Inspection Report

We are the regulator: *Our job is to check whether hospitals, care homes and care services are meeting essential standards.*

The Jessie May Trust

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Tel: 01179616840

Date of Inspections: 14 November 2013
13 November 2013

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We inspected the following standards as part of this inspection. This is what we found:

Respecting and involving people who use services	✓ Met this standard
Care and welfare of people who use services	✓ Met this standard
Cooperating with other providers	✓ Met this standard
Safeguarding people who use services from abuse	✓ Met this standard
Supporting workers	✓ Met this standard
Assessing and monitoring the quality of service provision	✓ Met this standard

Details about this location

Registered Provider	The Jessie May Trust
Registered Manager	Mrs. Elizabeth Lewington
Overview of the service	The Jessie May Trust is a registered charity which offers respite and support to parents and personal care to children with life limiting illnesses in their own homes.
Type of services	Domiciliary care service Hospice services at home
Regulated activities	Nursing care Personal care Treatment of disease, disorder or injury

Contents

When you read this report, you may find it useful to read the sections towards the back called 'About CQC inspections' and 'How we define our judgements'.

Summary of this inspection

Why we carried out this inspection

This inspection was part of a themed inspection programme specifically looking at the arrangements for transition from children's to adults services. The programme focussed on young people aged 14-25 years with complex physical health needs.

This was an announced inspection.

How we carried out this inspection

We looked at the personal care or treatment records of people who use the service, carried out a visit on 13 November 2013 and 14 November 2013, checked how people were cared for at each stage of their treatment and care and talked with carers and / or family members. We talked with staff and reviewed information given to us by the provider.

What people told us and what we found

We inspected the Jessie May Trust agency over two days. During our visit we met with parents and children at a family group which was held quarterly at the agency office. Parents had absolute praise for the staff and the way in which the service was delivered. One parent told us "I couldn't do without them".

The agency offered nursing care from qualified nurses who were employed by the University Hospital Bristol. In addition the service offers respite care, end of life care, bereavement support and practical and emotional support to parents with a child with a life-limiting condition. Services are delivered in the family home.

We found that children's needs were assessed and reviewed in order that they received appropriate and timely support. Staff were highly motivated, caring and skilled professionals. The agency provided appropriate training, supervision and appraisals for the staff.

The agency provided social activities and many other opportunities for parents to get together. We looked at the quality assurance system which evidenced that the agency consulted with children, families/carers and other stakeholders in the evaluation of the service.

You can see our judgements on the front page of this report.

More information about the provider

Please see our website www.cqc.org.uk for more information, including our most recent judgements against the essential standards. You can contact us using the telephone number on the back of the report if you have additional questions.

There is a glossary at the back of this report which has definitions for words and phrases we use in the report.

Our judgements for each standard inspected

Respecting and involving people who use services ✓ Met this standard

People should be treated with respect, involved in discussions about their care and treatment and able to influence how the service is run

Our judgement

The provider was meeting this standard.

People's views and experiences were taken into account in the way the service was provided and delivered in relation to their care.

Reasons for our judgement

People expressed their views and were involved in making decisions about their care and treatment. On the second day of our visit, we joined parents and children for the quarterly family meeting. Parents told us that the agency staff were 'wonderful with their children' and 'very respectful'.

We asked parents how staff ensured that their children's wishes and choices were respected. We were told that some children were able to verbalise their opinion however, not all children were able to communicate their wishes or preferences. This resulted in parents making those choices on behalf of their children.

We spoke with staff about how they communicate with the children they work with to ensure that they take into account the child's likes and dislikes. Staff told us that several of the team used makaton to communicate, or pictures or a fabio the frog tablet, but it would ultimately dependent upon the child's needs. We saw a communication passport which the manager explained was being rolled out for every child. This was a document which gave information about how the child communicated, what their expressions and gestures actually meant and how to respond. In addition there was information about the likes and dislikes of each child and how they preferred their care to be given. The manager told us that this was a lengthy piece of work for each child. Staff needed to really get to the know the child well through observation and working alongside the family.The agency aimed to have a communication passport for all children who used their service.

We saw from the evaluation of activity days that children had been asked if they had enjoyed the day and what they had liked or not liked. We saw that smiley faces had been used and staff supported children to complete the feedback forms. In addition, staff documented responses from the children according to their level of participation, gestures and vocal enjoyment.

The Jessie May Trust involved children and parents in helping to decide how the service

was run. During the family meeting, we saw that parents decided what the final font type of the new Jessie May information leaflet should be. Documents evidenced that children were consulted as to what activities they would like to be provided, such as the teenage day.

We found that the assessment process in place for the provision of the service was very inclusive of parents and children. Parents had a major part in deciding the level of support they needed. Parents were asked to self-assess their support needs and could re-assess the number of hours provided if their needs changed. The manager told us that this method of parents deciding what level of support should be given was very effective and said "The system is never abused, more often than not parents will under estimate the number of hours support they receive".

Care and welfare of people who use services ✓ Met this standard

People should get safe and appropriate care that meets their needs and supports their rights

Our judgement

The provider was meeting this standard.

Care and treatment was planned and delivered in a way that was intended to ensure people's safety and welfare.

Reasons for our judgement

Children's needs were assessed and care and treatment was planned and delivered in line with their individual care plan. We looked at four care records held at the agency office. We saw that care plans gave an overview of the child's needs and described the way these needs were to be met. Assessments had been completed which focused on the child's health care, personal care and nutritional needs. Assessments were reviewed on an on-going basis as the needs of children could change quickly. Some of the care records had end of life wishes, which one parent told us that the Jessie May staff would support parents with.

Within two of the care records we saw there was a copy of the communication passport which detailed the likes and dislikes of the child and their communication needs. This information had been incorporated into the care plan. The manager explained that they were developing passports for all children.

We saw that there were signed agreements in place which confirmed that parents on behalf of their child had agreed to the way the personal care was to be provided by the agency. There was also a self-assessment carried out by parents on the number of respite hours they required.

Care and treatment was planned and delivered in a way that was intended to ensure people's safety and welfare. We looked at a copy of the information which was held in each child's home. This contained relevant risk assessments to maintain the safety and welfare of children. In addition, there were guidance notes on emergency care such as, in the event of a seizure. There was also a personal evacuation plan in the event of a fire and a risk assessment of the home environment.

Staff told us that at the start of the visit, they confirmed with the parent what care had already been given to the child, any behavioural concerns and emergency procedures. Staff completed the handover documentation at the end of each visit, which detailed information about the personal care which had been provided and medication administered. We saw from care plans that review of the child's needs was on-going and that the service was reviewed annually.

Cooperating with other providers ✓ Met this standard

People should get safe and coordinated care when they move between different services

Our judgement

The provider was meeting this standard.

People's health, safety and welfare was protected when more than one provider was involved in their care and treatment, or when they moved between different services. This was because the provider worked in co-operation with others.

Reasons for our judgement

People's health, safety and welfare was protected when more than one provider was involved in their care and treatment, or when they moved between different services. This was because the provider worked in co-operation with others.

We spoke with the manager who told us that the agency had a very good relationship with other organisations. Documentation evidenced that the agency were members of various groups such as, the Disability Advisory group and the Children's Palliative Care network for the south west. These groups were made up of a multi-disciplinary membership from within health, education, and social and voluntary sectors.

A recent development had been the invitation for the Jessie May Trust to participate as a stakeholder, in the Transition Commissioning for Quality and Innovation group which University Hospital Bristol was working towards this year.

We asked Jessie May staff if they attended children's review meetings within social care and education. They told us that some parents would ask them to and they would attend if invited. Sometimes the agency would be asked by the school transition worker to support them to contact and engage with the family.

We looked at the care records of four children. There were pre-assessment records which detailed the likes and dislikes of children. The records also contained information about the external agencies and services who were involved in the children's care and treatment, including health, education and social work contacts. Parents told us that the Jessie May staff would always support them to liaise with other professionals. We saw evidence within the care records that the Jessie May agency had requested the involvement of other agencies when required such as specialist health professionals and education.

The Jessie May Trust shared information as appropriate with other professionals. For example,with the consent of the parents, an end of life wishes documents was shared with the child's paediatrician.

The agency informed the GP and family when the child reached 19 years of age and were discharged from the service. As part of supporting families through the transition we saw that the agency had arranged hospital appointments, contact with the disability social worker, the continuing health team and the adult health care team.

Safeguarding people who use services from abuse ✓ Met this standard

People should be protected from abuse and staff should respect their human rights

Our judgement

The provider was meeting this standard.

People who use the service were protected from the risk of abuse, because the provider had taken reasonable steps to identify the possibility of abuse and prevent abuse from happening.

Reasons for our judgement

Children who used the service were protected from the risk of abuse, because the provider had taken reasonable steps to identify the possibility of abuse and prevent abuse from happening. Parents told us that the Jessie May agency workers were 'excellent' and they felt safe to leave their child in their care.

We spoke with the manager and three members of agency front-line staff. They were knowledgeable about what constituted abuse and were very aware of their responsibilities in relation to this. Staff told us they attended child protection training to level three and four and there were two yearly updates. The bi-annual updates were provided by a child protection paediatrician and a child protection nurse. Staff also attended quarterly safeguarding/child protection supervision meetings.

We found that staff were informed about the Mental Capacity Act however, staff had not received training in this and in the Safeguarding of Vulnerable Adults. We saw from a list of people who used the service, that at any one time there would be two or three young adults aged 18 to 19 years accessing the service. As young adults used the service, this training was a mandatory requirement.

We spoke with the training lead who explained they had been trying to source this training through their employer, University Hospital Bristol. During our visit the training lead was able to secure training for all of the team and this was to be delivered on 10 December 2013. We asked the manager to inform us of when this training had taken place.

Likewise, the bank agency staff had not received training in Safeguarding of Vulnerable Adults. This training had been arranged for mid January 2014 and an agreement was put in place which prevented any bank staff from working with a young adult until they had completed the training.

During the morning of our visit, staff attended a monthly caseload meeting where any issues including safeguarding concerns were discussed. A member of staff told us that all open cases were reviewed at the monthly meetings.

The manager described an example of a safeguarding concern they had raised with the local children's safeguarding team. We saw that incidents were recorded in the child's home records and an incident report completed and passed to the manager for action if required. Incidents were also recorded on a computerised log which were analysed and reviewed by the University Hospital Bristol. This showed that there were arrangements in place to help protect children and safeguard them against the risk of abuse.

The agency had an up to date safeguarding policy and procedures available for both children and young adults. This provided information on what constituted abuse and actions staff needed to take if abuse was suspected. There was a safeguarding referral document which gave information on who to contact in children and adult services. A whistleblowing policy was in place and this was available to all staff.

Children and young adults who used the service were protected against the risk of unlawful or excessive control or restraint because the provider had made suitable arrangements. Staff received training in the appropriate use of restraint and the agency had an up to date restraint policy.

Supporting workers ✓ Met this standard

Staff should be properly trained and supervised, and have the chance to develop and improve their skills

Our judgement

The provider was meeting this standard.

People were cared for by staff who were supported to deliver care and treatment safely and to an appropriate standard.

Reasons for our judgement

Staff received appropriate professional development and support. We spoke with staff who confirmed that they received one to one supervision with their line manager, one to one peer meetings and attended group team meetings. The nursing staff also received clinical supervision which was delivered by a consultant psychotherapist from the Bristol Children's Hospital. We viewed the supervision records of two members of staff which confirmed that staff received support on a regular basis.

Staff confirmed that they received an annual appraisal and opportunities for further personal development through an agreed development plan. Staff told us that they felt 'very well supported' by the management team and were pleased with the type of training they received which supported them to carry out their specific roles. One member of staff told us how that as a qualified nurse, there were some procedures such as using a syringe driver, which they did not carry out as an agency worker. To ensure their nursing registration was current, staff would work in mainstream services to ensure their competencies were up to date and their registration valid.

We spoke with three parents who told us that the staff were friendly, polite and did their job really well. One parent said "I couldn't do without them".

We looked at the training records which evidenced that staff had attended mandatory and other training. The training lead showed us the training matrix which flagged up when staff were due to update their training. Mandatory training included infection control, manual handling, fire training and resuscitation. The training lead was responsible for ensuring that all new staff to the team undertook the mandatory training as part of their induction.

The training lead told us that as part of the induction process new staff would be assessed for competency. However, if the new worker did not feel confident in performing a particular task then they would be offered more support/training and would not be expected to carry out that task until they felt confident. A member of staff told us that their skills and competency would always be matched to the needs of the child and the family. If a member of staff did not feel experienced or confident in supporting the particular needs of a family, then the team leader would make other arrangements.

Staff told us that specialist training was based upon the needs of the children they supported. Such as, epilepsy, enteral feeding and tracheotomy care. Staff could also suggest training if it was relevant to their role and to the families they supported. One member of staff told us about training they had recently completed in Islamic bereavement support. They told us that there were several families from different cultures and traditions and the course gave them some really good information about how they could support families in a way which respected their families' beliefs and faith.

Assessing and monitoring the quality of service provision ✓ Met this standard

The service should have quality checking systems to manage risks and assure the health, welfare and safety of people who receive care

Our judgement

The provider was meeting this standard.

The provider had an effective system to regularly assess and monitor the quality of service that people receive.

Reasons for our judgement

People who used the service, their representatives and staff were asked for their views about their care and treatment and they were acted on.

Clinical governance meetings were held quarterly and centred on the service improvements needed and safeguarding. The minutes confirmed that improvements and safeguarding matters were discussed. A care team business meeting held on the 6 November 2013 discussed the success of a recent teenage day, staff training requirements, feedback from a conference on a helpline for Islamic bereavement support and, up and coming events, such as the 'Tree of Light' festival. In addition, future service developments were discussed such as the allocation of a dedicated nurse for children going through the transition to adult services.

We looked at the agencies quality assurance system. We found that audits were carried out throughout the year, for example, incidents, complaints, staff training and competence, supervision and risk assessments which related to lone working and the environment of the homes visited. We found that the quality of record keeping for care plans and reviews was good, however we did not see that care records were audited as part of the quality assurance system. The provider may wish to note that all care records should be formally audited to ensure consistency in record keeping.

We saw that the manager had recently implemented an on-going review of how much time staff allocated to each task. They told us that it had already helped them to review and reallocate resources more effectively. We saw that policies and procedures were updated annually or as and when required.

There was an electronic system in place to monitor staff supervision, appraisal and training which was managed by the training lead. There was a paper copy of the training and supervision matrix which evidenced that staff had received training and supervision.

The agency monitored complaints and we saw that concerns had been properly investigated and addressed with the people concerned. Complaints, compliments and

incidents were entered onto a database which University Hospital Bristol monitored and analysed as part of their own quality assurance as they employed the Jessie May nursing staff.

We saw that the agency evaluated events such as the 'Teenage day', the Purple group and other play days and activities. An annual satisfaction survey was sent out to all parents along with a stamped addressed envelope to return the form. We looked at the latest returns which evidenced a high level of satisfaction with the service provided. We asked the manager if they consulted with stakeholders in relation to seeking their views on the service which the agency delivered. They explained that as part of the process of applying for funding, the agency was required to illicit the views of professionals and other agencies, such as, social care workers, doctors and the board of trustees.

We saw from documentation, that the staff team attended away days and staff told us that this was an opportunity to put forward ideas and suggestions for the service. Staff also told us that any suggestions, new ideas or concerns would always be listened to by the management team and they felt involved in developing the service.

About CQC inspections

We are the regulator of health and social care in England.

All providers of regulated health and social care services have a legal responsibility to make sure they are meeting essential standards of quality and safety. These are the standards everyone should be able to expect when they receive care.

The essential standards are described in the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010 and the Care Quality Commission (Registration) Regulations 2009. We regulate against these standards, which we sometimes describe as "government standards".

We carry out unannounced inspections of all care homes, acute hospitals and domiciliary care services in England at least once a year to judge whether or not the essential standards are being met. We carry out inspections of other services less often. All of our inspections are unannounced unless there is a good reason to let the provider know we are coming.

There are 16 essential standards that relate most directly to the quality and safety of care and these are grouped into five key areas. When we inspect we could check all or part of any of the 16 standards at any time depending on the individual circumstances of the service. Because of this we often check different standards at different times.

When we inspect, we always visit and we do things like observe how people are cared for, and we talk to people who use the service, to their carers and to staff. We also review information we have gathered about the provider, check the service's records and check whether the right systems and processes are in place.

We focus on whether or not the provider is meeting the standards and we are guided by whether people are experiencing the outcomes they should be able to expect when the standards are being met. By outcomes we mean the impact care has on the health, safety and welfare of people who use the service, and the experience they have whilst receiving it.

Our inspectors judge if any action is required by the provider of the service to improve the standard of care being provided. Where providers are non-compliant with the regulations, we take enforcement action against them. If we require a service to take action, or if we take enforcement action, we re-inspect it before its next routine inspection was due. This could mean we re-inspect a service several times in one year. We also might decide to re-inspect a service if new concerns emerge about it before the next routine inspection.

In between inspections we continually monitor information we have about providers. The information comes from the public, the provider, other organisations, and from care workers.

You can tell us about your experience of this provider on our website.

How we define our judgements

The following pages show our findings and regulatory judgement for each essential standard or part of the standard that we inspected. Our judgements are based on the ongoing review and analysis of the information gathered by CQC about this provider and the evidence collected during this inspection.

We reach one of the following judgements for each essential standard inspected.

✓ **Met this standard**	This means that the standard was being met in that the provider was compliant with the regulation. If we find that standards were met, we take no regulatory action but we may make comments that may be useful to the provider and to the public about minor improvements that could be made.
✖ **Action needed**	This means that the standard was not being met in that the provider was non-compliant with the regulation. We may have set a compliance action requiring the provider to produce a report setting out how and by when changes will be made to make sure they comply with the standard. We monitor the implementation of action plans in these reports and, if necessary, take further action. We may have identified a breach of a regulation which is more serious, and we will make sure action is taken. We will report on this when it is complete.
✖ **Enforcement action taken**	If the breach of the regulation was more serious, or there have been several or continual breaches, we have a range of actions we take using the criminal and/or civil procedures in the Health and Social Care Act 2008 and relevant regulations. These enforcement powers include issuing a warning notice; restricting or suspending the services a provider can offer, or the number of people it can care for; issuing fines and formal cautions; in extreme cases, cancelling a provider or managers registration or prosecuting a manager or provider. These enforcement powers are set out in law and mean that we can take swift, targeted action where services are failing people.

How we define our judgements (continued)

Where we find non-compliance with a regulation (or part of a regulation), we state which part of the regulation has been breached. Only where there is non compliance with one or more of Regulations 9-24 of the Regulated Activity Regulations, will our report include a judgement about the level of impact on people who use the service (and others, if appropriate to the regulation). This could be a minor, moderate or major impact.

Minor impact - people who use the service experienced poor care that had an impact on their health, safety or welfare or there was a risk of this happening. The impact was not significant and the matter could be managed or resolved quickly.

Moderate impact - people who use the service experienced poor care that had a significant effect on their health, safety or welfare or there was a risk of this happening. The matter may need to be resolved quickly.

Major impact - people who use the service experienced poor care that had a serious current or long term impact on their health, safety and welfare, or there was a risk of this happening. The matter needs to be resolved quickly

We decide the most appropriate action to take to ensure that the necessary changes are made. We always follow up to check whether action has been taken to meet the standards.

Glossary of terms we use in this report

Essential standard

The essential standards of quality and safety are described in our *Guidance about compliance: Essential standards of quality and safety*. They consist of a significant number of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010 and the Care Quality Commission (Registration) Regulations 2009. These regulations describe the essential standards of quality and safety that people who use health and adult social care services have a right to expect. A full list of the standards can be found within the *Guidance about compliance*. The 16 essential standards are:

Respecting and involving people who use services - Outcome 1 (Regulation 17)
Consent to care and treatment - Outcome 2 (Regulation 18)
Care and welfare of people who use services - Outcome 4 (Regulation 9)
Meeting Nutritional Needs - Outcome 5 (Regulation 14)
Cooperating with other providers - Outcome 6 (Regulation 24)
Safeguarding people who use services from abuse - Outcome 7 (Regulation 11)
Cleanliness and infection control - Outcome 8 (Regulation 12)
Management of medicines - Outcome 9 (Regulation 13)
Safety and suitability of premises - Outcome 10 (Regulation 15)
Safety, availability and suitability of equipment - Outcome 11 (Regulation 16)
Requirements relating to workers - Outcome 12 (Regulation 21)
Staffing - Outcome 13 (Regulation 22)
Supporting Staff - Outcome 14 (Regulation 23)
Assessing and monitoring the quality of service provision - Outcome 16 (Regulation 10)
Complaints - Outcome 17 (Regulation 19)
Records - Outcome 21 (Regulation 20)

Regulated activity

These are prescribed activities related to care and treatment that require registration with CQC. These are set out in legislation, and reflect the services provided.

Glossary of terms we use in this report (continued)

(Registered) Provider

There are several legal terms relating to the providers of services. These include registered person, service provider and registered manager. The term 'provider' means anyone with a legal responsibility for ensuring that the requirements of the law are carried out. On our website we often refer to providers as a 'service'.

Regulations

We regulate against the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010 and the Care Quality Commission (Registration) Regulations 2009.

Responsive inspection

This is carried out at any time in relation to identified concerns.

Routine inspection

This is planned and could occur at any time. We sometimes describe this as a scheduled inspection.

Themed inspection

This is targeted to look at specific standards, sectors or types of care.

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