Carers’ feedback on day activities for Learning Disability Partnership Board 18th July 2016

Amaze and the Carers Centre contacted carers to find out their views on day activities for the people they care for. We held a joint focus group meeting and spoke to other carers individually. We found that the priorities and concerns of all the carers were similar whether they were caring for someone approaching transition to adult services, in the 19 to 25 age group or an older adult, although this included a wish for age-appropriate day activities for their various age groups. We have therefore written a joint report.

Who gave us their views?

Seventeen family carers contributed. Twelve carers, caring for thirteen people with learning disabilities came to the group meeting. Additionally, four carers of adults with learning disabilities were interviewed by telephone or in person and another parent carer of a young person with autism responded by email.

Ages of person cared for: 14, 15x2, 16, 18x2, 19, 20, 21, 22, 23, 25, 26, 27, 29, 49, 58 years.

Did the person you care for use day services before they closed?

One focus of the feedback topic was about the impact of recent changes to council provision of day services. Two carers had experience of an adult day service closing and the person they cared for having all their day provision provided at another service (from Buckingham Road to Wellington House). Their experience of the change had been straightforward because their family member was continuing to receive a day service similar to their previous one and there was some continuity of staff and activities. They had felt reasonably well-informed and that the transition was handled carefully. However, it had left them with some concern that more change will follow.

Two carers of young people had experience of a service their son or daughter used for some daytime activity closing and not being replaced, but these were not council day services (Children’s Society Mentoring & Befriending Scheme for young people and Aspire Mentoring service). They drew attention to the value of mentoring and befriending services, especially for young adults.

What does the person you care for do in the day currently?

Some of the parent carers had young people still at school or college during the day in term-time. This was combined at weekends and holidays with various activities and services: PAs through direct payments; Extratime youth club and holiday youth schemes; activities with other families through Pebbles, National Citizenship Service summer programmes. One had just completed a supported internship course, but this had not led to employment. One was hoping to start Team Domineca in September, which should involve both college and work experience. These parent carers felt they did not have a clear long term plan for day activities for their young person, although some were engaged in transition planning. Two other parent carers had young people living in supported accommodation whilst still being at college. They had more sense of there being a plan for their future, although with some uncertainty about what would replace college when this came to an end.

The adults were using a number of different day activities:

- Wellington House
- Grace Eyre
- Supported Employment
- Part time voluntary work
- PAs used to facilitate varied community activities e.g. art course, allotment project/Moulsecoomb Wildlife Garden, volunteering with park rangers
- Activity at their supported living e.g. daily life activities
- Papermates
- Cookery classes
- Chailey Futures
- Heart Ventures
- Power Group
- Rocket Artists, My Marc art sessions,
- Gig Buddies
- Carousel including Blue Camel Club
- Extratime
- Spiral
- Cherish
- Beat Box
- No Boundaries

What is working well now?

Many of the existing activities were seen as positive and enriching. Carers were generally positive about the things listed above that their cared for person uses, for example reporting that the facilities or staff were good, despite other drawbacks or concerns which we explain below.

Aspects carers valued about the range of day activities they use now:

- Flexibility e.g. Grace Eyre agreeing to split budget so the person can have their own PAs as well as be in supported accommodation.

- Supported living arrangements that facilitate continued learning and use of life skills as well as providing safe and suitable accommodation. Residential providers that take people to both “mainstream” community activities e.g. cinema, birdwatching, trampolining, libraries and specialist ones such as Blue Camel, Spiral and Beat Box.
  He likes to visit the dump and the recycling facility there. The support workers from his house take him there and we hope it could lead to some related voluntary work eventually.
  They go to Beat Box in Worthing every week which my daughter really enjoys.
- Use of direct payments to employ PAs which offered flexibility, person centred choices of what to do and when, a way to follow interests and have inclusion in community activities rather than learning disability specific provisions. Also opportunities to meet up with others or be part of the PAs social circle.
- Outreach support workers offered some of the same benefits as PAs with less burden around recruitment and employments, but less flexibility.
- Voluntary or paid work with support that gave the person they cared for a sense of purpose and being valued.
  My son enjoyed the No Boundaries course and then they called and offered him a role helping out with future courses.
- Wellington House day service was highly valued by the two families using this. It offers company and “friends” with long term relationships. Good range of activities over 5 full days e.g. gardening in the community and teaching Makaton to children at a local school; also continuity.
  Staff get to know the carers too and can respond when you have a problem and have been really supportive to me.
- Activities for young adults that are age appropriate and link them with others in their age group. Extratime extending their age range over 18 was welcomed because it meant some continuity of friends and activities.
  The Youth Club on Wednesdays is an opportunity to socialise with other young people that he doesn’t get otherwise.

What is not working so well and why?

Nearly all the carers raised what they perceived as the slow speed of providing assessments and services. This was not seen as supportive. They felt it was often left to the carer to organise or coordinate things. It could mean anxiety and a lack of respite help when it was needed.

It feels like a lottery what you get or not.

There were profound feelings of uncertainty and a lack of a coherent plan. This led to fear for the future and questioning if future alternatives will be worse.

Sessions for many day activities were viewed as too short and/or too infrequent. Lack of transport could mean carer time being wholly spent taking the person to and fro with no real break. Also, transportation by the parent to and from activities meant the person was not independent and always with the carer.

Short term funding and short term projects were a concern. Carers were not sure if projects/services will still be there in the future, or that funding for the individual to do them will continue.

Some carers reported finding it complex setting up a mixed programme and filling a whole week with meaningful activities. They experienced piecemeal arrangements and said a mix of activities could offer variety but is difficult to manage. They spoke of being unable to plan their lives and that of the person they care for. A couple felt there was a gap around befriending to enable people to access activities with more informal support.

Getting the right balance between respecting an adult's right to make choices and positively encouraging them to participate and engage in things was an issue. Carers were concerned that paid carers or residential staff might not get that balance right, or that options that did not match interests would exacerbate this problem.

What if he doesn't want to do anything? Sometimes he needs persuading to go out or he'd never leave his room.

Carers who employ PAs through direct payments raised pressures around finding and employing PAs. There was also a concern about avoiding too much time alone with PA – the sitting in the coffee shop trap.

What do you do when it's raining? There's only so many times one can go to the Sealife Centre.

Carers felt that they need to closely watch, monitor and check what the person they care for does in the day. They were aware of staff turnover and that staff might be unaware of, or forget things that were important to keep the individual safe and happy.

When there is a gap or things go wrong it's the family that has to pick up the slack or get things sorted.

Some carers were not happy about the suitability of what is on offer. Grace Eyre did not suit one individual, but there was little choice of an alternative. Another wanted Autism Sussex, but was told this was impossible as their costs were too high. A couple of carers found Cherish problematic because it has no base, so the young people always have to go out. This did not suit those individuals who dislike constant change, or have medical needs that mean they need space for a rest. A carer of a young woman with autism felt there was a particular gap in activities suitable for girls/women with ASC.

Carers were keen for the people they care for to have opportunities to work, or do work-related activities. However, they found that supported employment, supported internships and work-start activities were often not realistic about the individual's needs, made promises they could not keep, or tried to shoehorn people into things that did not suit them. Issues included not enough support and insufficiently wide links with employers.

It didn't work. He got cross with her. There wasn't enough explanation of what she had to do. She does two mornings cleaning but I have to put a lot of work in to keep this going.

Carers sometimes hoped to use Adult Education but were concerned that it has been cut, or were unsure whether it would take their cared for person.

Have you had good information about day activity choices? Do you have choices around what day activities those you care for do now?

One carer mainly used the internet.

You don't get offered information. I research it myself online, google things, use websites and leaflets for leads.

Another carer had tried It's Local Actually, the Fed Centre for Independent Living's online directory of local activities.

However, most were less confident about this approach and felt that searching online meant doing too much filtering out of things that were not suitable or available. They wanted to be signposted to appropriate activities, or to get personal recommendations. No one had used the My Life website or even heard of it. Some had heard of the Local Offer but not used it.

I prefer personal contact not the internet. I look for information events like the Amaze Info Fair and Take Part (for sport/leisure). I join in with things hoping to make useful contacts. I use the Amaze newsletter and e-bulletin because I trust their information.

They were also concerned how the person they care for could get information and how this information could reach them. There was also a strong view that having a real choice had to include the chance to try things out to see if they suited the individual. This could take time. *My son needs time to get to know people and get used to new places and settle in; we won't know straight away if something is going to be right for him.*

Grace Eyre try to give him choices about what he does on his two days there.

Transport could be a limiting factor on choices. Some people had benefitted from the Travel Buddies scheme to become more independent in travelling for some journeys. They were sad that this has now ended.

What is the impact on the carers?

Carers wanted the person they care for to reach their potential and have a rich life. The whole family is affected if the cared for person's activities in the day are not working.

My son has his quirks and needs people who understand him. He will be challenging if he is not happy and settled, which takes him time.

Finding and managing a selection of activities he enjoys and can do is a job in itself. Who would do this if I didn't?

Uncertainty is great source of anxiety for carers, especially looking to the future.

What will happen to her when I am not there anymore? I worry about who will speak up for him, believe in him and give him a voice. Will he be labelled as having behaviour issues because people don't understand him?

Key messages picked by carers – what matters most

- Need coherence, a clear map or menu
- Listen to him/her
- Routine and structure is important, with a bit of variety and progression
- Meaningful activities are vital, that feel real and worthwhile, so they feel they are achieving, progressing, learning or contributing
- Need things that will last more than a few months, or a year or two
- Something reliable, that happens two or three times a week
- Some change and choice at least annually
- Communication with carers, even if person they care for is not living with them, including opportunities to see provision and meet the staff
- A key person who can take on the role the family takes now in watching over what they do and initiating change when that's needed
- Transport that is safe so they can reach things