

Consultation around “No Voice Unheard No Right Ignored” Green Paper for people with a learning disability and/or autism



healthwatch
Sunderland

Introduction

The Government launched its Green Paper ‘No voice unheard, no right ignored - a consultation for people with learning disabilities, autism and mental health conditions’ in March 2015 with the deadline for national feedback being the 29th of May. The consultation explores options for people with a learning disability and/or autism on issues such as how people can:

- be supported to live independently as part of a community
- be assured that their views will be listened to
- challenge decisions about them and about their care
- exercise control over the support they receive with a Personal Health Budget
- expect that different health and local services will organise themselves around their needs
- know that professionals are looking out for their physical health needs as well as their mental health needs

The primary outcome of the work of Healthwatch and Sunderland People First was to feedback a range of Stakeholder opinions into the national consultation and this was achieved. Our secondary aim was to provide a report, with an emphasis upon people’s views on the Sunderland experience that could be shared with local commissioners and providers.

Methodology

In order to increase the local relevance of this report, questions from the national consultation have been elaborated in order to ask specific questions around the Sunderland experience. In addition, Healthwatch Sunderland and Sunderland People First have a specific role to represent patient experience, and in order to do this effectively we decided to ask only a small selection of the questions from the 50 involved in the national consultation.

The following organisations took part in focus groups:

- Sunderland People First
- Autism in Mind (AIM)
- Patient Forum Group - Washington Community Resource Centre
- Customers from Fulwell Resource Centre
- Senior staff from Forensic services

In addition we received:

- An in-depth feedback questionnaire from Sunderland Carers Centre
- Several questionnaires from family carers
- The notes from a regional discussion group on the Green Paper attended by Sunderland People First and Healthwatch Sunderland.

Generalised summary of feedback

Specific needs of people with autism

- Autism is a lifelong condition and time limited training in independent living skills is not always useful
- There appears to be a significant decline in support for people with autism as they reach adulthood which is reflected in service provision. This is specifically seen as the case for people at the higher end of the autistic spectrum
- There were comments both from people with a learning disability and people with autism that services appeared more likely to be provided for people with a learning disability than with autism
- When arranging for somebody to live in a specific community, real consideration needs to be given for suitability for the individual with autism
- There should be much greater training around understanding the needs of people with autism for both the community and professional staff

The importance of support social networks and a fulfilling life

- Greater understanding is needed around the need for social friendships, networks and establishing good relationships with neighbours
- Greater emphasis needs to be placed upon having a meaningful and fulfilling life. Examples given included a meaningful routine including employment
- Living in the wrong community can lead to social isolation
- Several people commented upon the need for lots of training for independent living

Effective advocacy services

- We need to ensure strong effective advocacy services that are fully aware of how to support people with autism and a learning disability
- People need good sources of community advice
- There is some confusion around advocacy, which services provide it and what the Sunderland's advocacy strategy is
- It was commented upon that advocacy is not believed to be well funded or necessarily prioritised by commissioners

Community Safety

- We need to ensure the safety of people living in the community is paramount

- People with autism or a learning disability can be frightened or worried and need somebody to talk to
- People should be supported to be aware of the Safe Place Scheme and the location of safe places in their area
- People's homes should have excellent security including intercom systems and people should be aware of how to contact the emergency services

Information and communication

- Information should be presented in a variety of styles with an awareness of how different groups communicate
- Easy read and plain English styles should be provided
- The following were given as specific areas that would benefit from 'easy read':
 - Information around speaking up, understanding abuse and how to keep safe, knowing your rights and how to make a complaint
 - Awareness of a range of places to get advice and advocacy support
 - Information around different services and options
 - Information around understanding your condition

Issues that people feel are essential for good services

- Clear service pathways understandable to both the voluntary and statutory services
- Increased awareness and access to psychological services to stop people returning to hospital
- Joined up working between health and social care to ensure 'people are not passed from pillar to post'
- Detailed personal plans for people that help stop readmission into care
- Services need to have a 'joined up family approach' that recognises that families provide an invaluable scrutiny of services
- Regular contact with people and regular review of peoples care and plans.
- Long and short stays should be as close to home as possible
- Offer less restrictive options whenever possible

Specific comments on existing Sunderland Services

- There was recognition from carers about the large scale work around the integration of the Clinical Commissioning Group work-streams and the Local Authority work-streams. There a need to ensure there is adequate funding, with clear lines of accountability to ensure that the joined up approach works.
- Comments around Social Workers included:

- Hard to get hold of
 - Cases closed too early, not allowing enough time to get to know the person
 - Lack of autism awareness
 - Work appears more crisis driven with not enough preventative work
 - Need to inform people of wider options available in the community
- Lack of awareness about what services are available
 - Initiatives such as the Initial Response Team and the Crisis Team have been very successful in providing preventative community support to service users giving carers considerable peace of mind, practical support and guidance
 - A specialist team of Learning Disability nurses offers bespoke training around challenging behaviour to families in certain circumstances
 - The Transformation of Care Programme has been a success because the CCG Commissioners have been entirely transparent, visible and accessible

Empowering people at a more strategic level

- Wider involvement of people with learning disabilities, autism and family carers in the commissioning of new services from the council
- The involvement of people with autism has not been strong historically but a recent autism consultation event was seen as an example of improving practice.
- People may need support to be effective with help to develop and improve skills e.g. to participate in committees and interviews in a meaningful way.
- People should be involved in interviewing from the very start of a tendering process.
- People should be involvement in the recruitment of people who make decisions, including commissioners.
- People should be supported to participate in committees in a meaningful way.
- Experts by Experience should have a clear role in quality checking services.
- Care and Support Sunderland Ltd was flagged up as providing a good example of working cooperatively with families of people who are being supported in some homes, with reports given on a bi-monthly basis to a formal board of carers who act as a scrutiny commission.

How to ensure people with full capacity to make decisions are consulted properly

- Giving people time to think so that they can make informed choices.
- People's changing mental state needs to be considered as capacity can change over time.
- People need clear access to advocacy and peer support.
- Family should be involved in decisions
- There needs to be accessible information to support people to make an informed choice.
- People need to understand 'step by step' what their options are, including any consequences of decisions, such as refusing hospital treatment.

'Even for those who have sufficient capacity it is often very difficult to make informed decisions because people are not given all the information that will inform that decision. It is essential that as much salient information as possible is given to individuals or groups in a format that can be understood. Moreover, information giving should be an on-going process '

Comments raised by professional forensic staff

Historic situation:

- Historically Sunderland has excellent, joined up services that bridge the gap between the hospitals and community. Sunderland has been comparatively well funded and better organised than other areas in the North East.
- The Community learning Disability Teams are well- resourced.

Future concerns:

- With the changes to service providers there is a concern that the links with high quality residential services are less strong than when the council was the primary provider
- There is concern over the commercialisation and reorganisation of residential services and whether this will lead to a higher turn-over of staff, which will make providing repeat training to continually upskill staff a possible future issue
- Concern that as people leave NHS care there may not be the extra money needed to provide support in the community
- There are not enough services available at the moment for people and it is unclear how extra services will be funded.

Taking people with a learning disability out of the Mental Health Act

- Having people with a learning disability under the Mental Health Act has advantages that may not be recognised such as:

- Having a right to an advocate, free solicitor and a legal right to 111 after-care. ‘If you remove these statutes you are effectively denying people liberty.’
- The Mental Health Act is currently human rights act compliant. If you remove learning disability it deprives people of safeguards associated with the statutory legislation. ‘It actually flies in the face of Inclusion.’
- The Mental Health Act provides the means to challenge providers, for example families can challenge both admission to a hospital setting and they can delay a discharge if there was not a proper service for somebody in place in the community
- What happens if the community does not want people some of whom have committed very serious crime? Community rejection of individuals has the potential of leading to out of area placements

Recommendations

The primary purpose of this consultation was to feedback into the national consultation around ‘No Voice Unheard, No Right Ignored’ - which will lead to a White Paper with its own guidance on how services should develop.

We will therefore not be making any strategic recommendations that we hope will end up in the eventual Government White Paper.

Nevertheless as this consultation has specifically attempted to get a local feel, we do believe there are some basic areas that might be considered, or if they have already been considered shared with the wider public:

- An understanding of what general autism awareness training there is, and a way of ensuring such training is made available to both professionals and people in the community
- Encouragement of all services supporting people with a learning disability and people with autism, to promote, where appropriate, wide social networks that ensure people’s networks are not just centred upon people sharing the same services
- An understanding of what advocacy services there are that can specifically meet the needs of people with a learning disability and/or autism - in particular what specialist training they have received around autism and learning disability awareness
- Ensure that services understand they have a responsibility to support vulnerable people to be aware of the Safe Place Scheme.
- An audit around whether there is accessible information available for the areas mentioned in this report.
- Commissioners to look at how they involve Experts by Experience, including families, in the commissioning process and how Experts by Experience are empowered at a strategic level in the services they commission

- An understanding of what exactly is the reality of staff turnover across services, particularly is there a changing pattern that is effecting the quality of services?

Conclusion

We would like to thank all the people who took part in this consultation which involved approximately 40 people. All people's exact comments were fed back into the national consultation.

We hope that this short report will give a flavour of people's thoughts and point to some areas we can start to look at in Sunderland in order to answer the local issues participants flagged up as important.