National Institute for Health and Care Excellence

Mental health problems in people with learning disability
Scope Consultation Table
12th June – 10th July 2014

Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
The British Psychological Society	1	General	The Society welcomes the development of NICE guidelines in this area. We believe that it is important to be very mindful of the need to distinguish 'mental health problems' and 'challenging behaviours', which are the subject of separate NICE guidance currently under development. This is reflected in our comments below, for example, in relation to prevalence figures. Challenging behaviour may be associated with underlying mental health problems, but in many instances may have causes and functions that are not associated with mental health problems.	Thank you for your comment.
The British Psychological Society	2	General	Guideline title: As the draft scope document states, the term "Learning disabilities" is still widely used in the UK. However, as the document also acknowledges, the two main internationally recongized diagnostic classifications have moved to using the term "Intellectual disability" This term has also been adopted by the British Psychological Society both in order to be consistent with international terminology and to counter the confusion of 'learning disability' with specific learning difficulties. As such, we recommend that the term 'intellectual disability' is used in the title and throughout the guideline. The proposed title focuses exclusively on management, a focus we regard as overly narrow. Many of the factors referred to in the Scope as potentially giving rise to mental health problems in this population are within the societal, policy and service realm, indicating that the guideline should aim to include consideration of addressing risk factors and thereby aiming to prevent mental health problems where possible. Furthermore, the considerable attention on to how to assess mental health problems in this population, and the need for adapting methods and measures commonly used with the general population should be reflected in the focus (and title) of this guideline. We	Thank you for these comments. The use of the term 'intellectual disability' was considered when we developed the scope for the related NICE guideline on Challenging Behaviour and Learning Disability. We took the decision then to use the term learning disability and have decided to the same term for this guideline. We believe it would be unhelpful and potentially confusing for users of the two guidelines if they used different terms to refer to the same issue. We agree that a broadening of the title could be helpful and will consider using the following 'Prevention, assessment and management of mental health problems in people with learning disabilities.'

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			recommend broadening the scope of the guidance to: **Prevention, assessment and management of mental health problems in people with intellectual disabilities.**	
The British Psychological Society	3	3.1.a	As noted, *"intellectual disability is defined by three core criteria: low intellectual ability (usually defined as an IQ of less than 70), significant impairment of social or adaptive functioning, and onset in childhood. There are many causes of intellectual disabilities and often the cause is unknown".* We therefore recommend an addition to this section: *"Consequently, intellectual disability is an umbrella term for a highly heterogeneous population with diverse abilities and difficulties, rather than a single, homogeneous condition."*	Thank you for your comment. The intended meaning of this suggestion has been added to section 3.1a: *there are many causes of learning disabilities, and often the cause is unknown, so people with learning disabilities have a diverse range of abilities and needs.*
The British Psychological Society	4	3.1.c	People with intellectual disabilities not only experience high rates of physical disabilities but also high rates of sensory disabilities. Accordingly, we recommend adding the word "sensory" to the last sentence of this section. Furthermore, in distinguishing "health problems" and "mental health problems" the word "physical should be added to the former. *"People with intellectual disabilities may also have accompanying physical **and sensory disabilities**, and physical or mental health problems that further **affect** the levels of support they require."*	Thank you for your comment, 'sensory disabilities' have been added.
The British Psychological Society	5	3.1.d	The word "However" should be removed as there is no contradiction of anything proposed in the preceding section in what is proposed in 3.1d. In recognition of the huge influence of "person first" language and thinking in the field of intellectual disability, we suggest amending the first sentence to: *It is important to treat **each individual as a person first**, with ..."* Furthermore we recommend highlighting the importance of a person centered approach enshrined in UK policy, and ideally service delivery, and suggest this additional sentence to conclude this section: *"A person-centered approach to selecting the most appropriate approach to assessment and management is likely to be required in order to meet the needs of the individual."*	Thank you for your comment. "However" has been removed. A person -centred approach has been added.
The British	6	3.1.f	The Society recommend adding dementia to the list of common co-	Thank you for your comment.

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Psychological Society			morbidities, as the incidence of dementia, similar to epilepsy and physical health problems is increased in this population (as detailed in the joint guidance by the Society and Royal College Psychiatrists, Dementia and People with Learning Disabilities). We also recommend adding the word "assessment" to the last sentence, and deleting the word "can", given that comorbid difficulties should be considered as a matter of course and not of choice: *"It is important to consider such other problems in the assessment, diagnosis and management of any mental health problems."*	"Assessment" has been added, and "can" has been deleted. The umbrella term "mental health problems" will include dementia as well as the other mental health problems that are more common in this population.
The British Psychological Society	7	3.1.g	Population based estimates of mental health problems of 40% rely on the common (and we believe unhelpful) practice of classifying problem behaviours as mental health problems. Given that problem behaviours displayed by people with intellectual disabilities are covered by the NICE guideline on 'challenging behaviour', and, as noted above, may be due to a wide range of factors, not necessarily mental health problems, the Society believes that the Scope use estimates of mental health problems excluding problem behaviours. Current best estimates would put these at 28% in adults (Cooper et al., 2007). The figure of 36% based on Emerson et al (2007) seems an appropriate estimate in children and young people; this figure includes 'conduct disorder' but not 'challenging behaviour'. In view of our comment on the questionable inclusion of "problem behaviours", we suggest using the term "conduct disorder" in the penultimate sentence of this section. These comments indicate a general need to carefully define what is referred to by the term "mental health problems", which is not without complexities and therefore perhaps more appropriate for the early work of the guideline development group, rather than this scope.	Thank you for your comment. Prevalences of mental health problems are now quoted with and without problem behaviour/conduct disorder.
The British Psychological Society	8	3.1.h	Abuse and neglect are not "psychological factors" but rather should be integrated into the list of social factors. We also recommend expanding the social factors detailed to include factors well documented in the literature as placing people with intellectual disabilities at increasing risk of experiencing distress: *"Social factors such as abuse, neglect, poverty, multiple co-occurring life-events, impoverished social environments and networks, stigma,*	Thank you for your comment. This section has been revised accordingly. The examples given are there merely as examples; the list is not exhaustive.

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			exclusion, discrimination and hate crime; factors pertaining to race, ethnicity, culture, gender identity and sexuality that combined with intellectual disability can lead to double or multiple discriminations." Furthermore we suggest adding psychological factors that have received much attention, particularly attachment difficulties and trauma (Hollins & Sinason, 2000; Schluengel et al, 2013): *"Psychological factors such as attachment difficulties and trauma."*	
The British Psychological Society	9	3.1.i	The Society recommends an addition to the subsequent sub-clause: *"their symptoms inadvertently may be attributed to their intellectual disabilities" add: (commonly referred to as 'diagnostic overshadowing');"* We believe that the next sub-clause should read "symptoms may be misattributed to side effects of medication". The Society questions the value of singling out complex partial epilepsy when symptoms of mental health problems may be misattributed to a wide range of difficulties and conditions. In addition, the sub-clause on "primary care services" could be seen to ignore intense efforts over recent years to tackle health inequalities experienced by this population through a more proactive approach, such as the Dept of Health Direct Enhanced Scheme designed to encourage the provision of annual health checks for people with intellectual disabilities. Instead we recommend referring here to *"reduced access to appropriate health care, and delayed diagnosis and treatment"*, both of which have been widely documented recently (e.g. 2012 IHAL report on 'Health inequalities and people with learning disabilities in the UK). Finally, social factors referred to in comment 10 above, may also contribute to discrimination and negatively affect access to health and social support. We recommend this is reflected in an addition at the end of this section: "People with intellectual disabilities who experience mental health problems may be at further increased risk of experiencing health inequalities due to the cumulative disadvantage arising from discrimination that is rooted in gender, social, cultural and religious factors, and age."	An attempt has been made to avoid the use of jargon. The example of complex partial epilepsy is given merely as an example. The statement on primary care services is qualified by "most typically"; it does provide health promoting activities eg health checks and cervical screening, but most typically provides reactive care. A separate point k has been added regarding race, ethnicity, gender, sexuality, social , cultural and religious factors and age.

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The British Psychological Society	10	3.1.j	The Society believes that adding a focus on organisations and systems, given that they can often struggle to respond appropriately when someone with intellectual disabilities in their care develops mental health problems: *They can also affect their family and paid carers* ***and place significant stress on organisations and services.*** As noted in comment 8, we recommend using the term 'affect' instead of 'impact upon'.	Thank you for your comment. This amendment has been made.
The British Psychological Society	11	3.2.b	To signal that the person themselves should always be at the centre of practice, we recommend altering the order of the stakeholders listed, such that "the person with intellectual disabilities" is named before "family and paid carers etc", and not last in a long list.	Thank you for your comment. This has been amended to highlight that they need to work together with the person with learning disabilities.
The British Psychological Society	12	3.2.d	We view the terminology "psychological interventions" as distinctly preferable to the poorly defined term "psychosocial interventions". Furthermore, the use of the term "inaccessible" here is unclear, as it could be seen to refer as much to availability as to ability to engage with. Also the term "therapies" is poorly defined. Therefore we recommend: *"Some psychological interventions developed for the general population are not available, or in some cases potentially not accessible, to people with intellectual disabilities, and…."*	Thank you for your comment. The term psychosocial has been used to broadly capture a range of interventions and multicomponent interventions. The term inaccessible refers to both availability and suitability/ability to engage with.
The British Psychological Society	13	3.2.e	For clarity, we recommend adding the term "mainstream" in front of mental health services when contrasting these with specialist health services. Therefore for added clarification, we recommend amending the last sentence slightly: *…because they may fall outside the Fair Access to Care Services criteria used by social services* ***and may be judged not eligible for specialist health services.***	Thank you for your comment. The term "mainstream" has been added. This amendment has been made.
The British Psychological Society	14	3.2.f	The Society believe adding a sub-clause would be beneficial for clarity: *"The transition from child to adult services is often problematic,* ***and requires close co-ordination between child and adult services."*** On the point of out of area placements referred to in this section, we view it as imperative to refer to recent guidance and suggest adding the following sentence at the end of this section:	Thank you for your comment. The need for close coordination has been added. It has been added that placement a long way from home is contrary to recent guidance.

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			"Recent guidance from the Winterbourne View Joint Improvement Programme is that people should not be placed a long way from home, nor for long periods of time."	
The British Psychological Society	15	4.1.1.a	We recommend that 'older adults' should also be named explicitly, not least because of the increased prevalence of dementia in this population. Strydom et al. (2010) concluded that rates of dementia in people with ID and Down's Syndrome are much higher than in the general population (e.g. 30% for those in their 50s), and comparable with or higher than the general population in people with ID not due to Down's Syndrome. *"Children, young people, adults **and older adults** with mild, moderate, severe or profound learning disabilities and mental health problems and their families and paid carers."*	Thank you for your comment. Specific reference to the inclusion of older adults has been added.
The British Psychological Society	16	4.1.1.b	We believe that 'Down's Syndrome' should be added to the parentheses, as it is the most common genetic condition associated with intellectual disability and places those affected at increased risk of mental health problems and dementia: (For example, **Down's syndrome**, Prader Willi syndrome, Fragile X).	Thank you for your comment, the scope has been amended as you suggested.
The British Psychological Society	17	4.3.1.b	Further to comment 18 we recommend adding 'older adults': *"Recognition of mental health problems in children, young people, adults **and older adults** with intellectual disabilities."*	Thank you for your comment. Specific reference to older adults has been added.
The British Psychological Society	18	4.3.1.c	Further to comments 18 and 20 we suggest adding 'older adults': *"Diagnosis and assessment of mental health problems in children, young people, adults **and older adults** with intellectual disabilities. Including identification of contributory factors."*	Thank you for your comment. Specific reference to older adults has been added.
The British Psychological Society	19	4.3.1.e	"We believe that the term "accessibility" here requires clarification. The evidence suggests that people with intellectual disabilities experience many barriers in accessing both primary care and mainstream mental health services, but that ensuring accessibility and equitability of specialist services (for people with intellectual disabilities) should also not be overlooked as important, particularly at a time of constrictions of services and ever tightening "eligibility" criteria for such services (Emerson et al., 2012).	Thank you for your comment, 4.3.1.e refers to specialist services as well as primary care and mainstream health services
The British Psychological Society	20	General	*References* *BPS & Royal College Psychiatrists (2009). Dementia and people with learning disabilities: guidance on the assessment, diagnosis,*	Thank you

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			treatment and support of people with learning disabilities who develop dementia. BPS: Leicester and RCP: London. *Cooper, S-A., Smiley, E., Morrison, J., Williamson, A., Allan, L. (2007). Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. British Journal of Psychiatry, 190, 27-35.* *Emerson, E. & Hatton, C. (2007). Mental health of children and adolescents with intellectual disabilities in Britain, British Journal of Psychiatry, 191, 493-499.* *Emerson,E. Baines, S., Allerton, L., Welch, V. (2012). Health inequalities and people with learning disabilities in the UK: 2012. Improving Health & Lives: Learning Disabilities Observatory.* *Hollins, S., & Sinason, V. (2000). Psychotherapy, learning disabilities and trauma: new perspectives. The British Journal of Psychiatry, 176, 32-36.* *Schluengel, C., de Schipper, J.C., Sterkenburg, P.S., & Kef, S. (2013). Attachment, Intellectual Disabilities and Mental Health: Research, Assessment and Intervention. Journal of Applied Research in Intellectual Disabilities, 26, 34-46.* *Strydom, A., Shooshtari, S., Lee, L., Raykar, V., Torr, J., Tsiouris, J., Jokinen, N., Courtenay, K., Bass, N., Sinnema, M. and Maaskant, M. (2010), Dementia in older adults with intellectual disabilities-epidemiology, presentation, and diagnosis. Journal of Policy and Practice in Intellectual Disabilities, 7, 96–110.*	
Chartered Physiotherapists in Mental Health	1	4.1	Young people i transition from child services to adult services. This interface needs specific attention	Thank you for your comment, transition between services is covered in section 4.3.1 f.
Chartered Physiotherapists in Mental Health	2	4.2	Assessment units for young people / children withLD and mental health problems have faile our LD clients prvioeslt due to underskilled staff and poor regimes. Specific attention needs to be focussed on this provision	Thank you for your comment, the care setting will include assessment units for children/young people.
College of Occupational Therapists	1	3.1.h	The sensory environment can also be a significant contributory factor in distressed behaviour particularly for those with an additional diagnosis of autism.	Thank you for your comment. The examples given are there merely as examples, the list is not exhaustive
College of Occupational	2	3.2.f	People with learning disabilities and mental health problems may occasionally reside in prison or in a secure hospital.	Thank you for your comment. Secure settings have been added.

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Therapists				
College of Occupational Therapists	3	4.3.1.d	Appropriate, well graded occupation is a significant intervention that should also be mentioned here.	Thank you for your helpful comment, the scope has been amended to include this.
College of Occupational Therapists	4	4.4.e	We suggest this be *'Community participation and meaningful occupation'.*	Thank you for your comment, your suggestion has been added to the scope.
Contact a Family	1	1.1	Would like title changed to say 'Meeting the needs of people with learning disabilities and mental health issues' People with learning disabilities are more prone to develop mental health issues. Providing appropriate support early on can prevent problems developing. The word 'managing' gives the impression of professionals reacting to a problem that has arisen – rather than working to support an individuals needs.	Thank you for this comment we have made some changes to the title in light of your and other comments
Contact a Family	2	4.3.1.d	Would like to see interventions to support communication included as 'difficulty in communicating with others 'is a known to often lead to people developing mental health issues .	Thank you for your comment. Communication support will be covered within "other multidisciplinary therapies".
Coventry and Warwickshire Partnership Trust	1	3.1.g-i	3.1g) This section needs much more work. It is true that "The prevalence of mental health problems among people with learning disabilities varies depending upon the populations sampled and the definitions use." However, the next statement that 40% of people with LD have mental health problems and that this is greater than the general population is very tendentious and has never been adequately proved. Studies that have found high rates of mental health problems have generally viewed challenging behaviours as evidence of mental illness. Studies that have taken a more detailed, person-centred approach have found far lower rates of mental health problems- in fact often lower than in the general population. Whilst it is true that autism and problem behaviours are more common in people with LDs I would again urge you to critically examine the literature for true evidence that psychosis, dementia, ADHD etc are more common. A backward logic is often used i.e. a high proportion of people with LDs are given antipsychotics therefore there must be a high level of psychosis. This is clearly not true- the vast majority of antipsychotics are given for challenging behaviour	Thank you for your comment. Information has been added on problem behaviours/conduct disorder to clarify the rates. The rates quoted are from population based studies designed to measure prevalence, not extrapolations from drug use. The full guideline will review the evidence in detail.

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			where (often due to lack of Speech therapy, OT and Psychology services) people do not understand what the person is trying to communicate. Whilst there is evidence that dementia is more prevalent in people with Down's syndrome there is little evidence that dementia in the rest of the LD population is more prevalent. 3.1h) By far the greatest cause of "mental health" problems in this client group is lack of proper services leading to misunderstanding of communication and impoverished, boring lives with a lack of meaningful engagement. This is mentioned in the section but needs to be given far more prominence. At a time of national austerity there is a strong pressure to identify the cause of problems as internal (i.e. something wrong with the person themselves e.g. something about their learning disabilities that is causing the mental health problem (which incidentally you state and has never been proven)) People are then often "doubly- punished" by continuing to have an impoverished life and being prescribed strong drugs which will at best, strongly sedate them, and at worse have disabling side-effects. 3.1.i) While it is true that mental health problems are sometimes overlooked in people with learning disabilities, by many orders of magnitude the main problem in the field is that MH problems are vastly over-diagnosed. The reality is that the reasons people with LD do things and show the behaviours that they do is that their forms of communication are often very difficult to understand. The default position in the vast majority of services is to view the behaviour as signalling mental health problems rather than that the person is communicating that they want care, love, engagement, affection, interest, etc; in fact all the things that we all want in our everyday lives.	
Coventry and Warwickshire Partnership Trust	2	3.2.a-d	3.2 a) For the first time the document mentions "Misattribution of mental health problems in people with LDs" but this needs to be significantly expanded. 3.2c) The statistics in this section are staggering. For example, there is no evidence that 25% of people with learning disabilities have	Thank you for your comment. Overlooking mental health problems is considered in 3.1.i. The first sentence of 3.2.c has been revised to state "Psychotropic medication is commonly prescribed in people with learning

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			psychosis. I have worked for over 30 years with people with LDs and for 15 years with people with psychosis and other enduring mental health problems. My experience working with thousands of patients is that the prevalence of true psychosis in people with LDs is around that in the general population (if not a little lower). Therefore, it would seem that the vast majority of antipsychotic medication is given for behavioural problems – a form of treatment that Cochrane reviews have found to be generally ineffective if not harmful. Again I would urge NICE to review the evidence base for the use of antidepressants, anxiolytics, mood stabilisers etc in the LD population. I believe you will be surprised at the lack of convincing evidence for their use. 3.2d) It is important to recognise that many of the most effective psychosocial interventions are very accessible for people with LDs. For example, behavioural-activation approaches that are very effective for depression can be used with people with the most severe LDs. Similarly CBT, ACT, DBT and many other accredited therapies are being used for all major mental health problems in people with LDs across the country. However, you are right to state that access to these services is very patchy and many people have only got access to relatively ineffective medications.	disabilities." The evidence base for psychotropic medication will be reviewed during the development of the guideline. regarding 3.2.d, the evidence base regarding psychosocial interventions will also be reviewed during the development of the guideline.
Coventry and Warwickshire Partnership Trust	3	4.5	4.5 I think a major part of the investigation into economic aspects need to weigh up the costs of medication based approaches to issues in LD. The lack of evidence of effectiveness of, for example, antipsychotic medication for challenging behaviours needs to be weighed up against the growing literature on the disabling side-effects of long-term consumption of these medications. In doing this it is important to recognise that most people with learning disabilities do not have the same power to stop taking medication that people in the general population do. For example, it is estimated that over 30% of the general population stop taking SSRIs in the first few weeks after prescription because of distressing side-effects. Most people with LDs are not given the option of stopping taking the medication.	Thank you for this comment - we will take into account when developing relevant outcomes for the assessment of interventions
Coventry and Warwickshire	4	General	GENERAL: Whilst I welcome NICE looking into this area I believe that the scoping document as it stands reflects a very narrow	Thank you for this comment. In developing this guideline we will take into

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Partnership Trust			perspective that shows a limited understanding of the huge complexity of the field. I urge NICE to ensure that they meet with a very wide range of professionals including OTs, Speech and Language Therapists, Psychologists etc. NICE have got the opportunity to make some wide-ranging changes that could benefit many thousands of people with learning disabilities over the coming years. If, however, they maintain the current paradigm of diagnosis / medication to problems that are really communication / environmental in nature they will be complicit in the on-going impoverishment of the lives of some of the most vulnerable people in our society.	consideration a wide range of factors that could contribute to the development or maintenance of mental health problems, we expect this will include both communication difficulties and environmental factors. As with all NICE guidelines we will ensure that the composition of the GDG both reflects that needed to best address the scope and is mutli-professional in nature.
Mencap	1	General	Mencap welcomes the opportunity to comment on such an important topic and the fact that NICE is producing this guidance. Mental health problems are widespread and prevalent among people with a learning disability. At any one time, somewhere between 41 and 47 per cent of adults with a learning disability will be experiencing mental health problems, more than double the general population[1]. Mencap's health campaigning (Death by Indifference) has highlighted the discrimination that people with a learning disability face in the health service. We know that people with mental health problems can also face discrimination. As a result, people with a learning disability and mental health problems can face double discrimination. Therefore, we are concerned generally about the priority given to people with a learning disability and mental health issues, and strongly welcome the development of this guidance.	Thank you for your comments.
Mencap	2	3.1 i)	We welcome the recognition that for people with a learning disability and mental health problems, their "symptoms may inadvertently be attributed to their learning disabilities". We believe that the severity of this issue warrants its own section within the scope, explicitly stating that diagnostic overshadowing by health professionals, for example GPs, needs to be addressed[2].	Thank you for your comment. This topic will be fully reviewed during the development of the guideline.
Mencap	3	3.2	There is no mention in this section or in the draft scope of the statutory duty to make reasonable adjustments under the Equality Act. We know from our health campaigning that reasonable adjustments are often not made, for example reasonable adjustments to make sure mental health issues are spotted and people with a learning disability get effective treatment and support. This may mean	Thank you for your comment. An additional point has been added to refer to reasonable adjustments and the Mental Capacity Act. The evidence regarding health checks and health action plans will be fully reviewed during

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			longer appointment times, ensuring there is accessible information, and where people don't use formal communication taking steps to ensure families, carers or advocates are involved. It is also important that the Mental Capacity Act is highlighted in the guideline and the importance of it being understood and implemented by all staff; ensuring that people get the support they need to make decisions and that proper best interests decisions are made when people lack capacity. It is also important to highlight the value of annual health checks as this can be a key opportunity to spot mental health issues. It is important these are linked to health action plans, so people with a learning disability, those who support them and other health professionals understand the person's needs and treatment, and the person gets the right support to manage their needs.	the development of the guideline.
Mencap	4	4.3	We welcome the inclusion of 'accessibility of services' to people with a learning disability. However, just as important is the accessibility of information, for example easy read information. We believe that this issue should be included in section 4.3	Thank you for your helpful comment, the scope has been amended to include this.
NHS England	1	General	No comments.	Thank you
Nottinghamshire Healthcare NHS Trust	1	3.2.d	Music therapy is an effective alternative to more standard forms of counselling and psychotherapy for clients who find it difficult to connect with, express or differentiate between their emotions. Music therapy can be particularly helpful for those who find expressing themselves verbally difficult.	Thank you for your comment, music therapy among other interventions will be reviewed during the development of the guideline.
Nottinghamshire Healthcare NHS Trust	2	General	People are referred to music therapy with a wide variety of mental health problems, including: stress, anxiety, depression, psychoses and eating disorders. Music therapy is effective with people who have suffered past or more current traumas or who have issues in their lives that are causing them distress.	Thank you for your comment, music therapy would be covered under section 4.3.1 d) 'social and environmental interventions'.
Nottinghamshire Healthcare NHS Trust	3	3.1.c	do we need to highlight that a person with a learning disability is likely to have difficulties with understanding and expressing themselves rather than 'communicating'. People with mild / borderline LD can have significant difficulties understanding language. Research links on language impairment/esteem/mental health – see research by Judy Clegg University of Sheffield.	Thank you for your comment, 'limitations in understanding others' has been added.
Nottinghamshire	4	3.1.h	Contributing factor to mental health problems could include: not	Thank you for your comment.

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Healthcare NHS Trust			understanding what is happening and/ or expectation leading to anxiety.	Developmental factors are mentioned. The examples given are there merely as examples, the list is not exhaustive
Nottinghamshire Healthcare NHS Trust	5	4.3.1.j	Consider how sustainable interventions with staff teams and families are due to changes in staff and other family pressures/ dynamics.	Thank you for your comment, these are issues the guideline is likely to consider.
Nottinghamshire Healthcare NHS Trust	6	4.4	Speech, Language and Communication needs of individual recognised as an outcome? (consider research linking Specific language impairment / diagnostic overshadowing e.g. Clegg, J Bishop. D)	Thank you for your comment. The guideline will consider speech. Language and communication needs as a means to achieving the outcomes listed.
Nottinghamshire Healthcare NHS Trust	7	1	Mental health problems sounds so negative and such a poor way to start!	Thank you for this comment we have made some changes to the title in light of your and other comments
Nottinghamshire Healthcare NHS Trust	8	3.2.c-d	I would just like to raise awareness of physical well being affecting the emotional well being and that it is well evidenced. As a profession we use holistic methods to get our results. E.g. hydrotherapy, Rebound Therapy, sport and exercise to treat both and especially the "whole Person". It may not be the first line of treatment for some but for us it can often be or at least alongside medication treatment or to assist the coming off them.	Thank you for your comment. An additional point has been added regarding other approaches such as educational, occupation and developmental approaches, and promotion of healthy lifestyles.
The Priory Group	1	4.3.1.c	Appropriate diagnosis is critical to ensuring people with learning disabilities get timely access to the care and treatment that is right for them. There continue to be challenges in children with learning disabilities receiving an accurate diagnosis and appropriate needs assessment, through which they can gain access to specialist care and education that can provide them with the support they need. Too often in the current system people who do receive a proper diagnosis and assessment are being let down by poor integration between health, social care and, in some instances, specialist education. These gaps have a detrimental effect on patient care and outcomes, and often contribute in increased downstream costs to the health, care and education systems. The clinical guideline should look at ways to improve rates of diagnosis and assessment of mental health problems in children, young people and adults with learning disabilities, and examine ways	Thank you for your comment. We agree that appropriate diagnosis is extremely important and the guideline will address diagnosis as detailed in section 4.3.1.

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			to ensure greater co-ordination across all settings to ensure people's needs are fully assessed and an appropriate plan for managing their care is developed.	
The Priory Group	2	4.3.1.d	We welcome the inclusion of ways to manage and support those with learning disabilities and mental health problems to ensure they are provided with tailored, personalised care. With the largest network of specialist learning disability facilities in the UK, Craegmoor offers a flexible range of services that include: · Personalised care packages, tailored to the needs and preferences of our service users · Programmes that cater for users with a dual diagnosis · Access to an education and paid employment through local colleges and other agencies · Access to a supported living environment when the individual is ready · Support from a team of specialist learning disability advisors Results from the Craegmoor Quality Account for 2012-13 (available at: www.craegmoor.co.uk) show that 98% of our service users undergo an assessment of their needs and 98% of our service users have access to a named key worker. The final guidance should look to promote these vital elements of person-centred care.	Thank you for your comments.
The Priory Group	3	4.3.1.e	We welcome the inclusion of access to services as an area within the scope of the clinical guideline. People with learning disabilities and mental health problems often find access to services restricted as a result of poor diagnosis, delayed referrals, ineffective commissioning practices and a lack of clarity relating to responsibilities for delivering their care. The clinical guideline should look to promote tailored packages of care that are centred on the requirements of the individual, including access to the full range of services to meet their complex and evolving care and support needs. A diversity of providers is an important lever for improving patient care. It helps to drive the provision of better services, as well as delivering benefits to the NHS by stimulating greater productivity and efficiency amongst providers in a locality. However, the current lack of a level playing field for mental health providers from the public,	Thank you for your comment, this is an important issues that will be covered under section 4.3.1 e).

Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
			independent and voluntary sectors, through block contracts and repatriation, limits patient choice and access to the high-quality care. To help overcome these barriers, the guidelines should aim to promote access to services based on quality, rather than the nature of the provider and cost of the services they offer. To achieve this aim there is a need for greater transparency from providers on the quality of care they are delivering. This information should be available publically and easily comparable to drive improvements in care and inform robust commissioning decisions. In addition, quality accounts (in healthcare) and inspection and regulatory reports in health, care and education should all contribute to this process.	
The Priory Group	4	4.3.1.f	Young people with learning disabilities and mental health problems require access to high quality Child and Adolescent Mental Health Services (CAMHS) that meet their needs. However, CAMHS services are subject to widespread variations in access and quality across the country. The guideline should cover ways to ensure young people have access to high quality CAMHS services that are user centred and support the effective transition into adult services. The transfer of an individual from child to adult services presents various challenges for the individual and their carers, which can place additional and unnecessary pressure on those involved, if not managed effectively. We welcome the inclusion of both of these elements within the proposed scope of the guideline.	Thank you for your comment, these are issues the guideline is likely to consider.
The Priory Group	5	4.3.1.g	As set out above, people with learning disabilities and mental health problems may well be receiving funding for their care and support from a number of different agencies and organisations. The advancement of personal budgets, whilst positively putting the individual and their carer in control of their care, creates further fragmentation in this regard. Care co-ordination is thus a real challenge for people with complex needs – particularly where care for these individuals is delivered and who pays for their interventions. The NICE clinical guideline should seek evidence from providers and commissioners, both locally and nationally, to ascertain how a clearer pathway of care for people with learning disabilities and mental health problems can be most effectively managed.	Thank you for your comment. Evidence on care pathways will be reviewed during the development of the guideline.

Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
			The Priory Group of Companies, including Craegmoor, work closely with community healthcare professionals and commissioners to provide a stable and safe environment for the service user as part of a seamlessly integrated care pathway, from independent hospitals to residential services to supporting the individual. This ensures accessible psychological expertise, continuity of care and the delivery of positive and measurable outcomes. The individual may enter and leave the pathway at any point depending on their individual needs. Priory would be happy to provide further information to NICE on this model as part of the development of this guideline.	
RCSLT	1	3.1.c	Although this may be true of some people, it seems to underestimate the difficulties experienced by people with Mild LD. More accurate perhaps would be to say that the difficulties of people with Mild LD may be less apparent to those who do not know them well as people often develop strategies to conceal or attempt to over-come their difficulties. Individuals may need support in understanding more complex information, in sharing their needs and ideas and in interacting socially with others.	Thank you for your comment, this section has been changed to acknowledge this point.
Real Life Options	1	General	RLO are supportive of the Draft Scope as outlined.	Thank you for your comments.
Real Life Options	2	3.1.d	We would suggest that the word 'treat' is replaced with the word 'respect'. We would also want to see a commitment to person centred thinking in this section. It is important to respect each person as an individual and to be person centred in your approach.	Thank you for your comment. 'Treat' has been changed to 'respect' and a person-centred approach has been added.
Real Life Options	3	General	Whilst the draft scope references the autism guidelines at the end we feel there should be more stated within the guidelines themselves about the interaction between learning disability and autism and the potential impact on mental health.	Thank you for your comments, the aim of this document is to set out what should be included in this guideline. When developing the guideline the group will of course consider the interaction with the Autism guideline and how best to reference this.
Roche Products	1	4.1.1	Roche would welcome the inclusion of down syndrome in this clinical guideline. This is because 1 in 6001 children in the UK are born with down syndrome, which is the single largest known cause of learning disabilities. People with down syndrome may experience behavioural and emotional problems, including anxiety, depression, and attention deficit hyperactivity disorder. They are also more likely	Thank you for your comment. People with Down syndrome will be included in the guideline. This has been explicitly added to 4.1.1.b.

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			to have difficulty coping with the problems in positive ways, especially during adolescence. 1 Foundation for People with Learning Difficulties website (http://www.learningdisabilities.org.uk/help-information/learning-disability-a-z/d/downs-syndrome/)	
Royal College of General Practitioners	1	4.3.1	As well as services I would like an evaluation of promotion of good mental health including employment opportunities and physical health promotion through exercise and gardening	Thank you for your comment, such interventions would be covered under section 4.3.1 d) 'social and environmental interventions' and "occupational interventions"
Royal College of General Practitioners	2	4.3.1	There should be a section on co-ordinating services and continuity of health care professionals	Thank you for your comment. This would be covered under 4.3.1 g) g) Coordination and communication with key persons and services in the life of the person with learning disabilities.
Royal College of General Practitioners	3	4.3.1.d	I feel there needs full access to the full range of mental health services and boundaries that arise between secondary care mental health services and learning disabilities need to be addressed with a single point of access for people with LD, their carers and supporters and GPs. Consider the invest to save approaches in order to prioritise community care over long term institutional care.	Thank you for your comments. The guideline will consider accessibility of services, transition and coordination of services as set out in section 4.3.1.
Royal College of General Practitioners	4	4.3.1.d	What tools are useful to detect early warning signs of common mental health issues? How can current screening in childhood, transition and annual adult health checks be improved to detect mental health problems?	Thank you for your comment, these are issues the guideline is likely to consider.
Royal College of General Practitioners	5	4.3.1.e	What reasonable adjustments work to help detect and treat people with LD with mental health issues	Thank you for your comment, these are issues the guideline is likely to consider.
Royal College of General Practitioners	6	4.3.1.c	The detection of mental health problems in people with complex health needs including those who are non verbal and/or have profound multiple learning disabilities	Thank you for your comment. This group will be included in the guideline (4.1.1.a).
Royal College of General Practitioners	7	4.3.1.d	Include the specific issues around disability hate crime, abuse, torture and bereavement and loss	Thank you for your comment. Community interventions have been added to 4.3.1 and hate crimes added in 3.1.c
Royal College of Nursing	1	General	No comments.	Thank you

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Royal College of Paediatrics and Child Health	1	General	In addressing the above 3 questions, I have the following comments to make:- A key area for all these families is 'Respite Care' especially for those poorer families who are unable to pay for this privately. This could have been included in the 'Whole System Approach'. Although small in numbers, those children and young adults who survive severe head injuries will have a wide range of complications including intellectual disability. Some will also have co-morbid mental health problems. This group may be more difficult to manage given the sudden event unlike most other conditions eg Down's Syndrome where the family have time to prepare themselves for a more predictable course.	Thank you for your comment. The guideline will include respite care (3.2.e). People with learning disabilities due to head injury in childhood will be included in the guideline. The scope has not specifically named all the aetiological conditions it will cover for reasons of length, including other conditions with onset in childhood.
Royal College of Paediatrics and Child Health	2	General	The scope appropriately includes the broad definition of learning disabilities (mild, moderate & severe) rather than a clinically simplistic and impractical IQ 70 cut off It recognises the need to include syndromes which are associated with a range of learning disabilities but have high rates of mental health complications. It includes children, young people as well as adults.	Thank you for your comments.
Royal College of Paediatrics and Child Health	3	General	It addresses key areas of practice including risk and diagnosis, transition of care from child to adult services.	Thank you for your comments.
Royal College of Paediatrics and Child Health	4	General	It is asking appropriate questions and aiming to address the wide range of implications of mental health problems in this population.	Thank you for your comments.
Royal College of Paediatrics and Child Health	5	4.3	For children and young people, the support that may be available within schools, particularly special schools, should be considered (and so it is important to engage with school staff when dealing with mental health problems in those with a learning disability).	Unfortunately this is a clinical guideline, and therefore we are unable to make recommendations for teachers. However, the guideline may consider the interaction between healthcare professionals and teachers.
Royal College of Paediatrics and Child Health	6	4.3.1.j	It should be stressed that it is highly desirable to offer early, and continuing, support to families and carers when a person with a learning disability has mental health problems. Too often, meaningful help is only provided at crisis point or even after family breakdown. Instead the support offered should, hopefully, avoid crises and family breakdown.	Thank you for your comment, support for families and carers will be considered by the guideline development group, as set out in section 4.3.1j)

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Royal College of Paediatrics and Child Health	7	4.3.1.j	Often those with learning disabilities have communication difficulties and whilst it is clearly important to make every effort to communicate with them appropriately, the role of the family as advocates should be acknowledged. Therefore, the concern of a family regarding the mental health of a member with a learning disability should be listened to very carefully.	Thank you for your comment, these are issues the guideline is likely to consider.
Somerset Partnership NHS Foundation Trust	1	4.3.2	Will be important to consider differential diagnosis, signposting and gaps in provision ie when mental health services wont pick up although mental health / personality issues are the primary problem not LD. This could fall within the scope of 4.3.1. I service structures to support effective delivery of interventions	Thank you for your comment, section 4.1.1 a) specifies that services should include people with all severity of learning disabilities. Accessibility of services will be addressed (4.3.1.e)
University of Wolverhampton	1	3.1. a)	Definition of learning disabilities. The definition is not consistent with DoH definition: 'Learning disability includes the presence of: a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with; a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development' (Valuing People Now, DoH, 2001). The DoH definition is more culturally sensitive than the one included in the scope directly referring to an IQ.	Thank you for your comment. The definition used is to be consistent with the NICE guideline on challenging benaviour, and is in keeping with ICD-10 and DSM-5 criteria. It is also in keeping with the Valuing People definition, with the exception that Valuing People does not give a precise definition for "a significantly reduced ability.....", although the point immediately below the Valuing People definition does discuss IQ<70.
University of Wolverhampton	2	3.1 g)	Problem behaviours. The term 'challenging behaviour' replaced previously used term 'problem behaviour.' Although still not fully accepted, it is a preferred term as less stigmatising.	Thank you for your comment. A variety of terms are currently in use to describe these behaviours, and there are differing views on the best term. The term problem behaviour has been used in recognition that such behaviours are often a problem for the person with learning disabilities, causing them emotional distress, and sometimes limiting their occupational, recreational and residential opportunities, and community participation, hence highlighting a need for therapy and support.
University of	3	3.2 b)	Access to services. [addressing the needs of people from ethnic	Thank you for this comment. In the

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Wolverhampton			minority communities] 'A whole system' does not include voluntary and community sector and it may disadvantage people who rely on it. As stated in the 'Guidance for commissioners of mental health services for people from black and ethnic minority communities' published by Joint Commissioning Panel for Mental Health (2014) 'to create more accessible, broader, and flexible care pathways, commissioners should integrate services across the voluntary, community, social care and health sectors' and multiple points of entry into specialist mental health assessment/care are needed (including non-clinical routes). Further there is a need to providing services that should take into account their physical health too (enabling the concept of parity of esteem)	guideline we will focus on primarily on assessment methods and the provision of effective interventions. In developing our recommendations we will take into account the context in which the interventions are delivered and coordinated, and the need to facilitate good access to services. However, matters concerning the organisation and integration of services are one for commissioners and are outside the scope of this guideline.
University of Wolverhampton	4	4.2.a)	Care setting. [addressing the needs of vulnerable migrants and trafficked people] We feel that the specified 'care setting' are limited and may impact on opportunity to identify both people with learning disabilities and mental health problems in police cells and immigration centres.	Thank you for your comment. Police cells would be covered under 'criminal justice services', however immigration centres are outside the scope of NICE guidelines.
University of Wolverhampton	5	4.3.1 a)	Identification of people with learning disabilities at risk of developing mental health problems. Taking into consideration the high level of prevalence of mental health problems in people with learning disabilities, wouldn't it be better to focus on identifying risks factors for developing mental health problems or factors that could promote wellbeing?	Thank you for your comment, these are issues the guideline is likely to consider.
University of Wolverhampton	6	4.3 e)	Accessibility of services We think that 'pro-active' attitude in identifying mental health problems in people with learning disabilities should be added as this would encourage services to focus on identifying needs.	Thank you for your comment, this is covered under section 4.3.1 a).

These organisations were approached but did not respond:
5 Borough Partnership NHS Foundation Trust
5 boroughs NHS Foundation Trust Partnership
Abertawe Bro Morgannwg University Health Board
Ability West
ADHD Foundation
Allocate Software PLC
Alzheimer's Society

Amdipharm Mercury Company Ltd
Aneurin Bevan Health Board
Anxiety UK
Assocation of NHS Occupational Physicians
Association for Dance Movement Psychotherapy UK
Association for Family Therapy and Systemic Practice in the UK
Association for Real Change
Association of Ambulance Chief Executives
Association of Anaesthetists of Great Britain and Ireland
Association of Directors of Children's Services
Association of National Specialist Colleges
Association of Neurophysioloigcal Scientists
Association of Psychoanalytic Psychotherapy in the NHS
Autism West Midlands
Barchester Healthcare
Barnet Enfield and Haringey Mental Health Trust
Belfast Health and Social Care Trust
Betsi Cadwaladr University Health Board
Birmingham City Council
Birmingham Community Healthcare NHS Trust
Black and Ethnic Minority Diabetes Association
Black Country Partnership Foundation Trust
Boots
Bradford District Care Trust
Bristol Autism Spectrum Service
British Academy of Childhood Disability
British Association for Behavioural & Cognitive Psychotherapies
British Association for Counselling and Psychotherapy
British Association for Music Therapy
British Association of Art Therapists
British Association of Dramatherapists
British Association of Social Workers
British Medical Association
British Medical Journal
British National Formulary
British Nuclear Cardiology Society
British Paediatric Mental Health Group
British Red Cross

Calderstones Partnerships NHS Foundation Trust
CALM - Crisis, Aggression, Limitation and Management
Capsulation PPS
Care England
Care Quality Commission
Central & North West London NHS Foundation Trust
Central London Community Health Care NHS Trust
Challenging Behaviour Foundation
Chartered Society of Physiotherapy
Children's Services Development Group
Chroma
CIS' ters
Citizens Commission on Human Rights
Clarity Informatics Ltd
College of Mental Health Pharmacy
College of Optometrists
Complementary and Natural Healthcare Council
counselling for prisoners network
Crisis Prevention Institute
Croydon Health Services NHS Trust
Croydon University Hospital
Cumbria Partnership NHS Trust
CWHHE Collaborative CCGs
De Montfort University
Department for Education
Department of Health
Department of Health, Social Services and Public Safety - Northern Ireland
Deputy Parliamentary & Health Service Ombudsman
Derbyshire County Council
Dimensions
Diverse Cymru
Division of Education and Child Psychology
Doncaster Council
Drinksense
Durham County Council
Ealing Hospital NHS Trust
East and North Hertfordshire NHS Trust
East Sussex County Council

Economic and Social Research Council
Empowerment Matters
Epilepsy Society
Essex County Council
Ethical Medicines Industry Group
Expert Patients Programme CIC
Faculty of Forensic and Legal Medicine
Faculty of Public Health
False Allegations Support Organisation
Five Boroughs Partnership NHS Trust
Foundation for People with Learning Disabilities
Gateshead Council
GP update / Red Whale
Greater Manchester West Mental Health NHS Foundation Trust
Guidelines and Audit Implementation Network
Hafal - Wales
Havencare
Health & Social Care Information Centre
Health and Care Professions Council
Health and Safety Executive
Healthcare Improvement Scotland
Healthcare Infection Society
Healthcare Inspectorate Wales
Healthcare Quality Improvement Partnership
Healthwatch East Sussex
Healthwatch Plymouth
Hertfordshire Partnership NHS Trust
Hertfordshire Partnership University NHS Foundation Trust
Herts Valleys Clinical Commissioning Group
Hindu Council UK
Hiraeth Services Ltd
Hockley Medical Practice
Home Care Direct
HQT Diagnostics
Humber NHS Foundation Trust
Independent Children's Homes Association
Information Centre for Health and Social Care
Kent and Medway NHS and Social Care Partnership Trust

Lancashire Care NHS Foundation Trust
Learning Disability Wales
Leeds and York Partnership Foundation Trust
Leeds North Clinical Commisioning Group
Leicestershire county council
Leicestershire Partnership NHS Trust
Lincolnshire County Council
Liverpool adult ADHD - Ladders of Life
Local Government Association
London Metropolitan Police
Lundbeck UK
Luton and Dunstable Hospital NHS Trust
Manchester Metropolitan University
Medicines and Healthcare products Regulatory Agency
Mental Health and Substance Use: dual diagnosis
Mental Health Foundation
Mental Health Group - British Dietetic Association
Mental Health Matters
Mental Health Providers Forum
Mersey Care NHS Trust
Middlesex University
Mind
Ministry of Defence (MOD)
National Association of Primary Care
National Autistic Society
National Clinical Guideline Centre
National Collaborating Centre for Cancer
National Collaborating Centre for Mental Health
National Collaborating Centre for Women's and Children's Health
National Community Hearing Association
National Deaf Children's Society
National Development Team for Inclusion
National Institute for Health Research
National Patient Safety Agency
National Self-Harm Network
National Society for the Prevention of Cruelty to Children
Neonatal & Paediatric Pharmacists Group
NHS Choices

NHS Confederation
NHS Connecting for Health
NHS County Durham and Darlington
NHS Cumbria Clinical Commissioning Group
NHS Halton CCG
NHS Hardwick CCG
NHS Health at Work
NHS Improvement
NHS Leeds West CCG
NHS Medway Clinical Commissioning Group
NHS North Somerset CCG
NHS Plus
NHS Sheffield
NHS Sheffield CCG
NHS Somerset
NHS South Cheshire CCG
NHS Southern Derbyshire CCG
NHS Wakefield CCG
NHS Warwickshire North CCG
Noblecare
Norfolk Community Health and Care NHS Trust
North East Essex Clinical Comissioning Group
North of England Commissioning Support
North Staffs Mind
North West London Hospitals NHS Trust
Northamptonshire county council
Northern Health and Social Care Trust
Northumberland, Tyne & Wear NHS Trust
Nottinghamshire Office of the Police and Crime Commissioner
Nursing and Midwifery Council
Nutricia Advanced Medical Nutrition
Openspace Research Centre
Optical Confederation, The
Otsuka Pharmaceuticals
Oxford Health NHS Foundation Trust
Oxfordshire Clinical Commissioning Group
Oxfordshire County Council
Oxleas NHS Foundation Trust

Parents' Education as Autism Therapists
Partnerships in Care Ltd
Patient Assembly
PHE Alcohol and Drugs, Health & Wellbeing Directorate
POhWER
PrescQIPP NHS Programme
Primary Care Pharmacists Association
Primrose Bank Medical Centre
Prospect PBS Training Ltd
Protomed
Public Health Agency
Public Health Agency for Northern Ireland
Public Health England
Public Health England - Improving Health and Lives Learning Disabilities Observatory
Public Health Wales NHS Trust
Queen's University Belfast
RDaSH NHS Foundation Trust
Residential Community Care Services
Respond
Rethink Mental Illness
Rotherham Doncaster and South Humber NHS Foundation Trust
Royal College of Anaesthetists
Royal College of General Practitioners in Wales
Royal College of Midwives
Royal College of Midwives
Royal College of Obstetricians and Gynaecologists
Royal College of Pathologists
Royal College of Physicians
Royal College of Psychiatrists
Royal College of Radiologists
Royal College of Surgeons of England
Royal National Institute of Blind People
Scottish Intercollegiate Guidelines Network
Servier Laboratories Ltd
Sheffield Health and Social Care NHS Foundation Trust
Sheffield Teaching Hospitals NHS Foundation Trust
SIFA Fireside
Skills for Care

Social Care Institute for Excellence
Somerset Partnership NHS Foundation Trust
South Eastern Health and Social Care Trust
South West Yorkshire Partnership NHS Foundation Trust
South Western Ambulance Service NHS Foundation Trust
Southern Health & Social Care Trust
Southern Health Foundation Trust
Southern Health NHS Foundation Trust
St Andrews Healthcare
St Mary's Hospital
Staffordshire and Stoke on Trent Partnership NHS Trust
Stockport Clinical Commissioning Group
Suffolk County Council
Sussex Partnership NHS Foundation Trust
Tees, Esk and Wear Valleys NHS Trust
The Association for Psychodynamic Practice and Counselling in Organisational Settings
The Challenging Behaviour Foundaton
The Disabilities Trust
The Fragile X Society
The Fremantle Trust
The Hearing and Learning Disabilities Group
The Judith Trust
The Samaritans
The University of Birmingham
Therapy in Praxis
Tizard Centre
Treating Autism
Tuberous Sclerosis Association
Turning Point
Unite - the Union
United Kingdom Council for Psychotherapy
United Response
University Hospital of North Staffordshire NHS Trust
University Hospitals Birmingham
University of Warwick - Centre for Educational Development Appraisal and Reserch
University of Wolverhampton
User Voice
Voluntary Organisations Disability Group

WAVE Trust
Welsh Government
Welsh Scientific Advisory Committee
Western Health and Social Care Trust
Wicked Minds
Wigan Borough Clinical Commissioning Group
WISH - A voice for women's mental health
XCD Consulting Services T/A BrainTrainUK
York Hospitals NHS Foundation Trust
Yorkshire Ambulance Service NHS Trust
Yorkshire and Humber Strategic Clinical Network