

Julia's House Limited

Julias House

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	

Overall summary

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 and to pilot a new inspection process being introduced by CQC which looks at the overall quality of the service.

Julia's House provides a respite service for 69 children and young people with life limiting or life threatening

conditions. They are cared for in the hospice or in their own homes and are supported to access their local communities. Up to four children and young people can stay overnight at the hospice and up to eight children or young people can access day sessions at the hospice. Julia's House also supports the families of the children and young people who use the service.

The inspection was announced and took place on 8 and 11 August 2014. We told the provider three days before our visit that we would be coming.

Summary of findings

There was a registered manager at the service who had worked at the service for many years. A registered manager is a person who has registered with the Care Quality Commission to manage the service and has the legal responsibility for meeting the requirements of the law; as does the provider.

Most of the children and young people we met and visited 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 in the care of Julia's House. 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 good links and access to the specialist healthcare support they needed whilst using the service. All parents and professionals were happy with the care provided by Julia's House. 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. One parent told us: "When my son is in hospital they offer to go and sit with him and that makes a big difference, they just offer I don't ever have to ask".

Throughout our inspection we saw examples of creative personalised care that helped make the service a place where children and young people felt included and consulted about how they wanted to spend their time. 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.

Any risks to children and young people's safety and health needs were assessed and managed to minimise them.

We saw children and young people were supported to learn, play, develop and take part in and try new activities and experiences in the hospice, their homes and in the community. One parent said: "They do so much with him and so much more than we ever imagined he was able to do. They champion him it's amazing".

Children and young people were supported and cared for by their own specialist teams of staff. They were supported by at least one member of staff during sessions at their home or in the hospice.

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 needs.

There were safe systems in place to safely manage and administer medicines in both the hospice and in children and young people's homes. 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 and families were involved and consulted about all aspects of the service. 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 quality of the service provided.

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. Parents and professionals told us children and young people were safe in the care of Julia's House.

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. During our inspection staff were kind and compassionate and treated children, young people and their families with dignity and respect.

Parents and professionals told us Julia's House cared for the whole family not just the child receiving the service. They told us the staff routinely offered to do more than what the service initially offered.

Staff were aware of children and young people's preferences. Children, young people and their families were involved in decisions about the support they received and their independence was respected and promoted. Staff spent time listening and talking with children and their families. They took their time to make sure they explained things with children in ways they could understand so they could make choices.

Children, young people and their parent's wishes in relation to end of life care were sensitively discussed and planned for at the pace of each individual.

Outstanding



Is the service responsive?

The service was 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.

Outstanding



Summary of findings

Children and young people were supported to pursue activities and interests that were important to them both in the hospice and in the community. Staff made sure they had play equipment and technology to meet each child's needs. Each child and young person had their own play and occupation plan that was based on their skills and abilities.

There was a complaints procedure which children, young people and their families knew how to use if they needed to.

Information was shared effectively when children and young people moved between services. For example, there was a new project supporting young people making the transition to adult services.

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.

The management team had arrangements in place to assess and monitor that there were enough staff, with the right skills, knowledge and experience to meet the needs of people.

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

Good



Julias House

Detailed findings

Background to this inspection

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

Before our inspection, we asked the provider to complete a Provider Information Return (PIR). This is a form that asks the provider to give us some key information about the service, what the service does well and improvements they planned to make. We reviewed this and other information we held about the service such as any concerns or complaints, and information about incidents they notified us of. We last inspected Julia's House on 30 November and 1 December 2013 and the service met the regulations we inspected against.

On the first day of our inspection we spoke with and met six children and young people. The second day of our inspection we visited two children and young people in their homes whilst they were supported by Julia's House staff. We spoke with eight children and young people's parents. We contacted a further 15 parents by email to ask them their views on the service. We spoke with fifteen staff members, including care workers, nursing staff, the two directors of care and the registered manager.

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 lunch and during individual and group play and therapeutic activities. We reviewed a range of care records for five children and young people. We also reviewed records about how the hospice was managed. This included, staffing records, audits, meeting minutes, maintenance records and quality assurance records.

We contacted seven health and social care professionals who worked with the service to obtain their views. As part of the inspection we asked the managers to send us information about staff training, policies and procedures, audits and development plans.

This report was written during the testing phase of our new approach to regulating adult social care services. After this testing phase, inspection of consent to care and treatment, restraint, and practice under the Mental Capacity Act 2005 (MCA) was moved from the key question 'Is the service safe?' to 'Is the service effective?'

The ratings for this location were awarded in October 2014. They can be directly compared with any other service we have rated since then, including in relation to consent, restraint, and the MCA under the 'Effective' section. Our written findings in relation to these topics, however, can be read in the 'Is the service safe' sections of this report.

Is the service safe?

Our findings

We observed that children and young people were relaxed with staff both in the hospice and their homes. They played, smiled, laughed and gave staff eye contact. One child sought the physical comfort of staff and leant into them when they were unsettled. This showed they felt comfortable and safe with staff. Parents told us they felt their children were safe in the care of Julia's House both in the hospice and in their homes. One parent told us they had given consent for staff to take their child out in the community and they always felt confident their child was safe.

There were child and adult protection and safeguarding procedures in place. All of the staff had received children's safeguarding training as part of their induction and ongoing training. All staff were able to tell us about the types of abuse and how to report any allegations. Records showed 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 their home 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, one child had been assessed as at risk of developing pressure sores. The staff knew how and when they needed to reposition the child to reduce the risks of pressure damage.

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

Children and young people were supported by one or two staff at all times and all of their needs were met. The director of care showed us how the staffing for each child was calculated according to their needs. Children with assessed nursing needs were always cared for by a nurse and a care worker both in the community and at the hospice. Each child had a named nurse and a team of care workers and nurses. There was an electronic staffing scheduling tool used to plan each child's sessions in the

community and at the hospice. The schedules were planned two weeks in advance for community sessions, overnight stays and day sessions at the hospice. Parents and staff told us there were enough staff supporting each child to be able to offer community sessions or respite stays at short notice.

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.

We found medicines were managed safely. Each child or young person had a medication plan which detailed the medicines prescribed and whether they were administered orally or through their feeding tubes. Some children 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 or young person's medicines and how and when to administer them. We observed nursing staff administering medicines through a child's feeding tube. They administered these medicines as detailed in the child's care plan.

We looked at the medicines management systems in place in children's own homes and in the hospice. There were robust systems for handing over medicines when children and young people came to the hospice and when staff arrived at children's own homes, and for discharging medicines back to parents.

Medicine records both at the hospice and in children and young people's homes 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. One parent said, "my daughter has a very complex routine with her medication and the medicines need to be given at the correct times to make sure she is comfortable. All of her medicines are managed well".

The service did not routinely hold or manage controlled drugs but there were occasions when they did. There was the facility to store controlled drugs within the medicines

Is the service safe?

cabinet. However, this did not meet all of the good practice recommendations set out in Schedule 2 of the Misuse of Drugs (Safe Custody) Regulations 1973. The registered manager and director of care confirmed that they had also identified this and that there were plans to purchase and install specific controlled drugs storage by October 2014.

Environmental risk assessments were in place for the hospice and for each child or young person's home. 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 sensory equipment.

Staff supported children and young people to transfer to and from their wheelchairs with hoists and slings in a safe way and as described in children's moving and handling plans. Staff told us they had been trained in moving and handling, which was also confirmed in staff training records. Staff working in children's own homes checked the equipment before they used it. For example, a staff member showed us how they checked a suction machine before using it to clear the child's airway.

Staff followed infection control procedures for the children. Parents told us staff followed safe hygiene practices when providing care. For example, safe infection control

procedures were followed for one child having suction to clear their airway and another child having their food and medicines through their enteral feeding tube (a tube that goes into their stomach). There was a stock of protective equipment such as gloves and aprons for when they were working in the community and in children's own homes. They had disinfection wipes to be able to clean play equipment and toys after each visit. There was a programme of cleaning and disinfection for all equipment, play equipment, the sensory room and toys following each session and/ or overnight stay at the hospice. Protective equipment and cleaning materials were readily available at the hospice. The hospice was clean during the inspection. Staff were trained in infection control and regular infection control audits were undertaken to make sure that the policies and procedures were being followed.

There were policies and procedures in place in relation to the Mental Capacity Act 2005 (The MCA). The MCA was included in the staff induction programme and staff had a basic understanding of the Act. However, the registered manager and directors of care had identified that further training was required for staff to fully understand the implications of The MCA for young people aged over 16 years old. They had identified this in their training plan. There had not been any circumstances when the young people over the age of 16 had been deprived of their liberties.

Is the service effective?

Our findings

We observed children and young people being supported by staff. Staff had the skills and knowledge to be able to meet each child's complex needs. Staff were confident of their abilities to be able to support each child. Parents, staff and staff rotas told us that each child had their own team of care workers and nurses. This was to make sure that staff skills were matched with the needs of the child. One parent said: "my child has a consistent staff team of four or five staff and a named nurse. When new staff join the team they work alongside staff until they know my daughter and how to care for her". Another parent said: "The staff's skills are brilliant; my son has a very complex epilepsy plan which changes frequently and they work with his consultant. We are trying a new rescue medicine (emergency medicine) and the staff are very knowledgeable about it all."

Staff were trained so they could provide specialist care for the children and young people. The staff we spoke with had completed an induction programme and had annual update training. Staff training was a mix of on-line and face to face training. The competency of staff was regularly assessed to make sure they were able to put the training into practice. Each member of staff had their own personal training diary and staff received specialist training to meet the needs of the specific children or young people they were supporting. For example, some staff were trained in the use of airway suction (clearing breathing airways) whilst others were trained in enteral feeding (feeding through a tube into the stomach). 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's needs.

Staff told us they had one to one support and annual development meetings and felt well supported by managers to fulfil their roles. We saw records of these meetings and annual development plans in staff files.

We asked health and social care professionals, including paediatric doctors and specialist nurses, for their opinion of the service, and they all gave us positive feedback about the skills and knowledge of staff. One health care professional told us Julia's House staff and the health team involved in the care of one child had identified that there was a shortage of staff with nursing and assessment skills

in the management of end of life symptom control. This had resulted in Julia's House staff needing to be supported by specialist community health staff during a child's stay at the hospice. This was because the nursing staff did not routinely provide this type of nursing care and their skills and knowledge was limited. As a result, a specific training programme had been developed with the community nursing and hospital team to make sure staff had the skills and knowledge to provide this element of nursing care in the future.

We observed children and young people being supported to eat and drink or have their meals through their feeding tubes. Staff chatted with the children and young people throughout their meals, explained what they were eating and assisted them to eat and drink at a pace that suited them. For example, one member of staff supported one young person to eat their main meal and they followed the young person's non-verbal cues and eye movement to know when they were ready for their next mouthful. This reflected the details in the young person's care plan.

Each child and young person had a dietary plan in place for when they attended a session or stayed at the hospice or received support in their own home. These plans detailed whether they had their food and drinks orally or through their feeding tubes and how staff were to support them. Where necessary these dietary plans were based on the guidance of dieticians and speech and language therapists. Records of the food and fluids taken by each child and young person were kept so their food and fluid intake could be monitored.

Children and young people who used Julia's House had good access to health services and professionals when needed. Care plans showed the hospital and community health teams involved in supporting each child or young person. Whilst children and young people stayed at the hospice they had access to a local GP who prescribed any additional medicines and oversaw any immediate health issues. There was also access to the paediatric team at the local hospital and the community nursing children's team. Health care professionals told us there was good communication between Julia's House staff and themselves and that the staff sought advice and guidance when needed.

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

Is the service effective?

complex health needs. For example, one young person had brittle bones and was unable to reposition themselves. There was a detailed plan as to how staff were to move the young person without injuring them and to manage their pain relief. We saw staff followed this plan and effectively managed the young person's pain relief so they remained as comfortable as possible.

The hospice is a converted house and was well maintained and equipped to meet the complex needs of children and young people using the service. There was a lounge, dining area, sensory room and play/activity room with computers and sensory play equipment. There was play equipment for children and young people of all abilities. For example, there was a computer with a touch screen and switches and there were games consoles for children with different abilities. The garden had lots of sensory objects to play with, touch and smell. We saw children and young people used all areas of the hospice and garden.

The bedrooms and bathrooms had specialist equipment such as beds, cots and baths and sinks that were height adjustable. There was a ground floor bedroom suite with a separate room so parents could stay with their children. Staff told us, and we saw that, bedrooms and the play/activity room could be decorated with pictures and posters which reflected the interests of each child or young person. There was a range of bedding which also reflected the age and interests of the children or young people. One of the first floor bedrooms had a sofa bed so young people could have a siblings or friends stay over if they wanted.

The hospice was decorated and furnished with bright coloured murals and furnishings. When a child or young person was at the hospice for a session or stay their photographs, and things of interest to them, were displayed in the activity room and their bedroom.



Is the service caring?

Our findings

Staff supported the children, young people and their families with care and compassion. One child was unwell during their visit to the hospice and was very sleepy. The staff member working with them, stayed with them and gently talked with them, held them and gave them a hand massage with sensory oils. They supported this child with compassion and gave them comfort. At no time was this child left unattended or without comfort from staff.

Parents told us that staff were caring and kind and all staff were very committed to providing a high quality service for the whole family not just the child. One parent said: "They are all lovely girls they look after (child) so well they are so caring." Julia's House provided a support service for parents and siblings of children and young people who used the service. Parents spoke highly of the opportunities to meet other parents and families at regular events such as the summer BBQ. They also told us that the sibling support groups and events were invaluable to the families. There was a sibling support coordinator who arranged trips, group sessions and short breaks away for siblings so they had the opportunity to have peer support and fun away from the pressures of living in a family with a child with a life limiting illness. One parent told us, "Julia's House offers us as a family a truly holistic service, which is mainly delivered in our home." They also told us how staff had supported them through the loss of another of their children. This parent had driven for over an hour to drop off their child for the day, so they could spend the day doing fun things with their other two well children. All of the health care professionals told us one of the unique things about Julia's House was the service was focused not just on the child's needs but on the whole family. The flexibility of the support meant that each child could be supported in the best way for them. For example, with sessions in their home, community or at the hospice.

Parents told us staff were thoughtful and offered to do more than just the service provided. One parent said: "When my son is in hospital they offer to go and sit with him and that makes a big difference, they just offer I don't ever have to ask".

We observed staff treating children, young people and their families with dignity and respect. Children and young people and their family's preference of gender of staff was recorded in their assessments and was respected. We saw

staff spent time listening and talking with parents and siblings whilst they dropped their child off at the hospice. Staff talked and explained to children and young people what was happening and gave them choices in ways they could understand. For example, one young person chose what DVD they wanted to watch by eye pointing. For another child, staff used verbal choices and Makaton (a type of sign language) so the child could make their choice. Staff took their time to make sure children and young people were settled and happy throughout the sessions at the hospice and in their homes.

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 hospice. For example, music and massage therapies were provided in separate private rooms. Personal care was offered discretely. Staff had a good understanding of the balance between maintaining young people's privacy whilst staying overnight at the hospice whilst also acknowledging the need to monitor their complex health needs.

At the time of our inspection no children or young people were receiving end of life care at the hospice. However, staff showed us the bedroom suite, processes and resources available to individuals who required this specialist care in the hospice. We saw that the families of children and young people could be close to their relative during this time. This bedroom suite in the hospice was also available for families to stay close to their child after they had died and before their funeral. Staff told us they were led by each parent as to when and if they were comfortable and ready to have any discussions about their child's end of life care. There were regular assessments and reviews by hospital consultants, community nursing teams and Julia's House staff. From these, individual care plans would be developed which outlined the end of life preferences of the child, young person and their family and whether they would want this care at the hospice or in their home. One paediatric doctor wrote to us: 'The feedback from my own patients and families who use Julia's House, and my own experience during an end-of-life care episode is massively positive, that the staff are dedicated, focused on the needs



Is the service caring?

of the family (especially support for siblings), and form an essential part of children's respite and palliative care needs, including providing palliative care in the home environment.'



Is the service responsive?

Our findings

Our observations showed us staff were responsive to individual's needs. Staff responded to children's verbal and non-verbal gestures and communication. 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 communication plan. These plans included how they communicated and what they liked and did not like. For example, one child we met could understand what staff were saying but they were not able to verbally communicate. They would laugh and make a noise if they were enjoying something. Staff told us the child would look away or cry if they were unhappy. The child made choices by eye pointing and we saw that throughout the session staff gave them visual choices of things to do.

We saw that children were engaged in play or relaxation activities during their session at the hospice and in their homes. One child at home was doing messy painting with staff. The child signed using Makaton (a type of sign language) and told us they were having fun and they liked the staff. They told us they had been to the park earlier on their bike. Another young person at the hospice for the day used a computer programme with staff to tell a story and they used large touch switches to choose different options. They laughed, smiled and gave staff eye contact with staff during the activity. Staff understood each child's ability to concentrate on playing with toys or an activity and changed the activities when the child or young person became unsettled or bored.

Children and young people had their own activity or play/ learning plan that staff followed in the hospice or in their homes. Julia's House employed a 'play maker' who undertook individual assessments and developed a play plan that was focused on each child's needs and abilities. Parents and staff spoke very highly of the activities that children did and the impact that these play plans had on their child's well-being and development. One parent said: "They do so much with him and so much more than we ever imagined he was able to do. They champion him it's amazing". Another parent said: "They do lots of arts and crafts with my daughter and treat her as the teenager that she is". Staff told us the activities they provided were

individual to each child. For example, staff had songs and sounds on their phones for each child they supported. One child's staff team had the sound of a washing machine on their phones as this was the sound that relaxed the child.

Children and young people and their families' had their social, cultural and religious needs were considered. For example, one parent told us they had regular sessions from staff to support their child to go to church with them on a Sunday. They said that staff sitting with their child at church meant their child was able to be involved in worship on an equal footing with their siblings and the rest of the family and that was really important to them as a family.

Parents told us they had been asked for their consent and we saw records of parent's written consent for their child to receive care, treatment and support from Julia's House staff in the hospice, their homes and in the community. Staff sought children and young people's consent where they were able to make those decisions.

Parents and staff gave us examples of how the service had been responsive to their child and family's needs. One parent told us that when another of their children had become sick, staff had provided additional support in their home for the child who used the service, so they could look after the child who was unwell. During the inspection another parent was admitted to hospital and staff were quickly organised to support the family and child in their home the same day. Another parent told us how they had wanted their child, who was fed through a feeding tube, to experience the same meals as the rest of the family. This meant blending the food with liquids so it could be given through the feeding tube and the child could smell and taste the food. The parent said Julia's House staff immediately responded to this request, where other health professionals had been reluctant to try it. Staff supported the family in this decision and worked with health professionals to ensure this happened and that staff had the training to do this.

Children's and young people's needs were assessed and planned for. The care plans were child centred and focused on children's strengths, abilities and development and not on their life limiting conditions. Children and young people and their families had been involved in developing these plans. Health and social care professionals had also contributed to the plans. The care plans detailed the personal and health care support children and young people needed as well as focusing on their social and



Is the service responsive?

emotional wellbeing, play and learning, their end of life care and communication needs. The care plans also focused on promoting the children's independence. For example, one child's plan said how they liked to assist with the suctioning to clear their airway. We saw that staff encouraged the child to take part in this procedure in a fun way as detailed in the plan.

We observed a staff handover at the start of the day session at the hospice. This was led by the care worker who was working with each child or young person that day. The staff went through each child's care plan and gave the rest of the team any updates or changes so all staff had up to date information about each child that was attending the session. There was a system for parents to check into the hospice with their children so they could inform staff of any changes in their child's condition.

Care workers and nurses told us that any changes to a child's needs identified in the community were documented and phoned through to the hospice so that any changes could immediately be made to care plans. Parents told us the lead nurse for each child also visited them at least six monthly or as and when their child's needs changed to make changes to care plans. Staff gave us an example of where they had been responsive to the changing wishes of parents in relation to the end of life care for their child. Staff had been able to respond appropriately and follow the changed wishes of the parents. This was at the time of a critical incident at their home that had differed to the advanced decision that was documented.

Parents told us they knew how to make a complaint and that they were encouraged to raise their concerns. They said they felt comfortable raising concerns with staff, their named nurse and managers and that whenever they had raised any issues they had been addressed to their satisfaction. One parent said: "I was confident and happy with the way they managed our concerns and that they put things in place to make sure it couldn't happen again". Another parent said: "When we raised a concern, they just sorted it out they weren't defensive they just sorted it out".

Managers and staff told us they encouraged children, young people and parents to raise concerns and complaints. We looked at the complaints received by the

service since our last inspection in December 2013 including one complaint where the complainant was dissatisfied with the outcome. We found that all complaints had been investigated and complainants had been fully responded to in line the organisation's complaints procedures.

We spoke with parents, staff and looked at records about the way Julia's House supported children and young people when they moved between services. 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. Parents spoke positively of the co-ordination between Julia's House staff and the other professional's involved with their child. One parent said: "(named nurse) does all the chasing to make sure that any changes to my child's medications are shared between the consultant and everyone else involved".

The Julia's House staff were working with the local hospital on a project for early referrals for new-born infants with life limiting illnesses. This included considering referring parents to the service before the infant was born and linking in with the midwives. This was to make sure parents were aware and referred into Julia's House at an early stage to make sure new-born infants and parents received all of the support available. Staff and parents told us in the past parents had not always been made aware of and they did not fully understand the services Julia's House could offer. One parent told us: "We didn't access Julia's House until my child's first birthday. We didn't understand what Julia's House was about. We thought it was just a hospice and we wish we had a better understanding as soon as my child was born. We were so isolated for that first year and we didn't need to be. Staff here are so supportive and everyone is amazing."

Staff had identified the lack of service provision for young people in transition to adult services. There was a lead nurse responsible for a transition project and planning and they were working with a local adult day hospice to trial day sessions for young people. They would be supported by Julia's House staff at the adult day hospice as a way of introducing them to adult services.

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. Comments included: “It’s fantastic”, “An excellent service that has been consistent over the years”, “Everyone is amazing and the support is brilliant”, and, “my child has a good time and that’s the best thing”.

The registered manager showed us the newsletters that were used to share information with children, young people and families, staff and health and social care professionals. Children, young people and their families were consulted and were encouraged to be involved in the service. For example, there was an annual anonymous and confidential survey and in addition to this children, young people and their parents were consulted during the regular family events. An action plan was developed from the results and fed back to families. There were parent representatives on the board of directors and all parents had direct access to the board without having to go through the registered manager or directors of care. Parents told us they had been provided with a ‘Family Handbook’. This handbook included information on how to make a complaint, the professional boundaries between staff and families, the use of social media and policies such as infection control and medicines.

The registered manager visited the hospice at least twice a week and sat in on staff meetings, talked with staff, parents and children and young people visiting the hospice. The registered manager was also the chief executive of the charity and had additional management responsibilities apart from being the registered manager of the hospice. The directors of care were based at the hospice and were available to children, young people, families and staff. There was an out-of-hours system in place for staff who were working with children and young people in the community. This was so that families could quickly access advice and support when they needed it.

All staff told us they were very well supported and communication was good between managers and staff. They felt they could approach and talk openly with all managers and that the managers listened to them. Staff told us there was not a blame culture and learning from

complaints and incidents were shared at meetings and one to one meetings. All staff told us they enjoyed their work and they were very committed to the children and young people they supported. They could also access a counselling service 24 hours a day and seven days a week to seek professional emotional support when this was needed. There were bereavement sessions held for staff following the death of a child. One member of staff said: “I love it, I love working with the children and families, I think we make a really big difference and we can support families through the sad times. I always feel we’ve done all we could”.

Staff knew how to follow whistleblowing procedures and raise concerns. They were confident that any issues they raised would be addressed. We saw in complaint records an example of where a staff member had whistleblown and the action had been taken in response. The provider sought feedback from the staff through a confidential online and postal staff survey carried out directly by external independent assessors and used this feedback to identify any changes needed to the service. The provider had recently issued a similar anonymous survey to volunteers the results of which were expected shortly.

Staff told us there were regular staff meetings. Care and activities’ workers spoke highly of the newly introduced care team meetings. These meetings were separate from nurse and senior nurse meetings and focused on issues and areas of learning important to the care and activity workers.

There was an effective system in place to regularly check and monitor the quality of the service. For example, records showed the provider’s representative (nominated individual) conducted regular unannounced visits and presented reports to the clinical governance group. There was a comprehensive program of in-house regular audits that fed into the clinical governance group and that were also considered at the board meetings. Managers and named nurses regularly reviewed and observed the care and support provided both in the hospice and in the community. In addition to this, there were health and safety meetings that reviewed all incidents that were then fed into the finance and risk committee meetings. All complaints and investigations were reviewed by the board

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and the clinical governance group to make sure they were investigated appropriately. We saw action plans were put in place for any shortfalls identified and these were monitored and followed up by managers and the board.

There was strategic plan in place that was laid out as a monopoly board with pictures. This was sent to all children, young people and their families. This was an easy to follow way of sharing the four year plan. The registered manager told us feedback about the format from children and their families was positive and that it had made the information easier to understand.

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. This showed us that learning from incidents/investigations took place and appropriate changes were implemented. For example, a child had fallen over during a seizure and banged their head on the corner of a cabinet. Following this all sharp corners throughout the hospice were covered with soft plastic corner guards.

There were contingency plans in place for the service. This included individual emergency plans for children and young people, plans for infection outbreaks, staffing capacity, utilities and access to the building.

Staff worked in partnership with other agencies in developing and delivering services. Health care professionals told us there was good partnership working with Julia's House. One doctor told us they and their team have only positive feedback. They commented on how on how the team at Julia's House were clear about their roles and who leads the service. In addition to this, staff representatives were part of local and national palliative care networks for both children and adults to make sure that local and national best practice standards were met.

Julia's House staff were participating in a three year research project with Bournemouth University on the impact on families with children with life limiting illnesses. This project was anticipated to assist with future planning of the types of services needed both locally and nationally.

We found from staff records and from speaking with staff they understood their roles and responsibilities and professional boundaries. All staff were issued with a staff handbook, code of conduct and a clear description of their responsibilities and who they were accountable to. We saw from staff records and from discussion with the registered manager that any issues with a staff members' performance was followed up in annual appraisals or one to one support meetings or through the disciplinary process.