APPENDIX A

NHS
West Leicestershire
Clinical Commissioning Group

Engagement report – health short breaks for people with learning disabilities

Introduction

1. This report was commissioned by West Leicestershire Clinical Commissioning Group on behalf of East Leicestershire and Rutland Clinical Commissioning Group and Leicester City Clinical Commissioning Group. The report details feedback received from staff, carers and stakeholders during the project undertaken to explore how to deliver more choice of health short breaks for people with learning disabilities. The engagement took place in three stages. The first stage was to begin to engage and build a good relationship with carers; the second stage was to engage on the proposed closing of the residential home on Tournament Road in Glenfield and the opening of a new residential home, Grange 2, also in Glenfield and the third stage engagement on the peripatetic pilot.

2. One of the objectives within the joint Short Breaks Strategy 2009-2014 (report to the Cabinet 6 April 2010) was to offer more choice and health short breaks services to users with learning disabilities and their carers. After the closure of Primary Care Trusts, the three Leicester, Leicestershire and Rutland (LLR) Clinical Commissioning Groups (CCGs) agreed to continue with the implementation of this action. CCGs agreed to review the current residential bed-based health provision for short breaks commissioned from the Leicestershire Partnership Trust (LPT) and pilot a peripatetic model of services to offer more choice as part of the strategy. In the meantime the current bed-based residential health short break service continued to run as it always had and users were offered to try the pilot service in addition to whichever service they already received.

3. Transformation funding from CCGs has been used to fund a pilot peripatetic service where a health short break can be delivered in people's homes or elsewhere in the community. Currently short breaks are only offered in a residential setting for adults with learning disabilities. This engagement report details feedback gathered from the carers group, the implementation group and the transitions group, however, it was not possible to gain feedback from individual users and the reasons for this are explained further on in this report.

   This report will be presented at the following meetings:

   - **CCGs Commissioning Collaborative Board 31st October – papers by 25th October**

Subgroups/Programme Boards second

- City LD Subgroup 10th October – papers by 3rd October

- County LD subgroup 28th October –papers by 18th October
- LPT contract MH&LD Clinical subgroup – 15th October papers by 8th October

Integrated Commissioning Boards

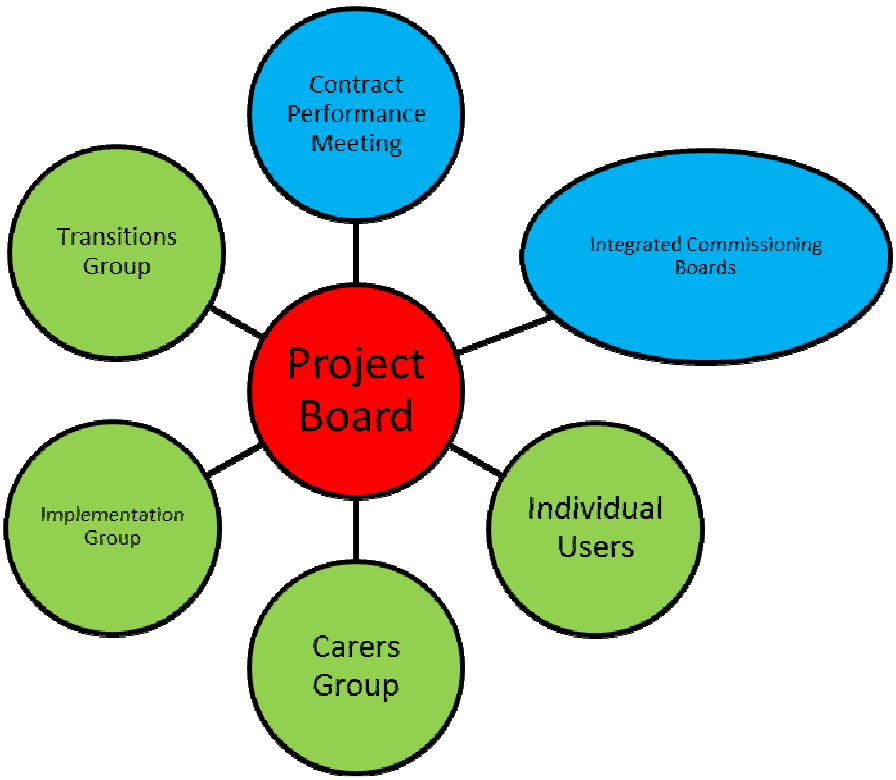
- City ICB first week of November
- County ICB – TBC Nov/Dec

Overview and Scrutiny

- County – papers by 4th November
- City and Rutland by 4th November

Overview

4. The diagram below shows the subgroups, and therefore the governance, associated with the project board. The groups involved in the main engagement activity were the implementation group, the transitions group and the carers group.



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5. The pilot was due to run from April 2013 until September 2013. The 62 families who currently use the health short breaks service were all offered the peripatetic pilot service although, initially, no one came forward to take part. Intensive engagement, with carers, was carried out as it was necessary to reassure them that the pilot was to be offered in addition to the services they were already receiving. It was also important to:

- Give reassurance that their voices would be heard and fed back to the decision makers;

- That no decision had been made about whether or not to commission the current residential service in the future.

6. The project engagement lead attended regular meetings with the carers, accompanied as required by members of the project board, to offer reassurance and to build a relationship of trust, openness and transparency.

7. Mechanisms were put in place so that carers felt that their voices were represented at the programme board by the attendance of an advocate from the Carers Centre, the WL CCG engagement lead and the Leicestershire HealthWatch representative.

8. A carers' issue log was also kept so that carers were reassured that their issues were noted and addressed by the project board wherever possible. The need to build this relationship with the carers meant that the pilot was delayed and ran for a shorter period than originally planned.

9. When engaging on a new service with any patient or public community it is vital to get feedback from the service users wherever possible. In the case of this engagement process it was important to comply with the Mental Capacity Act 2005. Using data from the continuing health care assessment, it was identified that of all the individuals who had identified heath care funding; 40 had a cognition rating of 'severe'; indicating that they were unable to make complex decisions about their life, and eight had a rating of high. For communication, the continuing health care assessment informed that 31 had a rating of high, 17 moderate and 1 low. Therefore, in keeping with the core principals of the Mental Capacity Act 2005, it was necessary for an advocate to feedback on behalf of individuals accessing the pilot. To understand more about the core principles of the Mental Capacity Act 2005 please visit:

   http://webarchive.nationalarchives.gov.uk/+/http://www.dca.gov.uk/legal-policy/mental-capacity/mca-cp.pdf).

10. Staff at the health short breaks units, who know the individuals accessing the units very well, were consulted about individuals' participation in the pilot and asked whether in their opinion an independent advocate other than the patient/clients primary carer/carers (usually the parent/parents, sibling or legal guardian) would be required. The response was 'no' in all cases. Staff felt that the carers were good advocates and would participate if they felt it would be of benefit to both the family and the individual.

11. Most of the individuals with learning disabilities accessing health short break services are not able to give informed consent about complex issues. The only way to determine if they would wish to participate in the peripatetic pilot would be for them to experience the service over a period of time and, by working closely with carers who know the individual well and assess whether they are happy with the service. This would not necessarily indicate a preference between the residential service and the peripatetic service.

12. For the seven individuals who have been involved in the pilot they have not been able to give informed consent for their participation, their primary carer

or carers feedback on their behalf, but from visits carried out so far there has not been any indication through non-verbal communication that they are unhappy with the new service.

Background

Eligibility Criteria for a Learning Disability Health Short Break:

- *a person who lives in Leicester, Leicestershire or Rutland and*
- *resides with an unpaid carer*
- *and who is over the age of 18 years*
- *who has a multiple and profound learning disability*
- *or who has a learning disability with significant challenging behaviour or*
- *who has a learning disability with significant physical health care needs*
- *may have some additional complex social care needs*
- *whose needs cannot be met in an alternative local setting*

Feedback from the engagement process

13. The first stage in the engagement process was to ask carers if they would support the moving of the Tournament Road residential care home to a more suitable building known as 2, The Grange, Glenfield. The reason for this was that the existing residential property at Tournament Road, Glenfield, was no longer fit for purpose; problems included limited access for wheelchair users and lack of access to washing facilities from all rooms. Carers were invited to an information sharing event and asked to vote on whether they agreed to the move or not - 99% agreed that the move should take place. HealthWatch were also asked for their opinion and agreed that the move would be a positive step. Carers who were unable to attend the event were also asked to complete a questionnaire to feedback their views on the proposed move. Again feedback was positive. Therefore the move went ahead and in April 2013 the new residential home was opened.

14. The second stage of the engagement process, as outlined in the introduction, was to build a good relationship with carers. Once these relationships were established, people came forward to take part in the peripatetic pilot. It was also important to gain feedback from the staff in residential homes to gain their views and staff members of the peripatetic service team were also asked to feedback their views.

15. The third stage was to engage with people in the transition phase. This relates to young people who are currently accessing health short breaks through health children's and young people services but will move into health adult services in the near future (please see feedback below).

The Peripatetic Pilot

Statistics for the evaluation of the health peripatetic short break pilot

16. The original projection of the pilot for available the available service was as follows:

Leicestershire Partnership Trust explained that 50% of staff hours would be available to provide a 'hands-on' service which given 4.6 whole time equivalent staff equated to 86.25 hours per week.

Over a 12 week period this gave 1,035 hours available.

There were seven families involved in the pilot.

Family 1 had approximately 450 hours. However this was only background support and the peripatetic staff were able to carry out other work whilst being available should this individual require immediate support.
Family 2 had 80 hours over 12 weeks
Family 3 had 132 hours over 12 weeks
Family 4 had 50 hours over 12 weeks
Family 5 had 36 hours over 12 weeks
Family 6 had 15 hours over 12 weeks. 18 hours were planned but the individual concerned was ill for one visit
Family 7 had 98 hours over 12 weeks

17. All families were given the opportunity to feedback on the service in the form of a questionnaire and in face-to-face conversations with staff. Feedback from all those who took part in the peripatetic pilot was positive - no negative answers to the questionnaires were received. Please find an example of the written and verbal comments below:

- Love the service – hope it continues.
- Are you sure? 'I don't want to be greedy'.
- It's great!
- It's been 20 years since I was last able to go out on a Saturday.
- Excellent service.
- I hope it continues.
- Peace of mind, when leaving a loved one.
- Feels able to ask questions regarding health matters that she has previously not understood.
- Approachable.
- Loves the amount on quality attention that [name disclosed] gets.
- [name disclosed] was happier and brighter and more alert
- This is an excellent service, very well planned and professional, a great help to us carers and a happy experience for [name disclosed]. Also [name disclosed] gets out in the fresh air with people he knows and a change of company.
- We are so pleased and grateful for this scheme it has made such a difference to us and [name disclosed], something very much needed and appreciated. We are so grateful, so a big thank you.
- [name disclosed] really enjoyed the outing and was very alert and happy for the rest of the day.

18. As only seven families had come forward to take part in the pilot, a questionnaire was sent out to the 62 families who currently use the health short breaks service. The questionnaire was sent from The Carers Centre to those families whom had been offered the chance to use the peripatetic service and their reasons why, to those who had then gone on to use the peripatetic service and their reasons why, and those who did not use the peripatetic service and their reasons why not.

19. Nine responses were received and a full report from The Carers Centre can be found at Appendix A. As a result of this questionnaire, feedback from seven families was increased to 14 families; seven who have accessed the peripatetic service and seven who have not. This represents 23% of families who currently use the current bed-based service.

20. Of the feedback received from those families who did not take part in the pilot, four could be considered as negative and three as neutral. Comments included:

    'We wanted our son to be out of the home' this comment indicates that the family understood the peripatetic service only to be offered as a service where staff came into the home to offer a short break service so that the carers could go out. This family felt that it was important for their son to have a break away from the home. In reality, as the peripatetic service is developed in some instances it may be possible for patients to have their short break by being taken out, to enjoy time away from home. This would of course depend on a number of factors including a detailed risk assessment.

21. The comment above also relates to a comment made in The Carers Centre report (appendix A), under the Professional Observation section, which reported that some people were concerned about their home space being invaded by professionals and not giving them the same level of respite. There was also a fear expressed by some carers that the peripatetic service would be eventually used to replace the bed based service (appendix A).

22. Other comments received included:

    Not interested in it full stop, our [name disclosed] is happy and contented and the service at Rubicorn Close is marvellous

    Would be very useful for emergencies but pilot scheme was about planned dates we have managed most of our life without this, we feel that changing habits would possibly damage routine and would not be good

I felt that I wouldn't relax and let someone else care for him while I wasn't around

This is an excellent service with dedicated, extremely efficient and dedicated staff

It has been a very positive experience… it has given us extra support as it has enabled us to see or visit family or even just go out

Staff response from staff working within the bed based health short break services

23. Questionnaires were sent out to staff based within the bed-based health short break homes services. It was suggested that staff could either complete them individually or as a staff group. Only three questionnaires were returned.

24. Of the three questionnaires returned, one theme raised was the lack of written information about the service and staff requested more information as to how the peripatetic service works. Information on the peripatetic service has been given to senior staff via regular staff meetings and in the initial stages through staff engagement (short breaks implementation group) where staff of all grades from each home, were invited to attend.

25. There is a need for further staff engagement via home meetings to give staff a better opportunity to ask questions about the new service. This is being arranged in conjunction with the home managers.

26. One response suggested that some of the team would not recommend the service to the carers who use their home although some of the staff would. The reasons why some of the team would not recommend the service to carers needs to be investigated further and the opportunity to discuss with the peripatetic team will be offered and reasons explored. The peripatetic team will attend meetings at the home to explore this further.

27. There was very positive feedback from the home that has most involvement with the pilot. This is possibly due to a greater understanding of how the service works and the opportunity to participate in the pilot. It is hoped that this is a good way forward to foster good working relationships and improve care provision.

Staff Feedback from staff working within the Peripatetic health short breaks team

	Positive Comments	Rationale/response	Action
1	Staff committed to making it work	Initially staff felt very insecure as they had not all applied for the job of developing a peripatetic short breaks service. There were no limits placed on the team by managers as to what was expected. This enabled staff to develop the service in a way that they felt that families were asking for. Because staff were able to work closely with the family this has given them greater investment in making the project work.	
2	Staff from residential short breaks involved	It has been positive to involve staff from outside the peripatetic team to encourage joint working and to increase opportunities for other staff to work in other environments. In addition it has had positive benefits for one family as it has increased their confidence in the residential service and enabled them to feel safe in allowing their son to attend the residential service as they have met the staff and seen how they work with their son at home.	Increase the quantity of staff currently working in residential short breaks to support more of the peripatetic service visits to increase staff understanding of the new way of working and job satisfaction
3	Staff from peripatetic short breaks have 'back-filled' residential short breaks	See also under 'bad' feedback. By using staff from the peripatetic team to work in the residential short break homes it has given them a more balanced view as to what the differences are within the service provision. It has made the peripatetic team more aware of the quality that the team can offer due to the high staffing levels available in the peripatetic service. It has helped to keep them in touch with the difficulties faced by the residential short breaks staff of having to	If the peripatetic service continues there will be more staff working flexibly across the short break provision.

		meet the care needs of several individuals at a time whilst also having to undertake many non-nursing duties such as balancing the safe and cleaning/washing etc.	
4	Peripatetic staff have been able to work with other agencies (non-health) modelling behaviour	One family have continued the use of an agency whilst the peripatetic team was also visiting. It was not considered appropriate to cancel the agency as the peripatetic service is only a pilot. In the meantime it was felt that it was of benefit to 'role model' behaviour for the agency staff as to how to interact appropriately with an individual with autism and challenging behaviour, The agency worker was well meaning but had not had training in this area.	If the pilot becomes a full time service it would be appropriate to reduce staffing so that there would only ever be two staff supporting the individual at one time. This could be either two health care staff or one member of staff from each team. If it is to be a member of staff from each team there needs to be formal agreements about interagency working and accountability.
5	Staff feel valued and are enjoying patient contact	Staff are getting a lot of job satisfaction at being able to deliver high quality care from a small team who work well together	Increase the opportunity for other short break staff to experience working within the peripatetic service
6	Adequate levels of qualified staff available to 'kick-start' the service	Having a higher level of qualified staff enabled more families to become involved in the pilot from the start. See also point from 'bad'	Change the ratio of qualified staff / unqualified to reduce costs.
7	Existing model available to follow	It has been helpful to be able to discuss the project from colleagues within the Diana service as to the problems they encountered when first setting up their service.	
8	Staff enjoying the opportunity to give high quality care	Job satisfaction is known to improve staff attendance at work especially when they feel that they are able to perform well.	
9	Provision of high quality care	Families have so far given very positive feedback of the service using the Net Promoter score cards. The use of Net Promoter score cards is likely to decrease if the service continues.	If the service continues it would be useful to continue to request regular 'customer satisfaction' surveys

10	Staff available to support the service	Levels of care were apportioned in accordance with staffing levels. This has enabled consistent staff for each visit from a small team. So far there has not had to be cancellation from the service due to staff unavailability.	It is important to continue to provide consistent carers for each patient
11	Most visits have been able to provide a 2:1 service	A risk assessment has been carried out for each visit to determine staff support levels. Due to moving and handling requirements there has needed to be two staff for home visits. This has also been a negative aspect as two staff are not required for the whole visit but it is not practical to have staff travelling around the area just to provide intermittent support	There is no easy answer to having to have two staff for one visit. The risks to the Trust are too great to compromise staffing levels for moving and handling and it is not always possible to factor in a second person calling at specific times in order to carry out moving and handling. Equally for the individuals with challenging behaviour it is too great a risk to leave one member of staff isolated without physical support from another member of staff.
12	It has provided a service that was not previously available to adults with a learning disability with health care needs		It is hoped that the service will continue to be able to offer carers a choice in their service provision
13	Staff have been able to develop very good rapport with families and earn their trust.	Families have self-selected to be part of the pilot. Time has been spent getting to know the family not just the patient as staff are very aware that they are working in the family home not an NHS environment. Carers have shown an incredible amount of trust in the staff leaving them in the family home. This is a tribute to the staff that has enabled this level of trust.	This level of trust needs to be maintained and can only do so by using staff who have good standards of integrity

14	Feedback from the families so far has been very positive	A quality service has been provided	It is important to continue with the standard set so far – see point 9
15	Meets CQC requirements	Because it is a new service it has been easier to set CQC standards from the start and to make sure that the team is aware of how the standards are to be met	On-going self-assessment of CQC standards to be maintained in line with current Trust practice

	Negative comments	**Rationale/response**	**Action**
a	Slow uptake on pilot from families	There was a natural reluctance from carers as they were not sure as to whether it would affect their current short beak provision.	Learn from the pilot and ensure that any future changes offered to carers are clear as to what longer term effects it may have on their current care packages if any.
b	Not much opportunity to trial the Pilot before the need to evaluate the service	Partly because of the slow uptake it has not been possible to run the pilot for 6 months before having to complete an evaluation	
c	Staff team unclear as to their future employment/role	At present staff are still not clear as to what the future holds for them as it is not certain as to whether the peripatetic service is going to continue.	Staff to be kept informed as to developments about the peripatetic service
d	'Back-filling' in residential short breaks has not given continuity of care and been difficult for staff who have not been providing residential care for a number of years	Each staff member has rotated to provide back-fill cover to give them an opportunity to work in the residential short break home. If the service continues staff will become more familiar with the residential service	
e	Late finishing of shifts	This is part of the change process and in order to develop a service that is flexible there is a need to look at different ways of working	

f	Working with staff from other agencies can be difficult as they do not understand the role and do not always follow care plans		Interagency agreements need to be developed as to who is the lead in any situation and support given to joint care plans.
g	Large amount of paperwork created in setting up service which took time to develop	Due to this being a new service it is necessary to review the paperwork available. In some instances this has lead to the creation of additional paperwork to ensure that everything is documented fully.	As the service progresses it will be important to review the paperwork used to ensure that it is all fit for purpose
h	Top heavy with qualified staff	See point 6 above	
i	Travel time to initial contact can increase length of working day		
j	Lack of literature to promote the service - no leaflet	Discussions about the production of a leaflet to promote the service were made early on in the project but it took a long time to produce. Unfortunately the leaflet was not completed until after the pilot was already running	
k	Insufficient time to meet frequently as a team due to other commitments – training, annual leave and the need to progress other Trust priorities	There has been a lot of change occurring simultaneously within the Trust requiring staff to continuously re-prioritise.	
l	Identity/purpose of pilot difficult to explain to carers/ families – not everyone is clear as to what 'peripatetic' means	As there was no clear remit at the start of the project so it difficult to give clear information to carers and other members of the Trust as to what exactly could be offered.	

m	Emergency cover not available	It was not envisaged that this new service would be able to provide emergency cover and this is being addressed in other projects. However it is an issue that it felt important to raise in the evaluation	
n	Service unable to provide support to individuals who are admitted to general hospitals	It was asked by more than one family if this would be a part of the new service. Many families find it incredibly stressful trying to support their disabled relative in a general hospital as they find that the level of support required by their family member is not available	
o	Care so far has only been provided in patients' homes and one day centre. There has not been an opportunity to provide support in other than health care residential settings	It has been of benefit to the project to start slowly but needs to look at other options if it is to continue.	
p	Expensive service for the Trust to provide	Costs have been expensive due to the high qualified staffing levels. This has been necessary in order to start the service up. Costs should decrease per visit if more junior staff are employed to carry out the visits releasing the qualified staff to set up new care packages.	

	Points to consider	**Rationale/response**	**Action**
l	How levels of care are agreed – what is the limit?		

ii	Lone worker arrangements – just how safe are they?	List of visits has been lodged with one of the residential homes but it has not always been successful as when staff have failed to phone in after a visit there has not been a follow up phone call to ensure that they are safe.	Residential staff to be made more aware of the potential risks to workers in the peripatetic service and their role in supporting their colleagues
iii	Carers not recognising the need for a clear handover of the current situation before they leave the home	As the service is new it has been difficult to introduce new systems. There has not been any incidences so far that have emphasised the need for a clear handover	Staff need to be more proactive in achieving a clear handover of responsibility
iv	Who is the 'Named Nurse' for the patient if the individual accesses health short breaks – Peripatetic service nurse or residential short breaks nurse?	The Trust is trying to rationalise the service it provides to families and avoid duplication. It is already looking at extending the role of the named nurse within short breaks.	Clear role definition is required to maximise opportunities.
v	One family wanted to participate but wanted to use it as a 'last minute' service. This is also a consideration for 'ad hoc' visits	See point m. It is not possible to have staff waiting 'just in case' they are required as this would not be best use of Trust resources. Staff also need to know what hours they are working with sufficient notice to promote a good work-home balance	
vi	Pilot only had one individual from Transitions and all the participants were existing service users	It was difficult to gain information from Transitions to be able to offer the pilot to families.	
vii	Peripatetic team consists of all English females	There was not a recruitment drive for specific requirements based on sex, ethnicity etc.	This needs to be a consideration based on uptake of the service to enable people's individual needs to be met

viii	No team member had alternative verbal language skills		As for point vii
ix	What equipment should staff be equipped with to take on visits - how medical should the visit become? E.g. thermometers, pulse oximetry?	There is a need to have a balance of not over 'medicalising' visits. If equipment is required to detect changes in health within the home it would be expected that the equipment would be available in the home	
x	If the service is to continue, consideration needs to be given as to the best way in which to expand the service in a sustainable manner (taking into account cost effectiveness)		
xi	Visits to families have not generally formed a regular pattern.	Families were asked as to what they required in the form of visits. Because this has been a pilot it has not required families to sign up to a regular slot each week/month. This has given an unbalanced view of availability which will need to be addressed if the project continues. It has been positive for the families as it has given them greater flexibility as the pilot has occurred over the summer holidays when people's routines are often disrupted. As more families become involved it will require greater commitment to regular slots to avoid any one family interrupting another's planned service or disappointment in the inability of the service to	

		provide the requested visits	
xii	Training for families / agency carers	It has been suggested that part of the peripatetic teams role could be to educate carers	Commissioning need to be clear as to what they require the peripatetic role to be
xiii	The problem of where to take an individual if the service is not provided in their own home and there is a need to access a 'safe haven'.	There is not always the possibility of using the health short break homes as a 'safe haven'. What other facilities exist?	

Feedback from people in transition

28. Due to circumstances, beyond the control of the project group, engagement with families in transition was limited by tight time constraints. For this reason the lead for the transitions group working in children's complex care looked at the eligibility criteria for a learning disability health short break and used it to inform the group of families in transition to engage with on the peripatetic service:

29. Eligibility Criteria for a Learning Disability Health Short Break
    - *a person who lives in Leicester, Leicestershire or Rutland and*
    - *resides with an unpaid carer*
    - *and who is over the age of 18 years*
    - *who has a multiple and profound learning disability*
    - *or who has a learning disability with significant challenging behaviour or*
    - *who has a learning disability with significant physical health care needs*
    - *may have some additional complex social care needs*
    - *whose needs cannot be met in an alternative local setting*

30. The transitions group then surmised that all young people with a severe, multiple and profound learning disability are known to the CAMHS LD (Children and Mental Health Services Learning Disabilities Team). It was acknowledged that another criteria is Learning Disabilities with significant health care needs and notes that if the Learning disability in these cases is a mild one these families may not have been consulted as part of this exercise. If for any reason it was necessary to consult on the proposed peripatetic service in the future, it is acknowledged that further and wider engagement and consultation would be necessary.

31. All families known to the CAMHS team were invited to attend an information event in early September. Although the focus of the discussion was on the peripatetic service, the attendees were also told about the current residential service.

32. Attendance at this meeting was low, so to engage with those families who had been unable to attend and including those that had a follow letter was sent with a leaflet to explain the peripatetic service model. Families were asked to feedback as follows:

    - What do you understand by the terms respite/short break care?
    - What sort of respite/short break care do you currently receive e.g. residential, sitting service at home, child/young person goes out with a P.A
    - What respite/short break service do you want for the future?
    - What is good about your current service?
    - If you had the chance to change your current service what would you like to see changed e.g. where the service is provided, length of time service is offered, flexibility of service etc
    - Initial thoughts on a peripatetic model as described in the attached leaflet

- Any other thoughts you have on the subject.

No feedback has been received.
Therefore further engagement with this group is recommended.

Feedback from other Stakeholders

33. Leicester City Council

The local authority has been engaged with the process from the start and has been involved in developing the new eligibility criteria and the pathway to access the service. Leicester City Council is supportive of the introduction of the peripatetic short break service as an addition to the current residential service, although resourcing the new service has seen a change in the way people are supported at Hastings Road Day Centre. We would like more clarity on how the service would be allocated, for example how often would families be able to access the peripatetic short break service and would this be on top of their current bed based provision.

34. Leicestershire County Council

We have been engaged with the project from the beginning and support the introduction of the peripatetic service as an addition to the current residential service. It is important that health and social care continue to work together in partnership to develop a joint strategic approach in offering a wider choice of short breaks for people with learning disabilities.

35. National Valuing Families and Carer representative

A good practice example recently we can take heart from has been the health short breaks work which I am overseeing as the Healthwatch representative (conflict of interest declared as my brother uses one of the services involved) but Louise and Andrea have been very keen to work with us carers and have listened very carefully to concerns, LPT have been so totally open and transparent about their services and this led to the move of tournament road service to Grange 2 – it really has been an excellent piece to on-going co-production to the extent I have recommended to Healthwatch that we jointly issue a press statement welcoming the new service, acknowledging the Healthwatch role of starting it all off raising the concern at a CCG board, the CCGs immediate response of calling a meeting for carers to be heard and the setting up of the project board which oversaw the issue of safety at the old location through to the opening this month of the new service at 2 the grange. Really joined up, very collaborative, full engagement and then the on-going pilot into the peripatetic model which so far is developing nicely and will offer choice and control to families if commissioned by the CCGs. On a personal note it has been inspiring to work with Andrea and Louise as they have listened to the carers and recognised the carers are scared and do see that different people will require different levels of support such as bed based for some others will prefer more modern style short breaks and that they need to be flexible. If this is the stance of

the CCGs I applaud the forward thinking and relish the on-going dialogues we need to promote.

Leicestershire Partnership Trust

36. *We have had extensive input into this report*

Issues Raised

- The first recommendation from this engagement evaluation would be that if at all possible the pilot be extended. Once feedback given by those who have taken part in the peripatetic pilot is circulated, other families may come forward. It is realised that due to the timing of the commissioning cycle this may not be possible. It is therefore suggested that highlight reports on any future feedback is presented to the board as more carers take part in the peripatetic service due to run until March 2014 and more feedback is received from those in transition (due to move from the younger persons short break service to adult health short break service service).

- Generally feedback received on the peripatetic service is positive, especially from those who have taken part in the pilot. This therefore indicates that this service would be valued and utilised. However, it is important to note that although the feedback is positive, if changes to the provision of Health Short breaks for people with learning disabilities meant a reduction in the bed based service at any point or a change in how many weeks/days short breaks were to be allocated, a full consultation would be necessary. Feedback in this report is based on the premise that the peripatetic health short break service is offered in addition to the residential short break service currently offered.

Recommendations

37. The feedback reported in this document is shared as widely as possible with decision makers across health and social care who are considering ways to offer more choice and health short break services to users with learning disabilities and their carers.

Please see below Appendix A – full copy of the report prepared by The Carers Centre

Appendix B – copy of the questionnaire sent out to families who took part in the Peripatetic Pilot

Appendix A

Carer comments / feedback on draft Engagement Report (no date /reference) Received with Project Board Meeting Invite 3-9-13 via L . Keran

Carer comments :

1. The carer at first did not understand what the service was; peripatetic meant nothing to them. They asked a worker what it meant and found out it meant someone coming into their house to look after the person they care for. They decided that their family situation meant that this sort of help was impossible and that what they need is the person they care for to be able to go out and about with support and for them to have a bed based respite.

2. How long did the pilot run for (12 wks.?) Is that long enough to cover a family's annual needs and give a true indication of effectiveness?

3. Did the seven individuals involved in the pilot so far give any indication through non-verbal communication that they are 'happy' with the new service?

4. How many members of staff were:
    a. Involved with each family? (In 12 weeks)
    b. How many staff per visit?
    c. Family 1 (L) = Full Time Day Care? Is that sustainable

5. Staff feedback comments 2,3 , 10 ,13 & d are contradictory

6. Is the pilot, in terms staff levels , competency (qualifications), time, service, care, resources, availability etc. a true indication of what would be implemented or is it merely a temporarily gold plated service to obtain positive feedback?

7. Vi of staff comments states :

    It was difficult to gain information from Transitions to be able to offer the pilot to families.

    How could this be permitted? The carers of those who currently use the bed based service have been requesting the opportunity to engage with carers of those in Transitions but throughout the project the two distinct groups have been kept separate.

Professional Observations

8. The health short breaks project commenced with the closure of one community based building based short break home (Tournament Road), albeit relocated to Grange 2 site with the Glenfield Hospital site. There are a number of timing issues which are subtle but important:

    a. At the outset the reasons for the closure of Tournament Road were not clear but as the proposals firmed up so did the rational (ie staff safety)
    b. The objective of the peripatetic service pilot was not clear until very recently. It was originally being offered 'in addition to' existing bed based breaks during the pilot but recently it has been confirmed that the whole pilot is not an alternative, or even being undertaken as a compare and contrast exercise, but purely as an additional service**.** The anxiety this has caused is evident in feedback received and potentially the disappointing levels of take up of the pilot service.

9. From feedback received some people did not understand the terminology being used: did this affect anyone who's written English is limited? This makes an issue of using plain language essential in any consultation. This has been lacking in some areas of the current engagement such as meetings and type & volume of information provided.

10. There is an issue of some people feeling their home space is being invaded by professionals and that this will not give them a break. The fear that it will be used to replace the bed-based services is still present with some carers.

11. Those who liked it seem to have primarily seen it as an additional service not a replacement service and that could affect findings if a decision was made in the future to use it as a replacement service

12. With a greater take up would the current levels of service be as effective with the same resource levels?

13. It's also clear that while a peripatetic service has possibilities, it cannot give the same level of support: this is obviously something that carers have recognised, and the feedback we've received so far suggests a degree of continuing distrust.

14. Realistically, the questions that need to be asked are:

    a. What constitutes an effective break?
    b. Can a peripatetic model provide an equivalent level of service that a bed based model can?

c. How will carers be able to take a meaningful break (more than a few hours) to recharge their batteries, especially when they suffer sleep deprivation when caring?

15. Is there mileage in looking at how bricks and mortar short break services in the social care field can be supported by peripatetic workers to provide training and health care support?

16. One of the issues that has not been acknowledged or addressed – probably due to a lack of understanding/personal experience – is the long term effect of caring on physical and mental health. There is plenty of evidence available from countless surveys that shows that longer term caring, for more hours, has a direct detrimental effect on health - including the General Household Survey 2000, Census 2001 and Census 2011, as well as the "Carers in Households 2009-10" survey. Short breaks of a few hours here and there are not necessarily sufficient as those stresses accumulate over the years.

17. From email dated 20.9.13 which states:

I have checked the letters that were sent out to carers of individuals accessing health short break care. The letter does state that users of the health short break care are eligible for trialling the pilot if they have a component of health funding but that Transitions individuals would need to be 100% health funded. It would not have been sent to anyone who was already assessed as 100% social care as they would not have been eligible.
Therefore carers who did not reply because their son/daughter was not 100% health funded did by choice not because we precluded them from the pilot.
From this statement it is clear that carers of those in Transition who are not 100% health (ie 50/50) were in fact excluded.

a. This is contrary to the definition and eligibility criteria agreed by the project
b. This clearly shows inequality in eligibility
c. This clearly shows discrimination based on age

18. The letter to which the emails refers states :

> *We are going to be trialling a small peripatetic service for 6 months, to those people who currently access our health short break homes and have a component of health funding and a number of individuals with a learning disability who are currently in transition to adult services and who are 100% health funded.*

It is not clear which of the two user groups the 100% health funded requirement refers.

19. The sample group size of those who trialled the pilot scheme is too small to use any demographic data and maintain confidentiality. To make best use of feedback additional data such as location, property type, family carer details

e.g. numbers, age, sex, carer needs etc. and cared for persons age/needs etc. is essential as this information could affect the suitability of the service for certain subsets of people.

Carer feedback forms:

Please see attached carer feedback forms which were agreed upon at the meeting dated 19 September 2013. These were sent out on 23.9.13 and to 30.9.13, a total of 9 forms have been returned

20. A total of 9 feedback forms have been received

21. Of the 9 received 2 are from the group of 7 carers who used the service and from who feedback has already been received.

22. As a result feedback has now been received from 14 families (7 who used the service and 7 who did not)

23. This represents feedback from almost 23% of the families who currently use the bed based service.

24. Of the feedback received from those families who did not try the pilot, 4 could be considered as negative and 3 as neutral.

25. Positive feedback was received from approximately 11% of the families who currently use the bed based service.

26. Approximately :

    a. 77% of families who us the current bed based service have not trialled the pilot or responded to feedback

    b. 90 % of families who currently use the bed based service have not trialled the pilot.

The question of why carers are not engaging about the peripatetic service need to be asked:

Are they receiving the information?

Are they happy with the existing service and have no wish to change?

Note:

There have been concerns expressed about information from the project being received by carers. The information sent from The Carers Centre has to be sent via LPT due to data protection issues. A suggestion would be to obtain feedback from families and carers (about the peripatetic pilot) directly when the bed based services are being used, the existing homes are visited and staff are engaged directly with the family.

This would also alleviate some of the concern about the low level of responses being received and low attendance levels at engagement events i.e. meetings etc.

Appendix B

Leicestershire Partnership NHS
NHS Trust

'Working with Carers and Partners'

Feedback on Peripatetic Health Short Breaks Pilot

If you would like help completing the questionnaire please contact us and we will be happy to discuss your needs with you.

1) Did the Service meet your relative's assessed and agreed needs? *(Please ✓)*
☐Yes ☐No

If not, how could we do things differently?

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2) Was the level of service provided agreed prior to commencement *(Please ✓)*
☐Yes ☐No

If not, how could we do things differently?

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3) Was the service flexible enough to meet your needs and those of your relative? *(Please ✓)*
☐Yes ☐No

If not, how could we do things differently?

---

4) Was the service able to meet you and your relative's cultural and religious needs?
(Please✓)
☐Yes ☐No

If not, how could we do things differently?

---

5) Do you notice any change in your relative's behaviour or health before or after the episode of care? *(Please✓)*
☐Yes ☐No

If yes, please give details

---

6) Do the episodes of care you receive enable you to have a rest from your caring role? *(Please✓)*
☐Yes ☐No

If not, how could we do things differently?

---

7) Were the staff punctual and professional during the episode of care? *(Please✓)*
☐Yes ☐No

If not, how could we do things differently?

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8) Is there anything else you would like us to know about your experience of the Peripatetic Short Breaks Pilot? *(Please✓)*
☐Yes ☐No

If yes, please comment here

Thank you for your time and patience completing this questionnaire

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To enable us to review the pilot comprehensively, we would be grateful if you would complete your name and your son or daughter's name. This will be kept confidential.
If you wish to complete this questionnaire anonymously, please leave this part blank

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