Kites Corner

Quality Report

James Hopkins Trust
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This report describes our judgement of the quality of care at this location. It is based on a combination of what we found when we inspected and a review of all information available to CQC including information given to us from patients, the public and other organisations

Ratings

Overall rating for this location

Are services safe?	
Are services effective?	
Are services caring?	
Are services responsive?	
Are services well-led?	

Summary of findings

Letter from the Chief Inspector of Hospitals

Kites Corner is operated by James Hopkins Nurses Limited. This is part of the James Hopkins Trust. The service provides respite care for children up to the age of six years who are severely disabled, life limited, or life threatened. The service currently is funded to support three older children who have been with the service for many years.

We inspected the service under our framework for community health services for children, young people and families using our comprehensive inspection methodology. We carried out a short-notice announced inspection on 15 and 16 July 2019.

To get to the heart of patients' experiences of care and treatment, we ask the same five questions of all services: are they safe, effective, caring, responsive to people's needs, and well-led? Where we have a legal duty to do so we review services' performance against each key question as outstanding, good, requires improvement or inadequate.

As the service was not given our usual length of time to prepare for this inspection, we have decided not to rate the service on this occasion.

Our key findings were:

- The service had not always maintained an accurate, complete and contemporaneous record in respect of each child, including a record of the care and treatment provided and any decisions taken in relation to their care and treatment. This included care plans, risk assessments and medicine administration records.
- The service did not have sufficient assurance that persons providing care or treatment for children had the qualifications, competence, skills and experience to do so safely.
- Not all staff had been provided with training, supervision and appraisal as is necessary to enable them to carry out the duties they are employed to perform. The information was not effectively recorded and monitored. This included mandatory, role-specific and safeguarding training.
- Staff had not effectively assessed the risks to the health and safety of children and done all possible to mitigate any such risks.
- There was not effective system of governance, assurance and audit to assess, monitor and improve the quality and safety of the services provided. This included a lack of governance to ensure the risks to health, safety and welfare of people who use the services were assessed, monitored and mitigated.
- The system for incident reporting and complaints management was not run in accordance with policy or good practice. Policies and procedures were not always being followed, and some were not realistic to the service being provided.

However:

- The caring provided to children and their families was outstanding in its compassion and level of support. There was an exceptional understanding of the needs of the children but also and specifically their families and carers. All the parents we met said they had complete faith and trust in the service and its staff.
- There were sufficient numbers of staff on duty to keep children safe and support families, and this was reviewed and safely managed.
- The environment and equipment were mostly clean, although some improvements were needed in some of the soft furnishings and disposal of waste.

Summary of findings

- There was effective multidisciplinary working with other health and social care professionals and organisations to provide wider support to children and their families.
- There were no barriers to access to the service which met the needs of children and their families as individuals, although there needed to be a recognition of equality and diversity. However, the organisation needed to review its level of risk in cancelling respite care for children who might be unwell given the service was led by a nursing team.
- The premises were designed and maintained to level to provide a wonderful environment for children and their families.
- There was a strong and supportive culture among the staff.
- There was a clear vision and strategy for the service with quality of care and sustainability being priorities.

Following this inspection, we told the provider that it must take some actions to comply with the regulations and that it should make other improvements, even though a regulation had not been breached, to help the service improve. We also issued the provider with three requirement notices. Details are at the end of the report.

Nigel Acheson
Deputy Chief Inspector of Hospitals (South and London)

Summary of findings

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Services we looked at:
Community health services for children, young people and families

Summary of this inspection

Background to Kites Corner

Kites Corner is operated by James Hopkins Nurses Limited. This is part of the James Hopkins Trust. Alongside its registration with CQC, it is registered with The Charity Commission and Ofsted.

The organisation is based in Gloucestershire and primarily serves the local community. The service is registered for treatment of disease, disorder or injury. It was established as a registered charity in 1989 with the aim, through respite care, of improving the quality of life for children up to the age of six years who are severely disabled, life limited, and life threatened. The service currently is funded to support three older children who have been with the service for many years.

Originally, support was through the provision of nursing respite care in the child's home. Since then, the organisation has expanded and now employs its own bank of nursing staff for home respite care and has built and opened Kites Corner – a multi-sensory respite centre and gardens. Little Kites is a service run at Kites Corner on Mondays to Wednesdays where children come to the centre for play, activities, care and support.

The service has been extended over the years and now has five beds at Kites Corner for children to stay overnight for respite care. Overnight care is arranged for Thursdays and Fridays and some Saturdays. The staff also arrange a holiday club in the summer months and take children on trips and outings to local places.

The service has a registered manager, Hannah Hulcup, in post since August 2014.

We last visited the service in 2013 and it was found to be compliant in all areas. On this 2019 inspection, we reviewed the service around whether it was safe, effective, caring, responsive and well-led. As the service was not given our usual length of time to prepare for this inspection, we have decided not to rate the service on this occasion.

Our inspection team

The team that inspected the service included a CQC inspection manager, a CQC inspector, and a specialist advisor with expertise in children's nursing and end of life care. The inspection team was overseen by Mary Cridge, Head of Hospital Inspection South West.

Information about Kites Corner

The main service provided by Kites Corner is respite for children under the age of six years, and their families. Since it opened in 1989, the organisation has helped 613 children and their families. It provides 1,500 hours of respite care each month for those who need it.

There are between 90 and 100 children registered with the service at any one time. The costs are met through The James Hopkins Trust's own charitable funding and some central funding from the clinical commissioning group and NHS England.

During the inspection, we visited the premises at Kites Corner. We spoke with nine members of staff including registered nurses, health care assistants, the play leader, and senior managers. We spoke with five mums who were using the service on the days we visited. During our inspection, we reviewed seven sets of children's records and six staff files.

There were no special reviews or investigations of the service ongoing by the CQC at any time during the 12 months before this inspection.

Summary of this inspection

The service directly employed 10 registered nurses, two care assistants and charity, fundraising and events staff. There were regular and occasional volunteers, as well a bank of nursing staff of around 20 nurses. The organisation supported children from the National Citizen Service to act as volunteers during the summer school holidays. We met a group of these children on our visit who were being shown around.

Summary of this inspection

The five questions we ask about services and what we found

We always ask the following five questions of services.

Are services safe?

- The organisation was unclear as to its mandatory training requirements, how many staff had completed this training and what the target was for compliance. Information we did have suggested the training levels were unsatisfactory. This included paediatric resuscitation and/or basic life support training.
- We were not assured all staff requiring training to level three in safeguarding children had this level of expertise. There was a lack of assurance around recruitment and criminal record checks for volunteers.
- Infection control had some shortcomings in the management of clinical and soiled waste. There was no audit of this area of safety.
- Some areas of care and medicine administration records were incomplete, inaccurate, or lacked sufficient depth. There was insufficient or no audit to look for shortfalls in record keeping.
- Not all risks to children had been assessed or updated, particularly in relation to staff driving children to and from the service.
- There was little evidence to show incidents were effectively reported and well managed.

However:

- Staff knew their responsibilities to identify and report on actual or suspected abuse and did so.
- The environment and equipment were safe, visibly clean and well cared for, but some soft furnishings were not suitable for effective cleaning.
- There were safe levels of staffing to care for children, although we were not assured as to the skill mix and experience of the staff.

Are services effective?

- There was insufficient assurance to say staff had received a regular performance review. The evidence available showed an insufficient number of staff had been appraised.
- There was insufficient evidence that staff were competent and skilled for the roles they undertook. There was no evidence to suggest they were not, but the service was not able to say how it knew staff were experienced and trained effectively.

Summary of this inspection

- There was limited evidence of how the service took account of cultural, religious and other diverse needs of children and families to provide effective care.
- There was no programme of audit to determine if children and their families were getting the best inputs to their care and the best outcomes.
- There was no evidence to suggest consent to care and treatment was not sought from parents or those with legal responsibility, but there was no documentation to support this. However, this was in the process of being improved and introduced.

However:

- Care and support were given in line with evidence-based guidance.
- The service adapted and was flexible to meet the needs of children and their families and focused on their quality of life.
- Pain was well managed, although without updated nursing plans.
- There was a strong multidisciplinary approach to the care and support given to children with other health and social care professionals.

Are services caring?

- The privacy and dignity of children and their families was respected and valued.
- Children and their families were treated with compassion. Staff were passionate to ensure children were not defined by their condition and enabled to live fulfilled lives.
- Staff took the time to interact with children and their families and were respectful and considerate.
- Staff fully understood the impact the children's condition had upon the whole family.
- Children and particularly their parents were given timely and excellent support to cope emotionally.
- Staff found ways to communicate with all the children and understood their responses.
- All those who were important in the life of the child were involved in decisions about care. Families and carers were listened to and supported.

Are services responsive?

- The service was planned to meet the needs of the children and families it served.
- There was flexibility, choice and continuity of care.

Summary of this inspection

- The premises were carefully and thoughtfully designed to meet the needs of children and their families.
- The individual needs of different children and their families were catered for.
- There were no barriers to children who qualified to use the service. They were all made welcome and accommodated.

However:

- The equality and diversity of children and families were not documented well and there was no evidence therefore to show they had been considered.
- We were concerned as to the service's skill-set in providing access for a child when they were a perceived risk. The organisation was risk-averse when it came to those it was prepared to take, despite children being in the care of qualified nurses.
- The complaints process was not well publicised and there was insufficient evidence to show how learning would come from complaints or concerns. Nevertheless, complaints were taken seriously and responded to, and they were few and far between.

Are services well-led?

- The nursing leadership required support to develop and use their skills to provide the service they wanted to deliver.
- The process to protect staff in lone-working situations was not effective.
- Governance processes and risk management were not effective to provide assurance the service was safe, effective and provided quality care and support. This had not been recognised by the board of trustees.
- There was a lack of audit and assurance around performance and safety.
- There were no systems to identify and manage risks to the service or those who used it.

However:

- The leaders were respected and supportive to their staff and each other.
- There was a clear vision and credible strategy to take the service forward and remain sustainable.
- Staff were, and felt, supported, respected and valued. The culture was centred entirely on the children and families who were cared for.

Summary of this inspection

- Staff were positive and proud to work at Kites Corner. They were open and honest and would speak up if they had concerns.
- There was good engagement with families and stakeholders, although it was not always easy to get useful feedback at all times to help develop and direct the service.
- All staff were committed to continually learning and improving services.

Detailed findings from this inspection

Overview of ratings

Our ratings for this location are:

	Safe	Effective	Caring	Responsive	Well-led	Overall
Community health services for children, young people and families	N/A	N/A	N/A	N/A	N/A	N/A
Overall	N/A	N/A	N/A	N/A	N/A	N/A

Notes

As the service was not given our usual length of time to prepare for this inspection, we have decided not to rate the service on this occasion. We will return to the service in the near future to re-inspect and rate.

Community health services for children, young people and families

Safe	
Effective	
Caring	
Responsive	
Well-led	

Summary of findings

- The service had not always maintained an accurate, complete and contemporaneous record in respect of each child, including a record of the care and treatment provided and any decisions taken in relation to their care and treatment. This included care plans, risk assessments and medicine administration records.
- Not all staff had been provided with training, supervision and appraisal as is necessary to enable them to carry out the duties they are employed to perform. The information was not effectively recorded and monitored. This included mandatory, role-specific and safeguarding training.
- Staff had not effectively assessed the risks to the health and safety of children and done all possible to mitigate any such risks.
- The service did not have sufficient assurance that persons providing care or treatment for children had the qualifications, competence, skills and experience to do so safely.
- There was not effective system of governance, assurance and audit to assess, monitor and improve the quality and safety of the services provided. This included a lack of governance to ensure the risks to health, safety and welfare of people who use the services were assessed, monitored and mitigated.
- The system for incident reporting and complaints management was not run in accordance with policy or good practice. Policies and procedures were not always being followed, and some were not realistic to the service being provided.

However:

- The caring provided to children and their families was outstanding in its compassion and level of support. There was an exceptional understanding of the needs of the children but also and specifically their families and carers. All the parents we met said they had complete faith and trust in the service and its staff.
- There were sufficient numbers of staff on duty to keep children safe and support families, and this was reviewed and safely managed.
- The environment and equipment were mostly clean, although some improvements were needed in some of the soft furnishings and disposal of waste.
- There was effective multidisciplinary working with other health and social care professionals and organisations to provide wider support to children and their families.
- There were no barriers to access to the service which met the needs of children and their families as individuals, although there needed to be a recognition of equality and diversity. However, the service needed to review its level of risk in cancelling children who might be unwell given the service was led by a nursing team.
- The premises were designed and maintained to level to provide a wonderful environment for children and their families.
- There was a strong and supportive culture among the staff.
- There was a clear vision and strategy for the service with quality of care and sustainability being priorities.

Community health services for children, young people and families

Are community health services for children, young people and families safe?

Mandatory training

- **The service provided mandatory training in key skills to all staff but did not ensure everyone completed it. The organisation's policy did not provide clarity around what subjects were considered as mandatory, who should complete them and when.** The senior nursing managers described to us a programme of mandatory training to be completed. This included paediatric resuscitation, safeguarding, manual handling, and fire safety. However, the mandatory subjects, and the frequency with which they should be refreshed, were not set out in the organisation's training policy.
- To seek other assurance from the organisation around this, we were provided with the training plans and spreadsheets showing staff attendance for 2018 and 2019. In 2018, completion rates shown were poor. For example, records stated only two out of 30 staff had completed manual handling training, 10 out of 30 staff had completed fire training and 15 out of 30 staff had completed basic life support training for children. The spreadsheet for 2019 showed some improvement, with seven out of 28 staff completing manual handling training (with a further 13 booked to attend in October 2019), 23 out of 29 staff completing fire training, and 18 out of 28 staff completing life support training. However, there continued to be many unexplained gaps.
- The training spreadsheet reported staff attendance for some subjects as being completed at another place of employment. Some staff had other employment in, for example, the local hospital or school. The organisation appeared satisfied to recognise the training staff they employed had completed in their other place of employment. However, we checked a random sample of staff files, where it was reported staff had completed certain training, and found no documentary evidence of this.

Safeguarding

- **Staff understood how to protect children from abuse and the service worked well with other agencies to do so. However, not all staff had received recent training. The organisation had not fully considered the national guidance when evaluating the training needs of its staff.** Staff we spoke with demonstrated an understanding of the different types of abuse to be alert to, and their responsibilities to report any concerns. They told us they would report and discuss concerns with the nurse coordinator or a nurse manager.
- Staff were alerted to those children who had a child protection plan and children who were looked after. This information was provided at the point of referral to the service and children's records were marked with a sticker to ensure all staff providing care to these children would be aware of any issues of concern or specific areas of risk.
- The service had not considered national guidance when evaluating the training needs of its staff and volunteers. Safeguarding training was mandatory for all staff and they were required to update this annually. However, the organisation's safeguarding policy did not set out what level of child safeguarding training should be provided for each staff role. The registered manager told us all staff were expected to complete level one training in child safeguarding, with four senior nurses trained to level three. They told us staff would complete level two training when this became available from the local authority's safeguarding children board. National guidance, 'Safeguarding Children and Young People: Roles and competencies for Health Care Staff' published in March 2014, recommends: "all clinical staff working with children, young people and/or their parents/ carers and who could potentially contribute to assessing, planning intervening and evaluating the needs of a child or young person and parenting capacity where there are safeguarding concerns", should be trained to level three.
- Training records showed that only ten out of 30 staff (33%) had completed safeguarding children training in 2018. A further seven staff were reported to have completed training at their other place of employment. However, we did not find documentary evidence of this in staff records. The 2019 training

spreadsheet showed 18 out of 28 staff (64%) had completed refresher training, with a further seven reported to have completed training in their other workplace.

- **There was inconsistency in the application of recruitment and criminal record checks and a lack of assurance from the organisation's policy as to when they applied.** Safety was promoted in recruitment and induction of staff and volunteers, but systems were not consistently followed. We looked at a random sample of six staff files and saw there was a thorough recruitment and selection process, which included checks with the Disclosure and Barring Service (DBS). This is a service which allows organisations to check candidates for employment for their suitability to work with vulnerable children and adults. There was a DBS policy (reviewed February 2019), which stated DBS checks were to be refreshed every three years (which was not a legal requirement, but good practice), and a central database had been set up to monitor this. However, 11 out of 57 staff had these checks outstanding.
- There was a lack of clarity regarding the vetting procedure for volunteers. The organisation's volunteer policy stated that volunteers would be subject to DBS checks. However, when we asked to review records for volunteers we were shown only details of young people undertaking short work experience placements. They were not subject to this process because their placement was so short, and they were always supervised. There was one volunteer listed on the central DBS database who had a valid DBS check recorded.

Cleanliness, infection control and hygiene

- **The service mostly controlled infection risk well. Staff used control measures to protect children, visitors, themselves and others from infection, although there was no audit and no risk assessment recorded for community work.** Rooms had gloves and aprons available to staff, although some were placed next to the sinks and liable to get wet. We did not observe the nursing staff giving personal care, but those we spoke with said they were aware of the need to use gloves and aprons.
- Staff were washing their hands as required, but this had not been audited. We observed staff using hand gel when they needed to and washing their hands before and after preparing food for the children. Hand gel was available throughout the building, including at the main reception for visitors to use. Staff wore short sleeves and minimal jewellery (bare below the elbow) to ensure effective handwashing. However, the service had not undertaken a hand-hygiene audit, despite a simple tool being part of the organisation's policy, and a requirement to undertake this each month.
- Staff were provided with gloves and aprons when they were working in the community. However, three of the assessments we looked at for children being supported at home did not cover any possible risks identified around infection control. The organisation did not have a process for monitoring infection control protocols in the community.
- **The premises were mostly visibly clean, although some furnishings were not easy to clean and showing signs of age and staining.** We noted in some areas, particularly the bedrooms, there were chairs provided for adults and children, which were fabric-covered. The upholstery had become stained over time as they were difficult to keep clean. A plastic chair looked dusty and was slightly sticky to the touch. Other furniture, such as the newly-purchased sofas in the 'snug' were made from a wipe-clean fabric and easy to clean.
- **There were no cleaning schedules on display or maintained to provide assurance of infection prevention and control.** None of the bedrooms or the sluice room had schedules to show when they had last been cleaned or when they were due. We were assured that a room would be cleaned immediately where a child who had developed an infection or potential infection when staying at Kites Corner. However, there was no clear process and no guidance from the organisation's policy to describe how this would be undertaken or validated. There was no schedule to demonstrate cleaning of other furnishings, such as curtains (we were told these were washed annually) or the covers on specialist wheelchairs used by the children. These did not appear to be unclean, but assurance around the care and maintenance could not be given.

Community health services for children, young people and families

Environment and equipment

- **The design, maintenance and use of facilities, premises and equipment kept people safe. However, a couple of electrical items in the kitchen had not had their most recent electrical safety test.** The premises were designed and laid out to keep children safe. Access to the premises was strictly controlled and all visitors to the service signed in and out of the building. Access to children's areas was further controlled, and staff had electronic passes or key-pads to access clinical areas and the bedrooms. Door handles were positioned out of children's reach and there was a suitable child-safe gate to prevent access to the upstairs area. There was appropriate non-slip flooring in areas where children would visit, and each area was clear and safe for children to move around. The service had enough equipment to help staff safely care for children which was mostly well maintained. However, in the kitchen, two items of electrical equipment were overdue for electrical safety checks.
- The large and varied sensory garden had been designed to provide a safe and carefully managed area for children and their families. It was well-maintained with support from local volunteers and specialist companies giving their time for free. This took place on Thursdays in the daytime when children were not at the service. We observed children being supervised in the garden at all times. The equipment and play areas had been designed to both stimulate children and to help them learn. The area was tidy, free of hazards and appeared safe for children, staff and visitors.
- The large play area was equipped with a variety of toys to entertain children with a range of different skills and abilities. Most of them were simple and well made. The toys were washable or wipeable and in good condition. There was a water-play unit, which was very popular during our visit and safely used with enthusiastic children and staff.
- The service had a suitable lift to take those who needed it to the large open-plan area on the first floor. This was used for entertainment and events. The lift had malfunctioned over the weekend and was booked for repair. No events were planned in the upstairs area when the lift was out of action, so it had not led to any safety concerns.
- **The premises were safely equipped for children's needs.** To safely move children who had limited mobility, there was specialist hoisting equipment in bedrooms, bathrooms and the sensory play area. Records were available to show this had been serviced. There were suitable baths with safety equipment in the rooms and staff told us they would never leave a child unsupervised in this environment under any circumstances.
- The service had a limited range of resuscitation equipment. The service did not keep oxygen on the site and any children prescribed oxygen would have a supply provided from home. There was a bag with a limited range of resuscitation equipment. The bag had been regularly checked and the contents were in date. Staff told us they would immediately call an ambulance for any child who had deteriorated or needed urgent care. However, we were concerned with the lack of assurance of all staff being trained and updated in training in basic life support or paediatric resuscitation. Records were unclear. There was a fire evacuation bag maintained on the premises. However, this was not on the overnight safety checklist and there was no list with the bag to detail what it should contain.
- Staff kept, and prepared food supplied by parents for their children. There was a separate fridge for children's food and staff monitored fridge temperatures every day. However, we noted that there was no guidance to staff in the recording log on the correct temperature range.
- **There was limited equipment for clinical and soiled waste.** The service operated without a macerator in the sluice and with limited equipment and facilities for clinical waste. There were not urine bottles, and no specific bags for receiving soiled linen (usually pink plastic bags). This was despite this being part of the organisation's infection control policy.

Assessing and responding to patient risk

- **Staff completed risk assessments for each child before accepting them for care and support.**

However, these were not regularly reviewed or updated. When a child was assessed for home respite or attending Kites Corner, a full assessment of their needs was undertaken. This included standard areas such as moving and handling and equipment needed. There were action plans produced at the time to support the child attending Kites Corner and what would need to be provided, could be made available, or provided by the family. However, in those records we reviewed, there was no regular update of these risk assessments and no dates for how often they needed to be reviewed. There were reviews when there was a significant change for the child or family, but not with any other regularity.

- **Staff acted upon children who deteriorated, but without any guidelines or procedures to follow. The service was limited in the risks it would accept with children**. Any child who was not well within the range of their condition was not able to attend the service at that time. Only those children who were a perceived low risk were admitted. There were no specific structured systems for monitoring a child (such as the paediatric early warning score maintained in an acute setting), but the staff demonstrated how well they knew each child they looked after. In the event of a concern or emergency, they would call for an emergency ambulance. This had happened in the past and staff said the ambulance service had been fast and responsive on site. Alongside this, most of the children were supported by the local NHS hospital and had open access, so concerns which might not be an emergency could be managed through that route.
- There was an on-call system with the nursing team for both Kites Corner and nurses in the community. Senior staff were at most around 20 minutes from homes and Kites Corner and would attend when required to provide advice, guidance or support. If a child was taken to hospital by their parents or an ambulance, the nurse would use their judgement to decide whether to accompany the child or may remain at the house to care for other children at home.
- We were concerned there was no behavioural or safe restraint training for staff to manage children who had a crisis or needed careful management of risks to themselves or others. Staff were not specifically trained to care for the acutely unwell child, and the service therefore preferred not to admit those children at the time. There was no guidance in the policies and protocols around the deteriorating child with the exception of calling an ambulance.
- **The service had not taken adequate steps to ensure the safety of children who were transported by staff in their own or a service-owned vehicle**. Some staff transported children to and from Kites Corner to attend day care sessions ('Little Kites'). There were agreements drawn up with parents, who were required to provide written consent for this activity. Staff were required to provide documents on recruitment or when agreements were established to provide evidence of their fitness to drive, and if using their own vehicle, evidence of valid insurance and MOT. We looked at the staff records of two staff who were engaged in this activity and there was no documentary evidence to provide assurance that this activity was safe.

Staffing

- **The service had enough staff to keep children safe from avoidable harm and to provide the right care and treatment.** The service worked with employed nurses and a bank of nurses, many of whom had been with the service for many years. Most worked at both sites – the community and Kites Corner, so were in regular contact with the service. Each shift had a range of staff. The Little Kites day session had enough nurses to provide individualised care for each child. This included a play leader, trained to support and provide individualised play for the children they supported. The play leader also supervised and mentored the volunteers who helped with the service. During overnight respite care, there were two qualified nurses and a healthcare assistant covering a full service. During the day, there was support to all staff from the three qualified nurse managers who were also on-call overnight.
- **The skill mix of nurses appeared to be safely managed, but this was without clear assurance of competencies which were assessed and monitored.** Nursing staff were all experienced children's nurses or healthcare assistants. Many of these also worked at the local NHS trust or community services for children. However, although we had no

cause for concern around their skills, experience and competence, there were no systems to provide assurance. The organisation had some records of competencies, and we were told these were checked annually. But there was a limited record of these and a lack of clinical supervision to assess key skills.

- **There was communication with healthcare professionals, although no medical review on site.** The service was led by nurses who had access to and linked with the named medical specialist for the child if required. The senior nurses had attended and participated in clinical case conferences and TAC (team around the child) reviews for some of the children and worked closely with other clinical professionals. This included dietitians, respiratory nurse specialists, physiotherapists and speech and language therapists.

Records

- **Staff kept records of children's care and treatment although these were mostly compiled by the parents and not comprehensive or clinically focused. They were inconsistent in places.** We reviewed seven sets of care plans and the records were sometimes contradictory, or not reflecting new information. For example, in one record, the feeding regime had changed in July 2019, but the old nutrition plan was in the front of the record. In another record, the care plan did not reflect the latest feeding regime as provided by the dietitian. Changes to care plans were noted on a communication sheet, but not updated on any overarching plan of care. Some key information was inconsistent. Some plans did not record who held parental responsibility. There were no clinical risk assessments of key areas such as nutrition plans or pain management plans. The records we saw did contain the latest information from the child's consultant or other healthcare professionals. However, the information contained in these letters did not clearly find its way into the care plan.

- **There was limited reference to the child's emotional, social, cultural needs alongside their physical health needs.** This aspect of the child's needs had limited recording in care plans and notes. We noted in one care plan a reference to a child not eating a certain meat. We asked staff if this indicated a specific religious or cultural preference. They were not aware of this but found a reference to the child's religion in a respite agreement. This was otherwise not recorded in the child's records and there was no place to specifically draw attention to cultural or religious needs or guidance.

- **There were no audits of care records.** Care plans were produced on admission, and although the families gave or were asked for lengthy information, the quality of the information was not improved. The organisation did not then produce a 'living' care plan which reflected the most current information, risk assessments, and action plans, which was compiled and owned by the nurses.

- **Records were stored securely and available to all staff providing care.** Records were maintained on paper and held securely in locked filing cabinets or a locked clinical room. There were a few records in the play area left unattended on tables and cupboards when we visited, but these were for children who were being looked after that day. There were no unauthorised people in the area and we were not concerned these records would be removed or tampered with.

Medicines

- **There was no evidence to suggest medicines were not administered safely.** The medicine administration records we reviewed (seven records) transcribed the prescription or 'as required' medicines for the children which were supplied by the parents. In the records we saw, the administration of the medicines was recorded and signed as given in accordance with the prescription.

- **The system used by the service did not always accurately record medicines. The records were not audited.** Children's medicines were brought to Kites Corner by the parents or carers of the child and followed the regime the child was prescribed at home. The service used medicine administration record charts to book in the medicines, record administration, and record them being returned to the parents when the child went home. In those we looked at (seven sets of charts) we found a number of errors or omissions. In one month, the medicines were not recorded as checked in, although they were the

following month. The administration describing the medicines was untidy and incomplete. One of the medicines booked in twice was past its expiry date. There was no indication of the type or strength of the medicine. Although there was no record of this medicine being used, the record did not state it was 'as required'. It was therefore unclear as to its purpose. It had been booked in to the service in June as four doses, and in July as three, so the medicine had been used at some point when expired. There were no records in the care plan about this issue, and it was not recorded as an incident. In another record, there was no date alongside the medicines booked out. In a further record, the medicines were neither booked in nor booked out with the parents. There was no systematic programme of audit to pick up these issues.

- **The service had limited use of controlled drugs, but no register to record them in the event it needed to.** The service managed and stored one of the schedule three controlled drugs in the cabinet it had installed for that purpose. This drug was not required to be stored in this way, but this was good practice to follow. However, the service did not have and therefore was not using, or could use, a controlled drugs register as is required by law for the management of controlled drugs. One of the senior nurses said they would obtain one for the service as soon as possible. We recognised the limited use and storage for this category of medicines, but the service said it recognised they could be brought to them with a child at any time.
- **The service did not monitor the temperature of the clinic room or have instructions with the medicines fridges to say what to do if one was outside of range.** The medicines and consumable clinical equipment were stored in a locked clinic room. Those we checked (around 20 items) were all in date, tidy and well looked after. All the packaging was intact and kept clean. The fridges were used either for medicines or feeds which required temperature-controlled storage. Although the temperatures were checked (and OK), the recording book did not tell staff what to do if the temperature was not within range. The temperature of the room was not monitored, although one of the senior nurses located a thermometer and placed this in the room directly. Other areas of concern included:
  - The staff were not marking the fridge temperature record to show when the service was closed. This suggested otherwise there were numerous gaps in the records.
  - There were two boxes of medicines in a cupboard which had been prescribed for an individual. However, the name had been crossed through to be illegible and the medicines not returned or destroyed.
  - There was a consumable (mini yankauer) which was close to its expiry date. There was no marking on the packet, as is good practice, to highlight this to staff.
  - There were two copies of the Children's British National Formulary (medicines guidance) in the clinic room which were out of date (2013 and 2014). These were removed by a senior nurse. We were told the service otherwise used the electronic version of this publication and not the printed version.

Incident reporting, learning and improvement

- **There was little evidence to demonstrate the service managed patient safety incidents well. We were not assured all staff recognised and reported incidents and near misses.** Staff recognised their responsibility to report incidents and knew how to report them. There was an incident reporting procedure (reviewed February 2019), which set out the responsibilities of staff and managers. However, none of the staff we spoke with could describe a recent incident they had reported or any learning which had been shared. Some staff struggled to describe an event which would require them to report an incident. They could not identify any recent learning arising from incidents, although they told us incidents and learning from them were discussed at staff meetings.
- We reviewed all incident reports from January 2018 to date, of which there were six 'general' incidents and

three medication errors. This was a small number. It was unclear whether this was a recording issue or whether it was indicative of a culture in which incident reporting was not actively considered.

- **Those incidents reported were investigated, but records did not show actions needed had been completed.** Managers had a process for investigating incidents. There was evidence in all but one case that incidents had been investigated and recommended actions were recorded. However, in most cases it was not recorded when remedial actions had been undertaken and completed. As there was such a small number of incidents, there was little analysis or identification of any themes recorded. One of the parents we spoke with had been told of an incident and was happy they were updated with actions taken to resolve the problem for the future.
- **Staff were open and honest, although duty of candour was not fully understood.** There was a culture of openness and transparency. Managers told us mistakes or incidents were openly discussed with parents or carers. A parent told us how they had been contacted following an incident and staff were open and transparent. However, there was a limited understanding of the requirement to invoke the duty of candour if something serious was to occur. The duty of candour is a regulatory duty that relates to openness and transparency and requires providers of health and social care services to notify patients (or other relevant persons) of certain 'notifiable safety incidents' and provide reasonable support to that person. There was a duty of candour policy (reviewed March 2019), which described the statutory duty but did not set out the process to be followed if an incident triggered the duty to be applied. Although there was a poster on the wall in the clinical room describing duty of candour, staff could not describe fully what it meant. However, there had been no incidents reported since January 2018 where duty of candour was applicable.

Are community health services for children, young people and families effective?

(for example, treatment is effective)

Evidence-based care and treatment

- **The service provided care and treatment based on national guidance and evidence-based practice.** Staff followed up-to-date policies to plan and deliver care according to best practice and national guidance. The service used a comprehensive assessment tool (based on a nationally recognised model) to assess the needs of referred children and the needs of their families or carers. This formed the basis of a care plan, which was updated in discussion with parents on an ongoing basis, and at least annually. The service also used a vulnerability assessment tool, which measured the impact of caring for a child with complex needs on the entire family.
- Protocols for managing symptoms of children's illnesses or condition were clearly set out in their care plans, for example, managing seizures and tracheotomy care. These had been developed by specialist healthcare teams and were shared with the service at the point of referral.
- The service held records for those children in its care who had advance care plans. Staff were aware of what they contained and how to respond in circumstances referred to within the care plan.
- **Care was adapted over time to meet the needs of the child and their family and to help them maintain a good quality of life.** This included responding to change or crisis in a family's circumstances. Staff knew or got to know the children and families who came to them for care and support. They were able to adapt in how they provided support as things changed. This included not just around changes to evidence-based care, but in smaller things which mattered to the family.

Nutrition and hydration

- **Staff gave children enough food and drink to meet their needs and improve their health. They used special feeding and hydration techniques when necessary.** The staff followed the guidance and

feeding regime for the child as it was provided at home. This required the parent or carer to bring the child's food and drinks to the service themselves, and staff were instructed on how they should be provided. Staff had specialist knowledge in areas such as enteral feeding and hydration techniques in order to provide effective care.

- **There was no clear evidence to show the service made adjustments for children's religious, cultural and other needs.** In the one record where a cultural statement was made by the family, this had not been taken any further to determine if there were other religious or cultural needs which should be considered.

Pain relief

- **Staff assessed and monitored children regularly to see if they were in pain and gave pain relief in a timely way. However, they did not have a nursing care plan for pain or symptom control.** The records we read had care plans around pain completed by the parents and not the nursing professional. There was no review of pain management in a timely way with all those involved in its management.

- **Staff supported those unable to communicate using suitable assessment tools and gave additional pain relief to ease pain.** Staff had a bond and clear understanding of the children they supported, and we could conclude from our conversations with them that they would identify if a child needed pain relief. The children's medicine records showed pain relief was given both as regular prescribed analgesia and when prescribed 'as required'.

Patient outcomes

- **Staff were not auditing the service to look at the effectiveness of care and treatment.** There was no evidence to suggest the children and their families did not get good outcomes from using Kites Corner and its services. However, there was no clear approach to monitoring and auditing the inputs to and outcomes from the service to look for successes or where it could be improved.

- Although it was fairly unique in the local area, the service had not looked at how it could receive a peer review of its service or benchmark against other similar services. There were other services, specifically children's hospices in the south west, providing respite services, but peer review with these services had not been organised as yet.

Competent staff

- **Although staff felt well supported, we were not fully assured the service made sure they were competent for their roles. Managers were not consistently or regularly reviewing staff's work performance. Policies, systems and processes were unclear, and records were incomplete.** We could not be assured staff were experienced, qualified and had the right skills and knowledge to meet the needs of children in their care. Staff told us they felt well supported for their roles and were able to access additional support and training as required. However, as with mandatory training, other core skills training records were incomplete and did not provide assurance all staff received the necessary training and support to undertake their roles effectively. There was no evidence to suggest from our conversations and observations with staff they were not competent for their roles, but the records did not provide the assurance required.

- There was no clear policy or training plan which set out the essential competencies required of different staff roles. Training data provided to us for 2018 and 2019 showed numerous unexplained training gaps. For example, in 2018 only five out of 30 staff received training in parenteral nutrition (where nutrition is administered via a vein). This was not included on the training plan for 2019. Only 11 out of 30 staff received training in Vagus nerve stimulation (emergency treatment for epilepsy), although this had significantly improved in 2019, when 20 out of 28 eligible staff completed this training. There were four staff who were reported to have completed this training at their other places of employment. Enteral feeding was also on the training plan for 2019 but no attendance data was recorded.

- **There was good access to specialist training when needed. Staff were given opportunities to develop.** One of the two deputy nurse managers was responsible for oversight and provision of in-house training. The service also supported staff to attend relevant external training courses and sought

specialist input from local healthcare specialists. The service had been proactive in the provision of specialist training for certain conditions to meet the individual needs of children. For example, five staff had recently been trained to perform female catheterisation in order to support a child using the service.

- **Managers gave new staff an induction before they started work. However, records did not provide assurance this happened consistently.** There was a structured induction programme. Staff were given an induction checklist, which they were expected to complete, under the supervision of a mentor, who would sign this off when all tasks and training were complete. However, staff records were poor. We looked at six staff files and only one had a fully completed and signed-off induction checklist. Two bank staff had no record of any induction at all.
- **Managers supported staff to develop through yearly constructive appraisal of their work. However, there was not a clear process, which meant that practice was inconsistent.** The organisation's appraisal policy (reviewed February 2019) set out a commitment to appraise staff annually, identify their training needs and produce a personal development plan. However, there was no supporting process, expectation, or methodology described. Appraisal was monitored by the senior team. Records showed that around 70% of staff had received a recent appraisal, but there were some unexplained gaps. We looked at six staff records and found little evidence of meaningful two-way discussions about performance and no evidence of personal development plans or objectives. We saw one staff member who worked infrequently had expressed in January 2018 some lack of confidence and had requested some specialist training. There was no plan documented to address this training gap and no further appraisal had taken place.
- There was limited formal clinical supervision. Staff supervision was provided in a team approach at staff meetings, which were held bi-monthly. Minutes were shared with those staff who were unable to attend. Otherwise, there was no formal or informal clinical supervision of most clinical staff. The registered manager did have formal supervision with a registered children's nurse at another service, which was good practice.
- **Multidisciplinary working and coordinated care pathways**
- **All those responsible for delivering care worked together as a team to benefit children and families. They supported each other to provide good care and communicated effectively with other agencies.** Staff liaised closely with multidisciplinary healthcare teams and other external agencies involved in children's care. This included attendance at multidisciplinary meetings to discuss these children's needs. Staff could access advice from specialists, such as dietitians, speech and language therapists, epilepsy nurse specialists, physiotherapists, respiratory nurse specialists and paediatricians. There were also established working relationships with the local children's hospice and local partners in education and social care.

Consent

- **Staff supported parents and carers to make informed decisions about children's care and treatment. However, this was not well documented. Consent for taking and using photographs was documented.** There was no evidence to suggest any care or treatment was provided without the full consent of the parent, guardian or carer. All those mums we asked said they had been fully consulted. However, the child's records did not capture these discussions or record how or when consent had been given. The service had recognised this to an extent and had developed a new template to add to a child's records to record the discussions around consent. However, these were yet to be implemented.
- There were records to show consent to take pictures of the children for use in their medical and medicine records had been gained in those files we checked. There was also consent recorded for the use of pictures for sharing with the parents, families and others who came to the service. Many of these were on the walls around the house and depicted happy and well-cared for children.

Community health services for children, young people and families

Are community health services for children, young people and families caring?

Compassionate care

- **Staff treated children and families with compassion and kindness, respected their privacy and dignity, and took account of their individual needs. We heard numerous examples where staff had 'gone the extra mile' to care for children and their families.** Staff showed a compassionate, respectful and considerate approach to caring for children and their families. Their interaction with children was warm, caring and friendly and it was clear that they had developed a special bond and a relationship of trust with both the children and their parents.
- **Staff were passionate in their desire to ensure children were not defined by their condition or disability and supported them to live fulfilling lives.** Play, sensory stimulation and socialisation were a significant part of the package of care provided. Staff took steps to provide a 'home from home' environment and atmosphere. Mealtimes were sociable and inclusive, with staff and children sitting together, irrespective of whether the children were able to eat.
- **We observed staff were attentive, friendly and affectionate in their interaction with children.** When they spoke about the children they were caring for they showed understanding of each child's individual needs, abilities, and their likes and dislikes. Play sessions were inclusive and children with limited communication or mobility were supported to join in all activities as they were able. Many children had communication difficulties, but this was not seen as a barrier and staff adapted their communication accordingly. They were alert to signs of emotional distress or pain.
- Staff we met showed a kindness and compassion to both the children, but also to their parents, family members and carers. We had numerous examples of the deep understanding and empathy staff had for the families and recognised and shared their compassion and kindness with them.

Emotional support

- **Staff provided emotional support to children, families and carers to minimise their distress.** Parents felt confident leaving their child in the care of staff. Several parents told us that staff understood their initial anxiety about leaving their child, which was acutely felt by parents of children with complex needs. They were encouraged to stay with their child as long as they wished and until they had developed complete trust in the staff. Staff constantly reassured them and provided detailed accounts and photographs to show them their children were content and happy in their care. One parent recalled that staff had told them they could telephone the service as many times as they needed to in order to be reassured and to relax when they were separated from their child.
- There was a genuine understanding of the impact that caring for a child with complex needs had on the family, and staff spoke of their responsibility to support families, not just children who used the service. Parents told us they viewed the staff as members of their extended family, such was the strength of the bond they had developed. One parent told us, "I think the staff genuinely love [the child]". Likewise, staff told us they felt privileged to work so closely with family members, to watch the children grow, and with families to help them to capture valuable memories and to be part of the 'family unit'. Parents told us the staff always asked them how they were and picked up when they were low in mood or struggling to cope. One parent, who was struggling to cope emotionally and psychologically, told us they felt the support they had received from staff was "life-saving". They told us they had once been offered an additional night's respite because staff had recognised how much this was needed.
- **Staff worked flexibly to support parents.** One parent said, "they bend over backwards to support us." A staff member told us that they attended hospital appointments with one mum, to support them to understand and process information they received

from health professionals. A parent told us they arrived at the service an hour before their child's play session started because this fitted with their school-run responsibilities, and they were able to use the play facilities with their child until the staff came on duty.

- **The staff looked beyond the imminent needs of the child.** We were told about a recent event where the mum of a child who used the service was having another baby. The service arranged to look after their child for the whole day to allow both parents to concentrate on the birth. Other families were supported when their domestic circumstances changed, for example a family was having building work at their home and were unable to bathe their child, so they were invited to use facilities at the service.
- Staff told us they knew cancelling a respite or play session had enormous impact on families and they did everything to avoid this by covering each other when short-notice absence occurred. A staff member told us about the significant efforts of staff to keep the service running during a spell of heavy snow, in order to avoid disappointing parents.
- The service considered the needs of siblings. Staff spoke passionately about what they saw as their duty of care to siblings, who may have less of their parents' time dedicated to them because of the intensive support for their unwell child. Parents told us they were able to bring their other children to the service so that they were involved as a family. They could use the play equipment and the service held numerous events. This included Easter egg hunts, and Christmas and Halloween parties where siblings participated and played alongside the other children. One family told us their whole family had visited the circus, an activity which they would not have been able to afford or to do, without the support of Kites Corner staff.

Understanding and involvement of patients and those close to them

- **Staff supported and involved families and carers to understand their child's condition and make decisions about their care and treatment.** We observed staff communicated effectively with children. There were communication plans for those children who could not communicate verbally, and families had been involved in developing these. Staff clearly had got to know the children in their care well and knew how to communicate with them and understand signals and ways in which they sent messages.
- Parents told us they continued to be involved in any decisions about their child's care. There was ongoing dialogue at all times. Staff and parents had a 'handover' each time the child came to Kites Corner so that staff and parents were always updated about the child's wellbeing. Staff reported back to parents about children's emotional wellbeing following each contact.
- Staff had access to and knowledge of other services in the local area. However, all the children who came to Kites Corner were under the care of a number of health and social care professionals, so had a series of interactions with other services. Nevertheless, the service had a wide network of health and social care professionals and other organisations who could offer support to the children, families and other carers.
- We recognised and were told how everyone involved with the child outside of the health and social care professionals was recognised and welcomed by the service. This included, for example, families where the parents might not be together, and staff made sure all those who needed to be involved were included.

Are community health services for children, young people and families responsive to people's needs? (for example, to feedback?)

Planning and delivering services which meet children's and families' needs

- **The service planned and provided care in a way that met the needs of local people and the communities served.** The service had been established in the late 1980s to provide respite nursing care for the families of children meeting the referral criteria. Since then it had developed and evolved into a service now also providing overnight respite care, a daytime service, and a holiday club for visits to local places. Families who used the service said this met their needs and was an invaluable service in their lives and that of their child. One mum told us, "It's amazing.

The staff and the centre are fantastic and very welcoming." Another mum who had support a number of years ago said, "We want every family in Gloucestershire to have the support, care and empathy we had."

- **The facilities were appropriate for the care delivered.** The service had developed in a purpose-built house to include a large play area for children, a large sensory garden, and an open-plan room with facilities to be used as a cinema. There were bedrooms for children to stay overnight, a snug, kitchen, and conservatory. There were facilities for staff and others to work away from the main areas and have privacy with parents if needed. The facilities provided excellent opportunities for both play and a peaceful and safe environment to stay, eat and sleep. A new sensory room was being installed when we were on site, and staff and parents were very excited about how this would be received by the children.
- **There was engagement with families in the design of the service.** Families were given the opportunity to participate in many aspects of how the service was designed and run. Coupled with that was the participation of the founding family who along with one of the senior team at the organisation, had experienced life with a child with a life-limiting condition who gave of their knowledge and personal experience.

Meeting the needs of people in vulnerable circumstances

- **The service was inclusive and took account of children's individual needs and preferences, although needed to improve how it recognised and recorded equality and diversity information about children and their families.** There were no barriers to any child who met the criteria described at the start of this report being supported by Kites Corner. The service recognised and adjusted to communication needs of children with disabilities and sensory loss. There were no barriers to children living in vulnerable circumstances or under the care of the local authority. However, the holistic care provided did not provide strong evidence through children's care plans to reflect the child's or family's cultural context.
- **Staff made reasonable adjustments to help children and families access services.** On a practical level, there was safe access to the property for wheelchairs and this applied both to children using wheelchairs coming to Kites Corner, but also to any visiting older child or adult who used a wheelchair. There was a lift within the premises to gain access to the upper floor. Corridors were clear and with non-slip floors. There were tasteful and child-friendly decorations on the walls for children to touch and sense as they arrived. There were posters and images of happy children who used and had used the services over the years. On an emotional level, the service made sure parents had time to adjust to using the service. They were given time with their child to settle in, and they could stay as long as they needed, without anyone being judgemental. The service was open to parents who just wanted to come and spend some time in the garden for peace and quiet, with or without their child.
- Staff described some of the adjustments they had made to meet the needs of families. For example, this had included staff not wearing a uniform on duty and accepting that some families did not want the nurse to bathe their child. There was no direct access in the service to interpreters, but the local NHS hospital had offered to support the service should they need this kind of help. Otherwise, family members usually provided any interpretation, although this was not often required.
- **The service coordinated care with other services and providers.** There was regular contact with other healthcare professionals and staff attended TAC (team around the child) meetings to provide input and hear new information. The staff also had contact with social services for looked-after children and were aware of parental responsibilities and delegations of authority.

Access to the right care at the right time

- **People could access the service when they needed it and received the right care in a timely way. However, we felt the service was possibly too risk averse when it came to be managing an unwell child.** There was a low threshold for the risks the staff were prepared to manage, even though there were always qualified nurses on site. This was something

the manager of the trust said they would consider and address whether they were being as responsive to children as they could be, without putting others at risk.

- The service had clear admission criteria for the service and had raised awareness of the service among local clinicians and health and social care teams. This ensured children and families who could benefit from the service were put into contact with staff. Most referrals were made by health or social care professionals, but staff told us anyone was able to contact the service and ask if they qualified for support.
- There was a structured and effective process for referrals to be processed and admission to the service arranged. At the time of our visit there was no waiting list for children, although some were receiving a limited service until September 2019, when some further capacity to provide support was anticipated.
- Services were generally always available as planned. The staff said they would endeavour to manage any unexpected or unplanned absence with their bank team and had plans to enable them to open in adverse weather conditions.

Learning from complaints and concerns

- **The service would take complaints seriously. However, it had not taken steps to ensure parents knew how to give feedback and raise concerns about the care their children received.** Most parents we spoke with were not aware of a formal mechanism to make a complaint, although they told us they would have no hesitation in doing so and they were confident their concerns would be taken seriously. However, there was no information displayed in the service or on the website, which advised parents about how to make a complaint.
- The organisation's complaints policy (reviewed February 2019) stated, "The policy should be made known to all third parties, so they are aware how to raise concerns and what they can expect to happen next." The registered manager showed us a respite agreement drawn up with parents, which informed parents they could contact managers of the service if they had concerns or wished to make a complaint. However, this was the only written information made available to parents about complaint procedures. (The document also contained inaccurate information about the role of CQC in relation to service complaints. We drew this to the attention of the registered manager).
- **Not all staff were aware of the policy and what should happen with a complaint.** Staff beyond the senior team were not familiar with the complaints policy and they were not aware of any complaints received by the service. They told us they would refer any complaints to the nurse in charge or a manager. They thought any complaints would be discussed at team meetings.
- **There was a process for capturing negative feedback which was not submitted as a formal complaint. However, it was not always used as intended.** There was a 'comments, compliments and complaints' book where staff were expected to record minor issues. This system had been started in October 2018, and there were instructions to staff on how to use the book, with examples. However, we saw that on one occasion it had been used by staff to report out of date equipment. This should have been reported through the incident process. The somewhat informal process was not following the organisation's complaints policy and was not referred to in the policy. This required that minor concerns were confirmed in writing and received a written acknowledgement and response.
- **Staff said they would investigate any complaints and share lessons learned with all staff. However, there was limited evidence of this due to the small number of complaints received.** The service had recorded no formal complaints being made or received in the last two years, although when we reviewed the incident folder we saw one incident had been raised as a complaint by a parent. This had been dealt with promptly and the parents reassured, but it was not dealt with in accordance with the complaints policy. Another parent told us of a complaint they had made which had been dealt with well, but there was no record of this in a register of complaints.

Community health services for children, young people and families

Are community health services for children, young people and families well-led?

Leadership of services

- **Leaders were visible and approachable in the service for children, families and staff.** All the staff we met commented upon the senior team and their close working relationship together and with the wider team. They said they were always able to approach anyone to discuss successes or concerns. They had clear priorities in providing a quality service to children and their families.
- Beyond the senior team, we met and talked with five staff who told us managers were always available and supportive to everyone. This had included a supportive approach towards a member of staff who had experienced personal problems outside of work.
- The leaders did not have the required support to develop and use their skills, knowledge, experience and integrity to resolve the issues described in this report and deliver the service they wanted to provide – safe, effective and with strong quality assurance.
- We did not meet the board of trustees, but our review of the service found they did not have sufficient assurance to meet their governance responsibilities around the quality and safety of the service. The vision and strategy talked of governance, but from a financial and trust-accounting perspective. It did not include the safety and effectiveness of the service.

Service vision and strategy

- **The service had a vision for what it wanted to achieve and a strategy to turn it into action. The vision and strategy were focused on sustainability of services and the long-term future.** The service had recently produced and published on its website it's strategy for the next five years. This document, 'Strategic Business Plan 2019-2024', described how the organisation would move through the next five years after it celebrated 30 years since it was established in 1989. It described "putting children and families we support at the heart of everything we do". The strategy was realistic, with its values and sustainability as key priorities. However, as we have said above, the governance strategy did not extend to the quality, effectiveness, and safety of care provided by the organisation.
- This was a unique service for Gloucestershire and there were few other services in the UK which offered this form of respite care for children and families. It was therefore not designed specifically to align with local plans for the wider healthcare economy but for a specific group of people in the county of Gloucestershire where the founding family came from. This it did exceptionally well.

Culture within the service

- **Staff felt respected, supported and valued. They were focused on the needs of children receiving care and their families.** We spoke with five of the nursing staff beyond the senior team. They all told us they loved working for the service and felt proud to be a part of it. There was a great sense of teamwork, camaraderie, and shared values. Staff felt respected and valued.
- The culture was centred on the children and their families and this was paramount throughout. Alongside that, the staff we met said they felt supported at all times. They said they felt valued and were a close-knit group. The staff also commented on their close relationship with the team who looked after the charitable trust's commercial and fundraising team – they were based in the upstairs part of Kites Corner. Staff said they felt they gave each other space but were equally always there for each other in what could sometimes be an emotionally tough job.
- **The service had an open culture where families, carers and staff could raise concerns without fear.** Staff told us they would not hesitate to report concerns to managers and believed these concerns would be taken seriously and acted upon with integrity and sensitivity. The organisation encouraged openness and honesty throughout all levels of staff. Everyone we spoke with recognised the importance of staff being able to raise concerns without fear of retribution. One member of staff told us the service was so dedicated to the children and families it supported, that staff were always encouraged to bring

ideas or talk about anything which was worrying them. We were told there had been changes and improvements from many big and small ideas coming from staff and families.

- **The process for protecting staff in situations of lone working was not effective. Risk assessments of the environment were undertaken and acted on, although not updated with any frequency.** Although there was no evidence to suggest staff were not safe, or the service did not value their safety, the systems around lone-working and the policy to support this were not effective. Due to the nature of the service offered for home respite care, a number of the nursing staff made their own arrangements with families around the times they spent with them at home. These staff were required under the policy to let the service know their movements for their own safety. However, this was not being carried out with any consistency by the staff, and the service did not have an immediate solution to resolve this.
- The homes and environments in which staff visited were assessed by a senior nurse before staff visited, and any risks identified were recorded. The senior team would then decide what safety systems needed to be used to protect staff. This included, for example, two members of staff working together, or staff only attending at certain times. Staff were also made aware of situations within the family which might put them at risk, and strategies were found to avoid these where possible.
- **There were some arrangements for providing staff with the development they needed, and this had been arranged with a number of staff.** However, due to the lack of an effective performance review and appraisal, this was not linked closely enough with the needs of the service and relevant and linked career development.

Governance, risk management and quality measurement

- **There was a significant lack of effective governance processes in the care and treatment aspect of the organisation.** The nursing side of the organisation did not have an effective process which gave assurance the care and treatment provided was safe, effective and provided quality care. There was no evidence to suggest the service was not unsafe or ineffective, but as seen above in other parts of this report, very little of those areas we inspected had assurance or evidence to support our routine questions.
- There were team meetings and staff meetings, but they did not cover those areas where we found shortcomings. For example, there was no assurance around whether the service was meeting its key performance indicators. This would have included reports on appraisal and training compliance, audits and investigation outcomes, incidents and complaints management. There were good discussions about the service in terms of reports of the children and families, but large aspects of the service were not reported.
- **There was no risk register for the service**. There was no overarching document which captured those risks which the organisation ran, and how it was managing them. There was therefore no-one in the nursing team taking ownership of the risks in the organisation or being responsible for their oversight.
- **There was no systematic programme of internal audit in the nursing service to monitor quality and operational performance**. There was a full internal audit programme in the financial and charitable arm of the organisation, with sign-off by a local firm of accountants. However, the nursing arm had not identified a clear programme of audit, such as care records, medicines records, infection control, and others, which should have identified a number of the concerns we have raised above.
- **The service was not providing and had not been asked to provide a performance report from the nursing team to the board of trustees.** Therefore, the board of trustees was not being given or asking for performance or quality assurance. There was a report on the service, but this was not a comprehensive look at quality, safety, audit, risk or performance.
- **Feedback was used, but unstructured.** Feedback from families was discussed throughout the organisation, but without a clear and effective system for capturing complaints, incidents or issues, it was not possible to be assured this was entirely open and transparent.

- **Policies and procedures were not entirely accurate or complete and did not always reflect the service provided.** We reviewed a number of policies, which had been through a recent review, but some of these were not in line with the service being provided or were poor on detail. The appraisal policy, for example, did not go into any detail as to the objectives of this performance review and how and when it should be conducted. The organisation's policy for mandatory training did not provide clarity around what subjects were considered as mandatory, who should complete them and when.
- **Staff at all levels were clear about their roles and accountabilities and had regular opportunities to meet and discuss the service.** All the staff we met were clear about their roles and responsibilities. This included both the nursing team and the team that managed the charitable trust. Each member of staff and team interacted well with one another. There were regular meetings, although as we have reported above, these did not contain information about governance, safety, audit and quality of care.

Public and staff engagement

- **Leaders and staff actively and openly engaged with families, staff, the public and local organisations to plan and manage services.** The service wanted to hear from all those who used the service in order to improve and learn. It had established a families' involvement group to look for ideas, support and how it could improve services. This had some success, although it was mainly around large-scale projects or events where support was provided. It was not easy for the service to get as much engagement as it wanted, as the families had significant time-commitments in caring for their child. However, the overnight service had been developed following feedback and consultation from families and carers.
- The facilitation of the families' involvement group also provided support from one parent to another. Parents of older children who had left the service were welcome to attend meetings and were able to provide guidance and advice from their own experiences.
- There were positive and collaborative relationships with external partners, although due to the unique nature of the service, the organisation did not have an extensive group of stakeholders it could call upon for support or involvement. Nevertheless, it had good working relationships with the local acute hospital and specific teams, and the local children's hospice. There was otherwise limited oversight from commissioners or NHS bodies providing funding support.
- The service produced a specific newsletter for families and a more general one for local people, stakeholders and interested parties called Fly the Kite. The most recent was a 30th anniversary newsletter reflecting on how far the service had come. It included reports on events with the children and fundraising events. The trust had an open day each year, and the most recent had taken place on the Sunday before our visit on the Monday morning. We were told this had been a great success with hundreds of visitors coming through the doors. It was impressive to note how this event had not disrupted the service and the whole house was back to its normal routine, including our visit, on the Monday morning.

Learning, continuous improvement and innovation

- **All staff were committed to continually learning and improving services.** Staff and managers were proud of the way in which the service had expanded and improved its service to children and parents over the last five years or so. They also remained ambitious about future expansion. The service had expanded its premises, which had allowed it to offer a wider range of services in purpose-built premises. There was a successful charitable fund-raising team, which had helped raise money for these and ongoing improvements to the service. At the time of our inspection the service was excited about a new sensory room for children which was being installed.
- The service had researched care and treatment and trained staff to support children with complex nutritional needs. For example, it had trained staff to administer blended diets where these were being given to children at home. The service had recently trained staff to perform female catheterisation in order to support a specific child to be able to use the service. This would otherwise require the child to attend hospital for this procedure.

Community health services for children, young people and families

- **There were no issues we could identify in relation to the future sustainability of the service.** From accounts and information registered with The Charity Commission, and from staff evidence, we could see the organisation was financially stable. The trust used The Charity Commission's tool for financial controls. There were sufficient funds to safely run the service and ensure continuity of care and support. There were funds available for urgent areas, such as unplanned maintenance, and for longer-term projects.

Outstanding practice and areas for improvement

Outstanding practice

- The service, almost entirely through its charitable fundraising, provided an outstanding level of support to parents and carers in Gloucestershire which was otherwise unavailable to them. This included day-care, holiday club and overnight respite. It also enveloped the whole family in the organisation, and staff were there for anyone who needed them. The level of empathy, understanding, and compassion shown to families and carers and the children themselves was outstanding. A number of the staff had personal experiences and had left quite different careers outside of healthcare to work with and support the organisation.

Areas for improvement

Action the provider MUST take to improve

- Maintain an accurate, complete and contemporaneous record in respect of each child, including a record of the care and treatment provided and any decisions taken in relation to their care and treatment. This must cover care plans, risk assessments and medicine administration records.
- Provide all staff with training, supervision and appraisal as is necessary to enable them to carry out the duties they are employed to perform. Ensure this information is recorded and monitored. This includes mandatory, role-specific and safeguarding training.
- Assess the risks to the health and safety of children and do all possible to mitigate any such risks. This included transport of children.
- Have assurance that persons providing care or treatment for children have the qualifications, competence, skills and experience to do so safely.
- Establish and maintain an effective system of governance, assurance and audit to assess, monitor and improve the quality and safety of the services provided. Ensure the risks to health, safety and welfare of people who use the services are assessed, monitored and mitigated.

Action the provider SHOULD take to improve

- Check that all staff or volunteers who work for the organisation meet the policy and rules around criminal records checks.
- Review the service for any areas we identified to be improved in relation to infection prevention and control and management of clinical waste.
- Keep the electrical checks of equipment up to date and any equipment which needs regular checking to be monitored.
- Review the issues we have raised around medicines, including clear instructions for the fridges around temperatures and indicating when the service was closed. Hold a controlled drugs register, remove medicines that do not belong to the service, remove out of date guidance, and establish a simple system for medicines or consumables reaching their expiry date.
- Re-establish the incident report system to demonstrate this is effectively used and understood.
- Take account of cultural, religious and social needs of children and families to avoid any discrimination, lack of awareness of adjustments required, or different support to be given.
- Determine whether the service is too risk-averse in its access to children given the skills and knowledge of the nursing team.
- Establish an accessible system for identifying, receiving, recording, handling and monitoring complaints.
- Provide a mechanism for the service to improve and give the leadership team the skills to provide the service they want to deliver.

Outstanding practice and areas for improvement

- Review the lone-working arrangements to ensure these are effective.
- Review the policies and procedures the service uses to ensure these are accurate, complete and reflect the service provided.

This section is primarily information for the provider

Requirement notices

Action we have told the provider to take

The table below shows the legal requirements that were not being met. The provider must send CQC a report that says what action they are going to take to meet these requirements.

Regulated activity	Regulation
Treatment of disease, disorder or injury	Regulation 12 HSCA (RA) Regulations 2014 Safe care and treatment The service did not assess the risks to the health and safety of children and do all possible to mitigate any such risks. This included transporting children. Regulation 12 (2)(a)(b) The service did not have the assurance that persons providing care or treatment for children have the qualifications, competence, skills and experience to do so safely. Regulation (12) (2)(c)

Regulated activity	Regulation
Treatment of disease, disorder or injury	Regulation 17 HSCA (RA) Regulations 2014 Good governance The service had not maintained an accurate, complete and contemporaneous record in respect of each child, including the records of the care and treatment provided and any decisions taken in relation to their care and treatment. This related to care plans, risk assessments and medicine administration records. Regulation 17 (2)(c) The service had not established and maintained an effective system of governance, assurance and audit to assess, monitor and improve the quality and safety of the services provided. The service needed to ensure the risks to health, safety and welfare of people who use the services were assessed, monitored and mitigated. Regulation (17) (1)(2)(a)(b)

Regulated activity	Regulation

This section is primarily information for the provider

Requirement notices

Treatment of disease, disorder or injury

Regulation 18 HSCA (RA) Regulations 2014 Staffing

The service had not provided all staff with training, supervision and appraisal as is necessary to enable them to carry out the duties they are employed to perform. The service had not ensured this information was recorded and monitored. This included mandatory, role-specific and safeguarding training. Regulation 18(2)(a)