling and how I am coping."*

The young people completing the survey recognised that the nurse was helping them to think about their longer-term wellbeing, as well as helping to provide interesting distractions while they were undergoing boring or painful treatment:

*"Discuss my condition and symptoms."*

*"Talked about my health and transitioning."*

*"She always distracts me from the needles and talks to me about things I like."*

*"Talk about my condition and she will answer any questions that I have. She also gives me advice on how to manage my condition."*

*"We chat about feminism [while I] have my infusion."*

The children were asked about the best and worst things about being supported by a Roald Dahl Specialist Nurse, and these are summarised in Figure 5.3.

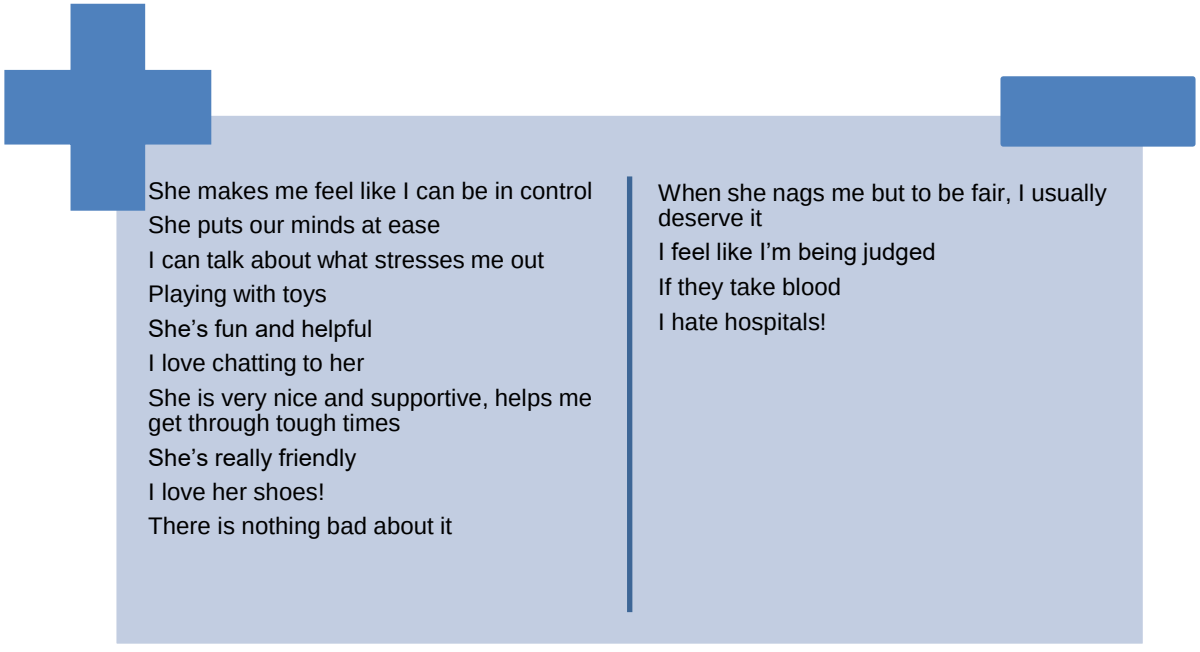


**Figure 5.3 Positive and negative aspects of visiting the Roald Dahl Specialist Nurse**

Some of the young people completing the survey recognised that the nurse was helping them to be more accepting and independent in managing their condition:

*"She reassures me about any concerns I may have. She cares for me and always makes me feel at ease having epilepsy."*

*"I love chatting to her. Makes having Crohn's a bit easier."*

*"Easy to talk to and helps me understand and learn about my condition. Always gives me good advice."*

*"She makes a difficult time easier and helps me manage things for myself instead of taking over. She's also ridiculously fun and enjoys a hot chocolate!"*

The children and young people were generally extremely positive about engaging with their Roald Dahl Specialist Nurse, with 88% (n=22/25) stating that their nurse is friendly and two thirds (66.67%, n=18/27) 'agreeing a lot' that they like visiting their nurse. A high number also agreed a lot that the nurse explains things in a way they understand, and includes them in the treatment decisions (Table 5.1).

**Table 5.1 Levels of agreement and disagreement with Roald Dahl nursing activities**

| Question | I agree a lot | I agree a bit | I can't decide | I disagree a bit | I disagree a lot | Total |
|---|---|---|---|---|---|---|
| *I like going to see my Roald Dahl Specialist Nurse* | 66.67% (18) | 18.52% (5) | 11.11% (3) | 3.70% (1) | 0.00% (0) | 27 |
| *My Roald Dahl Specialist Nurse is friendly* | 88.00% (22) | 0.00% (0) | 12.00% (3) | 0.00% (0) | 0.00% (0) | 25 |
| *My Roald Dahl Specialist Nurse talks to me about my condition* | 77.78% (21) | 7.41% (2) | 11.11% (3) | 3.70% (1) | 0.00% (0) | 27 |
| *My Roald Dahl Specialist Nurse explains things to me so I can understand* | 80.77% (21) | 7.69% (2) | 7.69% (2) | 3.85% (1) | 0.00% (0) | 26 |
| *My Roald Dahl Specialist Nurse includes me in decisions about my treatment* | 76.00% (19) | 8.00% (2) | 16.00% (4) | 0.00% (0) | 0.00% (0) | 25 |

Children and Young People were certainly appreciative of their Roald Dahl Nurses, commenting:

*"Sometimes I feel that she is the only one who really understands how I feel and knows so much about my epilepsy. I can ask for a phone chat anytime and she makes time for me. She always knows what to say and reassures me."*

*"[She] is fab, she's been so helpful to me and my family. We'd be lost without her."*

*"She is amazing and always there if we need her. She's always one phone call away."*

*"I never feel lost or stuck because I know I can trust my Roald Dahl nurse."*

# APPENDIX 6

# Mixed methods: synthesis of findings

**Table 6.1 Mixed methods synthesis of findings**

| Topics | Nurse and Manager Interviews | Nurse Focus Groups | Lead Clinician Survey | Parent and Child Survey | Synthesis |
|---|---|---|---|---|---|
| **Transition to post and early service development** | Stressful where role boundaries are fluid, setting up a service from scratch. Resistance to change systems and processes, unrealistic expectations of some clinicians (e.g., induction too short) | Transition to new post stressful for existing employees and those new to organisation. Good training and support an exception rather than the norm. Difficult to move away from old role | Not always clear at the time of writing the business case what they actually wanted them to do. Few had considered the need to provide cover for the nurse's work during absence - casework built up rapidly | Not highlighted | Weak convergence |
| **Crossing boundaries of care** | Strong emphasis on liaison rather than direct clinical care. The right services involved at the right time. Work across professional boundaries in order to mobilise resources: healthcare, social care, education and housing | "Link between families and the rest of the world" and the "missing link" between families and the medical staff. Multiple contacts, sign-posting and networking, liaison | A key role across the entire pathway, helping to ensure continuity between settings, educating service providers and users. Networking with other health professionals and across healthcare boundaries. A single point of access and contact for the service | "Being a point of contact and coordinating my child's care across hospital services." Providing advice.<br>Liaison with schools and other non-healthcare services highly valued | Strong convergence |
| **Philosophical approach to role** | Clinical philosophies were primarily family-centred care, encompassing holistic management, evidence-based practice and empowerment | High volumes of safeguarding and non-healthcare interventions. Advocacy and empowerment of selves and others. "Holistic family-centred care that our consultant colleagues do not have the capacity to deliver" | Recognised a child and family-centred approach to care and treatment | Huge difference to their own, their child's and their family's lives. Support and care for the whole family is widely recognised with parents stating that their nurses were: amazing, appreciated, a godsend, invaluable, incredible, and worth their weight in gold. Allowed a parent to 'be a mum' and supported their mental health. | Strong convergence |
| **Core values and skillset** | Patient advocacy, being passionate, empathetic and motivational. Professional excellence, highly proactive, | High degree of insight into their role beyond clinical care. Communication, innovation, efficiency and knowledge, | Individual skills highlighted including advocacy, empathy, enthusiasm and being proactive | Willingness to go the extra mile. A friendly and impartial person, providing emotional support. Advocating for | Strong convergence |

| Topics | Nurse and Manager Interviews | Nurse Focus Groups | Lead Clinician Survey | Parent and Child Survey | Synthesis |
|---|---|---|---|---|---|
| | enthusiasm, resilience/ team spirit | many examples aligned clearly to leadership in advanced practice | | parent and CYP. Helpful and caring, a good listener, “A credit to her profession” | |
| **Digital technology and physical resources (access and bureaucracy)** | Multiple systems housing patient data. Poor access to technology, poor physical spaces (offices and consulting rooms) | All re-iterated by many nurses, particularly frustrations with multiple systems requiring many different log-ins etc. | Bureaucratic issues: IT support and the lack of existing infrastructure were cited as some challenges in setting up the role | Not highlighted | Weak convergence |
| **Workloads on non-clinically related tasks** | Admin takes away from frontline clinical care. Safeguarding role huge. Need for support workers, mental health input, administrators, translators | Not cost-effective for a nurse to be doing work suited to a lower band. Family support workers or administrative support essential. Safeguarding | Excessive input to caseload administration. Need for additional Roald Dahl Specialist Nurse, or other healthcare input to support them as caseloads expand | Not highlighted | Strong convergence |
| **Sustainable caseloads - size and complexity** | Lack of initial clear boundaries means caseload expansion is inevitable: 'exponential caseloads'. Difficult to transition patients, yet new ones added every week. Look beyond numbers - many patients highly complex | Articulated how and why caseloads grow - must gain control quickly with tighter criteria. Emotional blackmail to take more patients, so need support from clinicians and managers from start with clear inclusion / exclusion criteria | Size of the caseload is less important than the complexity.<br><br>Caseloads are often too high (1/4 not sustainable), with 65% growing since inception of service.<br><br>A 'recipe for burnout' if not addressed | Parents indicated that some of their children had complex conditions exhibiting multiple organ system disorders. 28% of children were unstable and required round the clock care, with 14% needing multiple A&E visits in the last year | Strong convergence |
| **Challenges of evaluating impact of nurse rather than service** | Complexity of patients means Roald Dahl Specialist Nurse is one of multiple interventions. No definitive 'before and after' evaluations: collect efficiency and productivity data (e.g., admissions, calls) and patient satisfaction. High subjectivity so difficult to systematically | All noted how difficult it is to categorically prove their impact (such as preventing admissions) and recognised the need to gather qualitative data such as parent feedback | Cannot confidently state cause and effect as the nurse does not work in isolation. Takes time for impacts to be apparent. Challenging to identify positive impacts on saving money and reducing demand on services (which may increase). Clinicians were divided on whether the nurses | Not highlighted | Strong convergence |

| Topics | Nurse and Manager Interviews | Nurse Focus Groups | Lead Clinician Survey | Parent and Child Survey | Synthesis |
|---|---|---|---|---|---|
| | quantify and compare collective impact | | had an impact on readmission rates | | |
| **Stakeholder perceptions of impact** | Interventions were felt to lead to reduced waiting times, A&E visits, hospital admissions and duration of stay. Increasing efficiency, reduced wastage and improving patient experience. "Active change agents." | All stated impacts in: cost-effectiveness; responsiveness; flexibility; time per patient; preventing escalation. | Positive impacts on service provision, e.g., psychological and practical support; MDT working; improving access to services; coordination of care/navigating healthcare system. Positive feedback from families | For ¼ of parents unscheduled Roald Dahl Specialist Nurse contact had prevented urgent GP/consultant appointments. Advice / reassurance prevents escalation. 'Liaison nurse'. Securing resources and coordinating appointments | Strong convergence |
| **Impact of the child's condition on the family** | Recognise stresses on the wider family. Provide a support network for parents, always strive to be contactable | Not highlighted | Not highlighted | Wider impact of illness on the family: on a 'roller-coaster' and need to give things up or change plans at last minute. Stressful | Weak convergence |
| **The growing importance of transition** | Re-shaping of transition pathways important for all Roald Dahl Specialist Nurses, not just transition specialists | Not highlighted, other than a reason for caseload expansion | Transition from child to adult services emerging as important issues requiring specialist support. Some centres interested in exploring transition posts to work alongside Roald Dahl Specialist Nurses | Not highlighted | Weak convergence |
| **Role of Roald Dahl's Marvellous Children's Charity** | Enthusiasm for working with Roald Dahl's Marvellous Children's Charity, excellent support early in role, good recruitment feedback, ongoing CPD support | Not highlighted | Importance of Charity pump-priming for these "Cinderella services". Assistance in recruitment and on-going support for nurses CPD highly valued | Not highlighted, other than affectionate terms such as "crocodile nurses" | Weak convergence |

Strong Convergence = More than two sets of data agree on key topics

Weak Convergence = Two sets of data agree on key topics

Divergence = Strong findings present in only one set of data, or findings disagree across data sets