

**Short Breaks- supporting children and young people with complex needs
Feedback from the market research exercise undertaken at
the Short Breaks Fayre 15th and 16th January 2010**

Total number of responses: 18

We have worked with parents and carers to identify a range of exciting opportunities for the use of the John Parkes Unit. We would like to know whether you would use any of the services listed:

Overnight stay away from the home	13
Overnight stay in the home	3
Nursing staff	5
Day Care away from the home	8
Day Care in the home	2
Trained care staff	7
Emergency respite	8
Ventilation	1
Palliative care	2
Holiday schemes	15
Day trips	14
Sensory room/ sensory toys	10
Hydrotherapy access	8
Computer access	3
Young teen facilities	6
Activities and play workers	10

These services could be bought with your direct payments. Would you change the way that you currently use your direct payments to buy any of these services if they were provided from the JPU

If yes; why ?

1. We're familiar with the Unit, we've used the Child Development Centre
2. Yes if JPU did provide more day care as it is close to home. My child isn't medically complex enough to qualify for JPU at the moment
3. I would be concerned about the attention my child would get there

4. As my child gets older they need more interaction than just one carer
5. My child is 12 with Downs Syndrome and behavioural problem. I would use the unit if it was open to more children. From what I've read in the papers it is unfair that so much money is spent on medically complex children there must be a more cost effective way of running the Unit.
6. My child has learning difficulties and behavioural problems it would be good if there were supportive groups and networks from the JPU as there are for the under 5's- you get ideas from other parents.
7. Yes but I would expect my budget to reflect my son's attendance at JPU
8. Friendly, safe trained care. Trusted.
9. I trust JPU and have built a relationship with staff there

If no; why not ?

1. No- prefer care in own home
2. No- most facilities are already accessed at school
3. No- would prefer to use local, home-based activities

Further comments:

1. Exploration of use of JPU for educational purposes when local authority takes responsibility for education from April 2010 ? Current issue with post-16 provision for some groups of young people-further issues will be developing due to raising of the participation age.
2. Would like to see it (JPU) remain open.
3. For John Parkes to remain open for children with complex medical needs and for extra financial allowance to be given through fair access to carers breaks.
4. I would like to see JPU developed further to meet all needs

Feedback from former users:

- X was becoming very distressed when X was being transported to JPU. X was also self-harming. X is now receiving home –based respite –which X loves.
- X was bored! X is a complex young person with medical needs but also requires social interaction with other children –who like playing on X boxes and computers. X asked to stop going to JPU. X is starting home- based respite with a family, whereby both X 's medical and social needs can be met.
- X is now having home-based respite. X is due to have a complex operation. Whilst X had respite in JPU X kept contracting infections. The Consultant was not happy for the operation to go ahead as the risk of cross infection was too high. X is now receiving home based respite. The infections have reduced and the surgery is going ahead. Also, X is an only child and loves the interaction with the carer's children.

- X has home-based respite through a direct payment. Feedback from mum re JPU was that X would often return home after respite looking unhappy, also physically the effects of X not perhaps being moved around as much as X should have been were evident and X was often very stiff for a few days. This was often dependant on the staff that were on duty, and also as X is not so demanding I believe at times X did not always get the stimulation / attention needed.
- X now has respite at Robins, mum made a formal complaint regarding respite at JPU and stated that X was left in bed for long periods of time during the day, lack of staff and lack of stimulation and social opportunities.