

**Report from the Carers' Forum  
15<sup>th</sup> September 2010**



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## **Introduction**

The Carers' Forum was organised by the Carers' Centre Bath and North East Somerset in partnership with Rethink, Bath and North East Somerset Council and NHS Bath and North East Somerset. Break activities were provided by Give Us a Break.

Sonia Hutchison, Chief Executive of the Carers' Centre introduced the day. The Forum had 4 Workshops, one discussed carers needs regarding employment and life-long learning, one discussed the new structure of Learning Difficulties Services in Bath and North East Somerset, one planned setting up a support group for carers with a neurological condition and the final group provided additional support for carers with learning difficulties through support staff and easy read documents to comment on the national refresh of the Carers' Strategy.

## **Executive Summary**

### **Employment and Lifelong Learning Workshop.**

- Lack of confidence and ability to identify strengths and skills.
- Need support to re-enter the workplace and good structures to make it possible.

### **Getting your voice heard if you care for someone with a learning disability**

- Need better communication, clear lines of accountability and consistency of services.
- Some carers are interested in being more involved.

### **Carers with Learning Disabilities Workshop**

- Need to listen to the carer, give time to communicate and need clear communication
- Important to have breaks and have nice respite for the cared for person
- Need help to manage money and emotional support.

### **Developing a support group for those caring for someone with a neurological condition**

## **Employment and Lifelong Learning Workshop.**

### **Issues facing carers entering/sustaining employment or lifelong learning:**

- Loss of skills, knowledge of working practice and confidence.
- Become isolated without social contact of work.
- Loss of self-worth and value when unemployed for a period of time.
- Big gap on CV, difficult to explain gaps in employment or training.
- Difficult to identify what transferable skills you have after being unemployed due to a caring role.
- Need help and support in recognising the skills that have been accrued as a carer.
- Lack of knowledge and fear of completing an application form, CV or attending an interview.
- Lack of knowledge where to access job seeking help and support.
- Fear of discrimination, and assumption that if you have a caring responsibility you will be unreliable.
- Greater need for flexibility of hours for both courses and employment.
- Reluctance from the carer to ask for help from an employer as could lead to discrimination.
- Can become too difficult to juggle work with caring as the caring role begins to increase.
- Expectation that as a carer you will be happy to volunteer rather than have paid employment.
- Fear that in the current climate employers would rather take people who are already in work and do not need retraining.
- Rejection by employers causes further lack of confidence and fuels frustrations.
- Money, impact of wage on benefits, tax credits/caring. Fear of being worse off employed. Need help to identify how much they would need to earn before it impacts on their benefits/income.
- Adult education including non-accredited courses often too expensive.
- Quality, access to and continuity of replacement care.
- Resistance from the cared for person.
- Resentment with caring, feeling of no way forward without the focus of work.
- Need good career guidance.
- Need good financial advice
- Need back to work courses to brush up skills and confidence.

### **What can Employers do to help?**

- Counselling made available through work.
- Flexible working to suit the individual needs, should become the norm rather than exception.
- Job share schemes.
- Carers leave to be run in a similar way to sick dependent leave.
- Incentivise employers to employ carers.
- Good, honest feedback from employers after an unsuccessful application/interview.
- Reassurance from employers that to mention you are a carer will not impact on your job application.

### **What can The Carers' Centre do to help?**

- Influence GUAB partners to continue courses specifically for carers after March 2011.
- Influence educational institutions to run courses at more flexible times.
- Promote carer awareness, raise profile of issues facing carers.
- Increased marketing and publicity.
- Influence/train local employers in carer awareness and the benefits of employing a carer - qualities, skills etc.
- Influence services that provide replacement care to be of highest quality, consistent and flexible.

## **Getting your voice heard if you care for someone with a learning disability.**

### **What do carers think of the new LD services?**

- Seems like a good new structure.
- It would appear to be better focused.

### **What concerns have arisen from the structure?**

- No local service specific to Keynsham.
- Will there be easier access to services needed?
- Will there be the same accessibility for carers to persons with a knowledge of the individual.

### **What are the main areas of concern generally for LD carers?**

- Communication.
- Family contact and social services contact.
- Need child with LD to be placed in housing as near to parents as possible.
- Not being informed of changes- being informed after event.
- More training for support workers.
- Need to monitor that the right checks are being done-legal monitoring of carers.
- That the services will continue as they are
- Not informed of changes - don't all have access to internet-would not have known about restructuring if had not come today.
- Need a contact point for us to contact us who will inform us.
- Need to re look at who can have responsibility for money when family members can't give consent.

### **How do carers feel they can better influence LD services?**

- Need to see the parent is important and family is important.
- At meetings and forums and by writing letters.
- By complaining- but don't know who to complain to sometimes.
- Would like to be heard better.
- As above with groups like carers centre and Parent carers aiming high to have direct input & they can present views to LD services.
- Would like more input into transitions.
- Working in partnership with family.

### **How can carers who sit on the partnership board be representative of the LD carers community?**

- No comments on this.

### **Would carers be interested in a LD carers group that feeds into the partnership board?**

- Yes.
- Yes- every few months.

- My son goes- carers should not go-have to let go.
- Need to hear back when issues are raised.

### **General Issues raised**

- Carers asked about more communication about how money is monitored and spent with and on their cared for person.
- Important to have accountability about what happened in transitions and to make sure plans are put in place early on.
- Need to be told the process clearly-so it is clear why there is no social worker holding a case - need to send information to carers.
- Need to be told things-if you are not told things-you have no power.
- We would like to know where the bungalow is that replaced millward house-and how to contact them.
- Important to offer lots of job opportunities.
- Send more information to invite carers to the partnership boards- Bath, Keynsham and Midsomer Norton.
- Partnership board-ideas need for how carers want to be represented.
- Issues with carers feeling intimidated at person centred meetings as some key people don't go to the meetings.

## **Carers with Learning Disabilities Workshop**

### **National Carers Strategy Refresh**

#### **Carers to have respect and support from services:**

- Care workers need to listen to what the carer is saying.
- Carers need to be treated with respect by care workers and health professionals. They need to listen to the carer as they understand what the cared for person wants and what is too much.
- Carers need to be given time to speak and explain themselves.
- 3 carers felt they were being taken advantage of by care workers and cleaners, they felt they were being ignored and also sometimes criticised, and that the workers were being lazy and not doing their work.
- Need for good communication between carers and workers.
- Carers want to be treated as someone who understands the cared for person's needs.
- Doctors need to listen to what carers say about the carer's health - they are the experts.
- Carers need to be respected for the knowledge they have on the cared for person's condition.
- Carers need to be told about the type of treatment the cared for person may be having/ be told about their condition and diagnosis. One carer said 'no one explained the health problems to me so I was doing things that made it worse. I had to get a book and educate myself'.

#### **Carers to have their own life:**

- 2 carers said they would like the cared for person to go into 'a nice respite' so they could go away.
- Two carers talked about the need for easily accessible transport, 'I don't drive, public transport is very bad'.
- One carer going on holiday next week said 'I am really worried about leaving mum, it would have helped to have someone there for the whole week, I worry about her falling in the night'.
- One carer said 'I worry about how my partner will be when I'm not with her. I have peace of mind and feel at ease to leave her when I can tell she is being well looked after, when care workers understand her and listen to me'. This carer said he would like a break, he is really tired but he 'needs to know she is being well looked after to be able to relax'.
- 'It helps my confidence to take breaks, it can get too much without taking a break, I can sometimes get in a state'.

#### **Carers to have enough money:**

- The carers felt that employers can lack empathy, one said 'it is difficult to get to work on time sometimes, flexible working hours would help' this carer also said 'I feel victimised for being late'.

- The cared for people are receiving benefits that the carer cannot access.
- 'A budget would be helpful'.
  
- Extra expenses that were mentioned for being a carer:
  1. Washing machine use
  2. Taxis
  3. Fuel
- 'You have to be able to budget but sometimes need help'
- 'Carers allowance doesn't keep up with inflation, it needs to be more'.

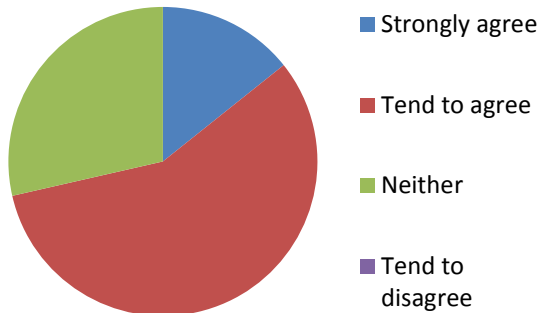
#### **Carers to stay well:**

- Employers need to be flexible with carers going to appointments.
- 'It helps to have someone to talk to about how I am feeling'.
- Difficult to move cared for person, two carers now have problems with their back, both said training and support in moving and handling people would help.
- Workers did not listen to problems with house and equipment that was needed.
- Need to have health problems recognised earlier, 'we need to be taken seriously'.

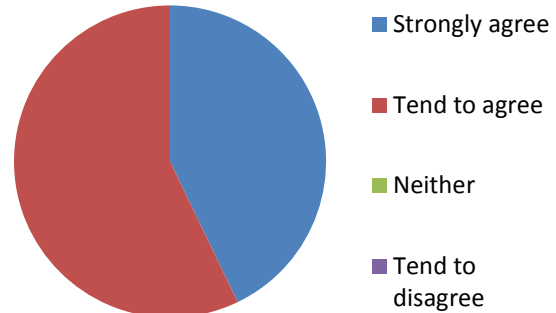
Developing a support group for those caring for someone with a neurological condition

## Evaluation of the Event

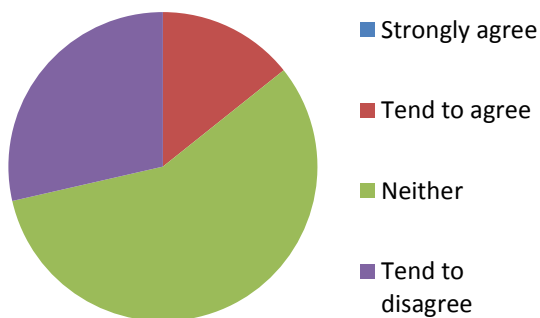
**The aims of the event were clearly explained**



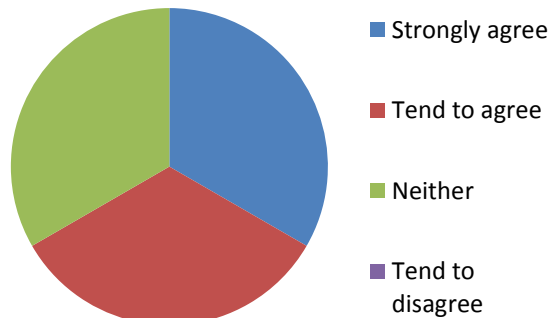
**I felt that my views were listened to at the forum**



**There was too much time listening to others**



**I would like to see more events such as this**



**What did you think about the different activities that were available during the forum?**

Good choice. Unable to take part. Good. Very good and a chance to be oneself.

**Did you feel there was enough time spent in groups? Was it an effective way to give your views?**

I hope so. Reasonably so. Yes otherwise discussion tend to wander. Yes. Yes just right - very open and inclusive. Yes and yes. Yes to both questions.

**Do you have any other comments about the venue, catering, timing of the event or the forum itself?**

All nice. Good catering, venue nice and spacious. Venue and timing fine - would appreciate more healthy food options i.e salads and cold cuts etc. Not so many carbs please. Thank you. Very good venue and food was excellent, company of other carers and helpful staff.

**Are there any big issues facing carers that we have not discussed today?**

What happens if we fall ill? Too much pressure on carers in residential homes as parents age and die. With future funding, being possibly difficult after March I hope support will still be available, even if we have to pay partly for transport, lunches etc.

**Is there anything else you want to add?**

Are parents allowed to disagree with government policies concerning their 'child' 'provider' without recrimination from managers/staff of home. Too much financial secrecy. Thank you for everyone's hard work