

Learning Disability Development Fund (LDDF) Progress report



Name of project: Carers Link (Transition)

Project Lead: Sue Winter

Sub Group overseeing project: Chairs Planning Group

Project Targets from original bid:

- Two parent carers supported to participate in the Learning Disability Partnership Board
- One parent carer supported to participate in the Transition Forum
- Parent Carers given an opportunity to feed in and out of a wider parents group (parents of teens)
- Links made with Parent Carers Council.
- Mentoring/training given as needed to ensure active and informed participation.

How the project will do this work:

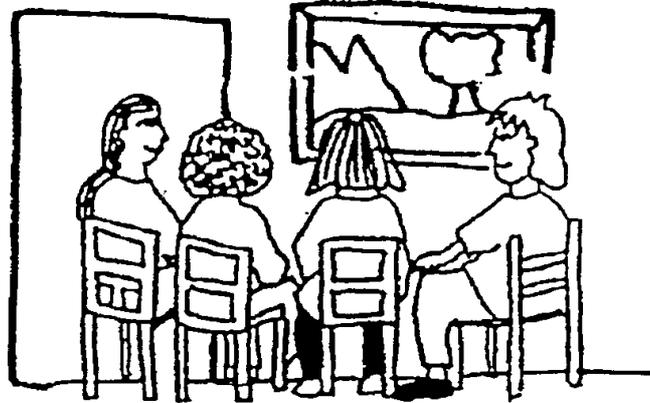
- Amaze will carry on supporting parent carers to be involved in Partnership Board meetings, sub group and the Transition Forum. This support includes pre meetings where we discuss the agenda and minutes and debriefing discussions after the meeting.
- This support will be provided by Sue Winter, Amaze's Transition Development Worker, who has been working with parent carers for eight years.
- Sue will work with our parent carer representatives to make sure that they have regular, frequent chances to feed back the information they learn from the partnership to other parents. She will also make sure that other parents of teenagers get the chance to tell the representatives how they feel about what is happening for their families.

How much 2010/11 LDDF money the project got: £6,706

Name of person completing this report:

Sue Winter, Transition Development Worker, Amaze

What the project has done in April through October 2010:



- **Parents with teens get together and lunch**

Amaze invites parents with teens to get together on a termly basis to share experiences and information and where they can learn more about the work of the Learning Disability Partnership Board.

22 parents attended the get together and lunch **in May**. Each parent had a chance to **share how things are going with their teenager**. We welcomed two visitors who are workers from Southwark Contact A Family. They wanted to find out how **parents in Brighton and Hove share information, learn from one another's experience and about our work with the Learning Disability Partnership Board.**

- **Learning Disability Partnership Board**

Claire attended the Partnership Board meeting in May with Sue and Juliette and Claire attended the meeting in July and all three of us attended in September.

Claire attended the Transition Forum in June with Sue where we learnt more about Health Transitions for young people with learning disabilities. We agreed we would ask parents whose children are over 18 years old, with ongoing health conditions, how they have experienced the transition from children's health services to adult

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health services. We contacted parents through the Compass. Amaze runs the Compass, which is a voluntary register for disabled children up to 20 years old, in the city. We sent out 43 questionnaires and 10 parents responded. We collated the information from their responses and presented this information to the Transition Forum members in September. This information will be used to help professionals improve how they support young people through the transition from children's to adult health services.

Claire and Juliette met with Andy Bradley from an organisation called Frameworks 4 Change. Andy has offered to help us to improve what happens for young people as they become adults. Andy is keen to work with families and young people who are going through transition to adulthood and professionals whose work it is to support them. Andy has good links with people in Sheffield who have done some very good work with families and young people and workers there to improve Transition Planning. Claire and Juliette met with Andy to share their experiences of starting to plan for the future for their young people. Sue met with Andy and Lynn Ley, the Transition Team worker, to discuss Transition work and how we might learn from the good work that is happening in Sheffield. Naomi Cox and Jenny Brickell have met with Andy to talk about how we might work together to do this. Andy is going to let us know how much this will cost to do the work. We hope this work will go ahead in early 2011.

Sue and Lynn Ley will be meeting in November to discuss Person Centred Transition Planning.

- **Training**

Sue and Claire ran three training sessions for 12 parents of teenagers about planning for their young people's future. We told them how we represent parents with teenagers views on the Learning Disability Partnership Board and the work of the Board.

What we've been doing between November 2010 and March 2011

12 parents attended the Parents with Teens get together in **November**. We discussed transport issues for their teenagers.

Claire, Sue and Juliette attended the Learning Disability Partnership Board meeting in January 2011. Sue and Juliette attended the meeting in March.

We met with Helen Zeida, from Frameworks 4 Change, who is helping Andy Bradley with the Personalised Transition Workshops that are starting in May. Claire and Juliette talked to Helen about what their experience of being parent representatives is like. We agreed that we need to hear more from parents whose teenagers have severe learning disabilities as most of the parents who come to the Parents with teens get together meetings don't have teenagers with severe learning disabilities. Sue organised a meeting to be held at the end of April for parents with teenagers who have severe learning disabilities. Claire and Juliette will tell them about their work as representatives on the Learning Disability Partnership Board and the Transition Forum. Debbie Collins will come too; to discuss how we can link the work we do on the Learning Disability Partnership Board with the work of the Parent and Carer Council. We will hear from the parents who attend what they feel are the main issues that they are concerned about regarding their teenagers transition to adulthood.

The Future:

The Carers' Link Work continues to be funded by the Learning Disability Development Fund