Disability Sheffield
Centre for Independent Living

# Continuing Healthcare

## The experiences of disabled adults in Sheffield

# Why Disability Sheffield?

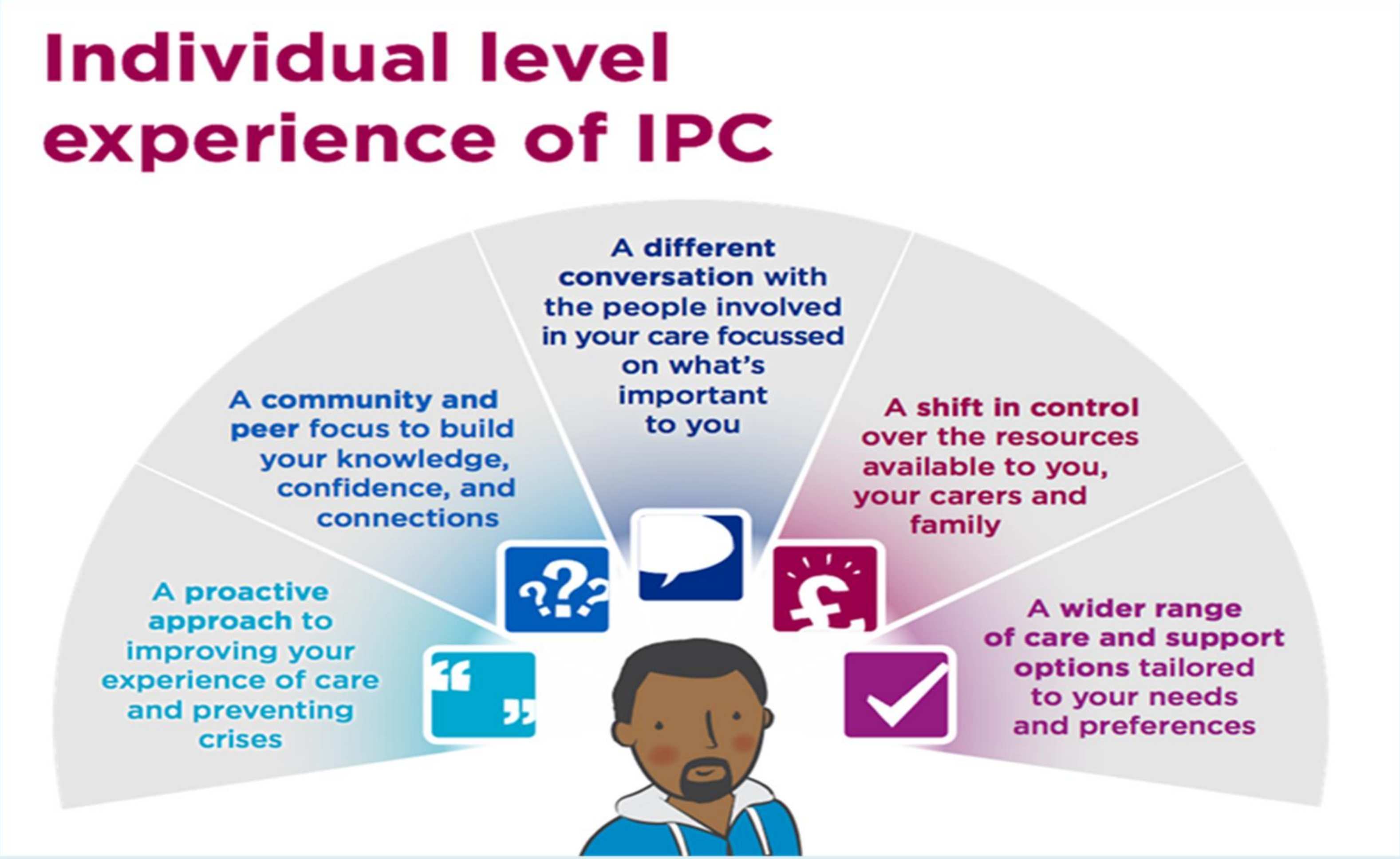
- Disabled People's Organisation – working in Sheffield for 14 years to promote independence and choice for disabled adults in the city
- Advocacy and Information service
- Disability Hub – supporting voice and influence of Disabled people
- Individual Employer & PA development group, PA register

# Personal Health Budgets

- Gearing up for Change – funded by NHS England
- Since October 2014 adults and children in receipt of CHC have been legally entitled to a Personal Health Budget (PHB)
- 416 people in Sheffield had a PHB last year. Moving towards all home packages being done as a PHB


5.

# Integrated Personal Commissioning



## Individual level experience of IPC

A proactive approach to improving your experience of care and preventing crises

A community and peer focus to build your knowledge, confidence, and connections

A different conversation with the people involved in your care focussed on what's important to you

A shift in control over the resources available to you, your carers and family

A wider range of care and support options tailored to your needs and preferences

# IPC in Sheffield

Aim was for it to not only lead to increased numbers of people receiving a PHB but for the overarching principles to lead to more integrated, person centred work across health and social care.

Disability Sheffield CEO sat on IPC Board,

Disability Sheffield supported attempts to set up a co-production strategic group to ensure that work was routed in co-production.

Question for CCG – what initiatives are currently being developed that will make this ambition of person centred care a reality for people?

# Issues we are seeing

- Eligibility – lack of consistency, people who’s needs have increased but lose funding
- Offer of Care – often way below what people previously had with social services, and insufficient to meet all their needs.
- Lack of recognition / understanding of social care needs
- Lack of case management – no contact with CHC staff, or negative contact with them
- Feelings of co-ercion, bullying, strong culture of ‘professional knows best’
- PHBs have become a paper exercise, no real choice or control

“They weren’t taking all her needs into account. They didn’t talk about her social needs at all, it was as though she was just meant to exist, not live a life.”

“They told me as a carer that they couldn’t provide support for my family member to enable me to go to work. ‘we don’t do that’ I was told.”

“I felt as though everything I said, all the information I presented was simply disregarded.”

“I feel crushed by the system that is supposed to be helping me.”

“I felt bullied and intimidated by the staff I came into contact with.  In then end I wouldn’t meet them without the advocate being in the room because it was so bad.”

“Nobody actually talked to me about what I needed. They seemed to make decisions sat at their desk reading notes. It wasn’t about me.”

“I feel trampled on and not listened to.”

“Without the support of the advocate I would have topped myself by now. The process made me ill.”

# What is the experience of others?