National Development Team for Inclusion

Supporting Commissioners to help people thrive in their communities

Information sheets for families or supporters

Introduction

You are being invited to take part in a short piece of fact-finding work being carried out by the National Development Team for Inclusion (NDTi). Before you decide whether to take part, it is important that you understand why the work is being done and what your involvement would mean. Please read the following information carefully and discuss it with others if you wish.

Taking part is completely voluntary.

Before you decide whether you are happy to participate, we would like you to understand why this work is being done and what it would involve for you. We will be happy to answer any questions you have. Please ask us if anything is not clear.

Background

This work is part of a third phase of a piece of work called “Foundation for a strategy”. This phase of the project aims to identify **what “good commissioning” looks like** for people with learning disabilities and autistic people; particularly those who need bespoke, flexible support that is not always available through existing services.

Purpose of the work

We have been asked to develop a **toolkit for commissioners** to strengthen community-based support across London.

Insights from people with lived experience, families, providers, and local leaders will shape the final toolkit.

Scope

We want to find out what people who support family members or loved ones with a learning disability and autistic people think about the community support they have received.

What is good about the support the person you support received and what is bad.

The Project Team

The team who will be conducting the fact-finding work are:

Helen Toker-Lester, NDTi Associate helen.toker-lester@ndti.org.uk

Why have I been invited to take part?

You have been invited to take part because we want to talk to lots of different people who have experience of supporting an autistic family member or loved one or a family member or loved one with a learning disability.

We want to hear your thoughts and your views of community support in your local area.

As part of this piece of work, it is very important that we hear from a range of people, and we would like to hear your views. Your perspectives can help us understand what effective, person-centred commissioning should involve.

The project involves several stakeholder groups:

- People with lived experience
- Families
- Providers
- Advocates
- Local leaders

The timeline of this piece of work is as follows:

- **Talking to stakeholder groups:** 10th – 18th June 2026
- **Project delivery:** 31st August 2026
- **Toolkit first draft:** 31st July 2026
- **Feedback and final report:** 31st August 2026
- **Data Retention/deletion:** 31st March 2027

Do I have to take part?

It is up to you to decide whether to take part in this work. If you agree to take part, we will then ask you to sign a consent form. If you choose not to take part, it will not affect you in anyway.

What will happen to me if I take part?

We will talk to you about what you think about community support for your loved one or those you support. You can choose not to answer questions, and you can choose to stop at any time.

You will be invited to take part in an **online workshop**.

The meeting will last no more than 2 hours. We will use audio transcription in Teams to capture participants' discussions and assist us in creating session notes. These notes will be anonymised to ensure confidentiality. You will **not** be asked to share sensitive personal life stories; only your views and insights about commissioning of services.

Workshops will explore:

- What good commissioning looks like
- Gaps, challenges, and opportunities
- What helps support people well in the community

You will receive this information sheet and a consent form before the workshop.
You can give consent by:

→ Signing the consent form in advance
→ Giving verbal consent at the start of the workshop

We are committed to making taking part as inclusive as possible. Reasonable adjustments can be provided where needed, including Easy Read materials, communication support, regular breaks, and the option for a supporter or advocate to attend. Please let us know in advance if there is anything you need to tell us about how we can try to support your participation.

Consent is ongoing - you can withdraw at any time.

What will happen if I don't want to carry on with the work?

You can withdraw your consent at any time by leaving the meeting. You can also request that the responses you have shared be deleted by emailing Equallivesteam@ndti.org.uk up to 15th July 2026. *Please note, once anonymised themes are incorporated into analysis, removal may not always be possible*.

How will you use the information I give you?

The information we get from you and other people taking part in this work will be used to develop a toolkit for support and health services in your area.

→ Findings will be brought together into a final commissioning toolkit.
→ The toolkit will be shared with London commissioners and relevant partners.

Workshop participants may request a copy of the final output from your local commissioners.

If you provide us with your name and contact details, they will be stored securely on NDTi systems that comply with Government Security Classifications and GDPR.

- Notes taken during the session will be anonymised at the earliest opportunity.
- Identifying details (names, locations, roles) will be removed or changed.
- Personal data will be stored for 12 months after the project ends and then deleted.
- You may be quoted in the toolkit, but it will not be possible to identify you.

If you provide any contact information to us it will only be used to:

- Respond to your registration
- Arrange to invite you to the meeting
- Provide you with the necessary details to attend the meeting
- Send any relevant resources before and after the meeting

In the final toolkit, we will not use your name or any information that directly identifies you. Reasonable steps will be taken to protect your anonymity, including removing or changing identifying details wherever possible.

Although we will remove names and other direct identifiers, in some cases, people may still be recognised indirectly through their role, organisation, or the specific context they describe, particularly within specialist provider or commissioner networks. Any quotes or examples used will be carefully reviewed and, where needed, amended without changing the meaning, to minimise this risk. Everything you tell us in the meeting discussion will be kept confidential within the NDTi project team.

The exception to the confidentiality agreement is if you tell us something that indicates that you or someone else is at risk of harm. We would discuss this with you before telling anyone else, unless we feel doing so poses a risk to anyone.

There will be no personally identifiable information about individuals using services or providers in the toolkit - only generic needs and demand trends.

If participants wish to receive direct feedback about this work, you will need to liaise with the local authority/commissioning bodies.

What will you do with my personal information, and what rights do I have?

Your name and contact information you give us will be stored electronically on NDTi's internal ICT systems. These are compliant with the official level of the Government Security Classifications Scheme, and meets the requirements as outlined within the Cyber Essentials Scheme and are compliant with the General Data Protection Regulations (2018).

- Access to the information will be restricted, and only key members of the team working on the project will be able to access it.
- Notes from the meeting will be kept separately from your personal information.

Under General Data Protection Regulation (GDPR), we need to tell you what the legal basis for us processing your personal information is. This is 'consent' – through reading this information sheet, agreeing to participate and signing the consent form, you are consenting to us processing the personal information detailed above for the purposes of this piece of work.

Your rights regarding your personal information are detailed below. You can exercise your rights at any time, by making a request to NDTi's Data Protection Officer either verbally or in writing.

The right to be informed: This Participant Information Sheet provides you with information about how we will process your personal data and keep it safe, how long we will keep your personal data and, if applicable, who we will share it with.

The right of access: NDTi have processes in place to ensure that we respond to a subject access request without undue delay and within one month of receipt.

The right to rectification: You have a right to have inaccurate personal data we hold about you rectified, or completed if it is incomplete. We have one calendar month to respond to your request. In certain circumstances we can refuse a request for rectification.

The right to erasure: You can ask that we erase your personal data.

Expenses and payment

We are not paying anyone to take part in this piece of work.

Risks or benefits of taking part

We do not anticipate that there are any significant risks with taking part in this work. However, you may find some of the subjects sensitive or difficult. If you find any of the questions sensitive or difficult you do not have to answer them. You can take time out of the meeting if you would like a break, or you can stop taking part entirely at any time.

We hope that you will enjoy discussing what good support in the community should look like. We also think that other organisations and individuals will benefit from hearing your views.

For support, you can access resources through the Mental Health Support Network provided by Chasing the Stigma | Hub of hope. Additionally, we will be offering debrief sessions if you require further support. Please get in touch with Helen Toker-Lester directly in the first instance via email helen.toker-lester@ndti.org.uk by 15th July 2026 to arrange a call.

Who is organising and funding this work?

The National Development Team for Inclusion (NDTi) is the organisation leading this work. NDTi is a not-for-profit organisation working to enable people at risk of exclusion, due to age or disability, to live the life they choose. To find out more about NDTi please call 01225 255 268 or visit our website: www.ndti.org.uk

This work is funded by NHSE, through a transfer of funds to ADASS who manage the oversight of delivery.

Further information and contact details

If you need any more information, or would like to talk about any part of this work, please contact Helen Toker-Lester helen.toker-lester@ndti.org.uk or Rebecca Krzyzosiak, Programme Coordinator, 01225 965144 or Rebecca.Krzyzosiak@ndti.org.uk

What if there is a problem?

If you want to complain about anything to do with this work, please contact Nic Crosby, Small Supports Programme Lead, NDTi:
Email: nic.crosby@ndti.org.uk
Telephone:07854 331 48

What if I want to exercise my rights under GDPR around the personal information that is held about me?

You can do this at any time, by making a request to NDTi's Data Protection Officer either verbally or in writing. NDTi's Data Protection Officer is Sally Richens, Executive Director, NDTi, 4 Queen Street, Bath, BA1 1HE. Telephone: 01225 255 268. Email: office@ndti.org.uk

How can I complain to the Information Commissioner's Office?

Whilst we encourage that you discuss any concerns you may have about how NDTi hold or process your data with our Data Protection Officer, you have the right to complain directly to the Information Commissioner. The Information Commissioner can be contacted at: Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF. Telephone: 0303 123 1113. Website: https://ico.org.uk/concerns/