



PaCConnect on Home Adaptation - Wednesday 18th March 2015

1st Part: Parent Carers get together ...

- Fiona, PaCC Co-Chair introduced the plan for the forum and ground rules
- Pippa, PaCC Parent Rep clarified that today forum is about Home Adaptation. At PaCC we are aware that there are many parent carers who experience problems with Housing and we plan to look into it sometimes in the future
- People attending:

Pippa: child age 6, in the process of home adaptation; Sue: child age 9 at Downs View, went through significant adaptation and would like to share her experience; Tim: child age 9, council accommodation, neighbours/difficult situation; Fiona: child age 9, not been through adaptation; Lynne: child age 17 autistic, went through adaptation and after a long process a bathroom was fitted on ground floor, main problem was with need of drive outside the house to park the car, eventually the drive was given; Amanda: child age 14, 3 years ago moved to a new property so that adaptation could be carried out, work hasn't started yet, process very difficult; Paolo: parent carers council co-ordinator; Steve: child age 6, can't do adaptation, trapped with communal garden, but maybe there could be temporal measures to make the situation more liveable; Lisa: child age 8, she hasn't been through the adaptation process but has knowledge on homeless and people living on private rented accommodation who would like to move into council property.

Everyone in the group had 45mins to look into the specific issue they faced, details, any ideas that could help and any questions or worries on how to get there. Please see tables below.

Specific difficulty	Details	Ideas	Questions & worries
1st parent: Mobility, Mia doesn't walk (yet)	Increasingly difficulty to pick her up and carry her	What happened: a) stair lift; b) building work to widen doors for wheelchair access; c) outside wheelchair lift Two years later: a) stair lift; b) building work to widen doors ...	a) Stair lift - 1st one wasted public money! It took 6 months of measuring! Fighting for the stair lift, fighting to keep her bedroom. b) Builders - some very great, some were shysters c) We wanted a ramp - had to have a lift! When it breaks down we can't get out of the house ...
1st parent: Personal care - washing, double incontinence	Carer care for washing and changing	a) Ripped out bathroom. Put in new bath up and down. b) Fitted a bed that goes up and down with cot sides	a) Bath didn't work properly for two years, repair men came every month, they recognised my voice on the phone ... Eventually found out that the workmen had installed it wrong ... Shower, we had to pay for it, they ripped out our brand new bathroom and put in a shower without ever consulting us about it, then we had to pay for it ...

<p>2nd parent: In 2012 OT and Social Worker did home visit with 'plans', told us home no longer appropriate. We need to move or convert 3/4 of living room.</p> <p>In 2013 we moved to new house, need adaptation, specifically picked as downstairs room next to garage.</p> <p>In 2015 - three years on ... Still waiting, daughter three years with no bathroom. Seizures worsened, now overnight care needed, no room for carer space, won't consider</p>	<p>Daughter no longer able to go upstairs safely. We worried about seizures; mobility was affected also at risk of seizures on the stairs.</p> <p>Moved, doubled mortgage! Daughter now in downstairs room but no bathroom.</p> <p>Due to start April 2015 Had to forget the carer's space.</p>	<p>Need downstairs room looked at stairs gate, not safe.</p> <p>Naively thought now we had got the house the process would be smooth.</p> <p>How will things improve? What is nationally led what local?</p>	<p>We were very concerned, big family of 6, would lose living space. Needed to find finance quickly to move. How to afford it? Very difficult situation/pressure! Meanwhile daughter can't bathe at home. Carrying her up to bed. Moved to safe space downstairs</p> <p>No clear communication, no 'leaflets' even, timeline not explained, told by surveyor "parents found the extra money", no money as all in the mortgage. Daughter still can't bath at home, very stressed!</p> <p>This process needs to be easier, who would have thought adaptation would be one of the most stressful things in my life?</p>
<p>3rd parent: Personal care: 6ft 4 in small wet-room</p> <p>Supervision: playing with shower, microwave, washing machine, etc.</p> <p>Me: stairs</p> <p>Steps to garden: both of us</p>	<p>Bouncing about, low ceiling</p> <p>Going in kitchen, me not able to get there to see what he's up to</p> <p>I struggle on stairs</p> <p>Steps to garden both difficult</p>	<p>Changes to wet-room</p> <p>Making ground floor open plan</p> <p>Bannister</p> <p>Bannister</p>	

<p>4th parent: Continence issue. Mobility and behavior and safety</p>	<p>Toilet not on the same floor as kitchen and living room</p>	<p>Commode or build a toilet in the garden. Re-model floor of house.</p>	<p>How would we start this process? Is there an eligibility criteria? How long does the process take?</p>
<p>5th parent: Lack of space. Constant noise. Smoking</p> <p>6th parent: My child is really unsafe on the stairs.</p> <p>7th parent: Unsafe garden, neighbor risks also won't often leave the house to go to public places.</p> <p>Noise.</p>	<p>Cannot use communal garden so kids are like contained prisoners!</p> <p>He has mobility and stamina issues. He will try to tip himself off the top step or try to fling over the bannister.</p> <p>No fencing.</p> <p>No carpet, tenancy requirement</p>	<p>Need to move out!</p> <p>Build fence and gate</p> <p>Fit carpet</p>	<p>Could I get the bannister stabilised and the gap above it fill it in? Is there a tall stair gate available on loan until the house is adapted?</p> <p>Funding and access's right issues</p> <p>Funding? Who's responsible?</p>

2nd Part: Parent Carers are joined by Professionals ...

For the second part of PaCConnect on Home Adaptation we were joined by Sarah Routledge, Senior Occupational Therapist at Seaside View, Alex Dickie, Housing Adaptations Technical Team Leader at Brighton & Hove City Council and Jenny Brickell, Head of Integrated Child Development and Disability Services at Seaside View Child Development Centre who participated as an observer.

- Sarah Routledge, Senior Occupational Therapist at Sea Side View, Social Care OT, employed by Local Authority. Sarah works in a small team of five OTs, everyone part time hours. Carry out legal responsibilities of the Council, assessment of child's abilities in the home environment, how the child manages everyday activities, enable the child to fulfil his/her potential. The team looks at the home environment and focuses on good solutions that meet the needs of the child. The team is also involved in environmental safety issues.

Parent should contact Seaside View and ask for an assessment to be carried out. There is a referral form to fill in, the form can be done over the phone, emailed to the parent, or another professional involved can complete it with you. The team will assess the child in different settings, not just the home, e.g. school to gain a fuller picture of the child's needs. Adaptations can include rearranging a room to improve wheelchair access, ramping access or hand rail next to the toilet and so on, but also bigger and major adaptations. The team will assist parent/carers in applying for a Disabled facilities Grant; to get surveyors and architects involved who will draw up specifications and the plans for adaptations. It is a lengthy process; recommendations will be signed and agreed by the parent/carers. The OT's role is to confirm that the proposed works are 'necessary and appropriate' under Housing legislation.
- Alex Dickie, Housing Adaptations Technical Team Leader at Brighton & Hove City Council. Alex works in a team which include four home improvements officers and grant officers. The team receives recommendations from OT. For private rented accommodations there is a disability grant; there is a different system for council properties. On average the team assesses 500 major adaptations per year of which between 5/10% are for children and rest for adults. DFG, or Disability Facility Grant, is £30,000 max. There is a grant application, a hefty form, which will include quotes and evidence of work to be done. Brighton & Hove City Council works with a partner agency Mear Home Improvement Agency to support parents or people can find their own help/agency; agency's fees can be included, up to 15% of the total grant. The team assesses that the proposed adaptations and costs are reasonable and practical. The grant is not means test for children, whilst it is for adults. Home adaptations applicant in case of child needs to be an adult.
- Questions from parent carers:**

Assessment:

Q: I've been told that it is only the needs of my disabled child that are taken into account, so all our family living space is being taken by him for bedroom/bathroom but he and his sisters will struggle to be together as a result. Another parent commented that there is not information passed on, no leaflets, the whole process, including grants and panel (*see below*) is not clear

A: OT advocates for the whole family, OT looks at impact on parents and siblings. There are cases when unfortunately space is taken away. Some space will be sacrificed as for example the dining room.

A: Health OT employed by NHS has a different remit than Social Worker OT employed by the Council / adaptation

Q: What's the procedure when child grows up and needs changes?

A: Yes we do a new assessment of need & a new grant may be applied for to adapt for new need. When we consider a grant we take into account the child's needs for upto the next 5 years. In those situations parents need to do a referral back to services for fresh assessment.

Short term loan equipment:

Q: Is there any short term loan equipment available, e.g. commodes, shower chairs, stair-gates?

A: Yes, it is possible; anything that is assessed for may be borrowed for short time via the community equipment store. Assessment & provision for that can be a quick process.

Bathroom adaptations may be considered & be put in even if we know the family will eventually move on.

Timescale:

Q: We had an email from a parent carer who couldn't make it today; apparently she has been waiting for 2 years. Is there a minimum standard time-line for waiting time, e.g. home assessment within X amount of weeks?

A: OT has a referral priority system where we assess case by case and we define **Urgent** -as for example family breakdown/parent can't lift the child/terminal care/ Homemove property viewing support. **High**- e.g. planned surgery, significant challenging behavior involving risk to child/family. **Pending Allocation** (chronological order of date of referral) as for example 'my child is 3 not sure if my house is suitable'. We assess urgent/high cases quite quickly; there is a short waiting list at the moment. From recommendation to work to be done can be a length of time. At the moment there is no legal requirement for length of time on waiting list, if urgent it is dealt within days. For council properties people need to look into Homemove bidding.

Perhaps that particular case has other issues? **Pippa to follow up.**

Panel:

Q: 'Hidden' panel, can we have more information about the panel? Can parents attend it?

Q: Can we write a personal statement to be considered at the panel?

A: Panel's role is to provide scrutiny for jobs that cost over £10,000 and to decide the approval of the grant. The panel will look into practicability and feasibility of adaptations. The OT's role is to present the Adaptation Recommendations in the form of a Report to the Adaptations panel. The OT represents the family at panel and a copy of the report is given and agreed by parents/carers beforehand. The OT is seeking in principle agreement to proceed with the works.

Grant:

The grant application can be approved or refused in 6 months; the average time is 2/3 months. Council property is quicker. Below here some links to important information:

Disabled Facilities Grant Legislation (Housing Grants, Construction and Regeneration Act 1996):

<http://www.legislation.gov.uk/ukpga/1996/53/contents>

DFG best practice guidance from Adaptations Consortium:

<http://careandrepair-england.org.uk/wp-content/uploads/2014/12/DFG-Good-Practice-Guide-30th-Sept-13.pdf>

DFG overview on gov.uk:

<https://www.gov.uk/disabled-facilities-grants/overview>

Council Property:

Q: It would be good to have links with Housing people

A: There are links.

Q: Would not be good if the Council manages the issue before the move become the solution?

A: Yes. There are some local authority properties that are already adapted. The OT can complete a Housing Needs Assessment to support the Homemove application. Other professionals can help with Housing Needs Assessments, e.g. Social Worker or GP can help out in situations; assessment needs to be clear.

A: In relation to Homemove, time is a big factor, how long you have been bidding and of course banding - keep bidding.

Q: Could representative from Homemove sit on the panel? Also it would be good to have a mutual exchange scheme for people to move to other properties.

Below here some links to important information:

A: There is representation from Housing Services on the panel.

Information leaflet on adapting your home for council tenants:

http://www.brighton-hove.gov.uk/sites/brighton-hove.gov.uk/files/5043%20Tenant%20Housing%20Adaptations%20A5%20booklet%20-%20web%20jan%2015_0.pdf

Brighton and Hove City Council webpage on

<http://www.brighton-hove.gov.uk/content/health-and-social-care/occupational-therapy-service/adaptations>

Environmental issues:

Q: Can adaptations help with resolving environment issues/barriers?

A: Yes, adaptations can be used for that, reasonable adaptations include those outside the house. In fact central government clarified that access to the garden is included. In relation to noise, there are solutions, for example to fit carpet or ticker carpet; the tenancy management should look into that. DFG doesn't include that also and neither sound proofing. Alternatives could be social care top up, the OT can support with charitable funding social care top up.

Transition:

Q: For a parent carer there are lots of issues, lots of phone calls, lots to do.

A: adult after 18 will get means tested for DFG. The benefits system will start. The disabled person is assessed. The Adult Social Care OT will carry on working with the young adult.

Information & Communication:

Q: Why is there such a lack of information including rules & regulations, parent choices and information in ongoing work? Why is there also lack of information about funding, length of waiting time, assessment, eligibility criteria?

A: There is information available, we have leaflets and website has information. We have also an info pack on commercially available safety equipment which has been put together. We have in draft a new pack on environmental safety advice /equipment. We will be asking **PaCC to proofread the info pack**. We could also **put together a flow chart** for this to be done and what to expect. LO to include some information. Also provide information about initial assessment.

A: From a professional point of view sometimes the process is frustrating as there is nothing to communicate.

A: Communication is improving / will improve with integrated services. In relation to Seaside View we make sure that when people leave messages they are followed up.

A: Education Health and Care Plan (EHCP) will flag up issues. People involved in the process need to be included. In that way issues can be picked up. Parents can directly contact Seaside View if they really struggle to get in touch.

A parent commented that Seaside View receptionists are actually very good.

Q: Is Home Adaptation included in the Local Offer? We think it should be!

A: Not sure and that's a good point - we will have a look at that.

Below here some links to important information:

Advice on VAT on adaptations and equipment:

<https://www.gov.uk/vat-builders/disabled-people>

Information leaflet on adapting your home for private sector tenants (owner occupier, private rented or housing association)

http://www.brighton-hove.gov.uk/sites/brighton-hove.gov.uk/files/4640_Housing%20adaptations_mar15.pdf

Adaptation Team email:

adaptations@brighton-hove.gov.uk