



Easy Read Advocacy Review

for people with a learning disability
and autistic people who are inpatients
in mental health, learning disability or
autism specialist hospitals

An easy read summary



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in partnership with:



Introduction



NDTI has worked with

- **Bringing us Together**



- **The Challenging Behaviour Foundation**



- **People First Independent Advocacy**



- **Speakup Self Advocacy**

About the work we did



We looked at advocacy for people with a learning disability and autistic people, who are staying in mental health, learning disability, and autism specialist hospitals.



When we say 'We' in this report we mean these organisations.



We asked lots of different people what advocacy is like to make sure that everything is understood properly.



We also talked to families to find out what it is like to support and speak up for their family members with learning disabilities and autism.

What people said they wanted from advocacy



We spoke to 562 people, including people in groups, which gave us good information for the review.



Easy to get to, speak to and see the named advocate

Advocacy needs to be easy to find and easy to access.



People said that they would want to have one named person who is their advocate. Who they can get in touch with easily when they need it.

Person centred advocacy support



People said they wanted their advocate to be with them for as long as they need, to take the time to get to know them better and to understand how important advocacy is for the person.

What people said they wanted from Advocacy



People said they wanted to be able to get lots of different types of advocacy such as self advocacy, group advocacy and independent peer advocacy.



Independence

People said they still want advocates to not work for, or be employed by, the hospitals.



People also told us lots of times that they want advocacy to be paid for separately.



Understanding social care and whats possible for people

People said they wanted their advocates to know more about what support is available for people when they leave hospital.

What people said they wanted from Advocacy



They want their advocates to know about things such as what a personal health budget is, having a tenancy and information about section 117 aftercare.



People said they want their advocate to believe they can have a good life and have high expectations for them.



“Advocates need to come from a ‘can do’ perspective not a ‘cannot’!



People need advocates who will stand up for them and not judge them based on other people they have supported or what the advocates feel the person is able to do”. **Self advocate**

What people said they wanted from Advocacy

Good relationships with advocates



People and their families said how important it is for advocates to put the time and effort into having good and effective working relationships with their advocates.



Strong communication skills with the person, staff, professionals and commissioners



People and their families said they wanted their advocate to have good communication skills so they can make sure the person is heard.



People also want advocates who are confident to challenge professionals and commissioners when it is needed.

What people said they wanted from Advocacy

Confident, skilled and knowledgeable advocates



People said advocates need to be well trained, supported and have a good understanding in order to be the best advocates they can be.



Protecting the person's rights

People and their families said it's important that people's rights are heard and listened to.



Advocates need to have a good understanding about the Human Rights Act, the Mental Capacity Act, the Care Act, the Mental Health Act and the Equality Act.



"Knowledge of the law and rights for advocates is a problem. The advocates in the hospital might be the mental health advocates and not know much about the Care Act. To get a successful discharge, this is really important!" **Self-advocate**

What people said they wanted from Advocacy

Families must be included and listened to



Families said they want to be heard, appreciated and be able to be included in decision making. Professionals need to listen to and act on the experiences and views of family members.

Our recommendations (what needs to change)

There are things that need to change. We think these are:



1. There needs to be independent advocacy support available for people when they are in hospital and when people live in the community.



2. The way advocacy is paid for needs to be the same wherever you live, so that people get the advocacy they need.



3. Advocacy should be person centred to help people live their lives. People should be able to have an advocate for as long as they need.



4. Advocates should be available on the wards and visit people.

Our recommendations (what needs to change)



5. We need rules that are the same all over the country about training, support and supervision of advocates.



6. Information about advocacy for people, families and professionals needs to be correct, accessible and good quality.



7. We need to check that good advocacy is available, works well and is easy for people to get.

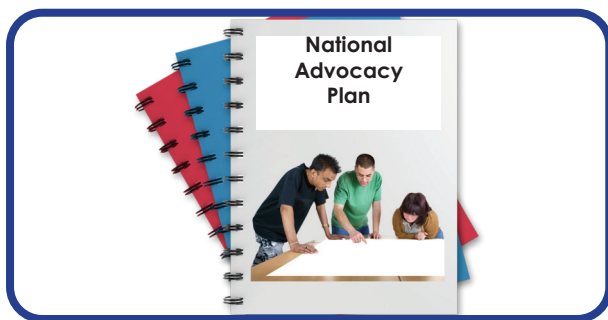


8. Advocates should be working with people's family members.

Our recommendations (what needs to change)

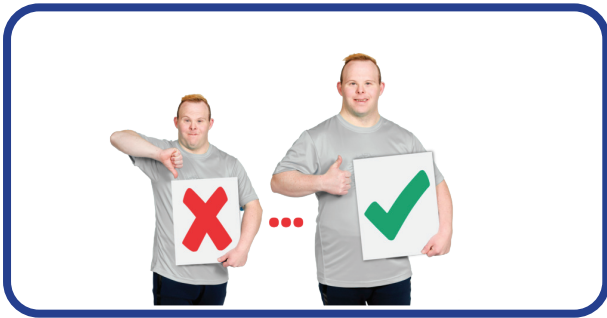


9. People with a learning disability and autistic people should have more jobs in advocacy, training and quality checking.



10. There needs to be a national advocacy plan and a group of people who will make changes in the plan happen, so that people have better advocacy.

What happens next



This review has shown that independent advocacy is very important and that people with a learning disability and autistic people need to be able to get it.




When it works well, advocacy can change people's lives and make sure people have the right support to live their best life.



This is what people with a learning disability and autistic people need.



This easy read was created by Speakup Self Advocacy. Graphics and photos by photosymbols  and NHS England September 2023.