

Learning disability and autism, dementia and mental health

Patient, carer and family engagement and communication during the coronavirus (COVID-19) pandemic

December 2020, Version 1

Contents

Equality and health inequalities statement	2
1. Introduction	3
1.1 Purpose.....	3
1.2 Why have we developed this non-statutory guidance?	4
1.3 Legislation, statutory guidance and policy.....	5
2. Good practice in engagement and communication for different parts of the system.....	7
Appendix 1: Advice for patients, families and carers	12
1. Advice for people with a learning disability, autistic people, people with mental health conditions and dementia about engaging with services	12
2. Advice for family and carers about engaging with services.....	14
3. Advice for parents and carers of children and young people (including foster carers).....	16
Appendix 2: Useful links	17
1. Easy read resources – official publications from Public Health England (PHE) and NHS England and NHS Improvement.....	17
2. Easy read support to use digital technology.....	17
3. Other useful websites and links	18
4. Resources – place-based approach to reducing health inequalities	18
5. Developing local resources	19
6. Voluntary organisations contact details.....	20

Equality and health inequalities statement

Promoting equality and addressing health inequalities are at the heart of NHS England and NHS Improvement's values. Throughout the development of this guidance we have:

- given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and
- given regard to the need to reduce inequalities between patients in access to and outcomes from healthcare services, and to ensure services are provided in an integrated way where this might reduce health inequalities.

This guidance has been assessed to identify potential equality impacts of the COVID-19 pandemic on people with mental health needs and a learning disability and autistic people. It is acknowledged that people with mental health needs, a learning disability or autism who contract COVID-19 may require reasonable adjustments. We know that adults with Down's syndrome and people with a learning disability may be particularly at risk of a poor health outcome if they contract Covid-19. Further, it is acknowledged that the COVID-19 pandemic has affected many people's mental health and wellbeing.

Health services must continue to have due regard to their obligation to advance equality under the Equality Act 2010; this includes recognising and factoring-in the vulnerability of different groups of people with protected characteristics; and inequalities in access, experience and outcomes in health services. The [Advancing Mental Health Equalities Toolkit](#) helps identify and address mental health inequalities in the round. Partnership working with voluntary and community sector partners is also encouraged to facilitate wrap-around support for vulnerable people, and to maximise engagement with underrepresented groups.

1. Introduction

1.1 Purpose

This is one of a suite of resources for [mental health, learning disability and autism coronavirus guidance](#), which should be consulted in parallel. These resources cover:

- managing capacity and demand within inpatient and community mental health and learning disability and autism services
- patient and carer/family engagement and communication
- workforce considerations during the coronavirus pandemic
- supporting patients of all ages who are unwell with the coronavirus in mental health, learning disability, autism, dementia and specialist inpatient facilities.

This guidance is for:

- commissioners
- providers of acute, community, primary care and specialist services

Information is also provided for family members and carers.

It relates to matters that require particular emphasis in the context of the coronavirus (COVID-19) pandemic but does not cover all the matters that readers need to have regard to in exercising their legal responsibilities.

Advice for patients and families is given in Appendix 1.

The principles in this document are broadly applicable across a range of community health, mental health, learning disability and autism services and settings, but some content is likely to vary in its applicability across different patient/user groups. We have included illustrative examples of specific groups and service areas that may require additional considerations. Local services are encouraged to develop their own tailored strategies for different groups.

This guidance relates to children, young people and adults during the pandemic. It will be updated as required and **only applies during the COVID-19 pandemic**.

When the guidance set out in this document no longer applies, this will be clearly communicated.

Communicating effectively and engaging patients, families and carers is more important than ever during this time of uncertainty. Effective communication is essential in ensuring appropriate care and respect for patients' rights, and those responsible for caring for patients should identify any communication difficulties and seek to address them. Providers and commissioners should ensure accessible information is available for patients, families and carers in line with the [accessible information standard](#), including easy read information. Co-producing with people with lived experience and their families will make sure your information is accessible.

1.2 Why have we developed this non-statutory guidance?

The COVID-19 pandemic has demanded a change in the pace and delivery of healthcare. Local areas, providers, clinicians and commissioners are having to plan and deliver healthcare in ways that are unusual and different. For particular groups of patients and their families this can add challenges. This guidance is designed to support the system in managing these and working with groups of patients with additional needs at scale and in a way that they may not have done previously. It is non-statutory and does not take precedence over existing statutory guidance issued under the legislation set out below.

Children, young people and adults who have a learning disability, are autistic or both and/or have mental health conditions or dementia experience greater health inequalities than the rest of the population. This includes higher rates of physical and mental ill health and of premature deaths.

It is vital to recognise the key roles that families, parents and carers of this group of people play and the immense pressure they are under in relation to the circumstances arising from COVID-19. Changes in routines and difficulties in accessing familiar people and places may greatly impact on this group of children, adults and older adults.

It is also important to note that information and guidance published during the COVID-19 pandemic has raised concern that people who have a learning disability, are autistic or both, or people with dementia, mental health conditions or complex health needs may receive a lesser quality or quantity of care, intervention and support than other people. Therefore, all clinicians and commissioners need to be mindful that these groups and their families may have increased anxiety about the care and treatment they may be offered or receive.

During this period, it is important to note that some people may be more vulnerable due to social distancing restrictions and changes in care and support. If there are any concerns in relation to the safety and wellbeing of an individual, safeguarding policies and procedures should be followed as usual.

1.3 Legislation, statutory guidance and policy

The key legislation relevant to the matters covered in this guidance includes:

- The Coronavirus Act 2020
- The Equality Act 2010
- The Human Rights Act 1998
- The Mental Capacity Act 2005
- Care Act 2014
- The Mental Health Act 1983
- Health Act 2009
- The Health and Social Care Act 2012.

The [NHS Constitution](#) for England October 2015 sets out rights for patients, public and staff. It outlines NHS commitments to patients and staff, and the responsibilities that the public, patients and staff owe to one another to ensure that the NHS operates fairly and effectively. All NHS bodies are required to take account of the constitution in their decisions and actions.

NHS England has also produced non-statutory [Guidance to support NHS Commissioners on their Equality and Health Inequalities legal duties](#).

Statutory guidance that relates to engagement and communication includes:

- [Patient and public participation in commissioning health and care: statutory guidance for CCGs and NHS England](#) May 2017
- [Patient and public participation guidance – a summary to support patient and public participation in commissioning health and care: Statutory guidance for CCS and NHS England](#) May 2017
- [Care and support statutory guidance issued under the Care Act](#) Department of Health, 2014
- [Mental Health Act 1983: Code of Practice](#) Department for Health
- [Mental Capacity Act 2005 Code of Practice](#) Department for Constitutional Affairs (now Ministry of Justice), 2007.
- Equality and Human Rights Commission [Codes of Practice](#).

Users of this document should have regard to existing statutory guidance issued under legislation and codes, standards and guidance issued by their health and care professional regulators and other NHS documents including:

- [Implementation Guidance for the NHS](#) phase 3 response to the pandemic includes urgent actions to address inequalities in NHS provision and outcomes
- Staying Mentally Well: [Winter Plan](#)
- [NHS Operational Priorities for Winter and 2021-22](#)
-

2. Good practice in engagement and communication for different parts of the system

<p>All parts of the system, commissioners and providers, including social care settings</p>	<p>All should work to empower, reassure and protect patients, families and carers through ensuring:</p> <ul style="list-style-type: none"> • Communications are, where possible co-produced, and delivered locally so they are tailored to local services and population needs. • Information is clear and accessible; see Appendix 2 for helpful links. • Online information is up to date, including information for people who are new to services on how to access support. • Support is available locally from helplines, online chat or other forums (supported by local voluntary and community sector organisations), to help people look after themselves and the people they care for, and ensure they get the help they need when they need it, including NHS 24/7 urgent mental health helplines. • Essential changes to individual appointments or local services are clearly communicated to the people affected and alternative arrangements explained if changes need to be made to reasonable adjustments because of COVID-19. There should be transparency about those decisions and consideration given to the fact that legal duties to make reasonable adjustments and to meet human rights should not stop during a pandemic. • Continued work in partnership and co-production with people with lived experience and their family members and/or carers, both strategically and individually, is vital. At this time, parents can be an even more vital and productive part of the multidisciplinary team (MDT). Use them to help you. Be conscious that at a time where decisions are having to be made quickly without co-production, and result in reduced autonomy and control, people with a history of trauma may experience psychological harm. Attention needs to be paid to reducing the harm of such changes and trauma-informed approaches can assist with this. <p>Additionally, to meet the needs of these vulnerable groups:</p> <p>Consider what reasonable adjustments (as set out in the Equalities Act 2010) are necessary to ensure effective engagement and communication, including during appointments –</p>
--	---

	<p>for example, where people cannot use digital technology to access healthcare, telephone calls or having an advocate or family member use the technology for the person while explaining what is happening and ensure these are in place.</p> <ul style="list-style-type: none"> • Pay particular attention to health and communication passports and any ReSPECT forms. • Be aware of diagnostic overshadowing: when the symptoms of physical ill health are mistakenly either attributed to a mental health/behavioural problem or considered inherent to the person’s learning disability, mental health or autism diagnosis. Family and carers are essential in helping to understand the ‘norm’ and what is different for individuals when they are unwell. • Be open, honest and transparent in the way you work; tell people about the evidence base for decisions and be clear about resource limitations and other relevant constraints. Where information has to be kept confidential, explain why. • People with a learning disability or dementia, or who are autistic, may lack awareness of and be less able to report symptoms because of communication difficulties. Therefore, people should be alert to the presence of signs as well as symptoms of the virus (‘look beyond words’); see Coronavirus (COVID-19): what you need to do. • Do not make assumptions about the use of do not attempt cardiopulmonary resuscitation (DNACPR) recommendations. Recommendations on DNACPR should only be made on an individual (person-by-person) basis and in consultation with the person and their family. The ReSPECT process supports health and care professionals, patients and/or their families to have person-centred conversation around emergency care planning which has patient wishes at its heart. Where the person has been assessed to lack capacity to discuss CPR, the statutory principles of the Mental Capacity Act 2005 must be followed. Please see: letter from Professor Steve Powys and Ruth May and further guidance issued by the Resuscitation Council. • Note the clarification made in relation to the use of the clinical frailty scale, which should not be applied to people who have a learning disability, are autistic, or both. • Make use of learning disability and mental health liaison nurses who have particular expertise.
--	--

	<ul style="list-style-type: none"> • Consult independent mental health advocates and independent mental capacity advocates in accordance with mandatory requirements. • Use patient advice and liaison services (PALS) and independent advocates where possible to support people with concerns. • Consider that use of Personal Protective Equipment (PPE) can be frightening for people who may struggle to understand why it needs to be used. • For more helpful information please see the specialty clinical guidelines for supporting people with a learning disability, and autistic people for all clinical specialties. • Be mindful of the reported disproportionate impact of COVID-19 on people from black and ethnic minority groups (BAME). Engage with local community groups to understand how communication can be improved and co-produced for - BAME communities.
<p>Acute medical settings</p>	<ul style="list-style-type: none"> • Going into hospital can be a frightening experience, particularly for someone with a learning disability, dementia, mental health condition, or who is autistic. Staff involved in screening and treatment should be aware if people have these conditions and be prepared to take extra time while assessing and treating them. • The suspension of visiting has now been lifted. The clinical area should be discussing arrangements for visits. These are currently limited to a close family member or someone who is important to the person, as set out in the visitor guidance (October 2020). • People with dementia are much more prone to develop delirium (a state of confusion) if they develop an infection – being aware that a person may have dementia will alert staff to this increased risk. • Make use of psychiatric liaison and learning disability liaison nurses to support patients in general hospitals with mental health needs and/or a learning disability, and autistic people. • For those who are in a mental health, autism and learning disability inpatient setting, providers must apply the guidance set out in the letter to the system from Claire Murdoch and Ray James in relation to visiting in these settings and the latest guidance on visiting in all healthcare settings
<p>Primary care</p>	<ul style="list-style-type: none"> • Primary care can use information about their patients with a learning disability via the flagging system and their annual health checks, to support reasonable adjustments when communicating with people who are in the vulnerable and extremely vulnerable (COVID-19) categories. Consider how to support people who will

	<p>have difficulty understanding the restrictions and self-isolating. See Appendix 2 for easy read resources to support this.</p> <ul style="list-style-type: none"> • If you are supporting people who already access secondary care mental health and/or learning disability services, make sure they know NHS services are open to support them.
<p>Community services (eg paediatrics, therapies, health visitors, wheelchair services)</p>	<ul style="list-style-type: none"> • Consider arrangements to ensure continuity of care and of supplies of essential products. • Consider how to support families whose children are considered vulnerable (see SEND risk assessment guidance), • Consider using more flexible direct payments during this period, including payments to people living in the same house or where payments are being used for equipment.
<p>Health commissioners</p>	<ul style="list-style-type: none"> • To help mitigate the anxiety people and families may feel and help them create a plan, try to ensure there is one place from where they can get the information they need. This information could include: <ul style="list-style-type: none"> – How can I or the person I care for stay safe and happy? (e.g. top tips for: reducing anxiety, exercise, routines, familiarity, preferred interests, reasonable adjustments) – What can I or the person I care for do if at risk of crisis? (e.g. mental health illness symptom escalation, escalating behaviours that challenge, what help can I ask for?, reasonable adjustments) – What can I or the person I care for do if crisis point has been reached? (e.g. crisis care lines, reasonable adjustments, community C(E)TR, inpatient care) • Signpost links to local and national organisations and their resources, as well as the resources in Appendix 2. • During this time, people may have concerns about quality of care and staffing shortages. Where appropriate, ensure families and people who use services know you are reviewing this, and are clear about how they can contact you with concerns and how they can make a complaint. • Ensure that where you commission services, the voices of the people who use those services, patients and families are heard and acted on, including by their having continued access to advocacy, and that quality concerns, including safeguarding concerns, are acted on. • Engage with individuals and families as part of commissioner oversight visits to understand what people’s experiences are of the

	<p>quality of care. Use technology to support this where visits are not possible.</p> <ul style="list-style-type: none"> • Support joint delivery of services and provision to children, young people and adults where there are joint responsibilities to do so (e.g. through the Children and Families Act 2014).
<p>Mental health, learning disability and autism providers</p>	<ul style="list-style-type: none"> • It is more vital than ever to hear the voices of people using services, to ensure the speedy decisions providers are having to make are informed by what would be most helpful to people in the current circumstances. • While many co-production activities may be paused, finding ways to involve experts by experience in decision-making and generating ideas can really support our response to COVID-19. • In addition to all statutory requirements, individuals who are most at risk of admission to a mental health inpatient setting and their families must be given a named contact and know where to find information locally so they can stay up to date. This may be a social worker, community mental health nurse, care co-ordinator, CAMHS worker or commissioner, but make sure there is a named contact. • It is important that statutory advocacy is maintained to ensure the patient's voice is heard. This might mean using alternative or augmentative communication methods. Ensure wards and patient environments have technology to support this and information that tells patients how to access advocacy during this time. Providers should continue to ensure technology follows appropriate information governance requirements. The Information Commissioner's Office statement complements a joint statement from the health regulators. More questions about information governance can be directed to the NHSX IG policy team. • Experts by experience have told us that maintaining connection between the people who use services and their care team through some medium (telephone, letter, text, email; using easy read) is key to reducing people's anxiety. Some NHS trusts have developed letters, written by experts by experience, to send to everyone who uses services, or developed useful resources for people to draw on at this difficult time, including recovery college online courses and resources.

Appendix 1: Advice for patients, families and carers

1. Advice for people with a learning disability, autistic people, people with mental health conditions and dementia about engaging with services

We are living through a difficult and unprecedented time that is challenging for many people across the country. For people with a learning disability, autistic people, people with a mental health condition or dementia there may be extra challenges, and people may experience a whole range of difficult emotions or be experiencing emotional distress. Some may be struggling with feeling lonely and isolated, some perhaps are feeling anxious or worried, or are struggling to get basic needs like food and medicine.

We want you to know that NHS services, including mental health and learning disability services, are still very much open and here to support you. This document offers advice on how to get in touch with services and to get access to the support and help you may need.

Accessing support from services

- Don't let a concern about coronavirus stop you from seeking medical care or attention when you need it – whether your symptoms are linked to coronavirus or not. NHS services are open to support you, so please do contact them.
- If you are worried about coronavirus, use the support lines that are available.
- Use the [accessible information available on coronavirus](#) on official sites such as gov.uk or nhs.net, NHS.uk or any other local NHS or government site.
- In these difficult times, be aware that services may be affected and may need to work in different ways. They should explain if any changes are made to your care and support. Face-to-face appointments may not be possible, but services should talk to you about this and offer an alternative.

- If you are in hospital you should be supported to maintain contact with your family using the telephone or the internet. Staff should support you to do this. Visits are allowed too in line with the latest [visitor guidance](#). There is also specific guidance about visiting people who are in a mental health, learning disability or autism inpatient setting sent in a [letter](#) from Claire Murdoch, National Mental Health Director and Ray James, National Director for Learning Disability and Autism that sets out expectations for visiting in these settings.
- Make sure people understand the impact on you (or if it is appropriate, your family) if your care and support package has changed. You can contact the central advice and duty teams in your area to discuss this. You can find this number on your local authority website. Your social worker should be giving you information about this. If you need to find out details about your local authority, see [find your local council](#).
- You can challenge any rules or decisions made for whole groups of people, rather than on an individual basis, because they affect your care and support package (this is sometimes called a blanket restriction or decision). Changes should only be made on an individual basis after your needs, and the risk of changing your care and support, has been considered.

Some things you can do to help

- Don't be afraid to ask for advice or support – talk to friends, family, advocates and others who support you; stay connected with people. You can do this using the telephone, Skype, Facetime, Microsoft Teams, WhatsApp, and there are lots of other apps that will support you with this. You can find resources for: [Easy Read WhatsApp Guidance](#) and [Easy Read Microsoft Teams Guidance](#).
- If you don't have access to, or find it difficult to use these things, talk to someone you trust about what might be the best way for you to stay in touch, and let them know you need help if you do.
- Let people know if you don't have the right equipment to communicate with them via the internet or social media; you might be able to get some help with this. Talk to your social worker, keyworker, care co-ordinator or other professional involved with your care and treatment.

- Be prepared – try to make sure your health passport, health action plan and any other health documents you have are up to date. You can ask your supporter, friends, community nurse, social worker or carer to help you do this.

2. Advice for family and carers about engaging with services

As well as looking after your own wellbeing and planning ahead (see government [guidance on health and wellbeing](#) and [Carers UK resources on wellbeing](#)), it is important that family and carers:

- Are not afraid to ask for help if (you) or your family member is at risk of crisis (e.g. through your social worker, health commissioner or local authority helpline).
- Know the current status of important appointments (in education, health or social care), what is happening about them and how or when they will happen (e.g. if they are being reorganised or moved online).
- Ensure fear of COVID-19 doesn't prevent them from seeking urgent medical attention for other non COVID-19 illnesses during this period (e.g. toothache) or from keeping up to date with existing health needs (e.g. putting in prescriptions for medications). Health services are putting in place lots of precautions to prevent the spread of COVID-19, with many reconfigured to separate patients with symptoms of COVID-19 from those without.
- Are not afraid to raise concerns and challenge:
 - any discrimination in care and treatment that does not respect your family member's rights and their need for reasonable adjustments
 - diagnostic overshadowing: this can be when a health professional assumes that the behaviour of a person with a learning disability, mental health condition, dementia or an autistic person is part of their disability or is a symptom of mental illness, without exploring other factors that may be causing the behaviour – e.g. being physically unwell. Be confident about challenging diagnostic overshadowing by clearly sharing what is normal for the individual, what has changed and why you are concerned

- decisions made about care and treatment without appropriate risk assessments
- where you see the do not attempt cardiopulmonary resuscitation (DNACPR) recommendation being made because of a disability diagnosis, age or other protected characteristics, rather than on an individual, person-centred approach. A DNACPR decision means that if the person's heart stops beating, they have a cardiac arrest and will be allowed a natural death rather than CPR being attempted.
- Keep in touch when unable to physically visit your family member (e.g. in a care home or a mental health inpatient setting where visiting has been restricted to prevent the spread of coronavirus), and work creatively with commissioners and providers to ensure contact continues remotely and the needs and rights of your family member are respected. Contact providers about visiting arrangements as face-to-face visiting is now supported in line with the latest [visitor guidance](#). If you have difficulty accessing or knowing how to use technology, then let professionals know if you either don't have the equipment or knowledge and ask them how they can help with this.
- Recognise the challenging conditions many clinicians and professionals are now working in – and understand if things are not always done as quickly as you might like, but don't leave things unaddressed if they are important for you or your family member.
- Seek information and advice from trusted sources, both locally and nationally (e.g. www.nhs.uk, Contact, Challenging Behaviour Foundation, National Autistic Society, Childline, MIND, Rethink, Carers UK, Dementia UK), as well as booklets such as *Supporting carers and care staff to understand and respond to changes in behaviour in people with dementia during the COVID-19 pandemic*, to help you and your family member stay safe and happy: <https://www.dementiavoices.org.uk/supporting-carers-and-care-staff-to-understand-and-respond-to-changes-in-behaviour-in-people-with-dementia-during-covid-19/> [copy link to browser].

3. Advice for parents and carers of children and young people (including foster carers)

- If you are the parent or carer of a child or young person, the [Council for Disabled Children](#) has a range of support and advice available in relation to COVID-19.
- The Department for Education has information and guidance on its website about what is happening for children and young people, access to schools and how children they class as vulnerable continue to be supported. See [Coronavirus: guidance for schools and other educational settings](#).
- The Department for Education, NHS England and NHS Improvement, and the Department for Health and Social Care will be preparing some frequently asked questions answers in relation to children and young people. If you have any questions you can send them to CDQuestions@ncb.org.uk or through your [local parent carer forum](#).

If you are a young carer looking after a family member, you can find more information by visiting [support for young carers](#). You can also find helpful information from the [Department of Health and Social Care](#).

Appendix 2: Useful links

1. Easy read resources – official publications from Public Health England (PHE) and NHS England and NHS Improvement

- [Local Restriction Tiers](#)
- [Advice for people who are most likely to be very poorly if they get coronavirus.](#)
- [Staying alert and safe](#)
- PHE has also produced [Advice on education and childcare and Easy read advice about Coronavirus](#)
- NHS England and NHS Improvement sent an '**at risk**' letter to the group of people whose physical health conditions mean they are at the greatest risk from coronavirus. An easy read version of the letter can be found [here](#)
- [NHS 111 guidance and video help for people with a learning disability or autism](#)
- [NHS England guidance on the restoration of community services](#)
- [Ask Listen Do](#) – Information and resources to make giving feedback, raising concerns and making complaints about education, health and social care easier for children, young people and adults with a learning disability, autism or both, their families and carers.

Other useful guidance:

- Guidance on [shielding and protecting people who are extremely clinically vulnerable from COVID-19](#)
- [Priority Groups for Coronavirus \(COVID-19\) vaccinations](#)

2. Easy read support to use digital technology

- [Easy read guide to downloading and using WhatsApp](#)
- [Easy read guide to using Microsoft teams](#)

3. Other useful websites and links

- [Books Beyond Words resources](#)
- Mencap [Easy read handwashing advice](#)
- [National Autistic Society guidance and helpline](#) for parents, young people and staff
- [Mencap easy read guide to coronavirus](#)
- [Place2Be guide to helping parents](#) answer questions from their children and to support family wellbeing
- [Young Minds – Talking to your child about coronavirus](#) 10 tips from their Parents Helpline to support family wellbeing
- [Carers UK COVID-19 guidance](#)
- [Overbook](#) – an interactive resource designed to support and reassure children aged seven and under, by explaining and drawing the emotions that they might be experiencing during the pandemic
- [Every Mind Matters](#) – support during COVID-19
- [Photo symbols coronavirus posters](#)
- [Purple All Stars handwashing video](#)
- Video showing [Makaton signs to aid communication about coronavirus](#) for people with a learning disability.
- The Learning Disability Professional Senate has developed two resources for people with learning disabilities and their families:
 - [Resources to use with people with learning disabilities through the coronavirus restrictions](#)
 - [Resources to support families/carers of people with learning disabilities through the coronavirus restrictions](#)
- [Resuscitation Council UK](#) resources pages on decisions relating to cardiopulmonary resuscitation.

4. Resources – place-based approach to reducing health inequalities

Public Health England has developed these resources in collaboration with the Local Government Association, Association of Directors of Public Health and NHS

England and NHS Improvement to complement the wealth of existing work on health inequalities at a local level. They include:

- [COVID-19 Place based approach to reducing health inequalities overview](#)
- [COVID-19 Summary of guidance and support for vulnerable groups](#)
- [COVID-19 Suggestions for mitigating the impact on health inequalities at a local level](#)
- [COVID-19 Health Equity Assessment Tool \(HEAT\) for local areas](#)
- [COVID-19 Data tools to support local areas](#)

5. Developing local resources

To support the development of local resources, NHS England and NHS Improvement have the following resources.

Advice about making information accessible

- [Advice about using good language](#) to talk about disability and on keeping jargon out of conversations
- [Guide to making information accessible for people with a learning disability](#)

Specific advice on working with people

- [Involving people with a learning disability](#)
- [Find your nearest self-advocacy group](#)
- [Involving autistic people](#)
- [Involving family carers](#) – especially when their child is unable to give feedback themselves
- [Find your nearest parent carer forum](#)

Help getting feedback

- [Ask Listen Do](#) – resources to help autistic people, people with a learning disability and family carers give feedback, raise concerns and make complaints.

6. Voluntary organisations contact details

1. A list of some voluntary organisations who offer support to people with a disability and or family carers. This list is not definitive: there are other relevant national and local organisations.

Name of organisation	Type of people they support	Website and contact number
Council for Disabled Children	Disabled children, young people and their parent carers; health and local authority commissioners; designated clinical and medical officers (SEND); designated social care officers (SEND)	www.Councilfordisabledchildren.org.uk
Challenging Behaviour Foundation	Families of children, young people and adults with a severe learning disability and behaviours that challenge	www.Challengingbehaviour.org.uk 0300 666 0126
Mencap	People with a learning disability and their families	www.Mencap.org.uk 0808 808 111
Contact	Families of disabled children	www.Contact.org.uk 0808 808 3555
Learning Disability England	People with a learning disability and their families	www.Learningdisabilityengland.org.uk 0300 111 0444
National Autistic Society	Autistic people and their families	www.Autism.org.uk 0808 800 4104
MIND	People with mental health conditions and their families	www.Mind.org.uk 0208 215 2243
Rethink	People with mental health conditions and their families	www.Rethink.org

Young Minds	Children and young people with a mental health condition and their families	YoungMinds - children and young people's mental health charity 0808 802 5544
Dementia UK and Admiral Nursing Support	People with dementia and their families	helpline@dementiauk.org 0800 888 6678
Alzheimer's Society	People with dementia and their families	National dementia helpline: 0300 222 1122
Carers UK	People with caring responsibilities for others	www.carersuk.org/help-andadvice/coronavirus-covid-19/coronavirus-covid-19
BEAT – The UK's Eating Disorder Charity	People with an eating disorder and their families or carers	BEAT website BEAT Coronavirus resource
National Domestic Abuse Helpline	Women and girls at risk	The freephone, 24-hour National Domestic Abuse Helpline: 0808 2000 247 www.nationaldahelpline.org.uk/
Women's aid	Women and girls at risk	www.womensaid.org.uk/information-support/ www.womensaid.org.uk/covid-19-coronavirus-safety-advice-for-survivors/

