

### Attitudes to standing frame use

Here is a summary of our qualitative research findings from 5 focus groups involving physiotherapists, parents, clinicians, and educational professionals.

## Physiotherapists – perceptions of standing frames

7 physiotherapists from around the UK who worked in a variety of services took part in a focus group.

- Standing frames are:
  - generally used to maintain range of movement and prevent hip problems
  - should not interfere with the child's quality of life

"There is an emphasis on walking and standing... I think we sometimes really need to re-focus ... We need to look at each child individually and what they're actually doing and how it functions."

- Standing frames
  - give the child an opportunity for a change of position and can help them participate in different activities

"I think, actually, I'd probably use them for as a change of a position from a seated position where they're still well supported and they can still kind of access lessons or other activities."

• It is important to integrate the standing frame into the child's life in the most convenient way possible. This is difficult as children get older because of size, space, and transport.

"I think most of our kids are going into mainstream won't stand, because where are you going to put the standing frame? They're in different rooms for every lesson. They don't have that lesson every day of the week. So if they're going to stand they tend to stand at home... But then who maintains it?"

 Physiotherapists try to make sure they are considering the child's and family's needs.
 These change as the child grows.

#### Parents – perceptions of standing frames

3 mothers from the North of England and 8 mothers from the South of England took part in 2 separate focus groups.

- Standing frames are mostly used for improving the child's body structure and function. Some parents believed the standing frame was originally prescribed to help their child walk:
- "I think if somebody had sat me down and said 'You know, this brain damage is so severe that your child is probably never going to walk', then I might have been able to concentrate on other therapies rather than putting everything into trying to get him to walk."
- Effort is required to make standing frames as enjoyable as possible for children. Different activities can be enjoyed whilst standing: "He loves his stander, absolutely loves it. He's quite happy in the lounge watching something on TV or he'll come in the kitchen, because he's got a tray on the front. He'll cook for me or whatever else."
- There are many challenges associated with standing frame use including funding, the child's symptom severity, type of standing frame, professional engagement (from physiotherapists, teaching staff, etc), the child's size, moving/handling, and the child's tolerance:

  "It needs two people to get her in and she's never very comfortable, it has to be built up. If you haven't got a very pro-active TA, it's not going to happen."
- Seeing their non-ambulant child standing in a frame can be very emotional:

"I know the first time I ever saw my son in a standing frame, it was like 'Look how tall he is!'... I was just amazed."

#### Clinicians - perceptions of standing frames

2 orthopaedic surgeons, 2 paediatricians, and a mechanical engineer took part in focus group.

• The child's quality of life is more important than standing frame use:

"These kids are having a hard life. It is not the right thing to make them suffer more. So you've really got to think about the benefits of standing frames... bone density is fine, but if you don't have an increased rate of fractures, what does it matter?"

 Standing frames may not be a worthwhile pursuit if the child dislikes it. The benefits and challenges of standing frame use must be weighed up:

"You realise that some children hate it and the parents hate it... You really do start to doubt..."

 There was disagreement over whether standing is necessary, especially if children can participate in activities whilst in their wheelchair. However, one participant strongly believes that standing is important:

"Standing is a physiological need of the body. It's not a luxury. So coming from that perspective, you need to align the body, the hips, the spine that goes along with it... So be it, they stay in the chair but long term they may have be affected in adulthood because of not doing the physiotherapy and the stretching early on."

# Educational professionals – standing frames in the school setting

5 special support assistants and 4 class teachers from a special school in the UK took part in a focus group.

- Standing frames are useful for giving children a stretch, improving bladder and bowel function, and helping with upper body/upper limb strength: "It gives them a lot of relief"
- It is important to position the child in the best and most comfortable way possible for the task at hand:

"If a child is uncomfortable sitting in a chair and their bottom needs a rest, there's no way they're going to concentrate on what you're doing ... if they're in a standing frame and they're uncomfortable, they're not going to learn either."

- Standing frames can be useful for some activities: "In a stander, they feel more involved because they're higher up... Art and craft stuff they perform better."
- But standing frames can make socialising with peers more difficult:

"They've got this ring of exclusion around them because everything is massive."

• Participation in classroom activities and lessons is affected by the students' position:

"As a teacher, where do you stand when you've got one child who is up here and yet all the other ones are really low down and obviously you want that eye contact and that face to face communication with them and that can be quite hard."

 Education staff check with the child using a standing frame to make sure they are comfortable, have a choice, and are positioned appropriately for the activity they are doing. The staff did not have confidence in their ability to use the standing frame because of lack of training.

If you have any questions or are interested in the next stages of the project, please contact: Dr Jill Cadwgan (Chief Investigator)

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