Public Health England

Protecting and improving the nation's health

Substance misuse and people with learning disabilities: making reasonable adjustments to services

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. We do this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health, and are a distinct delivery organisation with operational autonomy to advise and support government, local authorities and the NHS in a professionally independent manner.

About the Public Health England Learning Disabilities Observatory

The Public Health England Learning Disabilities Observatory (PHELDO) was set up in April 2010 to provide high quality data and information about the health and healthcare of people with learning disabilities. We are also known as Improving Health and Lives (IHaL). This name was suggested for the Observatory at a consultation with self-advocates organised for the Department of Health by Mencap. The information helps commissioners and providers of health and social care to understand the needs of people with learning disabilities, their families and carers, and, ultimately, to deliver better healthcare. PHELDO is a collaboration between PHE, the Centre for Disability Research at Lancaster University and the National Development Team for Inclusion. Since April 2013, the Observatory has been operated by PHE.

Contents

Easy-read summary

Some people with learning disabilities drink alcohol or take drugs to relax and have fun.

Some people with learning disabilities drink alcohol or take drugs to help them cope when things are difficult.

They might have been abused. They might be lonely or sad.

Some of these people may start to do this too much.

Drinking and taking other drugs might cause problems in their lives.

These people might need support to help them stop using alcohol or other drugs.

Drug and alcohol teams don't always know how to support people with learning disabilities.

Learning disability teams don't always know how to support someone with drug and alcohol problems.

The law says public services should put 'reasonable adjustments' in place to help people with learning disabilities use services.

This means they need to change their services so they are easier to use.

This report has examples of easy-read information. This can be used to help people with learning disabilities who have problems with alcohol and other drugs.

This report contains examples of how local services have put reasonable adjustments in place. This is to help people with learning disabilities who have problems with alcohol and other drugs get better care.

Drug and alcohol teams and learning disability teams should work together.

This will help people with learning disabilities who have problems with alcohol and other drugs to get the support they need.

The pictures in this report are from Photosymbols: www.photosymbols.co.uk

Introduction

This guidance is to help professionals in drug and alcohol teams or learning disability teams support people with learning disabilities who have substance misuse problems. It summarises what the research tells us about the particular problems faced by this group of people and what approaches work best.

This report is the 13th in a series of reports looking at reasonable adjustments in a specific service area (see Appendix A). The aim of these reports is to share information, ideas and good practice in relation to the provision of reasonable adjustments.

We searched for policy and guidelines that relate to people with learning disabilities and substance misuse problems. A summary of this information is below. We looked at websites to find resources that might be of use. There is a brief description of these and information about how to obtain them in the resource tables.

We put a request out through the UK Health and Learning Disability Network, a major email network for people interested in services and care for people with learning disabilities. This request was also circulated through local and regional networks of PHE's drug and alcohol team. We asked people to send us information about what they have done to improve substance misuse services for people with learning disabilities. We were sent some examples of resources and good practice case studies. Examples of what has proved useful are given at the end of the report.

What we mean by learning disabilities

A person with learning disabilities will have:
- a significantly reduced ability to understand new or complex information and to learn new skills (impaired intelligence)
- a reduced ability to cope independently (impaired social functioning)
- which started before adulthood, with a lasting effect on development

This does not include conditions like dyslexia, which cause a specific difficulty with one type of skill but not a wider intellectual impairment.

We estimate that 1,087,100 people with learning disabilities, including 930,400 adults, were living in England in 2015. The number of people with learning disabilities recorded in health and welfare systems is much lower, for example, GPs identified 252,446 children and adults as having learning disabilities on their practice-based registers.[1] Those on the registers are likely to be people with more significant learning disabilities.

What we mean by reasonable adjustments

Under the Equalities Act 2010,[a] public sector organisations have to make changes in their approach or provision to ensure that services are accessible to disabled people as well as everybody else. Reasonable adjustments can mean alterations to buildings by providing lifts, wide doors, ramps and tactile signage, but may also mean changes to policies, procedures and staff training to ensure that services work equally well for people with learning disabilities. For example, people with learning disabilities may require clear, simple and possibly repeated explanations of what is happening, and of treatments to be followed, help with appointments and help with managing issues of consent in line with the Mental Capacity Act. Public sector organisations should not simply wait and respond to difficulties as they emerge: the duty on them is 'anticipatory', meaning they have to think out what is likely to be needed in advance.

All organisations that provide NHS or adult social care must follow the accessible information standard[b] by law. The standard aims to make sure that people who have a disability, impairment or sensory loss are provided with information that they can easily read or understand with support so they can communicate effectively with health and social care services.

PHELDO has a database of examples of reasonable adjustments made by health services (www.ihal.org.uk/adjustments/).

Substance misuse and people with learning disabilities

How much of a problem is this?

Some people with learning disabilities misuse alcohol or illicit drugs and some misuse prescribed medications.[2,3] Various studies have looked at the extent of substance misuse in people with learning disabilities. These are likely to underestimate the problem, as some used self-report measures and others only included people known to learning disability services.[2,4,5] It is important to note that little is known about the health of the 'hidden majority' of adults with learning disabilities who do not use learning disability services.[6] It is this group of people with more mild learning disabilities who are most likely to misuse alcohol or drugs.[6-8]

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[a] www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga_20100015_en.pdf

[b] https://www.england.nhs.uk/wp-content/uploads/2015/07/access-info-spec-fin.pdf

Overall, the evidence indicates that people with learning disabilities are less likely to misuse substances than the general population.[5,7,9] However, some people believe that when people with learning disabilities do drink alcohol there is an increased risk that they will develop a problem with it.[9,10] This idea has been challenged by Simpson (2012)[11] who argues that alcohol is an important part of socialising for many people in our culture. He questions why there is a tendency to view drinking alcohol as problematic for people with learning disabilities, rather than as a sign of enjoyable social inclusion.

As increasing numbers of people with learning disabilities are living more independently in local communities they are more likely to have access to alcohol and other drugs and, therefore, there is a need for appropriate services to support those who misuse substances.[5,9] It can be difficult to recognise that someone has mild learning disabilities but they may still need a different approach in terms of their treatment and support.

Secondary analysis of child self-report data at age 11 years collected in the UK's Millennium Cohort indicate that children with learning disabilities are more likely to experiment at an early age with potentially harmful levels of alcohol. Public health work aimed at reducing harmful drinking in children must recognise that those with learning disabilities are a high risk group. Interventions should be targeted appropriately.[12]

Why do people with learning disabilities misuse substances?

Research shows that some groups of people with learning disabilities are more likely to misuse substances than others. For example, people with profound and multiple learning disabilities are simply unlikely to have the opportunity. People with learning disabilities have an increased risk of substance misuse if they have borderline/mild learning disabilities, are young and male, or have mental health problems.[13,14]

Interviews with people with learning disabilities who were misusing alcohol or drugs showed that the main reasons for this could be described as 'self-medicating against life's negative experiences'.[9,14] These included reasons related to 'psychological trauma', such as bereavement or abuse, as well as reasons related to 'social distance from their community', such as isolation and loneliness.

Other risk factors for substance misuse in people with learning disabilities include:[3-5,7,9,13,14]
- living independently
- boredom/lack of meaningful occupation
- desire to be socially included/loneliness
- limited social skills/low self-esteem
- lack of family contact
- impulsivity
- negative life events (for example, neglect, abuse, bereavement)

- unemployment
- poverty

What problems does substance misuse cause?

In the general population, alcohol is the main risk factor for preventable death in those aged 15-49 and the rates of people dying from liver disease are increasing.[16] Alcohol misuse is also associated with other physical illnesses, such as stroke, and is linked to increased violence.[9] For these reasons, one of Public Health England's (PHE) top seven health priorities is reducing harmful drinking and alcohol-related hospital admissions.[16]

Clearly there are negative physical and social effects of substance misuse. For people with learning disabilities, these have been shown to include:[2-5,9,13,14,17-19]
- deterioration in physical and mental health
- alienation/social difficulties
- cognitive deficits
- aggression/mood changes
- verbal and physical aggression
- risk-taking behaviour (including suicide)
- increased epileptic seizures
- inpatient admissions
- greater risk of offending behaviour – people in forensic learning disability services often have problems with substance misuse
- being vulnerable to exploitation
- financial impact, including potential loss of housing
- effects of stopping prescribed medication in order to be able to drink alcohol

Substance misuse services and people with learning disabilities

Although only a small proportion of people with learning disabilities are known to have substance misuse problems, they are a doubly disadvantaged group and currently services are not meeting their needs.[2]

In one study the main places where people reported getting help were:[9]
- learning disability services – these provided a positive educational role and acted as a liaison with other services
- mainstream addiction services – the people that were positive about these services had received support on a one-to-one basis, rather than attending group sessions
- primary care services – GPs tended to give basic advice and information leaflets and antidepressants were often prescribed to address mental health issues

A few small studies look at the effectiveness of targeted interventions for substance misuse in people with learning disabilities. Interventions have included medication,

support groups and behavioural programmes.[14] Evaluation is difficult due to the lack of any widely used, standardised measures for this group.[4] Thus, there is a need for more evidence-based treatments.

Barriers to treatment

Research shows that neither learning disability services nor substance misuse services have all the skills and training resources to support people with learning disabilities who have substance misuse problems.[2,5] Staff in drug and alcohol services do not have appropriate training for working with people with learning disabilities. Staff working in learning disability services do not have knowledge about assessment, treatment and management of substance problems.[2,3,5] Due to a lack of integrated service provision, people with learning disabilities may fall between the cracks of specialist learning disability and mainstream addiction services.[3,7,9,14]

Barriers to substance misuse treatment for people with learning disabilities include:[2,3,5,7,9,14,19,20]
- failure of drug and alcohol services to recognise someone has a learning disability
- failure of learning disability services to detect drug and alcohol problems in people they support and to refer them to mainstream services
- some drug and alcohol services specifically exclude people with learning disabilities
- lack of integrated services and no clear pathways or protocols in place regarding inter-agency working
- lack of recognition in mainstream alcohol and drug policies
- health promotion messages are too complex

In general, mainstream drug and alcohol services fail to adapt the way they work in order to make services accessible to people with learning disabilities. Issues that may need to be considered are:[2,3,5,14,18,20]
- people with learning disabilities may not benefit from group work in the same way as people in the general population
- apparent lack of co-operation may be due to a lack of understanding, rather than a lack of motivation to engage in treatment
- adapting the way in which they engage – alcohol and drug professionals reported using the same assessments they use for the general population
- simplifying the information that is provided – easy-read resources are listed in Table 3
- people with learning disabilities may be dependent upon carers and paid staff to make the positive life changes emphasised in mainstream drug and alcohol services

What do we know about what works?

As mentioned above, there is a lack of evidence-based guidance about effective treatment for this group. However, the literature does identify some approaches and strategies that may be helpful:[2,3,5,7,9,14,19,21]

- partnership working between mainstream addiction services and learning disability teams. Integration of these services might help a move from crisis intervention to a preventive approach. A 'link person' between services has been recommended
- a personalised approach that tailors interventions to someone's individual needs
- interventions and information need to meet the specific communication and learning needs of individuals
- people with learning disabilities may benefit from a one-to-one approach rather than group work
- both substance misuse services and learning disability services should be screening for misuse problems/learning disabilities at initial assessments
- training for mainstream addiction staff in how to work with people with learning disabilities and how to modify their assessment and treatment approaches
- training for learning disabilities professionals around substance misuse
- widening the person's social support networks
- greater family involvement in treatment
- appropriate training and resources for support workers
- access to wider specialist services that can help people to address the reasons behind their substance misuse (for example, bereavement services, support for sexual abuse)
- the use of techniques such as motivational interviewing

Some examples of what works in terms of adaptations to systems and individual approaches are given later in the report.

Capacity and consent

The Mental Capacity Act sets out the law regarding capacity and consent. It provides guidance about the correct process in cases where there are concerns that an individual may not have capacity to take an informed decision. One of the key principles of the Act is that a person is not to be treated as unable to make a decision merely because he/she makes what is considered to be an unwise decision. Professionals supporting someone with learning disabilities and drug or alcohol problems may have difficulties making decisions about capacity in some situations where people are apparently wanting to make unwise choices. The Code of Practice provides guidance to anyone who is working with adults who may lack capacity to make particular decisions. This can be found at www.gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-code-of-practice.pdf

Safeguarding

People with mild to moderate learning disabilities are vulnerable to exploitation. Drug and alcohol teams are likely to come across some people with learning disabilities who are being coerced into commercial sex or working in the drug trade. Concerns should

be raised with local authority safeguarding teams if they or others are thought to be at risk of harm, or causing harm. There may be times when it is appropriate to go directly to the police. The local authority safeguarding team will decide whether to proceed with a full enquiry. If the concern does not meet criteria for an enquiry, there is still a duty to give advice or signpost to other services where appropriate.

Ideally, informed consent should be obtained before a referral is made. If the individual refuses to consent to information being disclosed, a decision needs to be taken as to whether information sharing is justified. This is necessary in some cases, for example, where others are at risk of serious harm. Drug and alcohol teams should have their own protocol for such situations.

SCIE has published guidance for frontline practitioners and managers who work with adults who have care and support needs and who may be at risk of abuse or neglect. The guidance identifies a number of challenging safeguarding dilemmas, and aims to make clear how these should be handled within the new legal framework of the Care Act. It includes information about what to do when a person who has full mental capacity acts in a way that is a risk to their safety or wellbeing. This guidance can be found at http://www.scie.org.uk/care-act-2014/safeguarding-adults/adult-safeguarding-practice-questions/

Resources

The four tables that follow list all the information and resources we have found in relation to substance misuse services.

- Table 1 lists guidance and policy about the management of substance misuse. There are very few references to people with learning disabilities in these documents but the information about general substance misuse policy may be of use to learning disability professionals
- Table 2 lists websites and resources that may be of use to professionals/family members and carers who want more information and resources about substance misuse
- Table 3 lists the accessible resources we have found. This is where you can find information to use with people with learning disabilities
- Table 4 lists all the relevant free apps we have found about monitoring alcohol intake. None of these are designed for people with learning disabilities

Some resources may be available from more than one site, but we have only given one link. We have only included resources that are free to download, although some of the websites may also include resources you can buy.

Table 1: Policy and guidance about the management of substance misuse

Theme	Description	Provider	Link
Drug Misuse and Dependence: UK Guidelines on Clinical Management	Guidance on the treatment of drug misuse in the UK. They are based on current evidence and professional consensus on how to provide drug treatment for the majority of patients, in most instances. This is intended for all clinicians, especially those providing pharmacological interventions for drug misusers as a component of drug misuse treatment. Although there is a section on specific treatments situations and populations, there are no references to people with learning disabilities in it	Department of Health (England), the Scottish Government, Welsh Assembly Government and Northern Ireland Executive	http://www.nta.nhs.uk/uploads/clinical_guidelines_2007.pdf This is currently being reviewed and updated
The impact of drugs on different minority groups: disabled people	An overview of the evidence relating to people with disabilities on: • the extent and nature of drug use • the need for and access to prevention and treatment programmes • interaction with the police and criminal justice system as a result of drug-related activity	UK Drug Policy Commission	http://www.ukdpc.org.uk/publication/the-impact-drugs-different-minority-groups-disabled-people/
Alcohol-use disorders: diagnosis and management of physical complications	This guidance offers best practice advice on the care of adults and young people with alcohol related physical complications. There is reference to the fact that information, treatment and care should all be accessible to people with learning disabilities. The only specific suggestion though, is consideration of a lower threshold for admission to hospital for medically	National Institute for Health and Care Excellence (NICE)	https://www.nice.org.uk/guidance/cg100

Theme	Description	Provider	Link
	assisted alcohol withdrawal		
Alcohol-use disorders: diagnosis, assessment and management of harmful drinking and alcohol dependence	This guidance offers best practice advice on the care of adults and young people with alcohol dependence or who are harmful drinkers. There is reference to the fact that information, treatment and care should all be accessible to people with learning disabilities, but no guidance on how to do this	National Institute for Health and Care Excellence (NICE)	https://www.nice.org.uk/guidance/cg115/resources/alcoholuse-disorders-diagnosis-assessment-and-management-of-harmful-drinking-and-alcohol-dependence-35109391116229
Drug misuse in over 16s: psychosocial interventions	This guidance offers best-practice advice on the care of people who misuse drugs. There is reference to the fact that information, treatment and care should all be accessible to people with learning disabilities, but no guidance on how to do this	National Institute for Health and Care Excellence (NICE)	https://www.nice.org.uk/guidance/cg51
Substance misuse interventions for vulnerable under 25s	Guidance on community-based interventions to reduce substance misuse among vulnerable and disadvantaged children and young people. It contains no references to people with learning disabilities	National Institute for Health and Care Excellence (NICE)	https://www.nice.org.uk/guidance/ph4
Quality governance guidance for local authority commissioners of alcohol and drug services	This document is for local authority commissioners and their strategic partners. It describes what quality governance is in relation to alcohol and drug treatment, why it is important, and provides an overview of the responsibilities of provider organisations, commissioners and national and regional bodies. It contains no references to people with learning disabilities	PHE	http://www.nta.nhs.uk/uploads/quality-governance-guidance-for-local-authority-commissioners-of-alcohol-and-drug-services.pdf

Theme	Description	Provider	Link
Drug prevention, treatment and recovery for adults: joint strategic needs assessment (JSNA) support pack	This document outlines six principles that local areas might consider when developing plans for an integrated alcohol and drugs prevention, treatment and recovery system. The principles have prompts to help put them into practice. There is reference to the fact that information, treatment and care should all be accessible to people with learning disabilities, but no guidance on how to do this	PHE	http://www.nta.nhs.uk/uploads/jsna-support-pack-prompts-adult-drug-2017-final.pdf
Adults – alcohol JSNA support pack 2017-18: commissioning prompts Planning for alcohol harm prevention, treatment and recovery in adults	This document outlines five key principles that local areas might consider when developing plans for an integrated system. These are followed by a series of prompts to help put them into practice. It contains no references to people with learning disabilities	PHE	http://www.nta.nhs.uk/uploads/jsna-support-pack-prompts-adult-alcohol-2017-final.pdf
Young people – substance misuse JSNA support pack 2017-18: commissioning prompts Good practice prompts for planning comprehensive interventions	This document outlines four key principles and useful prompts that local areas might consider when commissioning universal and targeted drug, alcohol and tobacco prevention interventions, and specialist interventions for young people already experiencing harms. It contains no references to people with learning disabilities	PHE	http://www.nta.nhs.uk/uploads/jsna-support-pack-prompts-young-people-2017-final.pdf

Table 2: Resources about substance misuse for professionals/family members and carers

Theme	Description	Provider	Link
Drugs and Alcohol website	This website has information about regional drug and alcohol teams. There are also facts and figures, publications, toolkits and resources. There is nothing specific to people with learning disabilities	Public Health England	http://www.nta.nhs.uk/
New psychoactive substances (NPS) in prisons: A toolkit for prison staff	This toolkit supports custodial, healthcare and substance misuse staff by providing information about the extent of NPS use. It provides advice on how to manage the problem from a clinical, psychosocial and regime perspective. There is nothing specific to people with learning disabilities	Public Health England	www.nta.nhs.uk/uploads/new-psychoactive-substances-in-prisons[0].pdf
Working with Substance Use website	Online resources for health and social care professionals working with people who are misusing substances. The main aim of these resources is to provide a basic understanding of a number of substance-related topics to inform and develop practice	Manchester Metropolitan University	workingwithsubstanceuse.wordpress.com/ Case study about a young man with learning disabilities at workingwithsubstanceuse.wordpress.com/skills/working-with-supporting-family-members/working-with-young-people-and-families/
Drinkaware website	Drinkaware's website provides evidence based information, advice and practical resources which raise awareness of alcohol and its harms.	Drinkaware	https://www.drinkaware.co.uk/

Theme	Description	Provider	Link
	The website has free alcohol education resources which are aimed at 9–14 year olds. These resources include lesson plans and videos		
Substance Misuse Skills Consortium web site	An interactive, online resource providing access to the guidance, evidence, implementation guides, manuals and other resources needed by treatment services wanting to implement the skills framework	Substance Misuse Skills Consortium	http://www.skillsconsortium.org.uk/skillshub.aspx
FRANK	This website has information about different types of drugs and their effects. They can be contacted in a variety of ways for confidential advice	FRANK	www.talktofrank.com
DrugWise website	This website provides information on drugs, alcohol and tobacco which is topical, evidence-based and non-judgemental	DrugWise	http://www.drugwise.org.uk/
Drink Wise Age Well website	This website provides information on alcohol and getting older. The organisation supports health and social care providers and community organisations to recognise and respond to risky drinking in people aged over 50. There is a library of downloadable resources	Drink Wise Age Well	http://drinkwiseagewell.org.uk/professionals/

Table 3: Accessible resources about substance misuse

Theme	Description	Provider	Link
Alcohol: information for service users	An 8-page, easy-read booklet about alcohol. It has information about what alcohol does to your body and the amount of alcohol that is in different drinks	Cheshire & Wirral Partnership NHS Foundation Trust	www.easyhealth.org.uk/sites/default/files/Alcohol%20-%20Information%20for%20service%20users.pdf
Coming for a drink?	A 21-page, easy-read booklet about alcohol. There is information about what alcohol does to your body. There is also advice about drinking sensibly. There is information about how to judge if you are dependent on alcohol and what you can do about this.	The Elfrida Society	www.easyhealth.org.uk/sites/default/files/coming_for_a_drink.pdf
What happens when you drink too much?	An 8-page, easy-read leaflet about what happens to your body if you: • drink too much • drink too much most days • drink too much for years	Manchester Learning Disability Partnership	www.easyhealth.org.uk/sites/default/files/What%20happens%20when%20you%20drink%20too%20much.pdf
Consequences of drinking alcohol	An easy-read booklet about the short and long-term effects of drinking alcohol. There are top tips for drinking less alcohol	Speech and Language Therapy at The Greenfields, Birmingham Learning Disability Service, Birmingham Community NHS Trust Foundation Trust	www.improvinghealthandlives.org.uk/adjustments/?adjustment=398
Consequences of using cannabis	An easy-read booklet about the short and long-term effects of using cannabis. There is also advice on giving	Speech and Language Therapy at The Greenfields, Birmingham Learning Disability	www.improvinghealthandlives.org.uk/adjustments/?adjustment=399

Theme	Description	Provider	Link
	up or cutting down	Service, Birmingham Community NHS Trust Foundation Trust	
My Recovery Action Plan (My-RAP)	A document that uses easy-read and pictures to create a plan for people who wish to address drug or alcohol issues	Cambridgeshire Drug and Alcohol Action Team (Based on original document from Lanarkshire NHS)	http://www.cambsdaat.org/professionals/professionals-resources/
Alcohol diary prompt	A picture-led resource to use with people with learning disabilities or communication difficulties when discussing alcohol and creating an alcohol diary	Cambridgeshire Drug and Alcohol Action Team (Based on original document from Cheshire and Wirral NHS)	http://www.cambsdaat.org/professionals/professionals-resources/
Guide to common drugs	A 14-page, easy-read leaflet about illegal and legal drugs. It gives information about: • what each looks like • how they are usually taken • how they might make you feel • the dangers	Cambridgeshire Drug and Alcohol Action Team	http://www.cambsdaat.org/wp-content/uploads/2016/01/Easy-Read-Guide-to-Common-Drugs.pdf
Common drugs poster	An A1 chart/poster with photographs of common substances and details of the side effects which are depicted with graphics	Cambridgeshire Drug and Alcohol Action Team	www.tes.com/teaching-resource/drug-chart-11198097
Alcohol screening test	An easy-read version of an alcohol screening test	Derbyshire Healthcare NHS Foundation Trust	www.improvinghealthandlives.org.uk/adjustments/?adjustment=412
Alcohol weekly diary	A simple document for recording how much alcohol someone has drunk, when this was and where they were	Derbyshire Healthcare NHS Foundation Trust	www.improvinghealthandlives.org.uk/adjustments/?adjustment=413
I want to drink less	An easy-read sheet for recording agreed actions around drinking less alcohol	Derbyshire Healthcare NHS Foundation Trust	www.improvinghealthandlives.org.uk/adjustments/?adjustment=414

Theme	Description	Provider	Link
Easy-to-read drug facts	This American website talks about different drugs, drug abuse, addiction and treatment. There is an option to click on the button that says "Listen" on any page and the computer will read the text to you	National Institute on Drug Abuse	https://easyread.drugabuse.gov/
Relax for 15 Minutes - An accessible guided meditation	Narrated guidance for a 15-minute relaxation exercise. This uses simple words and any abstract concepts have been avoided or explained. Relaxation exercises can help people to deal with anxiety that is often associated with substance misuse.	Camden Council	https://www.youtube.com./watch?v=_Jhkno7rZz4

Table 4: Apps related to monitoring alcohol intake

Theme	Description	Provider	Link
Drinks Tracker	This app helps someone to keep track of how much they are drinking over the week. It gives information about how much someone is spending on alcohol. There are practical tips on cutting down	PHE	Available in Apple i-store: https://itunes.apple.com/gb/app/one-you-drinks-tracker/id1082307338?mt=8 Available in Google Play: https://play.google.com/store/apps/details?id=com.PHE.drinkstracker
Drinkaware	This app helps someone to track alcohol consumption and spend over time. It can also calculate units and calories and be used to set goals to help moderate drinking	Drinkaware	Available in Apple i-store: https://itunes.apple.com/gb/app/drinkaware-track-calculate/id901389586?mt=8 Available in Google Play: https://play.google.com/store/apps/details?id=uk.co.drinkaware&referrer=utm_source%3Dwebsite%26utm_medium

Theme	Description	Provider	Link
			%3Dreferral
DrinkControl	DrinkControl tracks and converts alcohol intake quantities, such as glasses, bottles or cans, into the standard units of alcohol. It lets someone know when they are going over the limits (set by moderate drinking guidelines) and how much they have spent on drinks. It can provide statistics and charts as well as a personal infographic on what has been drunk	E-protect	Available in Apple i-store: https://itunes.apple.com/gb/app/drinkcontrol-free-track-drinks/id456207840?mt=8 Available in Google Play: https://play.google.com/store/apps/details?id=lv.happymoments.drinkcontrol&hl=en

Examples of reasonable adjustments and case studies

Below are some examples of where services have worked to make changes to their systems and pathways or to develop resources with the aim of improving outcomes for people with learning disabilities and substance misuse problems.

Reasonably adjusting a drug and alcohol service

The Purple Star Strategy project team has been working in the Welwyn-Hatfield area since January 2015 to deliver equitable and accessible health services for people with learning disabilities. The Purple Star is a Kitemark symbolising a high standard of support for adults with learning disabilities. The quality standards that a service requires in order to be awarded a purple star are outlined at www.hertfordshire.gov.uk/purplestar

The team worked with Spectrum Change Grow Live, the commissioned drug and alcohol service in Hatfield for those needing support with recovery.

The action plan for the service included:

- raising awareness of learning disability in the staff team through training delivered by learning disability nurses and the health Expert by Experience, a young man with learning disabilities

- introducing the Learning Disability Screening Tool[c], endorsed by public health to assist with identifying people who have learning disabilities
- introducing a number of reasonable adjustments into the service, including easy-read leaflets and information (for example, the service leaflet), harm minimisation and making a complaint. An easy-read section of the Spectrum website was developed
- recognition by the Spectrum team of how to support people with additional needs by using relevant and targeted approaches to recovery. This includes full adoption of the Purple Folder for people with learning disabilities
- environmental improvements to building access, toilets and signage
- joint working including developing a local referral pathway for people with learning disabilities with substance abuse problems between Spectrum and the community learning disability nurses
- ongoing monitoring and reporting between the learning disability champion and the community learning disability service in Hertfordshire

Spectrum Change Grow Live was recently accredited as a Purple Star provider by Hertfordshire's Community Learning Disability for a second year. Wider adoption of the Purple Star by drug and alcohol services in Hertfordshire is being considered.

Project partners: Hertfordshire County Council, Health and Community Services, Community Learning Disability Service
Further information, please contact Hilary Gardener, Strategic Liaison Learning Disability Nurse - Primary Care. Email: hilary.gardener@hertfordshire.gov.uk

Joint working initiative

This project is a collaboration between PHE, RISE (Drug and Alcohol Treatment Service) and the Community Team for People with Learning Disabilities provided by the London Borough of Ealing and London North West healthcare NHS Trust. This work has built on the Hertfordshire model (described above) and is about implementing joint working initiatives between the substance misuse and learning disabilities teams. The aim is to improve the recovery outcomes for people with learning disabilities and substance misuse problems through the introduction of reasonable and manageable service level adjustments.

The initial work included:
- learning disability awareness training for RISE staff – this incorporated training around the types of reasonable adjustments that could be made
- substance misuse training for the learning disability team
- identifying a learning disability champion within RISE
- identifying a substance misuse champion within the learning disability team

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[c] https://gcmrecords.wordpress.com/about/the-learning-disability-screening-questionnaire-ldsq/ last accessed 9/09/2016

- the development of joint operating procedures between the services
- changes to the initial screening and referral forms to improve the identification of people with learning disabilities

The pilot is based on Certitude's 'Treat Me Right' model, which aims to help people with learning disabilities get a better experience when they use health and other public services. The model has a series of steps which this pilot has been following:

1. Get as many staff as possible on learning disability awareness training.
2. Set up a champions' network.
3. Develop a policy or guidelines about how to support people with learning disabilities in the substance misuse service
4. Map care pathways, considering particular reasonable adjustments that can be incorporated at various points.
5. Adapt care plan templates and other forms for people with learning disabilities.
6. Discharge plan – many common issues can come up when someone needs to be discharged from services.
7. Flagging systems and audits – track people with learning disabilities within substance misuse treatment and audit cases to monitor effective joint working.
8. Reasonably adjusting the substance misuse service – for example, developing easy-read posters, leaflets, signage and appointment reminders.
9. Effective links with the community team for people with learning disabilities, piloted through joint multi-disciplinary meetings to review cases.

Initial data analysis showed that while RISE supports a large number of people with treatment, only 16 of these people (or just under 1%) in 2016/17 were known to have learning disabilities. RISE is now monitoring the database to see if more are identified. The learning disability community team are undertaking a parallel exercise to identify people with drug and alcohol problems.

This work is ongoing and next steps include following 2 people with learning disabilities using the RISE service to obtain their feedback at regular intervals. RISE will also compared the recovery outcomes of people with learning disabilities with those of the general treatment population.

Learning Disability and Substance Misuse Pilot Project
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Educating people with learning disabilities about drugs and alcohol

Cambridgeshire Drug and Alcohol Action Team (DAAT) identified that people with learning disabilities can struggle to access and understand information about alcohol and substance misuse. In response, the DAAT worked with VoiceAbility Cambridge (an advocacy service for adults with learning disabilities) and attended their Speak Out Council service user meeting. At the meeting, a DAAT member delivered a presentation with a self-advocate, giving general information about drugs and alcohol. This was followed by a workshop exploring:

- why do people use drugs or alcohol?
- how can we stay safe around drugs and alcohol?

Cambridgeshire Constabulary held a session where people with learning disabilities were able to ask questions about drugs and look at, touch and smell real substances. Using real substances was important as some people with visual impairments rely heavily on senses such as smell. Lessons included:

- health professionals don't always ask about alcohol and drug use
- use of alcohol is common and may be seen as part of an independent lifestyle and to help individuals feel more confident in social situations
- people with learning disabilities are not always sure about interactions between alcohol and prescribed medications
- there is a danger of exploitation with vulnerable people being targeted for their prescribed medications that also have a street value (for example, Tramadol)
- younger self-advocates have seen friends or family members with substances but were not aware, until the session, that these were illegal drugs
- there is a need for more accessible information about drugs and alcohol and how people can stay safe

Following this workshop, Cambridgeshire DAAT adapted existing resources and created new resources. These are listed in Table 3 and include:

- an easy-read version of 'My Recovery and Action Plan' to create a plan for people who wish to address drug or alcohol issues
- an accompanying prompt sheet that uses pictures of common alcoholic drinks to start a conversation about how much alcohol someone drinks
- a drugs prompt booklet with pictures of common substances and their effects
- an A3 poster with photographs of common substances and details of the side effects, which are depicted with graphics

The DAAT team ran a training session for learning disability health and social care teams to introduce the resources above. They have also been shared with the adult drug and alcohol treatment service, traveller community teams and substance misuse staff at prisons and custody staff at police stations.

Cambridgeshire Drug and Alcohol Action Team
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Adapting substance misuse practice

Gill Baker is a learning disability nurse also trained as a clinical nurse specialist in substance misuse. She has worked in a service development role to adapt substance misuse practice for people with learning disabilities. This work includes:
- adapting evidence-based approaches
- developing shared pathways
- introducing a train the trainer model
- providing consultancy and succession planning for learning disability services

In her work she has adapted traditional methods and approaches to assessment and treatment to meet the needs of people with learning disabilities at each stage:
- engagement – the use of a flexible assessment process with time for the individual to tell their story as opposed to the assessment being a tick-box exercise
- motivation – thinking about what is good and bad about drinking and using adapted readiness to change scales
- active treatments – increase coping skills, problem solving skills, safe limits education and compassionate mind therapy
- relapse prevention – the use of self-soothing and distraction techniques produced in an accessible format

The emphasis of her work is on taking a joint approach between learning disability and substance misuse services in order to improve the outcomes for people. Joint assessments are undertaken and a pathway between the services were developed. Two case studies have been published to illustrate how this worked in practice (Baker et al, 2007).[2]

There have been a number of challenges to the ongoing success of this work in Derbyshire. It is specialist work and only relevant to a small cohort of people. Additionally, the existing tendering processes mean there are frequent changes of providers. In order to ensure the sustainability of this type of joint working, local areas will need to address such issues and the work should be officially commissioned.

Derbyshire Healthcare NHS Foundation Trust
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The case studies below are examples we have been sent. They describe how support was provided to an individual and the types of reasonable adjustments that were made. For reasons of anonymity we are not linking these case studies to the services, but we would like to thank the following teams for their contributions:

- Avon Forensic Community Learning Disabilities Team
- Catch 22's substance misuse service
- Derbyshire substance misuse service
- Portsmouth Community Learning Disability Team – Solent NHS Trust

Reducing alcohol use and associated self-harm

Mark has learning disabilities, autistic traits and borderline personality disorder. He began misusing alcohol in his early 30s. He was referred to the community team due to an increase in his self-harm, which appeared to be accompanied by excessive alcohol use.

Mark had identified that when he felt upset and distressed he would leave the house, often in the early hours of the morning, to go walking in quiet isolated places. He would drink large quantities of spirits and self-harm in the form of cutting himself. This would lead to contact with the emergency services.

He was seen by a community nurse who completed a risk assessment of his self-harming behaviours and alcohol use. It was recognised that the use of alcohol increased the risks related to his self-harm as it had an anesthetising effect and resulted in deeper cuts.

The initial nursing assessment resulted in a range of interventions that were designed to help Mark safely manage his alcohol use:
- referral to a psychologist to explore his feelings of low self-esteem and lack of worth, which contributed to his self-harm
- education about the effects of alcohol use on the body and a personalised programme exploring the impact of drink specific to Mark's self-harm, risk behaviours such as walking alone at night and his engagement with supporting services. All information was provided in an accessible format, specifically designed for his needs based on a speech and language therapy assessment
- a traffic light system that provided guidelines for safe and unsafe drinking
- alternative strategies for coping when feeling distressed
- a prescription for medication designed to reduce alcohol use, with close monitoring by a psychiatrist and community nurse
- referral to an occupational therapist to explore more meaningful occupations designed to raise self-esteem, provide opportunities for more positive self-identity and to structure his time more effectively
- links were made with mainstream alcohol misuse services and resources were shared. Mark accessed substance misuse counselling. He agreed that the community team could discuss his specific learning disability needs with the substance misuse team so they could better meet his needs

Mark reported that following this work he had a better understanding about why drinking was 'bad for him'. He reduced both the frequency and quantity of his drinking. He now only drinks at social events and will limit his drinking to 2–3 low alcohol drinks. His-self harming has reduced both in frequency and severity.

Making reasonable adjustments to an inpatient drug and alcohol service

Paul is a young man with mild learning disabilities. He has a history of offending and was referred to the forensic community learning disabilities team by his probation officer. He successfully stopped using heroin when prescribed Buprenorphine (a heroin substitute) through a specialist NHS substance misuse service. He continues to be monitored regularly by this service, supported by the community learning disability nurse or the forensic learning disability team in a shared care approach.

Paul also uses alcohol in excess and some other non-prescribed drugs. Several attempts to detox from alcohol in an inpatient setting have not been successful and supporting him to reduce his alcohol use in the community proved to be very difficult. Paul and his carer, a close family member, recognised that his health was being affected and they both requested that he be considered for a further attempt at detox in an inpatient setting.

At a meeting of the substance misuse service, community and forensic learning disability teams, Paul and his carer, the following issues were identified:
- Paul had struggled to understand the rationale behind the therapeutic recovery-based phase of the treatment programme and so had discharged himself before this was complete
- Paul found working in groups very difficult. He often struggled to understand what was being talked about but did not feel comfortable asking for help or explanations
- Paul was worried about not having regular contact with his carer

It was agreed that a further referral to the inpatient drug and alcohol treatment unit would be arranged. Prior to his admission a multi-disciplinary meeting agreed a number of actions:
- Paul would be allocated a named nurse from the inpatient team who had some knowledge and understanding of learning disabilities
- Paul would have someone to support him during all groups and that his understanding would be checked regularly
- the CLDT/forensic team would visit Paul each afternoon to go through what he had learned during the morning groups and they would liaise with the inpatient team if it was evident that Paul was struggling
- regular visits from Paul's carer were arranged
- there would be a pre-admission assessment where Paul and his carer were able to ask questions and to discuss any concerns

- the aims of the admission would be agreed and the rules of the unit explained to Paul in a manner that he understood

With support, Paul was able to understand that remaining for the entire programme would help him to develop some important coping strategies that he could use in the community. He completed his detox from alcohol successfully on this occasion; agreeing the implementation of the plan prior to his admission was crucial. The individual support from familiar learning disability professionals helped him to make sense of what he had learned in the therapeutic group sessions and meant he participated in group work. Their input also led to the inpatient team using accessible information, such as a pictorial timetable, to help Paul understand the structure of each day. A better knowledge and understanding of what was important and what was difficult in Paul's life helped to identify some meaningful strategies that he could implement in the community

Paul continues to have shared care support in the community to help him with his ongoing substance use needs. He currently remains free from heroin use and has significantly reduced his alcohol use. Whilst Paul is not currently abstinent from alcohol use, he is now making better choices about what he drinks and how much. He continues to require support around remembering to use some of the strategies that he learned in the inpatient treatment unit and is likely to benefit from ongoing education around alcohol use.

Increasing independence and social inclusion

Tim was in his late 20s and lived at home with his mum and dad. He was able to carry out many aspects of daily living but due to his learning disabilities he struggled to organise tasks and needed verbal prompts throughout the day.

Tim was referred to substance misuse services with a reported addiction to 'legal highs', specifically a synthetic cannabinoid called Pandora's Box (now illegal). Tim was spending all his benefits on this (up to £60 per day). When money ran out he was making threats to his mum to get her to give him money and the police had been called on a number of occasions. Tim had no money and was unable to take part in any social activities due to social isolation caused by dependency, his learning disability and lack of money or support to engage in his local community.

Tim had previously struggled to engage in the drug treatment process and found the assessment process complicated. He didn't want to go to appointments in the drug service with other drug users, as this felt "scary".

He and his family wanted him to stop using drugs and he had been accepted by the local substance misuse team and allocated a key worker. This service had been trained

to identify communication needs and a screening tool identified Tim as suitable for input from a speech and language therapist (SaLT). Her communication assessments showed:

- Tim had very limited reading skills and needed symbols, pictures and drawings to help him understand basic written information
- he struggled to process and retain more than three key pieces of information and was not aware of his comprehension difficulties
- his speech was clear and he had good superficial social skills and smiled and agreed with people, making them believe he had understood what was being said
- Tim's yes/no response was heavily influenced by Tim wanting to please the person asking him a question and therefore could not be relied upon

The SaLT also suggested other reasonable adjustments. The things that helped were:

- sessions taking place at his home to help manage his anxiety
- accessible drug diaries to record his daily use
- setting targets about drug reduction
- support to find voluntary work at a local farm – this led to some reduction in drug use in the day

The SaLT referred Tim back to social care as his mother's health was deteriorating and she felt unable to care for him anymore. At a person centred review/risk meeting, Tim shared his concerns:

- he believed that he would become aggressive if he stopped using 'legal highs'
- he was terrified that he might be very ill when withdrawing

This insight allowed the team to make a new plan for an inpatient detox programme for two weeks. The SaLT worked with Tim's keyworker from the substance misuse team to organise:

- funding for the detox visit
- accessible resources and photos about the detox unit
- visits to the unit and a chance to ask questions
- a communication profile for the detox unit, which explained Tim's communications needs and his likes and dislikes
- follow-on input from the psychologist from the local learning disability team to offer Tim support to learn different ways to express and manage emotions
- an appointment with a psychiatrist in case there were implications for anxiety management
- a tenancy in his own flat with support from a charitable organisation following his return from detox
- a clear visual plan for Tim explaining what would happen when he returned and who would be doing what to support him

Tim returned home drug free after 10 days in detox and was settled into his new accommodation. He returned to his voluntary job and remained drug free. He was discharged from substance misuse services two months later but continued to be supported in the short term by psychology services, while he learnt to develop new coping skills.

Support to develop alternative interests

This case study describes how a young man with a diagnosis of autistic spectrum disorder (ASD) was supported by his local substance misuse service. There may be wider learning in considering appropriate reasonable adjustments for people with learning disabilities.

Steve referred himself to the service when he felt his drug use had become a problem. He was using cannabis, MDMA, new psychoactive substances, ketamine and LSD. The service arranged an assessment at the family home and, at this, Steve discussed the wider issues he experienced in relation to his ASD. These included finding it a struggle to say 'no' to substances and difficulties in relating to family and friends and understanding the consequences of his behaviours. He also talked about his hobbies, particularly his love of music.

The initial care plan focused on harm reduction, supporting Steve to reduce the use of substances and offering access to the 24-hour support/crisis line that is staffed by substance misuse practitioners. Together Steve and Julian (substance misuse service support worker) developed a care plan tailored to Steve's needs: providing psychosocial interventions including drug education; harm reduction to address poly-drug use and routes and patterns of use; exploring the risks of both physical and psychological health.

The substance misuse service support worker focused on:
- harm reduction, supporting Steve to reduce the use of substances and offering access to the 24 hour support/crisis line staffed by substance misuse practitioners
- working with Steve to develop a care plan tailored to his needs
- providing psychosocial interventions including drug education
- harm reduction to address poly-drug use and routes and patterns of use
- exploring the risks of both physical and psychological health

Sessions were provided weekly with additional support by phone. Steve struggled initially with reducing his drug use. Julian encouraged Steve to focus on his interest in music and his relationships with family and friends, in order to increase his self-confidence and resilience. Steve was supported to explore career development and prospects within the music industry. This included the service arranging a meeting with a sound engineer and other visits, to a local radio station, for example. This gave Steve a positive distraction from using substances and he was able to start to focus on making positive choices and explore

the negative effects of substance misuse. As he reduced his use of substances he became more determined to be drug free. Music became a coping mechanism to help reduce his cravings.

Steve reduced his use of MDMA, ketamine and research chemicals. His cannabis use has significantly reduced and he has improved his relationship with his parents and peer group and developed more confidence.

What worked for Steve was:
- tailoring care plans and approaches to meet his individual needs and wider vulnerabilities
- incorporating harm reduction, wider psychosocial interventions and advice into his care plan
- supporting him to find positive activities to focus on – this helped develop Steve's resilience and self-worth

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Appendix A

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