

# Guidance for TCPs

## How to involve the right people in your plans

# Key things you should do

Follow this guidance when involving children, young people and adults with a learning disability and/or autism, and their families, in the work of your Transforming Care Partnership (TCP).

- ✓ Recognise and value the expert views of individuals and families.
- ✓ Make their involvement meaningful. Find out the best way to involve them and check it is working.
- ✓ Think about communication needs and make sure information is accessible.<sup>1</sup>
- ✓ Make sure your work engages, supports, encourages and facilitates involvement.
- ✓ Do wider consultation with people who aren't part of the TCP. People on the TCP board should have experience of a broad range of issues.
- ✓ Think about how to engage different groups. For example, work with schools and specialist colleges to engage children and young people. Hold meetings with different groups of people to see what their specific needs may be.
- ✓ Help people share their experiences. Telling your story can be hard, so people may want to bring someone with them to give support. Provide funding to cover these costs.

“Transforming care partnerships will need to engage with and involve a broad range of people.”

*Building the right support*



<sup>1</sup> You should refer to the Accessible Information Standard. Find it at [www.england.nhs.uk/ourwork/accessibleinfo](http://www.england.nhs.uk/ourwork/accessibleinfo).

## Why should you involve different groups?

You can achieve more by working together. By involving children, young people and adults with a learning disability and/or autism, and their families from the outset, you are more likely to create support and services with good outcomes.

To make this happen, engage people with real-life experience when making decisions – including those who have been in an inpatient unit, and their family members. It is vital their voices are heard. These people can give you crucial insight into issues, support and services, and what solutions might work.

Children, young people and adults with lived experience and their families can also give feedback on whether change is happening and making a practical difference.

## How do you find the right people?

You need a strategy to find the people with the most relevant experience, who will give you valuable insight. This should include people not linked to traditional groups or networks. Work with families and carers to learn about the needs and experiences of people less able to engage directly with you.

People who have experience of inpatient services and their families may have struggled to access local services in the past. It would be helpful to acknowledge this when you approach them, and be clear that you are working to improve services and you support and value their contribution as vital.

Your strategy will require a budget for resources. Resources might include people to support and implement the strategy, travel and replacement care costs, information in different formats, support to take part in meetings, or other things.

## Who should you involve?

Engage with local providers supporting people with a learning disability and/or autism (including schools and colleges for children and young people), local support groups, advocacy services, carers' organisations and charities. You should also engage directly with local inpatient services, and people placed outside of their local area.

You should involve children, young people, adults, and their families (identified by local areas):

- in local inpatient units
- in out-of-area inpatient units
- who have had care and treatment reviews and Improving Lives team reviews
- in care services supporting people with a learning disability and/or autism who display challenging behaviour
- getting input from specialist behaviour support teams, multidisciplinary teams (MDTs) or professionals. Social services annual reviews can identify people at risk of admission. Consider people who lost contact with services too
- at risk of admission (on local risk registers)
- who have moved out of inpatient units into the community
- in secure inpatient services in the criminal justice system
- at 39/52 week residential schools
- at local special schools and colleges
- families identified at risk of family crisis or placement breakdown.

## How do you involve people meaningfully?

Involving people goes further than asking what they think. To help people to get involved in your work:

1. make sure you **share clear information** about the TCP work and the ways to get involved
2. ask children, young people and adults with learning disabilities and/or autism about **how to share** this information. You may need a mixture of written, spoken and creative approaches
3. you could create a **wider reference group** of people with learning disabilities and/or autism, and their families, so those unable to join meetings can still be involved. This group could elect members to sit on the TCP
4. make it clear **how people are recruited**. Publicise this in relevant local places like autism and learning disability groups (including partnership boards), carers' groups, GP surgeries, community centres, on social media and in the local paper
5. show the **impact of people's involvement** with examples of plans changing or being improved following feedback
6. involve people of **different ethnic backgrounds, ages and genders** and give them the support they need
7. make it clear to people that **they only need to represent themselves** – not everyone else in their position
8. keep the information you want from people focused, but do not limit it
9. make it clear that **personal experiences** from individuals are just as valued as views which represent a broader range of experiences from wider networks
10. treat all views **sensitively** and with understanding – the meetings should be a safe space to raise issues.



## What practical support should you offer for TCP meetings?

“Social care and health commissioners will be accountable to local populations and will be expected to demonstrate that they have involved users of care and their families in planning and commissioning appropriate local services to meet the needs of people with challenging behaviour.”

*(Transforming Care: a national response to Winterbourne View Hospital)*

When involving children, young people and adults with a learning disability and/or autism in your work you should:

1. check if they have any **accessibility needs**, and, if so, how you can support them. For example, an autistic person might be sensitive to bright lights or background noise
2. make it clear that **advocates and carers** can come too, for support, and provide funding for this
3. be clear about **the purpose of the group** and what is expected of people, using clear terms of reference and an agreed way of making decisions
4. help people to **talk through what will happen** at the meeting with the TCP beforehand and send out any documents at least two weeks in advance
5. help people **de-brief** after the meeting and get their feedback. Did they feel engaged and were they able to contribute? Use this to inform how future meetings work
6. choose a **suitable, accessible venue**. Help people with a learning disability and/or autism to visit the venue in advance if they want to
7. at the start of a meeting, **set out the agenda and breaks** (see example overleaf) and give an idea of timings. Try to stick to your schedule. Remember that people with a learning disability and/or autism can have difficulty processing and remembering information
8. let people come to **parts of the meeting only**, depending on their needs. Provide a breakout room or somewhere for people to go if they want to take time out, along with someone to show them the way
9. use **plain English and easy read formats** to make information clear. If in doubt, offer both
10. Allow enough time for the meeting to go at a manageable pace and check that people are able to keep up. You may need to allow time for extra conversations that come up.

## How to involve people outside of meetings

1. Aside from coming to meetings, offer a range of options for how people can get involved in local plans and developing services by:
  - setting up a consultation group for people with a learning disability and/or autism and family carers
  - consulting with existing local groups, including carers' groups
  - producing easy read summaries of TCP proposals for people to review.
2. Offer resources in a range of formats so people can access them in the best way for them.
3. Use clear, literal language and avoid using jargon.
4. Use images to support what you are saying.
5. Use clear, correct and specific information as not doing this could be stressful for participants.
6. Make sure people know who to contact with any questions or issues.
7. Be aware that one-to-one work carried out by someone who understands how the person communicates may be the best way for those with more complex needs to feed into the process.

### Further support

If you have any questions, or would like further advice on involving people with a learning disability and/or autism and who display behaviour that challenges please get in touch.

- For autism support, contact The National Autistic Society at [campaign@nas.org.uk](mailto:campaign@nas.org.uk)
- For learning disability support, contact Mencap at [campaigns@mencap.org.uk](mailto:campaigns@mencap.org.uk)
- For support on involving people with severe learning disability and behaviour that challenges and their family carers, contact The Challenging Behaviour Foundation at [info@theCBF.org.uk](mailto:info@theCBF.org.uk).

This leaflet can also be downloaded at [www.autism.org.uk/TCPguide](http://www.autism.org.uk/TCPguide)