

Meeting Notes

1 Ledbury Road parents meeting

25 November 2015 – The Shirehall

Jo Davidson outlined the agenda and confirmed that we would be unable to discuss any individual cases as we are in legal proceedings with some of the families present at the meeting.

Agenda

- 1) Timeline
- 2) Progress in relation to potential takeover of 1 Ledbury Road
- 3) Parents perspective on the discussions about 1 Ledbury Road rotas

Notes of meeting

Timeline

Jo Davidson confirmed that the core assessments have been completed and the council is still in discussion with some families to finalise plans and fully recognise that there are some issues with regards to these with some of the families.

She also outlined the following draft short breaks for children with disabilities timeline with the parents present at the meeting.

Family discussion about assessments and plans	By mid - December
Implementing plans for individual families and for services	From end of November
Any transfers to existing services where appropriate	To commence December 2015
Future 1 Ledbury Road contract discussions	To commence December 2015
Broader consultations in respect of overall policy and provisions for short breaks	To commence December 2015

Jo Davidson - Some of the core assessments are still not completely signed off as these are with the parents for their consideration.

The consultation will involve a broad set of issues in respect of short breaks. We will use various methods to undertake the consultation and some of this may involve face to face discussions. As a guide there would be a three month consultation. It was also confirmed that during the consultation period, new providers of short breaks may come on stream. With regards to the consultation, we are currently taking advice on this and once we have concluded these discussions, we will publish these details. It is envisaged that consultation

will include some face to face discussion. Sometimes we are looking for views from individual families, children and young people and their siblings.

Ben Boyle - Transfer of families, what does this mean?

Jo Davidson – This is where the needs may have changed for the individual; for example individuals may transfer from something that was bespoke to a provision that provides more support.

Mel Boyle - Overnight respite what do we have in respect of provision? The parents confirmed that the provisions available for some children currently in addition to 1 Ledbury Road are Acorns Children's Hospice and Martha Trust.

Jo Davidson - There have been individual discussions with families with regards to needs and this will continue to happen as appropriate. We have been waiting for agreement of assessed needs to enable us to meet with the CCG and have a discussion as to how we can avoid the cliff edge at the end of March 2016. Also once we have all the details of the assessments, it will provide us with a picture of what is required in relation to short breaks.

Direct payment and eligibility criteria consultation will form part of the broad consultation as well as short break provisions. We have to ensure that we have consulted on the broad range of services and provision that are available; as the council has a responsibility to provide services to meet all identified needs.

Individual core assessments need to be checked and should be saying this is what the council is saying and this is what the families are saying; all views need to be articulated within the assessment. The validity of core assessments need to identify what the individuals, families want and the professionals' assessment as to what is needed.

Jamie Miles - Clarity needed to ensure a consistent approach for all families to ensure the process is completed fairly for all to make sure the assessments accurately reflect what the families are saying. Parents have asked to see drafts and this has not been the case; it should be agreed between all parties and parents should not have to re-write documents.

Jo Davidson – The complaints procedure is there to protect all members of staff, parents and families. There have been issues with regards to some agency staff turnover; but we all need to recognise that we are all under pressure.

Sue Herrington - Parents feel that on occasion they are constantly battling for service provision for their children and the situation is stressful for all.

Vanessa Lewis - The staff at 1 Ledbury Road are saying that the interaction with the parents is causing stress for them. We need to ask for the parents' support to understand that the staff are doing the best that they can. It is the frontline staff that are often the ones experiencing the parents' anger and frustration.

Richard Aird – I think that it's wrong that parents are blaming those that are running 1 Ledbury Road.

Ben Boyle – The staff at 1 Ledbury Road are fantastic, providing good respite for children, this lands directly at Jo Davidson's door. We understand that there are restrictions with regards to finance and social workers and that this is a national issue.

Vanessa Lewis - Confirmed that they are still having problems recruiting to ensure that 1 Ledbury Road is staffed.

Richard Aird – We hope that the consultation / draft policies that are put forward need to contain the need for emergency capacity and continuous investment and evolution of provision. There needs to be a good offer of provision that is able to change to meet the changing assessed needs.

Mel Boyle - We don't want the children with disabilities team moving over to the children in need team because they are at risk. We understand that the consultation will be a mix of approaches and that this will ensure that we are able to engage as widely as possible.

Karen Aird – Parents are becoming very emotional and extremely stressed and it will be the parents that become the voice of those that are experiencing issues within their families.

The parents at the meeting have asked that **Vanessa Lewis** feeds back to the staff at 1 Ledbury Road that they are great with the children.

Progress in relation to the potential takeover of 1 Ledbury Road

The parents at the meeting confirmed that there is a meeting happening on 3 December which has been arranged by a charity and confirmed that this is not to do with their group 'Save No 1 Ledbury Road'. The charity is offering to work with the parents to see if they could partner with them

Vanessa Lewis has confirmed that she will attend meeting on 3 December.

The parents confirmed that they need to wait and see what is being suggested and what the outcome of the meeting on 3 December is.

Save No 1 Ledbury Road parents group went to see Dave and Elaine at the council and they confirmed that the parents would need at least 12 months to put a robust business plan in place.

Alison Talbot-Smith – There are historical reasons in respect of the CCG holding the contract, but that there is recognition that this is a council responsibility. The CCG will fund any medical requirements.

Richard Aird – Clarification needed on overnight costs, to understand why alternative provision is being suggested when this is in excess of the costs at 1 Ledbury Road.

Alison Talbot-Smith – CCG / council / WVT need to have a range of provisions for short breaks; we recognise that work is taking longer than expected and this process needs to continue.

Richard Aird – Why has a family been persuaded to move their child from 1 Ledbury Road to Martha Trust? **We cannot comment on individual families at this meeting.**

Alison Talbot-Smith - There has not been a governing body decision of the CCG on what the care needs as opposed to the health intervention requirements that may be needed. Then there will be discussion following completion and collation of all of the core assessments. The purest view subject to discussions, with regards to specific health care needs and/or short breaks respite. There may be some core assessments that require continuing health care (CHC) assessments. The CCG has committed to completing an assessment if required. It needs to be recognised that there is a continuum of care and

health needs and that these may flex over a period of time.

Core assessments are key to the decisions that need to be made; this will ensure that the needs are met in the most appropriate way and the CHC would be identified as being required within these assessments.

Jo Davidson - There is progression on recruitment of short breaks foster carers, there are two under assessment and there are a further two going through the selection process.

Vanessa Lewis - WVT is interested in having the conversations with regards to charities etc. to run services from 1 Ledbury Road during the day, but this needs to be explored.

Richard Aird - De-registration has this moved forward?

Vanessa Lewis - There has not been any further progress on this at this stage.

Richard Aird – What’s happening with the sensory room?

Vanessa Lewis – The equipment in the sensory room is going to be moved.

Update on the names of providers of services and what services are going to be provided.

Karen Aird – What happens in January if the last staff nurse goes?

Vanessa Lewis - If 1 Ledbury Road is unsafe then it will not open.

Jo Davidson – Contingencies would include alternative arrangements for domiciliary care provision if needed or direct payments. The contingency arrangements may mean that the same level of service is not provided.

Parents’ perspective on the discussions about 1 Ledbury Road rotas

Mel Boyle circulated parent / carer feedback regarding the new 1 Ledbury Road timetables (attached below).

Parent / carer feedback regarding new 1 Ledbury Road timetables

'We've lost 3 days respite in December. Days have been changed, impacting on other activities, why does it take so long to send out timetables? We used to have 3 months in advance!'

'We've lost 2 days respite, we can't plan anything, timetables are so late coming out, it's just yet another thing to worry about'

'If we are to lose respite days it's really important they communicate early. There have been times we've only known very late in the day'

'I've got one week night for the whole month, its rubbish!!'

'I still don't know my December hours! Despite emailing last week I still don't have my hours [as of 24/11/2015]'

'Lack of notice is a big issue not having bookings in advance, we can't plan anything'

'I have no rota for December [as of 24/11/2015], in November they've changed our days since sunshine bungalow closed. I have a totally confused child who is thrown out of routine and is very distressed'

'We've had to cancel an Acorns play day because the timetable came out so late which is really upsetting as we only get about 4 a year! We don't want to cancel Ledbury Road instead because in comparison it's much more vital!'

'One respite day is from school on Friday then I have to pick up at 2 the next day so I can't do anything with other kids over the weekend...then another is me drop off at 3pm and collect following morning at 11 so I wont bother expecting that one as any use as we live so far away'

'It's been very upsetting for the children having to cope with the adjustments to the days, the new staff, which children they are with, different rooms etc. Rotas that are coming out so late in the month, it gives little chance for families to plan very far in advance. My child depends on diaries etc for how their day/week/month will go and if there are gaps, because we don't have the dates, it makes the children very anxious'

'The problem we've found is we've booked Marches, then the Ledbury Road dates come out and they clash!'

'We've had no weekend respite for two months. We feel Ledbury Road is not working with us at the moment and the inconsistency is causing alot of anxiety for my child'

'No changes to our respite yet, still waiting for December dates'

'Feeling broken! Received our December rota, we have got even less hours than November! Last month's hours were horrendous; God knows how we're going to cope in December!'

Mel Boyle - The rotas are causing issues as parents are unable to plan anything and are having to cancel other respite outlets. There appears to be more respite lost for December.

Vanessa Lewis - WVT has to share out what is available due to the Christmas shut down. Recruitment has been difficult – two people short listed and they didn't turn up, no one appears to be interested and currently have one staff nurse left. January could be even worse as the service cannot be manned completely by agency staff. Currently the hours are shared across those that are accessing 1 Ledbury Road.

Ben Boyle – Do you think it will continue to run until March?

Vanessa Lewis – Have been told by Richard Beeken that 1 Ledbury Road will continue until end of March; staff have not been told that the provision will be closing at this time.

Sue Herrington – 1 Ledbury Road is a shell of what it was.

Vanessa Lewis - Concerned that rotas have not been received; will feed this back especially as some have already been received.

Staff only have a rota a month in advance and there is no flexibility. Would it be better to

have a rota that is fixed unless there has to be cancellations due to sickness or staff being off?

How can we ensure that the rota is a fixed rota and that all parents are able to provide information with regards to their fixed commitments? This information has to be sought from all that attend 1 Ledbury Road.

Mel Boyle – How about putting a flyer in the kid's book bags for the parents to be able to communicate with them with regards to the fixed activities.

Vanessa Lewis – What is the best time to approach this; the core assessments may say something different; so don't want to contradict what they are saying in here.

Ben Boyle – Is WVT continuing to look for nursing staff after Christmas?

Vanessa Lewis – We would need to seek information from the WVT chief executive, but there is the commitment to continue to provide the service as long as it needs to be provided. We recognise that there is a need to improve on the communications to all parents and carers.

We will work in getting a new fixed rolling rota, but this will be subject to staff being available.

The next 1 Ledbury Road parents meeting with council / CCG / WVT will be arranged for January 2016.