

CHES – Family Faculty Working Group (1) 19 June 2024

Organisers: Jen McAnuff, Richard Sutton, Bel McDonald, Fleur Boyle

Attendees: Julia, Lisa, Catarina, Heather, Rebeka, Anna

1) Bel started off the meeting by sharing the ground rules and the link to [PenCRU's policy on involvement payments and expenses](#).

2) Then Richard led us into the introductions where we all said a bit about ourselves.

3) We did a warm-up activity creating a word cloud about two questions:

- What words come to mind describing the early years for you and your child?
- How about therapy services in the early years?

You can see the word cloud below.

People made comments and suggestions:

- I remember age 0-5 years like it was yesterday.
- I wish I hadn't rushed away the early years.
- If your child's diagnosis is easily recognised, it's easier. I was inundated with support. Otherwise, services are not as accessible. Fighting for diagnosis and services is a different experience.
- Hidden disabilities were ignored – e.g. the emotional, social, and cognitive side, whereas physical needs more obvious and therefore were better met. It's difficult to explain the difference between physical, developmental, cognitive age.
- Worry about expecting too much from services, aiming too high. Having to fight for services – but there's nothing there. A negative experience of a special school with no communication system in place. There is little coordination. It's like people are commissioned to write endless reports, rather than any useful provision. Constant meetings, paperwork, and appointments. Felt invaded at times. It was like we couldn't enjoy our child.
- Negative aspirations from professionals from the start, it's perhaps a bit better now. "Wait and see", "he will learn in his own time", "maybe that's just how s/he is" – but this wastes time.
- Some positive experiences of services. A good commissioner recently. A better school. Basic communication rights in place. A positive experience of the PACT trial. Swimming lessons.
- Services have retreated over the last ten years, it's harder for parents now. Things weren't great back then but they are worse now.
- The focus of this activity invited more negative comments. There are positive experiences too but it's easier to reflect on the challenges than what's good. Two different word clouds would have been better.

4) We gave some background to the CHESSE study and summarised some of the PPI feedback we have had so far.

People made comments and suggestions:

- The term 'self-care' doesn't encapsulate feelings of confidence, self-sufficiency, empowerment, agency, autonomy, and independence.
- Self-care is about 'learning life habits' and 'supporting development in everyday activities'.
- What is 'self' if a child struggles with awareness of their own body? Parent self-care is important too.
- What is 'care'? It may be a loaded term. What is care to one might not be care to another.
- 'Life skills' and 'independence' – is this relevant if my child has very complex needs? Some parents will think these don't apply to me.
- Little things in self-care aren't necessarily recognised as positives. But baby steps at the child's individual level are essential. Achieving milestones so issues don't become hard to unpick in the future (e.g. crawling and using stairs, if that's possible).
- The new CHESSE intervention should be positive. It should emphasise a mindset for the future, early training in self-care activities, sustainable habits that need to happen over a long time, building up techniques for the future. For example, getting gradually used to having your teeth brushed brings major benefits in the future. CHESSE should also emphasise problem-solving and using different techniques for self-care (e.g. rolling during pad changes). Choosing your battles and priorities is also important.
- There were other good examples including an early assessment of learning to use media, emotional aspects that contribute to constipation, and how to do things like checking your son's testicles.

5) We talked about strategies for recruiting parents and their young children into the CHESSE study. People made comments and suggestions:

- Parents want to know what's the point of the study? Can I trust you? How much time is it going to take me, how much hassle, do I have to drive anywhere? Prioritise the headline information. Be accurate and honest. CHESSE – what does it mean at first glance to the man on the street?
- Endorsement of the study by a parent would build trust.
- Remember that parents are busy and receive a lot of information. They want to see the essential elements quickly and then dive deeper if interested.
- Having to click links is off-putting.
- Language matters – not too formal and official, make everything as plain as possible (even the dense legal information).
- A layered approach is helpful – start with the headline information.
- Questions are engaging e.g. 'Struggling with X? Want to improve Y?'
- Beware of acronyms. And a good layout is important. More user testing needed.
- Don't lead people too much in designing recruitment materials. Enable people to brainstorm, start from scratch, look at examples.

6) Finally, we looked at a draft questionnaire that we will use in CHES to gather economic information:

- People made comments and suggestions about the draft questionnaire – we have recorded these separately on the draft itself.
- People talked about other issues related to economics: no effective childcare for disabled children made it hard to keep working; trying to juggle full-time work and parenting for several years can lead to burnout; trying to cram in part-time work with caring; having to leave a 20-year career; giving up work to help the school look after my child; and needing to buy private services.
- Some people agreed to look at the draft questionnaire in more detail and email it back to Bel.

Actions:

Please send your comments on the draft questionnaire by the end of Monday 16th July.

Jen to share interoception training materials.

Jen to share book details: [“A World Without Words” by David Goode](#).

People can email to Bel any good examples of recruitment materials or flyers.

Thank you for coming to the session. We hope you will join us for the next one.

