

Devon's Learning Disability Partnership Board

County Carers' Forum Meeting

6 February 2007

Minutes

1. Welcome

Carolyn Elliott (Assistant Director, Learning Disabilities) welcomed everyone to the meeting and asked members of staff from Adult and Community Services and the voluntary sector to introduce themselves.

Carolyn said that Anne Brand had kindly offered to chair the meeting.

2. Apologies

Apologies had been received from Barbara Wilson, Linda Stapleton (PPI Manager, North Devon) and Wendy Fallon.

3. Update on Learning Disability Structure and Service Developments

Before she talked about the new structure, Carolyn Elliott said that she hoped everyone present would have a positive attitude to starting the County Carers' Forum again. She referred to the full meeting of the Learning Disability Partnership Board on 24 November 2006 where Carers had spoken about feeling left out of the restructuring of services which made them feel frustrated, fed up, angry and depressed.

Action: Carolyn is committed to helping the Forum start again and needs to rely on Carers to work with her on this.

Carolyn asked each Carer to introduce themselves and say one thing about how they are feeling which would be recorded on the flipchart or people could write them on post it notes if they did not wish to speak publicly (see attached sheet).

Carolyn thanked everyone for their comments and said that the Forum needs to help tackle these issues so that things can be different. She said that the Government has many agendas which are always changing, but currently they are:

- To join up Health and Social Care with one pot of money
- That every family should have its own budget

Carolyn highlighted the fact that local authorities all over the country have financial difficulties which need to be tackled by the Government.

Devon's Recovery Plan shows that Learning Disability needs to save £3,000,000 next year. More creative ways of managing money need to be explored, such as the Short Breaks Strategy, but the budget is very tight.

Carolyn said that she is well aware that this affects people's lives, and invited Carers to contact her individually with their concerns and ideas.

LD structure changes

- It had been necessary to find a way of cutting down on management costs.
- One way to do this would have been to include Learning Disability in generic services.
- It was decided to retain a specific Learning Disability structure – the chart was available although contact details needed to be added. (Please let Hilary Allen know if you would like an updated chart. 01392 208639)
- The new structure was a different way of managing services with Service Managers for Health and Social Care covering the whole county. This will help to achieve equity across Devon.
- Health – people's needs change and the Service Manager will be able to respond to this.
- Action Plans will be prepared to enable equity county-wide.

Carolyn asked carers to let her know what they would like her to talk about at future meetings of the Forum.

Carers asked Carolyn some Questions

- Why have East Devon Carers not been included in the 'Take a Break' scheme? Why has money not been put in to this?
Carolyn explained that there wasn't any money for the 2006/07 financial year, but there will be £60,000 from April for the 2007/08 financial year. We will be able to join the service from April. The scheme provides a sitting service and people in the scheme get subsidised rates for support (£2.50 per hour). The rest of the cost is contributed by Devon County Council. It is a good scheme, but it takes money away from other things. Carolyn asked the Forum to help in the decision about the total money available for respite services.
Anne Brand said that a sitting service scheme has been running in Exeter, but not for learning disability.
- Carers in North Devon are keen on the scheme. Sitters would need specific training. How would this be done?
Decisions need to be made as to how to spend the money in the most effective way, as £60,000 will not go far.
- Will the £60,000 come from Short Breaks?
No. It is from the Carers' Grant money and Learning Disability gets a share (approx £250,000). There is an extra £60,000 in order to take part in Take a Break. Some more of the Carers' Grant money could be added to this.
- How can supported living and private providers of services be monitored for quality?
As a result of the Cornwall Report Devon must not be complaisant. In-house residential services are inspected by CSCI. Supported living is not regulated, but Mencap and BILD have put forward REACH Standards to

ensure that supported living is different from residential care. The Local Authority must monitor this, and Devon County Council is looking at ways of monitoring these contracts which are often expensive and profit making. There is a need to manage the market.

- Did Carolyn know that there was often no support for clients in supported living after the office closed at 5pm?
Carolyn said that she did not know this and wondered if support after 5pm was being paid for. Carolyn asked Carers to send her more information so that she can prepare a response.
- Why are assessments not always effective?
Carolyn agreed that assessments are a critical part of decision making and every effort should be made to ensure they are effective.

Anne Brand thanked Carolyn for her input into the meeting.

4. Feedback on meeting between Northern Devon Family Carers and David Johnstone (Director, Adult & Community Services)

Dinny Cope presented a report (attached) from Northern Devon Family Carers and explained that the group has been in existence for about 16 years. The group had withdrawn its support from the Learning Disability Health and Social Care Partnership as they did not feel their involvement made any difference.

At the meeting with David Johnstone (Carolyn Elliott and Sue Turner of the Valuing People Support Team also attended) NDFCG asked for the following:

- Firm proposals on tackling issues
- Changes in services need to improve services
- Evidence of improvements
- Evidence that Carers' contributions had made a difference
- Carers should stay involved

Actions as a result of the meeting

- Information must be shared
- Working should be transparent
- Accountability
- Consultation

The NDFCG feel that Carers have a wealth of experience which is a wasted resource if they are not involved. Person Centred Planning would identify the needs to be met and management need to know what is actually happening on the ground. As a result of the meeting the following actions were agreed.

Action: to follow up the evaluation report done in North Devon and to add a further 17 families to the study.

Action: David Johnstone to visit a family in North Devon.

Anne Brand thanked NDFCG and Dinny for the report and their ongoing work.

5. Short Breaks presentation

Steve Robinson (Short Breaks Strategic Lead) and Glenn Walpole (Short Breaks/Fulfilling Lives Manager, Mid Devon) gave a presentation on the more flexible arrangements for providing short breaks and the pilot scheme that has been running successfully in Mid Devon.

The aim is to join up the Short Breaks service with the Fulfilling Lives service in order to provide a more flexible service and to use the money available more effectively and efficiently to benefit more people.

Carers asked some questions

- How many Carers are there in Devon?
Carolyn Elliott replied that the Government only requires statistics for people who are eligible for services, but there will always be more people who are cared for but not eligible for services.
- Although the SWAPS scheme is excellent, how can Carers be certain that the placement is appropriate?
Glenn replied that during the pilot scheme in Mid Devon there have been lots of conversations with Carers and now surgeries are held every 2 months to monitor how things are going. Carers book individual appointments for the 'surgery' to discuss their particular needs/issues. This is now going to be extended to the Fulfilling Lives service as the surgeries are proving so successful.

People were invited to talk with Glenn and Steve during lunch.

6. Where do we go from here?

June explained the history of the County Carers Forum which has a constitution and a bank account. It is a county wide group with the purpose of obtaining Carers' views and concerns, as well as keeping Carers informed about services and issues throughout Devon. They also have a number of places as members of the Learning Disability Partnership Board. However, a fresh start is needed and responses to a questionnaire sent out last year showed that Carers want to meet countywide but perhaps less frequently, such as quarterly.

- Dinny Cope said that in 2004 Linda Stapleton had been asked by Sam Newman to carry out a review of carer involvement, which resulted in a Framework and Action Plan which has not been fully implemented. She suggested that Linda Stapleton should be invited to the next meeting.
- June pointed out that considerable progress has been made since then with the appointment of Carers Support Workers, and Carers Grant money made available for Take a Break, etc.

- Dinny said that Carers will need to feel fully involved and listened to and that a structure is needed to ensure this happens.
- Anne Brand suggested that an independent facilitator could help with this and there is money in the bank account which could fund this. She suggested a pilot scheme is set up. Dinny said that Carers need to have an input into choosing the facilitator.
- Bill Smith, who said that he had been on the previous committee, felt that managers should be at the meetings in order to take on board Carers' issues. This needs to work in Localities first.
- June recommended that there should be Carers representatives from each area, but that they could network via email, letters, phone calls etc if attending meetings is difficult.
- Rosemary Huxtable said that local groups had worked in some areas, such as Mid Devon, and it is good to have the chance to start again.
- Bill Smith said that Carers are not involved in DPT, for instance there are no Carers on the Clinical Cabinet. *Carolyn Elliott replied that DPT is principally a Mental Health organisation and that the Clinical Cabinet is in fact a professional group. However, there does need to be a way of collecting Carers' views effectively.*

Actions

- **Carolyn will support the County Carers' Forum as the way of collecting Carers' views.**
- **Carolyn will speak to her managers about supporting local groups which can feed into the County-wide group.**

In conclusion, Anne Brand made the following points:

- It is important to remember that Carers can have influence at a national level. We should try to influence the Political Agenda.
- Exeter Mencap is funding a conference with high profile speakers as a result of the earlier conference 'What are we education our children for?'
- Exeter Mencap is strong and has some very capable people amongst its members.
- Suggest that the Forum meets again in about a month's time and that Linda Stapleton is invited.

- Dinny will circulate Linda's work on the Forum.
- Bridget McEleney-Smith said that the meeting had been very positive and productive and that it is essential that an Action Plan for the working of the Forum should come out of the next meeting.

Carers' thoughts and feelings

Uncertainty
Dejected
Flexibility
Deterioration
Anger
Sidelined
Let down
Exhausted
Concerned
Lack of structure
No progress
Nervous

Lack of meaningful activity
Defeated
Limited support for health needs
Supported living is 'unsupported'
Carer isolation
Closure of centres
Powerless
No support
Frustrated
Tired out
Anxious
Scared

We need sensible services at sensible prices

Who decides if someone is learning disabled - the Government Social Security system or local Social Services?

Are you aware Copperfields (a new, modern respite unit in Exmouth) is only open 1 weekend in 4 because they can't afford to staff it? What a waste of a great resource.

Please may we be given specific financial information re annual allocation to Learning Disability services?

Inclusion of Carers who, through working, transport or other issues are unable to attend meetings.

Implementation – no more talk.

What has happened to sheltered work services in Exeter? They seem to have been abolished!

Vital for clients in Residential Care to have some day care outside the homes – not just a drink and a cake in supermarket cafés.

Transition Protocol says Adult Services should attend Year 9 Reviews. Protocol not in place in most schools – so far only 2 special schools and now 12 mainstream schools. My daughter's Year 11 review is due this year and so far there has been no contact from Adult Services. Why?

Why isn't there any inspection for supported living facilities and providers?