

Wessex Children's Hospice Trust

Naomi House Children's Hospice

Inspection report

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Ratings

Overall rating for this service

Outstanding 

Is the service safe?

Good 

Is the service effective?

Good 

Is the service caring?

Outstanding 

Is the service responsive?

Outstanding 

Is the service well-led?

Good 

Summary of findings

Overall summary

This inspection was unannounced on 8 and 9 December 2015

Wessex Children's Hospice Trust runs two hospices, Naomi House and Jacksplace. Naomi House is for children up to the age of 16 or 18 years old and Jacksplace is for young people and adults from the ages of 16 years to 35 years.

The hospices support babies, children, teenagers and young adults with life limiting or life threatening conditions and provide accommodation for respite (short breaks), emergency care, day care and end of life care. Both hospices have bereavement suites and provide family support services.

We last inspected Naomi House and Jacksplace in January 2014 and they met the regulations.

There is a registered manager who has been in post since 2011. 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.

Most of the children and young people we met had complex needs and were not able to tell us their experiences because of their complex ways of communicating. We observed how the staff interacted with the children, young people and their families.

Parents told us their children were safe at the hospices. Children and young people sought reassurance from staff and were relaxed with them. This indicated they felt comfortable and safe with staff. Staff knew how to recognise any signs of abuse and how they could report any allegations.

We saw children and young people received care and support in a personalised way. Children and young people had access to the specialist healthcare support from the medical and nursing teams at the hospices. Their complex medical needs were well managed and staff were trained to meet these specialist complex needs. Risks were assessed and managed and there was focus on positive risk taking so children and young people could safely try new experiences. All parents and professionals were happy with the care provided by Naomi House and Jacksplace. Staff knew children and young people well and understood their complex needs.

Staff were very caring and showed children, young people and their families kindness and compassion. Staff were very motivated and demonstrated a commitment to providing the best quality care in a compassionate way. Parents told us they and their children were cared for to a high standard and this included ongoing bereavement support for families. They spoke of excellent relationships with staff who understood their needs and preferences and who devoted time to them. Siblings and other family members such as grandparents were also cared for. Staff treated children, young people and their families with

respect and dignity. Children and young people's privacy was maintained at all times during the inspection. Sensitive planning for end of life care and post death care and support was provided to children, young people and their families. Bereaved families told us that the ongoing support and care provided had been invaluable.

There was a holistic approach to children's and young people's care with the physical, well-being, social and spiritual needs of each child and young person given equal importance, together with the needs of those closest to them.

Children and young people and their families received a very responsive service. Their needs were fully assessed, planned for and met. The service was creative and responsive to the changing needs of children and young people and had developed services in response to the local communities changing needs. Children, young people and families were involved in developing the service and this was based in their needs.

Children, young people and staff had fun together and there were lots of play and activities that were based on their preferences and needs. Children's individual sensory needs were met by the specialist equipment available.

The head of adult services was aware of their responsibilities in regard to the Deprivation of Liberty Safeguards (DoLS). These safeguards aim to protect people living in hospices from being inappropriately deprived of their liberty. These safeguards can only be used when there is no other way of supporting a person safely.

Parents and professionals gave positive feedback about the qualities, skills and knowledge of the staff. Staff were recruited safely and received an induction, core training and specialist training so they had the skills and knowledge to meet children and young people's complex needs.

There were safe systems in place to safely manage and administer medicines in both hospices. Children and young people were protected from the risks of infection by the systems and equipment in place.

We found the hospice and equipment was well maintained. The hospice was designed and decorated to meet the specialist needs of the children and young people.

There was a children, young people and family focused culture at the service. Children, young people, families and staff were involved and consulted about all aspects of the service. Staff were proud of the service they provided and were fully committed to the children, young people and their families. There was a clear management structure and staff, children and young people and their families felt comfortable talking to the managers about any concerns and ideas for improvements. There were systems in place to monitor the safety and drive the continuous improvement of the quality of the service provided.

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.

Parents and professionals told us children and young people were safe in the care of Naomi House and Jacksplace.

Medicines were managed safely.

Staff knew how to recognise and report any allegations of abuse.

Staff, relatives and professionals told us there were enough staff to keep children and young people safe. Staff were safely recruited.

There were effective infection control systems in place and staff had access to protective equipment, such as gloves and aprons. People had access to equipment that was maintained and serviced.

Good 

Is the service effective?

The service was effective.

Staff had effective training and support to carry out their roles. Parents and professionals felt staff were skilled and knowledgeable in meeting children and young people's needs.

Children and young people were supported to eat and drink and had the specialist diets they needed.

The environment had been adapted and specialist equipment was provided to meet the individual needs of the children and young people.

Good 

Is the service caring?

The service was caring.

Staff were kind and compassionate and treated children, young people and their families with dignity and respect.

Outstanding 

Parents and professionals told us the hospices cared for the whole family not just the child receiving the service. They told us the ongoing care and support provided was invaluable to families.

Staff had developed good relationships with children, young people and their family and there was a happy, relaxed atmosphere throughout the hospices.

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 families and contact maintained if this was what the family wanted.

Is the service responsive?

The service was very responsive to children, young people and their families.

Staff responded quickly and appropriately to children and young people's needs.

Staff understood children and young people's complex ways of communicating and responded to their verbal and non-verbal communication and gestures.

Children and young people were supported to pursue activities and interests that were important to them and met their individual needs. Children and young people's educational needs were met during their stays.

There was a complaints procedure which children, young people and their families knew how to use if they needed to. There were robust systems for checking learning from complaints had been embedded into practice.

Information was shared effectively when children and young people moved between services. The service ensured the transition and ongoing care and support between the hospices was based on the needs of the individual young person.

Outstanding 

Is the service well-led?

The service was well-led.

Observations and feedback from children, young people, parents, staff and professionals showed us the service listened to their views and acted on these.

Good 

The trustees and managers were visible and accessible to children, young people, families and staff.

Staff spoke of an open, supportive, positive culture that encouraged their views and input. Staff felt very well supported in all areas and felt involved, listened to and appreciated at all times.

There were systems in place to monitor safety and drive improvements in the quality of the service. There was learning from accidents, incidents and complaint investigations.

Naomi House Children's Hospice

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 was unannounced and took place on 8 and 9 December 2015.

The inspection team was made up of an inspector and a specialist advisor. The specialist advisor had experience of children's and young people's palliative and hospice care.

We spoke with and met with four children in Naomi House and eight young people in Jacksplace, some of whom were attending day care. We spoke with five parents of children and a young person during the inspection and with three bereaved parents by telephone following the inspection. We spoke with the registered manager and 26 staff. This included the head of governance, head of Jacksplace and adults services, head of community services, family support team members, medical and nursing staff, care workers and play and activity workers. In addition we spoke with one of the trustees of the board.

We used the Short Observational Framework for Inspection (SOFI). SOFI is a specific way of observing care to help us understand the experience of children and young people who could not talk with us. We observed how the staff interacted with the children, young people and their families. We looked at how children and young people were supported during their stay. We reviewed a range of care records for eight children and young people. We also reviewed records about how the hospices were managed. This included, staffing records, audits, meeting minutes, training records and governance records.

Following the inspection we spoke with five professionals who work with the hospices. They included community children's nurses, a paediatric respiratory specialist nurse, a consultant paediatrician and a

nutrition specialist nurse.

Is the service safe?

Our findings

We observed that children and young people were relaxed with staff in both hospices. They played, participated in activities, smiled, laughed and gave staff eye contact. Children and young people who were independently mobile sought out staff company and physical contact. This showed they felt comfortable and safe with staff. Parents told us they felt their children were safe in the hospices. One bereaved parent we spoke with said they also, "Felt safe and looked after".

There were child and adult protection and safeguarding procedures in place. All of the staff had received children's and adult's safeguarding training as part of their induction and ongoing training. Staff were able to tell us about the types of abuse and how to report any allegations. Staff told us and showed us that child protection referrals had been made when they were required.

Risks to children and young people's safety were appropriately assessed, effectively managed and reviewed. These areas of risk included any potential hazards in the environment, pressure sores, nutrition, medicines, falls, access to the community, behaviours that challenged others and epilepsy management. Staff demonstrated that they knew the details of these risk management plans and how to keep the children and young people safe. For example, staff described one young person's epilepsy and what action they needed to take when they had a seizure. This included the use of swiping a magnet over the person's implant. For another child there was a positive approach to supporting them with some of their behaviours that may present challenges to others. We saw staff supporting the child as detailed in their plan.

There was a focus on positive risk taking so children and young people could participate in activities or try new experiences. For example, children and young people who were ventilated and had a tracheostomy (a tracheostomy is a medical procedure in which a tube is surgically implanted into a person's windpipe) had been supported to use the hydrotherapy pool. This had previously been assessed as not possible but following a full risk assessment a child had been able to spend a period of time in the pool. They were supported with high numbers of trained staff and specialist floatation devices to make sure they were safe at all times.

There were emergency plans in place for each child and young person. These included emergency evacuation plans for all children, resuscitation plans and epilepsy protocols and management plans for those children and young people with epilepsy.

Environmental risk management systems were in place for the hospices. There were maintenance records for servicing of equipment, fire systems, boilers and the building. Audits were undertaken to make sure all equipment and the building were checked and serviced as required. Robust systems were in place for the maintenance of equipment such as hoists, specialist beds and equipment.

All incidents and accidents were recorded and analysed to identify what had happened and actions the service could take in the future to reduce the risk of reoccurrences. For example, one young person developed a pressure area. The staff spent time with the young person and reminded them of the

importance of re positioning. The incident and actions taken were included in the monthly update to all staff, the young person's plan was updated and the care team discussed the incident to minimise the risk of reoccurrence. This showed us that learning from incidents/investigations took place and appropriate changes were implemented.

We reviewed the daily and staffing planners for a two week period, these detailed the children and young people who were staying, the young people that were attending for day care in Jacksplace, and the staff and volunteers working that day. Staffing levels were determined following the assessments of each individual child or young person. For example, when some young people were staying at Jacksplace staffing levels were increased in the evenings and overnight to reflect that the young people were participating in activities in the community in the evenings and at night. Nursing and care staff were allocated to each hospice to ensure there were enough staff to meet children and young people's needs. In addition there was at least one member of the play/activities team on duty.

Recruitment practices for staff and volunteers were safe and relevant checks had been completed before staff worked unsupervised at the home. These checks included the use of application forms, Nursing and Midwifery Council (NMC) checks, an interview, reference checks and criminal record checks. This made sure that children and young people were protected as far as possible from staff and volunteers who were known to be unsuitable. However, the copies of proof of staff identification were not always kept on their recruitment files. Human resources staff took immediate action to ensure that copies were obtained and kept on file.

We found medicines were managed safely. Each child or young person had a medication plan which detailed the medicines prescribed and the route they were administered. For example, orally, intravenously, using in situ ports or through their feeding tubes. Some children and young people were prescribed PRN 'as required' medicines such as epilepsy or pain relief medicines. The plans detailed when the medicines needed to be given, the dose and the maximum dosage in 24 hours. Staff were knowledgeable about the child's or young person's medicines and how and when to administer them.

We observed nursing staff administering medicines through a young person's feeding tube. They chatted to the young person and explained that they were administering their medicines. They administered these medicines as detailed in the young person's care plan. Medicine records in both at the hospices detailed that medicines had been given as prescribed and detailed in their plans. Parents told us they were confident that staff administered their child's medicines correctly.

There were robust systems for handing over medicines when children and young people came to the hospices and for discharging medicines back to parents. Medicines were checked by nursing and medical staff and up to date information about children and young people's medicines was sought before they arrived at the hospices.

Medicines were stored safely. In Jacksplace young people who were able to, could manage their own medicines following a risk assessment. Their medicines were kept in secure storage in young people's bedrooms. At Naomi's House there was dedicated space for medicines preparation and secure storage. The space had been fitted with specialist lighting and staff told us this made the preparation and recording of medicines easier. When nursing staff prepared and administered medicines they handed the telephone to other staff so they could concentrate and were not disturbed.

Staff told us and records showed that they received training in medicines management and also specialist equipment such as syringe drivers. Their competency for administering medicines was assessed including

medicines calculations tests at regular intervals.

Children and young people were protected from the spread of infection. Staff washed their hands prior to undertaking any procedures with children and young people. As result of a hand washing and infection control audit, a mobile sink had been provided in Jacksplace so staff had easy access to handwashing facilities. There were supplies of protective equipment such as gloves and aprons. The hospices were well maintained and clean throughout the inspection.

Is the service effective?

Our findings

Parents told us staff were skilled in providing effective care. Staff were described by parents as being skilled and knowledgeable and they followed care plans about meeting children and young people's needs. Parents all commented positively about the staff and one said, "They are wonderful".

Children and young people's health needs were assessed and planned for to make sure they received the care they needed. All of the children and young people we met had complex health needs.

Children and young people were supported by specialist children's or adult learning disability nurses, the care team, a team of two GPs and three consultant paediatricians. The consultant palliative care paediatrician and some of the nursing staff worked at the local hospital for part of their working week. This meant they knew children and young people at both the hospital and in the hospices. In addition nursing staff skills were maintained and developed by them working in another medical setting.

We asked health care professionals, including paediatric consultants and specialist nurses, for their opinion of the service, and they all gave us positive feedback about the skills and knowledge of staff. A paediatric consultant from a local hospital told us they had no worries at all about the medical care of the children and the hospices were unique and very special. A specialist nurse said they commended the specialist consultant at Naomi House who they held in very high regard, they told us staff are professional and very thorough.

One parent said the staff put their child's needs first and there is always a doctor on call.

Children and young people's nutritional needs were assessed and care plans were recorded regarding food and fluids. Where needed the advice of the speech and language therapy service was sought so staff had guidance on supporting children and young people with foods and fluids. Staff and children were observed eating a midday meal together in Jacksplace and Naomi House. There was a relaxed atmosphere with children, young people and staff, parents chatting or communicating with each other. Staff involved and talked with children and young people as they sat and ate their meals together. Specialist diets were provided and there was a choice of food.

In Naomi House consent was sought from children's parents and this was reviewed before each stay. For example, where a child's parent wished for them to be monitored by CCTV or a listening device because of their night time seizures or specific health conditions, written consent was obtained. In addition parents were given information on how their child's privacy and dignity would be maintained whilst using CCTV and or listening devices.

In Jacksplace young people gave their own consent where they were able to. This included developing their emergency care plans and making advanced care plan decisions.

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.

Young people over the age of 18 can only be deprived of their liberty to receive care and treatment when this is in their best interests and legally authorised under the MCA. The application procedures for this in hospices are called the Deprivation of Liberty Safeguards (DoLS).

The head of Jacksplace had made appropriate referrals to the supervisory bodies under DoLS for young people prior to their stays at Jacksplace. They were seeking advice from each authorising body as to their requirements for applications. For example, whether they needed to apply prior to each stay or whether an authorisation would cover a fixed period of time.

Some young people and adults had been assessed as not having capacity to make decisions about some aspects of their care and treatment. There was a prompt in young people's records for staff to consider the person's capacity to make specific decisions on a daily basis. We saw staff had completed this to make sure they had involved the young person in making decisions.

Two of the young people staying at Jacksplace did not have the capacity to make decisions about whether listening devices or a safe bed space were used. They had the written consent of their parents recorded in their care plans. However, as these young people were adults these decisions should have been made in their best interests following the principles of the Mental Capacity Act 2005 (MCA). The registered manager and head of Jacksplace and adult services understood how the principles of the MCA applied to this situation and took immediate action to ensure these best interest decisions were made and recorded in line with the MCA. To demonstrate this the provider sent us a copy of the 'Emergency Care Plan for Young People Aged 16 and over'. This included a mental capacity assessment, a record of the people involved in making any best interest decisions and the decision made.

Staff were trained so they could provide specialist care for the children and young people. The staff we spoke with had completed a comprehensive induction programme and had update training. There were two team study days a year and a regular Friday afternoon teaching session.

The provider had developed a competency framework for the nursing and care team. This included all of the skills needed to meet the needs of an individual child or young person. The competency of staff was regularly assessed whilst a child or young person with specific needs was staying at the hospices to make sure they were able to put their training into practice. Staff were very knowledgeable about the children and young people and their health conditions and how they communicated. Staff told us that they did not work alone with each child or young person until they were confident they could meet the child or young person's needs. They were trained to meet the specific needs of children and young people. For example, all nursing staff were trained in tracheostomy care and invasive ventilation (This is a method to mechanically assist or replace spontaneous breathing using a mechanical device inserted into the skin. For example, using a tracheostomy). This may involve a machine called a ventilator so they could all effectively care for children and young people with these medical needs.

Staff spoke very highly of the practice educators and the training programme. Staff said they were very well supported in their work and had regular supervision sessions as well as an annual appraisal of their work. Staff had group supervision sessions facilitated by the family support team. There were various meetings where staff could also discuss the needs of children, young people and their families or issues about the

running of the hospices. These included staff 'handover' meetings where information was communicated from one staff group to the next team coming on duty. We observed one of these meetings in each hospice where staff demonstrated they knew the needs of the children and young people in the hospice.

Naomi House has recently been refurbished and rebuilt. All of the bedrooms and communal areas have overhead tracking for hoists. This meant children and young people could be safely moved without the need for mobile hoists. There were five family rooms so that parents and siblings could stay with children during their stay. One of these family rooms was fully accessible for wheelchair users.

The bedrooms in Naomi House had listening devices and CCTV, piped oxygen, a television and lunar projector that projects lights and patterns on to the walls and ceilings. The hospices have specialist technology installed so children and young people can control their environment by using computer tablets.

A walkway has been built between Naomi House and Jacksplace this allows children and young people to access the hydrotherapy pool from both hospices without going outside. Additional communal rooms have also been built that children, young people and their families can use. For example, one child used 'Treetops' with staff to watch a movie on the large screen.

The décor and design of Naomi House and Jacksplace reflected the age group of children or young people and adults who used each hospice. Both hospices were well equipped with specialist equipment and fully accessible bath and shower rooms. Both hospices have a post bereavement suite where families can stay with their child or relative following their death.

Is the service caring?

Our findings

Positive caring relationships were developed with children, young people and their families. We observed that staff were very caring and compassionate towards children, young people and their families. They made sure children and young people were content, comfortable and having fun wherever possible. Staff showed concern and responded quickly and calmly when children and young people were unsettled or upset. For example, they constantly reassured one young person who was distressed because they needed to have suction to clear their airways and a nebuliser. Staff gave the young person their full attention and sat talking with them during and after the intervention. The young person smiled, laughed and gave staff eye contact once the intervention was completed.

Another young person needed medical treatment that could only be provided at the hospital. The staff were very concerned about the young person's wellbeing. This was because their parent was away. Staff arranged an urgent appointment for the procedure and took the young person, with another one of their relatives, to the hospital in the hospice's own transport. This meant the young person was not distressed by going to hospital in an ambulance and they were supported by staff who knew them well, understood their communication and could reassure them and their relative. The staff made sure the young person returned to Jackspace as soon as possible after the procedure. The young person appeared calm and relaxed on their return.

Parents and relatives told us staff understood their emotional needs and focused on their wellbeing as well as the wellbeing of their child. Staff were highly motivated and developed caring and supportive relationships with children, young people and their families. One parent told us whilst they were staying with their child at the hospice it gave them "time to be mum and not a carer". Another parent told us they very quickly felt safe to leave their child in the care of the service. They felt in part this was due to the effort made by the staff team pre admission and the preparation made prior to their stay. On arrival the staff in the hospice had made them feel very welcome and the staff were responsive and sensitive to their and their child's needs. They commented positively on the caring and supportive attitudes of staff and how this made them, as a family, feel cared for especially after their long stay at the hospital.

A third parent told us their child got a "high level of care" and that their stays are "stress free" and "always fun".

In addition to the nursing, medical, and care staff, the family support team provided ongoing care and support for children, young people and their families. This included bereavement support and counselling.

A bereaved parent told us they were receiving counselling and support from the family support team. They described the counsellor as being there for them but not intrusive. They said, "It's been extraordinary and they have normalised it and made it ok. We have just felt so looked after and I can't fault them. They can have a big shiny star from me".

Another bereaved parent told us they were receiving bereavement counselling which they said had, "Been

phenomenal. Its personal, its individual and we couldn't do without their continued support". They said that staff were great, "Staff just don't forget you" and that the service was there for as long as they needed it.

The registered manager told us the service was now also taking referrals for bereavement and family support for the families of children who have died that were not previously known to the service.

The hospices also provided a support service for siblings and other family members of children and young people who use the hospices. This included a grandparents and siblings weekend and other events to provide support for different family members.

One parent we met told us, "The sibling programme is the jewel in the crown". They said how much this had helped their other well child over the years. They spoke about how their well child had now got a strong group of friends outside of school with whom they could share their experiences of having a sibling with a life-limiting condition. This parent also spoke positively about the family support team. They said they feel they now do not need to be alone when they have to plan their child's funeral. They said the family support team staff always take the time to speak with them when they are at the hospice.

At the time of our inspection no children or young people were receiving end of life care at the hospices. However, staff showed us the bedroom suites, processes and resources available to individuals who required this specialist care in the hospices. We saw that the families of children and young people could be close to their relative during this time. These bedroom suites in the hospices were also available for families to stay close to their child after they had died and before their funeral.

The hospices sought parents and families informal feedback at a 'Remembering weekend' where bereaved relatives gathered to remember their deceased child or family member. They wrote their feedback on green leaves placed on a tree. Feedback from a bereaved sibling event was also sought from the siblings who attended. This feedback was then reviewed to see if there was anything the hospices could do better. In addition, following the death of their child at the hospice, one bereaved family wrote about their experiences of using Naomi House for the hospice's newsletter. The article included the following from one of the bereaved parents, 'We thought hospices were the last resort, and why would we want to send our child there, her life wasn't finished yet? That's what a lot of people think about hospices, that they are only for the end of life. However, we agreed to look around. You could see everyone was enjoying themselves. People were willing to show us everything, it was bright and colourful. Straight away we knew this was where XXX needed to be, not in the hospital waiting for something else to happen.'

Another bereaved family had provided a video story about their experiences of using the Naomi House and specifically the bereavement suite. In the video they commented about how important the suite was and how it helped them with the transition and emotions of losing their child. This video story was available on the hospices' website.

There were advanced care plans in place for children and young people where parents or the young people had chosen to do these. Some children had a newly developed 'Collaborative Advance Care Plan' in place. The Collaborative is a group of NHS and private sector organisations with the common goal of delivering the best possible care to children and young people with life limiting and life threatening conditions. Where advanced care plans were not in place emergency plans were available so that staff had sufficient information to safely care for a child while supporting the parents' wishes.

Children's and young people's care plans included 'parallel planning' and this is outstanding practice. This is where a child or young person has two plans in place for different circumstances around their condition.

This shows good preparation for the family for if and when the circumstances change and their child's condition deteriorates. This discussion was reflected in the advanced care plan or emergency care plans. This work allowed families to make realistic plans and gave them choices.

The staff promoted the privacy of children, young people and their families. The service kept any private and confidential information relating to the care and treatment of children and young people secure. Children, young people and their families had access to private spaces in the hospices. For example, music therapies were provided in separate private rooms. Personal care was offered discretely. Staff had a good understanding of the balance between maintaining children and young people's privacy whilst also acknowledging the need to monitor their complex health needs. The use of CCTV or listening devices was closely monitored in order to protect and maintain children and young people's privacy. The equipment was only used at night for monitoring purposes and recordings were automatically destroyed after 28 days. Parents we spoke with were positive about the benefits of the monitoring available. For example, one child staying at the hospice had sleep apnoea but at home their parents had not been able to monitor this. As a result of staying at the hospice they had a better understanding of their child's sleep pattern and staff were able to take action.

Is the service responsive?

Our findings

Children and young people received a very responsive service. Feedback from parents included a bereaved parent who told us in terms of the overall package they received from the hospice, "It's very individual, and it's responsive to your needs".

Our observations showed us staff were responsive to individual's needs. Staff responded to children's verbal and non-verbal gestures and communication. For example, staff asked one young person to eye point when making a choice and used PECS (Picture Exchange Communication System) with another child to understand what activity they wanted to do. All of the staff we met and spoke with understood children and young people's complex ways of communicating. This reflected what was in their care plans. The plans included how they communicated and what they liked and did not like. This meant these children's choices and needs were responded to quickly. They did not experience any delays in doing what they wanted to do and subsequently did not experience any frustration at their communication not being understood by staff. We did not see any children or young people showing any frustrations or negative behaviours because they were not understood by staff.

There was a pre assessment team who completed assessments and reassessments for children, young people and adults before they started using the services or before each stay. The nurse who completed the assessments and records ensured that any care plans were in place and updated before each stay. These assessments included contacting children's community nurses, consultants and the young person and or their parents. For example, one child's seizure and medicines plan had been updated prior to them coming for their stay.

A health professional told us with new children and young people and those who have not stayed for a while the service and they said the service was always proactive. They also told us the provider always sought out educational teaching and guidance for new equipment to make sure they could safely care for each child and young person. This meant the hospices were able to provide a service to children and young people with new equipment that they may not be able access elsewhere in the community. Another health professional said the service communicates well and they found them an invaluable resource.

There was a holistic approach to children and young people's care with the physical, well-being, social and spiritual needs of each child and young person given equal importance, together with the needs of those closest to them. Each child and young person had a comprehensive care plan in place. These were clearly laid out and staff told us they were easy to follow. These plans considered children and young people's medical, personal care, play or activities and their spiritual and well-being needs. There were daily handovers and we observed these in both hospices. This meant important information about the children and young people's medical, personal care and well-being were handed over to the staff coming on duty.

Children and young people and their families' had their social, cultural, spiritual and religious needs considered and planned for. There was a multi faith space in 'Treetops' that was accessible from both hospices. For example, each child and young person's care plan included their spiritual needs. These care

plans and staff we spoke with considered the importance this element of their needs and how meeting these spiritual needs contributed to the child's wellbeing and overall management of their physical condition.

There was a weekly multi-disciplinary team (MDT) meeting that was chaired by the head of family support services. This was an opportunity for the different professionals involved with children and young people to discuss new referrals and receive feedback about children or young people to ensure they received a planned, person centred and coordinated service. At the meeting we observed the views of the parents were also fed into the discussion. For example, the consultant spoke about a parent who had told them they had had a call from the family support team, which the parent described as invaluable because, "She is the lady who allows me to cry".

In addition to the hospices, the service was also very responsive to the needs of children and young people with both life limiting and life threatening conditions in the community who may not have previously accessed the hospices. The service was evolving to meet these needs and was looking at ways of developing the services further by working in partnership with other agencies and hospital trusts. For example, one child who was staying at Naomi House did not meet the service's criteria for ongoing support and respite but they were offering a step down stay for the child and their parents following surgery before they went home. In addition, the services were offering respite stays for children and young people who had high medical needs and were staying on the high dependency unit at a local hospital but were not yet medically fit to return home. One parent told us that as soon as they arrived at Naomi House from the hospital their child visibly relaxed and this had meant they were able to relax as well.

Professionals told us the service was very responsive to children's and young people's needs. One professional told us when they had requested last minute respite for children "They are as accommodating as they can be". They also commented positively about the new service that enables children and young people who are long stay in hospital, to be able to have respite at the hospices as "really good".

The service has developed a responsive emergency and end of life service for children and young people and has appointed a specialist children's nurse to manage this. They work closely with the children's community nurses. In addition they have joint funded specialist nurses with other children's hospice services to further develop community services to support children in their own homes.

Children and young people received a child and person centred service when they moved between services. For example, the hospice employed a paediatric consultant and a children's specialist nurse who worked both at the hospice and a local hospital. Because of the joint roles of these staff, the nursing staff at the hospice had been trained to meet the specialist needs of children with complex cardiac conditions and children who required overnight renal dialysis. This meant that the hospices could provide respite stays for these children and young people rather than them having to go into hospital. These children received continuity of care by being cared for by the consultant and nursing staff both at the hospital and the hospice.

We spoke with parents, staff and looked at records about the way the service supported children and young people when they moved between Naomi House and Jacksplace. We saw records of involvement in meetings between health, education and social care professionals so there was a co-ordinated approach for children and young people. Young people's transition was planned on an individual basis. For example, some young people started using Jacksplace from the age of 14 whereas others did not access Jacksplace until they were 18. A parent spoke highly of their child's transition between Naomi House and Jacksplace and knowing that their child was going to continue to be supported by the same staff was very important to

them and their child.

There hospice had developed a 'Takin' Charge project' with Action Duchene (A charity for Duchenne Muscular Dystrophy) for boys and young men aged between 14 and 19 years old. This project was focused on the boys and young men learning new skills and planning for their future. This included sessions for parents looking at 'letting go' and the sessions took place at Jacksplace and a local college. 14 boys and young men and their families including siblings took part in the workshops and project. The feedback had been evaluated and was being used to produce individualised plans for the boys and young men involved.

There was a specific play/activities team who provided both individual and group activities for children and young people. These activities were based on children's and young people's preferences and were suitable for each age group staying at the hospice. These activities often also included an educational element and were identified in the child's 'playing and learning' section of their care plans. Where a child or young person came into the hospices with homework or activity sheets this was included in their care plan. The hospices sent us examples of these care plans following the inspection.

Children and young people's educational needs were met during their stays at the hospices. There were links with a local school that some children attended. The head teacher had attended staff meetings and discussed how Naomi House and Jacksplace could contribute to the children and young people's Individual Education Plans (IEP) whilst staying at the hospices. Children and young people would bring a copy of their IEP or their 'all about me' folder, which outlined their goals and aspirations. The staff were then able to help children and young people work towards these during their stays at the hospice. For example, these objectives may have been a practical activity such as helping the child or young person learn to use a spoon or hairbrush.

The activities during the inspection included using the sensory room, the hydrotherapy pool, art, t-shirt painting, music, visiting Father Christmas in a local town for the children, watching movies on the large screen and being read to. A music therapist worked with children and young people on an individual basis. They were actively engaged in the sessions.

Children accessed the new sensory room that included specialist equipment that could be controlled by children making noises or using switches or touch and light sensors. This room included, lights, sound, smells, interactive responsive light systems. The staff were able to fully personalise all of the equipment so that when each child used the sensory room it was set up specifically for their sensory needs. This meant that each child or young person benefitted from an entirely personalised experience. For example, the sensory experience for one child included a child's favourite piece music and light projector show that they could stop and start the by making a noise or touching where the lights were projected. This gave them a unique experience that stimulated their senses and increased their wellbeing. Staff told us the new sensory room had meant that all children and young people with very differing abilities were able to control their environment in their own individual ways.

Parents knew how to raise any concerns and complaints and told us they were confident that if they did have any concerns they would be addressed. Parents did not raise any concerns with us. There were robust systems for investigating complaints and ensuring that any actions and learning were implemented. For example, following a complaint from a parent about a child's stay the findings and actions required were shared with all staff at the services. To make sure that the learning was embedded there was a full review of the child's next stay by the governance team. These findings were then fed back to the complainant. These findings were shared with staff and board members. Staff confirmed there was a positive culture about learning from any complaints.

Is the service well-led?

Our findings

During the inspection we saw parents were comfortable talking with staff and managers. All of the parents we spoke with felt they were involved, consulted and their views and opinions were listened to. None of the parents we spoke with had anything negative to say about the service they received they only had praise.

We also received very positive feedback from the professionals we spoke with. A hospital consultant told us they thought the service was fabulous and very professional. A specialist nurse said there always seemed to be a very positive attitude from all staff and that families give very good feedback".

Every member of staff we spoke with was motivated, very open and proud of the service they provided. Staff told us that the management team were very accessible and visible and they all felt able to approach them. They had regular opportunities to give feedback and felt involved. Staff knew how to follow whistleblowing procedures and raise concerns. They were confident that any issues they raised would be addressed.

There were three monthly care team meetings, regular family support meetings and the management team meetings on a weekly and health and safety meetings on monthly basis. Representatives from the management team attended and fed into quarterly board meetings.

The hospices were developing an electronic feedback system so children, young people and their families could provide instant anonymous feedback about the service. The hospices have previously used a system of sending surveys though an independent body but the head of governance told us that although the results were useful, they did not provide the specific information they needed to be able to develop and improve the service.

The head of Jacksplace was working with the young people one day a week so they gather their views and these were then reflected in their individual plans and plans for the service. For those young people with complex needs who may not be able to make their views known, their representatives are telephoned after each stay to gain their views. Any feedback received was acted on. The Head of Jacksplace plans to develop of an open forum to discuss with young people the development of both in-house care and day care activities. The first meeting was planned for a weekend in January 2016 so young people are able to attend. The feedback from this consultation and others is planned to be published on a quarterly basis.

The ongoing development of the service was based on feasibility studies and the identified needs of children and young people by health professionals in hospitals and in the community. For example, the upper age range for young people has recently been raised to 35 years old. The service was developing the service for children with specific medical needs by training the nursing and care staff to meet those needs. The registered manager told us they were appointing an adult consultant at Jacksplace to oversee the medical care of the young people and adults. They planned to further develop and train staff to specialise in either children's or young people and adults care.

There was an open culture about reporting and investigation incidents. Staff told us there was not any

blame culture about incidents and that learning was shared with them so they could change any practices they needed to. The head of governance sent a monthly newsletter by email to all staff to share any learning and outcomes from incidents and complaints. In addition learning was shared at staff meetings and changes were made to procedures where necessary.

We spoke with a trustee who told us they all work a day on shift once a year in the either of the hospices. This was so they could fully understand the work the hospices and to ensure they met with staff. The trustee told us they were often in the hospices and had regular contact with children, young people, parents and staff. The registered manager and staff told they had access to and contact with trustees if they needed to.

There was an effective system in place to regularly check and monitor the quality of the service. There was a comprehensive program of in-house regular audits such as medicines, infection control, privacy and dignity, hand washing, accidents/incidents, complaints and compliments that fed into the clinical committee group and that were also considered at the board meetings. In addition to this, there were health and safety meetings that reviewed all incidents that were then fed into the healthcare governance clinical committee meetings. All complaints and investigations were reviewed by the board to make sure they were investigated appropriately. At each board meeting the board received feedback about a child or young person's experiences whilst staying at the hospices. This included what went well and what they could improve. We saw action plans were put in place for any shortfalls identified and these were monitored and followed up by managers and the board.