

Rainbow Trust Children's Charity

Rainbow Trust Childrens Charity 9

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 9 provides personal care and emotional support to children experiencing very serious illness, resulting from birth abnormalities or onset of illness for other reasons. This is provided in people's homes, hospitals and in the community. Care workers provide support to both the children and their family members. The provider operates eight registered services in England and this local service operates in the West London boroughs. The service was providing support to 127 children aged from birth to 19 years and their families. At the time of this inspection there was one child who might on occasion require personal care.

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

People found this service good. They described the care workers as "Compassionate." They provided care and support in a very flexible manner to meet the changing needs of the families they worked with.

The team's five care workers were experienced and well trained. They specialised within the team and two were neonatal workers and three care staff worked with children and teenagers.

Care workers worked in partnership with healthcare professionals in hospital and the community. They also liaised with social care and housing professionals on behalf of families. They advocated on behalf of families and attended meetings, so the parent's views could be heard.

The registered manager assessed that they had the staffing capacity to start working with new family referrals. Care workers had a case load of allocated families and built up a working relationship with them.

An initial assessment identified immediate support needs and assessed risks to children and the family. Care plans were reviewed on a frequent basis to reflect changing care needs. People's diverse needs were supported. The Trust worked in line with the Mental Capacity Act 2005 and obtained people's consent to provide care and share information.

The registered manager and care workers had received safeguarding adult and children's training. They demonstrated they would recognise signs and symptoms of abuse and knew how to report concerns.

The registered manager was described as "approachable" and "supportive" by staff and they audited and undertook checks to assure the quality of the service provided.

Rating at last inspection: At the last inspection on 6 and 12 October 2016 the rating was good overall.

Why we inspected: This was a scheduled inspection based on the previous rating of good.

Follow up: We will continue with ongoing monitoring and re-inspect in line with our ratings schedule unless we receive information that is of concern that might result in us bringing the inspection forward.

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

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.

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Detailed findings

Background to this 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:

One inspector undertook this visit.

Service and service type:

Rainbow Trust Children's Charity 9 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.

The service had a manager registered with the Care Quality Commission. This means that they and the provider are legally responsible for how the service is run and for the quality and safety of the care provided.

Notice of inspection:

We gave the service 48 hours' notice of the inspection visit because it is small, and the manager is often out of the office supporting staff or providing care. We needed to be sure that they would be in.

Inspection site visit activity took place on the 20 May 2019 when we visited the office location to meet the registered manager and care workers; and to review care records and policies and procedures.

What we did:

Prior to our inspection we reviewed the previous inspection report and looked at notifications and information we had received about the service.

During our visit we looked at one child's care records and three staff personnel files. This included their recruitment and training documents. We looked at the systems in place to audit and check the quality of the service provided. We met and spoke with the registered manager and two care workers. We watched a video of a relative speaking at the Trust's national conference about the support they received from their Rainbow Trust Children's Charity 9 care worker. Following the inspection, we spoke with a third care worker and a relative who used the service.

Is the service safe?

Our findings

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

People were safe and protected from avoidable harm.

Systems and processes to safeguard people from the risk of abuse

- ☐ A relative told us they felt their children were very safe with their care worker. Staff had received both safeguarding adults and children training. Care workers told us training was updated on a regular basis and gave an example of recent training that had focussed on domestic violence. Staff demonstrated they would recognise signs of abuse and knew what action they must take to report concerns. They often supported families in hospital settings and had also attended training provided by the hospital.

- ☐ The registered manager said care workers could speak with them if they had a concern about a family by phoning at any time and meeting to discuss if they thought there might be a potentially abusive situation. They could also raise concerns in the weekly staff meeting. They told us they monitored accidents and incidents and the daily notes from visits to ensure all concerns were reported appropriately.

Assessing risk, safety monitoring and management

- ☐ The registered manager and/or the care worker 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. Where there was a high risk this was indicated by a high "Red" score.

- ☐ There was a lone working risk assessment and all care workers carried a mobile phone and used a car supplied by the Trust. The car had an application [App] that could track if their driving skills were safe and stated their whereabouts. Care workers used another phone App to communicate with the team should they require additional support or advice.

Staffing and recruitment

- ☐ The care staff 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 staff were available to meet people's needs.

- ☐ There were suitably robust recruitment processes in place. Prospective staff completed a written task and attended two interviews which were value based. The registered manager told us they assessed staffing capacity before working with a family to make sure that had sufficient numbers of staff to meet people's needs.

- ☐ The Trust had safe recruitment practices. For example, they checked employment references, identity and criminal records checks. There was also a six-month probation period to assess staff's ongoing aptitude for the role.

Preventing and controlling infection

- ☐ Staff received infection control training to support them to prevent cross infection that might harm a sick child. Staff confirmed they received supplies of gloves, aprons and hand sanitizer.
- ☐ Staff carried equipment to help manage car sickness, which was often an issue when transporting children from hospital after chemotherapy treatment. This included sick bags to prevent the spread of infection in their cars.

Learning lessons when things go wrong

- ☐ The registered manager told us of improvements they had made to the service when there had been a 'near miss' incident or something had not gone well. They gave examples of changing procedures when being asked to work with children's friends because of previous misunderstandings that they would take on this work. Also, they now ensured there would be adequate changing rooms for children and their families when they booked a venue for a festive celebration or a Trust event. This was in response to feedback from families that facilities had not been appropriate on one occasion.
- ☐ The registered manager told us they would refer a 'near miss incident to the Trust's Health and Safety Committee to identify measures to prevent a reoccurrence at all the Trust's locations.

Using medicines safely

- ☐ At the time of our inspection care workers were not currently administering any medicines to children they supported.

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.

People's outcomes were consistently good, and people's feedback confirmed this.

Staff support: induction, training, skills and experience

- ☐ All the care workers had previous experience of working with children or babies in relevant settings. They were experienced and well trained in their field of work. There was a six-month induction period when they received mandatory training and shadowed established staff. One care worker who specialised in neonatal care described shadowing an established care worker in the hospital and this introduced them to the families they were going to work with.
- ☐ Care workers were supported to attend training they felt would be relevant to their work. There were training refreshers for, bereavement and safeguarding adults and children. Trainers had provided bespoke training in bereavement support. Care workers told us they had found this very helpful in assisting them to undertake their work. When a training need was identified the registered manager supported staff attendance. For example, some care workers were going to attend a "mental health first aid" course as this had been identified as helpful to their role.
- ☐ Staff had monthly supervision from the registered manager, in addition to mandatory monthly, or more frequent if required, counselling provided by the Trust. This was provided to support staff to manage their feelings and emotions brought about by the work they undertook.

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

- ☐ The registered manager described that referrals came from different sources such as hospital, community nurses or families themselves. They would take the referral information provided into account and would visit the family to assess what support they required and provided information about the service. They would leave information leaflets that might be helpful and a service user guide for their consideration.
- ☐ The care workers were trained to undertake initial assessments. The registered manager described that the staff would shadow on at least three assessments before undertaking a minimum of six assessments in their presence. Once they have assessed the care worker as competent they could meet with families for the initial assessment if they wanted to take on the assessment role. Care workers described that the support identified during the assessment often changed as the working relationship formed and family's needs changed. As such care plans were flexible and reviewed on a regular basis to update the initial assessment.

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. The registered manager described that young people over the age of 16 were asked to give their consent if they had the capacity to do so. If their capacity was in question they would undertake a mental capacity assessment and with parents, relevant professionals agree a best interest decision.

- The Rainbow Trust Children's Charity fundraises to provide its services and used people's "Stories" for this. These were people's experiences of what happened to their child and how the Trust workers had supported them and often photos were used. The registered manager explained they obtained specific consent for the use of this material. They gave examples of consent being given for material to be used for one specific occasion and for other material to be used on the Trust's website.

Staff working with other agencies to provide consistent, effective, timely care

- Care workers worked closely with professionals in both hospital and community settings. They supported parents during multidisciplinary meetings and contacted professionals from different agencies that included housing and social services on parents' behalf.

- A relative told us that at times of stress they valued that the care worker could explain medical information and clarify what was being discussed. We saw that on occasion care workers attended meetings on a parent's behalf to contribute information and relay decisions. One care worker had advocated for the parent supporting other professionals to understand the complexity of the family circumstances.

Supporting people to live healthier lives, access healthcare services and support

- Care workers supported families to have healthier lives by giving emotional support at times of great stress. They were contactable by phone and would listen when parents needed to talk. They supported siblings to go out for walks, to do activities and have some meaningful play and leisure time. The service operated a sibling activity group at the Chelsea and Westminster Hospital in school holidays and this gave siblings an opportunity to have fun and relax from the family pressures.

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. Care 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.

Adapting service, design, decoration to meet people's needs

- The care and support took place in people's homes, in the community and in hospitals. However, the office environment was designed so that care workers could bring children for art or creative sessions if this was what they wanted. There was a large table to work on and some craft equipment, toys and board games were available and there was an area to relax or talk quietly. It was a welcoming space for children.

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.

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

- ☐ A relative told us their care worker was, "Compassionate" and had "Life experience" and said that, "People like that you really appreciate." They told us their main support came from their care worker and they clearly valued the care worker's expertise and consistent support. We were shown a video of another relative speaking to the recent national conference about another care worker from Rainbow Trust Children's Charity 9 in very positive terms. Their comments included that "It was more than time that [the care worker] gives to us," that they were "part of the family," and they spoke about the emotional support provided that they had found so valuable.
- ☐ Two care workers we spoke with described their work as a, "vocation" and all the care workers told us that they, "loved" their job. One care worker told us, "I check on them if I can't see them. I will call them and schedule to come round and have a catch up, we listen we don't judge and try to give them something, suggest meditation or a schedule a visit. Families will say you're like friend. We are professionals but still give a little bit extra...it's a trusting bond, a unique position of support whilst you are still doing your job."
- A pivotal part of their role was to provide emotional support to the children and families they worked with. They were highly skilled in this area and spoke with empathy about the children and families they worked with. They demonstrated an understanding of what parents were going through looking after very sick children whilst managing the rest of the family's well-being. There was also an understanding that each member of the family including the siblings may need different levels and types of support.
- ☐ The care staff received diversity and equality training. They described that the families they worked with in north west London were very, "multi-cultural". They therefore, worked with families from many different backgrounds. They described how they always ask families what support they needed and recorded if there was anything they should be aware of in terms of their diverse needs. Staff attended workshops to help them understand what families might need in line with their cultural and religious observances. This included end of life and funeral rites that were appropriate for the family's beliefs.
- ☐ The registered manager explained their work was about, "Understanding and not judging." They said it did not matter what the family structure was, their approach was the same. Their role was to support the ill child and the family members. There was a policy to give guidance for staff about discrimination, equality and the lesbian, gay bi-sexual and transgender plus [LGBT+] community. The registered manager showed us they were actively working with another manager on a diversity tool kit to identify diverse needs and to give staff guidance. They wanted the tool kit to measure their success at working with families who had diverse needs.

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

- One care worker told us, "I don't tell people what to do, we make a plan together." Care workers described working with families and the support provided was dictated by the requests made and what the parents wanted. However, because parents sometimes were not sure of what the care worker could do they would suggest where they could support.
- The registered manager demonstrated how care plans showed children using the service were involved as much as they could be while taking their ages into consideration. Feedback was sought from both children and families.

Respecting and promoting people's privacy, dignity and independence

- A care worker described to us that they are always mindful of the child's privacy when changing them. For example, if they were on an outing they would find a suitable changing facility and ensure they had the right equipment and change of clothes with them.
- Care workers described being respectful and sensitive to parent's changing emotional needs when they frequently supported children in hospital. They told us, "Having conversations in different rooms away from hospital staff... or taking parents for a cup of tea and asking about their feelings... If they are very upset, we may go away and give the couple some space and pop back onto the unit to be with the child."

Is the service responsive?

Our findings

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

People's needs were met through good organisation and delivery.

Planning personalised care to meet people's needs, preferences, interests and give them choice and control

- ☐ Care plans were person centred and contained relevant history and background information. The plans identified how the child and their family required their care and support to be given. Care plans incorporated the whole family's support needs. Plans identified, for example, play schemes for siblings in the holidays, support with housing issues for parents, as well as emotional support and personal care. The service was responsive and care plans were very flexible to reflect the needs of the family.

- ☐ Care plans were updated at least every six months, but often more frequently due to rapid changes of circumstance. Reviews monitored the effectiveness of the care plan outcomes. Staff evaluated with the parents if the support facilitated an improvement in their quality of life, stability and confidence, managing stress and quality time. This allowed staff to monitor and assess if the support was provided in the right way for the family and if changes or further input was needed.

Improving care quality in response to complaints or concerns

- ☐ A relative confirmed they felt they could raise a concern or complaint and it would be dealt with. There was a folder for the oversight of complaints, but no complaints were recorded. The registered manager explained that no complaints had been made. They felt this was because staff worked closely with families and any concerns were addressed immediately. Also, they asked for feedback from both parents and children and would address any areas for improvement.

- ☐ To support people to complain, a complaints form was given to people in the introductory service user pack. There was also a complaints policy and procedures. The registered manager described how they would acknowledge, investigate and apologise should a complaint be made.

End of life care and support

- ☐ The agency supported children experiencing very serious illness. Often children recovered from their illness, but sadly some children had a limited life expectancy. Therefore, care workers had received relevant training to offer appropriate care and bereavement support children and families. The care workers told us they had received tailored training to provide emotional support to parents and siblings.

- ☐ The registered manager told us, "If the parents want to talk to us, we can talk about grief and loss using words that are acceptable to the family...regardless of any number of training this is always a delicate subject, but we shouldn't be afraid of asking questions."

- ☐ The care workers worked alongside the family and healthcare professionals who cared for the child in both hospital and community setting. In instances where sadly a child did not recover from their illness the

care workers remained in contact with the family to offer whatever might be helpful. This could be practical or emotional support. The Trust continued to offer support for up to a year after a child passes away if this is wished by a family.

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.

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 team had clearly defined roles. There were two neonatal care workers who supported families with new born babies and three care workers who worked with young children and teenagers up to the age of 19 years. The care workers planned their own work load and they agreed support with individual families. They described families generally understood there might be times when one family needed support and calls might be altered to help that family. They remained in phone contact and there was a providers 24 hour help line should a care workers support be required urgently.
- ☐ The registered manager was clear about their leadership role and described how their team worked autonomously but they kept an oversight through phone calls, weekly team meeting discussions and at least monthly supervision. Staff told us, "As [registered] manager they work brilliantly, they are not a micro manager but supportive," and "[Registered manager] is a good manager, they are the right mix, puts us first. You need to feel understood and supported and if they need to come in and support they will."
- ☐ The registered manager told us they do undertake spot checks randomly to check care workers were attending appointments as stated in their calendar. However, they explained they expected the staff to be trustworthy and committed to their work. They undertook audits and checks to ensure the quality of the service provided. They described checking a sample of care records each quarter, at least two for each care worker. They gave an example that they check that documents are consistent in content, contact details and ethnicity are recorded, and call records are of a good standard and fully completed. They told us the provider is aiming for a consistent quality of service across the locations. Findings are shared with the national manager for comparison to flag where there are shortfalls to address.

Engaging and involving people using the service, the public and staff, fully considering their equality characteristics; Planning and promoting person-centred, high-quality care and support with openness; and how the provider understands and acts on their duty of candour responsibility

- ☐ The week prior to our inspection the provider had held a national conference. The registered manager told us they had helped organise this and felt it was an important event to motivate the staff and to celebrate the Trust's achievements. "Our staff conference let us know the truth, helps us see our job from another angle from the [Parents] point of view." There were inspirational talks by parents to demonstrate how care workers had made a difference to their life when coping with an unwell child. In addition, the event looked at how the Trust wanted to move forward and provide further services to more families.

- The registered manager told us they listened to the staff when they had raised issues. There had been a staff survey in January 2019 and issues raised included, the career route had been "flat" for staff and equipment was not supporting them in their role. In response, they had in their team just developed an advanced practitioners' role. This was a pilot and one care worker had been successful in applying for this. Smart phones had been purchased to assist in electronic note taking and sending emails. Several care workers told us they felt there had been positive moves forward.

- The care workers left feedback forms with parents and children. This occurred after reviews and after some activities, for example, the neo natal sibling group at St Thomas Hospital. There was an easy read feedback form that contained symbols that children could tick or colour in if they did not read well. Feedback reviewed was very positive about the support received. Forms could be returned via the worker or posted to the office location.

- The registered manager had commissioned outside agencies to do a "snapshot" audit to check parent satisfaction. The provider sent out a survey of all its locations and reported on the findings in their annual report. The 2017/18 report showed that 82% of families rated the overall service they received as excellent. 100% of children felt the Trust kept them safe. The registered manager told us should there be negative feedback about their location they would investigate and look to address the service deficiency.

Continuous learning and improving care

- The registered manager described they had taken part in provider initiatives to develop both their own knowledge and to benefit the service. For example, they had led the employee engagement group for two years and had been a link between the provider's senior management and the other staff. They were now part of the "Green team - Beyond recycling." They described they were raising "Green" awareness and had asked the team for ideas. They were, for example, moving towards a paperless office and other initiatives included planning joint car trips to visits.

- Some care workers were pursuing professional qualifications that would enhance their expertise and skills when working with children and families.

Working in partnership with others

- The care staff and registered manager worked in close partnership with healthcare professionals in several hospitals. They also worked alongside community health and social care professionals across West London for the benefit of children and families using the service.

- The registered manager had built good relationships with local enterprises for fundraising and support. The service had been donated items including arts and crafts equipment, toys to be given to children and their siblings, Easter eggs for families and toiletries were given so parents could have pampering sessions.

- The provider worked in partnership with volunteers across their service nationally. The service had several volunteers who supported the service by driving people to hospital appointments, helped with the administration and supported care workers in their role.