

Rainbow Trust Children's Charity

Rainbow Trust Children's Charity 3

Inspection report

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Ratings

Overall rating for this service

Outstanding 

Is the service safe?

Good 

Is the service effective?

Good 

Is the service caring?

Good 

Is the service responsive?

Outstanding 

Is the service well-led?

Outstanding 

Summary of findings

Overall summary

The inspection took place on 28 October 2016 and the inspection was announced. Following our inspection day in the office we spoke to family members and other professionals by telephone on 3 and 5 October 2016. Rainbow Trust 3 had not previously been inspected at this location.

The Rainbow Trust provides support to families who have children or young people with a life limiting or terminal illness. Support is provided to individual families, parents, children and young people. It also offers parents and children to come together in groups for support, to provide support to other parents or commemorate children who have passed away.

The service had a registered manager who had been in post. 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.

Without any exceptions family members and professionals who referred people to the service highly praised the registered manager and the staff.

The service was exceptionally responsive. We saw the service had been developed to meet a variety of family needs. Funding had been successfully sought to provide sibling support. The feedback from children and young people indicated they highly valued the support on an individual level and in group activities. The parents we spoke to repeatedly told us about the high levels of response from staff if they felt they needed support. They told us staff responded quickly to visit them and the support of the staff strengthened their coping abilities. They also spoke very highly of the practical support offered to them.

We found the culture of the organisation to be caring. Staff were provided with support through supervision meetings to allow them to reflect on their work and come to terms with family bereavement. Staff were then able to provide a consistent quality care as described by family members when they spoke to us. Parents spoke to us about the way staff supported them by being caring and meeting their family's needs.

Rainbow Trust 3 demonstrated they promoted children's rights as prescribed in the UN Convention of the Rights of Child. Children were given a strong voice in the project to influence their service and were also given different ways to express their voice either through play, art or talking with their allocated workers.

Children and young people were supported to give their feedback which in turn influenced the service. Participation of parents through the "Parent Voices Count" group further ensured the service learnt from people's experiences to inform and advise the service on how to improve.

The service had in place risk assessments which protected children from harm when they were working with families. Staff had been trained in safeguarding children and young people. They told us they felt confident

to discuss any of their worries about families with the registered manager.

We saw the registered provider had put in place robust recruitment procedures to ensure that staff were not only safe to work with families going through very stressful periods but also had knowledge skills and values required by the service.

During their induction period staff were provided with opportunities to learn about the service including meeting other staff from agencies with whom the service had strong partnerships working in place. Staff received training in line with their role and told us the Rainbow Trust supported their professional development.

The registered manager provided clear direction to the staff and led the service in line with the registered provider's business plan.

The service had contacted a local Islamic trust to enable them to reach more people from the local communities.

Most of the children and young people supported by the service were under the age of 16 and therefore the Mental Capacity Act did not apply to them. However we found the service used best practice principles and gave children and young people a choice based on their maturity and ability to weigh up advantages and disadvantages.

The service was continually monitored by the registered manager and the registered provider had in place a "Snapshot Day" where everyone who comes into contact with the service on the day is asked for their feedback. We saw the feedback on the day was overwhelmingly positive.

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 registered provider had a robust recruitment process in place which consisted of carrying out the required checks before staff could start work in the service.

Staff each had an allocated vehicle supplied by the Rainbow Trust. They carried out regular safety checks on the vehicle which were overseen by the manager.

Risk assessments were carried out on all activities with children. The assessments considered what risks there might be and what actions the staff needed to take to mitigate the risks in order to keep children and young people safe.

Is the service effective?

Good ●

Parents were confident that the staff had the skills and abilities to care for their children.

Staff were supported to learn through an induction period, essential training and managerial and non-managerial supervision.

Children and young people were supported through the best practice principle of them giving consent to participate in the service if they were of sufficient maturity and could understand the advantages and disadvantages involved.

Is the service caring?

Good ●

The service was caring.

Everyone we spoke to spoke positively about the caring nature of the staff.

The service had actively sought to support families from ethnic minority background and sought the support of another service to make this happen.

Parents described to us how staff had developed therapeutic

and very positive relationships with them and their children, which they were able to rely on in times of greatest need.

Is the service responsive?

Outstanding 

The service was exceptionally responsive.

We found powerful examples of how the service had impacted on the lives of children, young people and their parents who used the service. However it would be difficult to go into detail in the report as this would enable the people who were supported by service to be identified.

Staff had developed the service to meet the needs of the whole family. Parents told us staff rearranged their schedules to respond to their needs when they felt overwhelmed by their personal circumstances. They told us staff understood their needs and they felt better able to cope after talking to staff.

The service was highly responsive and had diversified their services to meet differing and unique family needs

Is the service well-led?

Outstanding 

The service was exceptionally well led.

Family members, other professionals and staff consistently made highly complementary comments about the registered manager. Other professionals told us about how the registered manager had managed the service. They told us the registered manager had made good decisions and did the right thing to deliver care to those who needed it.

The registered manager had made significant progress in carrying out the actions as described in their business plan. This meant the registered manager was working with the service to achieve its goals.

Staff, family members and other professionals strongly echoed the registered manager's findings when they carried out an analysis of the service. We found the registered manager continuously monitored the service and the outcome of their monitoring provided learning and guidance to move the work of Rainbow Trust 3 forward.

Rainbow Trust Children's Charity 3

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 28 September 2016 and was announced. The provider was given 24 hours' notice because we needed to be sure that someone would be available to assist us with our inspection. We spoke to family members and other professionals by telephone on 3 and 4 October 2016.

The Rainbow Trust provides care and support to parents and children where there are children with life threatening or terminal conditions in their family. The support is provided in hospitals, in family homes and in the community. From this location, known as Rainbow Trust 3 the service was provided to families in Wigan, Bolton, Stockport, Trafford, Manchester, Tameside, Bury, Rochdale, Salford and Oldham. At the time of our inspection there were more than 120 families accessing the service at various times, six of whom had been referred for the regulated activity of personal care.

Before we visited the service we checked the information we held about this location and the service provider, for example we looked at the inspection history, safeguarding notifications and complaints. A notification is information about important events which the service is required to send to the Care Quality Commission by law. We also contacted professionals involved in caring for people who used the service; including local authority commissioners.

The inspection was carried out by one adult social care inspector

Prior to the inspection we sent out questionnaires to staff and other professionals. Four out of the five staff responded to the questionnaires and 12 out of 39 professionals gave us feedback. During the inspection visit

to the office we spoke to the registered manager and one member of staff. We reviewed the records of the six children who were receiving personal care. Following the office visit we spoke with a further three staff members by phone, seven parents, one young person and four professionals. We used the information given to us to inform our judgements.

Before the inspection, the provider completed 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. We used this information to plan and inform the inspection.

Is the service safe?

Our findings

Parents told us they felt their children were completely safe with staff from the service. One parent told us that after their experience of working with a number of medical professionals they were reluctant to allow their child out of their sight but they completely trusted the staff. Professionals we spoke to had confidence in the service.

We found the registered provider had in place an extremely robust recruitment process. The Disclosure and Barring Service carry out a criminal record and barring check on individuals who intend to work with children and vulnerable adults. This helped employers make safer recruiting decisions and also prevented unsuitable people from working with children and vulnerable adults. We saw the Rainbow Trust had utilised the DBS checks as one measure to ensure the people they employed were safe to work with children and their families. Prospective staff members were required to complete an application form outlining their previous experience and providing the names of two referees. We saw these references had been obtained.

The registered manager also showed us that staff who were successful at the first stage interview were invited back for a second interview before which they were expected to complete a document about their personal goals, their professional goals, words used to describe them and their top ten questions for the management of the Rainbow Trust. The registered manager told us the second interview was used to ensure the people employed by the service were able to demonstrate the values and attitudes required by the service. Staff confirmed to us they had been through this recruitment process.

We saw that children and young people's medicines were administered by medical staff in hospitals or the community or their parents. The registered manager and the staff confirmed they did not routinely give people their medicines. However the registered manager was keen to extend the service and was happy for staff to be trained in giving people their medicines if it made a difference to family life. Staff we spoke to confirmed with us that there was no one to whom they currently gave medicines but were happy to be trained if it meant they were able to meet the needs of families.

Staff were trained in safeguarding children and young people from abuse. The registered manager told us the service was not currently working with any child or young person who was currently considered by other professionals to be at risk, however staff had attended and participated in child protection conferences. Staff told us they felt able to raise concerns with their manager if they were concerned about a child or young person.

We saw the service had a whistle-blowing policy which supported staff to tell someone about their worries. There was also a staff disciplinary policy. The registered manager told us there were no whistle blowing concerns at present and no member of staff was currently subject to disciplinary procedures.

We found Rainbow Trust 3 promoted the UN Convention on the Rights of the Child. Article 12 gives the right to any child under age of 18 to have a voice and be able to freely express their views on issues which concern them. We found the service actively listened to children and sought their views. For example, children and

young people's views were sought on the programme of activities held by the service over the summer period.

Similarly Article 13 states each child "Shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice". We saw children irrespective of their age were afforded the opportunity by the service to write down in words, provide oral feedback or supported to draw pictures representing their views.

We saw that the staffing levels in the service was funded by voluntary contributions and successful applications to other agencies for funding. At the time of inspection there were six people employed by the service including the registered manager. Professionals told us they wanted the team to grow because they were a much needed service. Families told us staff were reliable, turned up on time and always arranged to visit them if they needed support. This meant staff managed their caseload to meet the needs of families.

The service had in place a number of risk assessments for children's engagement in activities. Each risk assessment was prefaced with an equipment list including emergency contacts for parents and went on to describe the risks to children and how these should be mitigated. If children were attending an event open to the public, for example a cinema, staff were required to make themselves aware of fire exits. Where children were taken by the service to play venues the staff had accessed the risk assessments for each venue to keep children safe. Transport arrangements to and from activities were specified. The ratio of staff to children was appropriate for each activity. We found the service had comprehensive risk assessments in place which helped to keep children safe.

Emergency plans for children and young people were described in the risk assessments. These included the use of a first aid kit and accessibility to their parents. Parents told us they had given permission to the staff of the service to look after children and provided information on how to care for their children to reduce the need for emergency responses.

We found each member of staff had their own vehicle provided by the Rainbow Trust. The registered manager told us vehicle checks were carried out by the staff on a regular basis and staff submitted their safety checks to the manager to ensure they had been done. Staff confirmed they carried out these checks. The registered manager and the staff told us they had three different car seats in their vehicles to ensure children of all ages were kept safe. The car seats were given an annual check and replaced earlier if required. Staff told us they had cleaning equipment for their vehicles just in case any child should become ill during their journey.

Is the service effective?

Our findings

One professional wrote in their pre-inspection questionnaire, "The Rainbow Trust provides an invaluable service to many of the families I support within the Borough of Trafford. My interactions with all members of the team - support workers and managers have always been professional and productive. The ability of the support workers to provide such professional support, often within the family home and in very difficult circumstances, whilst still maintaining very appropriate boundaries (essential in this area of work) is to be highly commended and is a reflection of the excellent training and support they receive from their manager and the organisation as a whole." Other professionals stated, "This is a fabulous service that has provided exceptional support for families with complex needs" and "They provide the right sort of hands on support for families that need it and emotional support for families. I would promote their involvement with certain families and I would be confident that they live up to their reputation."

We saw staff had an induction period to assess their capabilities. New staff visited families with existing staff as a part of their induction plan. Families confirmed they had met new staff in this way. One professional from another service confirmed new staff visited their service and spent time with them as a part of their induction, in order to meet people and learn how the services worked together. Staff confirmed to us they had undergone induction periods.

Staff undertook essential training, including safeguarding, health and safety, food hygiene and first aid. Staff members spoke about how they felt supported in their learning with the Rainbow Trust. One member of staff was being supported to undertake further qualifications, whilst another member of staff told us they could go to the service if they had any ideas and the service would support their learning to carry them out. In the information given to families we saw additional training could be sourced for staff to undertake clinical procedures.

We found staff underwent an annual Performance and Development Review to look at the work they had carried out and review their progress. This meant staff and their manager understood the skills staff had and how they needed to further develop their abilities.

Parents talked to us about the skills of the staff and told us they were good communicators. Often dealing with challenging circumstances, parents spoke to us about how the staff listened to them and supported them to cope. Parents also spoke to us about the staff skills in working with children and young people and told us they felt confident in the ability of the staff to respond to their children's needs. For example, one parent described to us how children may "Just suddenly" refer to the impact of having a sibling with a terminal illness and then move on to another subject. The parent was confident the worker would listen and respond appropriately.

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. The Act applies to people aged 16 or over.

We found most of the children and young people using the service were under 16 years old. We found that where the service had worked with children or young people consent had been obtained from the parents, but also the children and young people had given their permission and had happily accepted the service. We found the service worked within the best practice principle of children being of sufficient maturity to weigh up the advantages and disadvantages of the proposed course of action and had given their consent.

We saw staff received regular managerial and also non-managerial supervision. The registered manager explained managerial supervision was used to check on the worker's well-being and look at their case load. The non-managerial supervision provided emotional support to staff working with emotionally challenging circumstances and allowed them time to think about their work and the impact it was having on them. Staff confirmed that they received this supervision. One staff member told us they were not sure what they would talk about in supervision but soon found they, "Had plenty to say." Staff acknowledge non-managerial supervision was of benefit to them.

We found the staff were not routinely required to provide food and drink to people who used the service. Children and young people's nutritional intake was either provided in a hospital setting or by their parents in their home environment. However, parents gave consent to activities which involved eating and drinking and were made aware that snacks and juice would be available at sibling group meetings. The risk assessments for each activity included staff must have in place medical information on each child, including any allergies. This meant that where the staff were engaged in feeding children and young people, information was gathered about each child beforehand and parents were given clear information about what was involved.

Staff supported the health of children and young people by working closely with medical professionals. One member of staff told us they did not carry out any invasive procedures like tube feeding but were willing to be trained. We found children's health needs were primarily met by medical staff or their parents. However, parents spoke to us about feeling low at times and they told us the staff supported their mental health needs and boosted their coping strategies.

Is the service caring?

Our findings

Everyone we spoke to described the staff as "Very caring." One family member told us they were "Fabulous". Another family member told us the staff were, "Brilliant." Parents told us that not only were staff caring but they also had the ability to instantly grasp what family members were feeling on any given day. One parent wanted to congratulate the manager for recruiting the, "Wonderful staff" who were able to understand the thoughts and feelings of others in an instant. One professional told us they had observed staff whilst caring for sleeping children on a hospital ward and saw staff had not lost their focus on the child. Another professional told us families place a, "Huge amount of value on the service."

Parents described to us the magnitude of having a child with a terminal illness and how some days if they contacted their worker and wanted to talk, the staff always responded quickly to them to offer their support. One parent said the staff were, "Special." The parents we spoke to only spoke of staff in glowing terms. The service had received many "Thank You" cards which repeatedly thanked staff for their caring ways and their kindness.

Parents spoke to us about the care they and their children received from Rainbow Trust 3. One parent told us the service provided was "Multi levelled." This meant the staff cared for people in different ways according to their needs. Parents told us staff who provided practical support by doing some ironing or taking their children to school. Others described needing emotional support when feeling overwhelmed. Families told us everyone on the team provided the same high consistent level of caring.

Parents told us how staff members had gone the extra mile for their benefit. We were told one staff member had attended the funeral of a child whose faith was different to their own and they had quickly needed to learn how to conduct themselves during the funeral proceedings. The service built up additional support including daily contacts if a parent wanted them to be involved in the last days of their child's life. One parent described to us their experience and the support from the service helped them to have the best end to their child's life. Another parent told us a staff member had used sport to help rebuild a child's confidence as they reintegrated into school life.

The registered manager told us the staff were used to getting to know families and by having conversations with them began to understand what support they needed. Families were also able with the consistent and reliable support to understand what the service was able to do for them. One parent told us they gave their child "100%" through the roller coaster of their illness. Another parent explained to us they had received excellent care from the service and said, "They will do what you need."

On reading through the daily notes we saw examples of the exceptional caring capacity of the staff. Where staff supported families to make important decisions, they gave families immediate information about food banks or counselling services and listened to the parents about their worries and fears. We found staff allowed people their privacy and dignity to come to terms with the enormity of their family situation. Parents told us they felt comforted knowing the Rainbow Trust 3 staff were there for them.

We found end of life care provided by the service to be well thought out and extremely caring. Children, young people and their families were supported in a number of different ways, either through one to one support or via group work. The service had in place a Bereavement Project and had set up an active parents group called, "Parent Voices Count." The group was supported by the North West Children's Palliative Care Network and the Rainbow Trust Children's Charity. Their goal was to support families and increase awareness amongst professionals of the needs of bereaved families. We saw the group had devised a booklet for other parents called, "A collection of hints and tips." The booklet gave an A-Z guide of practical tips and signposted parents to other sources of help. We spoke to a parent about the group who described to us the journey of a family going through the bereavement process. The parents group was being supported to consider a leaflet for parents which showed a road map for parents to help them understand their journey. This meant the service involved and enabled parents to support each other through difficult family times.

The registered manager spoke with us about the service having in place a Bereavement Support Competency Framework. We looked at the framework and found staff had been assessed against a number of competencies, including their ability to assess the emotional needs of children and families prior to and following the death of a child. Staff were also required to work in partnership with families, their own communities and professionals to ensure individual family outcomes were being met. Staff confirmed they had analysed these competencies with their manager. We found significant evidence of staff using these competencies with families, both to support them in leading up to the end of their child's life and thereafter. We found family well-being and support was placed at the heart of the service and the different family needs were respected.

Information was provided to each family in a pack at the start of the service. Parents confirmed to us they had received a pack and were aware of its contents. Each pack contained information about the service, the 24 hour help line and how to make a complaint. This meant when parents told us they could not always remember their first contact with the Rainbow Trust when they were in turmoil following their child's diagnosis they had a reference point about the service, what it did and how to make contact with them.

The staff worked with families as their support and advocate if required. We saw they spoke on behalf of parents when parents felt they did not have the inner strength to speak. For example one worker told hospital services a child had passed away when the family did not feel able to. Another worker afforded a parent the time to make their own decisions whilst their friends and neighbours were telling them what they should do. The parent was then able to make her choice with the presence of the worker to offer support and later the staff member supported them to seek information from other professionals about their other children. They also offered to be the child's voice with their consent in sharing information with their families. This meant staff in the service Rainbow Trust 3 had the skills to prepare parents and children to be supported using the principles of advocacy.

We saw that the service maintained confidentiality. Permission was sought from families to share information with other professionals. Parents felt confident in the service in respecting their confidentiality.

The registered manager and all staff we met and spoke to showed genuine concern for people. It was evident from our discussions staff knew people very well and had used their knowledge to form very strong therapeutic relationships.

Is the service responsive?

Our findings

Prior to the inspection we sent out questionnaires to professionals. One professional responded and said, "I value Rainbow Trust as a premier service. I feel it should be commissioned for all children with disabilities/illness/acquired injury when at times of crisis or greater need. It is a wonderful flexible service and meets the actual not perceived needs of the families in a very practical way. The staff are amazing, caring and generous and have the freedom to meet the families' needs in bespoke way which is what makes the service so unique. I only wish I could refer more children into this service." Another professional said, "A fabulous service that I would highly recommend."

We found powerful examples of how the service had impacted on the lives of people using the service, including caring for children with life threatening illnesses and their intensely personal experiences of some of their children passing away. One parent told us the support provided by the Rainbow Trust was "Unbelievable."

Professionals and family members we spoke to told us they found the service easy to access and the staff provided a quick response. One professional said the referral systems were, "Simple and straight forward." Some families told us that following a diagnosis of their child having a life threatening illness they were in turmoil, and after meeting an endless stream of medical staff they could not remember their first contact with the Rainbow Trust. However without exception they became an important part of their family support. One professional who had referred families to the service told us a family had said they, "Could not have done without the Rainbow Trust." Another professional told us the work of Rainbow Trust 3 prevents families sliding into crises and had reduced families needing more intensive support from other services.

The registered manager told us that following a referral it was important to let the families take the lead and open up conversations with family members to begin to develop trust and find ways to support each unique family. This meant the service was very person centred. We saw each family had been visited following a referral and an assessment of their needs had been carried out. The registered manager told us that this was only a beginning, as parents living with emotional distress may not be able to take on board the information, so plans develop as they go along. We saw the service responded at a pace led by families who gained trust in their allocated worker.

Each family had in place a plan with outcomes agreed by them and which described their needs and preferences. The outcomes took a holistic view of each family's circumstances and included improving their quality of life, increasing family stability and ensuring economic well-being. We found the registered provider had reflected the domains of the Common Assessment Framework guidance published by the Department for Children, Schools and Families to assess the needs of children and their families, and had broken down the guidance into areas relevant to their service.

We saw how staff recorded their contact with families. When staff visited families they recorded electronically which outcomes they had met. The electronic system produced a star chart as to what needs the staff had met. The registered manager explained the star chart demonstrated family needs and how the

service responded to those needs, as well as being able to monitor, assess and review. For example a family may have identified that they needed support to manage stress but they needed more support to increase family stability. These outcomes were used with the families during reviews of the service to have on-going conversations with families about how Rainbow Trust 3 could support them. We found the service provided different types of support and the support was led by people who used the service. This meant the service delivered very individual personalised care to families.

We asked parents how Rainbow Trust 3 responded to their needs. Parents described to us how staff started working with them where the family was at emotionally and practically and spoke about different types of support in hospital and when their child was discharged home. In hospital parents were grateful to the Rainbow Trust staff who could spend time with their child, which allowed them time to get a shower, have something to eat or deal with their domestic life. Offering play sessions was important to families, as some children had become withdrawn due to medical interventions. One parent told us they had observed a massive impact on their child as when they returned to their hospital bed they found their previously withdrawn child laughing with the staff member. One parent said the in-hospital support was, "Absolutely fabulous." Another parent told us the service visits they made to their child in hospital broke up the monotony of the hospital routine and their child became animated when their support worker arrived. This meant children in difficult circumstances had their lives improved by the staff.

When a child was discharged from hospital parents told us staff supported their family by continuing with play sessions and collecting siblings from school. One staff member was going into a child's school to support them engage with their peers at lunchtime. Every parent we spoke to valued the support of the staff and felt with their help their coping strengths were sustained.

We found in the daily records of families that parents often found themselves with lifestyles which fluctuated around their child's health, either because of new appointments or having a child who felt unwell. Staff recorded text messages sent by families to rearrange appointments and then planned their next visit to suit family needs. Family members told us the staff team were flexible, one parent described them as being, "Very flexible" and told us they did not feel worried about changing appointments. One staff member told us it was important to them that families felt the service was reliable and not intrusive. They told us when they arrived early for appointments they would work in their car to ensure they arrived at the expected time and not intrude on family life. This meant staff delivered the service on time, which built the trust parents described to us.

Staff members told us their company vehicle was very important to them. It allowed them to carry around toys, arts and craft materials and games so they could be prepared to respond to families and whatever was wanted by the family after they had arrived at the family home. One parent told us their child knew the contents of the staff member's car and would take the staff member out to their vehicle to choose what they wanted to do. We spoke to staff about the contents of their vehicle. They laughed and told us it contained everything they needed to respond to any situation.

Parents spoke to us about the impact of having a child with a life threatening illness had on their siblings. Some parents said it caused brothers and sisters to develop anxiety problems. We found the Rainbow Trust had responded by raising money for a Sibling Support Worker. One parent told us there had been a "Transformation" in their child's behaviour when they had accessed the sibling support and they wished they had, "Accessed the service earlier." Another parent told us about the guilt they had felt when they were occupied with their child who was ill, but felt the sibling support service had a very positive impact and allowed their child to believe they were not alone. We saw the service had run different sessions based on the ages of the children and young people and group arrangements were age appropriate. This meant

children were given the opportunity to fully participate in age appropriate activities.

We saw activities had been set up during the summer holidays. Children and young people had been invited and given feedback. Some of their comments were, "Today was loads of fun, I liked all the rides I went on and the staff listened to me", "The best day with other people and getting to know each other and "I made so many new friends." Observations of the children had included them engaged in conversation about their poorly siblings which showed they were not alone in their circumstances. We found the sibling group's aim to help children to deal with the emotions they may feel from having a sibling with significant medical needs was being successful. One young person wanted to share the very positive impact on them. They made a short film which was used by the Rainbow Trust to open their staff conference.

The staff team had recognised that families with children who have life threatening or terminal illnesses go through phases of feeling able to cope and at other times need high levels of support. The service had introduced an idea of a "Light Touch" service where families could access the service if they needed it. The service in turn would respond to requests for help without putting families through repeated referrals. This meant the service was highly responsive and families could come back to the service and access support when they needed it.

We found the service had further diversified to meet family needs. It had begun to offer support to families whose children were born prematurely. One professional said, "They are extremely flexible and have been a huge support to families on the neonatal intensive care unit, supporting in hospital and home."

Families had been invited to attend an event to commemorate the lives of children who had passed away. A detailed plan including music, the lighting of candles and readings was put in place. Families who attended the day were asked for their feedback and gave deeply private and emotional responses. The evaluation of the event demonstrated all who were involved had found it to be an extremely valuable experience.

The registered provider had in place a 24 hour helpline. The registered manager told us they believed that parents needed an emergency helpline which if taken away would reduce the layers of support and increase parental anxiety. Family members confirmed this to us; in particular single parents felt reassured they had in place out of hours support with an organisation they trusted. The Rainbow Trust was committed to keeping in place their helpline.

The registered manager told us there had been no complaints about the service. We asked families if they had made any complaints. One family member said, "Definitely not." Other family members confirmed they knew about the service but had never had a reason to complain. Professionals we spoke with told us they had not received any complaints about the service.

Is the service well-led?

Our findings

There was a registered manager in post. The registered manager was able to give us a good account of the service. They provided us with all of the information we needed, and it was organised and easy to follow and they demonstrated pride in their service.

One professional said, "I have referred many children/families to Rainbow Trust. All hold it in high regard. It is a lifeline, a shining beacon when light is low within a family." Another professional told us they thought the service was well managed. One professional told us the staff in the service speak to the referrers "Only when they need to" and attributed this to the good supportive local management of the service. Staff told us they felt well supported by the registered manager.

We saw the service had in place a set of values. One of the values was, "We aspire to do the right thing even when it is difficult and strive to work in an honest and transparent way." Other professionals spoke to us about the service as a charity working on limited financial resources and told us earlier in 2016 the service had to explain to referring agencies they could not take on new referrals due to their existing volume of work. One professional explained that whilst they would have preferred to keep on referring, they realised the registered manager had to protect the existing work and ensure they provided their "High quality service" to existing families. Another professional told us the service had worked hard to accommodate a referral for a child who was terminally ill. We found professionals valued the exceptional transparency and openness of the registered manager in doing the right thing.

We found further evidence of the registered provider being open and transparent. In the information pack the registered provider told families about the professional boundaries they expected staff to maintain. The information spoke about professional boundaries and told families, "You should always remember that your Rainbow Trust Worker is a professional and not a friend." This meant when working with families in very stressful situations the registered provider was clear about their role.

We saw the Rainbow Trust was in the Sunday Times top 100 not for profit organisations in 2016 and was ranked at 60. This was an improvement from 2015 when they were ranked at number 75. The justification for this ranking included 90% of the staff in the organisation believed they made a difference. This meant the registered provider had made staff feel valued, who in turn felt they were having a significant impact on people's lives. Families and professionals who spoke to us supported this view.

We found the culture of the organisation to be caring. Parents reported to us without exception the caring nature of the staff and the registered manager. Staff told us they felt they could be open with the registered manager. One staff member told us they could go to the registered manager with any problem and "Not feel judged." Another staff member told us they could go to the registered manager who would help them with ideas. Family members told us they found the registered manager very supportive. One relative said, "She instantly understood our situation."

We found the Rainbow Trust 3 to have a culture of a learning organisation, where it learned from the people

it served. It routinely sought feedback from people who used the service. We saw children and young people were given a voice through feedback on the service they had received. For example children and young people had been given post cards after activities and were asked to write down what they thought or draw a picture. We saw one child had drawn a picture of a sunshine, other children had written positive comments such as, "I liked it all best" and "I had so much fun today." This had led the registered manager and the staff to be informed about what they did next for children's activities. This meant children and young people drove their service and the management of the service had actively listened to the youngest people who used the service.

Based on feedback and knowledge of what works best within the service the registered manager had adapted and diversified the service to provide alternative types of support within limited resources. One of these initiatives was the provision of sibling support work to individual children. One young person had written, "The best thing about my worker is she isn't a formal counsellor so it's easier to talk about stuff that is going on." Every family member we spoke to highly valued the work of Rainbow Trust 3 and the opportunities to be better supported, brought about by the registered manager's ability to develop the service.

The service had received funding from the Big Lottery Fund for their sibling support group and from the BBC's Children in Need appeal for a support worker. We saw how the information was gathered and found the registered manager to be highly accountable in regular reports for how the monies were spent. They were able to demonstrate very positive outcomes for children and families. At the time of our inspection we saw the television trailer for the BBC Children in Need Appeal 2016 had been launched. This featured the work of the Rainbow Trust 3 in a video clip. We found the service had strong partnership working in place with their funders to promote nationally the fundraising appeal and the work of the Rainbow Trust.

We saw Rainbow Trust 3 had in place other strong partnership working with a number of other services who supported their work. In addition to the Big Lottery Fund and Children in Need we saw the service had in place links with other services. Other strong partnerships included the Myriad Foundation, the Merlin Project and a young volunteers group. Both projects when working with the Rainbow Trust 3 enhanced the working of the service. For example Myriad Foundation were supporting the service to reach ethnic minority communities whilst the Merlin Project had supplied tickets to take young people to a theme park for the day. The registered manager showed us four new stationary sets supplied by the young volunteers, which the service had decided to gift to children in hospital.

We also saw from the list of community professionals who referred to the service that Rainbow Trust 3 had a wide range of networks in place deliberately targeted at other professionals who also worked with children with life limiting or terminal illnesses. We spoke to some of these professionals. They told us it was very easy to work with the registered manager and the staff of Rainbow Trust 3. They spoke about having strong partnership links with the service as well as having trust and faith in the service to deliver the care families needed.

We asked the registered manager how they monitored the quality of service. They told us monitoring took place through staff meetings, staff supervision, contacts with other professionals and through the reviews they conducted with families. The registered manager demonstrated to us how they were able to review the needs of each family using electronic records which were updated by staff when they had contact with each family. This meant the registered manager could review the support each family originally thought they needed and what they were receiving. If there was a significant difference the registered manager told us this would prompt a review with the family. They contacted families by telephone to review the work and check if they were getting the right support for them. Families confirmed they had contact with the

registered manager to review their support needs. This meant the registered manager demonstrated the registered provider's values of listening to families and was able to demonstrate they drove the value of acting in an inclusive way.

The registered manager had also participated in some of the activities days throughout the summer and had observed the interactions between the staff and young people. They described their staff as being, "Exceptional." We saw the service had in place a "Snapshot View" day where everyone the service came into contact with on the day were asked for their feedback on the service. We looked at the 2016 "Snapshot Day" for the service and found feedback from parents and children and other professionals. From those who responded to the questions 68% of the families rated the service as excellent and 24% rated it as good. One hundred per cent of professionals rated the service as excellent or good. The registered manager had analysed the findings and found the length of time families had received the service had no bearing on how families felt, which indicated there was a consistency of quality in the service from the point of delivery. Families we spoke to strongly echoed the findings of the snapshot day and agreed with the registered manager's findings. The registered manager had used these findings to consider what they should next to share the findings and improve the participation of professionals in the service. This meant the registered manager looked at continuously improving the service.

The registered provider had a 2016/17 business plan. Staff attended an annual conference to hear about the performance of the organisation and the plans for the year. This meant the registered provider had systems in place to communicate with staff and provided strong leadership. We found the Rainbow Trust 3 service had made significant progress in achieving the business plan. For example they had a youth group in place, parents were involved as a part of the "Parent Voice" initiative and the registered manager had begun to put in place the "Light Touch" service. This meant the registered provider was working to the national organisational targets.

The Rainbow Trust 3 service had in place a "Local Operational Plan – 2016/17" which reviewed the history of the project and it contained an analysis of the communities in which the service worked. The registered manager had responded to the analysis and initiated work to drive improvements, for example in increasing the proportion of people from ethnic minority backgrounds using the service.

The service had an up to date statement of purpose. This is a document which tells people and their relatives what they can expect from the service.

We found the registered provider met the requirement of CQC registration as prescribed in the Short Breaks - Statutory guidance on how to safeguard and promote the welfare of disabled children using short breaks' published by the Department for Children, Schools and Families in 2010.

The registered provider had in place a data protection policy. Parents and carers were required to sign a data protection form which explained to them how their personal information would be used. The registered provider had included in their information to families about Data Protection that CQC may need to access the files held by the Rainbow Trust. We saw the service records were up to date and gave an accurate view of the families we spoke to during our inspection. The registered manager explained the service was in transition to ensure all records were held electronically. Staff used electronic tablets devices whilst out in the community. This meant their records were constantly updated. We saw people's personal information was protected and staff were only able to access the information after using a sequence of passwords. This meant information was stored in line with the Data Protection Act.

