

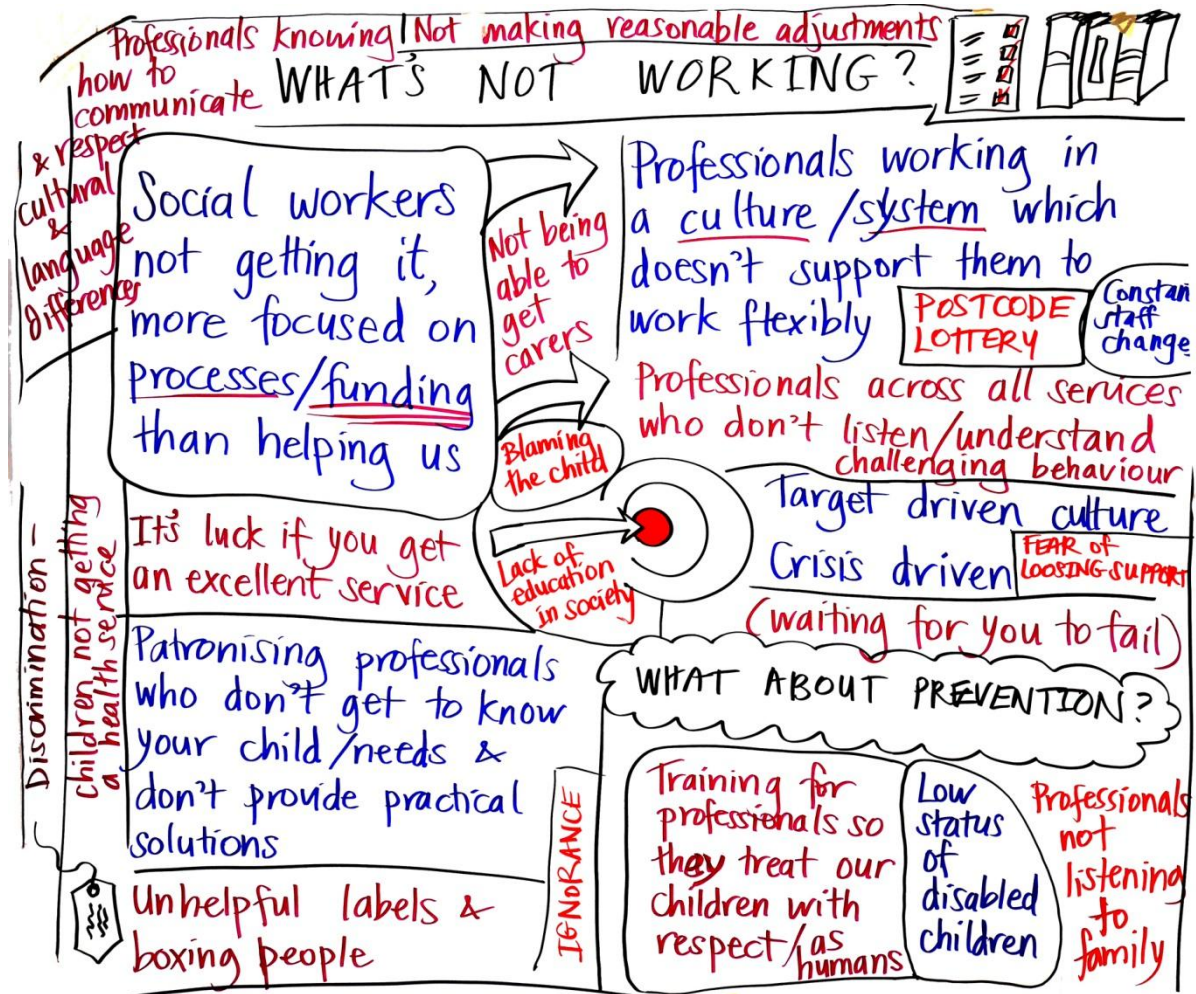
For children with learning disabilities whose behaviour challenges

**Note of a Workshop with Family Carers (0-18)**

29 November 2013

What works/does not work

Family Carers worked in pairs to record their experiences of what works and what doesn't work. The resulting discussion was recorded by Graphic Illustrator, Pen Mendonca.





## **Messages to key decision makers**

Family carers were asked to think about these throughout the workshop and add any key messages they wanted to communicate to key decision makers.

### **Messages to the Government:**

- Show that you value disabled children, including those with learning disabilities and behaviours that challenge
- The system needs to be more flexible – think about people, not processes
- Develop a joined up national strategy for children with learning disabilities whose behaviours challenge. This would require joint work by the Minister for Children, the Minister for Health and Care and the Minister for Disabled People, all of whom have responsibilities for this group.
- Review whether the Mental Capacity Act is working for children with learning disabilities whose behaviours challenge.

### **Messages to the Joint Improvement Board:**

- Challenging Behaviour is a form of communication
- The system needs to be more flexible – think about people, not processes
- Please prioritise the development of a joined up strategy for children with learning disabilities whose behaviours challenge, with clear pathways.
- Invest in training for professionals
- Develop and commission early intervention support and avoid crisis situations
- Have a named Challenging Behaviour Co-ordinator in each local area. Make this person responsible and accountable for ensuring families in that area receive the support and services they need.

### **Messages to the NHS:**

- Challenging behaviour is a form of communication. It does not need to be pathologised as a mental health issue to be addressed.
- Children with learning disabilities have the right to the same standard of care and treatment as other children, you may just have to work harder to ensure they get it.
- Ensure effective communication with children with learning disabilities – check how the individual communicates and seek help with communication if necessary – do not avoid communicating with them because you don't know how to.
- Ensure effective communication with families and treat them as partners. They are the experts on their family member and working with them and asking their advice will help you find solutions to treatment difficulties.
- GPs, hospitals and dentists should have a “red flag” on the system for children with learning disabilities whose behaviour is described as challenging. The red flag means they should be seen immediately on arrival, to avoid long waits, distress and disruption in waiting areas.
- GPs, hospitals, dentists and other settings must make reasonable adjustments. These are not just about access but about understanding and responding to the needs of the individual.

- Health passports can set out key information for health professionals (including reasonable adjustments required), so it does not have to be told repeatedly by family members. These should become usual practice.
- Liaison nurses in hospitals to help co-ordinate care and support families.

### **Messages for Local Authorities:**

- Challenging Behaviour is a form of communication
- The system needs to be more flexible – think about people, not processes
- Please prioritise the development of a joined up strategy for children with learning disabilities whose behaviours challenge, with clear pathways.
- Invest in training for professionals, especially Social Workers who need training in challenging behaviour and the skills to support families.
- Ensure effective communication with families and treat them as partners. They are the experts on their family member and working with them and asking their advice will help you find solutions.
- Develop and commission early intervention support and avoid crisis situations
- Have a named Challenging Behaviour Co-ordinator in each local area. Make this person responsible and accountable for ensuring families in that area receive the support and services they need, including:
  - Positive Behavioural Support
  - Sleep services
  - Communication support
  - Psychology

### **Messages for all professionals working with children with learning disabilities and their families:**

- Early identification of developmental delay should be routine
- Inform parents take forward/prevention activity where there is a high risk of a child going on to exhibit behaviours that challenge
- Early identification of behaviours that challenge should be routine
- Deliver the right information to families at the right time, in the right way
- Establish one key point of contact or key-worker to work across all disciplines and empower families to access all the support they need (including behaviour support, sensory assessments, SALT and support with eating and sleeping)
- Professionals must join up and co-ordinate services
- Professionals should work in partnership with families to develop clear pathways and plan for the future