

The Learning Disability Partnership Board has funded short-term projects with the Learning Disability Development Fund 2012-13.

The projects aimed to support the 6 priority areas in the Learning Disability Partnership Work Plan for 2012-13:

- Getting people ready for the next step and getting older – projects to support people developing life skills, supporting people to move, increasing awareness of housing options
- Information – providing accessible information or working with others to make information more accessible
- Making sure we include everyone – projects that support hard to reach groups to be represented
- Being healthy and getting Health Checks – projects that improve health or increase take up of health checks
- People being safe in services and the community – helping people be safe in the community, involving people with learning disabilities in checking the quality of services
- Making sure rights of people with learning disabilities are protected – increase understanding of people’s rights as citizens including the Mental Capacity Act

Please use this document to record your project’s progress and project evaluation to date and return by **Thursday 28th March 2013 to mark.hendriks@brighton-hove.gov.uk**

Project name: Complex Health Pathway

**Name of the organisation: Brighton and Hove Community learning
Disability Team**

LDDF monies awarded: £10,000

Is your project complete?: YES/NO

Expected project completion date*:26th April

Contact details for the project:

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*NB: If your project (as funded through LDDF monies) will not be complete by 31st March 2013, we will ask for a final evaluation according to the completion dates supplied.

Please provide a short (no longer than one page) description of project progress to date:

The project is the Pilot implementation of the complex Health Pathway and the development of a Complex Health Information Pack (C.H.I.P) for each person on the pathway.

The Project lead came into post at the end of November 2012, over 2 months later than planned due to delays in recruitment process.

The Following has been achieved to date:

1. Eligibility criteria defined and agreed.

The pathway will focus on people with severe/profound learning disabilities with at least 2 complex health conditions and/or with frequent admissions to hospital. A person with a mild learning disability who has severe communication difficulties and at least two complex health conditions will also be considered for the pathway.

2. Clients identified for the pathway

There were 19 referrals from existing caseloads. 10 clients were identified for the pathway. 9 clients have a severe or profound learning disability. 1 client has a mild learning disability with severe communications difficulties and profound physical difficulties.

The clients live in a variety of settings: family home supported living and residential accommodation.

3. Development of health Information pack (C.H.I.P)

The Project lead reviewed all information on file for each client and sought new information from carers/family and other professionals to develop the C.H.I.P. A working group of health professionals identified key documents across all agencies that would help ensure a client's health needs were met. For example, A hospital passport, eating and drinking guidelines etc. Each client on the pathway now has a C.H.I.P. It also contains a contact list of everyone who is involved with the person as well as some general information on Communication, capacity and consent, specific syndrome relevant to the client , and information on services

/support groups/websites which may be useful for carers .Eight have been shared with and delivered to their respective carers/family. 2 completed C.H.I.P have not been delivered yet due to unforeseen circumstances

4. Pre and post questionnaires and standards have been developed to evaluate the project.

Pre and post pathway questionnaires were sent out to 8 out of 10 clients' carers.

One client with a mild learning disability who was a frequent returner to hospital was thought to have a complex health condition, however during the process of developing the health information pack it became clear that the health condition was not complex but high risk if it was not managed appropriately due to mental health/ behavioural issues. This client was therefore not considered for the pathway.

One client (transition) was placed on the pathway and a health information pack made up but was not able to be shared with family due to complex circumstances. This will be shared at a later date.

Out of the 8 questionnaires sent out only 2 was returned. However the 6 carers who did not return the questionnaires gave verbal feedback when contacted.

It was felt that carers have not had the health information pack long enough to be able to use it and give feedback appropriately.

The initial view of the health information pack and the process of developing it has been positive:

- Well put together
- Quick and easy to access information in the pack.
- Useful at appointments with other professionals/hospital as it provides up to date and correct information about the person.
- Provides consistency in supporting client as everyone has the same information and working to the same guidelines.
- Amazing, I will take it to the day centre and share with the staff
- The info pack was very good and it was great to have an all-round picture of what 'H' is like and what she needs

The benefit of the pathway and health information pack was more evident in 2 cases where clients were waiting to be admitted to hospital. Developing the pack ensured that there was interagency working and family involvement. Relevant information shared between agencies so that admission was better planned and thus ensuring a positive experience for clients.

5. A data base has been set up to monitor and update the pathway. The data base will also provide information for future planning and evaluation.

With reference to one or more of the 6 priority areas in the Learning Disability Partnership Work Plan for 2012-13, please comment briefly on:

1. How has the project benefited people with learning disabilities?

- It ensures that all the health information which is essential to manage the health of the individual is up to date and easily accessible to everyone involved with the person.
- Family has found the pack useful to take to appointments especially hospital appointments as they now have all information on hand to pass on to professionals. They find the contact list of professionals in the pack particularly useful.
- The project has highlighted gaps in the care such as guidelines which are not in line with good practice
- It has helped to identify training needs of carers. In one case free mainstream training was identified and arranged for that particular staff team.
- Carers are becoming more aware of the health needs and what guidelines are in place.
- The pathway allows the liaison nurses to discuss interaction between treatments and plans from all other professionals at time of admission.
- The C.H.I.P enables carers to monitor and be informed of the person's health needs and therefore able to provide accurate information.
- It allows better preparation for attendance to outpatient and inpatient visits as liaison nurse will be involved automatically.

2. What difference did the project make?

(Something extra that was not happening already)

- It has made coordination of care more effective for the planned admission of 2 people. It has ensured that Liaison nurses are involved as part of the planning rather than intervening due to problems arising when already in hospital.

- Carers and families are becoming more aware of identifying pain and how it may be affecting the person, as a result of being introduced to the Disability distress assessment tool which is a key document in the pack.
- For a carer it has helped to clarify capacity/consent issues and procedure. It has helped to allay anxieties.

3. How will this project benefit people with learning disabilities in the long term?

- It will provide a proactive way of working with this specific group of people who have the most complex health needs and are most vulnerable.
- It will enable the team to target those with a severe/profound learning disability who do not have a current presenting need but are still vulnerable due to their complex physical needs (those coming through transition) They will receive an assessment of their health needs and appropriate interventions to ensure that a management plan is in place to prevent/minimise deterioration of their health.
- Good coordination of health care and better health surveillance for this vulnerable group.
- It will inform future care management reviews.
- Create more awareness of learning disability issues such as communication and Mental Capacity Act.
- It will enable carers and families to develop their knowledge and skills in meeting the health needs.
- Developing the C.H.I.P for each person will encourage better liaison and joint working across agencies.
- Better access to and more positive experience with mainstream services.
- The Liaison nurse will use feedback from the pathway to inform the hospital review in the development of services for people with learning disabilities in the acute sector.

**4. Will the project continue – YES/NO
& please explain why.**

This will be considered on full evaluation of the project. It is hoped that the work will continue through CLDT.

Is there anything else you want us to know?

Implementing the Complex health pathway provides a proactive way of working with this group of individuals who are most vulnerable and is in line with the report of the Confidential Inquiry into the Premature death of people with a learning disabilities (CIPOLD)

It meets some of the recommendations of the report :

- A health care coordinator allocated to people with complex or multiple health needs.
- The health Information pack is a step nearer to the introduction of patient-held health records
- The pathway encourages multiagency working which should ensure that barriers in individuals' access to healthcare and choice of treatments and investigations are reduced.
- Raising awareness around pain and Mental Capacity Act issues

Many Thanks for your project and for making a difference to people with learning disabilities.

The Learning Disability Partnership may invite some projects to present at a future board meeting.