



Marvellous Nurses

**the role, impact and contribution of
Roald Dahl Nurse Specialists**

**Highlights from the independent evaluation
undertaken by Sheffield Hallam University**



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I. Introduction

Roald Dahl's Marvellous Children's Charity, which provides specialist nurses and support to seriously ill children, was established in 1991 by Roald Dahl's widow Felicity, shortly after his death. There are currently over 200 Roald Dahl Nurse Specialists caring for over 40,000 seriously ill children and young people across the UK.

Roald Dahl Nurses are specialists at providing support, information and practical care for seriously ill children and young people, working in NHS Trusts and Health Boards across the UK. They are a vital lifeline to the whole family, supporting them clinically and emotionally.

Roald Dahl Nurses work with children and young people affected by complex, lifelong illnesses that are under-funded and under-resourced including epilepsy, rare diseases, sickle cell anaemia, and neuro-muscular conditions. Roald Dahl Nurses also support children as they transition into adulthood. Our incredible nurses are all senior, highly trained professionals who can 'make things happen' both in the hospital and the wider community setting such as with schools or GPs. Many will have completed courses in a variety of specialist areas and will be leaders within their areas of expertise. They will also be giving advice to other healthcare professionals as the areas they deal with are often complex and cross over into many other clinical specialisms.

Previous research has demonstrated Roald Dahl Specialist Nurses to be innovative, effective and well-received by various stakeholders, however, these evaluations were designed primarily for local dissemination, rather than sharing on a wider scale.

In order to better understand the contribution of Roald Dahl Specialist Nurses to children's healthcare, thus informing future investment strategies, Sheffield Hallam University was commissioned in late 2018 as the Higher Education Institution partner to independently explore and evaluate, from the perspectives of multiple stakeholder groups, the role and impact of Roald Dahl Specialist Nurses.

The project was led by Prof Julie Nightingale, and supported by a 'field' research team of experienced educators, who are registered children's nurses (Helen Monks, Tanya Urquhart-Kelly and Lesley Saunders). Dr Nancy Ali, Rachel Ibbotson and Dr Robin Lewis also supported the project.

The role and impact of Roald Dahl Specialist Nurses were investigated via a three-phase mixed methods research approach containing both qualitative and quantitative methods. Phase 1 (healthcare staff) data collection was primarily undertaken via semi-structured interviews with nurses and managers. This was supplemented by focus groups to explore emerging topics with the nurses, and online questionnaires with the lead clinicians (generally consultant paediatricians) for each service to provide a multi-disciplinary team perspective. Phase 2 (service users) data collection was via an online survey of parents and children in the caseload of Roald Dahl Specialist Nurses. The findings from each phase of the research were compared and contrasted in Phase 3.

**Sheffield
Hallam
University**

Please note that this document, which has been produced by Roald Dahl's Marvellous Children's Charity, is based on the research undertaken by Sheffield Hallam University. However, it does not endeavour to provide a summary of it; it just aims to briefly capture and highlight a selection of findings related to the impact of Roald Dahl Specialist Nurses. The full report from Sheffield Hallam University, containing references and appendices, is available to download on our website.

To learn more about our charity please visit our website: www.roalddahlcharity.org. If you need any further information about this report, our Charity or how to get involved, please email us at enquiries@roalddahlcharity.org or call us on 01494 890 465.

2. What is the role of a Clinical Nurse Specialist?

Due to advances in obstetric and paediatric medicine, increasing numbers of children and young people are now surviving previously unsurvivable or significantly life-limiting conditions. The way that health services are organised is therefore a crucial aspect of ensuring a high quality of life for these children and young people as well as their families.

The Kennedy Report "*Getting it Right for Children and Young People*" published in 2010, highlighted that there were a number of specific issues that needed to be addressed to improve the health outcomes for all children and young people. One of the key issues that Sir Ian Kennedy identified in his report was the need for improved coordination and integration of children's services.

The subsequent report of the Children and Young People's Outcomes Forum published in 2012, by the Department of Health, built upon the findings from the Kennedy report, outlining a number of key priorities, and introducing the establishment and implementation of family-centred care. In response to this, one of the priority recommendations was an emphasis upon the importance of the Clinical Nurse Specialist role, in the delivery of high-quality care for children and young people.

There have been numerous systematic reviews over the years that have looked at the contribution of the Clinical Nurse Specialist role to patient care, concluding that the Clinical Nurse Specialist role provides high levels of patient satisfaction, quality care, and a reduction in length of hospital stay. Having reviewed the available evidence, **the importance of the Clinical Nurse Specialist role in the care of children and young people is clear and unambiguous, providing safe, effective, and high-quality patient care.**

With complex conditions, care is often disjointed and fragmented, involving the input of a variety of health professionals with different roles and in different contexts. Evidence shows that **the Clinical Nurse Specialist role can save resources leading to greater efficiency and better outcomes.** This may be achieved through improved coordination of services, the provision of information and emotional and psychological support, as well as providing expert clinical and technical input.



Quality care



Coordination of care



Health outcomes



Patient satisfaction and safety



Effectiveness and efficiency



The benefit of the Clinical Nurse Specialist role to the NHS – and children and young people in particular – is that they are highly skilled in higher-level, strategic activities and are therefore able to coordinate the different parts of the healthcare system to enable them to better work together. The fact that the Clinical Nurse Specialist works strategically across different teams means that their experience may be invaluable to senior management as they can advise on the specific nature of service provision to inform service redesign.

It is clear from the evidence that **the Clinical Nurse Specialist role is particularly suited to the care of patients with long-term conditions** such as sickle cell disease or epilepsy. The ability to form longstanding and therapeutic relationships with the patient and their support network is invaluable in enabling the patient to deal with an often complex set of circumstances. Managing long-term conditions depends on the negotiation of a mutually beneficial partnership between patients, their families, and health professionals which fosters collaborative decisions and care management.

Clinical Nurse Specialist roles come at a significant cost, and it is clear that the current healthcare system has faced significant challenges in supporting and justifying this role.

The third sector plays an increasingly pivotal role in supporting and maintaining the health and social care system, particularly in finding the funds to cover activity that would otherwise be considered 'desirable but not essential' by senior NHS management.

Establishing Clinical Nurse Specialist roles has become one identifiable and practical way in which health charities play a role in supporting healthcare delivery. Many high-profile healthcare charities – including Macmillan Cancer Support, Marie Curie, British Heart Foundation and Diabetes UK – establish Clinical Nurse Specialist posts in their particular sphere of healthcare activity. Most, if not all, use the 'pump-priming' model of support.

Roald Dahl's Marvellous Children's Charity uses a successful pump-priming model to establish Clinical Nurse Specialists at NHS Trusts and Health Boards across the country.

There are over 200 Roald Dahl Nurses who currently care for over 40,000 seriously ill children and young people as well as their families.

3. Who do Roald Dahl Specialist Nurses support?

The research undertaken by Sheffield Hallam University recognises that Roald Dahl Specialist Nurses are a vital lifeline for seriously ill children and young people as well as their families.

Roald Dahl Specialist Nurses support children and young people affected by, amongst others, rare diseases, sickle cell, neuro-muscular conditions or epilepsy. While the specialties of these nurses appear to be extremely diverse, the common thread is that the children and young people looked after by these nurses are all living with complex **lifelong conditions**

that are **under-funded, under-resourced and under-recognised**. These conditions include progressive disease without curative treatment options, as well as irreversible but non-progressive conditions causing severe disability.

The children and young people in the caseloads of Roald Dahl Specialist Nurses live with a wide range of conditions, and while some are usually stable and live relatively normal lives for most of the time, others require higher levels of care including support for activities of daily living, and some are frequently hospitalised.

Children and Young People under the care of Roald Dahl Specialist Nurses

27.9%

are **unstable** and require **round-the-clock care**

29.9%

attend a school catering for **special education needs**

44.5%

had **missed at least 10 school days** in the last year due to their condition

11.6%

required **at least five A&E visits** in the last year

Many of these nurses' young patients have very complex conditions exhibiting multiple organ system disorders (for example cardiac, gastrointestinal and neurological) and consequently they are **under the care of several different consultants often associated with different NHS Trusts and healthcare organisations**. The navigation of the system and coordination of the care of these patients is highly complex and often exhausting for the parents, with many patients also having significant needs beyond healthcare.



“Our child is currently under 24 teams between several Trusts.”

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



There is a large body of existing evidence that has explored the lived experiences of parents whose children have chronic health problems. Unfortunately, these experiences are often dominated by **social isolation and significant struggles in coping with work and parental responsibilities, on top of looking after a sick child or young person.** Feelings of despair and helplessness are particularly heightened in young, deprived or ethnic minority families as they often do not know how to navigate the system to get medical, financial and emotional support.

Families supported by Roald Dahl Specialist Nurses experience particular issues due to financial hardship, lack of family support or being a migrant family with little knowledge of national or local systems and processes. Many expressed similar **concerns regarding navigation of the different systems within and beyond healthcare;** these confusing systems need to be mastered in order to ensure even basic care for their child and their wider family.

Nearly half of parents (47.6%) indicated that they often or occasionally experienced financial hardship while forty percent (40.1%) stated that their child's illness has had a significant impact on their employment or financial status. These factors all put an added strain on parents who had multiple responsibilities.

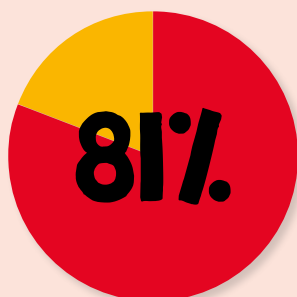
It is not, therefore, surprising that this study confirmed that **there is a wide impact from the child's condition on parents and the extended family.**

The consequences of caring for these children has an impact on the wider family who experience stress, anxiety and in some cases poor mental health. The extent of this impact is particularly high in some aspects of daily life, with fatigued parents feeling they are often on a 'roller coaster' of emotions, needing to give normal family things up or change plans at the last minute due to changes in their child's condition.

This uncertainty and worry is exacerbated when liaising with healthcare services, particularly in emergency or urgent care situations.

% of families under the care of Road Dahl Specialist Nurses recognising that:

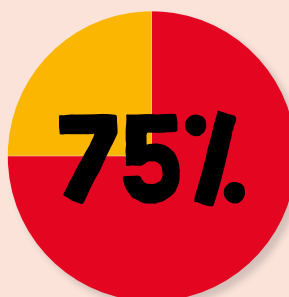
Sometimes I feel like we live on a roller coaster: we are in crisis when my child is acutely ill. But coping well when things are stable



Our family gives up things because of my child's illness



Fatigue is a problem for me because of my child's illness



Sometimes we have to change plans about going out at the last minute because of my child's condition

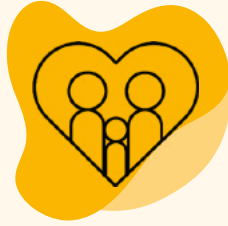


4. What are the impacts of Roald Dahl Specialist Nurses?

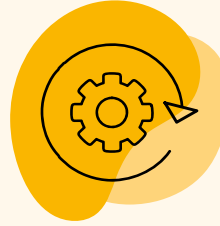
Roald Dahl Specialist Nurses' four impact areas



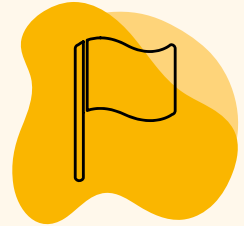
**Quality and
experience of care**



**Holistic
family-centered
care**



**Efficiencies and
cost-effectiveness**



**Leadership and
innovation**

4.1 Improved quality and experience of care

The research undertaken by Sheffield Hallam University has evidenced the positive impact of Roald Dahl Specialist Nurses in the quality and experience of care received by young patients in their caseload.

One of the main ways in which nurses support those under their care is by **providing families with information** about the nature, prognosis and treatment options related to their child's condition(s). Roald Dahl Specialist Nurses act as the **'one point of contact'** into the service for both parents and health professionals alike.

Quotes from parents of seriously ill children

Our Roald Dahl Specialist 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.

Our child has been transformed since our initial visit with the Roald Dahl Specialist 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 Specialist Nurse and the [clinical team].

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 Specialist Nurse.

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.

Parents highly appreciate the **'coordination of care'** provided by their nurses, with advice and liaison undertaken both within and outside healthcare boundaries.

The fact that Roald Dahl Specialist Nurses are able to offer families **a service more responsive, intensive and flexible than a consultant could offer is an aspect that is particularly valued.**

The majority of parents indicate that they have needed to contact their Roald Dahl Specialist Nurse between routine

appointments, with nearly three quarters of parents (72.9%) needing to contact them at least three times in the last year. Parents describe how this **accessibility and availability** of the nurses often provided quick answers to their worries, relieving their anxiety.

Nurses recognised that they 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".

“

...before [our Roald Dahl Specialist Nurses] I spent hours upon hours, days upon days chasing appointments, medication, explaining my daughter's condition, waiting for a call back. Roald Dahl Specialist 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.

”

“

[Our Roald Dahl Specialist Nurse] 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.

”

“

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 there for a chat and advice when I need it.

”

“

I am very impressed at how promptly [our Roald Dahl Specialist 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 research by Sheffield Hallam University has established that Roald Dahl Specialist Nurses exhibit a high degree of insight into their role, beyond the clinical care that they provide. While these nurses express their core attributes as **patient advocacy, being passionate, empathetic and motivational**, the parents they support express these qualities as “a willingness to go the extra mile”, a friendly and impartial person, providing emotional support and advocating for the parent and child.

Both the managers and lead clinicians identified qualities of Roald Dahl Specialist Nurses working at their NHS Trusts and Health Boards as **professional excellence, empathy, proactivity, persistence in overcoming challenges, enthusiasm, resilience and team spirit**. Many of these attributes are exhibited by professionals in high responsibility posts.



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 of Roald Dahl Nurse



The overall families' satisfaction with the care received from their Roald Dahl Specialist Nurse is extremely high, with a mean of 9.47 on a scale to 10. This demonstrates the positive impact Roald Dahl Specialist Nurses have on the quality and experience of care received by those in their caseloads.

Parents have described the profound impact that Roald Dahl Specialist Nurses have had on them and their families.

great
professional
support **helpful** beyond and above a 'fixer!'
invaluable
utterly vital
friendly face reliable **inspirational**
efficient **caring** best support
welcome
amazing
understanding



4.2 Provision of holistic family-centred care

Given the complex needs of children and young people in the caseload of Roald Dahl Specialist Nurses, a traditional patient-centred care approach would be inappropriate. **Family-centred care presents a shift of traditional approaches to the delivery of care that supports individuals within their family unit.** The core components of family-centred care are developing an effective relationship with the family and with health professionals working collaboratively with them when planning and delivering care for the child and young person.

In the context of working with children and young people with long-term conditions, this type of collaboration is particularly relevant as these children and young people are primarily cared for at home, with parents often taking significant responsibility for care decisions and delivering treatments. When parents become skilled and experienced in providing care for their child or young person, they shift from a passive to more active position when collaborating with health professionals.

The research by Sheffield Hallam University has established that **family-centred care is embraced as a core responsibility and value by Roald Dahl Specialist Nurses.**

Without the[ir] Roald Dahl Specialist Nurse, these families would have nothing.

Clinician

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.

Parent of a seriously ill child

I think if families didn't have that [input of Roald Dahl Specialist Nurse] it would be a disadvantage to the 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 of a Roald Dahl Nurse

Dignity and Respect

Health professionals listen to and value patient and family perspectives and choices. Patient and family knowledge, values, beliefs, and cultural backgrounds are incorporated into the planning and delivery of care.

Information Sharing

Health professionals communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.

Participation

Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.

Collaboration

Patients, families, health professionals, and hospital leaders collaborate in policy/program development, implementation, and evaluation of healthcare service design and in professional education, as well as in the delivery of care.



The behaviours and attitudes displayed by these nurses align with the four precepts of family centred-care, including: the provision of independent and unbiased education and counselling [information sharing], leading to empowerment of families and meaningful participation in healthcare decisions [participation]; advocacy for patient and family perspectives and values [dignity and respect]; safe-guarding and non-healthcare interventions [collaboration], taken on behalf of the child and their family.

Examples of family-centred care 'in action' are recounted by many parents who indicate how they highly value the non-clinical services provided by their Roald Dahl Specialist Nurse, particularly the emotional support they receive to help them to cope with their own mental health challenges and 'be strong' in order to better care for their child. Roald Dahl Specialist 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.

Parents of seriously ill children

"Our amazing [Roald Dahl Specialist Nurse] is a compassionate, knowledgeable voice, who is pretty much always available, this has massively reduced family anxiety. 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."

"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 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."

"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."

"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."

"She has been a light in our darkest times."

"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 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 Specialist Nurse."

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

The research found that Roald Dahl Specialist Nurses **work across professional boundaries and outside the traditional scope of nursing practice**, expanding their role to include supporting families in every possible way. Understanding that helping families get access to social services, financial aid or housing benefits (amongst other services) can be as crucial to the patient's and their family's wellbeing and quality of life as receiving good quality healthcare, Roald Dahl Specialist Nurses provide holistic management and

act not only as the **"missing link"** between families and the medical staff, but also as the **"link between families and the rest of the world"**. Advocating on behalf of the families to other external organisations, authorities or individuals, Roald Dahl Specialist Nurses work across multiple agencies to mobilise resources. **Striving to secure "the right services involved at the right time"** appears to be the essence of Roald Dahl Specialist Nurses' work.

Our Roald Dahl Specialist 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.

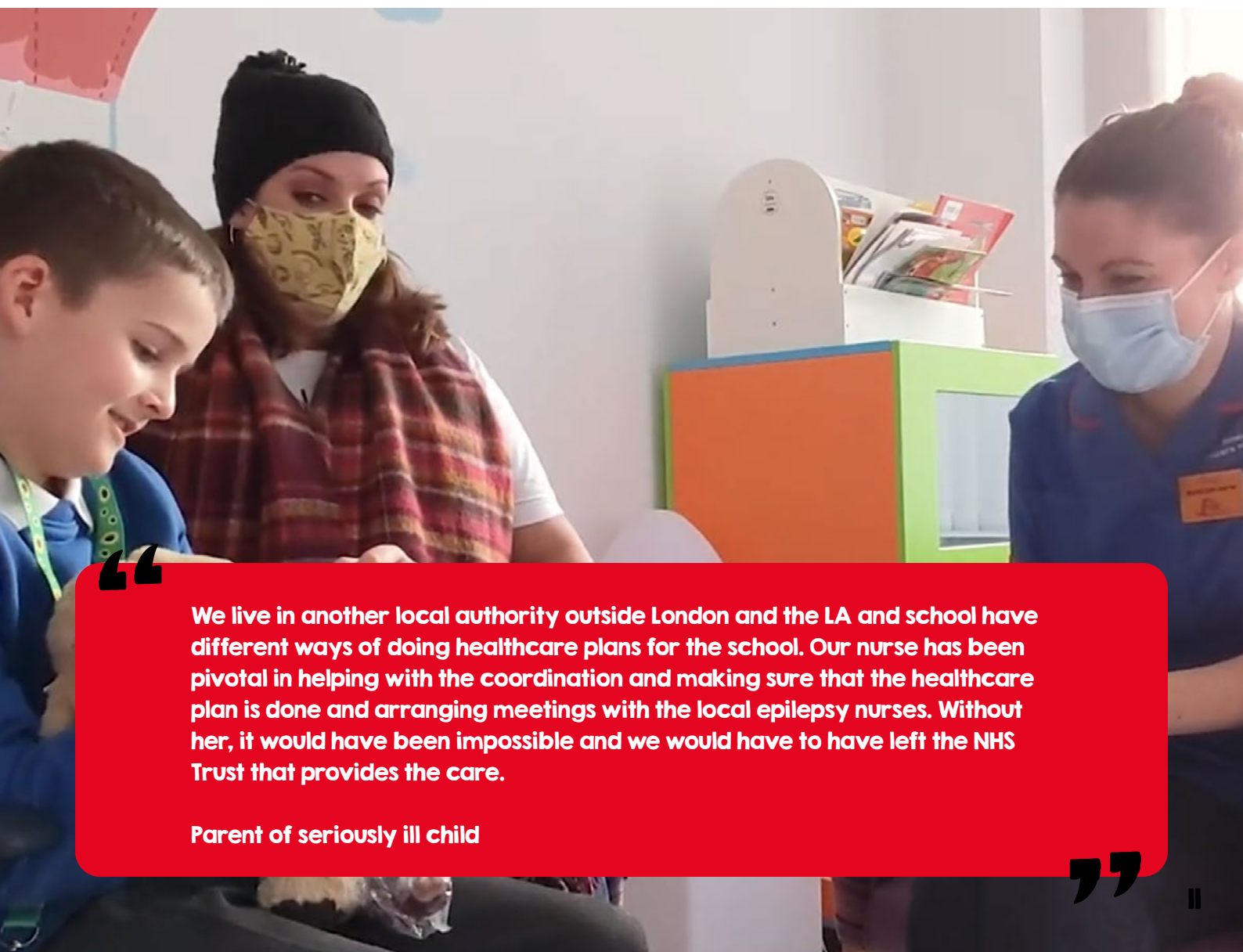
Parent of seriously ill child

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, better housing and safer housing for the children.

Roald Dahl Specialist Nurse

We live in another local authority outside London and the LA and school have different ways of doing healthcare 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.

Parent of seriously ill child



In the context of the provision of holistic family-centred care, **empowerment** is a key clinical approach used by Roald Dahl Specialist Nurses to deal with families and young adults as people and which avoids reducing the complexity of their experiences by looking at them through a strictly clinical lens. As such, these nurses succeed in promoting high levels of active family participation in patient management and building **therapeutic relationships based on trust and joint autonomy**.

Roald Dahl Specialist Nurses empower families to make the best decisions by providing and explaining medical information, teaching healthy strategies to self-manage their conditions and cope with difficult emotions as well as ensuring access to social and financial support services. The ultimate positive impact that a Roald Dahl Specialist Nurse can have is when patients and families are supported and empowered to no longer need their support.

“

We've managed to educate them [young people and families] 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.

Roald Dahl Specialist Nurse

”

“

She makes a difficult time easier and helps me manage things for myself instead of taking over.

Young person

“

She is easy to talk to and helps me understand and learn about my condition. Always gives me good advice.

Young person

”



4.3 Improved efficiencies and cost-effectiveness

The Sheffield Hallam University research found that Roald Dahl Specialist Nurses present themselves as **“active change agents”**, introducing a suite of interventions that they feel would lead to reduced waiting times, A&E visits, hospital admissions and duration of stay. They focus on increasing efficiency, reducing wastage and improving patient experience.

Roald Dahl Specialist Nurses provide timely access to suitable care, services and information – for example, providing medicines advice to parents out-of-hours to help stabilise their child, or rearranging appointments so that a child of concern can be seen by a consultant earlier than scheduled. This in turn reduces risks to their young patients health and relieves the anxiety of patients and families. Moreover, this also improves cost-effectiveness, as these nurses prevent escalation (preventing a major event requiring admission by intervening at an earlier stage) and reduce the number of missed appointments, A&E visits, hospital admissions and duration of hospital stays.

Many of these nurses also build inter-disciplinary teams from scratch and coordinate the work of different professionals to avoid duplication of effort; these actions save time and money.



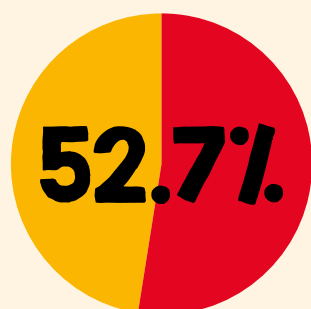
I think our team manager and the multidisciplinary team, they can see the value...What would happen if I wasn't doing that? They [family] would just constantly call or attend A&E, so to the wider Trust we are reducing hospital admissions ... we will see patients on the ward, and we'll get them home as quickly as we can.

Roald Dahl Specialist Nurse

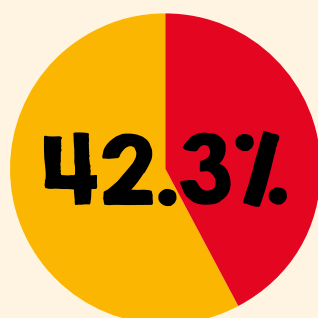


% of families who have averted having to access the following services due to timely contact with their Roald Dahl Specialist Nurses:

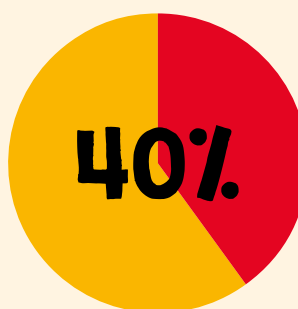
consultant appointments



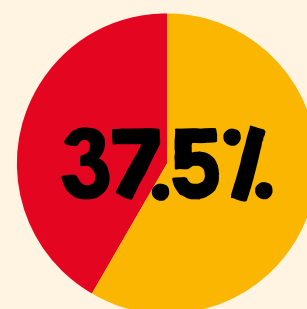
emergency visit to A&E



urgent visit to GP



admission to hospital



4.4. Demonstrating leadership and innovation

According to Sheffield Hallam University, many aspects of the work of Roald Dahl Specialist Nurses are synonymous with practice at an advanced level. In order to improve the quality and experience of care provided, deliver high-quality holistic family-centre care sustainably, and improve efficiencies and cost-effectiveness, these nurses deliver high levels of clinical reasoning, decision making and critical analysis.

The complex conditions and high levels of clinical uncertainty of those in their caseloads mean that Roald Dahl Specialist Nurses are not always able to follow

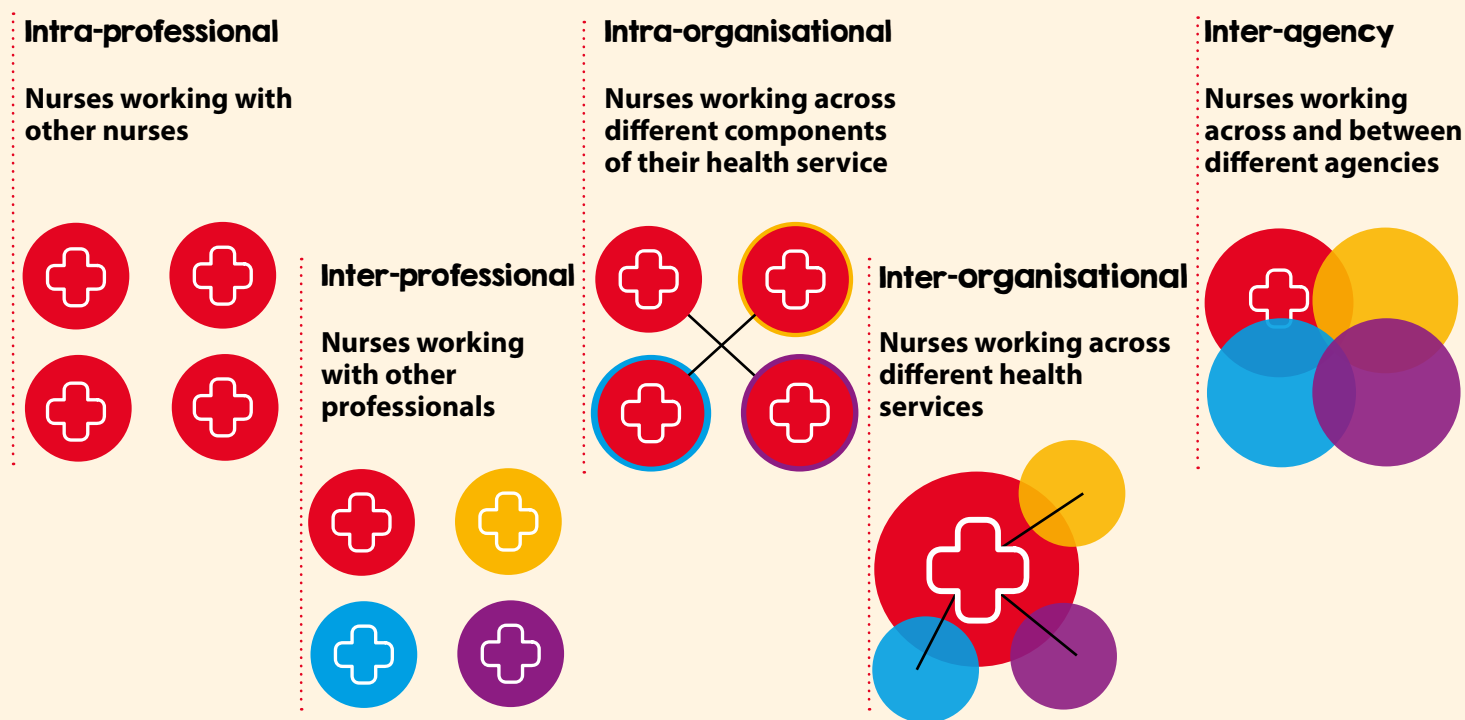
standard pathways of care or clinical protocols; they regularly have to use their leadership and innovation.

Roald Dahl Specialist Nurses note that **service development** represents a significant aspect of their role. It involves 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.

As a direct result of Roald Dahl Specialist Nurses' leadership, this research identified innovations that had a positive impact not only on patients accessing the services, but also on the teams delivering these services. These included improved psychological and practical support, better multidisciplinary team working, improved access to services, as well as better coordination of care and navigation of the healthcare system. The research also acknowledges the significant contributions these nurses make to policymaking

and setting benchmarks that ensure the delivery of standardised, good quality care across the NHS.

The collaborative nature of the Roald Dahl Specialist Nurses' role is key. These nurses work routinely not only at an intra-professional level but also at inter-professional, intra-organisational and inter-organisational levels to ensure the delivery of complex multidimensional care which addresses the various aspects of patients' needs.



A major distinctive component of the work of Roald Dahl Specialist Nurses is situated at an **inter-agency** level.

Although their roles may lie within a particular organisation, their remit encompasses proactively creating connections and facilitating care across organisational boundaries. Improving pathways that span services mean that these nurses spend significant time and energy creating and fostering inter-agency links and networks.

This inter-agency work, which is very often hidden from view, has promoted positive changes in organisational culture and openness.



She [Roald Dahl Specialist Nurse] 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 'crisis' against a planned clinic and this requires levels of competence, leadership and initiative that can be daunting.

Clinician



An obvious and powerful impact of Roald Dahl Specialist Nurses that extends beyond their immediate workplace, encompasses the **development of the healthcare workforce** within the field of paediatric care of children and young people with long-term conditions.

These nurses **share knowledge** and educate fellow healthcare professionals – including physicians, GPs, community and school nurses – as well as other professionals with limited healthcare knowledge, such as teachers and social workers. By offering teaching and training to professionals within and outside their Trusts or Health Boards, these nurses build **communities of practice and change culture**.

Roald Dahl Specialist Nurses use their creativity and innovation to question the status quo, drive forward change and address service issues, such as **“filling in the gap”** between hospital and community settings to create **“cohesive care”**.

This model of practice which emphasises the non-clinical roles, alongside the multi-agency nature of the work undertaken, presents a relatively unique model of nursing practice.

“
She has ‘upskilled’ a number of community and school nurses and involved them actively in patient care.
”

Clinician

“
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.
”

Roald Dahl Specialist Nurse

“
[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 marvellous, they’ve come, we never knew that, we never even thought of it, now we’ve put this in place. And actually a lot of that stuff is not at a cost, it’s only about behavioural differences.
”

Manager of a Roald Dahl Nurse

5. What are the recommendations for the future?

The aim of the research undertaken by Sheffield Hallam University was to explore, from the perspectives of multiple stakeholder groups, the role and impact of Roald Dahl Specialist Nurses.

Roald Dahl Specialist Nurses support children and young people living with complex lifelong conditions. These conditions include progressive disease without curative treatment options, as well as irreversible but non-progressive conditions causing severe disability. The complexity of many of these conditions mean that healthcare cannot be delivered in isolation as it is often inextricably linked to additional needs, for example in education, social services and housing. Roald Dahl Specialist Nurses have forged networks across these inter-agency boundaries to safeguard the child and family and make sure they are safe and supported in these other aspects of their lives, thus ensuring that the healthcare that is delivered has the maximum impact.

This research has categorised the depth and breadth of the role played by Roald Dahl Specialist Nurses; this is a unique role which goes beyond traditional nursing care to cross organisational boundaries to deliver holistic care for patients and their families. This role is not easy to step into and fill and Roald Dahl Specialist Nurses require a particular skill set beyond their clinical expertise including the core attributes of being passionate, empathetic and motivational, professional excellence, patient advocacy, empathy, proactivity, enthusiasm, resilience and team spirit. Innovation is a key driver for Roald Dahl Specialist Nurses, which has yielded new ways of working to improve patient care, experience and outcomes. **Sheffield Hallam University has evidenced that Roald Dahl Specialist Nurses, regardless of their specialty, location, organisation or service focus, have a profoundly positive impact on the stakeholders around them.**

Roald Dahl Specialist Nurses have proved to be **invaluable assets and indispensable not only for the children and families in their caseload, but also the NHS Trust and Health Boards where they work, the medical teams and the community at large.**

Roald Dahl Specialist Nurses establish themselves as drivers of service quality and become the linchpin around which the service revolves. Their impact on patients and families is clear for clinicians and their multi-disciplinary team to see:

“

... 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.

”

“

I do not think that there is any way the service at [hospital] will be able to function effectively without the Roald Dahl Specialist Nurse. If anything, my opinion would be that we need more than one or two of them. They are highly appreciated.

”

Passion, empathy, motivation, professional excellence, patient advocacy, proactivity, enthusiasm, resilience, persistence, team spirit, innovation

Parents have described the profound impact that Roald Dahl Specialist Nurses have had on them and their families. When asked about their overall satisfaction with the care received from their Roald Dahl Nurses, families indicated this was extremely high, with a mean of 9.47 on a scale to 10. The parent testimonies have highlighted that the care provided by Roald Dahl Specialist Nurses follows the philosophy of family-centred holistic care, and it is highly valued by them. Parents described their nurses as **“amazing”, “appreciated”, “a godsend”, “invaluable”, “incredible”, and “worth their weight in gold”**. The two following parent comments highlight two of the most important aspects of care that parents appreciated, that of educational and emotional support for parents, and acting as a care navigator and advocate for the parents and child: **“having a Roald Dahl Specialist Nurse has made coming to terms with my child’s condition so much easier to bear”; “without our amazing Roald Dahl Specialist Nurse, I would feel isolated, lost in the medical system and unsupported”**.

The findings from the research undertaken by Sheffield Hallam University have yielded three overarching recommendations: the requirement to demonstrate the value and impact of Roald Dahl Specialist Nurses, the need to support Roald Dahl Specialist Nurses and a need for future investment in Roald Dahl Specialist Nurses.

- Despite the challenging nature of gaining objective evidence of the impact of Roald Dahl Specialist Nurses, this is a necessary step to ensure the future successful expansion of the network of Roald Dahl Specialist Nurses. Evidence around key performance indicators, impact and value of Roald Dahl Specialist Nurses should not only be collected, but also shared and disseminated by Roald Dahl’s Marvellous Children’s Charity in appropriate professional forums.

- The role of Roald Dahl Specialist Nurses is unique and goes beyond traditional nursing care to cross organisational boundaries to deliver holistic care for patients and their families. This research found that Roald Dahl Specialist Nurses operate at an advanced level that requires a particular set of skills and core attributes. It is therefore necessary that Roald Dahl’s Marvellous Children’s Charity not only continues to support their training, education and continuing professional development, but also provides suitable tools and innovative solutions to lessen the workload of non-clinical, administrative and clerical tasks that Roald Dahl Specialist Nurses are required to undertake.

- Sheffield Hallam University has evidenced the highly valued role and profoundly positive impact of Roald Dahl Specialist Nurses. Moreover, it has recognised how these nurses can often become victims of their own success, having to deal with very high caseloads. **The findings of this research support the future establishment of more Roald Dahl Specialist Nurses across the UK whatever the specialty**, including transition of care, as long as the posts conform to Roald Dahl nursing service model. This encompasses serious lifelong conditions that affect both child and the wider family, a family-centred care focus, management of own caseload, long-term relationship building and the need for regular multi-agency working.



“There should be more Roald Dahl Specialist Nurses employed, they make a big difference to people’s lives.”

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

“They do an amazing job from all aspects...more need to be employed as they make a big difference.”

Every seriously ill child deserves a Roald Dahl Nurse



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