

Lagan's Foundation

# Lagan's Foundation HQ

## Inspection report

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### Ratings

Overall rating for this service

Good ●

Is the service safe?

Good ●

Is the service effective?

Good ●

Is the service caring?

Good ●

Is the service responsive?

Good ●

Is the service well-led?

Good ●

# Summary of findings

## Overall summary

This was an announced inspection carried out on 12 October 2016.

Lagan's Foundation is a charitable organisation that provides respite for families with babies or young children diagnosed with a heart defect or feeding difficulties. Lagan's provides at-home and in hospital support to parents across the country.

Lagan's operates from a domestic dwelling in the Horwich area of Bolton. The staff supporting families were highly trained volunteers.

The service had a registered manager in place at the time of our inspection. A registered manager is a person who has registered with the Care Quality Commission to manage the service. Like registered providers, they are 'registered persons'. Registered persons have legal responsibility for meeting the requirements in the Health and Social Care Act and associated Regulations about how the service is run.

The registered manager was supported by a small team consisting of a volunteer coordinator, a family liaison officer and a business development fundraising officer.

The last inspection was carried out on 23 April 2013; we did not identify concerns with the quality of care and support provided.

At this inspection Lagan's was supporting 25 families covering areas England and Wales. There were 59 families on a waiting list waiting support from the Lagan's team.

We looked at the care records for four families supported. All care records were stored electronically. The system used enabled all records and communication sheets to be scanned in to the system. The systems had a secured backup network in New York, Australia and Europe so data could be always be retrieved in the event of system failure.

We found care records were detailed, personalised and responsive to the children's and family's needs. The care records showed that a comprehensive assessment was completed prior to the support commencing. This ensured that the serious conditions that the child needed support with was conveyed to the registered manager and their team.

The service had robust recruitment procedures in place. Every volunteer had a detailed recruitment file. These were electronically stored.

We found the service had suitable safeguarding procedures in place, which were designed to protect children and families from the risk of abuse.

We looked at a selection of the policies and procedures. Every volunteer is provided with a condensed version of the policies and procedures for them to refer to as required.

New volunteers undertook a comprehensive induction programme, which included training at Alder Hay Children's Hospital. This was also part of the interview process and support workers had to pass this training in order to be offered part of the team. Lagan's also worked closely with Great Ormond Street Hospital for Children and Albert Royal, Wigan Children's Ward and other service across the country.

We saw records that show volunteers had weekly contact with the registered manager or more frequently if required.

We found that before any care and support was offered the service obtained written consent from parents. We were shown examples of the completed consent forms.

We contacted some of volunteers following our inspection who told us that they were fully supported by the registered manager and that the service was very caring, professional and thorough.

The registered manager liaised and worked closely with other healthcare professionals to share good practice and new ideas.

We found the service undertook a comprehensive range of checks to monitor the quality of service delivery. This included volunteer and family feedback surveys, care records check, incidents and accidents and complaints.

## The five questions we ask about services and what we found

We always ask the following five questions of services.

### Is the service safe?

Good ●

The service was safe.

We found that the service had suitable safeguarding procedures in place, which were designed to protect children from the risk of abuse or harm.

Individual and general risk assessment were in place. These were reviewed and updated as required.

### Is the service effective?

Good ●

The service was effective.

Volunteers undertook a comprehensive induction programme including training at Alder Hey Children's Hospital.

We found that before any support was provided, the service obtained written consent from parents.

### Is the service caring?

Good ●

The service was caring.

Lagan's provided care and support to children and families in their own home or at hospital.

Volunteers care and support in an appropriate manner with enteral feeding and daily care tasks which enables family to have a break or to talk with someone from outside the family.

### Is the service responsive?

Good ●

Is the service responsive?

The service was responsive.

We found the service had systems in place to routinely listen to family experiences.

People told us the support they received was invaluable.

### Is the service well-led?

Good 

The service was well led.

Staff told us they were well supported by the registered manager.

Regular audits were undertaken by the service and feedback was regularly sought from parents.

The registered manager liaised with other healthcare professional to share good practice and new ideas.

# Lagan's Foundation HQ

## **Detailed findings**

### Background to this inspection

We carried out this inspection under Section 60 of the Health and Social Care Act 2008 as part of our regulatory functions. This inspection checked whether the provider is meeting the legal requirements and regulations associated with the Health and Social Care Act 2008, to look at the overall quality of the service, and to provide a rating for the service under the Care Act 2014.

This inspection took place on 12 October 2016 and was unannounced. The provider was given 48 hours' notice because we needed to be sure that someone would be available to facilitate the inspection. The inspection was carried out by one adult social care inspector.

Prior to the inspection we looked at the information we held on this service including the last inspection report and any notifications the service had sent to the Care Quality Commission (CQC).

On the 12 October 2016 we spent time at the office and looked at four care records, three staff files, policies and procedures, training and supervisions and other records held at the service.

We received feedback from two healthcare professionals who worked closely with the service. We also had feedback from two volunteers and two family members to obtain their views and opinions.

# Is the service safe?

## Our findings

The Lagan's team of volunteers were skilled and experienced to care and support families of children with heart defects and feeding difficulties. They provided safe, effective care at home allowing families a couple of hours each week respite care. The volunteers assisted with daily tasks such as preparation of a meal, help with feeding and playing with the child. This allowed the parent some rest time or catch up on some well-earned sleep.

We looked at the risk assessments completed by the registered manager. The risk assessments covered health, feeding, medication and Nasogastric Tube (NG tube). NG is a special tube that carries food and medicine to the stomach through the nose. It can be used for all feedings. The risk assessment recorded the identified risk and how these were to be managed.

There were appropriate policies and procedures in place relating to safeguarding and whistleblowing. All volunteers had undertaken child protection as part of their induction. We contacted staff who confirmed they had completed safeguarding training.

There had been no safeguarding referrals raised, however the registered manager was fully aware of the procedures to follow if needed.

We looked at a selection of the policies and procedures. Every volunteer is provided with a condensed version of the policies and procedures for them to refer to as required.

We looked at the recruitment files for three volunteers. These were all held electronically. We saw that the recruitment process were robust. Files contained an application form, references, other proof of identity and a Disclosure and Barring Service (DBS) check. A DBS check helps to ensure people's suitability to work with children and informs the registered manager if there are any convictions against the applicant.

Volunteers told us they are matched with a family close to where they live and spent the allotted time with them; which was usually two hours a week. The same volunteer attended for each visit. This was important to help build good relationship with both the child and parent to get to know individuals needs and preferences. One volunteer commented that they had often heard the family they worked with say that this had been necessary help. It is such a simple task to spend two hours a week in someone's home to play with a child, but to parents this offers support and sometimes a shoulder to cry on. A family member told us, "I am fortunate that I have had the same volunteer for four years and have built up an excellent rapport".

The registered manager told us that they were contactable at any time to respond to telephone calls from worried parents and volunteers. One volunteer said, "[The registered manager] is always on the end of the phone or email for support and advice.

All volunteers were supplied with personal protective equipment (PPE) in order to help prevent cross infection when delivering personal care tasks.

The administration of medicines was dealt with usually by parents. Some medicines were added to the child's feed as required. Medicines were clearly documented on the risk assessment completed by the service. Volunteers also received training in the safe use of medicines to allow them to assist parents as required.



## Is the service effective?

### Our findings

We looked at the training provided to all volunteers on commencing work. Volunteers received training from Alder Hey Children's Hospital. Training covered: recognition of serious illness in children, basic life support for children and adults, infection control, moving and handling for infants and children with cardiac or feeding difficulties, cardiac care for infants and children in the community, play and assessment, nutrition and feed for children with cardiac problems and adverse feeding difficulties. The practical training was supported with written information and a DVD on child and infant CPR.

One volunteer told us, "The training was absolutely brilliant. We did Cardiac Pulmonary Resuscitation (CPR) training and a thorough training session on feeding issues and tubes. We also had training from the speech and language trainer. All the training was absolutely relevant and of the highest quality as it was all from practising experts". Another said, "I attended the initial training and have since been supported to do further training specific to the work I do". We asked a family member if they thought their volunteer was sufficiently trained and had the necessary skills for their role. They responded, "Absolutely, I've also attended the training sessions that the volunteers complete and it is packed full of relevant information". The training programme is also available to grandparents and other family members as they were often involved in assisting with a caring role.

We received feedback from a healthcare professional who told us, "I have worked with Lagan's Foundation since the charity started. I provide the training for the support workers in enteral feeding (Enteral feeding refers to the delivery of a nutritionally complete feed). Due to the children's complex needs many parents cannot ask family members for support. Lagan's Foundation trains their support workers to a high level so support workers can support the family in an appropriate manner which enables the family to have a break or just to someone from outside the family.

We saw copies of the volunteer training feedback forms. The responses were very positive, one comment included, "Found the training really clear and informative, really enjoyed it".

Due to cross country location of volunteers and their distance away from the main office, volunteers did not receive face to face supervisions. The registered manager contacted volunteers weekly or more frequently as required. Conversations were recorded and any actions required were addressed.

We looked at the care records for four families supported. All care records were stored electronically. The system used enabled all records and communication sheets to be scanned in to the system. The systems had a secured backup network in New York, Australia and Europe so data could be always be retrieved in the event of system failure.

We found that care records were detailed, personalised and responsive to the children's and family's needs. The care records showed that a comprehensive assessment was completed prior to the support commencing. This ensured that the serious conditions that the child needed support with was conveyed to the registered manager and their team. This would ensure the correct care was provided as required. The

records showed that after each visit a report sheet was completed and scanned on to individual care records. This meant the registered manager and the support team had immediate access to care records and had up to date information about people.

We asked a family member what information was kept at their home. We were told that that report sheets were not kept in the home but were brought on each visit by the volunteer and completed after each visit. As parents were in the home with the volunteer, they were fully aware of what the tasks completed.

We saw that consent forms were agreed and signed by both the registered manager and the parent giving consent to allow volunteer to visit and assist with care, that parents must not leave the premises but can take a break from their role as a care giver and that the parent remains ultimately responsible in dealing with any emergencies that may arise during the volunteers visit.

## Is the service caring?

### Our findings

We saw feedback from families who had been supported by the Lagan's team. One person commented, "I am so glad I finally plucked up the courage to contact Lagan's Foundation for support. We now receive help from [volunteers name] once a week and it's brilliant. One of the best things is that I now feel that I have someone to talk to who really understands what it is like to have a child with a heart defect'. Another family member said, "They are incredibly supportive and what is unique they have actually gone through what the families are facing and so it is not just ticking boxes, it is really heart felt care they offer".

Another parent told us, "I have so many positive experiences with the organisation when I was feeling very low and texted my volunteer to say leave the visit. My volunteer knew that it was completely out the norm for me and arrived to find me in flood of tears. I was so glad of her experience and professionalism in that situation. Not only has our volunteer supported us through many transitions' in our family life but also with external agencies. [Registered manager] is a credit to the world of care and has helped our family grow and develop to its potential by using their experiences and professionalism.

The service produced information which included details about the service for people who were looking for this level of support for their family. Information was also available on Lagan's Foundation website and a social media page.

People spoken with told us they were provided with all the necessary information about the service and had contact details of the registered manager and support staff in case people needed help or support in between visits.

Regular reviews and feedback were obtained from families by the registered manager to help ensure their views and opinions were taken into account when looking at the development and improvement for the service.

We asked if volunteers were respectful when visiting people's home. Comments included, "Always" and "Most definitely".

Families told us that their volunteer was reliable and always turned up on time for their support visit.

## Is the service responsive?

### Our findings

The care records we looked at included a significant amount of personal information, including family members involved in the child's care. There was also information about working and supporting siblings.

The care files included initial assessments, service agreements, an outline of support needs, staff guidance, work plans, running records, reviews, risk assessments, consent forms, positive outcomes, significant events and health profiles. All records we looked at were up to date and complete. The care files were easy to follow and clear. Visit records within the files were comprehensive and included descriptions of activities, health issues, behavioural issues, discussions with family and any concerns.

We saw that the service listened to families and tried to facilitate their wishes if possible. One family commented, "I could no longer cope with the day to day life as a parent with young children, one with multiple difficulties. In to my life stepped Lagan's. Why didn't I ask for help sooner, I was busy trying to prove to myself that I could cope that I couldn't see I wasn't. In steps my volunteer who has been a carer, an inspiration and a listening ear and much more to our family and someone I now have complete trust in".

The service worked closely with Bolton Clinical Commissioning Group (CCG). The CCG had provided a written reference for Lagan's to another agency. The reference was complimentary and included, 'Lagan's provides an invaluable service to those families especially children with a new diagnosis. They are able not just to provide a short break for parents but also help with support and navigation of services. Most of the children that meet the criteria will most often have developmental delay either to trauma in early life or a congenital disorder. Support in the early years will often help with parents feel more empowered to make choices around their child's life and care.

The service had a procedure on dealing with comments, complaints and compliments. There had been no complaints or concerns raised to the CQC. All the families we spoke with said they had no complaints. One relative said they had, "Absolutely no complaints about the service, they are really very good".

## Is the service well-led?

### Our findings

There were robust management systems in place to demonstrate the service was well-led. We saw the registered manager was supported by a volunteer coordinator and the business development funding officer. There was regular monitoring of the service. This showed us that the registered manager had oversight of the quality of the service offered.

The culture of the service was positive, person centred, inclusive and forward thinking. Information received from professionals, families and staff all felt this was an excellent, enabling and inspiring service. One person commented, "Not only has our volunteer supported us through many transitions in our family life but also with external agencies. [Registered manager] is a credit to the world of care and has helped our family grow and develop to its potential by using their experience and professionalism. They organise events that are understanding of family needs and restrictions and if it were not for Lagan's I truly believe we would be a lot worse off as a family".

We ask families and staff if they felt supported by the registered manager. One volunteer told us, "Yes I have regular contact with [registered manager] and also the family coordinator. She is always helpful and supportive and if she doesn't know the answer she will know someone that does". Volunteers felt comfortable to raise issues and concerns or put forward suggestions and said they would be listened and responded to. The registered manager told us that it had been the idea of one of the volunteers to condense important policies and procedures in to an A5 file so that volunteers could carry them with them should they need to refer to them quickly.

We saw evidence within care files, of excellent partnership working and all the professionals we spoke with felt the service worked well with a range of agencies and services. The service had also built up good relationships with outside agencies such as Alder Hey Children's Hospital, Great Ormond Street Hospital for Children and Albert Royal, Wigan Children's Ward and other service across the country.

No recent notifications had been submitted to CQC, however the registered manager was aware of what should be reported. She was also aware of the correct forms and systems to use.

A questionnaire was completed by families and these were evaluated by the service to ensure any concerns, complaints or comments were used to learn and develop the care delivery.

Regular formal and informal feedback from consultation with families was also analysed and used to drive improvements within the service. This showed us that the service enabled and encouraged families to provide feedback about their care, treatment and support they received.

We saw there were procedures in place to measure the success in meeting the aims, objectives and the statement of purpose of the service.

There were quality assurance systems in place to ensure aims and objectives were met. For example, we saw

that a number of audits took place; they included regular updates, compliments, comments and complaints, file audits, accidents and incidents.