

Review of compliance

The Jessie May Trust The Jessie May Trust	
Region:	South West
Location address:	35 Old School House, Kingswood Foundation Estate Britannia Road, Kingswood Bristol BS15 8DB
Type of service:	Domiciliary care service Hospice services
Date of Publication:	April 2012
Overview of the service:	The Jessie May Trust is a registered charity that provides respite (short term) personal care to children with life limiting illnesses in their own homes

Summary of our findings for the essential standards of quality and safety

Our current overall judgement

The Jessie May Trust was not meeting one or more essential standards. Action is needed.

The summary below describes why we carried out this review, what we found and any action required.

Why we carried out this review

We carried out this review as part of our routine schedule of planned reviews.

How we carried out this review

We reviewed all the information we hold about this provider, carried out a visit on 1 March 2012, observed how people were being cared for, talked to staff and talked to people who use services.

What people told us

We visited children in their own homes to observe the way the agency staff provided personal care and to speak with their parents.

We observed staff using appropriate methods to engage with the children. These methods included speaking to the child at eye level, using assistive technology to help children to play with toys and undertaking activities that the children enjoyed. The smiles and vocal noises showed us that the children enjoyed the interaction with the agency staff.

Parents told us that the staff were good and at the beginning of each visit they discussed the care already provided. We were told that following these discussions the agency staff then carried out treatment programmes, for example feeding their child, administering medication and playing with their child.

We asked parents about what actions they would take if staff told them that their child's preference differed from theirs. We wanted to know how they would respond, when staff supported their children to make choices. Parents told us that their child's happiness was most important and both parents said that they would respect their child's choice.

One parent told us that agency staff had supported them to devise an end of life plan. This discussion was difficult but it was complete and could be "put" away.

What we found about the standards we reviewed and how well The Jessie May Trust was meeting them

Outcome 01: People should be treated with respect, involved in discussions about their care and treatment and able to influence how the service is run

Overall, we found that this essential standard was being met.

There are systems in place for ensuring that parents who act on behalf of their children understand the care and treatment the agency can provide.

Outcome 04: People should get safe and appropriate care that meets their needs and supports their rights

Overall, we found that The Jessie May Trust was meeting this essential standard, but to maintain this, we have suggested improvements are made.

There are systems in place to assess the child's needs which ensure the agency can provide personal care that reflects the child's need. However, the choices made by the child are not always documented by the staff.

Outcome 07: People should be protected from abuse and staff should respect their human rights

Overall, we found that improvements were needed for this essential standard.

There are no clear procedures for the use of control or restraint and when these measures are appropriate to be used.

Outcome 13: There should be enough members of staff to keep people safe and meet their health and welfare needs

Overall, we found that this essential standard was being met.

There are sufficient numbers of staff to meet the respite care needs of people who use the agency.

Outcome 14: Staff should be properly trained and supervised, and have the chance to develop and improve their skills

Overall, we found that this essential standard was being met.

The staff working at the agency are competent and supervised to meet the personal needs of the children that use the agency.

Outcome 16: The service should have quality checking systems to manage risks and assure the health, welfare and safety of people who receive care

Overall, we found that The Jessie May Trust was meeting this essential standard, but to maintain this, we have suggested improvements are made.

There are effective systems in place to monitor the quality of personal care provided by the agency. The views of people acting on behalf of the children are not always used to

influence the way the agency is run.

Actions we have asked the service to take

We have asked the provider to send us a report within 14 days of them receiving this report, setting out the action they will take. We will check to make sure that this action has been taken.

Where we have concerns we have a range of enforcement powers we can use to protect the safety and welfare of people who use this service. When we propose to take enforcement action, our decision is open to challenge by a registered person through a variety of internal and external appeal processes. We will publish a further report on any action we have taken.

Other information

Please see previous reports for more information about previous reviews.

**What we found
for each essential standard of quality
and safety we reviewed**

The following pages detail our findings and our regulatory judgement for each essential standard and outcome that we reviewed, linked to specific regulated activities where appropriate.

We will have reached one of the following judgements for each essential standard.

Compliant means that people who use services are experiencing the outcomes relating to the essential standard.

Where we judge that a provider is non-compliant with a standard, we make a judgement about whether the impact on people who use the service (or others) is minor, moderate or major:

A minor impact means that 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.

A moderate impact means that 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.

A major impact means that 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.

Where we identify compliance, no further action is taken. Where we have concerns, the most appropriate action is taken to ensure that the necessary changes are made.

More information about each of the outcomes can be found in the *Guidance about compliance: Essential standards of quality and safety*

Outcome 01: Respecting and involving people who use services

What the outcome says

This is what people who use services should expect.

People who use services:

- * Understand the care, treatment and support choices available to them.
- * Can express their views, so far as they are able to do so, and are involved in making decisions about their care, treatment and support.
- * Have their privacy, dignity and independence respected.
- * Have their views and experiences taken into account in the way the service is provided and delivered.

What we found

Our judgement

The provider is compliant with Outcome 01: Respecting and involving people who use services

Our findings

What people who use the service experienced and told us

We spoke to parents about the way their child's care and treatment was assessed by the agency. The parents we spoke with told us which external professionals had made the referral for personal care from the agency.

Parents told us their visits were scheduled on a month by month basis and it was usual for them to have the visits they requested. We were told that they observed the agency staff working in their home's and if they thought the care was not carried out in the way that their child's preferred they would be able to tell the agency staff.

We asked parents about what actions they would take if staff told them that their child's preference differed from theirs. We wanted to know how they would respond, when staff supported their children to make choices. Parents told us that their child's happiness was most important and both parents said that they would respect their child's choice.

During our visit we observed the way staff engaged with the children. We saw members of staff use a combination of words and hand gestures to communicate with the child. Staff used objects known by the child to interact with them and undertook activities which they knew the child enjoyed for example using toys, music and brushing

their hair. We saw that the children enjoyed the actions of the staff because they smiled and made vocal noises.

Other evidence

We asked the manager to tell us about the way The Jessie May Trust operates. We were told that respite care could be provided to a child in their homes and referrals for personal care could be made by parents, social and healthcare professionals. Once the agency received the referral form, an assessment of need would be carried out at the child's home. We were told this visit would be an opportunity for the child and parents to meet the staff team and to discuss the services and facilities that the agency was able to provide.

We looked at the records of referrals received for personal care. A referrals checklist was used to ensure the appropriate information was sought about the child. The form sought information about the child's diagnosis, their needs and a summary of health care needs from other professionals, for example, the doctor or a paediatric consultant. Completed referral forms confirmed that parents, carers, health and social care professionals made request for personal care from the agency. Once the agency received the completed referral form, parents and carers were sent an acknowledgement letter about what to expect from the agency.

The Jessie May Trust had links with Lifetime services (the lead community based service for children with palliative care needs) and where there were Lifetime assessments the agency would use this assessment of needs. Alternatively the agency would conduct a formal review of the child's needs.

The manager told us about the information provided to parents about the agency. It was explained that families received written information and there was a Jessie May Trust file kept in the child's home. We found records of environmental risk assessments and key procedures such as signed consent forms for medication administrations and complaints leaflets.

Interpreters and pictures were used to ensure that the child's parents or carers could make sense of the information being given to them about the agency. Interpreters would be used on initial assessments where needed and when care agreements were being carried out.

We asked staff to tell us about the way parents and carers were supported to understand the personal care their child would receive. Staff told us that once a completed referral form was received, two initial visits were carried out at the child's home. Where there were Lifetime care plans in place these were discussed at the first visit. The second visit was where care agreements were signed and the personal care to be provided was discussed.

Staff said that these initial visits were carried out by the team leader and member of staff. The information about the agency was usually passed onto the parents by word of mouth.

We asked staff about the way they communicated with the children. We were told that during the initial assessments of the child's needs, there was a discussion with the parents about communication. We were told that some children could communicate

verbally but needed time to respond, while others used facial expressions.

Our judgement

Overall, we found that this essential standard was being met.

There are systems in place for ensuring that parents who act on behalf of their children understand the care and treatment the agency can provide.

Outcome 04: Care and welfare of people who use services

What the outcome says

This is what people who use services should expect.

People who use services:

* Experience effective, safe and appropriate care, treatment and support that meets their needs and protects their rights.

What we found

Our judgement

The provider is compliant with Outcome 04: Care and welfare of people who use services

Our findings

What people who use the service experienced and told us

We asked the families that we visited about the care and treatment provided by the agency staff. We were told that on each visit there was a discussion about what care had already been provided and about what tasks were to be completed by the agency staff. One parent said that at their tea-time visit the agency staff would assist with feeding their child and then engaged with their child socially. Another said that agency staff administered medication then spent time with their child. These visits gave them an opportunity to leave their child in "safe" hands while they did other things.

We observed staff using a range of "switch" toys to engage with the child. These toys were specially adapted and could be activated by children with sensory needs. The staff acknowledged that the toys may not be age appropriate but were chosen because they gave the desired outcome, for example, to enjoy music or colour. We observed that children smiled when the toys were activated, which indicated enjoyment.

One parent told us they had sought support from the agency to devise a funeral plan. They said this was a deeply upsetting task but now that it was completed, it could be "put away".

Other evidence

We looked at the copies of care files held at the agency office. We saw that copies of the Lifetime (lead community based services for children with palliative care needs) care. Lifetime care plans gave a full overview of the child's needs and described the way these needs were to be met and by which agency. We saw Jessie May

assessments and these centred on the child's health care, their personal care and their nutritional needs.

Additional information about the way the child played, learnt and about their social emotional, spiritual and communication needs were included within the agency assessments.

Signed agreements in place confirmed that parents on behalf of their child had agreed to the way the personal care was to be provided by the agency.

The manager told us that at each visit, the parents or main carers would tell the staff the personal care needs of the child. The member of staff would complete a "Home's safety checklist for Jessie May Trust visits" form. On these forms staff would record key information about personal care already provided. For example when was the child last fed, the personal care completed and the medication administered. Other information sought from the parents was about emergency procedures and the child's behaviour. At the end of the visit, a report about the visit was completed by the member of staff. The staff we spoke with about care planning confirmed that on each visit there was a handover from the parents about personal care already carried out. Parents would then be asked about the personal care that was required to be carried out by the agency staff. However, we did not see any evidence that the child had participated in the decisions about the personal care to be provided.

Copies of moving and handling risk assessments were not kept at the agency office. The manager told us that copies of risk assessments were kept at the child's home so that it could be updated. The updated risk assessment would then be available to the staff for the next agency visit. We looked at the moving and handling risk assessments held in the child's home. We saw that the risks were identified which included the safe systems for transferring, for example, the transfers from wheelchairs to bed. We found that there was no system for monitoring that safe systems were used and that the staff who updated the risk assessments were doing them in line with current good practice.

Staff told us that environmental and moving and handling risk assessments were completed by the team leaders on the first personal care visit.

Staff told us that if parents approached them about a funeral plan, The Jessie May Trust staff could support them with end of life plans. There were staff working at the agency that had lead roles with supporting parents to prepare for bereavement and for support through the loss of their child. Agency staff met with the parents to discuss their child's wishes during life, for example meet a pop star or go to school. Plans were made with the parents in the event that their child became unwell, if there was an acute life threatening event and for the period after death of their child. The staff that led on bereavement support to parents said that this support could be extended for up to five years following the death of a child.

Our judgement

Overall, we found that The Jessie May Trust was meeting this essential standard, but to maintain this, we have suggested improvements are made.

There are systems in place to assess the child's needs which ensure the agency can provide personal care that reflects the child's need. However, the choices made by the

child are not always documented by the staff.

Outcome 07: Safeguarding people who use services from abuse

What the outcome says

This is what people who use services should expect.

People who use services:

* Are protected from abuse, or the risk of abuse, and their human rights are respected and upheld.

What we found

Our judgement

The provider is non-compliant with Outcome 07: Safeguarding people who use services from abuse. We have judged that this has a moderate impact on people who use the service.

Our findings

What people who use the service experienced and told us

The parents we spoke with said that they would feel confident to leave their child with the agency staff. These parents confirmed that they felt their child was safe in the care of the agency staff.

Other evidence

We asked the staff to tell us about their responsibilities towards child protection. These staff told us they had attended child protection training to level three and there were two yearly updates. These two yearly updates were provided by a child protection paediatrician and a child protection nurse. It was further explained that staff attend quarterly safe guarding/child protection supervision.

Staff told us they were aware of the indicators of abuse for example signs of bruising, neglect and changes of behaviours. When we asked staff about what actions they would take if they suspected abuse, they said that in the first instance they would approach the parents. They said it was to establish a "picture" of facts and another member of staff said they would ask the parents to explain. Staff said that if their suspicions continued they would report it to the manager. When we gave feedback to the manager about our findings, we were told that the expectation was for staff to report any suspicions of abuse to the manager prior to asking questions of family members.

Staff told us that there were times when certain treatment programmes had to be undertaken which the child may not want to be carried out, for example physiotherapy,

nappy changes for babies and personal care for children. Staff said they would take steps to divert the child but there were occasions when they would "hold" the child to change them. Another said they would "swaddle" the child and we saw that the "Home safety checklist for Jessie May Trust visit" asked about restraint. This form prompted the member of staff to ask the parent for the agreed methods for restraint for certain procedures. However, risk assessments were not in place and staff had not attended appropriate restraint training.

Our judgement

Overall, we found that improvements were needed for this essential standard.

There are no clear procedures for the use of control or restraint and when these measures are appropriate to be used.

Outcome 13: Staffing

What the outcome says

This is what people who use services should expect.

People who use services:

* Are safe and their health and welfare needs are met by sufficient numbers of appropriate staff.

What we found

Our judgement

The provider is compliant with Outcome 13: Staffing

Our findings

What people who use the service experienced and told us

Parents told us that the agency contacted them in advance about the number of visits they needed each month. One parent said they were "happy" with the times they were offered. Another said they preferred tea-time visits which they had, but some weekends would be "useful"

Other evidence

The manager told us that the agency only employed qualified nurses or nursery nurses. The staff appointed to a visit would then depend on the type of nursing tasks needed. We were told that respite visits were for three hours and the parents were asked to assess the number of visits they needed during initial assessments. Agency staff would then score the child's level of needs and the number of visits depended on the score.

It was explained that the staff were aware of the respite care times parents wanted, for example, only school holidays or term time visits only. Parents were able to request the times of the visits in advance, for example, tea-time visits. Once the monthly plan of hours was devised the agency staff were asked about their availability to cover the hours needed.

The manager said that where there were no staff available, visits were cancelled. We were told that it was explained to parents during the assessment stage that there may be times when their visit could be cancelled. It was explained that at times when there were other priorities, for example, providing palliative care to children or babies, and visits had to be prioritised. We were told that care agreements told parents that there

were times when visits could be cancelled.

We were told that once the rota was devised, parents would be contacted by phone to confirm the visits. During the call the parents would be told the name of the staff that would be visiting, a post card would then be sent by post as a reminder of the visit.

Out of hours contact was not provided outside normal office hours, as parents were the first point of contact for their child. A nurse employed by University Hospitals Bristol NHS Foundation Trust (UHB) carries a pager which Jessie May staff could use to contact the nurse for support during these periods.

Our judgement

Overall, we found that this essential standard was being met.

There are sufficient numbers of staff to meet the respite care needs of people who use the agency.

Outcome 14: Supporting staff

What the outcome says

This is what people who use services should expect.

People who use services:

* Are safe and their health and welfare needs are met by competent staff.

What we found

Our judgement

The provider is compliant with Outcome 14: Supporting staff

Our findings

What people who use the service experienced and told us

The parents that we spoke with said that the staff were good.

Other evidence

The manager said that the Jessie May Trust staff had to attend fire training, moving and handling and managing violence and aggression training. Other courses that must be attended included Infection control, resuscitation and paediatric immediate life support, child protection levels two and three. Specialist training in enteral feeding, epilepsy, oxygen administration and tracheotomy care was also provided to staff.

The staff we spoke with confirmed that they had attended this training. Staff said that during their individual supervision and team meetings there were discussions about the training attended.

We asked staff about the way they were supported to fulfil their roles. Staff said there was peer, clinical and individual supervision meetings. Peer supervision was convened as needed and led by the staff. At these sessions agreements and decisions were reached about the way issues would be discussed with the manager. Clinical supervisions were from the clinical psychologist and these were team sessions. Individual supervisions were from the line manager and they centred on personal development, issues with other staff and performance

Our judgement

Overall, we found that this essential standard was being met.

The staff working at the agency are competent and supervised to meet the personal needs of the children that use the agency.

Outcome 16: Assessing and monitoring the quality of service provision

What the outcome says

This is what people who use services should expect.

People who use services:

* Benefit from safe quality care, treatment and support, due to effective decision making and the management of risks to their health, welfare and safety.

What we found

Our judgement

The provider is compliant with Outcome 16: Assessing and monitoring the quality of service provision

Our findings

What people who use the service experienced and told us

We did not speak to parents about the way the quality of the agency was monitored.

Other evidence

We asked the manager about the way the views of the people who use the agency could influence the way it operated. We were shown a document dated 2010, where an independent review of the service was undertaken. The views of the parents of the children that received personal care were sought and an analysis of their responses was undertaken. Parent's comments were based on longer respite care visits, overnight care and holiday care. The manager told us that the feedback received had formed part of the Jessie May Trust five year business plan.

The manager also told us about the service evaluation forms which were given to parents at the time when service agreements were signed. We looked at the completed forms received from parents between the period of June 2011 and February 2012. Overall good responses were received about the staff, the way staff engaged with their children and the contact arrangements with the agency. However, there were two comments made about particular staff and out of hours support. While the manager was able to show us that comments received from families were acted upon, comments received through the evaluation forms had been missed. The manager was aware that that the process required closer monitoring. We were told that the evaluation forms were not analysed to compile a report. It was the intention to further develop the quality assurance system so that feedback received could influence the way the agency operated.

We looked at the service improvement log and found that the source of the complaint, the nature of the complaint, the actions taken, the associated risks and the follow up action was recorded.

Clinical governance meetings were monthly and centred on the service improvements needed and safeguarding. The minutes confirmed that improvements and safeguarding matters were discussed. The copies of the most recent meetings showed that there were agreements made including the development of an action plan and the people responsible for completing these.

Our judgement

Overall, we found that The Jessie May Trust was meeting this essential standard, but to maintain this, we have suggested improvements are made.

There are effective systems in place to monitor the quality of personal care provided by the agency. The views of people acting on behalf of the children are not always used to influence the way the agency is run.

Action we have asked the provider to take

Compliance actions

The table below shows the essential standards of quality and safety that **are not being met**. Action must be taken to achieve compliance.

Regulated activity	Regulation	Outcome
Personal care	Regulation 11 HSCA 2008 (Regulated Activities) Regulations 2010	Outcome 07: Safeguarding people who use services from abuse
	How the regulation is not being met: There are no clear procedures for the use of control or restraint and when these measures are appropriate to be used.	

The provider must send CQC a report that says what action they are going to take to achieve compliance with these essential standards.

This report is requested under regulation 10(3) of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010.

The provider's report should be sent to us within 14 days of the date that the final review of compliance report is sent to them.

Where a provider has already sent us a report about any of the above compliance actions, they do not need to include them in any new report sent to us after this review of compliance.

CQC should be informed in writing when these compliance actions are complete.

What is a review of compliance?

By law, providers of certain adult social care and health 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 Care Quality Commission (CQC) has written guidance about what people who use services should experience when providers are meeting essential standards, called *Guidance about compliance: Essential standards of quality and safety*.

CQC licenses services if they meet essential standards and will constantly monitor whether they continue to do so. We formally review services when we receive information that is of concern and as a result decide we need to check whether a service is still meeting one or more of the essential standards. We also formally review them at least every two years to check whether a service is meeting all of the essential standards in each of their locations. Our reviews include checking all available information and intelligence we hold about a provider. We may seek further information by contacting people who use services, public representative groups and organisations such as other regulators. We may also ask for further information from the provider and carry out a visit with direct observations of care.

Where we judge that providers are not meeting essential standards, we may set compliance actions or take enforcement action:

Compliance actions: These are actions a provider must take so that they **achieve** compliance with the essential standards. We ask them to send us a report that says what they will do to make sure they comply. We monitor the implementation of action plans in these reports and, if necessary, take further action to make sure that essential standards are met.

Enforcement action: These are actions we take using the criminal and/or civil procedures in the Health and Social Care Act 2008 and relevant regulations. These enforcement powers are set out in the law and mean that we can take swift, targeted action where services are failing people.

Information for the reader

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