Response ID ANON-Y5NQ-W11D-A

Submitted to Learning Disabilities, Autism and Neurodivergence Bill: consultation
Submitted on 2024-04-20 11:20:00

About you

Are you responding as an individual or an organisation?

Organisation

What is your name?

Name:
Royal College of Psychiatrists in Scotland (RCPsychiS)

What is your organisation?

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Royal College of Psychiatrists in Scotland

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If you are responding as an organisation, please tell us which of the following categories best describes you?(select all that are appropriate)

Other (please say below)

Other (please say):
Professional Medical Body

If you are responding as an individual please tell us which of the following categories best describes you?(select all that apply)

Not applicable - responding as an organisation (see previous answer)

Which ethnic group best describes you?

Not Answered

What was your age last birthday?

Not Answered

Which local authority area you live in (or operate in if an organisation - tick all that apply)? Individuals should select only one.

Which of these options best describes how you think of yourself?

Not Answered

Which gender identity best describes you?

Not Answered

The Scottish Government would like your permission to publish your consultation response. Please indicate your publishing preference:

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Do you consent to Scottish Government contacting you again in relation to this consultation exercise?

Yes

I confirm that I have read the privacy policy and consent to the data I provide being used as set out in the policy.

I consent

Reach and definitions: who should the Bill include?

Which of these proposals do you agree with (if any), please tell us why?

Please give us your views:

We feel that there is merit to ring-fencing this Bill to the conditions which are associated with the greatest need.

We strongly support the inclusion of learning disability in this Bill, as this group experience the greatest marginalisation in society and have the greatest level of need, often with comorbid physical disabilities.

There is a need to ensure that the terminology of the Bill is future-proof, as diagnostic labels may change in future. It is important that terminologies are reviewed on a regular basis.

Within this, however, we acknowledge that there are people who are not formally diagnosed and thus disadvantaged within this proposal, but this is an issue of resource rather than definition.

The Scottish Government may wish to refer to the World Health Organisation (WHO) concepts of disability where the interaction between the neurodivergence and personal or environmental factors lead to impairment of functioning or disability.

Which of these proposals do you not agree with (if any), please tell us why?

Please give us your views:

We would agree that the term 'neurodiverse' covers too wide a group of people to be useful.

While 'neurodivergent' is a term which many people find to be a helpful umbrella term, it seems that the meaning is not yet fixed. For example, there does not seem to be agreement as to whether schizophrenia is a neurodivergent condition.

Without clear and universally agreed definition of 'neurodivergent', we would be against its use in a legal context as it lacks the precision necessary for legislation.

Is there anything else that we should consider in relation to this topic?

Please give us your views:

1 Resource
We would welcome a needs-based approach to learning disability and neurodivergent conditions. However, this Bill does not make any commitment to the funding and additional resources that this approach would need.
Where there are restricted resources, psychiatric diagnosis can be used as a method of gatekeeping, and this Bill seems likely to increase demand for diagnosis. At present, there is not the capacity in the NHS in Scotland to meet current need for diagnosis of neurodivergent conditions. This is illustrated by the fact that there are thousands of adults across Scotland who are currently awaiting an assessment for autism or ADHD. For other neurodivergent conditions, such as dyslexia and dyspraxia, there are no diagnostic services for adults outwith education or the private sector.

It might be argued that self-identification would mean that demand would not increase, but it seems unlikely that any service which currently uses diagnostic gatekeeping could accept self-identification. There is also the risk that self-identification perpetuates health inequalities, as self-identification is most available to those who already have access to a degree of information and support.

2 Children and Young People

In considering the reach and definitions in the Bill, consideration must be given to the specific needs of children and young people with learning disabilities.

Firstly, considering diagnosis, in many children a formal diagnosis of learning disability may take some time to be reached. Global Developmental Delay (GDD) is not mentioned in the current consultation – this is an early years term which often (but not always) leads on to a learning disability or other neurodiversity during childhood. We suggest the inclusion of those with GDD within the scope of the Bill to ensure inclusion of younger children. It should also be noted that 'Learning Disability' is not a term recognised universally in education settings, and where it is used, may be used in a different way, potentially leading to confusion with specific learning difficulties.
Secondly, we note some concerns about the broad coverage of the Bill and its implications for the specific needs of children and young people. The experience of our members is that when services and strategies for children with learning disability are included as one part of either general children's services or services for those with neurodevelopmental issues, there is potential for child-specific needs not to be met. For example, we welcomed that for the first time children with learning disability are mentioned in the CAMHS strategy and service specifications in Scotland. However, specialist Learning Disability (LD) CAMHS services remain patchy and under-developed, and children and young people with moderate, severe or profound learning disability are generally unable to access mainstream mental health and wellbeing services.

Thirdly, there is a general risk, but more marked in childhood, that those with the greatest need are potentially the ones most excluded from services. This includes, but is not limited to, those with more severe levels of LD, more complexity or comorbidity, more severe mental health problems, or more social exclusion or poverty. They are also the group least able to advocate for their rights and whose families are too exhausted, and socially excluded themselves, to be able to advocate for them.

Finally, we acknowledge that the focus of the bill is on the person with LD, but in childhood particularly it is difficult to separate the child from their family – high stress levels in parents and siblings will impact greatly on the child with a learning disability and vice versa. As such, we feel the Bill does not adequately reflect the needs of parents and carers, who are crucial in the systemic supports required by children and young people with learning disability.

Whilst the introduction to the Bill says that "neurodivergent people and people with learning disabilities" should be understood as referring to all age groups, the issues covered and references given do not reflect this. We would ask that the needs of children and young people are better represented in the next stages of the Bill, which, at present, is adult focused in many places.

3 Scope and terminology

We do not think naming specific conditions that cause learning disability (such as Down's Syndrome) in the Bill would be helpful. Such a list of specific conditions could never be exhaustive. It may be more helpful to explicitly reference those with more severe levels of learning disability (including profound and multiple learning disability (PMLD)), and those with additional high levels of physical and mental health complexity and social factors; such as those living in poverty, or high numbers of adverse childhood experiences (ACEs).

Statutory Strategies for Neurodivergence and Learning Disabilities

Which of these proposals do you agree with (if any), please tell us why?

Please give us your views:

Proposal 1: We would agree that a national strategy would be helpful in this area, but it would need to build on previous strategies for people with learning disabilities to ensure that specific needs of this group would not be lost in a strategy which includes a wider group.

Furthermore, it is imperative that the strategy aligns with, and references if necessary, other Government strategies or policies.

The Strategy must also be clear on its aims and objectives; be directed by a delivery plan with concise projects and timelines; and be allocated appropriate Government responsibility and accountability.

Proposal 4: A review schedule to ensure that a strategy is fit for purpose seems a positive proposal.

Proposal 5: We welcome the involvement of people with lived experience in developing strategy, but it requires expertise and resources to bring in a full set of representative views.

This will also need to include carers, advocates and multiagency professionals who work with children, young people and adults with more severe levels of Learning Disability and additional mental health needs who are unable to fully speak for themselves. If these individuals are not included, there is the potential unintended consequence of those with the highest and most complex level of need being further excluded.

Proposal 6: This has potential to be positive, but much depends on implementation. There can be unintended consequences of scarce resources being used on investigations rather than service provision.

Which of these proposals do you not agree with (if any), please tell us why?

Please give us your views:

Proposal 2: It is possible that different bodies will be working to different strategies and delivery plans, and this could cause a disconnect when they have to work closely together. Alignment and implementation of an national strategy would be a better approach.

Proposal 3: It is often the case that "guidance" is less likely to result in robust systems.

Is there anything else that we should consider in relation to strategies?

Please give us your views:

Any strategy will require sufficient resourcing to bring it into practice.

A key point of the current strategy for people with learning disability, and the implementation of the 'Coming Home' Report, will not happen fully due to lack of funding.

Any new strategy, national or local, will suffer from the implementation gap.

There may be resource-neutral interventions, but most will require resourcing, and this necessitates a resource being taken from elsewhere, if additional overall funding is not provided.

Indeed, any support for any of the proposals requires clarity on where resources will be taken from to fund it. The specialist resources need to be targeted at the highest level of need, complexity and risk.

Mandatory Training in the Public Sector

Do you agree with this proposal, please tell us why?

Please give us your views:

The College welcomes the provision of high-quality training which improves the experience that neurodivergent people and people with learning disabilities have when interacting with public sector agencies.

Training needs to be based on practical strategies for staff, rather than generic awareness-raising. This should include such factors as communication and environmental needs.

We also agree that the contribution of people with lived experience is an important part of the development of such training. However, there needs to be engagement with the full range of people with lived experience, so that the range of experiences of neurodivergence and learning disability are appropriately represented.

Making training mandatory could be positive, but only if this is properly resourced so that the training can be kept up to date and, very importantly, staff can be given time to properly engage with training. There also needs to be consideration as to how completion of the mandatory training will be evidenced and checked.

Furthermore, the Scottish Government should consider how training in degree level professions could be delivered at an undergraduate level to tackle misconceptions and enhance skills at an early stage.

Children and Young People:

Mandatory, and other, training needs to include those working in children's services, and cover the needs of those with more severe levels of LD and communication difficulties and those with biopsychosocial complexities who may not be able to actively participate in developing and delivering the training.

It is important that it is made possible for support staff and any practitioners to implement the advice in training; for example, where support staff need to spend longer with a person; or where clinicians and social workers (etc) need to offer longer appointments, carry out home visits, make specialist environments possible, or make preparations for hospital visits (etc).

Do you not agree with this proposal, please tell us why?

Please give us your views:

No comment

Is there anything else that we should consider in relation to mandatory training?

Please give us your views:

The evaluation of the Oliver McGowan mandatory training in England has been so-far based on participants' own evaluation of what they have learned from the training. This has been positive, but the intent of training is to change outcomes for people accessing services and it is not yet clear whether this has been the case. Implementation of mandatory training should be with a mind to the outcomes wanted and how this will be measured, rather than simply the number of people trained. This will also need to be appropriately resourced.

Scotland has pioneered hospital Learning Disability Liaison nursing services for adults and children. These services included training of staff and support for people with learning disability to access the full range of hospital care. They should be recognised in this Bill (and consultation), as they are an important part of the solution to training health staff and improving access which are key elements of the Bill. (Please note the following references:

Brown M, Chouliara Z, MacArthur J et al (2016) The perspectives of stakeholders of intellectual disability liaison nurses: a model of compassionate, person centred care. Journal of Clinical Nursing. 25, 7-8, 972-982. doi: 10.1111/jocn.13142

Easy-Read-Liaison-Nursing-Report-1.pdf (ldcop.org.uk)

Inclusive Communications

Which of these proposals do you agree with (if any), please tell us why?

Please give us your views:

Proposal 1: Providing alternative means of communication where needed helps with shared decision-making and is likely to improve the experience of those receiving a service.

Proposal 2: This is likely to help not just people with neurodivergent conditions and learning disabilities, but improve understanding for all. We would also hope that there could be examples of high-quality, easy-read documents presenting complex information (for example, on the Mental Health Act or Adults with Incapacity Act), provided at a national level. This would mean both a lack of duplication of effort across agencies, and operate as a model for more specific local information.

Proposal 3: Overarching strategies may provide consistency and guidance; but a balance needs to be struck between national direction and (what could be considered) interference from Government in local strategies.

Proposal 4: Enforceable matters are more likely to be implemented compared to suggested guidance and best practice which is often victim to limited resources.

However, the agreement is subject to these being given appropriate, additional resources – expecting this to be provided from current resources may mean that already stretched services may have to make cuts to core services to provide this.

Which of these proposals do you not agree with (if any), please tell us why?

Please give us you views:

No comment

Is there anything else that we should consider in relation to inclusive and accessible communication?

Please give us your views:

The College is in favour of inclusive communication for all. However, once more, proper funding is a key part of this, and we are aware of many cases where the lack of accessible communication is purely down to lack of funding.

To illustrate this point, examples we are aware of include:
- Organisations previously creating accessible information using well-recognised image banks which require a paid subscription had to cancel that subscription due to lack of funding, meaning poorer quality of accessible information.
- NHS appointment letters which were previously created by administrative staff in a personalised, easy-read format have been replaced by auto-generated letters which are not accessible, as a cost-saving measure.

For the public sector to produce the inclusive communications that are needed by - not only neurodivergent people and people with learning disabilities but other groups as well - staff need to be trained, be given the time to produce or provide the communication, and have access to any resources they need for that inclusive communication.

We would ask for consideration of an additional provision being built into the Bill to make ensure that the needs of those with the most challenged communication skills are being considered. This includes younger children, those with more severe levels of learning disability, and whose communication is further affected by severe sensory impairments or mental illness.

Data

Which of these proposals do you agree with (if any), please tell us why?

Please give us your views:

Proposal 1: This will be discussed in our response on accountability.

Proposals 2 and 3: improved data collection, at both local and national levels, helps to make informed decisions about service needs and appropriate provision.

Proposal 4: A Scottish version of the LeDeR programme may be helpful, but only if the findings are acted on. Whilst there have been some suggested improvements, it is less clear that circumstances have truly improved for people with learning disabilities in England since the programme commenced.

For example, in 2019 44% of cases reported to LeDeR were felt to be avoidable causes of death; in 2021 it was 49%, and 2022 42%. Any Scottish version of the LeDeR programme would need to learn not only from any successes of the programme, but also from its limitations.

An integrated approach to data collection and analysis is needed to research and address the underlying issues around the mortality gap for people with learning disabilities. This would include not just the mortality data (as in the LeDeR programme), but wider information, such as physical health and social inequality.

Which of these proposals do you not agree with (if any), please tell us why?

Please give us your views:

No comment

Is there anything else that we should consider in relation to data?

Please give us your views:

All of these would need proper resourcing, with additional staffing needed at local and national levels, to make them useful tools in improving lives. Data collection needs to be embedded in practice.

The Bill must ensure that data is collected across the lifespan. There should be a responsibility and powers for data to be requested regarding learning disability from other organisations, such as CAMHS workforce and waiting list data.

The Government needs to find a way of agreeing definition(s) of learning disability and terminology across agencies to [be able to] obtain accurate data, particularly in children's services with additional complexity of education having different terminology to health. There is also a need to actively promote research with, and for, people with learning disability to better understand their needs.

The Government also needs to ensure that learning disability and neurodiversity data is visible within mental health data; for example, within CAMHS datasets, including workforce and waiting times. Health and wellbeing outcomes data need to include physical and mental illness to ensure that those with the most severe and complex health issues are highlighted.

We agree that current data collection and analysis should involve people with lived experience, and include looking at intersectionality and particularly disadvantaged groups.

The College believes children and young people, especially those with more severe and profound learning disability, complexity and additional physical and mental health problems are a particularly disadvantaged group. There is a need for a focus for their needs not to get lost. Too much of Learning Disability-related policy and data is actually adult-only, as evidenced by many of the references in the consultation document. LD SS is an example of where 'people with LD' in the consultation means adults. It does not include statistics for children but this is not stated in the consultation document. The restarted data collection should include children.

The Bill consultation, as a whole, is adult-focused and there are a number of issues where it would benefit from additional references and links to evidence relating to children. Some suggestions are given throughout this response.

LeDeR in England includes children from age 4 with a learning disability diagnosis. We assume that the proposed equivalent in Scotland is adult only due to there being child death reviews, which would include children with learning disability. It will be important that there is linkage and cross-referencing between adult learning disability death reviews and child death reviews to ensure that there is joint learning and that learning disability aspects of child deaths are fully considered.

The suggestion of using qualitative as well as quantitative data to inform policy work is welcome. As well as (where possible) gaining the experiences and views of children and young people with learning disability. Parents and carers will also need to be involved for those of younger age and earlier developmental stages. Siblings can give a very helpful additional perspective for this group of children too. They should be considered for inclusion.

Independent Advocacy

Which of these proposals do you agree with (if any), please tell us why?

Please give us your views:

Proposal 1: The College has found that our patients highly value the service provided to them by Independent Advocacy, but advocacy services have long been underfunded and are not available to everyone who needs or wants them because of this.

Proposal 2: Further understanding of specific barriers would improve the design and accessibility of advocacy services, but again this would need to be accompanied by appropriate funding.

Which of these proposals do you not agree with (if any), please tell us why?

Please give us your views:

No comment

Is there anything else that we should consider in relation to independent advocacy?

Please give us your views:

There are existing gaps in the current, mandatory, provision of independent advocacy for people detained under the Mental Health Act. This represents a far smaller group of people than those covered in this Bill, which suggests that the goals of wider advocacy will need significant time, focus and resource to achieve.

Where there are limited resources, advocacy needs to be targeted towards those with the greatest need.

There is also a need to ensure that advocacy is available for children and young people with learning disability – children's advocacy services do not always have the expertise for those with severe communication difficulties.

We should also consider the provision for specific groups, including non-instructed advocacy for those with severe communication disorder, and for the small minority of children and young people, where there is concern that parent's or carer's view may not be in the child's best interest.

Health and Wellbeing

Which of these proposals do you agree with (if any), please tell us why?

Please give us your views:

Proposal 1: As in our response above, we are in support of a National strategy which local policies can then use as guidance in creating their own policy. High-level strategies can suffer from an implementation gap due to resource issues.

Proposal 2: As in our response above, mandatory training can be useful, but there are a number of considerations regarding resourcing, updating training and giving staff time to complete it, as well as measuring the outcome of training.

Proposal 3: As in our response above, we support inclusive communication, but this needs to be adequately resourced.

Any proposals that go forward must include children in a meaningful way, taking steps to ensure that children's organisations are informed of requirements.

Which of these proposals do you not agree with (if any), please tell us why?

Please give us your views:

No comment

Is there anything else that we should consider in relation to health and wellbeing?

Please give us your views:

Proposal 4: Patient passports are already in use in a number of learning disability services, and we agree that they can be very helpful in communicating the needs of the person accessing services. However, there are a number of issues which would need to be addressed before making them mandatory. Firstly, they are often not kept up to date with a person's changing needs and preferences, meaning that staff are using inappropriate and outdated information. Secondly, they are often not accessed or used when they are available. Thirdly, there are problems related to systems compatibility and information sharing. For a patient passport to be used across primary care, community health, ambulance services, inpatient services and local authorities, it potentially has to cross four or more computer systems. The Key Information Summary (KIS) shows that this is possible, but this system has needed active development and resourcing. Finally, there may be information governance issues in sharing such a passport automatically between health and local authorities. The PAMIS passport is held by the individual, which can solve some of these issues, but for people who cannot advocate for themselves, this relies on carers bringing the passport with them.

Proposal 5: The College agrees that measures are needed to address the avoidable premature mortality experienced by people with learning disabilities. There is some evidence that annual health checks do improve some outcomes for people with learning disabilities, but we would also support ongoing data collection and research to ensure that annual health checks are the best use of resources to achieve this outcome. There may be a case for extending the annual health checks to other groups who experience avoidable premature mortality if they are an effective intervention. However, this, firstly, needs to be appropriately resourced, so that the health checks are not taking resources from other services within health which may be equally or more helpful in reducing health inequalities. Secondly, avoidable premature mortality may be as high or higher for people with Severe Mental Illness or Substance Misuse Disorder as it is for autistic people without a learning disability, and we would want to ensure that additional health interventions such as annual health checks are rolled out on the basis of need, rather than whether a group happens to be included in any piece of legislation.

Consideration should be given to extending annual checks to include children and young people with learning disability, with suitable resources to provide these. Many 'behavioural' presentations referred to LD CAMHS are actually an expression of the child's distress due to unrecognised pain or discomfort or other physical health issue. Many children with learning disability see a Community Paediatrician at some stage, but only those with the most complex needs would have regular review throughout childhood and adolescence, with practice varying across the country. We find that children with learning disability and additional mental health and behavioural issues often rarely access their GP due to their anxiety and family concern about behaviour. This avoidance can lead to unidentified health problems and can escalate fears of healthcare facilities, which continue into adulthood.

Beyond the specific proposal for annual health checks, consideration should be given to additional routes to improve health outcomes in those with learning disability and neurodivergence. For example, consideration should be given to sufficient resourcing for psychiatric and mental health services with the expertise and role to support people with learning disability and neurodivergence in physical healthcare settings. Regular dental review and treatment is essential, and enabling access to dental care is a key part of physical health care, as well as audiology and ophthalmology. The environment in which in-patient care is delivered also has a key role to play in ensuring that health care is effective and meets patient's needs - noise, lighting, privacy, and space are all very important.

Lastly, there should be more depth of information and recommendations around mental health provision as well as physical health in the Bill – as well as there being significant co-morbidity/intersectionality between both for people with learning disability. This needs to include children as well as adults. We recommend that the "where we want to get to" section needs to specify mental as well as physical health, and children and young people as well as adults. The problems of those with comorbid mental disorder and learning disability are especially acute in children and young people who often do not have access to the full range of services – inpatient care, intensive home treatment, and early intervention, community wellbeing and prevention services.

Mental Health and Capacity Law

Do you agree with this approach?

Not Answered

Please tell us why?:

The College supports the proposal to review the definition of Mental Disorder in the context of the wider Mental Health and Capacity Law Reform Program, rather than make changes within this current Bill. The fact that definition of Mental Disorder is used across multiple pieces of civil and criminal legislation means that any changes may have consequences in many different areas, necessitating a wider consideration.

We also have specific concerns that any excision of learning disability and autism from the current definition of mental disorder would risk removing this patient group from the protections afforded through the existing Mental Health (Care and Treatment)(Scotland) Act 2003, as well as risking the deprioritisation of this group within already hard-pressed mental health services, and even risk their inappropriate diversion to the criminal justice system.

We have raised this position in response to the Scottish Mental Health Law Review ('Scott Review'). We believe it is important that the Bill references the outcomes of this review, as well as other Government policies and strategies, in order to ensure that there is no conflict with the wider program of mental health law reform.

In the information provided in this section it would be helpful to reference Child Protection as well as Adult Support and Protection. Children with disability, particularly those with communication impairments, behavioural disorders, learning disabilities and sensory impairments may be additionally vulnerable to abuse and neglect. Incidence of abuse of disabled children is likely to be under-reported.

Part 4: Specific Support Needs and Concerns - National Guidance for Child Protection in Scotland 2021 - updated 2023 - gov.scot (www.gov.scot)

We elaborate more on this in relation to children and young people with learning disability in the relationships section below.

While noting that this is to be explored via the Mental Health and Capacity Reform Programme, we would like to mention the complications of formally diagnosing mental illness in those with more severe levels of LD and communication difficulties. Psychiatric diagnoses generally are dependent on what a person says about their thoughts and emotions etc, as well as observable behaviour. As such, children and young people with learning disability (as well as adults with more severe levels of LD) who cannot communicate their thoughts and feelings often cannot be reliably given mental illness (or in some cases neurodevelopmental) diagnoses. This is also due to the fact that diagnostic frameworks were developed for people without LD and then applied to this population.

In these cases, our members tend to treat symptoms (e.g. anxiety, hyperactivity, mood fluctuation) rather than give formal psychiatric diagnoses. We would be worried about inadvertently further reducing access to mental health treatment for this already underserved group if learning disability is removed from the Mental Health Act. We would usually only be able to give a suspected mental illness diagnosis rather than being able to formally diagnose for the reasons outlined above.

In addition, it can be the complex combination of LD with other neurodevelopmental conditions and psychosocial stressors that cause difficulties which get to a level requiring hospital admission for assessment. Once these are appropriately assessed and managed no additional mental illness diagnosis may be appropriate.

Social Care

Which of these proposals do you agree with (if any), please tell us why?

Please give us your views:

Proposal 1: as with our more general comments, a national strategy which can then inform local policy and implementation is likely to be the most effective.

Proposal 2: for mandatory training to be effective for social care staff there needs to be appropriate resourcing, as noted in our previous responses on this. As with health staff, training needs not only money but time to complete.

Proposal 3: as noted in our previous response, much of the lack of inclusive communication is related to resourcing. For example, accessible appointment letters created by administrative staff have been replaced by automated letters which are not accessible as a cost-saving measure.

Which of these proposals do you not agree with (if any), please tell us why?

Please give us your views:

No comment

Is there anything else that we should consider in relation to social care?

Please give us your views:

The information in this section notes that "based on figures from the Independent Review of Adult Social Care (the work that led to proposals for a National Care Service), around 21% of the social care budget (£780m) is invested in services for people with learning disabilities". This suggests that people appears to actually mean adults. Equivalent information should be given for children and young people with learning disability.

The SDS section specifies it is for adults and children, which is welcome clarification.

The integration of health and social care is not happening consistently with children's services, with different arrangements in different health boards. This makes multiagency planning within some services difficult and working strategically across the lifespan or transitions for lifelong conditions of Learning Disability, Autism and Neurodiversity. This will be further complicated if the NCS does not include children. Flexibility of services like social care and housing to provide continuity across transition periods could make a huge difference for young people with the most complex needs.

Housing and Independent Living

Which of these proposals do you agree with (if any), please tell us why?

Please give us your views:

No comment

Which of these proposals do you not agree with (if any), please tell us why?

Please give us your views:

No comment

Is there anything else that we should consider in relation to housing and independent living?

Please give us your views:

Secure housing and appropriate support where needed are important to maintain good mental health, and we support policies which improve this for people in need.

This section also appears to be quite adult-focused. It would be helpful to consider instances where, for example, a young person needs to move out of their family home before they finish school and whether housing and care provision can be made available locally for them which can remain theirs on transition to adulthood. Often the registration of carers organisations and rules around housing provision mean that young people have to move again. This may also help reduce out of area placements in residential schools in cases where it is not possible for the child to remain in the family home but can still be taught at their local school.

Complex Care – Coming Home

Should there be a statutory duty upon the relevant public body or bodies (Integration Authority, Health Board, Local Authority) to hold a Dynamic Support Register? (Proposal 1)

Yes

Please tell us more?:

Where well-implemented, Dynamic Support Registers can help co-ordinate and focus work to get people home from hospital or prevent admission. However, holding a Dynamic Support Register is only the first step in ensuring that people with learning disabilities are not in hospital unnecessarily. There needs to be the resourcing of appropriate housing and support so that people can remain in the community.

There must be inclusion of children and young people in whatever is put into legislation.

Which of the options for the National Support Panel (Proposal 2) do you think has the most benefits?

Not Answered

Please tell us more?:

Any of these proposals would require to be appropriately resourced, otherwise the question would be of whether money that could be spent on support was being spent on investigation and review. We would be in favour of an alternate approach detailed below.

The College is not in favour of option B being put in place in isolation. Individual examples give much richer data and information.

Option C would require legal 'teeth' as in our members' experience the children and families they work with are rarely given priority and usually can't speak up for themselves. A combination of A and C may work be best.

Whichever proposal is ultimately put forward must include children. The Bill must ensure that only children and young people who really require hospital-based assessment and treatment are admitted to the LD CAMHS inpatient care once this becomes available. In addition, their admissions need to be as short as possible, with mental health, social care, education and family support being coordinated to enable treatment and support to continue at home or in the child's local community.

Are there any other options that you think we should consider?

Please give us your views:

Instead of a National Support Panel, it may be more appropriate for there to be a legal process for someone in hospital (or someone who is acting on their behalf) to challenge their ongoing stay. This would be a mechanism akin to the appeal against detention in excessive security under the Mental Health Act which resulted in the development of new services of medium security settings. In the experience of our members, it is the lack of provision of appropriate support and accommodation which is usually the barrier to discharge, so any appeal or review process needs to appropriately target these issues to create real change.

The Mental Health Act (or its replacement) needs to have more powers to ensure that social care is available for as soon as a person no longer needs hospital.

However, we recognise that this proposal is focussed primarily on people already in hospital.

There needs to be a mechanism for those at risk of placement breakdown, including risk of hospital admission (as is practised in England). This would require those with funding powers locally across agencies to look at more appropriate alternatives and closer to home. It would also be more inclusive of children and young people with learning disability, for whom there are currently no hospitals in Scotland to get stuck in. They are more likely to be stuck at home in very risky situations without appropriate support, or in residential schools or other accommodation. Some of these will be in just as restrictive an environment as hospital (if not more) but without the legal framework to offer protection. An important minority of them will actually have unmet mental health need and it is intensive local mental health provision or hospital admission which is required.

The need for hospital admission for people with learning disability across the lifespan for assessment and treatment needs to be better delineated. The legacy of institutionalisation continues to cause confusion and muddied thinking today. Hospital admission for people with learning disability should (as for the general population) be for assessment and treatment of physical or mental health conditions. It should not be as a last resort when no suitable care is available in the community.

We don’t have access to mental health beds at all for children with moderate, severe, or profound learning disability in Scotland. The impact of this is clear in the Scottish Needs Assessment 00527514.pdf (www.gov.scot) and it is accepted that provision is required. Adult LD Psychiatrists have raised their frustration about people being stuck in hospital for lack of social care placements once treatment over, with their patients lacking access to community activities and relationships, with their mental health and behaviour deteriorating as result. As a result, they don’t have beds for their patients who need inpatient mental health assessment/treatment. Often they remain in inappropriate Adult Mental Health wards or ill and distressed in community.

We need to develop a better understanding across agencies of the role of hospital for people with learning disability and get away from the legacy belief that hospital equals institutionalisation. We would not say that people with learning disability should never be admitted to acute medical hospitals for treatment of physical health problems as they will be institutionalised. If we think this for psychiatric admissions then we risk reducing access of people with learning disability to mental health services by confusing inpatient mental health care for people with learning disability with institutionalisation.

Psychiatrists generally do everything they can to avoid admission to hospital for people with learning disability. However, it can be life-saving, and hugely improve quality of life and improve inclusion in community when really needed. For example, properly assessing and treating major mental illness when present, or showing that it is not present when suspected. Medication rationalisation can sometimes be required to be carried out safely in a hospital environment, which also needs to provide a holistic MDT approach, including with respect to physical health. The Scottish Needs Assessment 00527514.pdf (www.gov.scot) carefully looks at when and why inpatient mental health care is required for children and young people with learning disability and services across the lifespan may find this information useful.

For some children with learning disability our members should and would admit sooner if beds were available, allowing shorter, more focused therapeutic admissions followed by discharge home; not waiting until everything has completely fallen apart. Access to all tiers of community mental and physical health services (as well as social care and education) for people with learning disability is essential in preventing unnecessary admissions and in properly delineating the need for and purpose of admission.

Patients can and do go home, especially where there are mental health, as well as sufficiently specialist social, care and education provision to support. This is more likely to happen when families haven’t already been completely broken prior to admission.

People with learning disability need and have a right to the same range of physical and mental health care as the general population:
- Prevention, early intervention, specialist community and hospital services.
- Reasonable adjustments to allow access to services – inclusion in mainstream where possible (with training & support), specialist where required to properly meet needs.
- Timely treatment – prevention, early intervention, community, intensive and inpatient mental health treatment is an important factor
- Education, social care and family support in preventing institutionalisation where people are stuck in hospital or leading highly restricted lives ‘in the community’.

The Coming Home work, dynamic risk registers and any panel system must include children and young people (as is the case in England’s Transforming Care programme). It makes no sense to start at age 16, when difficulties which lead to out of area placements are well established and entrenched. A number of young people are already in out of area residential schools by then and others end up in care placements or hospital soon after they leave school and families can no longer cope. The College has been advocating for the inclusion of children in this work for years, including in the Scottish Government Out of Area short life working group as long as 10 years ago.

LD CAMHS clinicians and their multiagency partners in children’s services can generally identify those most at risk of home placement breakdown many years before it happens. i.e. our members know who the next generation of adults placed out of area will be. Sometimes high-risk factors are identifiable even in preschool years. Our members know what interventions could help prevent this but rarely have services and service coordination to be able to do so. There needs to be better local services from early childhood to reduce risks, enable better trajectory and ensure local skills across the agencies to

work with those with the most complex needs and keep them local. Such service coordination and provision is well described in the Lenehen 'These are our Children' review and we would strongly recommend it being included in the references to the bill and to inform ongoing work:
Lenehan_Review_Report.pdf (publishing.service.gov.uk)

If there is no clear pathway for multiagency collaboration around admission and discharge for children and young people, via mechanisms such as the dynamic risk register and panels, the national LD CAMHS inpatient unit once open will quickly become 'blocked' in a similar way to Adult LD wards. Specialist LD CAMHS inpatient care (when required) should mean short-focused admissions with community services being available to continue treatment in the community.

A peer support network is proposed in the Bill (via HIS) for practitioners working with adults with learning disability. We have an LD CAMHS Scotland Network of Clinicians established 16 years ago which provides peer support and CPD, also contributing to national development in CAMHS and to consultations such as the present one. This is entirely run voluntarily by clinicians, despite seeking support on a number of occasions from government and NHS Scotland. The 2017 inpatient needs assessment recommended a national LD CAMHS clinical network to support the development of the inpatient unit and community services, linking with multiagency partners across Scotland. This could easily build on our well-established network and enhance it's already valuable work. It is not clear why such support has not been forthcoming and we ask that the LDAN Bill work includes the need for this.

Relationships

Which of these proposals do you agree with (if any), please tell us why?

Please give us your views:

Our responses to proposals 1-4 are in line with our previous responses in other parts of this consultation: we are in favour of access to independent advocacy, good data collection, inclusive communication, and national strategies which give guidance to local bodies.

However, all of these need to be appropriately resourced to be effective.

Where resources are limited, these need to be targeted to those with the greatest needs.

Our response to proposal 5 is as our detailed response in the section on accountability.

Which of these proposals do you not agree with (if any), please tell us why?

Please give us your views:

No comment

Is there anything else that we should consider in relation to relationships?

Please give us your views:

Proposal 3 includes mention of "support provided by professionals who have specialist training in learning disabilities". It is difficult to comment on this without more detail – what would the professional background of these people be? What level of specialist training would they have? Who would be responsible for employing them?

There are already difficulties in recruitment of professionals trained in learning disabilities so workforce planning would need to be carefully considered.

There is also a need in this section, as with others, to ensure that any of these proposals must include children and young people in practice. It is noted in the opening paragraph that children, young people and adults that have a learning disability or are neurodivergent have the right to the same opportunities as anyone else to live satisfying and valued lives and, to be treated with the same dignity and respect. However, the proposals and further detail are very much focused on adults.

As noted above, children with disability, particularly those with communication impairments, behavioural disorders, learning disabilities and sensory impairments may be especially vulnerable to abuse and neglect. Incidence of abuse of disabled children is likely to be under-reported.
Part 4: Specific Support Needs and Concerns - National Guidance for Child Protection in Scotland 2021 - updated 2023 - gov.scot (www.gov.scot)

On page 91 of the main consultation document it mentions that 68% of women with learning disability have experienced sexual abuse before turning 18. However, Child Protection and the need to prevent and recognise sexual and other abuse of children with learning disability is not included in any of the actions or proposals. This needs to be rectified.

Indeed, people with learning disabilities or neurodivergence may be more vulnerable to other forms of crime including financial exploitation, exploitation in perceived relationships, and 'cuckooing'. Similar approaches within the criminal justice system to support people reporting such crimes are important.

Data collection proposals should include data on relationships education at school for those with all levels of learning disability.

Access to Technology

Which of these proposals do you agree with (if any), please tell us why?

Please give us your views:

These are broad and non-specific proposals which we would agree with in principle, but we would need more detail in order to comment appropriately.

Which of these proposals do you not agree with (if any), please tell us why?

Please give us your views:

No comment

Is there anything else that we should consider in relation to access to technology?

Please give us your views:

Questions which would need to be answered regarding this issue would include:
- Which organisations would have responsibility for providing training and support?
- Who would deliver training and support?
- How would those staff be trained themselves?
- How would this be resourced?
- Which budgets would this support and training come out of?
- How would it be ensured that support and training was targeted to those most in need, to avoid reinforcing existing health inequalities?

Digital inclusion is welcome, but the Government needs to be mindful of the additional risks of, for example, online abuse and grooming. This needs consideration.

It would be helpful to cross-reference this section to work on online safety for children such as CEOP.

There should also be consideration of the positive use of technology for those with severe communication issues, such as Augmentative and Alternative Communication devices.

Employment

Do you agree with this approach? Please tell us why?

Please give us your views:

We support this approach, as this legislative landscape is already complex.

We also support an approach that includes all people who are in the most need. For example, data suggests that people with Severe Mental Illness have unemployment rates as bad as those for autistic people, and we would not want the employment support needs of either group to be neglected.

Work to increase access to employment needs to link more clearly with education proposals. Schools should be in a good position to recognise young people's areas of special interest and skills early on and link into work experience. For example, exploring what young people with learning disability and diversity could offer in meaningful ways to local employers.

Social Security

Which of these proposals do you agree with (if any), please tell us why?

Please give us your views:

As with our responses in other sections, we are in favour of national strategies which give guidance for local policy and implementation, appropriate training for staff interacting with people with neurodivergent conditions, and good data collection.

However, all of these proposals need to be adequately resourced to be effective.

Which of these proposals do you not agree with (if any), please tell us why?

Please give us your views:

No comment

Is there anything else that we should consider in relation to social security?

Please give us your views:

It is positive to see that Child Social Security is referenced in this section.
It is important that social security workers have an understanding of LDAN and also of fluctuations in level and type of needs of individuals caused by

additional mental and physical health problems.

Justice

Which of these proposals do you agree with (if any), please tell us why?

Please give us your views:

We broadly welcome these proposals as helpful to people encountering the criminal justice system. However, the proposals lack detail in some areas, and there is no consideration of resourcing.

We are aware of situations within prisons at the moment where the needs of people with learning disabilities have been correctly identified but cannot be met due to issues around resources or staffing.

If there is increased identification of needs, there must to be commensurate input to then meet those needs. The prevalence of learning disability, autism and ADHD within the criminal justice system is not currently accurately known, but from current research this may be upwards of 25% of people within the system. If the definition of neurodivergent conditions was wider than this the percentage will obviously be higher.

Which of these proposals do you not agree with (if any), please tell us why?

Please give us your views:

Proposal 2: We note that current screening tools are not appropriate for use in the criminal justice system, and if used will simply increase demand for full assessments which are already difficult to access due to resource issues.

Is there anything else that we should consider in relation to justice?

Please give us your views:

Proposal 6: in addition to diversion, we would recommend the provision of specialist courts for specific groups who have difficulties navigating the criminal justice system, to allow for the development of expertise and knowledge in criminal justice staff. Where diversion is used, there is the possibility of services not being appropriately provided, which also needs to be addressed.

We welcome the focus on children and young people in this section and the disability toolkit for Children’s hearing systems. Final proposals must ensure that youth justice systems are included.

Getting good data regarding LDAN in the criminal justice system would be easier if there were good identification and diagnostic services in childhood – earlier identification and support may also ultimately prevent young people entering the criminal justice system.

It is noted in the Bill document that people could be deemed unsuitable for diversion schemes due to their mental health or learning disability. This is not unexpected. Our members regularly come across children assessed as 'unsuitable' for various ‘universal’ services due to their learning disability, mental ill health and other complex needs. Reasonable adjustments need to be made to all services but we also need to acknowledge that inclusion in mainstream services does not meet the needs of all. Specialist provision needs to be made for some, to avoid the current situation of those with the most complex/severe needs in reality often getting the least services across health, social care and education.

Restraint and Seclusion

Do you agree with this approach?

Not Answered

Please tell us why?:

We agree that the issue of inappropriate used of restraint, seclusion and other restrictive practices affects a wider group of people than those covered in this Bill, and therefore any additional statutory guidance on these practices should cover all of those potentially affected.

It is also important that any guidance to reduce restraint includes training on/implementation of preventative measures, with capable environments that reduce anxiety and meet people’s emotional, communication, physical, mental health and sensory needs.

The restraint reduction bill would affect all children and young people but an LDAN or LD commissioner could have power to scrutinise the monitoring & implementation of other legislation/guidance to ensure it is implemented in a way that meets the needs of those with LD who can’t always speak up for themselves

It is good to see focus on children in this section, reflecting the work done in this area by parents and also involving professionals.

It is also important to note that restraint and restrictive practice can happen in any setting, including people’s own homes. The use of ‘safe spaces’ at school or home or use of rooms to withdraw to can (if misused) effectively be the same as seclusion, rather than providing the low sensory stimulation environment that they are intended to.

Transport

Which of these proposals do you agree with (if any), please tell us why?

Please give us your views:

We are in support of policies which will help those who have difficulty accessing transport to do so; however, as with other proposals, they would need to be resourced appropriately.

Which of these proposals do you not agree with (if any), please tell us why?

Please give us your views:

No comment

Is there anything else that we should consider in relation to transport?

Please give us your views:

The transport requirements for relatives and carers travelling to see people with learning disability or neurodivergence who have been accommodated or hospitalised at a distance from their original home address should be considered. This would, of course, require adequate resourcing which is already limited.

It is positive to note that recent reviews of the Blue Badge Code of Practice have amended eligibility criteria to include hidden disabilities, including distress when travelling, and for those with conditions which results in lack of awareness around traffic. This has previously been a big problem for families of those accessing LD CAMHS services.

There is a lot of good work described and proposed. It is disappointing and surprising that there is no mention at all of school transport. In our members' experience school transport issues are a major cause of anxiety and distress for our children. When it works well, it can be excellent, with drivers and support staff that understand and relate well to pupils. But this is not always the case. Last minute changes to arrangements, and children and families not knowing who will provide transport until very end of summer break can also cause real distress. Distress associated with school transport is a fairly frequent underlying cause of 'challenging behaviour' referrals to LD CAMHS services. There is a need to train and value people involved in transport – good transport arrangements can make huge difference to children's ability to access education and to enable calmer family life on return from school.

Education

Which of these proposals do you agree with (if any), please tell us why?

Please give us your views:

Improvements in training and data collection have the potential to benefit children and young people with learning disabilities and neurodivergent conditions; however, such changes would need to be appropriately resourced to be effective.

Proposal 1: Yes – would be helpful to have these specific reporting requirements to check needs of LDAN pupils are met and similar for wellbeing outcomes. A commissioner could actively monitor these.

Proposal 2 – yes, and we should link across agencies for this, e.g. LD CAMHS may be able to help with aspects of teacher training relating to mental health and behaviour (given appropriate resources). We do frequently have referrals for anxiety and behaviours associated with school-related issues. Better training opportunities for teachers and support staff in relation to LDAN and associated mental health issues would be very welcome. There needs to be more recognition of the crucial role of Pupil Support Assistants and thought given to career progression and acknowledgment of skills. Many of these staff are highly experienced and skilled, and can make a huge difference to whether the environment at school allows a child to thrive and learn.

There needs to be consideration of the increasing expectation on teachers and support staff, and how they get time and resources to implement any training that is given.

Proposal 3 – data is important. It is not clear how reliable disaggregated data on learning disability is, given the patchy nature of diagnostic services and differences in terminology between education and health professionals.

Which of these proposals do you not agree with (if any), please tell us why?

Please give us your views:

No comment

Is there anything else that we should consider in relation to education?

Please give us your views:

Timely access to direct child assessment by educational specialists, especially educational psychologists, to identify learning disability and specific learning difficulties would help prevent distress and exclusion. It would also minimise referrals to specialist mental health services for assessment of development difficulties and unnecessary 'medicalisation' of children. The extent to which Educational Psychologists carry out assessments for Learning Disability varies hugely across Scotland. In some places they do not carry out such assessments at all. BPS guidance states it should be a health-based assessment, but arrangements within Health services are similarly variable.

There are examples of where the child's planning system (GIRFEC) works well. However, this has lessened the use of Coordinated Support Plans which, unlike Childs Plans has legal duties for implementation.

2014 Act – a Commissioner for LD or LDAN could have oversight to check that the needs of children with LDAN are properly included.

It is important that there is flexibility in providing education for those with learning disability and additional mental health needs which can mean a fluctuating presentation and fluctuating need. If education arrangements are only based on when someone is at their best, this can lead to vicious cycles. For example, when getting back to education is part of someone's recovery, but their school does not have resources and skills to manage them until they are well.

In our members' experience, children and young people with learning disability and mental health/complex needs often have reduced access to education under the guise of 'flexible timetables'. These may be described as being because the child cannot cope with the school environment rather than because the school cannot (for resource reasons or otherwise) provide an appropriate environment for the child. Very long 'phased return' plans can effectively become part time school placements.

The National Neurodevelopmental Specification for Children and Young People makes clear that support should be put in place to meet the child or young person's requirements when they need it, rather than be dependent on a formal diagnosis. However, in reality diagnostic pathways are being developed, mainly for Autism and ADHD, with Learning Disability frequently being left out

The consultation document notes that under Article 12 of the UNCRC, every child and young person who is capable of forming their own views has the right to express those views freely in all matters affecting them, with those views being given due weight in accordance with the age and maturity of the child and young person. We also need to ensure needs of those who cannot formulate and express their views are also respected and spoken up for.

Children and Young people – Transitions to Adulthood

Do you agree with this proposal, please tell us why?

Please give us your views:

No comment

Do you not agree with this proposal, please tell us why?

Please give us your views:

No comment

Is there anything else that we should consider in relation to Children and young people – Transitions to adulthood?

Please give us your views:

The issues for young people with learning disabilities and neurodivergent conditions in transition to adulthood are well-known to those working in this area. As noted, the problem has been the implementation gap, with over-stretched services unable to provide what is promised in policy. The College does not feel that this issue is addressed in this Bill.

In order to get transitions right, we need to acknowledge and address the significant inequalities in CAMHS for children and young people with learning disability. The Lived Experience Advisory Panel (LEAP) is correct when saying that 'There might still be children and young people being admitted to adult mental health wards instead of a Child and Adolescent Mental Health Service (CAMHS) unit'. As noted in other sections of this response, for those with moderate, severe or profound Learning Disability there is still no inpatient care accessible in Scotland. Services for this group of children and young people are patchy and unequal also in parenting, early intervention, community wellbeing services and specialist community CAMHS.

Accountability

Which of the 5 options set out above do you think would best protect, respect and champion the rights of neurodivergent people and people with learning disabilities? You can select multiple options if you wish.

Option 2, Option 4, Option 5

Please give the reason for your choice(s).

Please give us your views:

We would support the expansion of powers and additional resourcing of the existing oversight bodies and structures as this will take advantage of extant expertise and experience. Indeed, the consultation highlights the fact these organisations are not specific to learning disability and neurodivergence. This can be a strength with exchange of ideas, commonality, lack of duplication, and a pooling of resources.

However, there would need to be a structure for how oversight is given to this and whether actually the main role of an LD or LDAN commissioner could be to ensure that the needs of these groups of people are being fully reflected in the work of the existing oversight bodies and structures.

Options 4 and 5 would, in addition to the above, provide valuable support and guidance for individuals and organisations. However, we would want to ensure that this was not resourced by reducing other services which provide needed support.

Children and young people must be appropriately included in whichever option is finally used, and there needs to be thought given as to how those with the most severe and complex needs are prioritised.

Are there any other options we should consider? Please give details.

Please give us your views:

Rather than a Commissioner it may be more helpful for there to be a locus within government which has oversight of the relevant areas. This would allow co-ordination and linkage of information and expertise to inform policy, strategy and implementation. On the ground there are multiple professionals and services involved – for example, even within psychiatry there are several different specialities that will offer valuable insights into the needs of patients as well as the needs of the services. Which specialties should contribute to this in itself will require specialist judgement and coordination to provide an appropriately nuanced view to Scottish Government that reflects the current reality and complexity of this landscape within psychiatric services.

The complexity of services is even greater if, as we advocate, children and young people are meaningfully included in the implementation of this Bill. A Commissioner or other arrangement (locus, champions, rapporteurship etc) needs to be able to link across all aspects of services for children and young people with learning disability. Reflecting the complexity of their needs, the on the ground services are multiple and they span many areas of policy in the Scottish Government. This can mean that no-one is responsible.

Any commissioner or other arrangement (locus, champions, rapporteurship etc) must also consult with carers and advocates for young children, and those with moderate, severe or profound learning disability, or additional issues like mental ill-health which impair their ability to advocate for themselves. DPOs are said to ensure that people's voices come first and do not need to be represented by anyone else; but we must be clear that not all people with learning disability can speak up for themselves, even with support. Any of the suggested arrangements must make a particular effort to include the needs of those with more severe learning disability and communication issues. There is rightly a focus of the Children's Commissioner to get the views of children themselves, but we must ensure that the needs of those who cannot give their views are not further disadvantaged.

The most important thing for the most excluded and underrepresented groups (including children and young people with learning disability and additional mental and physical health complexity) is that there is someone with the remit and powers to ensure that they are included and their needs considered across all existing parts of the government and public sector.

There could also be a role of a Commissioner (or equivalent) to be a source of information and advice for anyone who has serious concerns about the care, education or treatment of a child with learning disability. For example, where signposting or support is required to raise those concerns through appropriate channels. The complexity of service provision with multiple agencies involved can make it difficult to know where to take concerns and unfortunately there can be fear of the potential repercussions of raising concerns.

Evaluation

How did you hear about the Learning Disabilities, Autism and Neurodivergence Bill and our consultation?

how did you hear about consultation:

What format did you use to learn more about the Learning Disabilities, Autism and Neurodivergence Bill consultation?

Please help us improve our consultations by answering the questions below. (Responses to the evaluation will not be published.)

Matrix 1 - How satisfied were you with this consultation?:

Please enter comments here.:

Matrix 1 - How would you rate your satisfaction with using this platform (Citizen Space) to respond to this consultation?:

Please enter comments here.: