

Cope Children's Trust

# Rainbows Hospice for Children and Young People

## Inspection report

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## Ratings

Overall rating for this service	Outstanding 
Is the service safe?	Good 
Is the service effective?	Outstanding 
Is the service caring?	Good 
Is the service responsive?	Outstanding 
Is the service well-led?	Outstanding 

# Summary of findings

## Overall summary

This inspection took place on 31 May, 1 and 2 June 2016 and was unannounced.

Rainbows Hospice provides care for children and young people up to the age of 30, with life threatening or life limiting conditions. Services include specialist respite, palliative, end of life and bereavement care. The service provides support to families of children and young people both within the hospice and the wider community. The hospice supports families across the East Midlands.

Rainbows provides a residential respite facility for up to 14 children and young people at any one time, within designated areas of the hospice, within individual bedrooms. At the time of our inspection there were nine children and young people accessing respite care. The hospice is located on the edge of a housing estate on the outskirts of Loughborough. The facilities provided by the hospice include, a multi-sensory room, computer room, soft play room, hydrotherapy pool, music therapy room, separate lounges for children and young people, an art and crafts room and day care facility. Accommodation is also provided for parents and their families should they wish to stay. The grounds of the hospice incorporated a range of facilities for children to play, and distinctive areas of landscaped gardens for relaxation and a separate remembrance garden.

The service had a registered manager. A registered manager is a person who has registered with the Care Quality Commission to manage the service. Like registered providers, they are 'registered persons'. Registered persons have legal responsibility for meeting the requirements in the Health and Social Care Act 2008 and associated Regulations about how the service is run.

The provider had employed staff to undertake specific roles, which had a positive impact on the experience of children, young people and their families. For children and young people it presented opportunities for them to take part in activities and experience everyday activities, including play. Whilst for the families of children and young people, the provider recognised the impact of a child's health on the wider family and had created staff roles who led support groups for siblings and parents, the groups provided support through information, counselling and social events, and were well received by those who participated.

The inclusive approach of the provider, in response to feedback from parents had established the 'transitions project' and group, facilitated by a member of staff who had considered as part of its work the impact of the Mental Capacity Act 2005, (MCA) and its implications for young people who used the service as they transitioned to adulthood. The transition co-ordinator worked with young people and their parents, providing support as they transferred to adult services.

The provider worked in partnership with children, young people and their families by providing opportunities for everyone to comment and influence the care and treatment provided. This enabled staff to deliver person centred care, with staff supporting children and young people throughout the day, providing all aspects of their care and treatment along with play and the taking part in recreational activities. Parents

valued their relationships with staff who felt that the support they received had a positive impact on their life and that of their child's. Staff focused on the wellbeing of children and young people, and their families and worked together to share information for the benefit of the child or young person.

There were excellent recreational facilities, for which children and young people could access, and a range of holistic therapists were available to them and their parents. There was a commitment shown by all staff with regards to the quality of life of children and young people, with staff providing support so that they could take part in activities and play. Children and young people were observed playing, with other children, which included face painting, planting seeds, soft play and interactive games and relaxation in the multi-sensory room.

The provider and staff's commitment to the delivery of high quality care has been recognised by organisations external to Rainbows Hospice. Staff in a range of roles from the hospice have worked and continue to work with a range of organisations, which include NICE, Together for Short Lives and East Midlands Children/Young People's Palliative Care Network. Using their experience and knowledge to develop good practice, this has included their contribution as authors in publications. The Medical Director is the author of the Paediatric Symptom Control Manual, widely used within the field of palliative care.

We found the provider and staff promoted the safety of children and young people and their parents told us they were confident of their safety whilst at Rainbows. Any safeguarding issues were clearly identified in children's and young people's care plans. Each child and young person had a personalised care plan which assessed and balanced the risks associated with activities against the individual's quality of life and their wishes and expectations of care.

Young people who used the service and a parent we spoke with said medicine was managed safely and staff provided support where needed. We found nurses gave children and young people their medicine when they needed it and not at set administration times. This was a child centred approach. Medicine was stored safely within the service and staff responsible for the administration of medicine had their competency regularly assessed.

We found improvements were needed in some aspects of medicine management; however a majority of the improvements required would not directly impact on children and young people's safety, but would make the system of medicine management more robust. We spoke with the registered manager who told us they would make the necessary improvements. We received an action plan following the inspection detailing how the provider would implement changes, of which some action had already been implemented.

There were sufficient highly qualified and experienced staff, from a range of disciplines to meet the needs of the children and young people who used the service, reflective of their health, therapy and activity needs. Staff received regular training in areas relevant to their practice. Safe recruitment practices were followed when recruiting new staff.

People we spoke with were positive about the meals and the quality of the food and told us that choices were always available, which included special requests. Mealtimes were family oriented with hospice staff, children and their families eating together. Any special dietary requirements were noted in the care plan, which included where children and young people were artificially fed.

A child or young person approaching the end of life, and their family, could stay at Rainbows hospice. Anticipatory symptom management plans and medicines were in place in order to respond rapidly to escalating symptoms at the end of life to keep the child or young person as comfortable and as pain free as

possible.

Children and young people who died at Rainbows hospice and some who died elsewhere could access the 'The Quiet Room'. The provider had taken measures to ensure people's spiritual, religious and cultural needs were recognised and supported. The facility could be personalised for each child or young person by their family. Following the death of a child or young person bereavement support was provided to the family, for as long as they wished.

Bereaved families were invited to an annual remembrance day where all children and young people were remembered. Upon the death of a child or young person, the provider had a plaque engraved with the child's name, which with the parents' consent, was placed in the remembrance garden or taken by them to a place of their choosing.

Parents told us they accessed a range of services provided by Rainbows hospice, which responded to their individual circumstances, offering support and information and in some instances additional respite care. Parents and health and social care staff could refer a child or young person to the service. Regular admission panels ensured that all referrals were dealt with in a timely manner.

A complaints policy and procedure was in place. Where parents had raised a concern we found their concerns had been robustly investigated with the parent being kept informed at all stages of the investigation. Parents attended meetings to discuss their concerns. Parents told us that the outcome of investigations had been shared with them in writing, which included details as to how any changes to practices were going to be made as a result of the investigation and included an apology.

The Board of Trustees has a parent representative and includes people with a clinical and non-clinical background. The service works in partnership with other organisations to share and promote good practice, on a local, national and international level, which has included visits from health care professionals from a range of countries.

The service was well managed and led. The staff team learnt from any mistakes and were constantly striving for excellence. An effective system was in place to monitor and audit the quality of the service being provided. There was a homely, friendly and open culture in the hospice.

## The five questions we ask about services and what we found

We always ask the following five questions of services.

### Is the service safe?

Good 

The service was safe.

The provider and staff demonstrated robust systems for the protection of children and adults, which were underpinned by staff knowledge and training to protect children and young people.

Risk assessments were in place, which included individual assessments for children and young people that balanced risks associated with activities against the individual's quality of life and right to choose.

Children and young people were supported and cared for by sufficient numbers of staff. Staff were highly qualified and experienced and had a range of specialist skills, ensuring individuals were safe and had their needs met.

Children and young were supported by staff in all aspects related to their medicine, which included the use of equipment where required to ensure people received their medicines safely.

### Is the service effective?

Outstanding 

The service was effective.

Staff received regular training and had their skills regularly assessed to ensure they were competent to carry out their role. Staff knowledge and experience was shared with the wider health care community to improve palliative and end of life care.

Children and young people's records contained up to date consent forms relating to care, treatment and activities, and where appropriate followed decisions made under the Mental Capacity Act. Parents were supported to understand the implications of legislation and young people's rights as they transferred into adulthood.

Mealtimes were family orientated, and all meals were freshly cooked on the premises. Children and young people whose dietary needs were met artificially had care plans specific to their individual needs.

Staff supported children and young people to maintain their health and liaised with parents and external health care services where appropriate.

The design, adaptation and decoration of the hospice met the needs of children and young people in the promotion of their independence and facilitated their care, whilst providing a stimulating and interactive environment for play and activity.

### Is the service caring?

Good 

The service was caring.

Children, young people and their family members received a range of support from the different elements of the service. Parents spoke of the positive relationships developed and the support provided.

Children, young people and their parents were encouraged to express their views and were involved in decisions about their care, treatment and support with consideration and recognition as to how individuals communicate.

Privacy and dignity were respected and promoted in all aspects of staff interaction with children and young people. Following the death of a child or young person, staff continued to provide care and supported the family.

### Is the service responsive?

Outstanding 

The service was responsive.

Personalised care plans documented all aspects of care, which included social stimulation, interaction and play. Care plans for those receiving end of life care were regularly reviewed to enable staff to respond to changing needs and included information for their on-going care following death.

The provider had a positive approach to listening to parents and individuals using the service. A positive approach to learning from complaints was in place to drive improvement.

### Is the service well-led?

Outstanding 

The service was well-led.

The provider had developed the service to promote a positive and open culture by providing opportunities for parents and young people to comment on the services provided, through

questionnaires, support groups and participation in projects.

The Board of Trustees and managerial teams provided strong, effective leadership and provided a clear strategy for the long term development of the service.

The provider had robust systems to monitor the quality of care provided. Staff within the service worked collaboratively with external organisations to influence key policies and guidance in the care of young children with life limiting and life threatening conditions.

The provider and individual staff had gained external accreditation for their work. Staff shared their knowledge and experience with the wider health care community, locally, nationally and internationally.

# Rainbows Hospice for Children and Young People

## **Detailed findings**

### **Background to this inspection**

We carried out this inspection under Section 60 of the Health and Social Care Act 2008 as part of our regulatory functions. This inspection was planned to check whether the provider is meeting the legal requirements and regulations associated with the Health and Social Care Act 2008, to look at the overall quality of the service, and to provide a rating for the service under the Care Act 2014.

This inspection took place on the 31 May and 1 and 2 June 2016 and was unannounced.

The inspection was carried out by an inspector, a pharmacy inspector and a specialist advisor. The specialist advisor had experience working within children's hospices.

Before the inspection, we asked the provider to complete a Provider Information Return (PIR). This is a form that asks the provider to give some key information about the service, what the service does well and improvements they plan to make. The PIR was completed and returned to the Care Quality Commission. We found the information in the PIR was an accurate assessment of how the service operated. We sent out questionnaires to community professionals prior to our inspection and sought the views of commissioners.

We also reviewed the information that the provider had sent to us which included notifications of significant events that affect the health and safety of people who used the service.

We spoke with two children, three young people, and the parents of six individuals who used the services of Rainbows Hospice. We spent time with children and young people observing their participation in play, therapy and group discussions.

We spoke with the Director of Care (registered manager), the Chief Executive Officer, the matron, deputy matron, play specialist, sibling support worker, the cultural link worker, psychological and bereavement support co-ordinator, a youth worker, family support nurse and head of family support and outreach, social



worker, the transition co-ordinator, training co-ordinator, respiratory clinical specialist nurse, two members of the health care team, five nurses and the chef.

We reviewed the care plans and records of two children and two young people to see how their support was planned and delivered. We checked the medicines prescribed on eight prescription charts.

We also looked at a range of policies and procedures, quality assurance and clinical audits, reports of observations carried out by staff within the service and the minutes of meetings.

## Is the service safe?

### Our findings

We asked young people who used the service how they were kept safe at Rainbows Hospice. They told us, "It's friendly and they listen to you, the support I receive from staff with my moving and handling means I am confident that I am safe when equipment is used." "Knowing all the staff gives me confidence that they know how to keep me safe." "I like swimming here, I can't swim anywhere else." (the individual needed specific support to swim safely due to their health) And "I can go in the soft play and not worry about my tube."

Parents we spoke with had confidence in the staff team at Rainbows Hospice to keep their child safe. They felt staff were trained and motivated to provide good quality care and demonstrated a good understanding of their child's individual needs. Parents told us, "The staff here know all about her needs which means we are confident that she is safe." And, "Each time we bring our son for respite care they spend time asking about any changes to his needs, this means we know he is safe as they make any changes to his care based on our comments."

The provider had safeguarding policies and procedures for children and vulnerable adults and had an open and inclusive approach to ensure information about safeguarding was openly discussed and shared. There were nominated safeguarding leads for both children and adults.

We spoke with staff about safeguarding and found all staff understood the principles of safeguarding. They demonstrated an understanding that the children and young people may be at particular risk, due to their complex needs. All staff knew how to raise a concern and how to escalate safeguarding issues both internally and externally. Any safeguarding plans or concerns to a child or young person were clearly documented within their records and the responsibilities of staff to follow care protection plans documented.

There were systems in place to reduce risks to children, young people and their families. Assessments of any potential risks to anyone who used the services had been carried out and guidelines put in place so that any risks would be minimised.

An example of protecting individual's safety was for a person who was not able to communicate verbally who had regular seizures. The risk assessment was supported by a care plan and emergency care plan, detailing the care the individual required during a seizure. When we spoke with the member of staff supporting the person, they were able without looking at their records, to explain and talk to us about their emergency and rescue plan. This demonstrated that staff had the knowledge and understanding as to their role and responsibility in reducing risk and keeping people safe.

We spoke with a young person who could describe how they were involved in their care planning and risk management. They were able to tell us that they felt informed and listened to when talking in particular about their fluctuating ability. They were happy to know they could have the bedroom's audible alarm activated at times when they were unable to use the call bell. They liked that they could choose to have the sides of their bed up or down and said they preferred them up when they were sleeping and that staff

remembered to lower their bed so they could get out without assistance.

Equipment had been put into place to make sure that children and young people were supported in the safest way possible. For example children and young people living on permanent invasive ventilation were able to access the swimming pool. We observed a child being supported to access the hydrotherapy pool. In accordance with the child's risk assessment, they were supported by a nurse and a therapy assistant in the water, with a nurse watching on the side of the pool. This was to ensure the child who had a tracheostomy (an opening created at the front of the neck so a tube can be inserted into the windpipe (trachea) to help a person to breathe) was safe and that should an incident occur, sufficient staff with the appropriate training were there to provide care.

The environment had a range of systems to promote children and young people's safety. Bedrooms had listening systems installed which allowed for one way and two way communication, enabling staff to hear individual's when in their bedrooms, without having to disturb them. Staff within the therapy wing of the hospice used 'walkie-talkies', so they could communicate with each other should additional assistance be required. Internal doors were electronically operated with restricted access to different areas within the hospice and external doors were key coded to ensure visitors could not enter the hospice unannounced. CCTV was used to monitor external activity.

Environmental equipment promoted safety. For example ceiling hoist tracking was installed in bedrooms and bathrooms so that children could be safely transported between these rooms. 'Safe-space' cots and beds had been provided so that children who were at risk of harm when sleeping in a regular bed or cot were protected.

Equipment and the premises were well maintained and consideration had been given to people's safety and care should there be an interruption in the supply of essential utilities. A generator for an emergency power supply was in place should there be an interruption to the electricity supply. In addition a water tank could provide essential water if the mains supply was interrupted.

There was a clear process for clinical and non-clinical incident reporting including near misses. The Director of Care told us that the provider had ensured robust reporting of incidents through the adoption of a no blame culture, with outcomes and actions used as learning to improve or change practice if required. Staff told us they felt supported to bring any concerns to the attention of the appropriate person. All staff involved were invited to attend meetings along with parents/young people and used to examine the situation to see what could be learned for future reference. Staff were encouraged to complete a reflective practice template after such meetings to support their own appraisal and the revalidation requirements for nursing staff in order that they could evidence their learning and review of practices.

Our observations showed there were sufficient staff on duty to provide care and meaningful activities and engagement for all children and young people who were accessing respite care, day care or attending the young person's drop in session being held on one day of our inspection visit. All those using the service had their individual needs assessed which were used to determine staffing numbers. Where children required the support of two staff, this was provided. For example; children who required fully or assisted ventilation; or where they had behaviours that could cause them or others anxiety or distress.

Nurses we spoke with told us that staffing was proactive in that staffing levels were planned for the coming week, and not done in a reactive fashion. This promoted an effective use of resources and responsiveness to child and family needs and managed staffing and skill mix, which included a range of therapists. Staffing levels were also planned to support the services ability to respond to emergency respite and end of life care,

with a bed always being available to accommodate a child or young person in these circumstances.

Staff recruited to work at Rainbows Hospice underwent a robust recruitment and interview process to minimise risks to people's safety and welfare. Prior to being employed, all new staff had an enhanced Disclosure and Barring Service (DBS) check, at least two valid references and health screening. (A DBS is carried out on an individual to find out if they have a criminal record which may impact on their working with children or young people, which may impact on the safety of those using the service.) For nurses, a check of their Nursing and Midwifery Council registration was carried out. All staff had a further DBS check carried out every three years.

We looked to see whether children and young people's medicine was managed safely. Medicines that people brought in to the service were used in addition to medicines prescribed by the hospice doctors. Medicines were checked when a person was admitted to the service by a nurse to ensure medicines were suitable to use, with the involvement of the child or young person's parent. A nurse told us that every time a person returned to the service the medicines were re-checked, however, this was not always recorded. The registered manager told us that they would start recording this information immediately.

We found medicines were stored safely and securely. We found improvements were needed in some aspects of medicine management; however a majority of the improvements required would not directly impact on children and young people's safety, but would make the system of medicine management more robust.

Expired and unwanted medicines were disposed of safely and correctly. Medicines that required additional controls because of their potential for abuse (controlled drugs) were stored securely and monitored according to safe practice. Staff had access to emergency medicines in the event of an anaphylactic reaction. A GP visited daily to manage individual children's healthcare and medicine requirements. The provider used the local trust for the supply of all medicines including out of hours. Nursing staff could also obtain medicine from local community pharmacies out of hours.

A young person shared with us their views about their medicine and its administration. "The staff are cool, it's the people here that know how to look after me that I like. I have my own tablets but if I forget the nurses remind me, and I can take them when I'm ready. I don't have any pain now." We found nurses gave people their medicine when they needed it and not at set administration times. This was a child centred approach.

Nurses had to give medicine to some children through a tube in their stomach. There was not always enough information available on the prescription chart or in the care plan to let staff know exactly how to prepare and give each medicine safely. Staff had access to a standard protocol but this did not have enough information included and was not individual to the child. This meant there was a risk that medicines could be given differently each time and there was no record of how medicine was prepared. The registered manager advised us that action would be taken.

We received a timely action plan from the registered manager following our initial feedback at the inspection, evidencing their commitment to continued improvement in the promotion of children and young people's safety and welfare. The action plan provided information as to their plans to improve medicine management. They told us medicines and enteral feeding tube policies and care planning processes would be reviewed and the information cascaded to all nurses. A timescale by the provider for its improvements had been set for July 2016.

Staff locked away prescription pads securely but did not track prescriptions that came in or out of the service. This meant that if any prescriptions went missing, there would be no way of knowing which ones or

how many. We received an action plan from the registered manager which detailed the action being taken and that a timescale had been set for completion by July 2016.

The provider had recently implemented a competency checking system for all staff involved in medicines administration, which ensured staffs competence to manage medicine safely.

Staff reported medicine incidents and arrangements were in place to ensure incidents were investigated and an action plan was completed. This meant that lessons were learnt and the risk of the incidents re-occurring was reduced.

## Is the service effective?

### Our findings

We spoke with young people using the service who told us they had confidence in the staff to provide the care and support they required as they were knowledgeable and understood their individual needs. Young people's comments included, "It's friendly and staff listen to you, they know what they're doing. For me it means I am confident when I am here." "Here, I can relax knowing that the staff will look after me, if I have any questions they know the answers and how best to support me."

The effective use of staff experience, knowledge and roles meant children and young people had access to a range of services and support. We observed how staff with different roles within the service worked to provide good quality care and support. A parent told us, "I have every confidence in the staff; they are all so knowledgeable about [child's name]. They are able to provide all aspects of their care and help me to liaise with other health staff, as they give me information that I can use when speaking with them."

The provider had a programme to support staff development. The lead nurse for education and governance spoke with us about the leadership programme. This was in place for nurses to develop their leadership skills and included work based scenarios based on the services provided by Rainbows. These scenarios were used to look at how nursing staff would manage challenging and difficult situations. As part of the leadership programme participants were required to undertake a small 'change project' which they believed would improve the service they provided. Their project was presented to the staff team; the participant would then be required to assess the effectiveness of their suggestion and its impact. A participant of a leadership day in their feedback form had written. 'I just wanted to thank you for the leadership day...I think it was the most useful and enjoyable day of training I've had in the whole of my nursing career. Every part of the day was applicable and I feel very encouraged in my role and confident about improving my practice.'

The provider had employed a respiratory clinical nurse specialist (CNS), this had enabled children and young people with specific needs to have access to activities, which otherwise would have been difficult for them, due to the potential impact on their safety and welfare. Part of the role of the respiratory CNS was to assess the competency of nursing staff before signing them off as competent in managing a child or young person's care safely with regards to their specific respiratory needs.

We observed a child who was fully ventilated being cared for by a nurse who was being directly supervised by the respiratory CNS who was assisting the nurse to learn and understand the particular child's needs, risks and how to manage these. A child who required support with their breathing enjoyed time in the soft play room, running about playing hide and seek and jumping on the trampoline.

A learning disability nurse described how training in child development and play had enhanced their ability to successfully integrate play into clinical care and how to adapt play and activities for children and young people with different abilities.

The provider had facilitated additional training for some staff to further develop their skills and knowledge, in relation to physiotherapy, occupational therapy and speech and language skills. The role of therapy

assistant had been created, which enabled the children and young people to receive their required therapy, which included safe eating and drinking. The therapy assistants were able to initiate therapy interventions, making it a safer and more effective environment for individuals using the service. The additional resource enabled other staff to focus on their role, providing essential health care and support through activities and play.

We were able to observe how staff skills, knowledge and roles were used to support people effectively. We observed as a young person took part in a music therapy session, facilitated by a music therapist. We watched as the music therapist placed the chimes close to the person's hand. The music therapist sat next to the person and played the piano, slowly and quietly. When the young person (who had very limited physical movement) was able to touch the chimes and make a sound the therapist played the piano faster and louder in acknowledgement of the person playing the chimes. The young person reacted to this, showing enjoyment and their appreciation of the music.

We had the opportunity to observe the young person's drop in group, which was facilitated by the youth worker. The focus for the group was to provide support to young people in building and developing relationships where they have low self-esteem. We spoke with some of the participants of the group and asked them for their views about the drop in group. One young person said, "The group gives an opportunity for me to enjoy myself, and have a good laugh. The activities we do help me with my everyday life. The staff are good and you can discuss what you are thinking and feeling."

Staff received regular supervision and opportunities to attend meetings. A nurse told us they had a clinical supervision planned and available as a group. Clinical supervision was available on a one to one basis monthly with one session per year being mandatory. A range of other regular supervision was available to all staff, including safeguarding, peer and line management supervision. Staff said following significant events a team de-brief took place, which enabled staff to discuss how a particular situation was managed and how staff experience could be used for any future situations.

The provider through its staff liaised with external organisations as part of their commitment to staff training and development and the sharing of knowledge. Staff worked alongside recognised organisations providing sector specific guidance, including Strategic Clinical Network, East Midlands Children/Young People's Palliative Care Network, Universities, Together for Short Lives, the Royal College of Nursing, Hospice UK and Midlands Regional Transition Action Group. Rainbows as an organisation was an active member of the national children's hospice charity, Together for Short Lives and in partnership with other organisations had delivered through The Open University a day event to facilitate greater understanding and awareness of the needs of young people with life shortening conditions in relation to sex, sexuality and relationships.

We found there to be effective systems to facilitate communication amongst, staff, young people and children, parents and external health and social care professionals. We attended a group handover at shift change time and a one to one handover for one child's direct care. We found the handovers to be concise and included all the relevant information about each child and young person. The information shared during handover ensured that care delivered was safe and timely.

The Mental Capacity Act 2005 (MCA) provides a legal framework for making particular decisions on behalf of people who may lack the mental capacity to do so for themselves. The Act requires that as far as possible people make their own decisions and are helped to do so when needed. When they lack mental capacity to take particular decisions, any made on their behalf must be in their best interests and as least restrictive as possible.

People can only be deprived of their liberty to receive care and treatment when this is in their best interests and legally authorised under the MCA. The application procedures for this in hospices are called the Deprivation of Liberty Safeguards (DoLS).

We checked whether the service was working within the principles of the MCA, and whether any conditions on authorisations to deprive a person of their liberty were being met. We found one person had a DoLS authorisation in place; the DoLS did not have any conditions. We found the person's records included all the correct documentation and the young person was awaiting a visit by an Independent Mental Capacity Advocate (IMCA) to assist them in their decision making.

The registered manager was aware of the 'Gillick competence' (a term used in medical law to decide whether a child under 16 years is able to consent to their own medical treatment, without the need for parent permission or knowledge). Consent was sought for treatment and engagement and, when working with adults, mental capacity was assessed. Where it was found a person did not have capacity, it was discussed at a bimonthly meeting, which included representatives from external organisations.

We spoke with the Transition Co-ordinator who supported young people and their families as they transitioned into adult hood. Part of their role was to provide information about the Mental Capacity Act 2005 and its implications for young people with life limiting and life threatening conditions. The Director of Care spoke about a project they worked on in collaboration with Together for Short Lives entitled 'stepping up', which had included the views of parents of young people who used Rainbows. The project looked to produce a guide for parents and young people, to support them in enabling a good transition to adulthood, and the implications for both parents and the young person when making decisions about health and care needs.

Young people told us that mealtimes, the quality of food, and the choice offered were of a good quality. One young person when asked said, "[chef's name] food is 'beaut'. If they've got the food in you want, they'll cook it for you. We also get to order takeaways if we want." Individual needs in relation to food and drink were met and staff went out of their way to meet preferences. We saw that, for children and young people who were able to eat orally, there was flexibility of food choices and if a child or young person wanted something special to eat, this was provided.

Mealtimes were family orientated with hospice staff, children and young people and their families all eating together if they chose. Dietary requirements for health, included a Ketogenic Diet, (balancing of carbohydrate, protein and fat, tailored to the person) which the Chef was able to describe and diets to meet specific cultural needs, were provided for and the catering team were trained to provide. The catering team purchased Halal foods themselves to ensure the source was acceptable for families. Children and young people who were artificially fed brought in their own nutritional feeds and feed pumps and their usual regime was followed by the care team.

Each child and young person had a clear care plan in place with regards to nutrition, which included feeding regimes for those artificially fed. The times of feeds were documented in the care plan that moved with the child or young person around the service as they accessed the different activities Rainbows had to offer.

Every opportunity was taken to support a healthy life-style, enhance abilities and independence and balance risk with quality of life for those using the hospice. The service was supported by a local GP practice, which temporarily registered all those residing at Rainbows as a patient. One of the GPs at the local practice was the Director of Medicine at Rainbows; three additional GPs from practices across Leicestershire form the hospice medical team and all the GP's worked within a rota setting out their weekly visits to the hospice,



and in addition provided an on-call services.

The knowledge and expertise of the staff had a direct impact on the quality of care children and young people received. The Director of Medicine at Rainbows was the author of the widely used Paediatric Symptom Control Manual that is accredited by the Association for Paediatric Palliative Medicine (APPM). All members of the team received symptom control training which included traditional symptom management and also play interventions.

Discussions with other staff that held key roles within Rainbows, which included the play team co-ordinator, youth worker, family support nurse, family liaison worker and complementary therapist identified how they contributed to the holistic approach to children and young people's care and support and the maintenance of their health. Throughout our visit we saw staff engaging individuals in a range of activities, providing therapy and treatment. One person told us how they enjoyed swimming and accessing the hydrotherapy pool, they told us, "It helps me to stretch and relax." Whilst a second person told us, "The back massage helps me to relax." A parent of a child told us, "The swimming has a therapeutic benefit; it helps with chest secretions, helping him to cough and clear his chest."

A young person told us, "The buildings and gardens are nice." The Director of Care showed us around the premises which had been purpose built. Communal areas, including corridors, were bright and colourful and included opportunities for interactive play, with a focus on individuals with sensory impairments. The hospice took account of new play and therapy technology and in particular the needs of children and young people with chronic conditions who now have a longer life expectancy. The environment and the facilities provided contributed significantly in maintaining the health of children and young people. The facilities included a hydrotherapy pool which incorporated a Jacuzzi and a music therapy room, which provided a host of musical equipment. A multi-sensory room provided stimulation in a range of ways, which included the use of lights for those with sensory impairments and a computer system, where interactive floor games could be played. The hospice also benefited from a gymnasium and soft play room. One young person told us, "I do use the gym; it helps me to maintain movement."

Accommodation to meet the different age range and interests of children and younger adults was provided, with separate areas for relaxation and games, which included lounges and a computer room. Other facilities included separate parents' and family accommodation which included bedrooms with en-suite and interconnecting facilities for families.

Externally there was a garden area for all to access, which included specialist play equipment for children with a physical disability such as an adapted swing and roundabout for children who used a wheelchair. One parent told us how their child liked to use the adapted swing. They said, "It's the only chance they have to swing, local parks don't cater for the needs of children with disabilities, but Rainbows does." There was a traditional wooden travelling caravan and play house.

The outside space included an Eco garden, made up of wild flowers attracting insects from the overlooking countryside. There was a small pond which was securely fenced, and a pathway around the edge with seating areas. The 'Chelsea Garden', which was donated and had won silver at the Chelsea Show a few years ago, was used predominately as a quiet and tranquil area for parents and carers. There was also a sensory garden within the enclosed courtyard in the centre and a garden of remembrance, which was a separate part of the hospice located near the bereavement facilities.

Rainbows Hospice provided two 'cool rooms' referred to as 'The Quiet Suite' so that following a death, families could spend time with their child or young person should they wish to use it. Adjacent to the 'cool

rooms' was a family lounge where families could spend time together. The 'cool rooms' were neutrally decorated with the windows and beds facing towards 'Mecca', to meet the needs of those whose cultural and religious needs required this.

The Cultural Link Worker informed us of the reflection and prayer room that was available and accessible to families. The room had dedicated cupboards containing end of life care boxes which held practical items to support a range of religious practices and beliefs, such as prayer books and Holy water. They told us how they had liaised with the Muslim Burial Council and representatives of other religious groups, to ensure the facilities met the needs of people's diverse religious and cultural needs.

## Is the service caring?

### Our findings

During our visit we were able to speak with young people who used the service. They told us they enjoyed coming to Rainbows, which in part was due to the staff who knew them well and the relationships developed between others using the service. Young people went on to say that they enjoyed taking part in activities and the autonomy they had to make decisions. Young people's comments included, "I just love the place, and the hospice is lovely. Staff are jolly, they're just all lovely. I couldn't say a bad thing about any of them." A parent shared their views about the staff with us, they said, "The love that comes through the nurse and care team is evident."

One parent when we asked them what Rainbows meant to them said, "It's like all the services we receive make up a pyramid, of which Rainbows is at the top." A young person told us what accessing Rainbows meant to them. "Gives me a break and my mum. I like spending time with my mates, and I like to come in when certain people are here."

Parents of children told us how they valued the respite service provided by Rainbows and how the relationships, understanding and knowledge of staff facilitated their confidence and trust in the service provided. A parent we spoke with, who chose with other members of the family to stay at the hospice when their child accessed respite care, told us what it meant to them. "We're happy when we are here with [child's name]. Staff are caring, supportive and they will come to you, talk to you and give advice. It's a holiday for all of us, a break from cooking and cleaning and we get to spend time with [child's name] playing, whilst staff take care of his medical needs." A parent who stayed nearby when their child accessed respite care said, "It just keeps you going. I can have a lie in. When we visit [child's name] we can play with him and get to watch him play on the roundabout and use the swimming pool."

Comments from other parents about the respite service included, "We're extremely grateful for the support we get and it's such a lovely place. [Child's name] can experience fun, soft play, swimming which she wouldn't be able to do in the outside world. Here she can see that she can be around nurses without it being too medical like a hospital." "[Child's name], goes swimming in the hydrotherapy pool and he loves the multi-sensory room. When I tell him he's going to Rainbows he's so happy. He doesn't have any verbal communication, but expresses himself facially. His face lights up when you tell him."

Parents of children and young people spoke about the positive part the hospice played in their lives in relation to support they received, other than through the respite care. One parent said of the day care facility, "He goes three days a week, he takes part in cooking and gets a lot from sensory activities, such as the sensory garden, music and playing games. It gives us a break as his care package is intense and complex. It's a chance for us to recharge our batteries as a family."

Parents told us of the positive impact the range of services provided at Rainbows had on the family as a unit. They told us how their daughter accessed the 'sibling group', they went on to say how their daughter had with other children taken part in day trips and breaks away. One parent said of the "[child's name] brother comes to the 'sibling days'. It's nice for him to meet kids in his circumstance; they have sleepovers at

Rainbows, day trips, which have included tobogganing."

Parents spoke about the support available to them through 'family support workers'. One parent spoke about their allocated family support worker. "[Staff's name] has been brilliant; she is a good source of information about community resources which I can use." A second parent spoke of a family support worker saying, "[Staff's name] has assisted us with our finances, especially over Christmas. She's given us emotional and practical support." Whilst another parent said of their family support worker, "She's invaluable, offers comfort and reassurance in all aspects of my life. I can ring and cry and she helps me to understand how I am feeling, it's so comforting and she always follows through on things we discuss. She has put things in writing for me, to help me in the requesting of adaptations to our home so we can continue to meet [child's name] needs."

When we spoke to parents, they told us how getting together with other parents in groups facilitated by Rainbows' staff helped them. "We have coffee mornings, we get to sit and talk with each other and we can cry because it doesn't matter, we don't need to explain ourselves to each other." And, "We enjoy going to the 'family days', again no one really stands out, lots of big ugly wheelchairs and no one notices or comments, we support each other."

We spoke with the Psychological and Bereavement Support Co-ordinator, whose role was to support families. They told us how parents and families were supported after a child or young person's death. Rainbows had produced information entitled 'When a child dies', which included the services offered by staff at the hospice, such as counselling and support groups. To acknowledge and remember the loss of a child or young person, a plaque with their name and birth and death date was commissioned by the provider and could be placed in the remembrance garden or taken by families and put in a place of their choosing. An annual 'Remembrance Day' service was held at the hospice, to which families were invited to remember their child, through words, candles and music followed by a get together over tea and cake.

Each child and young person was allocated to a specific team of staff who built up relationships with the child, young person and family and identified their specific needs, likes and dislikes. The team made contact with family and other services involved in their care between planned stays in order to follow up how stays went and identify any concerns or other feedback. Each child had an 'All About Me' document that recorded what activities they enjoyed and didn't enjoy, what made them smile or made them unhappy. A parent told us, "The attention to detail for us is fantastic in [child's name] 'All About Me' document includes photographs of how I like his tapes on his 'tracheostomy' to be loose, and includes information where his creams are applied. The staff take everything on board, the designated teams means there is always going to be someone who will be looking after [child's name]." They went on to say, how his 'All About Me' document contained information as to how he communicated through facial expressions such as grimacing, and what this meant.

All the care interactions we observed were caring, respectful and age appropriate and met the needs of the individual. One child being supported by a nurse had no verbal communication, and communicated using Makaton, supported by a book of pictures, symbols and photographs of different rooms within the hospice. We saw the nurse use this throughout the day to explain what was happening and asking the child what they wanted to do. At all times the nurse interacted with the child, sitting on the floor with them being supportive. We had spoken with the child's parent earlier during our visit and they told us of the importance of staff communicating well with their son, as they became distressed if explanations were not provided.

We spent time in the play room with children and their assigned member of staff. A range of activities took place, which included face painting, planting of tomato plants and painting. Each child was supported by a

nurse, member of the health care team or a play therapist who actively encouraged and worked with each child or young person to involve them in the activity as much as they were able, given their complex needs. One child was seen to very much enjoy having their face painted. Later in the day we saw them painting the faces of a nurse, who wore their face paint throughout the day, making everyone smile.

We observed staff supporting a child in the multi-sensory room; they played interactive football via the computer system, which projected a miniature football pitch and ball on the floor. This was thoroughly enjoyed by the child, and they, along with the staff member, ran around the outside of the pitch when they won the game.

A child or young person approaching the end of life, and their family, can stay at Rainbows Hospice for as long as needed. The care team liaised proactively with health care professionals to ensure information as to the care being provided was shared to support a continuation of care. In some circumstances a child or young person was transferred from another setting, such as a hospital.

A child or young person following their death continues to be cared for by the staff who followed a bereavement plan which had been developed in conjunction with the family, and where appropriate the young person. Information within the bereavement care plan provided staff with information on spirituality, including specific needs with regards to religion and culture including contact details of faith/cultural leaders. The plan recorded the level of involvement parents wished to have in the dressing of the child's body including what they wanted their child to wear. Specific requests were also recorded, such as whether they wished the child's hair to be cut, or a hand or foot print taken. The bereavement plan included information as to funeral arrangements.

Bereavement support was available to families and was recorded as part of the bereavement care plan. Bereavement support consisted of practical advice and guidance as well as on going psychological and spiritual support. Family members had a range of support networks facilitated by Rainbows which they could attend, which included the 'bereaved parents group', 'sibling support group', 'drop in coffee group' and groups specifically aimed at Asian mothers and the dad support group. Staff were pro-active in providing support, with contact from a member of the Family Support Team taking place within a few days following a child's or young person's death. Families were offered a home visit or face to face visit at the hospice. Literature was made available to families, containing information about the services available.

Rainbows Hospice has a website which provides information about the services it provides, along with links to other organisations and support services. Information was accessible in different formats which includes, plain English, large print and in braille and a range of languages. We spoke with the Cultural Link Worker, who told us their role was to work with families providing cultural support. They were also a resource for staff at Rainbows, which included a translation service as they could speak four languages.

Part of the role of the Cultural Link Worker was to facilitate the Asian mothers group who met monthly and whose members consisted of parents of children who had used or currently used the services of Rainbows. The Asian mothers group provided information about services, and organised events and trips out to provide a social aspect for the group.

The role of the Cultural Link Worker included involvement in the Diversity Forum, providing information and training on differing religions and beliefs and its relevance to end of life care. An aspect of the Cultural Link Worker role was to consider the impact of all policies and procedures developed by the provider, with consideration to the protected characteristics as defined by the Equality Act 2010, in relation to age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or

belief, sex and sexual orientation. Minutes of meetings held by the Equality Analysis Monitoring Group recorded how the impact of policies and procedures were considered with regards to the protected characteristics, ensuring staff adopted policies which promote equality and diversity. Minutes of meetings identified that policies and procedures in some instances required additional clarification, making it clear that the safety and welfare of children/young people would take precedence.

## Is the service responsive?

### Our findings

All parents we spoke with who used the services said that they were fully involved in all aspects of their child's care and that the staff of Rainbows were able to adjust the service and care they provided to meet any changing needs. Parents told us how staff were able to respond when there were changes within the well-being of the child or young person, or within the wider family. One parent told us how additional respite had been provided when they had found it difficult to manage at home due to fatigue. "Our son's package of care is comprehensive and intensive at home, our family support worker will notify us if there's additional availability at the hospice for respite care."

Parents told us that when their child accessed respite care the handover of information between themselves and the staff could take two to three hours. They said this was essential so that staff had an up to date picture of their child's health and welfare, which was reflected in their care plans. One parent told us how staff rang them prior to planned respite, providing an opportunity for essential information to be communicated before the child's admission so that any changes could be planned for.

We sent out surveys seeking the views of health and social care professionals who work alongside children, young people and their families and the staff of Rainbows. Their comments were overwhelmingly positive and reflected the commitment and dedication of staff in supporting those using the service and their families. Comments made particular reference to the commitment of the provider and staff in the provision of an outstanding service with a continuous focus on improvement and excellence. Whilst reflecting how staff worked with other health care professionals, sharing their knowledge and skills for the benefit of children and young people.

The staff at Rainbows supported families and young people to prepare for changes in services as they moved from children led services to adult services. This support and guidance was provided by the 'transitions co-ordinator', supported by other staff in varying roles within the hospice. Rainbows had extended the service it provides from children to include younger adults up until the age of 30. The Director of Care explained how this had been necessary as children with life limiting conditions were now; due to advances in medical care, living well into adulthood. One parent spoke about their experience with us. "[Staff's name] has been brilliant, she's supported me by coming to MDT (meeting of health and social care professionals) meetings, helping me to understand the changes with regards to care packages and health related issues."

Parents told us planning their child's care had included discussing their end of life care. A parent we spoke with told us, "We've made plans with staff at the hospice and have visited the 'Quiet Room'. We want him, when he dies to be at Rainbows and be taken to the 'Quiet Room'. We have a resuscitation plan in place and this is reviewed when [child's name] goes for respite. We know that if he is ill he'll go straight to the hospice."

Young people we spoke with told us how the service was personalised to meet their needs. One person said, "We get to go on day trips, I've been go-karting and to the cinema. We have barbeques here and I like spending time in the garden. Staff listen to me and what I want." Staff during our visit were in the process of

planning the resources to support a young person in achieving a goal they had set for themselves reflective of their personal interest. Staff had liaised with a local business to enable the young person to achieve this, showing how the staff responded to people, enabling them to achieve their wishes.

Nursing and care team staff were supported by a range of staff with specific roles, which included assistant therapists, play therapists and music therapists. Each day was organised and planned with children and young people being allocated named staff. The individual needs of each child and young person was considered and matched to staff with consideration to their level of training and knowledge.

We spent time with the children and young people and saw how staff delivered responsive care that was personalised to each individual. Everyone had a minimum of one member of nursing staff or member of the care team staff dedicated to their care each day, and in some instances two staff dependent upon their needs. These staff were responsible for all aspects of the child or young person's care, which included their personal and health care needs along with their social needs, which included play and relaxation. Positive relationships between the children and young people and staff were seen and we saw many smiling faces and much laughter from children, young people and staff.

Children and young people were occupied in swimming, face painting, art and crafts, games and relaxation in the sensory room and running and jumping about in the soft play room, with staff and children playing hide and seek. We were told how massage was used to tell a story to a child or young person, through the use of specific movements and the accentuation of movements to respond to stories, for example massaging the back in a way to reflect a character in a book running.

The PIR recorded how the service had responded to requests for an increase in funded packages of care, which provided additional support over and above the care offered of 16 short break nights a year and emergency admissions. This had included 'step down' care for children and young people who were moving from hospital to home. As a result of this increase, the provider had dedicated two beds for this purpose. At the time of our inspection there were no children or young people at the hospice who were being supported in relation to 'step down'.

The PIR detailed how the service had been adapted as a result of the increase in numbers of children and young people with specific needs in relation to positioning, moving and handling and therapy programmes. The provider had identified that this had placed additional pressure on nurses and therapists and the delivery of care within Rainbows. As a result the provider created the four 'Therapy Assistant' roles from within the existing care team to increase the number of people with the necessary skills to support qualified therapists, enabling nurses the time to provide care.

Part of the area provided in supporting people into adult hood had been influenced by the 'transition project', which had worked with parents of young people. The provider in response had produced leaflets and information to parents and employed people to provide support and guidance, in working with parents, helping them to plan for the future. The service provided support to parents as their children entered adolescence. For those people who were nearing the age of 30 years, their needs were regularly reviewed and staff from Rainbows supported them as they were discharged from the services of Rainbows by liaising with other care providers.

The provider through its staff provided outreach specialist palliative care within the Leicestershire Community Children's Nursing Service and proactively supported the local neonatal and Paediatric Intensive Care Unit team, which included the provision of ambulance transfers to the hospice for end of life care. Thus enabling the staff to share their expertise and provide a service to parents and babies at this



critical time.

Anyone could refer a child or young person to Rainbows. Once a referral had been received information was gathered from the health and social care professionals involved in the individuals care. A nurse would then contact the family and arrange a visit so that further information could be gathered about the child or young person. This visit was also used by staff to provide information about the services offered by Rainbows.

The provider had an admissions panel, which met monthly where all referrals to the service were considered; upon a decision being made this was then shared with the family. Where emergency referrals for palliative or end of life care were received, these were managed as urgent cases and responded to quickly. The hospice at all times ensured there was a bed available to accept emergency cases, enabling a speedy response.

The Family Support Nurse receives referrals from parents, health and social care professionals for all services within Rainbows with the exception of respite care. Staff can refer children, young people and parents internally to other specialisms within the service, such as the community play specialist, family support workers, bereavement and counselling services, cultural services and social worker.

We spoke with people in a range of roles which supported children, young people and their families within the community. The Community Play Specialist told us how they supported parents with pre-school children who lacked confidence in 'playing' with their child as they were worried about the impact on the child's health. The community play therapist told us how they supported younger people within their own home who due to a deterioration in their health found it increasingly difficult to continue with their hobbies and interests. Equipment in some instances was provided or adaptations made to enable young people to take part and enjoy their lives. We were told of an example of where different art and craft equipment was introduced so that a person with reducing control of their hands and fingers could continue to enjoy this area of interest.

Children's and young people's care plans were person centred and included information as to how the person communicated. Care plans were written in partnership with the child or young person and their family. The purpose of care plans was to ensure that staff had clear guidance to follow which was as reflective of the child's home routine as possible. This included identifying details that enabled staff to ensure children and young people felt 'at home' for example having a favourite toy or bedtime routine. We saw staff encouraged children to take an active part in their bedtime routine, a child told us they were having a 'princess' bath and we saw them carrying towels to the bathroom.

Information provided by the provider within the PIR identified that within a period of 12 months they had received one complaint and 62 compliments. The theme of compliments was with regards to the friendliness of staff and the feelings of their child or young person being supported when at the hospice. Parents also recognised the support and sympathy during their loss with end of life care and through bereavement support. The complaint received had been responded to consistent with the provider's policy and procedure; the complainant had been kept fully informed at all times and had attended meetings with a range of staff, including the Director of Care. These meetings provided an opportunity for concerns to be discussed and reassurance given to the complainant as to how the issues raised would be used to develop the service and improve outcomes.

Young people we spoke with were confident about raising concerns. They said, "I never have any concerns, but I know I would only have to speak to a member of staff and it would be acted upon." A second person said, "If I had any concerns I would be confident in raising them with anyone here." Parents we spoke with

said they had been given information about raising concerns and believed any issues would be addressed quickly.

The Director of Care said that as a result of a concern expressed by a relative as to their right to make decisions and be involved in their child's care when they had attained the age of 18 years, they had identified a need for information to be made available to parents, informing them of the legalities around decision making as children entered adult hood. The 'transition project' was set up and briefings held, to which health lawyers were invited to provide information to parents and to share ideas. One of the outcomes from the project was setting up a dummy website which would be trialled by specialist schools and colleges, where they could access an interactive website providing information on relevant legislation and guidance. Feedback would be provided as to the website and used by the provider to develop the Rainbows website.

## Is the service well-led?

### Our findings

We found that the provider created a range of ways in which children, young people, their families and staff working at the hospice, were involved in the services development. Parent's participation in projects, such as the 'transition project' and 'nutrition group' influenced the service and parents' comments had been used to develop the service. This included an extension to the reception area, which was planned for later in the year and internal improvements to include a dedicated room for people who accessed the day facility to use for their personal care needs and would include a ceiling track hoist. Parents were offered the opportunity to take part in the interview process and parents we spoke with spoke as to how the staff employed were employed on the basis of their approach and understanding of children and young people.

People's views were sought annually about the service through a survey and following specific events such as family days. The family annual feedback survey was shared and published. It was accessible through the Rainbows hospice website and displayed within the hospice. The survey identified an overall satisfaction with the service provided and additional comments, both positive and negative, were included within the report. The survey asked parents if improvements and changes the provider had made had improved the service as intended for parents, children and young people. Responses to questions showed a majority of parents believed the changes had improved in relation to the paperwork completed upon admission for respite care.

Parents views following a family fun day and an Asian family fun day had been sought through an evaluation form. Comments from parents about the days were positive, reflecting on the activities taken part in with their children, and their enjoyment in playing and spending time with other families. Comments from the Asian family fun day included, 'Wow today Rainbows made our day. Super, we enjoyed. We got lots of fun and time with family together.' 'We had a fantastic afternoon, full of fun and certainly was great to see the staff and other parents. From beginning to end it was a perfect afternoon. Thank you.' The family fun day which had a theme 'ocean...above and beyond' had positive reviews from parents, 'it was a very good day. There was enabling a lot of interaction with the different tactile zones. My child enjoyed the whole day.' And, 'racing the boats, feeling the sensory objects in the sensory box.'

Newsletters for parents and staff were produced, and available through the Rainbows website. These newsletters provided information about planned events, including fundraising and photographs of children and young people engaged in activities both internal and external to Rainbows. Photographs used were with the consent of the parent and or young person.

Staff had their work annually appraised based on a values and a behaviour framework, to help drive the values and beliefs of Rainbows and to improve the child, young person and family experience. This had been further developed by the introduction of 'value based interviewing' (VBI). VBI has been shown to effectively identify candidates who are a 'better fit' for an organisation and therefore the right people to deliver the best service. Rainbows had used this approach to encourage candidates to evidence their skills and experience.

The service had a manager who was registered with the CQC and had relevant and up to date experience

and expertise to lead the service. The registered manager (Director of Care) was a registered nurse in adult and children's health and had worked as a health visitor working for both children and adults in palliative care. During our visit we found that the registered manager, matron and deputy matron were visible within the service, spending time with children, young people and the staff.

Recognition for staff's involvement in the development of children and young people's palliative care evidenced how the service's leadership used innovation, and recognised and encouraged staff in the delivery of care and their contribution and influence in the development of current guidance.

Staff of Rainbows had been involved in the development of specialist resources at a local and national level to promote care for children and young people with life limiting or life threatening conditions. Locally this has included the Palliative CNS working with community specialist teams one day a week, attending joint visits and providing additional advice and support.

The Director of Care is the co-chair of the East Midlands' Children and Young People's Palliative Care Network, working closely to identify local need and supporting colleagues in the development and audit of palliative care services. The Director of Care and a CNS contributed in the guidance around managing the care of individuals requiring long term ventilation.

On a national level the Medical Director, Psychological and Bereavement Support Co-ordinator and Youth Worker had worked with the National Institute for Clinical Excellence (NICE) Committee for End of Life Care in Infants, Children and Young People to improve the outcomes for this group. This had been achieved by them being members of a committee to produce, develop and provide information for services for commissioners, practitioners and managers in both health and social care. The Medical Director was the author of Paediatric Symptom Control Manual and had been awarded an MBE for their contribution to children and young people's palliative care.

We met with the Chief Executive Officer of Rainbows and spoke with them about the service. They spoke of the current 2012 – 2017 business plan and the draft plan for 2017 – 2022 which had been written and was currently under discussion with The Board of Trustees. Our discussions with the Chief Executive Officer and senior members of staff evidenced they understood the vision and values of the hospice. Key areas for development were understood which included the need to develop community outreach programmes for supporting children and young people on long term ventilation.

The Board of Trustees skills and competences were assessed at the time of their appointment and reviewed annually, and were supported by a 'Fit and Proper Persons' Policy which assured all required checks were undertaken when appointing Trustees. The Board of Trustees had an equal balance of business and clinical skills and included a parent representative. The diversity of the make-up of The Board of Trustees meant that the services provided were reviewed and considered from differing perspectives enabling the provider to be confident that a range of opinions and voices were heard in order that the service was well led, having a positive impact on those who received a service.

The Board of Trustees received a summary of the Clinical Quality Assurance Committee, along with standing agenda items, which included the hospice report, safeguarding, incidents and complaints along with equality and diversity, this information enabled them to have a good oversight of the service and enabled informed decisions to be made.

There was a clear management structure with senior staff allocated lead roles. Throughout the organisation staff understood their lines of responsibility and accountability for decision making about the management,

operation and direction of the hospice and its services. The management team demonstrated a strong commitment to providing children, young people and those closest to them with a safe, high quality and caring service and promoted high standards. All the staff we spoke with were enthusiastic about their work and shared the values and aims of the service.

The senior management team met twice a month, once with an operation focus and the second a strategic focus. Meetings regularly took place within the varying services provided within the hospice to ensure information was effectively communicated. Significant event audits had been introduced as a tool where by significant issues were discussed and lessons learnt. Everyone involved in the incident, including family members were involved.

The senior management team worked with a quality assurance dashboard based on the CQC's five keys questions is the service safe, effective, caring, responsive and well-led. An analysis of the information from the quality dashboard was used to develop action plans which were reviewed monthly. We looked at the action plans which evidenced how the provider used the information to develop the service and bring about improvement. A hand hygiene audit had shown the practice to be ineffective. Action was taken to share learning about effective hand hygiene and later audits identified improvements had been made. Individual external safeguarding issues were recorded, identifying the action required by staff in working in partnership with the young person, their family and other agencies to ensure people's safety.

Staff told us they valued the '10 @ 10' meeting held daily. This meeting took place for 10 minutes and was led by a senior nurse and used to pass on key current information. The 'theme' was repeated across the week so the majority of staff were captured and knew the latest information. This included, urgent policy issues, feedback from compliments or complaints, incidents and action underway, need to know information about individuals using the service, organisation and operational information, which included fund raising events. Staff told us that this daily update made them feel 'kept in the loop', and confident to deal with enquiries and queries from those using the service, aware of any sensitive situations and generally being valued as a team.

The provider was committed to improving the quality of life of children and young people with life limiting and life threatening conditions and recognised the value of liaising with health care professionals within the wider community. We sent out surveys seeking the views of staff and health and social care professionals who worked alongside children, young people and their families and asked them to comment on the management and leadership of the hospice and the services impact on the wider health community. One healthcare professional wrote, 'The staff at Rainbows strive for continual quality improvement and have established resources which are used by others in the children's palliative care sector within the UK and across the world. They are generous in sharing their knowledge and expertise and in developing partnerships with others in the sector.'

The provider had an open and transparent approach to sharing information. Rainbows Hospice produced an annual quality account, which provided information as to the services' priorities for the next twelve months. The report included information provided by people who had used the service, which had been gathered through questionnaires, the involvement of people who use the service and their relatives in the services development along with information gathered from complaints and compliments. Information gathered from audits was provided along with progress in identified areas for improvement. The report was accessible through the Rainbows website.

We spoke with the Lead nurse for Education, Quality and Governance, part of their role being to assess through observation the quality of care provided by staff. They had adapted 'sit and see', a tool to measure

care, compassion and kindness in care settings. This involved the recording of observations over a set period of time of staff interactions with individuals receiving care and the impact of care on the child or young person. A report as to the outcome of these 'sit and see' sessions was produced. Initial observations were carried out and repeated four to five months later to measure whether the feedback and action plan put into place had brought about any improvements. Areas identified for improvement had been the dining experience, where it had been identified the layout of the dining room tables had created an unintentional divide between staff and visitors sitting to eat their meal. A change to the configuration of the tables had been made and a commitment by staff to sit with children, young people and their parents to encourage social interaction.

The PIR provided information as to how the service and staff employed had been recognised for their contribution for the quality of the service. A nurse achieved a Nursing Times 'rising star' award in 2015 and the hospice was awarded the Royal Society for the Protection of Accidents (RoSPA) Gold Award for the tenth year running.

The PIR recorded how the hospice was being used as a model for the provision of palliative and end of life care for children and young people. Rainbows hospice had been visited by medical and nursing teams from a number of countries within the last 12 months, which had included Hungary, Ukraine, Singapore, Japan and Russia. We saw an e-mail sent from a representative of the visitors from the Ukraine, thanking the staff from the hospice for their warm welcome and the information gathered through meeting with staff and touring the hospice that they hoped to use to develop the services they offered.

As part of the provider's commitment to the development of the service the provider commissioned a PhD student to undertake research with families to identify areas of unmet need amongst both those who used the services of Rainbows and those who did not, and to identify why those who were aware of the hospice did not access the service. We spoke with the PhD student who told us they had met with parents across the East Midlands, interviewing people in their home. The outcome of their initial findings had been shared with The Board of Trustees, who were in early discussions as to how they could implement change in response to the initial findings. An outcome of the initial findings had identified a need to increase outreach work within the wider community through the provision of greater flexibility in respite, which need not necessarily be overnight but to support families in improving their quality of life by services being provided within their home. Evidencing the provider and staff continued commitment to the development of the service.