Shaping Our Future Together

Sonja Jacobs
Lead Speech and Language Therapist for Complex Needs
@SltSonja  @NHSBartsHealth
Parents and carers of children with disabilities are twice as likely than other parents to provide care for more than 100 hours per week (‘Caring More than Most’, Contact, 2019).

This group of parents and carers are more likely to have a low income, feel they have a poor quality of life with restricted social and life choices and have problems with their own health (‘Caring More than Most’, Contact, 2019).

Tower Hamlets had the fastest growing population of any Local Authority in the country between 2001 and 2011 with a 29% increase in the number of households during this time (Census data, 2011).

The census found that approximately 1 in every 25 CYP under the age of 20 years has a disability. The population of CYP in Tower Hamlets in 2017 was estimated to be around 75,500. It is therefore estimated that there are more than 3,000 CYP with a disability living in Tower Hamlets (Borough Profile 2018).
Experience-based co-design

- Questionnaires
- Mapping
- Interviews
- Workshops
- Joint event
Experience-based co-design

Questionnaires
- Parents / carers: 42
- Staff: 18

Mapping
Interviews
Workshops
Joint event

Health Professionals
Parents / carers
Acute Paediatric Therapies and Integrated Community Children’s Service

Parent & Carer survey

My child is:
- [ ] 0-4 years
- [ ] 5-11 years
- [ ] 12-19 years

My child attends:
- [ ] Not in nursery / school yet
- [ ] Special School
- [ ] Mainstream Nursery / School
- [ ] Other (please specify): ___

Please tick the services involved with your child’s care: (MEH = Mile End Hospital / Community, RLH = Royal London Hospital / Acute)

- [ ] Routine-Based Early Intervention Team (PSP) - MEH
- [ ] Community Paediatricians (Child Development Team / Neurodevelopmental Clinics) - MEH
- [ ] Community Children’s Nursing Team - MEH
- [ ] Community Dietitians - MEH
- [ ] Community Paediatric Dietitians/IDP - MEH
- [ ] Community Physiotherapists (Paediatric Respiratory Service) - RLH
- [ ] Speech and Language Therapy (for communication) - MEH
- [ ] Speech and Language Therapy (for feeding, eating and drinking) - MEH
- [ ] Occupational Therapy - MEH
- [ ] Occupational Therapy - RLH
- [ ] Play Team - RLH
- [ ] Other

Please circle your answer for each question:

1. People working with my child help me to feel like a good parent / carer.
   - [ ] Always
   - [ ] Mostly
   - [ ] Sometimes
   - [ ] Never

2. People working with my child care about my child and my family’s wellbeing.
   - [ ] Always
   - [ ] Mostly
   - [ ] Sometimes
   - [ ] Never

3. People working with my child give me enough time to talk so I do not feel rushed.
   - [ ] Always
   - [ ] Mostly
   - [ ] Sometimes
   - [ ] Never

4. People working with my child listen to me when I talk.
   - [ ] Always
   - [ ] Mostly
   - [ ] Sometimes
   - [ ] Never

5. People working with my child ask me about my priorities and ambitions for my child.
   - [ ] Always
   - [ ] Mostly
   - [ ] Sometimes
   - [ ] Never

6. I feel like part of the team around my child.
   - [ ] Always
   - [ ] Mostly
   - [ ] Sometimes
   - [ ] Never

7. I find my appointments useful.
   - [ ] Always
   - [ ] Mostly
   - [ ] Sometimes
   - [ ] Never

8. It is easy to contact services involved in my child’s care.
   - [ ] Always
   - [ ] Mostly
   - [ ] Sometimes
   - [ ] Never

9. Services share information about my child with each other so I do not have to keep repeating myself.
   - [ ] Always
   - [ ] Mostly
   - [ ] Sometimes
   - [ ] Never

10. Services provide us with enough information about our child’s difficulties.
    - [ ] Always
    - [ ] Mostly
    - [ ] Sometimes
    - [ ] Never

Any other comments:

If you can change one thing about these services, what would you change?

What is the main difficulty you have when accessing these services?

Thank you for your time ☺️
Experience-based co-design

- Questionnaires
- Mapping
  - 4 Patient Journeys
- Interviews
- Workshops
- Joint event

Parents / carers

Health Professionals
Experience-based co-design

- Questionnaires
- Mapping
- Interviews
- Workshops

Parents / carers = 7
Staff = 6

Joint event
Experience-based co-design

- Questionnaires
- Mapping
- Interviews

Workshops
- Parent/carers = 6
- Staff = 13

Joint event
Experience-based co-design

- Joint event
- Health Professionals
- Workshops
- Interviews
- Mapping
- Questionnaires

Parents & carers
shaping Our Future Together
Outcomes identified at final workshop

By 2020 we would like to...

1. Have an established parent steering / volunteering group.
2. Have an updated Barts Children’s Hospital website with relevant information including clear information and a directory of services such as medical, therapeutic, emotional and social support available as well as contact and referral details.
3. Have a clear standard operating procedure around contact with services i.e. ‘duty’ person, response times, contacting methods i.e. emails, team mobile phones
4. Have an improved appointment system where:
   - It is clear what the reason for appointment is (i.e. what is purpose of ‘routine’ appointment) and that there is clear reason for taking child out of school / education to attend the appointment.
   - There is a way of keeping in touch between appointments (i.e. skype, email, phone, “hot clinics”), especially to answer the questions that come up after appointments.
   - Clinic letters across services have a standard template for the plan, including:
     - When next appointment will be
     - Why / what for
     - Does child have to be present
     - Can it be done virtually / how else can aim of appointment be achieved
5. Implement a ‘what matters to me’ passport that is owned by parents / carers and used across all of children’s services to share information.
6. Have a dedicated lead professional for every family.
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@SltsSonja  @NHSBartsHealth