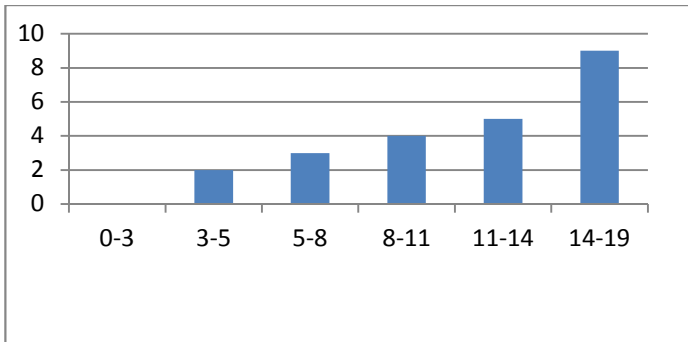


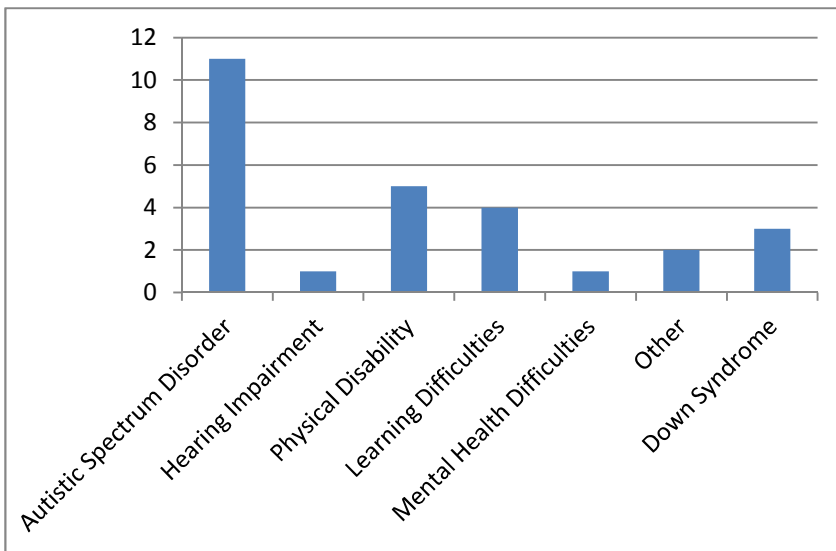
Appendix A – Demographic breakdown of workshop participants

Numbers on the y axis give actual numbers of participants.

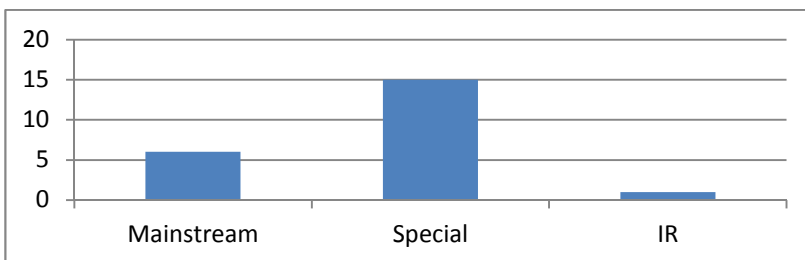
Age of disabled child:



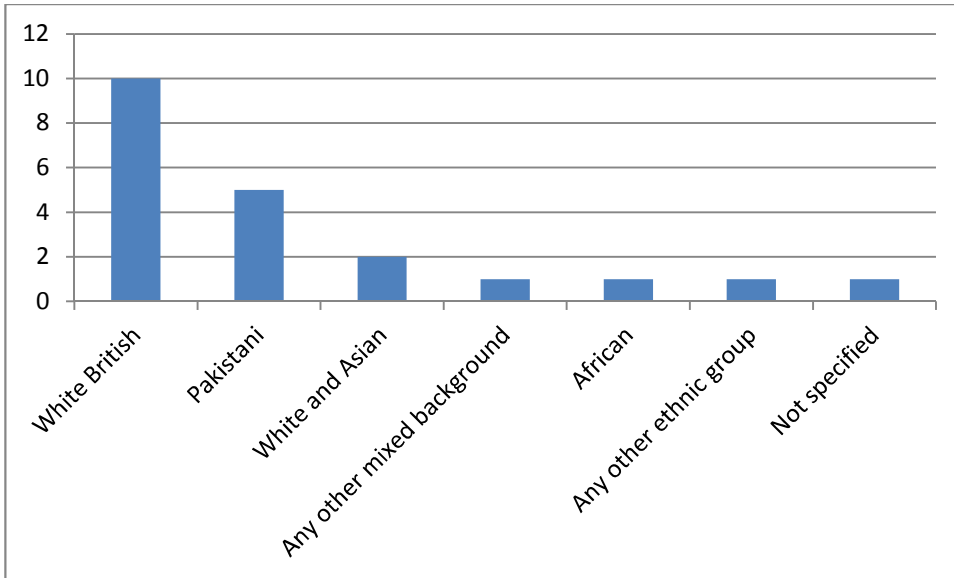
Child's main impairment:



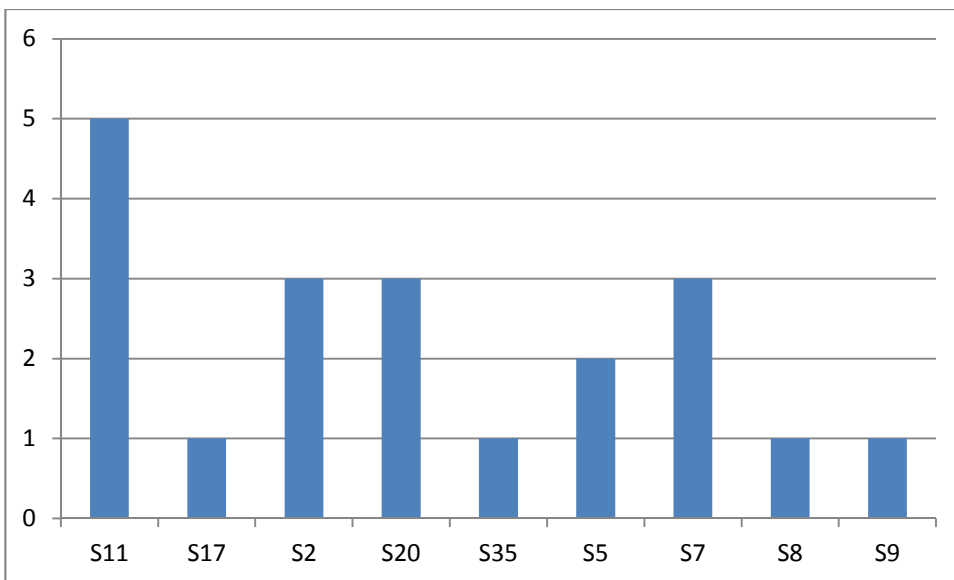
Type of school attended by disabled child:



Ethnicity of parent:



First part of postcode:



Appendix B - Workshop activity sheets

Workshop activity: Gaps in service

Cast your mind back to an instance when you were looking for **advice or support** in relation to caring for your disabled child, but were unable to find it (this could be from a service or an individual, but should be more than just getting information).

1. What did you need help with?
2. Why did you need this help (why were you unable to resolve this issue on your own)?
3. Where did you look for help?
4. How did you find out about services/people who might be able to help?
5. Why were they unable to help you?
6. How did NOT being able to get support impact on your family?

Case study

Emma is a single mother with two children: Lucy, aged 10, and Alex, aged 15.

Alex has autism, epilepsy and learning difficulties. He is non-verbal and attends a special school. He finds it difficult to cope with changes in routine, and may react by sitting or lying on the ground and, increasingly, by lashing out. Because of his behavioural issues, getting out and about is fraught with difficulties, especially as Emma doesn't drive. Alex gets middle rate DLA and Emma recently tried to get the higher rate, but this was turned down. Alex spends most of his free time at home on his PlayStation.

Lucy attends the local mainstream school in Y6. She hasn't got any diagnosed special needs, but has recently been displaying high levels of anxiety and obsessive behaviours related to a fear of germs, such as compulsive hand-washing. Lucy has refused to attend school on several occasions, forcing Emma to take time off work. Her teacher is not concerned as her grades are average; he says that many children get "exam nerves" when SATs are approaching.

Emma works part-time for 3 days per week. On the days that Emma works, Emma's elderly mother, who lives nearby, picks Lucy up from school and looks after Alex when he gets back on the minibus. She also looks after the children during the school holidays, but finds it increasingly hard to cope with Alex's challenging behaviour.

Emma's mother has just had a bad fall and fractured her hip. She will need a lot of help when she gets out of hospital. Since Emma's father has a heart condition and none of Emma's siblings live locally, most of the care will have to be done by Emma.

Emma would normally turn to her mother for practical and emotional support, but now that her mother is in hospital she feels she can't burden her with her problems. Emma suffers from chronic migraines, which are exacerbated by the stress she is experiencing.

Workshop activity: What should a good support service look like?

Design a service that would help the family in the case study. Think about:

1. Who should help this family?
2. What sort of knowledge/skills/networks would they need?
3. How should they provide this help?
4. How could the family find out about the service?
5. How would the service know whether their intervention had been successful ?
6. What are the indicators of a high-quality service?