With hemiplegia........
Behind what is a relatively mild physical impairment there may be a whole raft of invisible problems:

- **Medical:** visual impairment, epilepsy
- **Learning:** literacy, numeracy, visual spatial, distractibility, memory
- **Psychological:** behavioural, emotional, OCD, Aspergers
- **Plus:** most children with hemiplegia in mainstream education, constantly comparing themselves to and being compared with their typically developing peers. They may be bullied, teased or left out of friendship groups. They often develop low self esteem.
As a result

- families have to fight for recognition of, and support for, **all aspects** of their child’s hemiplegia

- in 1991 a group of parents founded HemiHelp, to provide information and support to families living with hemiplegia

- in 2011 the Hemiplegia Handbook was published, to bring together information for both professionals and families about the condition and living with it
HemiHelp treatment survey

• 237 parents responded

• Most are happy with treatment received but

• My concerns of 20 years ago are still relevant today
Parents’ main concerns

**Continuity** of treatment

**Communication** with parents

**Coordination** between clinicians
Continuity of treatment

• “It [physio] seems to be very hit and miss across the country. Weekly in Warwickshire was laughed at in West Midlands!”

• “Physios constantly changing, are always rushed, don't explain why, or the long term plan.”

• “Physio is once a month for half an hour. She is good but she tells me we should do the exercises every day. We couldn't be a normal family if we followed this advice.”
Communication with parents

• “I have found that questions are not answered, they are 'managed', i.e. not really wanting to give information out in case you ask for more treatment!”

• “Help or advice isn't often freely offered. It's a case of if you don't ask you don't get the input for your child.”

• “Health professionals often withhold info thinking that it would upset parents too much - this might be true, but I'd rather be upset and have all the facts, than blindly oblivious”
Coordination between clinicians

• “I feel nobody looks at my child as a whole person”

• “I feel that I am 'piggy in the middle' trying to tie the different elements together”
The consequences

• In many cases parents do manage to find their way around the system, but not all parents have the confidence to take on the professionals.

• When children are having treatments, such as orthotics and Botox, where more than one department is involved, lack of coordination can compromise the effectiveness of the treatment.
The consequences: Orthotics

• “The most recent orthosis was sent back twice for alterations and this took weeks, during which my daughter’s gait deteriorated considerably.”

• “Last year we had a 7 month wait for a new arm splint and this year a 2/3 month wait.”

• “With a splint he is a happy little boy who can kick a ball around and play with his friends. Without a splint he is a disabled child.”
The consequences: Botox

• “Main hospital is city. Local team are shire. Different systems and budgets.”

• “Botox was fine but link between community and local CDU was not good so intensive follow up was hard to sort out.”
Funding of treatment

- “Ben needed new splints and inserts and had to wait 8 months before funds were made available.”

- “When different specialists discuss things it just seems to be a matter of who is going to pay for treatment, not what is in the child’s best interests.”
Most effective?

- “Physiotherapy combined with OT in single sessions and the splints.”

- “Intensive therapy periods of interaction with OT, PT and school.”

- “Botox, with serial plastering and intense physio.”
NICE Childhood Spasticity Guideline

• Children and young people with spasticity should have access to a network of care that uses agreed care pathways supported by effective communication and integrated team working.

• Help children and young people and their parents or carers to be partners in developing and implementing the management programme.

• Offer contact details of patient organisations that can provide support, befriending, counselling, information and advocacy.
Implementation 1

• The aim of the network of care is to ensure that the experience of all children and young people reflects current good practice with regard to **continuity of care** through multidisciplinary and multi-agency working and timely access to treatment.

• The key mechanisms for achieving these aims are the use of **agreed care pathways**, **effective communication** and **integrated team working** in the network.

• To ensure **timely referral and increased access** to the network, specific members of the network team (for example a lead consultant with administration support) could be responsible for processing referrals from all sources.
Implementation 2

• **Assigning a lead professional** to each child or young person in accordance with local protocols and by consulting with parents or carers. The lead professional may be responsible for coordinating future planning and reviews.

• **Considering the family’s need of a key worker** to support them and refer on to other support services (for example Sure Start or social services). Some parents or carers may wish to be the family’s own key worker.

• **Considering the information needs** of each child or young person and their family. For example early support booklets, local directories or sibling support, please go to Directgov’s [Early Support materials and resources](#).
HemiHelp’s services:

- a telephone/email support service staffed by parent volunteers
- a home visitor service to help solve more complex problems
- training to help schools support pupils with hemiplegia
- a Facebook group and a Twitter feed (@hemihelp)
- putting members in touch with others who have faced similar difficulties
- developing a network of local groups
- a quarterly magazine
- information sheets on all aspects of living with hemiplegia, free to download from the website
- an online shop selling the Hemiplegia Handbook, Primary Schools Pack and other publications and a range of useful equipment
- sports and activity fun days and music and drama workshops for children
- conferences and workshops for parents and professionals
- HemiHelp is a certified member of the Information Standard
The Hemiplegia Handbook

• A book to dip into again and again to learn about all aspects of hemiplegia

• 4 chapters on the causes and effects of the condition

• 5 chapters on living with it, from diagnosis and benefits and where to find support, through family life and education to growing up and having children of your own.

• quotes from people who are bringing up a child with hemiplegia or have hemiplegia themselves,

• lists of useful resources and websites.