

The Jessie May Trust

The Jessie May Trust

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?

Outstanding 

Is the service responsive?

Good 

Is the service well-led?

Good 

Overall summary

The Jessie May Trust is a registered charity which offers respite and support to parents and nursing and personal care to children with life limiting illnesses in their own homes. They provide respite care visits for children and young people aged 0 to 19 years of age. Qualified nurses specialising in children's health care or nursery nurses provide the care and support due to the complexities of the children's health care needs.

We last inspected the service in November 2013 and no concerns were found.

There was 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.

Parents told us they were very happy with the care and trusted the nurses to support their child safely. Comments included "it is an amazing service we receive, all the nurses are exceptional and we trust them with our

Summary of findings

child” and “I cannot fault the service, the staff are friendly and my child enjoys the visits from Jessie May Trust” and “they spend time with my child playing and interacting which is positive as usually the focus is health appointments, it is a fantastic service”.

At the time of our inspection there were 83 children registered with The Jessie May Trust. Support varied depending on the assessment of the child and the requirements of the family. Each child had been assessed and a care plan drawn up involving the child, the parents and other professionals. Parents had been involved in a self-assessment of their needs which provided a score on the frequency of visits and support. Parents confirmed this was kept under review as the needs of their child changed. Care plans included both short and long term goals and wishes on the event of an admission to hospital and end of life care. Parents described to us how this was done sensitively taking into consideration the needs of the child and their wishes.

Clear records were kept of the visits and support delivered to each child. Parents and the nurses shared important information about how to keep the child safe and what was required on each visit. This included any medicines that may be required. The staff had received training in the safe administration of medicines. This included training on oxygen therapy.

Staff understood the needs of the children and young people they supported. They had received appropriate training to enable them to support the children in their care. Staff were aware of the importance of safeguarding children and their role in sharing information with other professionals. Suitable arrangements were in place to ensure only suitable staff were employed to work for The Jessie May Trust. The nurses were employed through the United Bristol Hospital Trust which provided additional support to the nurses in respect of clinical training and support.

There were systems to regularly review and monitor the quality of care. Feedback was gained from children, young people and their families at regular intervals to drive improvements. Parents were invited to attend regular meetings about the running of the service with some being a parent representative on the board.

Staff from the Jessie May Trust work with other professionals and participate in local networking groups to ensure they were working in partnership and following current good practice guidelines.

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. Staff had a good awareness of how to keep children and young people safe. This was done in partnership with the parents and the child. This was continually kept under review.

Staff understood their responsibilities in reporting any allegations of abuse to other partnership agencies and putting safeguards in place to protect the child.

Safe systems were in place to ensure children were supported with their prescribed medicines in their own homes.

Systems were in place to ensure there were sufficient staff. Staff recruitment procedures were followed.

Good



Is the service effective?

The service was effective. Children, young people and their families were involved in their care. Care plans clearly described the support needs of the child. Staff were knowledgeable about the children they supported. Where the needs had changed adjustments were made to the care and support.

Staff had a good awareness of their responsibilities around ensuring consent was obtained and the legislation that guided them. This included the involvement of other professionals, where decisions were made in the best interest of the child.

Staff had received training relevant to their role and the support needs of the children and young people they supported.

Good



Is the service caring?

The service was caring. We received positive feedback from parents on how the nurses really care about their child. Parents told us they could trust the nurses that supported them with the care of their child. They had got to know the nurses as they visited regularly and their child looked forward to the visits.

The staff were caring and the support given was based on the wishes of the child and the parent. Staff were professional whilst building positive relationships with the family and the child.

Parents and their children were involved in planning their care which included what they would like at the end stages of life. Parents told us this was done sensitively and at a pace that was appropriate to them. Support was offered to bereaved parents and contact maintained if this was what the family wanted.

Outstanding



Is the service responsive?

The service was responsive. Each child had been assessed and a care plan put in place on how this should be delivered. Care agreements were in place with clear information on what the child and the family could expect. This was kept under review as the needs of the child changed.

Good



Summary of findings

Continual monitoring of the children identified if additional visits were required for example when a child or parent was ill or a hospital admission. Parents confirmed the service was responsive to their child's changing needs.

Visits were planned including activities that were age appropriate and based on the interests of the children.

Parents felt listened to and complaints were dealt with promptly. This included offering an apology and information about what actions were taken to alleviate the concern.

Is the service well-led?

The service was well led. Staff spoke positively about the management structure of the service and the support that was in place for them. They described a team that was cohesive, working to the aims and objectives of the service in providing care and support to children with life limited conditions.

There were good links with other health and social care professionals in respect of supporting the children. Staff ensured they were following current good practice guidelines.

Arrangements were in place for checking the service to ensure standards were maintained. Feedback was received from parents and children on how the service could improve. Regular meetings were held which involved staff, parents and the board and showed continual commitment to driving improvement.

The Jessie May Trust

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 over three days. We visited the office of The Jessie May Trust on the 20 January 2015 and met with parents and children on the 21 and 22 January 2015.

Feedback was given to the registered manager, the chief executive and two nurses on the 26 January 2015. The provider was given 48 hours notice of the inspection. Because the service provides support to families in their own homes we needed to be sure that someone would be available to meet with us in their office.

The inspector was accompanied by a specialist advisor who had knowledge and experience of children and young people's hospice care.

Before the inspection we reviewed the information we held about the service. This included notifications, which are information about important events which the service is required to send us by law. We also looked at previous inspection reports.

During our inspection we observed how the staff interacted with the children, young people and their families. We looked at the care records for five children and young people who were using the service, staff training records, two staff recruitment files and other records about how the service was managed.

We spoke with six relatives of three children in person and made contact with a further four families by telephone. We also spoke with the registered manager, the chief executive, six nurses and three administrative staff.

Is the service safe?

Our findings

Parents said they were confident their children were safe when being supported by the nursing staff. They told us they were asked about any changes to their child before any care and treatment was delivered. Risk assessments were in place to keep the child safe. Parents confirmed they had been consulted about these and felt confident the staff were following them.

Parents told us visits were rarely missed by The Jessie May Trust staff. Where visits had been cancelled these were usually rearranged to suit the family. A relative told us “In 18 years of receiving a service only two visits had been cancelled, one due to weather conditions and the other was that another child’s need was greater in respect of their end of life care. They told us “I cannot fault the service it has been a life line for us as a family and for my child”.

Each child had a care file which contained information to keep them and the staff safe. Environmental risk assessments had been completed as part of the initial assessment process. These had been kept under review. The risk assessment included access arrangements, any known risks and advice for the member of staff to keep them safe. For example where there were pets in the home, the family had been asked to ensure the animal was not in the home during visits. The annually reviewed care agreement included an alternative contact in the event of an emergency. For example, if there was no one at home or the family did not return when the staff visited, they were able to contact a relative or named person agreed with the family.

Each child had personalised risk assessments. These covered a range of activities from play to nursing care delivery and how to do this safely. Where moving and handling equipment was used this was clearly described including the specific equipment. Staff confirmed they received regular training in safe moving and handling procedures. This was updated where the child’s needs had changed and new equipment was in place.

Staff were aware of how they could keep themselves safe as lone workers. Risk assessments and policy guidelines were in place. The Jessie May Trust nurses were employed by United Bristol Hospital (UBH) and shared some key policies. One of these policies was the lone working policy. The UBH policy made reference to a system of alerting

management that a member of staff was at risk, however this was not up and running. Senior management were in regular discussions with UBH about this system and had put in additional safeguards for staff when working out of office hours. Staff confirmed this was regularly discussed at team meetings including any risks to them or the children they supported.

The service managed medicines safely. Parents confirmed they discussed what medicines were required at the start of the visit and were aware that the nurses could only give medicines if it had been prescribed by a medical professional. They also confirmed the nurse clearly explained at the end of the visit what medicines had been given. Care records included a signed consent form for medicines to be administered by The Jessie May Trust staff.

The service had an infection control policy that the staff followed and meant practices were safe. Many of the parents said it was very important that if a member of staff had a cold or a cough they would prefer the visit was cancelled or rearranged as the risks to their child were higher due to their medical condition. This was respected.

Staff told us they had completed training in safeguarding children and young people and were aware of what constituted abuse and who they must report this to. Staff confirmed they would report concerns to the registered manager and these would be responded to promptly. Contact details of the local safeguarding team, police and other professionals could be found on the office notice board enabling the staff to contact the appropriate professionals. Staff confirmed they had contact details of the children’s safeguarding team at the local hospital where they could ask for advice and support. They were also aware of the adult safeguarding procedures to follow where an allegation of abuse involves a young person over the age of 18. Staff were aware how they could raise concerns using the service’s whistle blowing policy.

The registered manager was able to demonstrate how they shared information about any allegation of abuse with the local safeguarding team and what actions had been taken. It was evident the safety of the child was always paramount and this had been explained to parents when they agreed to have a service from The Jessie May Trust. For example, where children had an unexplained bruise it was clearly explained to the parents that this information would need to be shared with other professionals and followed up. Staff told us how this learning was shared with the team at

Is the service safe?

regular meetings specifically talking about child safeguards. An example was given where a child was noted to have unexplained bruising and after investigation it became apparent that the child had a medical condition which caused the bruising.

The nurses that worked for The Jessie May Trust were employed by United Bristol Hospital Children's Directorate. Recruitment in respect of advertising was completed through the hospital and the interviews were conducted by The Jessie May Trust. Support in relation to staffing matters was provided by the hospital's human resources department. The registered manager was involved in the decision process of employing staff ensuring they were suitable to support the children and young people.

The service had safe recruitment practices this ensured people using the service were protected. Regular checks were completed to ensure the nurses employed were registered with the Nursing Midwifery Council (NMC). The

NMC maintains a register of all nurses that are fit and able to work in the UK. The registered manager was aware of their responsibilities in ensuring suitable staff were employed.

There was sufficient staff to enable them to deliver the care and support to the children and their family. There were 23 nurses who worked for The Jessie May Trust and this included 11 bank staff. The staff were recruited for their skills as children and nursery nurses and experience of supporting children with life limiting conditions and end of life care.

As part of the initial referral process parents were asked to complete 'The assessment framework for respite in partnership with parents' (FRiPP). This was a tool which encouraged the parents to be engaged in identifying the level of support they required. The child and their family score themselves to enable the team leader to plan the number of visits that were required. This enabled the management to plan visits ensuring they had sufficient staff to support the children and their families.

Is the service effective?

Our findings

Parents described a service that was effective in meeting both the needs of the child and that of the family. Parents were complimentary about the staff and the support that was in place. No negative comments were received.

Comments included “they are amazing, the staff have the right skills to be able to support my child”, “I cannot fault the staff, they are very professional”.

Each child had a care plan that detailed their support needs. A copy was held in the main office of The Jessie May Trust and in the child’s home. Care plans were individualised and tailored to the need of the child. Parents confirmed they were involved in making decisions about the care their child received and these were reviewed at regular intervals with them.

The staff and the registered manager demonstrated their knowledge and understanding of the Mental Capacity Act 2005 (MCA), which applied to the younger people aged 16 or over. Staff were knowledgeable about the legal context of children and young people’s competence to consent to treatment and care. There were links with advocacy services to support the young people where they may require additional support in making decisions about their support needs. An advocate is a representative that speak up on behalf of a person.

Parents confirmed staff always asked what care and treatment was required at the start of each visit and a further discussion at the end explaining the support that had been given. Staff confirmed they always listened to the child or young person to ensure they were consenting to the care and treatment being provided. For example, if a child was upset with the activity then this would be stopped to ascertain the feelings of the child. An assessment would be carried out to understand what it was about the activity the child was unhappy with.

Parents told us they were general responsible for the day to day health care needs of their children in respect of medical appointments and liaising with health care professionals. Some parents told us the staff had attended meetings with them with health care professionals and they had supported them with asking appropriate

questions enabling them to plan for the future. One parent told us “they were excellent they supported me in making sure I had all the answers I needed and where I did not understand fully they explained what it meant for my child”.

Children and young people were supported where required with eating and drinking. Care plans included any risks such as choking or allergies. Staff told us the parents would usually leave snacks and drinks for their child. Where children were fed through a feeding tube direct to the stomach then clear instructions were available to staff. Staff confirmed they had received training in this type of feeding and had access to a dietician at the children’s hospital for support.

Staff had received training in supporting conflict and behaviours that may challenge. Staff described their role in supporting children where they expressed themselves using behaviours that may challenge. Staff used positive means to support the children, this may be through distraction. For example reviewing the activity to ensure it was meaningful for them and they were enjoying what had taken place. Staff told us they rarely used physical restraint to restrict movement unless a child was in immediate danger. Staff described when it was in the best interest of the child for example, where they were in immediate danger such as a busy road. There was a policy in place to guide staff on what was acceptable and what records should be maintained. Staff were clear the parents and other professionals would be consulted where restraint was known to be used. Staff described the positive relationships they had built with the children and often they could predict situations before they escalated. A parent described a situation when their child was arguing with a sibling and the nurse had promptly calmed the situation and changed the activity maintaining a calm atmosphere in the home.

Before staff worked alone with a child they undertook shadowing visits with an experienced colleague. This enabled them to meet with the child, their parents and to learn in the home environment how to care for them. Parents confirmed new members of staff were slowly introduced to their child enabling them to get to know them and the family. They told us this was important as enabled them to build confidence in the new member of staff.

Parents told us they had confidence in the staff who supported their child or children. The staff were

Is the service effective?

knowledgeable about their child's support needs and what was expected of them during a visit. A parent told us "it is the only time I leave my child, I have faith in the staff which enables me to go out and do things that I have planned". Parents told us initially when the staff visited they would stay in the home but as their confidence grew they could go out for a few hours, knowing their child was safe and being well cared for. Parents described a service that was working in the best interest of their child and they looked forward to the visits.

Staff received appropriate professional development and support. They received regular support, supervision and on going training and staff regularly met individually with their line manager. This enabled the member of staff an opportunity to discuss their role and any training needs. In addition, staff attended peer group meetings to discuss their roles, the needs of the children, training needs and share ideas. The nursing staff also received clinical supervision which was delivered by a consultant psychotherapist from the Bristol Children's Hospital. Records were maintained of these meetings and showed staff were supported in their roles.

Staff told us they felt 'very well supported' and were confident their training needs would be addressed enabling them to carry out their specific roles. All staff completed a corporate induction through the Children's directorate at the Hospital and then a specific introduction into the Jessie May Trust. Staff were given information

about their role, key policies and procedures and slowly introduced to the children. Staff competence was routinely checked to ensure they were working within guidelines and best practice.

There was a training lead who was responsible for monitoring and delivering some of the training. Some of the training was delivered by the children's hospital. Records showed all staff had attended essential training for example first aid, resuscitation and safeguarding, epilepsy, child bereavement, training, oxygen administration, ventilation and tracheostomy care. In addition staff received specific training relating to the children they supported. A member of staff told us they had been seconded to a children's hospice to build on their clinical skills and found this valuable whilst another member of staff had been seconded to an adult hospice.

Another member of staff told us they worked closely with the children's hospital to gain skills and competence with a clinical procedure. This was because they may not use this clinical skill in the community on a regular basis but needed to keep up to date with changing practices. Both staff told us they would share this learning with colleagues during team meetings.

Staff said the service provided them with valuable skills and knowledge. They said the parents were a valuable resource, knew their child the 'best' and shared in-depth knowledge about their child's condition and support needs.



Is the service caring?

Our findings

Parents described a service that was caring towards them and their child. Positive feedback was received from all the families that we contacted. Everyone told us about the caring support their child received from The Jessie May Trust that extended to the parents and other siblings. We received comments from a sibling who said “they have worked with our family and have been part of our family for many years, all the staff are lovely and take an interest in all of us”. A parent told us “they give 100% and go the extra mile to make sure we are alright”.

Staff described how they not only supported the child but the whole family. However, it was clear that it was the needs of the child that were at the forefront in the planning and delivery of care in consultation with the parents. Staff told us “no child is the same and it is about providing the best person centred care for the individual”.

Parents told us their child looked forward to the nurses visiting. They knew this because their child was relaxed in the company of the nurses or they would tell them or their facial expressions would indicate they were happy. One parent told us “it is really nice for my daughter to meet with the nurses who actively plays and engages with her as normally the only other contact is from professionals who are undertaking medical tasks”.

A small team of nurses would support each child and their family. This was to ensure continuity and enable the nurses to build a relationship with the child and the family. Parents confirmed they had a small group of nurses visiting them and they were aware of who would be completing the visit in advance. Some parents described the nurses as being part of the family and a friendly face they looked forward to seeing. They told us they could contact the office and speak with staff for advice or just to speak to a familiar voice who understood what was going on at any time.

We visited three children when they were receiving a service from the nurses. The children were relaxed in the company of the nurses and engaged in age appropriate activities. The nurses were communicating with each child using verbal communication, Makaton (using symbols and gestures suitable for children to support communication)

and pictures this depended on the child and their abilities. The staff were observed communicating with children at their level and maintaining eye contact. Communication passports were in place for the child detailing how they communicated. Parents confirmed the staff interacted with their child appropriately encouraging their participation.

Parents gave us many examples of how the nurses and The Jessie May Trust care, from listening, to increasing support when things got a bit tough. One parent told us “you have a conversation on one visit and they remember the next time and check out how things are generally going”. Parents confirmed the nurses had supported them when their child went into hospital. This was to enable them to have breaks to catch up on sleep, grab a bite to eat or spend time with siblings. They told us this was important to them as they trusted the nurses from The Jessie May Trust who had already built a relationship with their child.

Parents confirmed their involvement in making decisions about the care and support they wanted for their child during the visits. They were also encouraged to talk about end of life care and support. Parents acknowledged this was not an easy topic however the nurses were caring in their approach and never forceful. Some parents told us it was a relief to discuss openly what they wanted at the end stages of life which could be shared with the local hospice or the children’s hospital. Care records included an end of life plan and a ‘wishes document’. These were kept under review with the family and the staff to ensure the wishes were still current and relevant. The information focused not only on dying but the care the child would want whether at home, in a children’s hospice or hospital.

The Jessie May Trust offered guidance and support to families including making arrangements for funerals. One relative told us how the staff had developed a memory book for them about their child. The staff kept in touch with families for a further five years after the death of a child offering counselling and support. The family were asked if they were happy for the contact to continue. Cards were sent on the anniversary of the child’s death and birthdays. They also offered a support group for bereaved parents to meet with other parents in a similar position four times per year.

Is the service responsive?

Our findings

Parents told us they were very happy with the care and support that was provided by the nurses. They said the service was delivered flexibly for example, visits would be increased if the child's needs had changed or support would be given to a child if they had been admitted to hospital to offer family some respite. Parents spoke positively about how the nurses had supported them in meetings with other professionals advocating for their child and helping them understand what was being said.

Referrals came from professionals or directly from families. At the point of referral a nurse would visit the child either in their own home or the children's hospital. The registered manager told us there was no waiting list as it was important that all children referred who had a life limiting conditions had access to support from the Jessie May Trust. The support varied depending on the needs of the child. Some parents used The Jessie May Trust as a point of contact for telephone advice whilst others had regular visits.

As part of the assessment for each child, parents were asked to self-assess their needs in respect of time and support. From this assessment visits would be arranged weekly, fortnightly or monthly depending on the score of the assessment. The majority of the visits were for three to four hours.

There was a care agreement in place between The Jessie May Trust and the parents or the guardian. These were reviewed annually or as the needs of the child changed. Parents told us often it was the nurse that highlighted the need for the care agreement to be reviewed as the needs of their child had increased. This showed that the nurses were proactive in reviewing the care of the child in response to changing needs alongside the family.

In addition to the care agreement families were provided with information about what the nurses could offer, information about the records that would be maintained and health and safety of the child and the staff. The information provided included how to raise a complaint.

A weekly planner was on display in the office showing where each member of staff was and who they were supporting. There was a list of children in hospital that may require additional support and children who had requested

additional visits because they were home from school. Activities were highlighted on the weekly planner where these could be cancelled enabling the nurses to respond to an emergency.

Each child had a care plan that detailed the support they required. This covered all aspects of daily living and their health care needs. Records of visits were kept both in the home of the child and a copy kept in the main office. The nurses made a record of all care and support given. The records were informative and shared with the parents. There was a section for staff to complete to record any changes or important information that needed to be shared with other staff and the registered manager. Records were returned to the office on weekly basis and reviewed by the core group of nurses.

Important information was shared with other professionals involved in the care of the child. Parents were asked if they were happy for the information to be shared. Information sharing was discussed with parents and children when they first started receiving a service and formed part of the care agreement. Staff worked closely with the staff from the children's hospital, the local hospice, school nurses and other children's community services.

The Jessie May Trust support young adults up to their 19th birthday. Parents told us the nurses had supported them in accessing services for adults. This included liaising with the transition children to adult social care team and making referrals to professionals. A parent told us "the nurses have been really supportive when in meetings ensuring a smooth transition to adult social care, acting as advocate for their child and family".

Staff described how they supported families and children whose first language was not English. They were able to access translators in person or over the telephone. We were told about a nurse that spoke Turkish so they were linked with a family to enable effective communication enabling them to respond to the child's and family's needs. Children from a wide range of faiths were supported. Staff had access to information about how they could support the cultural needs of the family both for the living child or a child that had died. Information was recorded in the care plan about how people wanted to be supported with their cultural and religious needs.

Parents confirmed they had a core team of two to three nurses that regularly visited. This enabled them to build up

Is the service responsive?

a relationship with the nurse and the nurse with the child enabling them to respond to any changing needs of the child. Parents told us how on occasions the visits were increased may be due to illness of the child or main carer or during the school holidays. A parent told us that they were always asked when they would like a visit. They told us there was some flexibility. An example was given where a parent had to attend a health care appointment and the visit was arranged so the parent could go without the child.

Monthly care meetings were held with the core staff team where they would discuss the changing needs of the children. This ensured important information was shared and where relevant the care plan or risk assessments could be updated. Staff completed a record of each visit which included a section to record any changes or concerns.

Staff made contact with the local children's hospital to see if any children that were supported by The Jessie May Trust had been admitted to hospital. This enabled them to make contact with the family to see if they required support. A nurse planned to visit the children's hospital to meet with a number of families as their children had been admitted over the weekend. This showed the staff were able to respond to the changing needs of the children and provide support both in the home and hospital setting.

We observed three children being supported by the nurses. They were engaged in age appropriate activities which was very much led by the child and their known interests. A parent told us the nurses either use toys that were in the home or they would bring toys they felt were appropriate for the child. The Jessie May Trust support children from 0 to 19 years of age. For the young adults the nurses described how they supported them with activities to ensure they were age appropriate. This included music

sessions, sensory equipment, hand massages, reading and listening to music or painting nails. The nurses told us it very important to find activities the child or young person enjoyed.

Group activities were organised where children and families could meet together. This included an annual Christmas Party, summer fun days and activity days for the younger children and young adults organised in the school holidays. Staff told us that there was always a nurse available to support the children and young adults in the case of an emergency. Risk assessments were completed before and reviewed after the event. This included reviewing the venue to ensure it was suitable for children with disabilities. Feedback was sought from the children, their parents and the staff on how the day went. Some parents confirmed their children had taken part and the activities had been successful. These events included other professionals that supported children including art therapists, music and play therapists.

Parents confirmed they knew how to make a complaint. Everyone we spoke with said they could find no fault in the service being provided. A parent told us, they had raised a minor concern when they first started receiving a service. However, they were more than satisfied with how promptly it was addressed and not repeated by any of the staff who visited. Staff told us it was important to listen to the child and family to enable them to build trust especially as they were going into their homes. They told us by listening and acting promptly meant that a minor concern did not escalate in to a complaint. It was also acknowledged the importance of apologising for any mistakes and an explanation on the actions that would be taken to address the concerns.

Is the service well-led?

Our findings

The Jessie May Trust's values and philosophy were clearly explained to staff through their induction and training. There was a positive culture where children, families and staff felt included and consulted. A parent told us, "all the staff are amazing, they are caring, compassionate and really dedicated to support the young people and their families." All staff described a commitment to providing care that was centred on the child and their families and the importance of working with other professionals in the care of the child.

All staff told us they felt supported and enjoyed their work. They described a team that was not only caring towards the children but each other as staff. Staff could also use a counselling service to seek professional emotional support when this was needed. A clinical psychologist attended regular meetings with staff either as a group or individually to offer them emotional support and advice. This was offered to all staff including nurses and the administrative staff if required.

Some staff worked outside of office hours, some evening and weekends as part of the agreed care package. There was an on call system that if a nurse required clinical advice or support they could liaise with an on call manager at the children's hospital. Staff confirmed they had these contacts available to them. The Jessie May Trust does not provide a 24 hour service to parents and children. Contact details of other professionals and support groups was included in the care file kept in the child's home.

Monthly staff meetings were organised with minutes of discussions and any actions that were agreed. Leadership and quality meetings were organised to discuss the running of the service and manage any risks. Staff told us 'care and children at risk meetings' were also taking place fortnightly where they could discuss each child receiving a service. This was to ensure that the core staff were kept informed of any concerns, changes to the child's care or health needs. Records were kept of the meetings including any agreed actions and who was responsible for making it happen. These were followed up at subsequent meetings to ensure the actions had been addressed.

Staff had specific roles including bereavement support, training, workforce planning and quality assurance. Staff told us this ensured they were taking an active role in the

running of the service in monitoring and ensuring a quality service was provided. Staff completed evaluations of their role and outcomes for children and staff. This was fed back into the quarterly board meetings. The office was staffed by four administrators, the registered manager, the chief executive and the nurses. There was an open door policy and staff were observed interacting in a professional and friendly manner with each other. There was a staffing structure, which gave clear lines of accountability and responsibility. Staff told us they felt valued and listened to. A member of staff told us they were able to make suggestions for improvement and these were acted on.

The staff involved children, young people and their families in the assessment and monitoring of the quality of care. Parents and children were asked to complete an annual evaluation on the care and support they had received. This was reviewed to see if any improvements could be made to the service provided. The questionnaires we viewed showed everyone was highly satisfied with the quality of the care and support being given by the nurses.

Parents were invited to attend quarterly meetings where they could meet up with other relatives as part of support network. External speakers were asked to attend such as the clinical psychologist, a music therapist or a representative to talk about benefits and financial assistance. Minutes of the meetings were sent to all families keeping them informed. Their views were sought on how the service was run including staffing. Some parents had been elected to attend management meetings as a Trustee or a parent representative again ensuring parents were involved in the running of The Jessie May Trust. One parent commended the organisation in promoting their involvement and making them feel valued and part of the service.

The registered manager told us they had recently sent out questionnaires to other professionals to gain their views on the Trust. These had just been received and were still being collated in respect of any themes. Twelve responses had been received from professionals including staff from the children's hospital, hospice services and community paediatricians. All confirmed they were satisfied with the professionalism of the nurses and felt confident in the service provided. All would recommend the service. General comments included "always an advocate for the

Is the service well-led?

children and their families”, ‘I think we work really well together, care from JMT is excellent, very caring, compassionate and caring’ and ‘it is a highly valued service, which many of my families depend on’.

Regular checks were being completed on different areas of the running of the service and the delivery of care. This included checks on the medicines recording, care plans, training, recruitment information, workforce planning and health and safety. Where there were shortfalls actions had been taken to address these.

The registered manager maintained a log of complaints. This showed the organisation was proactive in reviewing the concerns raised and they learnt from the experience. Some of these were not complaints but incidents. The registered manager and the team demonstrated these had been fully investigated enabling them to feedback to the family and other professionals what action had been taken. The registered manager told us they received very few complaints from families or other professionals but felt that any incidents or near miss should be investigated as a complaint with feedback given to those people involved.

We reviewed the incident and accident reports for the last 12 months. There had been very few accidents. Appropriate action had been taken by the member of staff working at the time of the incident including reporting. There were no themes to these incidents, however the registered manager had reviewed policy guidance, risk assessments and care plans to ensure the children and the staff were safe. They had kept the parents and children informed of the outcome including making an apology. The registered manager was aware what they needed to report to us. This was done through a notification. A notification is information about important events which the provider is required to tell us about by law.

The registered manager told us they worked closely with the Children’s Safeguarding Board. The registered manager was also part of the child death review panel and provided information about children that had died whilst receiving a service. All professionals involved in the care of the child are required to submit a report about the care and support leading up to the death. The registered manager saw this

as being an important part of their role ensuring any learning from these reviews could be embedded into the practice and improve the quality of the care to the child and their families.

The registered manager regularly attended the Avon Palliative Care Strategy Group. This is a group of multi-disciplinary healthcare professionals representing a wide range of organisations who meet to offer strategic support and guidance across the region. In addition the registered manager was also the chair of both the South West Maternity and children’s Strategic Clinical Network and end of life care working group and the children’s palliative care network for the South West. Information from these groups was shared with the team and learning cascaded.

There were links with other organisations to make sure local and national best practice standards were met. There was a nominated member of staff who took the lead on safeguarding children and worked closely with the children’s hospital safeguard lead to ensure current good practice was being followed. Another member of staff had been seconded to a local adult hospice enabling them to build links with adult health professionals. This was viewed by the member of staff as positive in supporting children who were transitioning to adult social care and supporting the parents during this time. A parent told us the nurses had been very proactive in supporting them to access other health and social care professionals. They told us without this support they would have found it very confusing.

Links had been developed with a local nurse education provider to enable student nurses an opportunity to work alongside the nurses in supporting children and their families in the community. This was viewed positively by the nurses in developing their skills in supporting the child and the family in a holistic way and not just focusing on the illness or condition. This was clearly an aim of The Jessie May Trust to ensure the care was very much led by the child and the family whilst supporting them to manage their complex health care needs enabling them to remain at home.