

Response to a National Care Service (Scotland) Bill

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GDA's Response to a National Care Service (Scotland) Bill – Call for Evidence

About our organisation

Glasgow Disability Alliance is a disabled people's organisation, run by and for disabled people. We have more than 5500 members across Greater Glasgow, made up of diverse disabled people: people with long term conditions, and member organisations led by disabled people. We are also supported thriving network of associate members — people, partners and allies who support our aims.

Through fully accessible learning, coaching, and events GDA connects disabled people with each other, with opportunities and with decision makers. We recognise talents and strengths and support disabled people to build on these, participate and be leaders in their own lives.

Our Vision is a world where disabled people can participate and have our voices heard, on a full and equal basis, in all aspects of our lives, communities and wider society, with our human rights upheld and with choices equal to others.

Our Mission is to build the confidence and connections of disabled people, by delivering fully accessible programmes of support, learning, and capacity building, to enable disabled people's vital contributions and active participation in our own lives, in decisions which affect us, and in creating a fairer more equal society.

General questions about the Bill

1. The Policy Memorandum accompanying the Bill describes its purpose as being "to improve the quality and consistency of social work and social care services in Scotland". Will the Bill, as introduced, be successful in achieving this purpose? If not, why not?

Given nature of the legislation, as a framework Bill, GDA members found it difficult to establish whether the Bill, as it stands, would fulfil this purpose and this was prohibitive to discussions and deliberations. That said, disabled people and Glasgow Disability Alliance are supportive of an ambition for transformational change as the status quo is not acceptable and repeated attempts to become involved, have our say and help design solutions have failed at some local levels. So change is very much welcome and this was never more needed than following the catastrophic near collapse of social care during the pandemic where thousands of packages were reduced or halted at the outset leaving disabled people in peril and carers on their knees.

This response is the result of a series of events and discussions with GDA's Social Care Expert Group, it also draws on GDA's significant experience of dialogue with disabled people over two decades, including members representing the views and



experiences of younger disabled people, Black, Asian and minority ethnic disabled people and LGBT disabled people.

The success of the Bill will be dependent on more detailed amendments that make specific commitments around the creation, implementation and delivery of the service on the ground by individuals, local care boards and accountability at a Scottish Ministerial level.

The Bill, future amendments and the service created must be built on rights- human rights and the rights to Independent Living as enshrined in UNCRPD Article 19 – supported by this government cross party in terms of ambitions to incorporate the Convention into domestic law. It must also be shaped to respond to people and communities who need and use the services – in order to fulfil this purpose. This will help the purpose as above for the service to be achieved and ensure consistent and better outcomes for people accessing care and support across Scotland than is possible at this time, constrained by a level of need and demand outweighing resources available within and to some local authorities.

As such, our rights as laid out in the Bill and any Charter within the bill need to be enforceable in order to address the inconsistency, breaches of human rights and neglect of care that has occurred in Scottish social care in recent decades.

Moreover, a shared understanding of "improvement", referred to in the policy memorandum, is also essential to ensure this purpose in itself has meaning. If this is a definition of improvement from the perspective of cutting budgets, and thus cutting social care packages and neglecting needs, this is not in alignment with our definition of improvement as disabled people campaigning for our right to need satisfaction, (see SILC Response) independent living and social care.

2. Is the Bill the best way to improve the quality and consistency of social work and social care services? If not, what alternative approach should be taken?

The Bill provides a good starting point and legal basis to improve the quality and consistency of social work and care services. However, much more detailed commitment, as laid out in our below response to each section of the Bill, is needed to ensure disabled people's existing rights are protected and upheld in the creation and delivery of these services, which is essential to their improvement and consistency.

In addition to the firm foundations of a Bill, improving quality of social work services will require strong leadership and enabling leaders to be empowered to deliver quality and consistency and to lead. This will also depend on organisational culture – how staff are supported to treat each other within a context of rights and compassion and how the principles of the bill are measured in workplans relating to organisational mission and related policies.



GDA welcomes the safety net of national standards and accountability mechanisms but also recognises that delivery and planning for delivery would logistically work better at more local levels. With the caveats of the principles, standards and accountability we are hopeful that this can deliver improvements to the lives of disabled people and our families.

3. Are there any specific aspects of the Bill which you disagree with or that you would like to see amended?

As we refer to in our response to the Charter section of the Bill below, GDA members strongly disagree with Chapter 3, Section 11's statement that nothing in the charter is to "give rise to any new rights". We appreciate the intention to protect existing rights and responsibilities but in the context of social care cuts, unmet need and continual breaches to our existing rights in social care, as Derek Feeley found in his 2021 Independent Review of Adult Social Care, this might unwittingly undermine capacity or motivation for any progression towards or "realisation" of human rights, in line with the Service Principles commitments..

Disabled people and our families have unfortunately faced realities of life not only without the services and supports they require from social work and social care, but almost more impactfully, many have experienced a complete breakdown of trust in an agency which began life with a very different aim, [making] "further provision for the welfare of disabled, sick, aged and other persons and for regulating homes for disabled and aged persons and charities for disabled persons" National Assistance Act 1948 and "[promoting] social welfare by making available advice, guidance and assistance" as outlined in the Social Work Scotland Act 1968.

Evidence from GDA members is that the context of austerity and then Covid has created not only challenges in the delivery of care and support, but also in getting their voices heard and lived experiences believed- never mind influencing planning or co-designing actions. Disabled people have compassion and understand that challenges are largely driven by financial constraints but can no longer wait for the services they need to enable human rights and basic dignity. We are also aware that frontline workers are frequently in agreement with this position and need to be empowered to deliver the principles in the Bill.

In the context of not giving "rise to any new rights", GDA members called for the inclusion of named rights and commitments within the Charter from the outset that are fixed in legislation. Naming and protecting key existing rights such as the right to independent living, and capturing unmet need, and a clearer definition about the processes in place for upholding the charter, would provide assurance that disabled people's rights are protected.



4. Is there anything additional you would like to see included in the Bill and is anything missing?

As outlined below in our response to each portion of the Bill, there are several aspects of the Bill which require more clarity, additional information or an amendment to ensure the National Care Service improves quality and consistency, as well as protects disabled people's human rights, in social care.

With regards to the establishment of care boards, an amendment which lays out the requirements for membership of care boards, and the inclusion of large service user groups – specifically disabled people's organisations and carers organisations within this membership, would provide assurance about the commitment to embedding lived experience and co-design in the National Care Service's implementation. Since disabled people are disproportionately the highest users of social care and consume a large part of the budget, it would make sense to ensure full and meaningful participation at this level to improve quality of planning and to embed principles of co-design in the NCS from the outset.

In addition, with regards to the National Care Service Charter, an amendment within legislation committing to ensuring the "summary of rights and responsibilities" are codesigned by invested parties, such as service users and the care workforce, would be welcome.

GDA and our members are also keen to understand how investment will work in supporting the transformation of health and social care services and we are also keen to ensure that the new Service retains principles of both equality and human rights: it was felt that there must be an emphasis on equality to ensure that the NCS and does not follow a medical model approach.

GDA members welcomed the commitment in the legislation to review the Charter within five years of the first version being laid before the Scottish Parliament. However, an amendment should be added in section 12 to ensure this is reviewed every five years, similar to that of the strategic plan, and commit to involving service users, supported independently, as above, in this process.

Furthermore, an amendment, within the portion of the bill on transfer of functions, detailing some kind of provision for the transfer of powers and how this will impact the service user or ensuring any transfer is met with a planned transition to mitigate risk or ill effect on service users, care and the workforce, would be welcome to provide greater clarity.

Similarly, in relation to the portion of the Bill detailing provision for the inclusion of children's services and justice services, an amendment to this section requiring consultation and co-design with service users, wherever possible, as done in the preparation of transferring social care services, would ensure consistency, meaningful engagement/involvement and improved service delivery as the National Care Service expands.



With reference to the health and social care information portion of the Bill, GDA members also highlighted that an amendment in this provision, namely under the information standard (section 37), should be made to ensure that shared information was only done at the consent and the choice of the service user.

The Bill is silent on how housing will relate to the new NCS structures and processes. There is a very close correlation between housing and social care needs and a pressing need for housing, health and social care to be more closely aligned and more effectively working together.

Lastly, we refer to Dr Jim Elder Woodward's paper, supported by Scottish Independent Living Coalition members Inclusion Scotland, Glasgow Centre for Inclusive Living and GDA. The paper articulates a the Right to Need Satisfaction, which asserts that referring to Article 19 of the UNCRPD IN the Bill and in particular the Right to Independent Living is most appropriate and needed. This is particularly pertinent give the Scottish Government's commitment to incorporation and reflects the kind of society we aspire to – one with a Wellbeing economy, embracing kindness and enacting rights to enable disabled people to be equal citizens, participating in the lives of our families and communities.

5. The Scottish Government proposes that the details of many aspects of the proposed National Care Service will be outlined in future secondary legislation rather than being included in the Bill itself. Do you have any comments on this approach? Are there any aspects of the Bill where you would like to have seen more detail in the Bill itself?

GDA members had concerns that without commitments, specifically in relation to rights and transitions in care services, in primary legislation, there would be scope to ignore the 'recommendations' or 'principles' of the National Care Service as laid out in the policy memorandum or from Derek Feeley's Independent Review of Adult Social Care (2021).

As detailed below and above, namely GDA members would have liked to see more detail on a Charter of Rights and Responsibilities, transfer of services and accountability and the membership of care boards within primary legislation.

6. The Bill proposes to give Scottish Ministers powers to transfer a broad range of social care, social work and community health functions to the National Care Service using future secondary legislation. Do you have any views about the services that may or may not be included in the National Care Service, either now or in the future?

Fundamentally we support a National Care Service taking responsibility for improvement across community health and care services and we firmly believe that this must be done on a National basis. However, as detailed above in aspects



missing from the bill and our more detailed response below, it is essential that provision is put in place in primary legislation to ensure consultation, co-design and a human-rights based approach is adhered to, once secondary legislation is implemented.

7. Do you have any general comments on financial implications of the Bill and the proposed creation of a National Care Service for the long-term funding of social care, social work and community healthcare?

It is vital that sufficient, consistent and stable funding to the National Care Service is protected, be that through ring-fenced approaches or other means. Our members share concerns about the risk of privatisation and how funding will impact the commitment to scrap all non-residential care charges in this parliamentary session. In order to do this, adequate and stable funding is critical and commitments on how this will be funded and protected as the service grows and expands, is needed to reassure service users.

Clearly there are risks in terms of lack of funding and in this regard, GDA members feel strongly that there must be consideration of additional investment which Feeley referred to. Projected costings have varied between different stakeholders but it is certain that resources will be required and so additional investment must also be considered. GDA members raised the possibilities of revenue from progressive taxation – wealth tax, cracking down on tax evasion, reforming Scottish property tax, raising taxes on the most profitable businesses.

- 8. The Bill is accompanied by the following impact assessments:
- a. Equality impact assessment
- b. Business and regulatory impact assessment
- c. Child rights and wellbeing impact assessment
- d. Data protection impact assessment
- e. Fairer Scotland duty assessment
- f. Island communities impact assessment

Do you have any comments on the contents and conclusions of these impact assessments or about the potential impact of the Bill on specific groups or sectors?

The Equality Impact Assessment rightly identifies that the Bill could have a positive impact on people with protected characteristics, including disability, "given that stakeholders will be co-designing the service that affects them".



However, GDA members would have liked to see a more detailed Equality Impact Assessment of the policies, powers and structures put in place by the primary legislation, not just the process of co-design. Co-design of part of the process does not guarantee that the resulting policies or practises will have a positive impact on people with protected characteristics, as this is dependent on the co-design of the legislation as it develops, followed by policies and practices at delivery levels.

As such, a further Equality Impact Assessment must be carried out and published for scrutiny once secondary legislation is produced to adequately evaluate the impact of the policies in the Bill on disabled people and other people with protected characteristics.

In addition, GDA members would like to see more made of Equalities commitments in terms of advancing equality and making maximum use of the Equality Act and the Public Sector Equality Duty: the Bill and the NCS itself provide opportunity to tackle one of the major structural inequalities which disabled people face i.e. accessing the necessary health and social care services which support us to live a full life of participation, with choices equal to other citizens.

Questions about the Financial Memorandum

9. Did you take part in any consultation exercise preceding the Bill and, if so, did you comment on the financial assumptions made?

No

10. If applicable, do you believe your comments on the financial assumptions have been accurately reflected in the financial memorandum?

N/A

11. If the Bill has any financial implications for you or your organisation, do you believe that they have been accurately reflected in the FM? If not, please provide details.

N/A

12. Do you consider that the estimated costs and savings set out in the FM are reasonable and accurate?



13. If applicable, are you content that your organisation can meet any financial costs that it might incur as a result of the Bill? If not, how do you think these costs should be met?

N/A

14. Does the FM accurately reflect the margins of uncertainty associated with the Bill's estimated costs and with the timescales over which they would be expected to rise?

National Care Service principles (section 1)

15. In providing comments on this section of the Bill, please consider:

- Whether you agree with these principles as drafted?
- Whether there is anything in the principles you would disagree with or wish to amend?
- Whether there is anything important missing from these principles?
- Whether an alternative approach would be preferable?

GDA members welcomed the immediate acknowledgement that the services provided by the National Care Service are to be regarded as an investment in society essential to the realisation of human rights, enabling people to thrive and fulfil their potential, and enabling communities to flourish and prosper.

GDA members also raised concerns around the wording on the principle "must be centred around early interventions that prevent or delay care". GDA members wholeheartedly support a preventative approach that is based around early intervention, however, this is in congruence with the knowledge that disabled people often need social care support to live an independent life they want to live. Framing early intervention as being only focused on a way to delay or prevent social care, to GDA members, feels like a step backward and indeed seems to contradict sentiments about social care helping communities to flourish. At worst it was feared that this approach can lead to cuts to social care packages or reduced support. An additional point raised was that early intervention and prevention should not only be centred around hospital admission or discharge. Previously, it was felt that resources were concentrated at this end of the spectrum rather than flowing further down the system where significant preventative work happens in the health and care including the third sector.

Again it was appreciated that there is a principle committing to collaborating with people who are the main users and to continuously improve the services provided by the NCS in ways which promote dignity and advance equality and non-discrimination.



While GDA members broadly agreed with the spirit of the National Care Service principles included in the Bill, there were concerns about how these will be fulfilled and whether they go far enough to achieve the aim laid out in the policy memorandum to "improve the quality and consistency of social work and social care services in Scotland". In general, many members felt commitments around the principles of the National Care Service have been watered down since initial consultation.

Particular concerns were raised with regards to the principle "must be financially stable to give people long-term security". It was felt that this is an easy "get-out" clause in the context of financial pressures and continued cuts to social care packages at a local level, GDA members felt there must also be a commitment to "sufficient" financial stability that meets need. Financial stability, to service users, does not always translate to financial adequacy or sufficiency.

In relation to the principle outlining the National Care Service as an "investment in society that is essential to realisation of human rights", GDA members highlighted that "realising" human rights is insufficient to properly transform social care. In the context of social care in Scotland at present, where disabled people's human rights are consistently not met due to resources constraints and assessments determining these not high enough level of need, committing in principle to realising human rights through the service does not go far enough. GDA members called for core values such as dignity, fairness and respect, to be engrained in legislation of the Bill in the form of a Charter of Rights in social care and to be bolstered by enshrining the UNCRPD into Scots Law.

In addition, with regards to the principle outlining the National Care Service as "enabling communities to flourish and prosper", GDA members felt this was too wide a definition and could be misinterpreted or misunderstood to mean balancing the needs of most and sacrificing the rights of disabled people due to lack of funding. Members instead suggested stating "enabling service users, workers, families and communities to flourish, prosper and fulfil their potential".

Lastly, GDA members felt that a principle surrounding accountability should be included in legislation. This would signal a change in attitude and values in how social care is organised in Scotland.



Accountability to Scottish Ministers (Sections 2 and 3)

16. In providing comments on these sections of the Bill, please consider:

- Whether you agree with Scottish Ministers being given these overarching responsibilities?
- Whether there is anything important missing from these sections of the Bill?
- Whether there is anything you would disagree with or there are amendments you would wish to propose to these sections of the Bill?
- Whether an alternative approach would be preferable?

GDA members were broadly in agreement with what is in these sections of the Bill outlining the Accountability to Scottish Ministers. However, there were concerns that there is not enough detail and it leaves a lot to interpretation of the National Care Service principles themselves.

For example, the Bill states, when Scottish Ministers will discharge their duty to "promote in Scotland a care service designed to secure improvement in the wellbeing of the people of Scotland", that "everything that the Scottish Ministers do in discharging that duty is to be done in the way that seems to them to best reflect the National Care Service principles". Many GDA members highlighted that this leaves a great deal down to interpretation and does not provide assurance that there will be consistency in the accountability to Scottish Ministers in the National Care Service. Furthermore, in the context of austerity it was felt that rights would be traded for resources- or lack of them to be more accurate. It was asserted that good intentions in the context of lack of understanding about the reality of disabled people's lives and lack of knowledge of the rights we already have, leaves too much scope for potentially eroding human rights.

GDA members have concerns about the transitions of responsibility from local authorities to Scottish Ministers in social care and how this will impact them and the care they receive. Having clear plans for accountability and in what instances duties will be discharged and who they will be discharged to will provide the reassurance and stability needed to create a system that improves the wellbeing of the people of Scotland.

In addition, GDA members called for improvements in the way local delivery of care and unmet need is acknowledged and recorded. This should be included in reports made by local care boards to Scottish Ministers for accountability purposes, to monitor the standard of care services and as a crucial step to ensure the aim to "improve the quality and consistency of social work and social care services in Scotland" is achieved.



Establishment and abolition of care boards (Sections 4 and 5 / Schedules 1 and 2)

17. In providing comments on these sections of the Bill, please consider:

- Whether you support the establishment of care boards as set out in these sections of the Bill and provisions on financial assistance for boards?
- Whether there is anything important missing from these sections of the Bill?
- Whether there is anything you would disagree with or there are amendments you would wish to propose to these sections of the Bill?
- Whether an alternative approach would be preferable?

GDA members hoped for more clarity within legislation about how many care boards would be established and how many geographical areas this would cover. To mitigate risk when transferring services into new care boards, members called for clear commitments of how many care boards will exist at minimum and what the membership will look like.

It was felt that there might be useful learning from current boards to consider and build on where there is room for learning and a commitment to work cooperatively with the National Care Service. One concern about a focus on structures is that it inevitably takes away attention from the service users while being established and this can have unintended and negative consequences for service users. Similarly, staff in the system can be lacking direction and leadership whilst new structures are being built which causes delays and has impact on morale.

Questions were rightfully asked about how the new structures will impact on current HSCPs and decision making at the level of the IJB and about individual packages of care and support.

GDA members had concerns about commitments related to the membership of care boards not being laid out within legislation and raised the importance of disabled people and disabled people's organisations having meaningful representation and participation on these boards. It was felt strongly that disabled people cannot be hand-picked individually to represent perspectives of a diverse and wide body of people and that this would be best served by the independent support organisations – disabled people led organisations- where these exist, or service user groups. This would require resources and collaboration with DPOs and would be congruent with the principle about designing services collaboratively with the people they are there to support.

An amendment, including the requirements for membership of care boards and the inclusion of independent service user groups like disabled people's organisations within this membership would provide assurance about the commitment to



embedding lived experience and co-design in the National Care Service's implementation.

In addition, the statement within the Bill outlining that "Scottish Ministers may provide any financial assistance to care boards that they consider appropriate", raised questions about how the funding will work and who will be financially accountable. It was felt that more details are required as to how the financial operations and accountabilities will work.

Strategic planning and ethical commissioning (Chapter 2)

18. In providing comments on this chapter of the Bill, please consider:

- Whether you agree with these provisions?
- Whether there is anything important missing from this chapter of the Bill?
- Whether there is anything you would disagree with or there are amendments you would wish to propose to this chapter of the Bill?
- Whether an alternative approach would be preferable?

GDA agrees broadly with this section of the Bill covering strategic planning and ethical commissioning with an emphasis on the Scottish Government's own Approach to Service Design. If the Care Boards are to design responsive and effective services then they must first understand the reality of people's lives – Discover &, Define then design the solution – Develop & Deliver. At all stages, disabled people and social care users should be involved in this process.

GDA members raised that the commitment in the Bill that "before making a strategic plan the Scottish Ministers must consult publicly on a draft of the plan", was not sufficient to fully ensure lived experience is considered in the service strategic planning. GDA members suggested that it should be specified that service users, including disabled people, must be meaningfully involved directly in the drafting of the plan from the outset and that adequate time should be spent identifying and understanding the "problems" before producing the plan and designing solutions.

GDA members have highlighted the need for continual dialogue and involvement with disabled people and social care users, as well as co-design practice, within the National Care Service from implementation to delivery.

GDA also notes that there is no definition of "ethical commissioning" and how this can help to meet the principles of human rights outlined.



National Care Service Charter (Sections 11 and 12)

19. In providing comments on these sections of the Bill, please consider:

- Whether you agree with provisions to create a National Care Service charter?
- Whether there is anything important missing from these provisions?
- Whether there is anything you would disagree with or there are amendments you would wish to propose to this chapter of the Bill?
- Whether an alternative approach would be preferable?

GDA members welcome whole-heartedly the provisions to create a National Care Service Charter to outline and uphold rights in relation to the National Care Service. An immediate concern was however raised in relation to section 11's statement that nothing in the charter is to "give rise to any new rights". In the context of social care cuts, unmet need and continual breaches to our existing rights in social care, as Derek Feeley found in his 2021 Independent Review of Adult Social Care, this does not create capacity for any "realisation" of human rights and in fact may unintentionally undermine them, going against the Service Principles.

In this context, GDA members called for the inclusion of named rights and commitments within the Charter from the outset that are fixed in legislation. Naming and protecting key rights such as the right to independent living, including the right to need satisfaction and capturing unmet need as outlined by the Scottish Independent Living Coalition, would provide assurance that disabled people's rights are protected.

Additional ideas in the paper include a process of exploring rights separate to the support itself. Dr Woodward outlines 7 sub rights including the need for accessible information, pre-assessment support and peer advocacy, support and advocacy during the assessment, the right to produce self-assessment, to be present at decisions about resource allocation, to appeal to independent appeals process and to record unmet need. This chimes with GDA members, who have come up with the following rights to be included in such a Charter:

- Learn about equality and human rights including the UNCRPD so that you
 understand the rights we have to dignity, choice and control over our health, care
 and treatment including in decisions that affect us.
- Embed these human rights in the delivery of health and social care including in behaviours, assessment of needs and provision of services
- Remove resources available from assessment of need and instead take a rights based approach to assessing and meeting needs-including creating provisions to capture unmet need.
- Treat us with respect, understanding and compassion.



- Provide high quality, consistent and on-time care and support that meets our needs and choices to live the lives we want to live.
- Make all communications within the National Care Service clear, straight-forward and readily available in accessible alternative formats.
- Involve us at an individual level about our care, support and treatment and involve our disabled-people led organisations in planning health & social care as they understand our rights and can help you to codesign better services.
- Openly and regularly communicate with us to keep us up to date on the National Care Service development and any changes that impact us.
- Listen to us believe us when we tell you what we need, respect our choices and be flexible when our needs change.
- Be prepared to consider that the care someone needs might be housework/ cleaning, shopping, odd jobs rather than intimate personal care: even if this is needed, it might not be wanted.
- Provide a "person first", person-led service with rights-based solutions, built on the understanding that each person is different.
- Provide equal and accessible access to information on independent advocacy support at all points throughout our health and care journey.
- Ensure our consent informs access to our health and social care records and that our information is kept private, unless we give permission to share this.
- Provide us with independent advocacy and resource access to peer support to help us speak up or to speak for us about decisions which affect us.
- Be honest and explain the reasons for decisions or actions taken about our health, care or treatment and tell us what support we are entitled to if we disagree.
- Provide a clearly signposted and accessible complaints process and enable us to have support to have our voices heard or someone to speak for us in this process.

In addition, GDA members have concerns about the potential paternalistic framing of "responsibilities", in reference to our "rights and responsibilities in relation to the National Care Service". Specifically we are concerned that applying "responsibilities" in a context of reduced resources places undue pressure on families who may lack capacity to provide support and practical assistance to their disabled loved ones. This also applies pressure to disabled people in a bid to defend reduced services and place responsibility on disabled people and their families rather than the care system.



As such, the Charter and its contents, must be meaningfully co-designed with service users, such as disabled people. Human rights including the existing right to Independent Living should be embedded in the Charter's creation and

implementation. An amendment committing to ensuring the "summary of rights and responsibilities" are co-designed by invested parties, such as service users and the care workforce would be welcome.

Members welcomed the commitment in the legislation to review the Charter within five years of the first version being laid before the Scottish Parliament. However, an amendment should be added in section 12 to ensure this is reviewed every five years, similar to that of the strategic plan, and commit to involving service users – including disabled people and their organisations – in an ongoing dialogue and process of co-design. GDA members felt that giving "particular regard" to service users in the consultation approach leaves too much room for interpretation or tokenistic engagement, which moves away from the collaborative process of co-design seen so far in the National Care Service development.

Independent advocacy (Section 13)

20. In providing comments on this section of the Bill, please consider:

- Whether you agree with these provisions?
- Whether there is anything important missing from this section of the Bill?
- Whether there is anything you would disagree with or there are amendments you would wish to propose to this section of the Bill?
- Whether an alternative approach would be preferable?

GDA members raised concerns about the wording of this section, stating that Scottish Ministers "may" make provision about the provision of independent advocacy services. Over almost 2 decades and specific engagement sessions about this Bill, GDA members have consistently highlighted the need for independent advocacy to support disabled people to navigate the social care system, through applications, assessments, complaints and other aspects. This has become more pressing since the financial collapse and related austerity followed by Covid and the impact that this has had on the culture and practises of social work services across Scotland.

Access to both independent advocacy and peer support and advocacy has been found to be essential to raise aspirations, inform people about their rights and ensure more equal access to services. Protection of our human rights and ability to make decisions about our care and the lives we want to live cannot, unfortunately be taken for granted in a context driven by finances. As such, the provision of independent and peer advocacy should be committed to within the Bill on par with that of the



complaints service, stating that Scottish Ministers "must make provision about the provision of independent and peer advocacy services".

Complaints (Sections 14 and 15)

21. In providing comments on these sections of the Bill, please consider:

- Whether you agree with these provisions?
- Whether there is anything important missing from these sections of the Bill?
- Whether there is anything you would disagree with or there are amendments you would wish to propose to these sections of the Bill?
- Whether an alternative approach would be preferable?

Current and previous experiences of using the complaints processed have been found to leave issues unresolved and undermine trust, It is also unclear and disabled people remain unconvinced that there is any impartiality at local levels as funding is the driving force for all decision making. Broadly, GDA members were therefore in agreement about provisions for a National Complaints service within the National Care Service Bill. However, GDA members highlighted that the National Care Service complaints process must be an independent one, separate from service delivery, and transparent to ensure fairness and accountability

In addition, many GDA members raised that a statement about the duty to communicate the complaints process to service users in a clear, accessible way, in addition to accessing independent advocacy, must be included within the Bill to ensure it is fulfilled.

Moreover, GDA members had queries about accountability in relation to complaints, particularly in relation to ensuring that proper processes and confidentiality are adhered to. It was also felt that clarification is needed as to how a complaints service and ministerial authority will align with existing bodies like the Care Commission.

Fundamentally a new complaints process and related procedures should consider where decisions have undermined human rights for the disabled person and potentially for their carer/ family member/ loved one.



Ministers' powers to intervene (Chapter 4) – sections 16 to 22

Sections 16 to 22 of the Bill establish powers for Ministers to intervene with respect to care boards and contractors, for instance in case of an emergency or of service failure.

22. In providing comments on this chapter of the Bill, please consider:

- Whether you agree with these provisions?
- Whether there is anything important missing from this chapter of the Bill?
- Whether there is anything you would disagree with or there are amendments you would wish to propose to this chapter of the Bill?
- Whether an alternative approach would be preferable?

GDA members, across several engagement events, expressed consistent concerns about the lack of detail as to when a Scottish Minister would intervene in care board delivery, in what circumstances and if this would happen at all. For example, would this be in instances where there is failure to comply with the principles of human rights and will this be further explained in the regulations' requirements? It is unclear what is meant by "failed to carry out any of its functions" when we do not yet know the directions which will be give under section 16 such as whether they must comply with the principles set out.

GDA members felt too much scope was left for interpretation and a lack of stability and clarity when it came to accountability within the service. For example, what types of emergencies undermine "effective performance"? Would this include breaches of human rights? And which definition of human rights are we using – and who decides?

An additional statement clarifying the relationship between care boards and Scottish Ministers, and in what specific instances powers to intervene would be used and how, would provide more clarity and certainty about how these authorities will interact to provide services for disabled people.

GDA members are supportive of the intent of Emergency Intervention Orders to ensure that goods and services are upholding the wellbeing and safety of service users.



Connected functions (research, training, other activities and compulsory purchase (Chapter 5)

23. In providing comments on this chapter of the Bill, please consider:

- Whether you agree with these provisions?
- Whether there is anything important missing from this chapter of the Bill?
- Whether there is anything you would disagree with or there are amendments you would wish to propose to this chapter of the Bill?
- Whether an alternative approach would be preferable?

GDA members welcome a commitment to research and training which will enrich the NCS and the associated workforce to deliver high quality, consistent and human rights based services.

In particular GDA urges the Scottish Government Ministers to involve DPOs (Disabled People led organisations) in delivering disability equality and independent living training to NCS leadership and staff to help embed values and rights in the system.

Transfer of functions, including scope of services (Chapter 6 and Schedule 3)

24. In providing comments on these sections of the Bill, please consider:

- Whether you agree with Scottish Ministers being given these powers?
- Whether there is anything important missing from these sections of the Bill?
- Whether there is anything you would disagree with or there are amendments you would wish to propose to these sections of the Bill?
- Whether an alternative approach would be preferable?

GDA is broadly in agreement with this section of the Bill, however would seek more clarity about when and to what extent these powers will be used by Scottish Ministers.

An amendment detailing some kind of provision for the transfer of powers and how this will impact the service user or ensuring any transfer is met with a planned transition to mitigate risk or ill effect on service users, care and the workforce, would be welcome to provide greater clarity on this. We have raised concerns already that structural reforms can overshadow everything else: we firmly believe that there is a lack of emphasis in this section and overall on human rights and the principles laid out on the face of the Bill.



The over-emphasis on structures and processes will likely be of interest to those in the existing system and indeed, there may, in some areas be existing structures which can take on the function and the delivery, if co-operation and a commitment to the principles exists. However, we recognise that this is not straightforward and suggest that disabled people who need or use social care and our organisations as well as carer organisations are involved in ongoing dialogue with Minister, Government where appropriate and the new care boards.

Inclusion of children's services and justice services (Section 30)

25. In providing comments on this section of the Bill, please consider:

- Whether you agree with proposals to include children's services and justice services within the scope of the National Care Service, either now or in the future?
- Whether there is anything important missing from this section of the Bill?
- Whether there is anything you would disagree with or there are amendments you would wish to propose to this section of the Bill?
- Whether an alternative approach would be preferable?

GDA Members were weary that the findings of Feeley's independent review have become subsumed by a much bigger proposed change in terms of incorporating children's services and justice services. However, GDA members concluded that this benefits young disabled people and disabled children from a transitions perspective.

GDA agrees that Scottish Ministers should have the power to include social justice and social services in the National Care Service, as laid out in this section of the Bill, but feel that more evidence is needed and an incremental approach to such a radical transformation agenda is almost certainly more prudent. In addition, again, it is not enough to state that only "consultation" is needed before transferring these powers and GDA members feel strongly once more that lived experience must be embedded and that disabled people and their families and carers should become equal partners in planning for and delivering new structures and processes.

An amendment to this section requiring meaningful involvement and ongoing dialogue and co-design with service users, wherever possible, following a rights based approach and rooted in human rights based principles, as done in the preparation of transferring social care services, would ensure consistency, meaningful engagement and improved service delivery across the National Care Service.



Consequential modifications / Interpretation of Part 1 (Chapter 7 and Schedule 4)

26. In providing comments on this chapter of the Bill, please consider:

- Whether you agree with these provisions?
- Whether there is anything important missing from this chapter of the Bill?
- Whether there is anything you would disagree with or there are amendments you would wish to propose to this chapter of the Bill?
- Whether an alternative approach would be preferable?

N/A

Health and social care information (part 2 of the Bill)

27. In providing comments on this part of the Bill, please consider:

- Whether you agree with these provisions?
- Whether there is anything important missing from this part of the Bill?
- Whether there is anything you would disagree with or there are amendments you would wish to propose to this part of the Bill?
- Whether an alternative approach would be preferable?

GDA members strongly articulated that health and social care records must belong to them and that whilst they see benefits of information being shared to prevent repeated explaining of circumstances, they were clear that shared information is only to be done at the consent and the choice of the service user and that they must be able to set limits on who can access this information and to what extent.

There was hope that shared information across health and social care services would improve their experiences, reduce inconsistencies and precipitate shared working practices, values and a more efficient process of care and treatment.

However GDA members felt it was equally important that the service user, is included in regulations to be able to access information held about them, shared between the National Care Service and the National Health Service, as provisions lay out in section 36. This access may also be subject to the information standard as laid out above.



Right to breaks for carers (sections 38 and 39)

28. In providing comments on these sections of the Bill, please consider:

- Whether you agree with the proposed amendments to the Carers (Scotland) Act 2016?
- Whether there is anything important missing from these sections of the Bill?
- Whether there is anything you would disagree with or there are amendments you would wish to propose to these sections of the Bill?
- Whether an alternative approach would be preferable?

GDA supports the response of Carers Scotland.

Implementation of Anne's Law (Section 40)

29. In providing comments on these sections of the Bill, please consider:

In providing comments on this section of the Bill, please consider:

- Whether you agree with the proposed amendments to the Public Services Reform (Scotland) Act 2010?
- Whether there is anything important missing from this section of the Bill?
- Whether there is anything you would disagree with or there are amendments you would wish to propose to this section of the Bill?
- Whether an alternative approach would be preferable?

GDA members support the direction of travel of Ann's law in strengthening residents' rights in adult residential settings and giving nominated relatives or friends the same access rights to care homes as staff while following stringent infection control procedure.

The pandemic shone a light on the vulnerability of disabled and older people living in case homes and the need for ongoing connections to families and friends to maintain health and wellbeing.



Reserved right to participate in certain contracts (section 41)

30. In providing comments on this section of the Bill, please consider:

- Whether you agree with the proposed amendments to the Public Contracts (Scotland) Regulations 2015?
- Whether there is anything important missing from this section of the Bill?
- Whether there is anything you would disagree with or there are amendments you would wish to propose to this section of the Bill?
- Whether an alternative approach would be preferable? $\ensuremath{\text{N/A}}$

Regulation of social services (Sections 42 and 43)

31. In providing comments on these sections of the Bill, please consider:

- Whether you agree with the proposed amendments to the Public Services Reform (Scotland) Act 2010?
- Whether there is anything important missing from these sections of the Bill?
- Whether there is anything you would disagree with or there are amendments you would wish to propose to these sections of the Bill?
- Whether an alternative approach would be preferable? $\ensuremath{\mathsf{N/A}}$

Final provisions (part 4)

In providing comments on this part of the Bill, please consider:

- Whether you agree with regulation-making powers conferred on Scottish Ministers by section 46 of the Bill?
- Whether there is anything important missing from this part of the Bill?
- Whether there is anything you would disagree with or there are amendments you would wish to propose to this part of the Bill?
- Whether an alternative approach would be preferable?