

Rainbow Trust Children's Charity

Rainbow Trust Children's Charity 6

Inspection report

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Ratings

Overall rating for this service

Good ●

Is the service safe?

Good ●

Is the service effective?

Good ●

Is the service caring?

Good ●

Is the service responsive?

Good ●

Is the service well-led?

Good ●

Summary of findings

Overall summary

About the service:

Rainbow Trust Children's Charity 6 provides personal care and emotional support to children with serious illnesses. This is provided in people's homes, hospitals and in the community. Support workers provide support to both the children and their family members. The service was providing support to 86 children aged from birth to 19 years old and their families. Not everyone who used the service received personal care. CQC only inspects where people receive personal care. This is help with tasks related to personal hygiene and eating. Where they do we also consider any wider social care provided. At the time of this inspection there were four children under the age of 16 who might on occasion require personal care.

People's experience of using this service and what we found:

Relatives said they were supported by support workers who were kind and caring. Some families had been receiving support from consistent support workers for three to four years, whereas other families had been receiving care and support for shorter periods of time. Relatives told us having the support worker was like an addition to their family.

Children were supported to stay safe as support workers understood their responsibility to report any concerns and follow guidance in place in relation to people's individual risks. The Trust had a robust assessment process in place alongside its referral criteria. People were supported to have maximum choice and control of their lives and support workers supported them in the least restrictive way possible and in their best interests; the policies and systems in the service supported this practice.

Support workers understood equality and diversity. Children's care plans were detailed, and support workers used these to understand the care people required. Care plans had been developed around the needs of the whole family. Children were included within the planning and reviewing of care where this was possible due to age. Families were always included and were always the driving force behind what care and support was required. Children's privacy and dignity were respected, and their independence promoted.

Relatives told us they were supported and encouraged to participate in events organised by The Rainbow Trust. Relatives told us this was a good opportunity to meet other families and talk to other people going through similar situations. Siblings of children receiving care had taken part in siblings' days out where they were supported to develop their own independence and receive support from support workers.

Relatives told us they felt the support provided by the Rainbow Trust had been consistently good and support workers had been flexible and compassionate to meet their needs as a family. Relatives told us they thought highly of the management team. The registered manager was responsive and wanted to improve the service to benefit families who received support now and in the future.

Quality assurance audits were carried out to help ensure the service provided safe and of high quality. Actions identified from these audits were addressed. Children, relatives and professionals were asked for

their feedback and this was used to help improve the service. Management and support workers worked alongside other agencies to help improve the support people received.

For more details, please see the full report which is on the CQC website at www.cqc.org.uk

Rating at last inspection and update:

The last rating for this service was good (published 07 February 2017).

Why we inspected:

This was a planned inspection based on the previous rating.

Follow up:

We will continue to monitor intelligence we receive about the service until we return to visit as per our reinspection programme. If we receive any concerning information we may inspect sooner.

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.

Details are in our safe findings below.

Is the service effective?

Good ●

The service was effective.

Details are in our effective findings below.

Is the service caring?

Good ●

The service was caring.

Details are in our caring findings below.

Is the service responsive?

Good ●

The service was responsive.

Details are in our responsive findings below.

Is the service well-led?

Good ●

The service was well-led.

Details are in our well-led findings below.

Rainbow Trust Children's Charity 6

Detailed findings

Background to this inspection

The inspection:

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

Inspection team:

The inspection was carried out by two inspectors.

Service and service type:

Rainbow Trust Children's Charity 6 offers personal care and emotional support to children experiencing very serious illness. Support is given to both the children, their siblings, parents and when appropriate their extended family. Support is flexible to meet the changing needs of the children and their family.

Notice of inspection:

This inspection was announced. We gave the service 48 hours' notice of the inspection. This was because it is a small service and we needed to be sure that the provider or registered manager would be in the office to support the inspection.

What we did before the inspection:

We used the information the registered manager sent us in the provider information return (PIR). This is information providers are required to send us with key information about their service, what they do well, and improvements they plan to make. This information helps support our inspections.

We reviewed the evidence we had about the service. This included any notifications of significant events, such as serious injuries or safeguarding referrals. Notifications are information about important events

which the provider is required to send us by law.

During the inspection:

We spoke with five members of staff including the registered manager, two national managers and support workers. We checked care records for four people, including assessments, care plans and risk assessments. We looked at five staff files including two volunteer workers. We also looked at recruitment records, quality audits and training records.

After the inspection:

We spoke with three relatives by telephone about the care and support their families received. We also continued to liaise with the national manager to clarify some additional information provided.

Is the service safe?

Our findings

Safe – this means we looked for evidence that people were protected from abuse and avoidable harm.

At the last inspection this key question was rated as good. At this inspection this key question has remained the same. This meant people were safe and protected from avoidable harm.

Systems and processes to safeguard people from the risk of abuse:

- Relatives said they felt their children were safe when receiving support from The Rainbow Trust Children's Charity 6. One relative told us, "I know my children are safe when they are with [support worker]. She treats them just like family and I couldn't be happier." Another relative told us, "I trust [support worker] without hesitation. I personally feel safe when they are here, and I know my children do too."
- Support workers had a clear understanding of the different types of abuse, how to recognise these and what to do should they witness any poor practice. There were comprehensive safeguarding and whistleblowing policies in place.
- Support workers said they received the training they needed to understand safeguarding processes and to keep people safe. A support worker told us, "It's about the protection of the children. If there was an issue I would report it."

Assessing risk, safety monitoring and management:

- The registered manager and support workers completed assessments to identify risks to the child and their family members. Risks included, eating, personal care, outings, drinking and the environment. Additional risks specific to the individual family circumstances were assessed and measures put in place to mitigate the risk of harm.
- There was a lone working risk assessment and all support workers carried a mobile phone and used a car supplied by the Trust. The car had telematics inside to assist in locating where the vehicles were to ensure support workers were kept safe. The trust had introduced a new alarm system for support workers including a panic alarm which escalated up to manager and the police if required.

Staffing and recruitment:

- The provider had maintained a consistent level of support workers. The majority of the support workers had worked for the provider for a number of years. This had enabled support workers to get to know families and provide a consistent, familiar and friendly face to families.
- The support workers liaised with families to establish what support they required each week. The intensity and duration of the support varied according to each family's circumstances. This meant there was a flexible arrangement for making sure support workers were available to meet people's needs. Support workers also attended weekly team meetings with the registered manager to discuss workloads and share information.
- The provider had sought additional support from a reliable team of volunteers. The volunteers assisted with tasks which then enabled support workers to spend more time with people and families. These tasks included transporting people and families to hospital appointments
- Support workers were recruited safely. This meant people were supported by support workers who were of good character and suitable to work with vulnerable people. Checks were done on applicants before they

were offered employment. These checks included checks with the Disclosure and Barring Service (DBS). The DBS inform potential employers of any previous convictions or cautions a person has.

Preventing and controlling infection:

- Support workers received infection control training to support them to prevent cross infection that might harm a sick child. Support workers confirmed they received supplies of gloves, aprons and hand sanitizer.
- Support workers we spoke to had a good understanding on infection control. A support worker told us, "We carry gloves and aprons and it's good practice to have a spare t-shirt to change between visits. We take advice from families and the hospital on visits like making sure we dispose of nappies in the right bin if the child is having chemo."

Learning lessons when things go wrong:

- The registered manager had made changes following an accident or incident when required to prevent reoccurrence. For example, information sharing methods have been developed to enable support workers and management to share and discuss useful information in relation to a child's support.
- The national manager told us that the trust's health and safety committee would meet to discuss and review any accidents and incidents. This was a national process which was replicated across all of the trusts. At the time of our inspection the national manager told us there had been no incidents or accidents to review for this trust.

Using medicines safely:

- At the time of our inspection support workers were not assisting or administering any medication to children.
- The national manager told us support workers were trained on specific medications or techniques should the need arise for them to become involved. The parents would provide written guidance to support workers about what medication is required, when it is required and what the medication is for. For example, if a child is prescribed a course of antibiotics then the parents would instruct support workers if they ever needed assistance to administer the medication.

Is the service effective?

Our findings

Effective – this means we looked for evidence that people's care, treatment and support achieved good outcomes and promoted a good quality of life, based on best available evidence.

At the last inspection this key question was rated as good. At this inspection this key question has remained the same. This meant people's outcomes were consistently good, and people's feedback confirmed this.

Assessing people's needs and choices; delivering care in line with standards, guidance and the law:

- The management team completed a pre-assessment on children prior to receiving any support. The national manager told us referrals were received from parents or professionals such as doctors or community nurses. The registered manager arranged a visit with the care worker to see the family and discuss what the needs of the child and the family were. Assessments would take place at the family home, hospice or hospital to suit the needs of the child and family.
- Following the initial visit to a family, a plan was developed based on the support needed. This included information around transport to hospital, providing support in hospital, supporting siblings and any support the child required such as eating and drinking, personal care and emotional support.
- Support plans followed best practice guidance where possible. There was best practice guidance in place around nutrition, swallowing and oral health care where applicable.

Ensuring consent to care and treatment in line with law and guidance

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. This applies to young people over the age of 16 years.

We checked whether the service was working within the principles of the MCA, whether any restrictions on people's liberty had been authorised and whether any conditions on such authorisations were being met.

- Parents were asked to sign their consent to the care provided and this was obtained during the initial assessment process. The national manager described that young people over the age of 16 were asked to give their consent if they had the capacity to do so. A mental capacity assessment was completed where required and relevant professionals were involved in subsequent best interest decisions. At the time of inspection no one over the age of 16 had been receiving support.
- The national manager told us that advocates were sought for children and parents who required support in making some decisions. An advocate's role is to ensure that people, particularly those who are most vulnerable in society, are able to: Have their voice heard on issues that are important to them. Defend and safeguard their rights. Have their views and wishes genuinely considered when decisions are being made about their lives

Staff support: induction, training, skills and experience:

- Support workers were supported to attend training which enabled them to safely support children and families. Training had been provided in areas such as bereavement, food hygiene, infection control and manual handling. Support workers had received bespoke first aid training which was individual to the trust and used real life examples to educate support workers.
- The national manager told us they conducted competency checks on support workers discreetly by obtaining feedback from families and professionals. They told us that due to sensitive nature of work it relied on the feedback to suitably assess how support workers were conducting themselves. All the feedback received had been positive.
- Support workers had monthly supervision from the registered manager, in addition to non-managerial supervision provided by the Trust. This was provided to support workers to manage their feelings and emotions brought about by the work they undertook. A support workers told us, "I feel really well supported. It can be difficult when there are issues. [Name] is a non-managerial supervisor and we have a one to one with them every month. You can talk about anything that's bothering you, your caseload and about me. I have it once a month but can book in more if I need to. I also have management support once a month."

Supporting people to eat and drink enough to maintain a balanced diet:

- Care plans stated if people had eating support needs. There were prompts, for example, to state if the child or siblings had any food allergies or a history of choking. Support workers confirmed this was an area they looked at very carefully with reference to allergies, but they did not often support children to eat. In most instances, family members would undertake this role and provide the food and drink to be consumed.

Staff working with other agencies to provide consistent, effective, timely care; Supporting people to live healthier lives, access healthcare services and support:

- Support workers worked closely with professionals in both hospital and community settings. Support workers supported parents during multidisciplinary meetings and contacted professionals from different agencies that included housing and social services on the parents' behalf where necessary.
- Support workers supported parents to take their children to healthcare appointments. The support ranged from providing transport, acting in an advocacy role or interacting with the child and siblings so the parent could concentrate on talking with the healthcare professional.

Is the service caring?

Our findings

Caring – this means we looked for evidence that the service involved people and treated them with compassion, kindness, dignity and respect.

At the last inspection this key question was rated as good. At this inspection this key question has now remained the same. This meant people were supported and treated with dignity and respect; and involved as partners in their care.

Ensuring people are well treated and supported; respecting equality and diversity:

- Relatives told us that support workers were kind and caring and at all times treated their children and the family with respect. A relative told us, "I have felt supported, [Support worker] has become like a family friend. She is so easy and lovely to talk to, she has helped me and my family so much. I have always found her to be kind and caring towards the whole family. I don't know how I could have coped without her help." Another relative told us, "[Care worker] has been genuinely amazing. They always have the right answer at the times I need them the most. It's like a huge weight was lifted off of me when [care worker] came into our life."
- Relatives also told us they felt support workers had spent time getting to know them as a family. This enabled support workers to develop close bonds with the children and families they supported. A relative told us, "I can talk to them [care worker] about anything. They know us and what we like and don't like. They know [child's name] history and everything they have been through. It's really nice to have someone who can come in and just play with [child's name] when they need it without having to explain everything."
- Support workers spoke of how much they enjoy working with the families they supported. A care worker told us, "We all go a bit above and beyond. We will all do really long days, especially with hospital appointments. We're very flexible but I wouldn't dream of leaving them. We can also assist them with things like forms or signposting them to other services." Another care worker told us, "We get all different cultures so it's about taking the lead from the parents and working with the family closely."

Supporting people to express their views and be involved in making decisions about their care:

- Children and families were always involved in making decisions about their care and support. Children's care plans reflected what the child (dependent on age) or the family had asked for. A care worker told us, "Plans can change quite regularly and on other occasions you look at the plan after six months and see it's still working. It's led by the parents and where the children are old enough they are always part of our discussion."
- The Rainbow trust had an ethos from the management team to the support workers which meant that the primary focus was always on hearing the child's voice. This was at times through the parents of the children who were able to communicate what their child wanted and needed. Feedback was obtained from children and siblings who were able to give their views on the care and support being provided. All of the feedback we viewed was positive.
- The provider ensured care plans were reviewed thoroughly every six months. as well as ongoing and dynamic reviews. Reviews monitored the effectiveness of the care plan outcomes. Support workers evaluated with the parents if the support facilitated an improvement in their quality of life. This allowed

families and support workers to discuss how the support had been and if any changes needed to be implemented. A relative told us, "We always discuss the care and support we receive. We don't really set dates as it's discussed all of the time as [child's name] needs could change and do change quite quickly at times. Rainbow Trust are so quick to adapt to any changes we need."

Respecting and promoting people's privacy, dignity and independence:

- Relatives told us they felt support workers promoted their family's privacy and dignity. A relative told us, "Sometimes when we need to talk with the doctor at the hospital about something that is private or requires my full attention. [Support worker] respects this and is always on hand to take [child's name] away or distract them with toys and games so we can talk in private." Another relative told us, "I have never had any concerns, no matter the situation [support worker] always acts professional."
- Support workers were aware of their responsibilities to ensure children's dignity is maintained. A support worker told us, "I always make sure I protect the dignity of the child. For example, if we are out and I need to change a nappy, I will ensure it is done as discreetly as possible."
- Support workers ensured that the children's and families independence was maintained. Support workers told us they always asked what the child's or the family's preferred option was and take direction for them. A relative told us, "I think [support worker] is great, she knows how to take charge if they need to but also they respect that this is a family and she is brilliant at supporting us a family to do the little things ourselves, things we may have forgotten about."

Is the service responsive?

Our findings

Responsive – this means we looked for evidence that the service met people's needs.

At the last inspection this key question was rated as good. At this inspection this key question has remained the same. This meant people's needs were met through good organisation and delivery.

Planning personalised care to ensure people have choice and control and to meet their needs and preferences;

- Care plans were person centred and contained relevant history and background information. Care plans identified how the child and their family required their care and support to be given. A relative told us, "It's not just [child's name] they think of, it's all of the family, my other daughter and my husband have been included and this has been such a relief. The way they plan their support has been invaluable to us as a family."
- Children and families were supported to achieve personal wellbeing goals. The trust had a process in place called 'outcomes star', which looked at six areas managing stress, quality time, economic well-being, quality of life, grief and loss and stability and confidence. Criteria had been clearly set out for each of these six areas which gives a scale of how families are feeling in each area. This also allowed families to have control over setting goals they wanted to achieve and working with the care worker to achieve their goals. A relative told us, "It has been helpful to talk through setting of goals, it might be something small like improving our emotions or giving some stability to [persons name] in their daily life."
- Each family support worker had their own caseload of families they supported and managed their own workload and work time. This meant they could be responsive when a family suddenly needed extra help or needed emotional support. A support worker told us, "We review the families we support, and I will always be flexible so that I can be there for the families when they need me. Sometimes I need to rearrange bits, but I will always do my best to ensure the families get everything they need."

Supporting people to develop and maintain relationships to avoid social isolation; support to follow interests and to take part in activities that are socially and culturally relevant to them;

- The service provided support and guidance to children and families around a variety of different and personalised activities. Because support workers knew the children and families they supported well, they were able to suggest activities they may have found beneficial. For example, the sibling of someone being supported by the service was able to take part in a carol singing concert, which had been important to them. The care worker attended the concert with the family and provided support to the child so that the sibling could participate, and the parents were free to spend time watching and supporting the sibling.
- Children and families had support to take part in family days out arranged by The Rainbow Trust. Relatives told us of the importance of these events being organised. It enabled people with similar experiences to get together and talk, share ideas and gain confidence. A relative told us, "I love the family days. To meet other people who are going through similar things to us and to find out how they are dealing and coping. My daughter getting to realise that she isn't the only person out there in her situation of having a poorly sister."
- Support workers spent time getting to know children and families which enabled them to spend time doing the things which brought joy into people's lives. Support workers knew the people they cared for and

supported. People told us about the little things that support workers did on a daily basis which supported the child's interests. A relative told us, "Every time [support workers name] just knows what to do. They know what [child's name] likes and enjoys and sometimes it's just a simple thing like playing a game or singing but that simple thing can mean the most to [child's name] in keeping them doing the things they love."

Meeting people's communication needs:

Since 2016 onwards all organisations that provide publicly funded adult social care are legally required to follow the Accessible Information Standard (AIS). The standard was introduced to make sure people are given information in a way they can understand. The standard applies to all people with a disability, impairment or sensory loss and in some circumstances to their carers.

- Care plans contained guidance for support workers about how to meet people's communication needs. Care plans detailed how each person liked to communicate such as verbal or nonverbal.
- People would be assessed on their communication needs during the pre-assessment prior to receiving any support. This would then be reviewed should their communication needs change.
- The Trust had child friendly feedback forms in place. These had been given to children so they could have their voice heard with regards to the care and support they were receiving. The feedback forms had been designed with pictures making them child friendly.

Improving care quality in response to complaints or concerns:

- The provider had a system in place for people to raise a complaint should they wish. Relatives told us they knew how to make a complaint, but they had never had a reason to complain. At the time of inspection, no complaints had been received. A relative told us, "I have never made a complaint. I have never had any reason for concern. The only concern I have is losing [care worker] and the support from the Rainbow Trust."

End of life care and support:

- The Rainbow Trust supported children with life threatening conditions. Often children recovered from their illness, but sadly some children had a limited life expectancy. Support workers had received relevant training to offer appropriate care and bereavement support to siblings of children and their families. A trained staff member in bereavement had delivered training to support workers. A support worker told us, "We have a bereavement champion from another team who supports us. It's about listening and explaining that families are different. We don't give a time limit on it (ending their support)."
- Support workers worked alongside the family and healthcare professionals who cared for the child in both hospital and community setting. In instances where a child did not recover from their illness the support workers remained in contact with the family to ongoing practical and emotional support for up to a year after a child had passed away.
- Families received support in areas they had been struggling with following the loss of a child. The Rainbow Trust had assisted families with raising money to pay for headstones and support workers had also supported a family through attending a coroner's court inquiry.

Is the service well-led?

Our findings

Well-Led – this means we looked for evidence that service leadership, management and governance assured high-quality, person-centred care; supported learning and innovation; and promoted an open, fair culture.

At the last inspection this key question was rated as good. At this inspection this key question has remained the same. This meant the service was consistently managed and well-led. Leaders and the culture they created promoted high-quality, person-centred care.

Managers and staff being clear about their roles, and understanding quality performance, risks and regulatory requirements:

- The service had a clear vision around how they supported families in line with the trusts own values. The registered manager was clear about their leadership responsibilities. When the registered manager was unable to work through sickness the national manager took over with the same values. This created a team working ethic amongst management and support workers. A support worker told us, "The whole organisation is completely focussed on what we do. We see the CEO who comes into team meetings. It's such a supportive organisation. All the organisation works together and the values they are cohesive. It's all focussed on the families."
- The provider had robust quality audit procedures in place to monitor and maintain the level of service and make improvements where necessary. The provider conducted audits in care plans to review and ensure the most up to date information was held for children and families. The national manager told us through the audit process changes are being made to the database system as there had been errors in how data was captured. This was ongoing work that would be constantly reviewed.

Promoting a positive culture that is person-centred, open, inclusive and empowering, which achieves good outcomes for people:

- Relatives spoke about feeling empowered to make choices and being completely included in everything they were being supported with. A relative told us, "I work with [care worker] and we set goals together, both what we as a family want to achieve and what [care worker] can help us achieve. We always talk about how things are going and make changes together along the way. It's really set us up to make more progress as a family than we had thought we could."
- Support workers spoke about how proud they felt working for the trust and what it meant to them to support children and families. A support worker told us, "I feel really privileged that the families do let me go in. I go in a stranger at such a difficult time of their lives. As a team we are good at being ourselves. Every day I walk away from a visit and think I have made a difference. There is nothing quite like us for families. We are a whole package for the family, working with siblings through to grandparents."

How the provider understands and acts on the duty of candour, which is their legal responsibility to be open and honest with people when something goes wrong:

- The registered manager understood their role and responsibilities to ensure notifiable incidents such as safeguarding and serious injuries were reported to the appropriate authorities and the CQC. At the time of inspection, no reportable incidents had taken place. However, both support workers and management

knew how to report incidents or accidents should this change in the future.

Engaging and involving people using the service, the public and staff, fully considering their equality characteristics:

- Feedback was obtained annually from children, their relatives and professionals through a feedback questionnaire. We observed recorded comments were positive. A professional left a comment saying, "For one particular family it made the world of difference. Rainbow Trust were a lifeline."
- The provider sought feedback from families by using satisfaction surveys. All of the comments recorded were positive. A comment read, "Rainbow trust has made a huge difference to our life's. The first few months without hospital and emotional support were very stressful and frightening. My child is more relaxed and feels safer when our support worker takes us to hospital." Another comment read, "Rainbow trust has really helped us keep together as a family throughout treatment. All volunteers are friendly, helpful and amazing."

Continuous learning and improving care; Working in partnership with others:

- The registered manager and support workers worked in close contact with several large hospitals. Referrals were often received from the hospital's as well as support workers building professional relationships with hospital staff whilst assisting families with health visits and appointments. This ensured smooth transitions for children and families who attended appointments or received treatment in hospital.
- The registered manager had developed an open relationship with children's community nurses. The registered manager told us, "We liaise to keep up to date what is happening with families. It might be we are told something before the families, so we can prepare to support the family as best as possible. I can call the children's nurse and ask what is happening. For example, I can ask what a new medication is and what the side effects of the medication might be, so we can better plan our support."
- The registered manager had also developed a close relationship with a children's cancer charity. This charity had an overview of financial situations for families and as such could apply for certain grants for things like washing machines or other utilities.