



What Parents and Carers Said About Overnight Support for Children and Young People with Disabilities

Who?

Parents and carers of children and young people who have overnight support of some sort

Other parent and carers who have an interest in this and wanted to share views

How many?

74

How?

Paper and online questionnaire, 2 parent and carer focus groups and email communication

When?

March and April 2019

What's important?

- It's really valued and appreciated when you have it
- Its seen as essential
- 'A life saver'
- Child needs to be treated as a child – not a service user
- Trust is key – it's not a break if this isn't there
- Paying attention to what's important to the child – whatever that may be
- There is a particular concern about health and medical needs being met. This is important for all but for some it is actually potentially life threatening if it's not done right
- Need a genuine interest and pay attention to detail
- Reliability
- It's a **really** big deal for parents to let others care for their child – especially at the start. Sometimes it's the first time ever.
- Concerns over other people's ability to meet health needs, medication, to 'notice' and pay attention to the things that are crucial to some young people
- First impressions count – it's got to feel right
- Travelling time and arrangements if its outside own home
- For some nurse led care is needed
- Weekends and holidays are the times of greatest need
- Quality is key
- Compassionate support and understanding for whole family – really appreciated when it's there but conversely has a negative impact when it's not

Themes

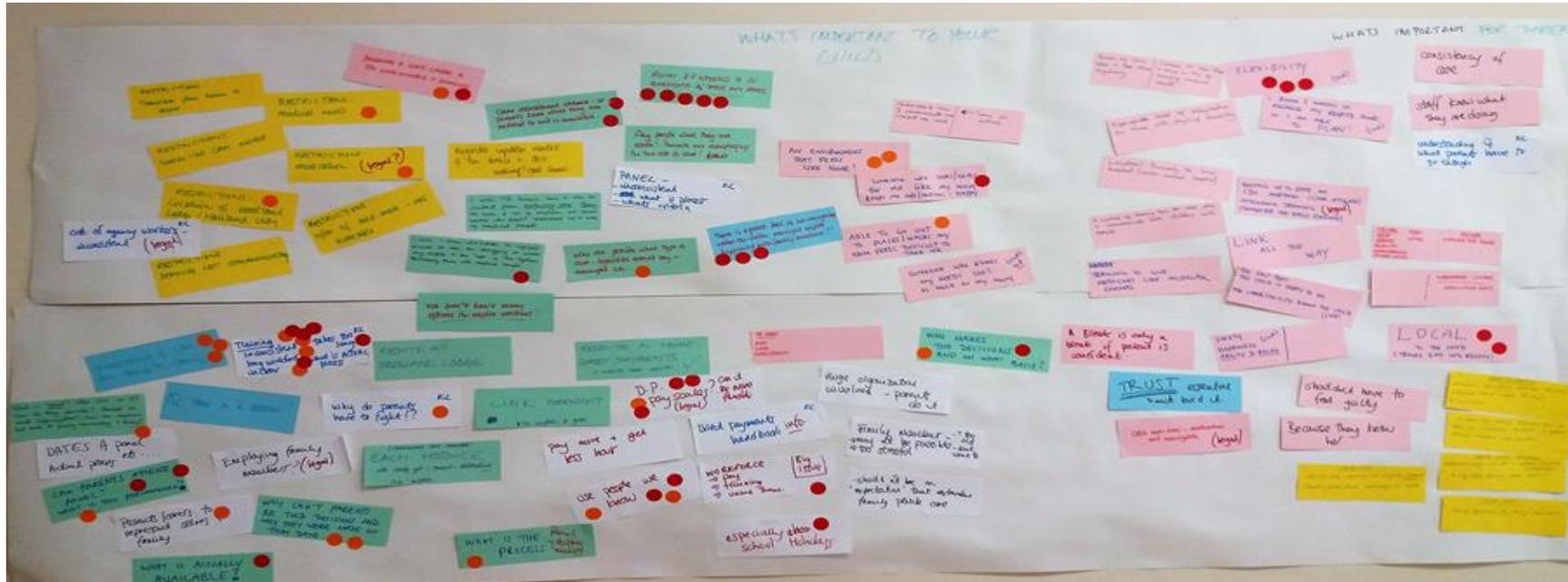
- An element of guilt when you have good support – because you know of others who need it don't have it
- Worried about losing support
- Takes ages to get the support in place – whatever it is
- Mix of people wanting it in own home, a workers home or a residential place – depends on the child or young person and the family. There is no 'one size fits all'.
- For some the amount of equipment, medication etc. that needs to be moved and preparation involved makes support in home best
- Payment for direct payment workers is too low – so hard to find quality workers
- Training requirements are unclear
- Would rather have less hours support and pay more per hour to have good quality, reliable support
- Managing Direct payments is hard for some
 - Confusing
 - Payroll service not very good (you have to do it for them!)
 - Can we make it simpler?
 - It's hard to find workers
- Parents and carers spoke and wrote very powerfully about the emotional aspects of needing support, the process of getting support and the impact this has on the whole family – and that there needs to be more understanding of this

Some Suggestions and ideas

- There is no one size fits all – want to have a variety and genuine choice
- Re Direct payment Workers
 - Better, simpler info about how it works – maybe an information book or guide
 - More flexibility of who can do overnights in a child's home
 - Direct Payment workers to be able to provide support in their home
 - Use Teaching Assistants, child minders and others who may already know the child and have skills
 - Family members
- Nurse led care for those who need it – might have to just accept its needed
- Activity type weekends/holidays that can combine a short break with something meaningful, fun and skill/independence learning for the child
- Support to go on NCS, Duke of Edinburgh awards and other things like it
- Have a time line of process of getting overnight support so all know
- And linked to this some clarity about all that's available
- Can community support or other providers provide some overnights linked to holiday clubs
- Maybe make use of some residential and other facilities in schools in the holidays
- What about short breaks in other places – eg caravans by the sea (Mencap have one)
- Sharing direct payment workers

Offers of Help

- Parents and carers pleased that this is being looked at
- Many offered to be involved on going in practical ways and in sharing views on developments



Notes from the sticky wall at one of the parent's sessions.

Summary compiled by Pinpoint and CCC on behalf of the Overnights Breaks Project Group