

Rainbow Trust Children's Charity

# Rainbow Trust Childrens Charity 1

## 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?	Outstanding ☆
Is the service well-led?	Good ●

# Summary of findings

## Overall summary

This was an announced inspection which took place on the 19 June 2017.

This was the service's first inspection since registration in May 2016.

Rainbow Trust is a national organisation providing services to children and their families across the UK. This branch in Sunderland offers services to children and families where children have life threatening or terminal conditions. The service works with families in hospitals, in their own homes and in the community. They provide care and support directly to the child or young person affected by a life threatening or terminal condition, their siblings or their parents or carers. At the time of our inspection there were five children receiving the regulated activity of personal care from the service.

The service had a 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.

We found that children's care and support was delivered safely and in a manner of their or their representatives, choosing. Children and families were supported in a way that reflected their wishes and assisted them as distinct individuals.

Staff were well trained and encouraged to look for new ways to improve their work. Staff felt valued by the registered manager and this was reflected in the way they talked about the service, the registered manager and other staff.

Staff received regular in depth supervision from the registered manager as well as additional support from a trained therapist to help them deal with the issues their roles managed. Staff were trained and supported to be leaders in their field by a specialist provider.

Children who used the service were initially assessed and then matched up with suitably trained staff to support their needs, and if people requested changes to how support was delivered these were facilitated quickly. The service worked within the principles outlined in the Common Assessment Framework (CAF) to make plans and decisions involving the child or young person and in their best interests. (The CAF is a shared assessment and planning framework for use across all children's services and all local areas in England. It aims to help the early identification of children and young people's additional needs and promote co-ordinated service provision to meet them.) We found the service involved children and young people and worked within the UN Convention on Children's Rights.

The service had developed a family support network at the hospital wards where families spent much of their time. This offered families a chance to discuss their feelings and find mutual support.

We found every child or family member receiving support had an individualised care plan and risk assessments in place. Staff were aware of risks and worked alongside other agencies to minimise those risks.

There were high levels of contact between the staff, children and their families with staff seeking feedback and offering support as family's needs changed over time. Children and their families were able to raise any questions or concerns with the service and were confident these would be acted upon. No one we spoke with had any issues or complaints about the service they received.

Staff worked to keep children, their siblings or their families involved in activities that mattered to them wherever possible. Relatives thought that staff were caring and supportive and sought their advice and support when working with their children or their siblings.

The registered manager was seen as an experienced leader, by staff, external professionals and people's relatives. The registered manager was trusted and had created a strong sense of commitment to meeting families diverse needs, supporting their staff and developing a better service.

## 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

Relatives told us they felt safe leaving their children in the care of the service. Support plans and risks had been assessed by the service and staff deployed to reduce risks.

We found information was given to families on professional boundaries; it was made clear to families what they could and could not expect from staff employed by the service.

We saw staff and volunteers to the service were interviewed, provided references and underwent Disclosure and Barring checks before they started volunteering, after which they received regular supervision and support.

### Is the service effective?

Good ●

The service was effective.

Staff received non-managerial supervision with an independent person to support them when working with children with a terminal or life threatening condition.

Staff received specific training as required to meet each individual child's often complex needs before starting work with them.

We saw staff and volunteers to the service were interviewed, provided references and underwent Disclosure and Barring checks before they started volunteering, after which they received regular supervision and support.

### Is the service caring?

Good ●

The service was caring.

Relatives and professionals told us they found the staff to be very caring towards the children using the service and their families

We found staff were engaged in supporting families through major life events. We saw staff were engaged in children and

young peoples' end of life plans and supported families through bereavements and in the longer term as required.

Staff and other professionals told us how Rainbow Trust staff supported parents through complex meetings with health service personnel.

### **Is the service responsive?**

The service was exceptionally responsive.

Professionals told us the service responded very quickly when they submitted an initial referral. We saw the service worked closely alongside families according to their needs and had created bespoke agreed measurable outcomes in place.

Children, siblings and families were supported to maintain education and leisure activities that were important to them. Feedback and reviews systems identified progress and where the service could develop further to meet unmet needs.

The service had set up parents' groups in the hospital to support parents and prevent them from becoming isolated.

**Outstanding** 

### **Is the service well-led?**

The service was well led.

We saw Rainbow Trust had in place a set of values which led directly to how the service was delivered by staff and volunteers.

Parents told us the registered manager had been supportive and approachable. We found the registered manager encouraged staff to be open, transparent and reflect on their professional goals and learning.

We found the service had diverse community links including contacts with other professionals and links with alternative providers of activities for children.

We found the service was monitored and improvements were made as a result of feedback obtained from staff, children, parents and other professionals.

**Good** 

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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 is meeting the legal requirements and regulations associated with the Health and Social Care Act 2008, to look at the overall quality of the service, and to provide a rating for the service under the Care Act 2014.

This inspection took place on the 19 June 2017 and was announced. We gave the service 48 hours' notice as it is a domiciliary service and we needed to be sure staff would be available. The visit was undertaken by an adult social care inspector who visited the service's office on 19 June and made further telephone calls to families and external professionals over the following two weeks to gather further feedback.

Before the inspection we reviewed information we held about the service, including the notifications we had received from the provider. Notifications are changes, events or incidents the provider is legally obliged to send us within required timescales. We planned the inspection using this information.

During the inspection we spoke with six staff including the registered manager. We spoke with three relatives of children using the service as well as three external professional who had regular contact with the service.

Four care records were reviewed as was the staff training programme. We also reviewed two staff recruitment files, supervision records and staff meeting minutes. The registered manager's quality assurance process was reviewed with them.

## Is the service safe?

### Our findings

Relatives told us they felt the service their children received thought about their children's safety. One relative told us, "I have the same worker and they know when I need help as I am at the end of my tether. They keep in touch with me and text to say if they are nearby so we can meet up". Another relative told us they hadn't expected all the other advice and emotional support that came with the service, and both they and their child felt safe and satisfied by the service to date. An external professional told us they had shared information about a possible risk with the service and they had taken steps to reduce those risks as soon as they started working with the person. They told us "It was a real crisis for this family and the staff got involved quickly, offering what was needed and making sure the family came through a hard time".

We spoke with staff about their safeguarding training and their knowledge. We saw that staff had attended appropriate training for children's services and were aware of the process to report any concerns.

We saw the registered provider had in place risk management plans which covered five areas – environment, drinking, eating, outings and personal care. The risk management plans identified if there were any risks to the child and what to do to mitigate those risks. We also saw the risk management plans had a section to check if there were any on-going concerns regarding domestic violence and child protection issues. This meant the risks included those known to children's well-being as outlined in 'Working Together to Safeguard Children 2013'.

The registered manager told us they would review incident records after each event, looking for ways to reduce future likelihood of events occurring. The registered manager showed us the process they used to assess each child prior to them commencing any service, creating an initial support plan alongside the person, any relatives and external professionals. This identified any risks in the person's home environment or that may occur as a result of delivering any care, for example moving and handling whilst providing personal care.

Staff told us they were able and encouraged to raise any concerns or suggestions they had about the safety and wellbeing of children. They told us the registered manager was open to suggestions, and they knew how to contact external organisations to raise any concerns if necessary. Staff had attended relevant training to support this and we observed this process in action at their weekly team meeting.

The registered manager told us how they assessed for staffing requirements when initially assessing people and that most support was one to one. Where risks were identified, then additional staffing was available to meet people's needs, for example if supporting multiple siblings with differing care or support needs. One parent told us how the service had supported different members of their family at different times. They told us that each child had different needs and that the service had fully assessed how best to support each child before starting work with them.

We looked at personnel files to make sure staff had been appropriately recruited. We saw relevant references and a result from the Disclosure and Barring Service (DBS). A DBS checks if people have any

criminal convictions or are barred from working with vulnerable people. We saw that these DBS checks had been obtained before applicants were offered their job. Application forms included full employment histories and we saw that previous employer and character references had been checked. Applicants had signed their application forms to confirm they did not have any previous convictions which would make them unsuitable to work with vulnerable people. We saw the same process was in place for any volunteers that supported people.

We also found the registered provider complied with the statutory guidance 'Short Breaks Statutory guidance on how to safeguard and promote the welfare of disabled children using short breaks' published by the Department for Children, Schools and Families in 2010. This meant the service had in place rigorous recruitment procedures to protect children.

Staff told us and training records confirmed they were trained and processes were in place to support children with medicines if required. At the time of inspection no one was being supported with regular medicines. The registered manager had an audit tool to use if medicines were to be administered by staff.

During our inspection we found the provider reduced the risk of cross infection. We saw hand sanitisers were provided to staff. Staff confirmed that they had personal protective equipment at all times.

## Is the service effective?

### Our findings

Relatives and external professionals all told us the service offered was effective at providing suitable staff to meet people's needs. One parent told us, "I really didn't know what to expect. Our life had been thrown into chaos by [name's] diagnosis and Rainbow Trust staff got involved very quickly. First on the ward, then with [sibling] then with [name] so we could take a break from the hospital". They told us that over this time the worker had been skilled and able to meet the changing needs of the family and they appreciated their expertise and knowledge of the hospital system. Another parent told us, "Rainbow Trust have been my navigator through the maze of hospitals, doctors and nurses. They don't talk in jargon and have helped me keep my head above water".

The staff we spoke with told us they had undertaken all necessary training to help them meet the needs of the people they supported. This included obtaining extensive training in medicines management, health and safety and awareness in safe working practices such as lone working. Staff told us the training they received was relevant to their roles in both a hospital and community setting and when supporting families in their own homes. We saw from the registered manager's records there was a procedure in place to ensure that staff were prompted to attend regular refresher training and updates. Staff had also been provided with one off specialist training for specific people's needs, for example in stoma care.

Staff told us due to the nature of the issues they deal with including trauma and bereavement they attended non managerial supervision sessions with an independent registered counsellor. These sessions provide them with confidential support and the opportunity to reflect on their feelings when working with children with life threatening and terminal conditions. The registered manager explained staff needed this support when dealing with families who had been bereaved alongside their normal managerial supervision. Staff we spoke with about this told us this was essential in supporting their wellbeing and ensuring best practice by supporting them to be professional when dealing with very emotive issues..

Records also showed us that staff had supervision meetings with their manager in line with the registered provider's policy. We found staff were getting regular supervision support from their line manager and that this was detailed and monthly. Staff also received an annual appraisal of their work, setting goals for progression as well as identifying their achievements. We saw on a notice board in the meeting room a list of current objectives. The staff explained to us these were their targets following their appraisal which they could share with each other so they could support each other to meet them. We reviewed these with some staff and saw that objectives such as a parent's support group had been developed and was now expanding.

Staff told us they were encouraged to raise any suggestions or issues by the registered manager. We listened to the comments made in the team meeting, we observed where staff were given the opportunity in the meeting to communicate with each other and share what went well and what could have been improved. This meeting was attended by a new senior manager from the provider.

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. CQC monitors the operation of the Mental Capacity Act 2005.

Records showed us that children's representatives' consent had been sought by staff as a part of the initial assessment process where this applied and that the registered manager was aware of the implications of the MCA for children aged 16-17.

We saw from written records the service regularly liaised with other health and social care professionals in children's care. This included social workers, nurses, specialists and GP's. Staff we spoke with were able to tell us about the implications of children's diagnosis and how best to support them.

## Is the service caring?

### Our findings

Parents we spoke with told us the service offered was caring towards their children and towards the family as a whole unit. One parent told us, "[Name of staff] has been unbelievable. They have become part of the family now and got us all through some tough times. When [name of sibling] needed someone to talk to and get them out of the house, Rainbow Trust were there". All the families we spoke with told us they felt the staff and service provided was compassionate and caring towards them. One person told us how the service had helped arrange a respite break for the family. One professional we spoke with told us, "All the staff from Rainbow Trust I have either met or spoken to have all been extremely caring." Another external professional told us, "I have great faith in Rainbow Trust; I would be more than happy for them to work with any future clients".

The registered manager and staff understood children's individual needs and told us how they supported them to retain and regain control over their life. Staff we spoke with knew the details of families past histories and their individual personalities and had been able to get to know them well over time.

We saw the service had policies and procedures in place that referred to upholding people's privacy and dignity. In addition the service had policies in place relating to equality, this helped to ensure people were not discriminated against. Staff had read these policies as part of induction or when they were brought into place by the provider. We saw in care plan records and meeting notes where people's individual choices had been supported and advocated for by the service.

The service had in place an information pack for families when they started to use the service. The pack included leaflets on the work of Rainbow Trust, a card with the Trust's 24 hour helpline number, compliments, comments and complaints leaflet, a contact card with the registered manager's details and information about other suitable local services.

The registered manager told us that staff attended meetings to support families and help them get the best information from clinicians when they were hearing difficult news about their children's health conditions. Staff we spoke with about this told us that they had to help families take in a lot of information and then ensure this was understood by taking notes for them. External professionals told us Rainbow Trust staff acted as peoples 'natural advocates' by supporting families understanding and involvement at these complex meetings with healthcare professionals.

We saw the service had in place a confidentiality policy. Clear information was given to families and professionals about confidentiality boundaries in the information pack and what families could expect from their workers. We spoke to professionals about the working relationship between Rainbow Trust staff and families. They told us staff developed effective trusting relationships with family members. Family members told us they valued and trusted the staff.

The registered manager told us how staff were supported to maintain the values of the provider organisation, of empowerment and respect to people. Staff we spoke with reflected these values back to us

when we spoke with them, and in the way in which notes and records were updated. We saw that discussion about these values took place at team meetings and in supervisions and appraisal.

The registered manager and staff told us they did not have a service specific end of life plan for children and young people but they were included in the NHS end of life plan. Staff had received specialist training in supporting children and families with end of life care and provided support for families after the death of a child.

## Is the service responsive?

### Our findings

Parents told us the service was very flexible and innovative in how it supported their children and the wider family. One parent told us, "I didn't know what to expect, but Rainbow Trust have been outstanding. At first it was about supporting us at the hospital, giving us a break or just sitting and talking to us. Then it was about support for [sibling] so they could do the fun stuff that stopped when we got [name's] diagnosis". An external professional we spoke with told us that the service was always responsive to each child they referred. They told us they were clear about what they couldn't do for family's right at the beginning. They said, "If it's about parent support, or about support for the child, siblings or even grandparents they flex to meet their emotional needs. Or about finding other services for children during the school holidays. They can be very inventive and adjust as the family's needs change as treatment progresses." Everyone we spoke with told us they felt the service offered was family and person centred and focused on doing their best for each individual in the family.

Staff told us the registered manager visited families to discuss their needs following an initial referral. This collected key information relating to the child's illness, their siblings and wider family, hospital contacts and other professionals, and if a Common Assessment Framework (CAF) was also in place. (The CAF is a shared assessment and planning framework for use across all children's services and all local areas in England. It aims to help the early identification of children and young people's additional needs and promotes co-ordinated service provision to meet them). The registered manager told us when they met families for the first time they were often distressed at the recent diagnoses. As a result of this, they gave parents key information and then arranged to contact them again. We saw there were initial assessment notes on computer records, compiled by the registered manager and other staff.

We looked at the electronic records of four children and saw each child had a personal support plan which described their individual needs in detail and in plain English. Each plan had personalised measurable outcomes for example to develop quality time, manage stress, or create a quality of life. The guidance outlined in 'Short Breaks Statutory Guidance on how to safeguard and promote the welfare of disabled children using short breaks' published by the Department for Children, Schools and Families in 2010 states "This should lead to agreed outcomes about services to be provided to the family and an agreed process for review which is an integral part of the assessment and children in need plan." We found children and families had agreed with the service what support they needed and their input was sought throughout the process.

Rainbow Trust also complied with the NICE quality standard QS55, which stated, 'Children and young people with cancer, and their families and carers, have their psychological and social needs assessed at different stages during and after their treatment. These assessments should result in a care plan that can be used to get extra help and support if they need it'. We saw the service was assessing need and providing the extra help and support as their illness or support needs changed over time. Records showed and staff confirmed the service was always responsive and flexible to the need of the child or their family at that contact.

The service used an outcome focussed tool or 'flower' to set goals against six broad areas titled, managing stress, quality of life, stability and confidence, economic wellbeing, grief and loss and quality time. The initial assessment of a child and their family's needs would then set highly personalised goals under these areas. The outcome goals would be reviewed, re-evaluated and then either met or adapted as the child's and families circumstances changed. Staff we spoke with told us they used the flower guidance as a tool to start a discussion with families, and then to review how effective the service's support had been. This involved discussion and a chance for families to be at the heart of the goal setting. Parents we spoke with told us this discussion had been helpful in assisting them to gauge how well they were doing and helping them to see any progress or improvement in their circumstances. One parent we spoke with told us, "I didn't even realise how helpful this process was until we had been getting support for six months. It was then as we went through the goals with [staff] that it dawned on me what we had achieved together and how subtle the support plan had been." Care records we looked at showed this tool was used in a highly person centred way to support individual children and their families with very 'soft' emotional goals as well as very practical issues such as finances.

We found the service and their records had reflected the domains (For example, health and stability) of the CAF guidance published by the Department for Children, Schools and Families to assess the needs of children and their families, and had broken down the guidance into areas relevant to their service and the needs of the families they supported.

Computerised records showed how staff recorded their contact with families linking this to their work with the outcome areas or goals. This resulted in an electronic analysis being available to demonstrate the outcomes staff had addressed and they were able to measure the impact they had on families. We also saw staff recorded a relationship star, this demonstrated who was important in a child's life. This meant staff were aware of who was in a child's network and be aware of key people and professionals in a child's life. Staff we spoke with were aware of the need to be conversant with this list of key people to help develop the relationship with the child.

The registered manager told us family needs informed how long the service continued to work with families. We found the service responded quickly to the changing needs of families as children's illnesses either progressed or children moved back home. The registered manager told us reviews were carried out at least six monthly intervals or as required when needs changed. She explained in addition to the electronic analysis, they visited the families to review the care plan together and refocused their work if necessary. One parent told us, "The biggest fear I have is losing the services of Rainbow Trust, they have been indispensable these last years and have turned so many fears into positives."

The service had in place a system for developing new work in response to identified need and creating additional bespoke support to families. For example, we saw the service ran a sibling group, a service form was in place to describe the group, its intended outcomes and how it would be run and evaluated. The group was under pinned by the work of a well-known researcher on siblings of disabled children. One parent we spoke with told us the support to their child's sibling had been essential in supporting their family's emotional wellbeing. They told us they had experienced anxiety about neglecting their child's siblings whilst being so hospital based. They told us the support offered had helped their other child to continue a social life of their own and keep up at school.

The provider employed a fund raiser who rose funding to help deliver local social and recreational activities. This fundraising service had been centralised by the provider, but in discussion with the registered manager they told us how they met with the fundraisers regularly and shared local expertise and knowledge. A parent we spoke with told us how their wider family had become involved through fundraising. They told us this

"Helped us say thanks to Rainbow Trust for what they have done, as well as raise the profile of their essential work."

Since our last inspection the service had set up a successful parents support meeting, held at alternating hospital wards. In discussion with the registered manager and staff they told us how this afforded parents a unique chance to meet and share experiences as well as take a break from their caring roles. Plans were being developed to further expand this support to families based on feedback from people attending.

The registered provider had in place a robust complaints policy; in the information pack families were provided with a compliments, comments and complaints leaflet together with who to contact details. The form provided a simple flow chart telling people what to do if they had 'something to say.' We found no complaints had been made about the service. Family members and professionals we spoke to confirmed they had not made any complaints, but were aware of how to if the need arose.

## Is the service well-led?

### Our findings

Parents we spoke with told us they felt the service was well led locally by the registered manager and the staff team they had contact with. One parent told us, "When I have ever had to call the office they have been quick to come back to me and [staff] gets answers to any questions very quickly." Professionals we spoke with also told us they found the service to be, "Well organised and quick to respond to anything" and "[Name of registered manager] is very committed to their work. The service takes on anything we ask and is very proactive".

Staff told us they found the registered manager to be, "Good at leading the team", "There when any of the team need support or advice" and "Professional yet personable".

The provider organisation had a set of clear goals and values, we saw these displayed in the service's offices and staff were able to tell us how these were put into practice. For example, by the support the organisation offered to its staff through specialist training and one to one counselling and support. Staff we spoke with were all very proud of the organisation they worked for and felt the service offered was effective and supportive of families at critical times in their lives.

The provider had specified strands to its business strategy, high quality family support, to speak up for families with a seriously ill child, to extend partnership working, to develop our volunteer teams and to be our best. These strategies were implemented locally through the development of services based on local needs, such as the hospital parent support meetings as well as the continued training and development of volunteers.

The provider published a twice yearly magazine for families who used the service and the public at large. In the last magazine the provider published satisfaction against the five strands of the flower, based on the outcome tool used by local services. For example, in the category 'quality of life' 95% of families reported a better quality of life after using the service. The registered manager told us how they used local feedback from reviews of people's care and support to help develop the service locally as well as feedback to staff on the positives. Staff we spoke with told us that meetings focused on the positive outcomes of their work as well as the things still to do.

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. Records we requested were produced promptly and we were able to access the care records we required. The registered manager was able to highlight their priorities for the future of the service and open to working with us in a co-operative and transparent way.

The registered manager and staff knew the children and families they supported well and were able to explain people's individual likes and preferences in relation to the way they were provided with care and support.

Staff told us staff meetings took place regularly and minutes of meetings were available for staff who were unable to attend. We observed a meeting as part of the inspection and we saw this was thorough and afforded all the staff and opportunity to contribute. Records of previous meetings showed that actions raised had been addressed in a timely fashion and that new referrals were discussed.

Quality visits were carried out by a representative from head office to the local service. They checked the office, spoke to people and the staff and checked a sample of records regarding the standards in the service. They also audited and monitored the results of the audits carried out by the registered manager to ensure they had acted upon the results of their audits.

External professionals we spoke with told us the service was very good at supporting families in a hospital environment, as well as the community. One professional told us, "Rainbow Trust can guide families through the complex hospital world by relating it to the real world. Medics and nurses can forget about the non-medical needs of children and families and Rainbow Trust focus on that side of things brilliantly". They also told us that Rainbow Trust staff were respected and trusted by medical staff. The registered manager told us how they developed this trust. For example, by arranging training for staff on working in isolation rooms in hospital. By showing that staff could be trusted helped develop that trust between partner agencies.