

Rainbow Trust Children's Charity

Rainbow Trust Children's 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 

Overall summary

This inspection took place on 23 February 2015 and was announced. The registered provider was given 48 hours' notice because the location provides personal care and support to children and their families; we needed to be sure that someone would be in.

We last inspected this service in January 2014. At the time of our last inspection the service was meeting our regulatory standards.

The Rainbow Trust is a national organisation providing services to children and their families across the UK. Rainbow Trust 1 in County Durham offers services to children and families where children have life threatening

Summary of findings

or terminal conditions. The services works with families in hospitals, in their own homes and in the community. They provide care and support direct to the child or young person affected by a life threatening or terminal conditions, their siblings or their adult parents or carers.

The service is registered with the CQC to provide personal care to children and young people in their homes. At the time of our inspection there were 81 children receiving a service, 23 of whom required personal care. Parent's comments on the personal care service they have received in their own home and in the community have been included in this report.

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 every child and young person had a personalised care plan and risk assessment in place. Staff were aware of risks and worked on a multi-agency basis to minimise those risks.

We found regular quality monitoring of the service had been undertaken. We saw each section of the service e.g.

a siblings group or a parent support group had a service form which described the nature of the service and the service outcomes. Children and their parents were asked to contribute to the evaluation of the service.

We found the registered manager had mapped where staff lived and had considered the distances to maximise the hours staff could spend with families.

We found the registered provider worked within the principles outlined in the Common Assessment Framework to make plans and decisions involving the child or young person and in their best interests.

We found the registered provider involved children and young people and worked within the UN Convention on Children's Rights.

The registered provider had put in place a 'Tribute Day' and invited families along who had lost a child through illness or disability. People had been asked for their feedback to improve the day.

Professionals who referred to the service told us the service was very responsive to families and provided a flexible service to meet individual family's needs.

We also found Rainbow Trust 1 adhered to the NICE quality standard QS55 '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'.

Summary of findings

The five questions we ask about services and what we found

We always ask the following five questions of services.

Is the service safe?

The service was safe.

People told us they felt safe leaving their children in the care of staff from the Rainbow Trust 1 service in County Durham.

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 Rainbow Trust.

Staff received specific training in peg feeding to meet each individual child's needs every time a child was identified as requiring this method of treatment.

Good



Is the service effective?

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.

We found the service provided families with consistent support in that they had a main worker and a back-up worker to support them. The latter supported the family when their main worker was not available.

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

Good



Is the service caring?

The service was caring.

People and other professionals told us they found the staff to be very caring in exceptional circumstances.

We found staff were engaged in supporting families through life events. We saw staff were engaged in children and young peoples' end of life plans and supported families through bereavements including Tribute Days.

Staff and other professionals told us how the Rainbow Trust staff supported parents through difficult meetings with health service personnel when they were being told about their children's life threatening conditions.

Good



Is the service responsive?

The service was responsive.

Professionals described to us a prompt response from the service when they submitted a referral. We saw the service worked with families according to their needs and had agreed measurable outcomes in place.

Outstanding



Summary of findings

We found the registered provider had successfully sought funding to run children's groups at the Great North Children's Hospital when a need was identified for support between clinical sessions.

We found the service following consultation with health staff, had set up parents' groups in the hospital to support parents and prevent them from becoming isolated.

Is the service well-led?

The service was well led.

We saw the registered provider had in place a set of values which permeated the services. We saw evidence of the values in action.

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

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

We found the services provided were regularly monitored and improvements were made as a result of feedback obtained from children, parents and other professionals.

Good



Rainbow Trust Children's Charity 1

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 23 February. The registered provider was given 48 hours' notice because the location provides personal care and support to children and their families; we needed to be sure that someone would be in.

The inspection was carried out by one adult social care inspector.

Before the inspection we gathered and reviewed information about the registered provider. We spoke with eight staff including the head of care, the registered manager and the project staff. We reviewed five children's electronic records and spoke to four parents. We sought information from other six professionals including social workers, children's community nurses, staff working for another children's charity and hospital staff. We looked at four staff records, and quality monitoring audits.

Before the inspection we did not ask the registered provider to complete a Provider Information Return (PIR). This is a form that asks the registered provider to give some key information about the service, what the service does well and improvements they plan to make.

Is the service safe?

Our findings

People told us they felt safe leaving their children with staff employed by Rainbow Trust 1. One person told us they always bring their child back in a clean state and the staff tell parents about the outing with their child. Professionals told us they did not have any safety concerns when referring children and their families to the service.

In the information packs given to families we saw there was a page on 'Professional Boundaries' which showed how to keep staff and family members safe. The sheet told families Rainbow Trust staff were not allowed to invite families to their home, will not share personal information, cannot accept gifts or accept offers of labour from family members. We also found clear expectations on families, 'We recognise that you may be having a difficult time due to your child's illness, however we expect families to treat our staff with respect at all times'. This meant people were clear about the professional boundaries expected by the registered provider.

We saw the registered provider was working with other professionals to keep children safe for example they were supporting a family where professionals had concerns. We found the service responded promptly to areas of concern and sufficient information was gathered to ensure workers were able to safely support such children and their families. At the team meeting we attended the registered manager shared information about a new family referred to the service and gave the team background information so they were aware of the family circumstances to keep them safe. This meant the team were able to safely offer support to the family if needed and knew of their circumstances if the family needed support from the wider team.

We saw the registered provider had in place a safeguarding policy and staff received training in safeguarding during their induction and had regular updated safeguarding training. Staff told us about the policy the different types of abuse and what they were required to do if they had concerns about a child or young person. The staff told us they would report their concerns to their registered manager and if they were not available to the head of care. This meant staff were aware of the registered provider's requirements on safeguarding and the actions they needed to take if they had concerns about a child.

Most of the parents we spoke to told us staff did not assist with their children's medicines. However staff told us before working with a child where medical intervention was required they received training specific to each child to reduce risk, and could not have a child on their caseload for whom they had not been trained. For example, staff told us before working with a child who needed to be fed through a tube directly into their stomach using a percutaneous endoscopic gastrostomy (PEG) they had undertaken training pertinent to the individual child. One professional confirmed this approach was undertaken and said staff were "child specific competent." Parents could be reassured that the risks to children where specific procedures needed to be carried out were addressed by the service.

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 and outlined in 'Working Together to Safeguard Children 2013'.

We saw the registered provider was developing work to include more of the Children's Voice in line with Article 12 of the UN Convention on Children's Rights. We spoke with staff who ran the children's groups. They told us they talked with the children about what they enjoyed and observed children's responses to activities to learn about what they liked the most. They described a recent visit to a football ground and to a children's show at a local theatre and told us how children responded to the visits and what they had said. This meant staff were listening to children and parents could be reassured children were doing things they liked and being kept safe.

We looked at the reporting of accidents and incidents and found all staff had in their cars reporting books. Staff told us if there were any accidents or incidents to report they would immediately tell their manager. This meant staff were able to immediately record any incident or accident. The registered manager confirmed staff contacted her to discuss and incident or accident.

During our visit we found the registered provider reduced the risk of cross infection. We saw hand sanitisers were

Is the service safe?

provided to staff in their team meeting. Staff confirmed that they had personal protective equipment and if a child vomited in their car the car was valeted to prevent cross infection.

We saw the registered provider had in place a whistle blowing procedure. We checked with staff about whistleblowing procedures. They told us who they would speak to their manager if they had any concerns and would also speak to the registered manager's manager.

We found there were robust recruitment procedures in place which included a DBS (Disclosure and Barring Service) check and obtaining two written references from previous employers. We saw all staff completed an application form and had given details about their past experience. This meant the registered provider could check to ensure new staff were of suitable character for the role and had the right experience. Staff confirmed they were not allowed to work with families until all checks were clear. We 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.

We found the service was able to safely recruit and support volunteers. During our inspection a new volunteer was introduced to the staff group. We saw the volunteer had undergone an interview with the service, a DBS check and provided two references. We saw volunteers also received an induction and support through supervision.

We saw each member of staff had their own vehicle made available to them by the registered provider. The registered provider had in place monthly car checks and the registered manager in the team meeting followed up with staff if there were any actions still to be carried out to keep their vehicle safe. We asked the registered manager about transporting children in vehicles. They told us each staff member transported children and young people in age appropriate car seats which were fitted by an appropriate specialist. We found parents could be reassured the registered provider had taken the necessary action to keep children safe in their vehicles.

Is the service effective?

Our findings

One professional told us, “The first family I referred to the Rainbow Trust stopped me in the hospital car park one day, months after they left the [hospital], to thank me for sending a referral. They stated they did not know how they would have coped without the Rainbow Trust, and were passionate about promoting the charity to other families.”

We saw the registered provider worked with other professionals, families and children using children’s planning mechanisms, for example the Common Assessment Framework to make plans and decisions involving the child or young person and in their best interests.

Staff told us due to the challenging nature of the issues they deal with including bereavement they must attend non managerial supervision sessions with an independent manager/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 have been bereaved outside of their normal managerial supervision and it had helped staff explore safeguarding issues to take to their line management where necessary. This meant the registered provider had considered the impact of the work on staff and put in place additional support mechanisms which gave the required support to staff, and allowed them to support families living in difficult circumstances.

We also saw staff had supervision meetings with their manager in line with the registered provider’s policy. Supervision meetings occur between a staff member and their manager to discuss their progress, any concerns they may have and what their training needs were. The registered provider’s policy placed an emphasis on supervision and gave guidance on interruptions to the meeting and what to do if the supervision meeting was cancelled. We found staff were getting regular supervision support from their line manager in line with the registered provider’s policy.

Staff told us they were encouraged to raise concerns. We listened to the comments made in the team meeting 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. We learned the Basil Brush pantomime went well as did the visit to a local football club. The staff said the children wanted to go on the actual pitch but were not allowed to do that. The staff reflected on the impact of their work in the meeting and had observed children and young people coming together for support during activities. We found staff were aware of the outcomes they were working to and had agreed with families.

We saw each family had a main support worker and a secondary worker. When the first staff member was not available to support the family e.g. when they were on annual leave the secondary worker stepped in to support the family if required. At the team meeting we observed discussions between staff about what families’ needs. Staff used their diaries and communicated with each other to support families and ensured the required transport for children’s hospital appointments was covered. This meant the team worked together to ensure they effectively met the needs of families.

We found the staff met on Mondays in the office to carry out administrative tasks. The registered manager explained this had been for staff to access computer systems to update notes, however staff had now been given electronic tablets and their notes were updated as they carried out their work. We found the weekly staff meeting continued to provide support to staff to avoid them becoming isolated.

Staff told us they all had job descriptions, were aware of their roles, and had shadowed other more experienced workers when they began their employment. We saw the registered provider had in place comprehensive induction checks lists including introduction to the Rainbow Trust, use of vehicles, and delivery of front line care. These check lists were signed with dates to say staff members had completed their induction. We found parents could be reassured staff were given an appropriate induction to support them and their children.

Staff told us they had completed their essential service training. This included manual handling, safeguarding and food hygiene and first aid. Staff told us the first aid course had been adapted to meet their specialist needs. We looked at the staff records and saw staff had completed their mandatory training as well as other training appropriate to their role. This included palliative care and

Is the service effective?

grief and bereavement training. We found staff had received the appropriate training to work with families in need of support by having children with life threatening conditions.

In the information pack provided to professionals we saw there was a sheet on 'Invasive Procedures' which said, 'Rainbow Trust Family Support Workers undertake specific invasive procedures with some of the children in their care.' The information sheet goes on to describe that staff undertaking these procedures had received training from the children's nursing teams and each request for this type of intervention was considered on an individual basis and was regularly reviewed by the nurse in charge of the child's care. Staff confirmed to us they had received training under these circumstances for example the use of oxygen with certain children and had received on-going support from nursing staff. We spoke to nurses who had made referrals to the service and they told us they had trained staff to carry out such tasks.

We saw on a notice board in the meeting room a list of targets. 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. The registered manager explained each year staff were required to set themselves three to five business targets, three to five people targets and two personal targets. The latter two targets remain confidential, other goals were to do with the service and by sharing the goals staff were able to share information and support each other and progress the service. We saw the goals included diversifying activities on offer and developing community contacts. We looked in staff files and found the targets had been agreed in appraisal meetings and were monitored. This meant staff were encouraged to support the ongoing work with families and continue to explore further options to meet family needs.

At the time of our inspection the service was not working with children and young people to whom the Mental Capacity Act 2005 would apply. However the registered manager demonstrated to us an awareness of the act should a young person be referred to the service and where their mental capacity would need to be assessed.

Is the service caring?

Our findings

One parent told us they found the service to be very caring, they told us, ‘It’s as if (staff member) were caring for their own children.’ Another parent told us they met their Rainbow Trust worker in the intensive care unit at the hospital and found them, “Kind and helpful” at a time when their “head had been all over the place.” One professional said, “The staff from the Rainbow Trust I have either met or spoken to have all been extremely caring.” Another professional said, “I do not signpost any family to a service I would not be happy to use myself, and I am very comfortable referring to the Rainbow Trust.” We were told by other professionals the service was ‘Very supportive to children and families’. This meant people were confident in the staff to care for them and their children.

During our inspection we attended a staff meeting where staff told us about significant family events arranged to include children with life threatening or terminal illnesses. They told us they supported children and families before and during these events. In the meeting staff shared information about a family member’s wishes about the use of language to avoid them becoming upset if any member of the team spoke to them again. The team reflected on their use of language to reduce the impact of any unintended distress caused on families.

The registered manager and staff told us they do not have an end of life plan for children and young people but with the registered manager’s agreement they were included in the health service end of life plan which may involve them working flexibly and having contact with families at weekends. This meant families continued to experience the continuity of support as their needs potentially increased. We found the service was tailored to meet the individual needs of families.

The service had in place an information pack for families. The pack included an information for families leaflet on the work of the trust, a card with the Rainbow Trust 24 hour helpline number, a compliments, comments and complaints leaflet, a contact card with the registered manager’s details and information about local provision, for example hydrotherapy sessions and the siblings group, ‘Time for Me’. These meant families were provided with the information they needed to engage with the service.

The registered manager told us they had begun to have discussions about working with families whose children were in a neo-natal unit and how some of the language they used in their information pack was not appropriate. The registered manager told us they were reviewing the information to provide parents with more appropriate language. Professionals working with the service confirmed this was the case. We found the service was sensitive to the needs of families.

We saw the registered provider had in place a confidentiality policy. Clear information was given to families and professionals about the registered provider’s 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 good and trusted relationships with family members. Family members told us they trusted the staff.

We found the registered provider supported bereaved families through a ‘Tribute Day’. A Tribute Day brings together families who had been bereaved through the loss of a child. The provider sought the family’s views about the day. One person said, “I can see the love and dedication in your eyes, this isn’t just a job to you all, you genuinely care. This has been a lovely day, it’s been the staff, you three have made this day worthwhile.” Other people wanted to thank the service, one person said, “Thank you, thank you for everything you have done.” This meant the work carried out by the service had impacted on families who were appreciative of the support they received.

Where children were present for assessment and understood what was happening they were included and their voices listened to. This meant the registered provider was adhering to Article 12 of the UN Convention on Children’s Rights. Parents told us they felt listened to by the staff. This meant the registered provider was fulfilling their expressed value of listening to people.

We discussed with the registered manager meeting the needs of children and families from different ethnic groups. We saw this information was gathered at the time of referral and people’s religious preferences were noted during the assessment. The registered manager told us there was no one currently involved in the service from these groups. However they also advised us that differences between ethnic and religious groups were more pronounced during end of life care and following death.

Is the service caring?

They told us work had been carried out in another region and staff had access to this information should the need arise. This meant staff were able to be informed about different cultural requirements.

The staff told us they have attended meetings to support families and help them get the best information from clinicians when they are hearing difficult news about their children's health conditions. Although none of the families we spoke with told us staff had experience this support,

one professional told us they had known staff had taken notes for parents during meetings and go through them with the family afterwards. The staff told us at times they needed to fulfil an advocacy role for families to enable them to get the best out of meetings. One professional told us they had a "Natural advocacy role supporting parents who find themselves in very challenging circumstances." We found staff were able to support families using advocacy.



Is the service responsive?

Our findings

Professionals told us the service was flexible and the staff responded to the individual needs of families. One parent told us their worker comes on the days they were needed and they will contact them if they get stuck in traffic to let them know they are on their way. One professional told us, "It is a lovely service" and one which fills a gap in provision." We found professionals valued the Rainbow Trust 1 due to the type of support it could offer to families.

Staff told us the registered manager following a referral, visited families to discuss their needs.

We saw completed referral forms with pertinent information relating to the child's illness, their siblings, hospital contacts and other professionals, and if a Common Assessment Framework (CAF) was in place. One professional said, "I have found my contact with the charity is always acted upon very quickly, the referral is easy to make and I know it will be reviewed and parents contacted quickly." Other professionals told us they had experienced a very prompt response when they had contacted the service to ask them to do something with a family. This meant families in need experienced support at the times they needed it.

The registered manager told us when they meet families for the first time they were often distressed at recent diagnoses. As a result of this they gave parents service information, made suggestions about potential help, and then arranged to contact them later. We saw there were assessment visiting notes on file, complied by the registered manager; one family who was unable to make a decision was left with the information to help then decide. The family then took up the service. One professional told us, "They are great at drilling down with families what they need." Families told us the service was flexible for them and they could choose what they needed.

We looked at the recently implemented electronic records of five children and saw each child had a personal support plan which described their needs. Each plan had 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 families had agreed with the service what support they needed.

We also found Rainbow Trust 1 adhered to 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. One professional told us the service in their experience was serving a client base which was 'poorly understood'.

We found the service was outcome focussed and outcomes were broken down into targets, for example, quality time included providing opportunities for planning and time together as a family. The economic well-being target included providing transport to regional specialist hospitals for families. We saw the family outcomes had been informed by the initial family assessments. We found the registered provider had reflected the domains 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.

We saw when staff recorded their contact with families they linked their work with the outcome areas. 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. The registered manager told us the system was relatively new and had been designed specifically to demonstrate the service outcomes.

The registered manager told us family needs informed how long the service worked with families. We found the service responded to the changing needs of families as children's illnesses either get progressively worse or children moved home from hospital. The registered manager told us reviews were carried out at six monthly intervals. She explained in addition to the electronic analysis, they visited the families to review the care plan and refocused their work if necessary.



Is the service responsive?

We saw the service had in place a system for developing new work and diversifying 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. The registered manager and the staff explained to us, parents of children may experience feelings of guilt dealing with a sick child and trying to care for their siblings. We saw the service gave parents information about the group. Staff were aware of why the group was in place. We saw parents and children were asked to evaluate the sibling group to ensure they continued to meet their needs.

We found the service employed a fund raiser who raised funding to deliver the work. We found the service had raised funding to run children's groups at the Great North Children's Hospital between clinic times. Staff told us there was a gap when clinicians on Fridays between morning and afternoon were not available. We found Rainbow Trust 1 had responded by providing children's activities. One parent told us it was 'great' because children had something to do. This meant the service had identified additional needs, and had sought ways to meet the needs.

We saw staff were concerned about parents being isolated in caring for sick children in individual rooms. The registered provider undertook a consultation exercise with

NHS staff and parents to find out if they would like a parents group setting up. NHS staff requested if any groups were to be set up they needed to be set up on each ward to prevent any cross contamination taking place. We saw the registered provider had responded to the request and parents groups had been set up per ward. Initial feedback from the parents showed they valued coming together with other parents. We found Rainbow Trust 1 had identified parental needs and met them.

We saw the registered provider had in place a complaints policy; in the information pack families were provided with a compliments, comments and complaints leaflet together with who to contact addresses. 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.

Staff told us about the need to reduce family costs. We saw the Chief Executive had sent a letter to families explaining they would have to charge if there were additional costs. However staff told us they worked with activity providers to secure free activities. This meant families were supported to care for their children at no extra cost. One person told us the staff gave them a break by taking their child to the 'Giant's Den' or to 'Water world'. We found staff provided additional support to families by maximising free opportunities to support children.

Is the service well-led?

Our findings

We saw the registered provider had in place a mission which was the, 'Rainbow Trust provides emotional and practical support for families who have a child with a life threatening or terminal illness'.

We saw the service had their values displayed on the office wall staff learned about the values during their induction to the organisation. We found the values permeated the information given to families and professionals in their respective information packs. We found evidence of the values in action for example people told us they were included in the service and chose what they needed to help support their family.

We also found staff were valued and supported by the registered provider. This was demonstrated through the use of non-managerial supervision. The registered provider also took their responsibilities as an employer seriously and gave families information about protecting staff from second hand smoke. Families were asked, 'To do everything possible to have a smoke free home when staff visit'. The Head of Care also told us the registered provider had arranged for personal safety training for staff in line with their lone working policy. We saw evidence in staff files of personal safety training from the Suzy Lampugh Trust had been provided. This meant staff had been given advice on how to keep themselves safe in the community and families were expected to engage in keeping staff safe.

To provide further support to staff the manager required each member of staff to send her a text to say they had arrived home safely following visits to families. Staff confirmed they sent their manager a text to tell her they were safe.

The provider had in place an annual conference to which all staff were invited. We saw at the annual conference staff were given information about the Rainbow Trust's performance and their future plans. This meant the provider enabled staff to be clear about the direction of their work.

In line with the registered provider's service processes people told us they had met the registered manager when they came to introduce the service. One person said the registered manager was organised and put things in place which were beneficial to all the family. Another person told us the manager had been kind and helped them work out

what they needed. We found the registered manager had given people a pack of information for their reference with information on how to raise concerns. This meant the service had in place systems to ensure openness and transparency in their relationship with families.

We found the registered provider took responsibility for good practice in supporting families in need and had in place a 24 hour help line. The registered manager explained to us that managers were on a duty cover rota and had access to the nationwide data to help them support families.

Staff were submitted time sheets and broke down time spent doing various tasks. The registered manager told us they monitored the time sheets to ensure staff were maintaining 20-25 hours per week contact time with families. We saw the manager had mapped the homes of staff with family homes to measure travel time and reduce the time taken by staff to drive to families. This meant the manager was measuring the use of staff time to maximise time available to families.

We found the service had in place diverse community links. We saw records of contacts with physiotherapist, occupational therapists, schools and community provision for children. We saw referrals to the service came from a variety of sources including teams working with children with disabilities, paediatric nursing services and from the charity CLIC Sargent children's cancer team. The registered manager provider told us they have update meetings with the latter team to discuss progress and referral rates to the Rainbow Trust 1 service. A member of CLIC Sargent team confirmed the meetings took place.

We found the culture of the service to be positive. Staff were encouraged in the team meetings to be open and discuss what went well and if there was any learning from other events. We saw staff had been engaged in evaluating the tribute day where they described what they liked about the day and what they would change. For example staff said they liked the fact that some families had three generations attending and the numbers attending had doubled from the previous year. Staff described needing to be ready earlier as there were some families who had arrived earlier than expected. The registered manager showed us the quality monitoring carried out by the service

Is the service well-led?

with families and of the children's groups. This meant the service was audited to see if improvements could be made and through reflective practice demonstrated a culture of continuous improvement.

We found the registered provider continued to develop the service to include the voice of children and young people. For example the registered manager showed us work they had developed to engage children and young people in evaluating the service, and explained to us how they envisaged it being used. We found the registered manager was looking for innovative ways to include the child's perspective in their work.

We discussed with the registered manager the registration with CQC for personal care and the types of personal care offered. The registered manager told us that where children were in hospital they did not deliver personal care and parents wanted to be able to care for their children themselves. The registered manager told us staff found they were required to change nappies but these may be required within the normal expectations of a child's developmental stage. However the registered manager was also able to show us where children through illness, disability or developmental delay would require additional continence support. The registered manager also showed

us that where parents gain a trusting relationship with staff they may ask for more personal care support for their child, for example with showering. We found the registered provider met the requirement of CQC registration as prescribed in the Short Breaks - Statutory guidance on how to safeguard and promote the welfare of disabled children using short breaks' published by the Department for Children, Schools and Families in 2010.

We found the registered provider continued to strive for excellence in working with others. We saw meetings were in place with other providers to continue to develop new work and evaluate current working arrangements. One professional told us the service attended their network day to promote their work. We found the Rainbow Trust 1 service in line with the registered provider's overarching business plan 2014-2017 had begun the development of neo natal work. This meant the leadership of the service was linking the registered provider's strategy to front line work. We received feedback from a professional in a hospital involved in the work and they spoke very positively about how the work had been developed by the manager. We found the service was extending its work and utilising the skills of its staff to support families in other challenging circumstances.