

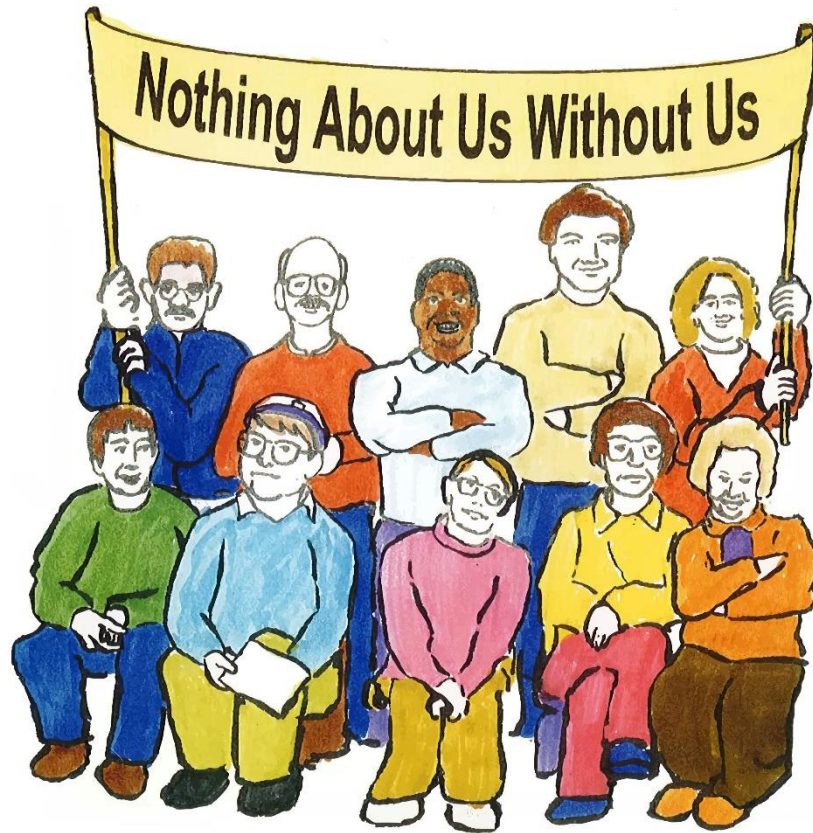


Public Health
England

Protecting and improving the nation's health

Meaningful engagement

Donna Glover
29th November 2018



Our First Advisory Group



- The first Advisory Group was in the East of England and met twice a year
- People who were part of the group were also on national and/or regional groups paid for by Valuing People Now funding
- The plan was to get our public health work talked about in regional and national groups (the learning disability forum groups)
- This didn't happen well as the regional forum stopped meeting

Our Second Advisory Group



- The second Advisory Group was set up when we moved into PHE and meets 3 times a year
- The groups that run it are Changing Our Lives, Inclusion East and Inclusion North
- The groups take it turn to host and run the meeting
- The groups are paid for their input to the meetings
- We have self-advocate members with a wide range of needs and family carers
- The group inform and influence our work
- Representatives attend our annual steering group
- We work in a more proactive way now, at the planning stages
- We invite other organisations along to some meetings

Examples of their input



Helping us plan the work programme in terms of suggestions on the topics for:

- Secondary analysis
- Systematic reviews
- Reasonable adjustment guides

Most recently we asked for their advice about how we could work to increase uptake of the flu vaccination for people with learning disabilities

We ask their opinion on our easy-read (more accessible) written information

We work with individual members or their groups on specific events

They have provided advice for how other parts of PHE can engage with people with learning disabilities



Postural Care work

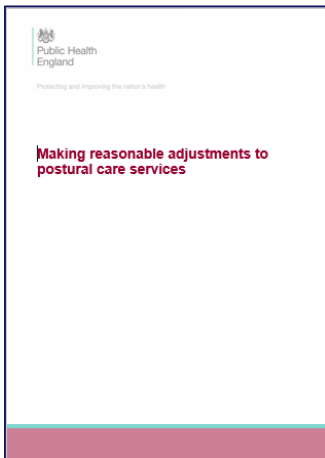


Our work around postural care was been driven by the Advisory Group

It is a specific topic but one which the group felt was important

As part of this work we have:

- Undertaken a systematic literature review
- Presented at a postural care conference
- Written a reasonable adjustment guide
- Contributed to the development of a new postural care strategy
- Guest edited a special health edition of PMLD link which included several articles on postural care



Social Care Resources



We did a survey with users of our website and this showed that we are not reaching social care professionals as well as health care professionals.

We discussed this with the Advisory Group.

They said:

- This was a problem that we needed to address, as health is everyone's business
- We needed to create some resources aimed at social care frontline staff
- Shorter fact sheets better than a long report
- Supporting set of slides for each fact sheet
- Available [here](#)



Reflections



What has worked well:

- Increasing the number of meetings a year
- Wider representation from across the country
- Consistency of members
- The group getting to know each other better
- More frequent contact from us and updates

What could be better:

- We have had turnover of group members
- Representation from children
- Getting the optimum size



PHE's learning disability equality objectives

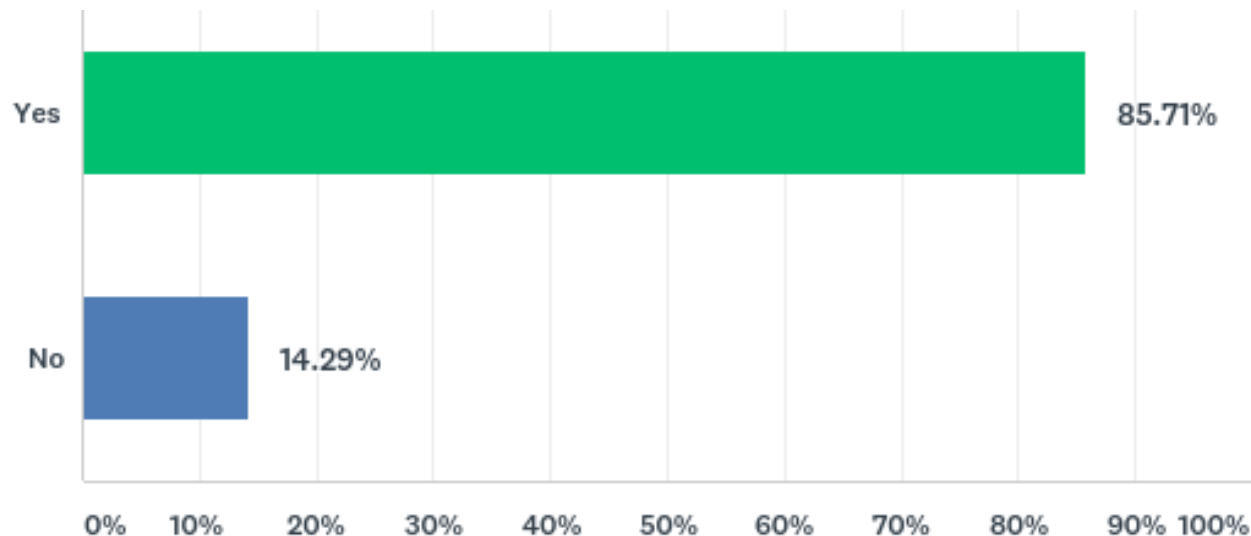
- Routinely produce and evaluate information on aspects of health and care for people with learning disabilities in forms appropriate for health and social care professionals, family carers and people with learning disabilities. This will be provided in booklets, web pages, webinars, face to face events and videos
- Continue to collect and report place-based data and information relating to health and the wider determinants of health of people with a learning disability to support local planning
- Continue to work to improve the availability and reporting of data relating to the health and healthcare of people with a learning disability

Loss of the 'SAF'

What was the joint health and social care learning disability self-assessment framework?

- information from all local areas about how well the needs of people with learning disabilities were being met
- included health and wider determinants such as housing, employment
- it asked that conversations took place locally, with people with learning disabilities, to rate using red, amber or green ratings
- in most areas this meant that the learning disability partnership board reported information
- all numbers and information were analysed and a national report published, showing how areas were doing compared to others

Did the SAF help areas know how well local services were doing?



“It brought services together to discuss the positives and things we need to improve for people with learning disabilities. It tried to hold professionals to account when asking for evidence for the SAF”

“As it is a self-assessment, the challenge locally was important.”

“It gave a voice to people with a learning disability and their carers - also ensured accountability of providers of mainstream services on how they met the needs of people with a learning disability on their local area”

It gave people a say...

When...

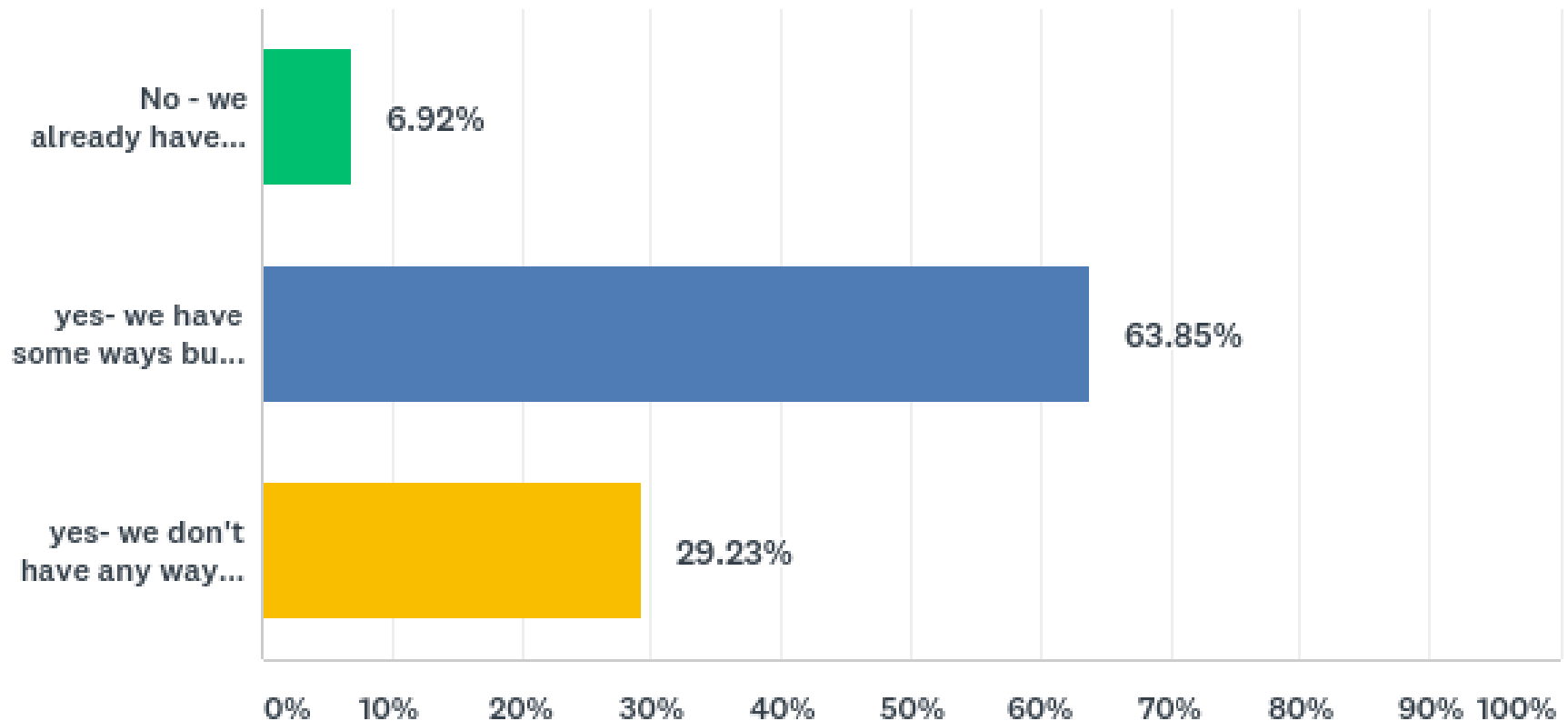
- Enough people and families knew about it and were involved
- There was a strong inclusive mixed partnership board
- People were given the right time and support to be involved

But...

- It was sometimes overly bureaucratic, just ticking boxes or “NHS speak”
- Sometimes national timings got in the way of a full process
- Sometimes people and families didn't know where the money was going but professionals did

Do we need new ways for people and families to influence local plans?

Over 93% of people who took part said we do!



Questions

