

Rainbow Trust Children's Charity

Rainbow Trust Childrens Charity 9

Inspection report

Unit 2
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Date of inspection visit:

06 October 2016

07 October 2016

12 October 2016

Date of publication:

23 November 2016

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

The inspection was carried out on 6, 7 and 12 October 2016 and was done by one inspector. The service was given 48 hours' notice because the location provides a domiciliary care service and we wanted to make sure someone would be available to speak with us. The last inspection took place on 18 October 2013 and the provider was compliant with the regulations we checked.

Rainbow Trust Children's Charity 9 provides support to children who have life threatening or terminal illness. The charity provides support to the children and their families in their own homes, in hospital and in the community. The regulated activity is personal care but this is provided only when needed, for example, changing a baby's nappy when providing support. At the time of inspection there were 112 children being supported by the service and two received occasional support with personal care.

The service had an experienced registered manager 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.

Procedures were in place to safeguard children against the risk of abuse. Staff understood the importance of keeping children safe and of reporting any concerns.

Risks were assessed so action could be taken to minimise them.

Staff recruitment procedures were in place and being followed. Staff were available to meet the needs of the children using the service.

Staff received the training and supervision they needed to provide them with the knowledge and skills to care and support children and their families effectively.

Staff respected the rights of children and their families to make choices about their care and support and knew to act in their best interests.

Staff were able to support children with their nutritional needs when they required it.

Staff knew children's healthcare needs and supported families to attend appointments. Staff knew the action to take in an emergency to summon help and support children and their families.

Parents were very happy with the service their child received and felt the whole family was well supported by the service. Staff understood the importance of providing person-centred care and support to each child and their family.

Staff understood the end of life care and support children and families needed and provided an ongoing service to support the family through their bereavement.

Care records reflected the care and support children and their families needed, including any personal support needs for children using the service. Records were reviewed periodically to keep the information current.

Procedures for raising complaints were in place and parents were aware of how to raise a concern so it could be addressed.

Families could contact the service easily and were happy with the way the service was run. Staff said the provider and the registered manager were very supportive and accessible.

Systems were in place for monitoring the service being provided and to identify areas for improvement so this could be achieved.

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. Procedures were in place to safeguard children against the risk of abuse. Staff understood the importance of keeping children safe and of reporting any concerns.

Risks were assessed so action could be taken to minimise them.

Staff recruitment procedures were in place and being followed. Staff were available to meet the needs of the children using the service.

Is the service effective?

Good ●

The service was effective. Staff received the training and supervision they needed to provide them with the knowledge and skills to care for and support children and their families effectively.

Staff respected the rights of children and their families to make choices about their care and support and knew to act in their best interests.

Staff were able to support children with their nutritional needs when they required it.

Staff knew children's healthcare needs and supported families to attend appointments.

Staff knew the action to take in an emergency to summon help and support children and their families.

Is the service caring?

Good ●

The service was caring. Parents were very happy with the service their child received and felt the whole family was well supported by the service.

Staff understood the importance of providing person-centred care and support to each child and their family.

Staff understood the end of life care and support children and

families needed and provided an ongoing service to support the family through their bereavement.

Is the service responsive?

Good ●

The service was responsive. Care records reflected the care and support children and their families needed, including any personal support needs for children using the service.

Records were reviewed periodically to keep the information current.

Procedures for raising complaints were in place and parents were aware of how to raise a concern so it could be addressed.

Is the service well-led?

Good ●

The service was well led. The registered manager was experienced and was managing the service well.

Families could contact the service easily and were happy with the way the service was run. Staff said the provider and the registered manager were very supportive and accessible.

Systems were in place for monitoring the service being provided and to identify areas for improvement so this could be achieved.

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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 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 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.

The inspection was carried out on 6, 7 and 12 October 2016 and was done by one inspector. The service was given 48 hours' notice because the location provides a domiciliary care service and we wanted to make sure someone would be available to speak with us.

Before the inspection we reviewed the information we held about the service and the registered manager 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.

During the inspection we viewed a variety of records including recruitment and training details for four staff, care records for three children using the service, monitoring records, staff allocations, the operational plan and other documentation relevant to the inspection. We also viewed a selection of the provider's policies and procedures.

We spoke with the registered manager and the five staff – three family support workers and two neonatal support workers, which was the total staff team at the time of inspection. We contacted three parents of children using the service to get feedback about the service their children received. Following the inspection we requested feedback from five health and social care professionals representing four organisations who referred children to the service. We received feedback from one healthcare professional on behalf of the health and social care professionals within their organisation.

Is the service safe?

Our findings

Policies and procedures for safeguarding and whistleblowing were in place and being followed to protect children from the risk of abuse. Staff said they had received safeguarding training and that they would take appropriate action to report any concerns. We gave staff safeguarding scenarios and they were clear on the action they would take, including reporting concerns to the registered manager. Staff knew to contact the local authority if their concerns were not acted upon, however they were confident that the registered manager would take appropriate action to escalate any concerns they might raise. The registered manager was clear on the processes to follow and said he would inform the relevant local authority of any safeguarding concerns that were brought to his attention.

We asked parents if they felt the support workers kept their children safe and all confirmed they did. One replied, "100% safe – she is absolutely fantastic. I trust her." We asked staff how they would keep children safe. Comments included, "I would assess every situation I'm in – environment, risk of accident, ask parents to inform me of any changes in circumstance."

The service had an assessment that was carried out prior to providing care and support. This included a section to assess the environment and ensure it was safe. A moving and handling risk assessment document was also completed to identify any moving and handling needs a child had so these could be met. There were also individual assessments for areas of risk that needed to be managed, for example, personal care support, nasogastric feeding tube and chemotherapy treatment. Staff also risk assessed other situations, for example, outings, eating and drinking and the environment for outings and family days. We saw a comprehensive assessment for a family day at an adventure playground that covered children and staff, identifying each area of risk and the action to take to minimise it. Staff understood the importance of ensuring all risks were identified and action taken to minimise them. We asked staff about emergency situations and they were clear on the action to take to provide first aid and summon the emergency services.

Recruitment procedures were in place and being followed to ensure only suitable staff were employed by the service. We asked staff about the recruitment process they went through and they had completed an application form and been interviewed by two people. In the recruitment records we saw completed application forms with employment histories. Pre-employment checks included health declarations, two references including previous employers, criminal record checks such as Disclosure and Barring Service checks and proof of identity documents including the right to work in the UK. Photographs of staff were taken and they were issued with identity (ID) badges. We saw staff were wearing their ID badges when they attended the office and they confirmed these were used when supporting families also.

Each support worker had a caseload and new referrals were only taken on when there was capacity to do so. Each support worker managed their own caseload and the assessments identified the input each family required. If a child's condition deteriorated and the support worker needed to spend more time with a family then this was discussed and staff worked together to ensure all calls were covered. Timesheets were completed to evidence the work carried out.

The service did not manage medicines for any children using the service as parents were responsible for this. The registered manager said if it was necessary for the service to become involved with medicines management then staff would read the policy for medicines management, receive training and be assessed for competence prior to providing assistance in this area.

Is the service effective?

Our findings

We asked parents if they felt staff had the correct skills and knowledge to provide their family with the care and support they needed. They all agreed staff did and one parent said, "Excellent, I can't fault [support worker]."

Staff received the training they needed to provide them with the skills and knowledge to care for children and their families effectively. One support worker said, "If you want training you can ask and you'll get the training." Another said, "They are very keen on offering as much training as possible." Staff told us they received training in a wide range of topics including end of life and bereavement, safeguarding, food hygiene, moving and handling, infection control, seizures, health and safety. The service had a consultant paediatrician staff could speak with to discuss specific diagnoses and associated issues and they also did an annual presentation day when staff could discuss relevant topics. New staff completed induction training and the provider had introduced the Care Certificate, an induction programme for care workers new to health and social care.

Staff had one to one supervision with the registered manager every 4-6 weeks and this covered a variety of topics relating to staff wellbeing, workload, training, objectives and development. Staff also had non-management supervision with a trained counsellor. Staff said these sessions were very good and provided them with the support they needed to be able to maintain their strength and ability to support children and their families. If staff were dealing with a particularly complex case or end of life care they were encouraged to attend additional sessions and also could access telephone support from the registered manager and the counselling service. They had also set up a buddy system so staff could contact each other if they needed to discuss areas of their work and receive peer support. Staff said all these systems worked to ensure they had the support network they needed to be resilient, to maintain a good professional relationship with families and to be able to provide them with the support they needed.

Information about the Mental Capacity Act 2005 (MCA) was displayed in the office. The registered manager confirmed they did not have any young people over the age of 16 years who were unable to make decisions for themselves and parents of younger children had the legal right to act with and on behalf of their children. Staff knew the importance of listening to children and their parents and of always acting in the best interests of the child and their families.

Staff provided support with nutritional needs where required and said they were aware of any dietary restrictions or special diets children required. There was a folder with information about nutrition relating to children receiving chemotherapy, diet restrictions or intolerances and tube feeding. There were several booklets from cancer charity groups with information about nutritional needs and helping children to eat. These also included information about dietary needs for different religions and cultures and staff were clear about these and said they respected and followed any dietary requirements. Food was provided by the parents and it was only if children required snacks and drinks when out with the support worker that staff would be involved. Staff understood individual dietary restrictions, for example, eating problems, choking risks or children with feeding tubes, so they could provide the correct support. The provider had a healthy

eating policy. The registered manager said when they ran drop-in sessions for families they provided healthy option snacks.

A healthcare professional told us, "Feedback from parents using our services has highlighted as particularly valuable the support to attend hospital appointments which Rainbow Trust provide." One support worker told us that with permission of the parents they contacted healthcare professionals involved with the care of the child to discuss and better understand a child's healthcare needs, for example, training around specific types of seizures. Information about each child's diagnosis and the health and social care professionals and any other agencies providing care and support was gained at the assessment visit, so staff were aware of the input each child was receiving. Staff would take children and parents to attend hospital appointments and provided as much support as each family required during each visit to help the families get the most benefit from each appointment. Staff said they could also request input from healthcare professionals if they felt a child required it, for example, contacting a community nurse for advice. The service provided neonatal support and two staff were specifically trained and experienced in this area, so they could support families when the baby was in hospital and afterwards with attending hospital appointments. This meant the service was providing families with the support they needed from staff who had the knowledge and skills to do this effectively.

Is the service caring?

Our findings

Parents were very happy with the support they received. The service provided care and support to the whole family and this was reflected in the comments we received from parents which included, "[Support worker] is a gem, she really is lovely." "[Support worker] helped me to have time for me and to be able to go shopping. He's a really good listener, I could talk to him for everything." "Always caring and kind and makes [child] very happy. There to play and have fun, not just for hospital appointments." The service had received thank you cards from parents and these too demonstrated the care and support families had felt. Comments included, "Thank you so much for everything you have done for us. Your Charity has made a huge impact on our family" and "Words can't express our gratitude for your endless support during the most difficult time of our lives." One member of staff explained, "You are supporting the whole family, finding out how they all feel. Not assuming – follow their lead and asking them, judging what input they want you to have."

We asked staff what was most important to them when providing care and support. Comments included, "Respect their culture, their privacy. That you understand they are going through a very difficult time. To have really good communication skills. To work with people very inclusively, understanding they are a family and we are there to help and supporting the whole family, finding out how they all feel" and "You wake up every day and it is a job you are always happy to do, knowing you are helping people."

Prior to providing support an assessment was carried out at the home of the child and the support workers said they shadowed the registered manager so they got to meet the child and their family and could start to develop a relationship. They were clear that the assessment was the starting point to identify the needs of the child and their families and that these could change and the system would be updated to reflect these.

Staff understood different cultures and religions, so they could respect these. There was a 'diversity toolkit' and staff attended a presentation of this as part of their induction training. Information was available about a range of different religions and the customs, processes and procedures to be followed. Staff told us about families whose first language is not English who attended hospital appointments. Where possible an interpreter would be arranged so the parent could better understand the important information they were being given about their child's diagnosis and the care and treatment they required. This provided the parent with the knowledge they needed to provide appropriate care and support to best meet the needs of their child.

Staff had received training in end of life and bereavement to help them provide the support families needed. The service had a bereavement support protocol and staff completed a bereavement support competency assessment to identify that they had the skills and knowledge to provide bereavement support to families. Information was available about different religions to understand the different rituals and procedures to be followed to meet the religious and cultural needs associated with death and dying. Staff understood the importance of ensuring cultural and religious needs were followed and the wishes of each child and their families were respected. One support worker said, "You don't make any assumptions about what the funeral will look like."

Is the service responsive?

Our findings

We asked parents about the way staff responded. One told us, "[Support worker] always checks with me first that it's okay to say something to [child]." We asked staff what was important when planning the care and support they would give. Comments included, "Not assuming – follow (family) their lead and asking them what they want. Judging what input they want you to have." "It is a tailored approach to each family."

A healthcare professional said, "The Rainbow Trust are very collaborative. They are particularly good at liaising to ensure continuity of services, for example, when a child or family no longer require the services ensuring that there is a planned and staged withdrawal to enable parental and child adjustment." The service provided care and support to families that continued after the death of a child, and recognised the importance of caring for the whole family for as long as they needed the support.

Care records identified the needs of each child and how these were to be met. These were person-centred and included any personal care a child required and we saw records had been updated if their condition changed. Staff completed a record of each visit so the information was kept up to date.

The service provided a weekly neonatal sibling drop-in group at the Chelsea and Westminster Hospital. One support worker said, "It's eclectic and you have to be really flexible and responsive to whatever comes up each week." This provided siblings with somewhere safe to be with experienced staff where they could play games and take part in activities so parents could spend time with their babies. We saw feedback from families who had experienced this and one person had commented, "This group is so helpful and the kids look forward to coming. It means I can spend time with the baby knowing the other children are safe."

The service arranged family support meetings in places where siblings could also attend, for example, a play area, where staff could provide support for the whole family. One parent told us how they had valued meeting with other parents with the same issues to face. "It was lovely to share your experience and it gives you hope and having someone who really understands what you are going through."

Information for staff was available in the office and included a list of useful contact details including support groups, counselling services, equipment support, voluntary services, day trips, holidays, sibling support and other charity organisations. Staff could pass this information onto families so they had the opportunity to access additional help and support. Staff told us about a residential activity camp for children with life-limiting illnesses, which was a week long and tailored for the children so it was completely inclusive. They also had information for assisting families with grant applications and to get equipment and access activities for children.

Systems were in place so that families could raise any concerns to be addressed. The provider had a 'Compliment, Comment or Complaint' leaflet and a copy was included with the service information given to families. Parents confirmed they would be confident to raise any concerns and felt these would be addressed but said they had no complaints about the service. One parent said, "I have no complaints. It is someone to talk to, so sweet and kind." The service had not received any complaints and the registered

manager said if they did they would ensure they were fully recorded, investigated and responded to.

Is the service well-led?

Our findings

We asked parents what they thought about the service. They all said they would recommend the service and comments included, "It's really amazing that they exist and they do exactly what they say. They are wonderful and I can't praise them enough" and "I cannot thank them enough for what they do. It is something every parent in the same situation needs." One parent told us about a review that had been carried out with the registered manager and said they found it "really helpful, he was really kind and lovely."

We asked staff about how the service was managed. Comments included, "I would 100% recommend them. The service is second to none. Rainbow Trust will support a family for as long as they need it.", "Everyone is so dedicated to the work of Rainbow Trust" and "I shout from the rooftops that I work for Rainbow Trust, I really love it."

Feedback from healthcare professionals regarding the service included, "Rainbow Trust is one of the most collaborative organisations I have encountered. We work together in clinical situations, in training and development, e.g. training for Neonatal Palliative Care staff, research and development (developing outcomes and resilience as key priority areas) and in writing and presenting. In my experience, Rainbow Trust are always keen to share ideas and learning and always with the child and family firmly at the centre of their thinking and actions."

We asked staff about the support they received from the organisation. Comments included, "All the leadership team are very approachable, very focussed on personal wellbeing and ask how you are.", "It has got to be one of the friendliest places I've ever walked in to. Everyone has been so nice, so helpful. You don't feel you can't ask and no-one is pushing you to take on more than you can cope with" and "A warm, friendly place to work and you feel you make a difference to people's lives."

We asked staff about the registered manager and comments included, "[Manager] is a great manager and makes you feel very safe. He is the perfect balance between being supportive but also managing. I can talk to him about anything. He always checks we are okay and is very, very supportive. He is also very good at making sure things get done, without 'hounding' you." "[Manager] has a good balance. He knows when to be professional and when to be informal" and "We can get hold of him at any time, he is always available."

Weekly staff meetings took place on a Friday and staff had the opportunity to come together and discuss their week and any issues arising from it, plus the registered manager followed a team agenda for the meeting to provide any updates, for example policies and procedures. This also gave the opportunity to identify any areas of training and to make sure all staff were able to manage their caseload well. The provider attended meetings every three months and was involved with training. Staff said the provider was approachable and had a good knowledge of different medical conditions. Staff undertook induction training at head office and said the management team attended the training to introduce themselves. The registered manager encouraged staff to discuss any issues so they could be addressed. The provider had a process called 'situational behavioural impact', where staff provided constructive feedback about the impact the behaviour of a member of staff had on them. This would then be discussed openly so that the situation

could be addressed. Staff felt this was a good system and encouraged them to deal with any issues that arose in their work and promote good working relationships.

The registered manager had undertaken training including time management, medical workshops, a life coach course and the mandatory training. The registered manager said the provider was supportive and kept the managers up to date about the organisation and any changes taking place. The registered manager was part of the employee engagement group and said they were a mix of staff who came together to look at specific projects for the company, for example, looking at company values and seeing if these could be improved upon. The company had meetings every 6-8 weeks to discuss operational issues and also had presentations from guest speakers. The registered manager said these meetings provided an opportunity to meet with other managers and discuss together to find solutions to issues.

Surveys were carried out for families and stakeholders to provide feedback about the service and the information was collated and used to make any improvements needed. We viewed the feedback from the last survey and the comments were all positive and praised the service provision. The service was listed in the top 100 'Not for Profit' organisations rated by a national newspaper each year and this was based on surveys staff completed, giving their opinions about the service. The registered manager had an annual operational plan and this was a work in progress that was reviewed and updated every three months to reflect the progress being made.

The provider produced a variety of leaflets to give families information about the services Rainbow Trust provided, a biannual magazine and also a year book, all of which provided comprehensive information about the service, its' progress and achievements and also plans for the future.