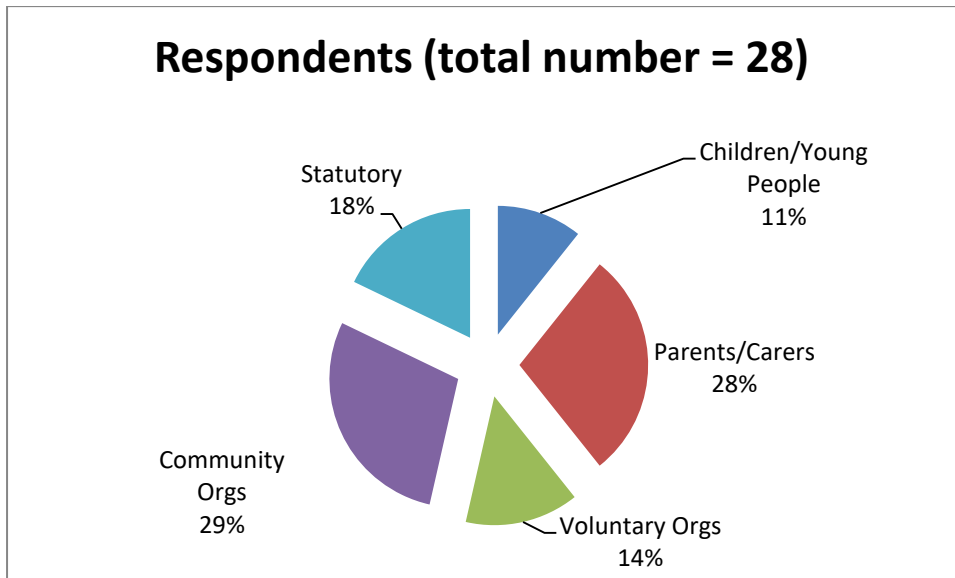


Feedback from Our Journey through Disability consultation



Recommendation	Number of respondents highlighting this as a high priority in Belfast
Top 5 highlighted in green	
1: Professionals must realise parents are experts and take responsibility to listen to them closely. This demonstrates their commitment to value parents' knowledge.	18
2: Parents support a person-led approach where services place an individual and their family in the centre, assess need and build services around the family accordingly.	22
3: The Group recommends a legislative change regarding the process for transitioning to adult services. This should be on the basis of development rather than chronological age. Transition planning between children and adult services should commence at least 5 years before it occurs. The role of a key worker is of vital importance and families need more support initially at the start of their journey.	19
4: Health and education services need a more joined-up approach in terms of statementing, therapies and transitioning. This includes	25

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effective communication across Allied Health Professionals recognition from services of the medical, social and educational models.	
5: Family require a single point of contact from an early stage of diagnosis of disability for their child. This role should co-ordinate the process of services for families to inform and signpost to services and local support.	19
6: Information should be available for families through an A-Z of services online and packs which provide support services from families on a local level. Packs should also include information on a child's diagnosis.	13
7: Families require good communication. Whether formal diagnosis of disability or undiagnosed additional need, parents would like information on what they should expect from services and a timeline where appropriate.	19
8: Better communication across services is required to share information, saving families from giving the same information on a regular basis, and to avoid appointments occurring on the same day at different locations. This should serve as a Passport which is recognised among relevant services.	17
9: Support from key agencies is required to bring parents, families and services together through events such as Our Journey to provide the opportunity to share knowledge, experiences and support with others who have begun their journey. Services should endeavour to create opportunities to embed this into their practice and support this process.	11
10: Opportunities are needed to build capacity with parents through training opportunities and	13

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sessions to help complete forms which require specialist information such as PIP and DLA.	
11: It is important for ALL children of all abilities to have access to a social group: inclusion with youth groups and similar organisations/activities to build and maintain friendships and promote socialisation. These may be specific to disability/additional needs or universal and should cut across all sectors. Specialist equipment and support should be provided to ensure this.	18
12: Out of Hours services and support including Short Breaks need to be increased: These provide vital support to families who require support outside of office hours.	16
13: All relevant professionals should be eligible to attend CDC Clinics, and parents should also have appropriate and effective representation at MDT meetings.	13
14: Parents and siblings need time for self-care. This is vital and should be supported in order to care for their child/siblings and themselves. Services should provide opportunities and resources for self-care through information and signposting.	18
15: Parents who had their journey recorded which were used on the day have consented to having them used constructively to benefit families and improve their experiences with services. The event Planning Group has recommended that the videos are used to help with induction of new staff and for students in disciplines such as Social Work and Nursing.	12
16: There is a need to train staff on daily issues facing parents on navigating services, and to encourage better communication with other services.	11

Recommendation Top 5 highlighted in green	Number of respondents highlighting this as a high priority in Belfast
17: Parents recommend a better understanding of the issues surrounding disability and additional needs; initiatives such as the JAM care should be supported and rolled out, as well as awareness raising on conditions across services and communities.	15
18: Members of the Planning Group have expressed an interest in participating in training programmes for staff in relevant services in order to relay their experiences in other to support the building skills and knowledge of staff	14
19: Members of the Planning Group have agreed that Co-Production as a process and ethos works well when done correctly, and that services need to further embed Co-Production with families on a strategic and individual level.	17