

Consultation Response

A National Care Service for Scotland: Consultation

The Scottish Commission for People with Learning Disabilities November 2021



A National Care Service for Scotland: Consultation A response by the Scottish Commission for People with Learning Disabilities

The Scottish Commission for People with Learning Disabilities (SCLD) welcomes the opportunity to respond to these important proposals on developing a National care Service for Scotland.

SCLD is an independent charity and non-governmental organisation. SCLD aims to make a significant contribution to creating an environment in Scotland in which systems and culture are changed to ensure people with learning disabilities are empowered to live the life they want in line with existing human rights conventions.

At SCLD we base everything we do on what people with learning disabilities tell us.

In responding to this consultation, SCLD has:

- Listened to its own Expert Group, a group of people with learning disabilities living across Scotland
- Met with learning disability support organisations who have themselves listened to the views of people they support

On this consultation

SCLD has serious concerns about the way this consultation has been carried out. In the Independent Review of Adult Social Care, Derek Feeley states:

it is vital that we amplify the voice of lived experience at every level in our redesign [of the social care system]. We have a duty to co-produce our new system with the people who it is designed to support

And yet, at this very first stage of the process of redesign, people with learning disabilities and others who get support from the social care system have faced major barriers to participating, which they have faced as a direct consequence of the design of the consultation.

People who use social care support must be involved in the development of the national care service. This is not just political correctness or the right thing to do: co-production leads to better results with better outcomes for people¹.

Yet this consultation has excluded people with learning disabilities in at least five ways: firstly by the short timeframe, initially even less than the usual 12 weeks; secondly, by not having an easy read version of the document available at the start of the consultation period; thirdly, by the poor quality and inaccessibility of the easy read when it was developed in a rush; fourthly, by the lack of other available formats that would have improved flexibility; fifthly, by the inaccessible nature of the consultation events held by the Scottish Government which people with learning disabilities were unable to take part in.

It would be wrong not to acknowledge that civil servants from the consultation team attended an engagement event held by SCLD and communicated the essence of the proposals well. However, the only way that people with learning disabilities will come to trust and get involved in the process in future is if the Scottish Government reviews the timeline for passing these proposals into legislation, and recalibrates it to ensure that at every stage there is enough time for Feeley's mandate for a collaborative process to be honoured.

The focus of the consultation is on the design of a new structure and a new system.

A National Care Service (NCS) was recommended by Feeley in his Independent
Review of Adult Social Care, a report that was broadly welcomed. However, there is
a concern that these proposals focus too much on the structure itself. The document
seems to suggest that this new structure will itself be transformative for people's

¹ Iriss (2019)

lives. It lacks the focus on outcomes that Feeley gives, and his implicit warning against focusing too much on the structure:

'Social care support is the means to an end, not an end in itself. The end is human rights, wellbeing, independent living and equity, as well as people in communities and society who care for each other.' (Independent Review of Adult Social Care, p.9).

The stakes could not be higher: without a proper sustained focus on what a national care services should deliver – human rights, wellbeing, independent living and equity – and without the involvement of people that use social care support in a genuine collaboration, the development of this national care service could easily become an empty exercise.

How SCLD developed its response

SCLD facilitated three meetings of its Expert Group, which comprises people with learning disabilities from across Scotland. Each meeting focused on a different part of the consultation. Members of the consultation design team attended the first meeting and summarized some of the key proposals to set the context for the discussion that followed.

In addition, SCLD invited a number of organisations that support people with learning disabilities to consult the people they supported, and then to share their findings at an online event.

1. Improving care for people

Improvement

SCLD agrees that improvement should be a key focus of the NCS. We also support the three areas of improvement named by Feeley:

- Self-Directed Support (SDS)
- Safety and quality in care homes
- Commissioning and procurement processes

We are aware of many people with learning disabilities' being dissatisfied with the support they receive. People told us about multiple reasons for this: challenges in finding the information they need about services, the assessment process, dissatisfaction with providers, lack of communication from social workers, the inflexibility of support and a feeling that they lack both control and meaningful choice. All of these can be addressed through improvements in SDS.

The competitive nature of commissioning and procurement has not always produced the desired outcome of good value and high-quality services. In particular, competitive commissioning makes it hard for people with learning disabilities to be involved in co-designing services. In addition, when competitive commissioning drives down costs one outcome is a lower paid workforce and a higher turnover of staff. People have consistently told us how important it is to have a positive long-term relationship with staff that support them. Therefore, it is right that any Improvement Programme should concentrate on these areas.

SCLD also recommends that the Improvement Programme should focus on Transitions. The experience of moving from children's services to adult services is regularly challenging and unsatisfactory for people with learning disabilities and their families. Typically, as well as a change of support provider, this move also includes leaving school and attempting to find work or another positive destination, and sometimes leaving the family home and starting to live independently. Ensuring that this progression goes smoothly requires a close collaboration between a range of organisations and is not always achieved across many parts of Scotland. Therefore, a focus on Transitions in the national Improvement Programme would be very helpful.

Having said this, it is wrong to assume that benefits will result automatically from the NCS taking responsibility for improvement across community health and social care services. The wording of Question1 and others gives rise to significant concerns that the Scottish Government believes that outcomes for people will be improved by structural change alone.

It is crucial that any Improvement Programme is both co-designed and co-delivered by people with lived experience. This involvement must recognise the investment of time and other resources needed to make this kind of collaboration work. The NCS must utilise the expertise of individuals and organisations that have been working in this way for some time.

Access to care and support

SCLD agrees that access to care and support needs to improve. People with learning disabilities told us they have experienced many of the issues identified in the consultation document, especially:

- The complexity of the system
- The lack of a consistent point of contact
- The application of eligibility criteria
- An inflexible system
- A system that focuses on crisis management rather than crisis prevention,
 capacity building and protection of human rights
- People having to tell their experiences of trauma and their individual story repeatedly

In addition, people have told us about their difficulty in finding accessible information that tells them what they need to know, in particular what they have a right to expect and, as we stated above, their difficulty in accessing support at the start of their adult life at the point where support from children's services is removed.

SCLD supports the reform or removal of eligibility criteria. However, as with many of the proposals in this document, SCLD believes that changing the structure will not automatically bring about the desired outcomes. It must be replaced by a different form of assessment built on rights and capacity building, one that reflects the aspiration quoted in the Feeley Review 'social care should be a springboard not a safety net'.

The focus on developing community based supports that can be accessed without a referral or full assessment is one we welcome. However, mainstream or universal community resources already exist which people with learning disabilities feel

excluded from or do not know how to access. An important part of this increased focus on preventative support should be an investment in workers to support people to access community resources. Importantly, they should also work with community groups and resources to become more inclusive. Local Area Coordination and community link workers are two viable models².

We fully support the commitment to involve people with lived experience in the design, development and delivery of new support services from the outset, as this will increase the probability of these services being effective in supporting people to live independently. However, again, there must be a recognition of the investment of time and other resources required to make this collaborative working effective. In particular, people with learning disabilities tell us that they find many community resources and community-based services inaccessible. To address this, it is not enough that 'the people of Scotland' are involved in the service design: services that are intended to be used by people with learning disabilities must be co-designed by people with learning disabilities and fully human rights and equality impact assessed.

SCLD would support a 'no wrong door' approach that would ensure that wherever a person makes an approach to access support, that first contact then takes responsibility for ensuring that this person is given the support they need to navigate the system and secure an assessment of their support needs within a coordinated system of support.

SCLD generally supports a GIRFE approach that is based on GIRFEC. However, it should be remembered that mistakes were made in the development and implementation of the GIRFEC approach, in particular around data sharing, but also in making information about the approach accessible to every child and every parent. Eventually, many GIRFEC resources were developed in accessible formats, but only after a lot of effort was made by several organisations calling for this oversight to be rectified.

² SCLD (2015)

It is crucial that these mistakes are not repeated. People with learning disabilities tell us how angry and exhausted they are by repeatedly being excluded from services that are 'for everyone'.

SCLD supports a coordinated system that means that people can tell their story only once. However, it must be recognised that any such system relies on data sharing arrangements that do not exist and will be far from straightforward to develop. People have told us that they would not be happy with every professional automatically having access to all their private information. A data sharing arrangement needs to be developed that allows people to hold their own data and give informed consent to the details of each data transaction. People with lived experience, particularly people with learning disabilities, should be involved in developing such a system.

Using data to support care

SCLD has long believed that robust data on the experience of people with learning disabilities, including how having a learning disability intersects with other protected characteristics, is absolutely vital in the promotion of equality and the protection of human rights. Without this data, we are unable to talk authoritatively about the population of people with learning disabilities, or plan and implement services and interventions that improve the lives of people with learning disabilities. A recent report by the Fraser of Allander Institute highlighted the particular invisibility of people with learning disabilities within data collections in Scotland, and the difficulties this causes in terms of effective policy interventions:

"It is difficult, if not impossible, to effectively operationalise a policy if you have no idea how many people need to draw on support, nor do you know what their current situation is and therefore what assistance they actually require."

³ Fraser of Allander (2021)

Pivotally, lack of data significantly hampers our ability to measure human rights and equalities impacts across the board. This has never been demonstrated more clearly than during the Covid-19 pandemic, where it took more than 8 months to report on how many people with learning disabilities have died from Covid-19.

It is acknowledged that adult social care data in general requires urgent transformation. In February 2020 the Office for Statistics Regulation published a systemic review into adult social care statistics in Scotland.⁴ The report identified a number of issues that make it difficult to build a full picture of the state of adult social care in modern Scotland. These included gaps in data collection, resources weighted towards health data, inconsistencies in data definitions, poor data quality, delays in reporting and inaccessible data.

It is crucial that all these points are taken into consideration in the design of a minimum dataset to accompany the new NCS. Taking action to significantly improve data that allows for the disaggregation of equalities information, including whether a person has a learning disability, is critical to improving decision-making, accountability and, importantly, people's lives. This will require significant investment in data infrastructure and workforce. While it is pivotal that we put this in place as a matter of urgency, it is equally important that we ensure that the right data is collected in the right way, with human rights and equalities embedded. This will require effective engagement with people who utilise services, including people with learning disabilities.

Complaints and putting things right

It is important that people know who to complain to. Many people told us they did not know who to speak to if they needed to complain. Some knew who to speak to within

⁴ Office for Statistics Regulation (2020)

the organisation that provided support, but not who to go to if their own support organisation did not respond positively. Some people we spoke to had complained without a successful outcome. Therefore, SCLD supports proposals to have a single point of contact for people to contact outside their support provider.

We are also aware that the Scottish Government plans to develop a Commissioner for Learning Disability and Autism. Consideration will need to be given to the development of this role and the contribution it may or may not have in providing a single point of contact for people wishing to pursue a complaint.

However, this is not sufficient. Some people told us that knowing about the Health and Social Care Standards helped them successfully change the agency that supported them. They felt that people should know about not only these Standards, but also their human rights which must be respected, protected and fulfilled by the proposed Community Health and Social Care Partnerships. SCLD recommends that as part of the development of the NCS, there is a national programme to communicate people's human rights and their rights to receive social care that meets the Health and Social Care standards, with accompanying accessible resources.

SCLD found in their research into advocacy services that advocacy provision is inconsistent across the country, but largely inadequate for people with learning disabilities who need support to make a complaint. ⁵

2. National Care Service

SCLD does not agree that the creation of a National Care Service will, in and of itself, bring about the outcomes stated in the Independent Review of Social Care: 'human rights, wellbeing, living independently and equity' (page 9).

⁵ SCLD (2018)

In the same report, Feeley reported being told repeatedly by people who used or delivered social care about an implementation gap:

This 'implementation gap' was often referred to in terms of the differences between what is set out in legislation and guidance and what actually happens on the ground (p11).

In other words, the experience of many people is that legislation guarantees little or nothing. For any benefits to arise it is essential that the Scottish Government learn the lessons of past exercises in structural change. Most recently, the integration of health and social care has required enormous investment of time and financial resources to bring about the structural changes involved, without always bringing about improved outcomes for people in the short term.⁶ For example, we are aware of one Health and Social Care Partnership where health employees and local authorities still use two different IT systems that do not allow effective data sharing.

As well as legislating for structural change, three other factors are crucial for positive change to arise. These are:

- Investment
- Leadership and culture change
- The involvement, from the start and at every stage, of people with lived experience

Although the Scottish Government has pledged a 25% increase in social care spending, it is unclear whether this will be a sufficient investment to fund all the proposals in this consultation.

The current eligibility model of social care means that current unmet demand is impossible to quantify, and that this will only become clear when Feeley's proposed human rights-based model replaces it⁷

⁶ Scottish Government (2019)

⁷ Slasberg (2021)

This is only one additional cost of the proposed new care system. Others include:

- Meeting current unmet demand
- Investing in community-based services
- Covering the loss of care charges when these are abolished (£1.3 billion in 2013, including residential care charges⁸)
- Implementing new minimum terms and conditions for workers
- Cost of new structures e.g., establishing a Social Care Commissioner
- Investment in independent advocacy services
- The increased cost of including functions other than social care

Failing to invest at the required level significantly increases the risk that the proposed NCS will fail to deliver the transformative changes in outcomes for people. Therefore, SCLD recommends that at the earliest opportunity a financial assessment is carried out to establish the true level of investment required to meet all the proposals in this consultation. This assessment should include a financial assessment of anticipated future demand arising from demographic changes, as recommended by Feeley.

In the same way, without strong leadership at all levels, including the leadership of people who use social care, the new structure is unlikely to bring about the outcomes of human rights, wellbeing, living independently and equity that Feeley envisioned.

SCLD agrees that there is a need for consistency across the country and improvements in the sharing of good practice. For example, the current practice of charging for social care and support is both inconsistent and arguably a breach of human rights. SCLD believes care charges should be ended.

However, SCLD has concerns about how consistency is both defined and delivered. There are many examples of national initiatives aimed at raising standards and providing consistency having unintended negative consequences. For example, the

⁸ Audit Scotland (2013)

establishment of league tables for secondary schools has been heavily criticized for prioritizing academic achievement over pupil wellbeing.

A measure of consistent high performance should be a reduction in inequalities for those who are most marginalised across the country. SCLD welcomes the commitment to placing human rights and equity at the centre of Scottish Government decision-making.

Furthermore, the Public Sector Equality Duty (PSED) requires that equality must be at the forefront of the Scottish Government's mind when it is working to deliver the Feeley Review recommendations. People with learning disabilities face the starkest inequalities across a range of indicators, from employment to mortality rates⁹ 10. It is vital that people with learning disabilities enjoy the benefits of any new service equally, and that these benefits are reflected in reduced inequalities. Therefore, SCLD recommends that all performance monitoring systems and measures are fully human rights and equality impact assessed.

If a sufficient level of investment is provided, strong leadership prioritised and the involvement of people with lived experience, including people with learning disabilities, in the development of the NCS is legislated for, SCLD supports the proposal that the NCS should define the strategic direction, quality standards and the framework for person-centred operational delivery of community health and social care at a local level.

SCLD supports the proposal that the NCS should oversee social care provision at national level for people whose needs are very complex or highly specialist. This is a group of people who have faced the most extreme health inequalities, and whose families report experiencing a post-code lottery when it comes to receiving support, especially in more remote areas where specialist support can be limited. A national

⁹ SCLD (2019)

¹⁰ Scottish Learning Disabilities Observatory (2021)

accredited approach to learning and development for staff working with children, young people and adults with very complex needs is required.

Any national oversight of the care and support for this group of people should have their voice and the voices of their family carers at the heart of planning, implementation and evaluation. PAMIS, a voluntary organisation that supports people with profound and multiple learning disabilities, could usefully play a lead role with this.

In addition, SCLD believes that the name of this proposed service should be reviewed. Many people with learning disabilities are very clear that they do not want or need care; they require support to live independently, an entitlement that is enshrined in Article 19 of the United Nations Convention on the Rights of Persons with Disabilities¹¹. SCLD believes that the National Care Service should be renamed to reflect the ethos of human rights that is intended to characterise its work.

3. Scope of the National Care Service

SCLD agrees that children's social work and social care should be included within the proposed NCS. Many people with learning disabilities have reported poor experiences of moving from children's services to adult services. Many of these harmful experiences result from poor communications between the two service systems. We are supportive of children's social work and social care being included because of the benefits of an all-age system that increases the chances of a smooth transition into adulthood for young people.

A second group of people who could benefit from the inclusion of children's services is parents with learning disabilities. Many of these parents report serious difficulties in finding the right support to parent effectively. Again, many of these problems stem

¹¹ United Nations (2006)

from un-coordinated working between children's services and adult services.

Regularly, the parents are assessed as being ineligible for support by adult services, whereas children's services provide support for the children only.

This anomaly was recognised by the Independent Care Review. In its final report The Promise, it called for the systematic provision of universal family support services that are capacity-building, holistic and non-stigmatising ¹² Having children's and adult services sitting within the same service is an important step to delivering this provision. SCLD recommends that the NCS becomes the mechanism for the provision of universal family support services.

Notwithstanding SCLD's support for the proposed inclusion of children's services in the NCS, SCLD understands the caution about this proposal from the children's sector. Similarly, there are concerns about the inclusion of Healthcare, Adult Services Social Work, Nursing, Justice Social Work, Prisons, Alcohol and Drug Services, Mental Health Services and a National Social Work Agency. We believe these concerns are based on a lack of discussion and consultation about the issues and potential impacts and benefits.

To identify how to improve adult social care in Scotland, the Scottish Government set up an Independent Review. This provided the Scottish Government with evidence about where the delivery of adult social care is falling short and made a strong case for redesign.

We do not believe that the equivalent evidence gathering, engagement with service users and analysis has been carried out to determine how best to improve these other services and whether they might fit within a new National Care Service.

Therefore, SCLD is not convinced that a sufficient case has been made to broaden the scope of the NCS to include these services at this time.

¹² Independent Care Review (2019)

There are clear advantages to health services and social care and support services working together within the same service. However, there are also concerns expressed by people with learning disabilities that health becomes the 'senior partner' in this service. Disabled people have preferred a social model of disability for many years, where the cause of disadvantage is found in the barriers society creates for disabled people, and have rejected a medical model that perceives someone's impairment as the cause of their disadvantage. People with learning disabilities are concerned that a health culture based on a medical model of disability could come to dominate the proposed community health and social care partnerships. As discussed previously, SCLD requests a reconsideration of the name of the proposed National Service to include the word 'Support' which reflects the aims of fulfilling human rights and building capacity.

4. Reformed Integration Joint Boards

For the reasons discussed earlier, SCLD is not confident that reforming the structure of Integration Joint Boards (IJBs) to become Community Health and Social Care Boards (CHSCBs) will improve the lives of people with learning disabilities and others. This will only happen if system and structural changes are accompanied by:

- Properly costed investment
- Strong, values-driven leadership and culture change
- Comprehensive involvement of people with lived experience of using social care, including people with learning disabilities and family carers where appropriate

SCLD agrees that local people who have lived experience of using social care, including people with learning disabilities, should be involved in the design, development and delivery of support services. Many people with learning disabilities have told us of times when they have been excluded from practices that have intended to include them.

It is commendable that this consultation proposes embedding inclusive practices within the workings of the CHSCBs, but such inclusion requires a significant investment of time and other resources. Therefore, SCLD recommends that plans to involve local people in the design, development and delivery of support services are human rights and equality impact assessed to ensure that all barriers to their participation are recognised and removed.

The availability of a range of good quality and affordable housing options that meet the needs of disabled people are a necessary pre-requisite of independent living. Therefore, it is crucial that proposed CHSCBs develop excellent working practices with local authority housing departments and housing associations. For people with learning disabilities in particular, the planning and availability of housing stock and the planning and delivery of housing support must be closely coordinated.

SCLD is concerned that the establishment of the CHSCBs will prioritise the development of internal joint working in the short to medium term, at the expense of strengthening external partnership working. SCLD therefore welcomes the commitment in the consultation to develop effective joint working with Housing. The idea of making CHSCBs statutory consultees for strategic planning on various issues may help, but will not be sufficient. SCLD suggests that this is an area that requires significant future focus.

5. NCS Commissioning and procurement

SCLD broadly supports the idea of national standards and processes for social care commissioning and procurement. The aim and purpose of these must be to achieve high quality, person-centred outcomes to meet individuals' needs, rights and preferences to live a full and independent life as well as fairer employment conditions and workforce development for social care staff.

As part of SCLD's consultation process on the NCS, people with learning disabilities told us they thought that paying support workers at a higher level and improving their

working conditions was essential for them to receive good support. Providers also told us that a proper review of workforce pay and terms and conditions is required to properly recognise and value social care staff for their skills and the vital nature of their work. The point was also made that direct services and contracted services should have better parity.

A number of support providers told us that they would welcome proposals that address the competitive element of commissioning and procurement. There was a strong feeling reform is required to make it easier for support providers to work in partnership rather than competing on costs for tenders which creates unnecessary rivalry, mistrust and significant upheaval for people who use services and care and support staff. It was also noted that in the present system, the commissioning process is often undertaken back to front, with tenders going out before support planning processes, which should inform the tender, take place.

Feeley proposed a new approach to commissioning which results in a "fairer, rights based, improved social care support system with a relentless focus on quality, outcomes, participation and collaboration." He recommended this new approach should entail a shift from competitive to collaborative commissioning with a focus on a person's needs, not solely cost alongside core requirements for ethical commissioning to support fair work requirements and practices at a national level. SCLD is fully supportive of this aspiration.

We support the Scottish Government's proposal for Standards and Processes for ethical commissioning and procurement to include core criteria on workforce terms and conditions and the need to meet personal outcomes. We believe these criteria must also include people's experience of the quality and flexibility of care and level of provision for training and support for staff.

The Fair Work Convention Inquiry¹³ identified constraints imposed on employers by the commissioning system as a significant contributory factor to low pay and

¹³ Fair Work in Scotland's Social Care Sector (2019) – Fair Work Convention

challenging working conditions in the social care system. It is critical that the Scottish Government's approach to ethical commissioning and procurement pays close attention to the findings and recommendations of this inquiry and that the Public Sector Equality Duty is incorporated into the Scottish Government's National Commissioning and Procurement Structure of Standards and Processes.

It is unclear, at present, in what way the proposed Structure of Standards and Processes will lead to the development of more collaborative commissioning and genuine alternatives to competitive tendering in procurement decisions as recommended by Feeley.

Providers have real concerns that a competitive tendering process pits organisations against each other and risks a 'race to the bottom' on both price and quality. Its short-termism also diverts significant time and resources to applying and reapplying for contracts creating uncertainty for providers and the workforce and impacting on continuity of care and support for people with learning disabilities and others. The current approach also risks undermining strategic needs assessments which should be central to successful commissioning. One provider felt there were many unanswered questions around what the Government is actually proposing and cautioned that a move to more 'collective tendering' could threaten more bespoke provision.

Feeley recommended that "Commissioners should focus on establishing a system where a range of people, including people with lived experience, unpaid carers, local communities, providers and other professionals are routinely involved in the codesign and redesign, as well as the monitoring, of services and supports."

The Scottish Government proposals must ensure that the commissioning and procurement process becomes more equitable and transparent, and involves genuine co-production with all stakeholders. This should include opportunities for people with learning disabilities and their organisations not just to direct their individual support but to use their experience to support the planning and design of services. We believe it is critical that the development of the Structure of Standards and Processes is genuinely collaborative and that a transformative approach

requires extensive involvement and engagement with support organisations and people with learning disabilities.

6. Regulation and complaints

In our consultation with people with learning disabilities some people were unclear about who to complain to when they felt service standards were not being upheld, and some were unsure about who had responsibility for enforcing standards of care and support. There was a lot of frustration expressed that people had not received the services they expected or needed during the pandemic. While it was acknowledged that SSSC do have the power to cancel social workers' registration, the point was made that the SSSC Code of Practice could be strengthened if it was established in law.

SCLD is aware that complaints and regulation responsibilities are currently shared between a number of organisations including the Local Authority Commissioners, Health and Social Care Partnerships, the Scottish Human Rights Commission, The Equality and Human Rights Commission, the Public Sector Ombudsman, Office of the Public Guardian, the Mental Welfare Commission, the Care Inspectorate and the Scottish Social Services Council. This is a complex system of interconnected roles and organisations and one of which the development of a new National Care Service must be cognisant if it is to ensure that people do not become lost within it.

We are also aware that the Scottish Government plans to develop a Commissioner for Learning Disability and Autism and consideration will need to be given to the development of this role and the contribution it may or may not have in the handling of complaints and regulation.

The people who took part in our consultation events felt there needed to be better communication between regulation agencies. With regard to the key roles of the Care Inspectorate and SSSC, people questioned why they are separate organisations and whether there is merit in merging the two bodies.

There was also a range of views about whether the emphasis should be on an improvement approach or more of a sanctions based approach. It was felt that inspections should involve more engagement and involvement of people with learning disabilities and be less paperwork based.

SCLD believes that a revised regulation framework for social care could help ensure people with learning disabilities enjoy consistent, high quality standards of care and support and that robust and effective action could then be taken where this is not the case. In our view, effective, transparent and independent scrutiny of care services and the workforce is best achieved through the regulatory bodies that sit outwith a National Care Service (NCS). We are supportive of the idea of a set of core principles to inform revised arrangements for regulation which are people centred and human rights based.

At our consultation events people with learning disabilities and providers raised a number of issues that should be considered within this set of principles:

- People with learning disabilities should be involved in the design and implementation of scrutiny approaches. One person we spoke to had experience as a lay assessor with the Care Inspectorate and was confident that supported people were able to speak more honestly to someone who has lived experience.
- People with learning disabilities who receive social care also require accessible information and support to know what standards to expect; the duties on staff and services to support and protect them and to understand their human rights. One person said that when they had made a complaint, the regulatory body had sided with the care provider and they then did not know who else to complain to. It was also felt individuals' relationships with managers within their support service can make it harder for them to make a complaint. It was mentioned that the SCLD Human Rights Town app is a

practical tool that can help people know what their rights are and help inform this ¹⁴.

- Complaints processes must also be accessible for people with learning
 disabilities. It is essential that people are supported to understand their
 organisation's complaints procedure and know who to speak to if they wish to
 raise an issue. One person felt that their experience of making a complaint
 had been a real struggle but said that knowing their rights and having the
 support of an independent advocate had made a big difference. Others said
 that having to put a complaint in writing created a barrier to making that
 complaint.
- It was suggested that the pandemic had demonstrated the potential of technology and that people should be able to make complaints by video in the same way they would by letter or email.

7. Valuing People Who Work in Social Care

The reimagining of social care support in Scotland must be motivated by the delivery of better outcomes and ultimately a better quality of life for people, rather than by systemic and structural re-organisation.

In the Independent Review of Adult Social Work, Feeley emphasised that 'Social care support is the means to an end, not an end in itself. The end is human rights, wellbeing, independent living and equity, as well as people in communities and society who care for each other' (Independent Review of Adult Social Care, p.9).

People with learning disabilities have told us that paying social care staff a fair wage and improving their working conditions are important elements in receiving good support. In our consultation events people emphasised the importance of a skilled and professional social care workforce.

¹⁴ Human Rights Town - the app! - SCLD

However, some people said that they had little or no contact with social work professionals apart from being assessed for support eligibility. There was a feeling that much of social workers' current focus is diverted to 'gatekeeping' and budget management rather than using their professional skills and knowledge to work directly with people. Another issue for people with learning disabilities is a lack of knowledge on the part of many social workers around learning disability. It constitutes a negligible part of the undergraduate curriculum, and people frequently report poor communication and a sense that their social worker does not understand their situation or experience.

Where people have trusting and sustained relationships with support workers and social workers, they report that this is immensely valuable. A strong relationship depends on building up trust. People told us that these are the factors that help them to trust their social workers or support workers:

- Being there
- Being physically and emotionally present for them
- Listening to what they have to say
- Doing what they say they will do

Building this trust requires continuity within the workforce. Individual workers not only need to feel valued enough to stay in the profession, they also need to be enabled to continue supporting the same person for as long as both parties are happy to do so.

SCLD believes, therefore, that valuing the workforce properly will make a career in social care a more attractive prospect, and will increase the probability that good workers will be retained within the sector. In our view, this requires improved terms and conditions and pay for the social care workforce. Providers we spoke to also felt a review of workforce pay and terms and conditions is required to properly recognise and value the skills and the vital nature of social care and support.

However, in addition to better pay, social care staff should also receive better training, and have greater freedom to do the job they are trained to do. Valuing the workforce in this way should be a reciprocal arrangement: in return social care staff must be expected to deliver flexible, human rights-informed support, work in a

collaborative way that gives as much control as possible to the person they are supporting, and wherever possible provide the continuity of support that people need to live their best life.

The Fair Work Convention Inquiry¹⁵ identified constraints imposed on employers by the commissioning system as a significant contributory factor to low pay and challenging working conditions in the social care system. It identified a need to reform social care commissioning and procurement work to achieve Fair Work.

Indeed, the Independent Review of Adult Social Work recommended 'Rapid delivery of all of the recommendations of the Fair Work Convention, with an ambitious timetable for implementation to be set by the Scottish Government' (Recommendation 42). However, disappointingly this recommendation does not feature in the Scottish Government's proposals for a National Care Service.

The consultation document does propose a 'Fair Work Accreditation Scheme'. While this has potential to improve the pay and conditions of employees whose organisations elect to sign up to it, we do not believe it will guarantee consistency, fairness and equality that the social care workforce requires.

The proposed national commissioning and procurement standards presents an opportunity to include a Fair Work contract to address the current inconsistencies and inequalities experienced by the social care workforce. We urge the Scottish Government to consider a timetable for the implementation of the Fair Work Convention (FWC) Inquiry in Social Care recommendations in full as an effective way to achieve equality for the social care workforce, and achieve high quality human rights focussed, person centred care and support for all.

What is missing	g from	the NCS	proposals?
-----------------	--------	---------	------------

¹⁵ Fair Work in Scotland's Social Care Sector (2019) – Fair Work Convention

The National Care Service consultation does take on board most of the most significant recommendations from the Feeley review, the most important, of course, being the establishment of the National Care Service itself. However, a number of the Feeley review recommendations are omitted from the consultation, in the sense that they are not directly reflected in the Consultation proposals or questions.

SCLD is concerned about these omissions: the Feeley Review was widely welcomed, and the Scottish Government agreed to implement its recommendations. If the proposed legislation is seen as the vehicle for implementing Feeley's recommendations, there is a possibility that these outstanding recommendations may not be implemented. The implication of not addressing these recommendations in the consultation is discussed below.

Recommendations not included in the National Care Service Consultation

It should be noted the consultation only features 43 of the 53 Feeley review recommendations as "relevant recommendations". This means that 10 of the recommendations in the Feeley review are not featured in the consultation. The following Feeley review recommendations are not featured at all in the consultation:

Recommendation 2: Delivering a rights-based system in practice must become consistent, intentional and evident in the everyday experience of everyone using social care support, unpaid carers and families, and people working in the social care support and social work sector.

Recommendation 13: Local assessment of carers' needs must, in common with assessment of the needs of people using social care support services and supports, better involve the person themselves in planning support.

Recommendation 14: Carers must be represented as full partners on the Integration Joint Boards and on the Board of the National Care Service.

Recommendation 28: The Scottish Government should carefully consider its policies, for example on discharge arrangements for people leaving hospital, to ensure they support its long held aim of assisting people to stay in their own communities for as long as possible.

Recommendation 30: There must be a relentless focus on involving people who use services, their families and carers in developing new approaches at both a national and local level.

Recommendation 41: Commissioning and planning community based informal supports, including peer supports, is required to be undertaken by Integration Joint Boards and consideration of grant funding to support these is needed.

Recommendation 42: Rapid delivery of all the recommendations of the Fair Work Convention, with an ambitious timetable for implementation to be set by the Scottish Government.

Recommendation 49: Prioritising investment in social care as a key feature of Scotland's economic plans for recovery from the effects of the Covid-19 pandemic.

Recommendation 52: Robustly factoring in demographic change in future planning for adult social care.

Recommendation 53: Careful consideration to options for raising new revenues to increase investment in adult social care support.

These omissions are concerning and the following highlights some potential issues which could arise from their omission.

Making sure support is person-centred and supports the human rights and individual needs of both carers and those receiving care

It is noteworthy that three of the recommendations which were omitted - recommendations 2, 13 and 30 - recommend a more person-centred and rights-based approach to social care. These recommendations are important because they offer practical suggestions on how the individual needs of carers and those receiving care should be considered at both a personal and more institutional level. It should also be considered that recommendation 14, which says that carers must be represented as full partners on the Integration Joint Boards and on the board of the National Care Service, is not included in the relevant recommendations in the consultation. This recommendation is important because it would ensure that carers could take an active role in the decision-making processes of the National Care Service.

The consultation does note a commitment to a human rights-based approach towards carers and those receiving support and does include a number of recommendations from the Feeley review which promote a person-centred approach. However, as stated previously, the focus on the structure of the proposed NCS and not on the other factors – investment, leadership, culture change, co-production - needed to bring about better outcomes for people is concerning and is reinforced by the omission of these recommendations.

Covid-19

Aside from in the Issues and Problems section in the chapter on Nursing, the issues created by the Covid-19 pandemic are seldom mentioned in the consultation. The consultation tells people very little about how the Scottish Government's Covid-19 economic recovery plans will relate to social care. In particular, it should be noted that recommendation 49 from the Feeley review, which says that the Scottish Government should prioritise investment in social care as part of the Covid-19 economic recovery plan, is not addressed at all in the consultation.

Funding

While the issues surrounding commissioning and procurement are discussed quite extensively in the report, it is not clear how the National Care Service will be funded and where this funding will come from. Among other things, the Scottish Government has promised to ensure a high standard of universal social care in the community, increase the amount of money spent on free personal care and nursing for residential care, and increase the scope of the social care sector to encompass issues such as drug and alcohol services and criminal justice. It is clear from the consultation that more funding will be needed to establish and run the National Care Service. However, the omission of recommendations 41, 49, and 53 from the Feeley review result in a lack of clarity regarding where this funding will come from.

Delayed Discharge

Another important recommendation from the Feeley review which is not listed as being relevant to the consultation is recommendation 28. This addresses delayed discharge from hospital and people being able to get support in their own community. The consultation does mention in the section on "Access to Care and Support" that the National Care Service will offer more services which focus on prevention and early intervention and more community-based provision to reduce the number of people in hospital or institutional care. However, the consultation does not mention changes to discharge arrangements or the rules surrounding discharge.

Coming Home is a report based on independent research carried out into the scale and impact of people with learning disabilities' being placed in residential out-of-area settings¹⁶. The Scottish Government supports both the report's findings and its recommendations, which include reversing this situation as a matter of urgency so that those living out of area may be able to return closer to home, and those who are deemed 'hard to place' have support services designed closer to home, so that family and community ties are maintained.

Therefore, the fact this this recommendation has not been addressed by the Scottish Government in its consultation paper greatly concerns SCLD. It suggests that their view of the proposed NCS may be that if the structures are put in place, these issues will be resolved as a matter of course. If that is their view, SCLD would strongly disagree.

Fair Work Convention

One of the recommendations which was not listed in the consultation was recommendation 42, which recommended that the Fair Work Convention should be fully implemented and that the Scottish Government should lay out a timetable for this implementation. The consultation does feature a chapter on Fair Work in which the Scottish Government has proposed a commitment to implement Fair Work principles within the National Care Service and its institutions. Whilst "Scotland's ambition to become a Fair Work nation by 2025" is mentioned in the "Valuing people who work in social care" section of the consultation no firm timetable for the implementation of the Fair Work Convention is offered.

Demographics

¹⁶ Scottish Government (2018)

The fact that the consultation has not acknowledged recommendation 52, which says that demographic change should be factored into future planning, is problematic. Scotland has an ageing population – this is important because as people age they are more likely to require social care. This could mean that the social care sector and a new National Care Service is likely to feel increased pressure in terms of the demand for services and funding as it goes into the future. For this reason, it is important that proper plans, including plans for future financial investment, are made to ensure that demographic change over time is addressed.

Conclusion

Given that the Scottish Government's intention is that the proposals in the consultation will be legislated on, it is highly likely that every relevant organisation will prioritise fulfilling its legal duties arising from that legislation. SCLD is concerned that the recommendations from the Feeley report that are **not** reflected in this document will not be prioritised. Yet these are some of the most important recommendations from that independent review for delivering a service where human rights are embedded, and independent living, wellbeing and equity are assured.

Therefore, SCLD recommends that the Scottish Government amends its proposals to ensure that these 'missing' recommendations are incorporated into recommendations for the development and delivery of the National Care Service.

Summary

SCLD welcomes the commitment of the Scottish Government to implement recommendations from the Feeley report. While SCLD conditionally supportive of the development of a national care service, we believe the following actions are needed to increase the probability of such a service delivering the outcomes of fulfilling and protecting human rights, and enabling independent living, wellbeing and equity, that Feeley described in his review of adult social care:

- The Improvement Programme should focus on Transitions as well as the three areas identified by Feeley.
- The Improvement Programme is both co-designed and co-delivered by people with lived experience.
- The investment of time and other resources required to make collaborative working effective is acknowledged and built in to the timeline of delivering the National Care Service.
- Services that are intended to be used by people with learning disabilities must be co-designed by people with learning disabilities and fully human rights and equality impact assessed.
- As part of the development of the NCS, there is a national programme to communicate people's human rights and their rights to receive social care that meets the Health and Social Care standards, with accompanying accessible resources.
- At the earliest opportunity a financial assessment is carried out to establish
 the true level of investment required to meet all the proposals in this
 consultation. This assessment should include a financial assessment of
 anticipated future demand
- All performance monitoring systems and measures are fully human rights and equality impact assessed.
- Any national oversight of the care and support for this group of people should have their voice and the voices of their family carers at the heart of planning, implementation and evaluation.
- The National Care Service should be re-named to reflect the ethos of human rights that is intended to characterise its work.
- The NCS becomes the mechanism for the provision of universal family support services.
- A timetable should be considered for the implementation of the Fair Work
 Convention (FWC) Inquiry in Social Care recommendations in full as an
 effective way to achieve equality for the social care workforce, and achieve
 high quality human rights focussed, person-centred care and support for all.

- The Scottish Government amends its proposals to ensure that 'missing' recommendations from the Feeley report are incorporated into recommendations for the development and delivery of the National Care Service.
- Take action to significantly improve data that allows for the disaggregation of equalities information, including whether a person has a learning disability

Andy Miller Strategic Lead, Participation and Partnerships Andy.m@scld.co.uk

> Lorne Berkely Strategic Lead, Evidence and Rights Lorne.b@scld.co.uk

> > Ruth Callander Evidence and Data Adviser Ruth.c@scld.co.uk

Matthew Muirhead Development Worker, Evidence and Rights



Contact us

Website: www.scld.org.uk

Twitter: **@SCLDNews**

Facebook: **@ScotCommission**

Instagram: @scldnews

The Scottish Commission for Learning Disability Suite 5.2 Stock Exchange Court 77 Nelson Mandela Place Glasgow G2 1QY

