

Response to the Department of Health Consultation on the Reform of Adult Social Care

June 2022

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Summary of Recommendations

- 2.10 the Department of Health adopts a human rights based approach to the development of a new social care strategy. In addition, to the ECHR, UN ICCPR and UN ICESCR, this strategy should adopt and, for the purposes of benchmarking, utilise the FREDA Principles.
- 2.13 the Department of Health ensures effective participation in any further steps taken in developing implementing, monitoring and evaluating this strategy.
- 3.6 the Department of Health assesses the level of resources necessary and, with the NI Executive, ensures that the maximum available resources are utilised and ring fenced for the development of this strategy.
- 3.7 the Department of Health maintains a participatory process in the development of the budget relating to the proposed strategy and engages in meaningful consultation with those affected by the strategy and their representative organisations.
- 4.4 the Department of Health develops a clear and realistic timeframe for delivery, using appropriate benchmarks and indicators for each agreed action. This should include provisions for regular reporting to the NI Committee for Health, and an annual report on progress.
- 4.5 the Department of Health ensures that outsourcing of responsibilities to private entities or civil society is subject to a human rights-based procurement process and will be monitored, including for human rights compliance.
- 4.6 the Department of Health ensures that external agencies, particularly civil society organisations, are appropriately resourced to ensure their long-term sustainability in the provision of care.
- 4.8 the Department of Health commits to consistently collect, monitor and publish robust data that is comprehensively disaggregated and offers an opportunity for comparison across time and jurisdictions.

- 5.4 the Department of Health ensures that decisions on cost bandings as part of the tariff setting exercise are informed by human rights standards and principles that centre on the dignity of those availing of social care services.
- 5.9 the Department of Health ensures that it is made explicit that the principles guiding the implementation of future legislation operate within a human rights based framework, which incorporates the full range of international human rights standards ratified by the UK.
- 5.10 the Department of Health ensures that any future legislation is accompanied by a Human Rights Impact Assessment that takes account of all the UK's international human rights obligations.
- 6.7 in assessing appropriate wage levels for social care workers, the Department of Health considers whether the current rates of pay reflects an inherently discriminatory evaluation of the value of social care work.
- 6.8 that, at a minimum, wages should be set at a living wage level.
- 6.11 that safe staffing levels are determined in consultation with service providers and allocated the necessary funding.
- 6.13 the Department of Health includes within the strategy a commitment to comprehensive human rights training for all social care staff. This training should be mandatory and be subject to periodic review and evaluation.
- 7.8 the Department of Health, as part of the development of a regional strategic 'In Control' action plan, considers the inclusion of those who face barriers to engagement in consultation processes.
- 7.10 the proposed legislative duty on Health and Social Care Trusts to provide information and advice on care and support options includes a requirement that this is tailored to a range of communication requirements.

- 7.14 the Department of Health includes specific action on the deinstitutionalisation of care through the lens of the UN CRPD. This should be completed as a matter of urgency.
- 7.16 the Department of Health adopts the recommendations from the COVID-19 Inquiry in relation to the management of the pandemic in care homes, ensuring that learning is disseminated across the sector and that a human rights based plan is in place for any future outbreak. This learning should be incorporated into the future strategy to ensure that the isolation experienced during the COVID-19 pandemic is prevented in any future pandemic or societal emergency.
- 8.3 that specific provision for these services is guaranteed within the future strategy in close consultation with the relevant services providers. This will require the appropriate allocation of resources and clear monitoring mechanisms.
- 8.5 the Department of Health ensures that the future strategy includes provision for those who are transitioning into adult social care services.
- 8.6 as part of introducing the offer of preventative/support visits for anyone aged over 75 by an appropriately trained professional, the Department of Health incorporates learning from the application of the scheme in Denmark and ensures that there are appropriate guidelines and quality assurance indicators.
- 9.3 the Department of Health ensures that the proposed legislative duties include legislative provision for the right of carers to access respite care services.
- 9.7 as part of the review of the Caring for Carers strategy and development of a new strategic approach, the Department of Health adopts a human rights based approach with specific consideration to rights of child carers, including the right to participation, as protected by the UN CRC.

- 10.3 the Department of Health ensures that the philosophy of care clearly states that it is grounded in human rights and that staff must act in full compliance with ECHR rights, as per the Human Rights Act.
- 10.7 the measures proposed to reduce the possibility of any care home resident having to move home are monitored as part of the Regulation and Quality Improvement Authority's inspections of care homes.
- 10.10 the Department of Health ensures that the strategy includes a clear, expeditious complaints mechanism that is accessible and includes a transparent and meaningful process by which to appeal decisions. The Strategy should include a commitment that comprehensive, fully accessible information on these processes is available to those availing of social care services and their carers.
- 10.13 the Department of Health ensure that fully accessible, independent advocacy services are available to everyone supported within the social care system.

1.0 Introduction

- 1.1 The Northern Ireland Human Rights Commission (the NIHRC), pursuant to section 69(1) of the Northern Ireland Act 1998, reviews the adequacy and effectiveness of law and practice relating to the protection of human rights in Northern Ireland (NI). The NIHRC is also mandated, under section 78A(1) to monitor the implementation of Article 2(1) of the Protocol on Ireland/NI of the European Union (EU) Withdrawal Agreement, to ensure there is no diminution of rights protected in the 'Rights, Safeguards and Equality of Opportunity' chapter of the Belfast (Good Friday) Agreement 1998 as a result of the United Kingdom's withdrawal from the EU. In accordance with these functions the following statutory advice is submitted to the Department of Health in response to its consultation on the reform of adult social care.
- 1.2 The NIHRC bases its advice on the full range of internationally accepted human rights standards, including the European Convention on Human Rights, as incorporated by the Human Rights Act 1998 and the treaty obligations of the Council of Europe (CoE) and United Nations (UN) systems.

 The relevant regional and international treaties in this context include:
 - European Convention on Human Rights 1950 (ECHR);²
 - UN International Covenant on Civil and Political Rights 1966 (UN ICCPR);³

¹ The NI Executive is subject to the obligations contained within the specified regional and international treaties by virtue of the United Kingdom (UK) Government's ratification. In addition, section 26(1) of the NI Act 1998 provides that "if the Secretary of State considers that any action proposed to be taken by a Minister or NI department would be incompatible with any international obligations... [s]he may order direct that the proposed action shall be taken". The NIHRC further recalls that section 24(1)(a) of the NI Act 1998 states that "a Minister or NI department has no power to make, confirm or approve any subordinate legislation, or to do any act, so far as the legislation or act... is incompatible with any of the [ECHR] rights".

² Ratified by the UK in 1951. Further guidance is also taken from the body of case law from the European Court of Human Rights (ECtHR).

³ Ratified by the UK in 1966.

- UN International Covenant on Economic, Social and Cultural Rights 1966 (UN ICESCR);⁴
- UN Convention on the Rights of the Child 1989 (UN CRC),⁵ and
- UN Convention on the Rights of Persons with Disabilities 2006 (UN CRPD).⁶
- 1.3 In addition, there exists a body of 'soft law' developed by human rights bodies of the CoE and UN. These declarations and principles are non-binding, but provide further guidance in respect of specific areas. The relevant standards in this context include, inter alia:
 - UN CEDAW Committee General Comment No 6;7
 - UN ICESCR Committee General Comment No 3;8
 - UN Principles for Older Persons;⁹
 - UN Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care; 10
 - UN ICESCR Committee General Comment No 14;11
 - UN CRC Committee General Comment No 5;12
 - UN ICESCR Committee General Comment No 20;13
 - CoE Committee of Ministers on the promotion of human rights of older persons;¹⁴
 - UN CRPD Committee 2017 Concluding Observations to the UK;15

⁴ Ratified by the UK in 1966.

⁵ Ratified by the UK in 1991.

⁶ Ratified by the UK in 2009.

⁷ UN CEDAW Committee General Comment No 6: Effective National Machinery and Publicity', 1988.

⁸ E/1991/23, 'UN ICESCR Committee General Comment No 3: Nature of States Parties' Obligations', 14 December 1990.

⁹ A/RES/46/91 'United Nations Principles for Older Persons', 16 December 1991.

 $^{^{10}}$ A/RES/46/119 'UN Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care', 17 December 1991.

¹¹ E/C.12/2000/4, 'UN ICESCR Committee General Comment No 14: The Right to the Highest Attainable Standard of Health', 11 August 2000.

¹² CRC/GC/2003/5, 'UN CRC Committee General Comment No 5: General Measures of Implementation of the UN CRC', 27 November 2003.

¹³ E/C.12/GC/20, 'UN ICESCR Committee General Comment No 20: Non-discrimination in Economic, Social and Cultural Rights' 2 July 2009.

¹⁴ Recommendation CM/Rec(2014)2, 'CoE Committee of Ministers to Member States on the Promotion of Human Rights of Older Persons', 19 February 2014.

¹⁵ CRPD/C/GBR/CO/1, 'UN CRPD Committee Concluding Observations on the Initial Report of the UK of Great Britain and NI', 29 August 2017.

- UN CRPD Committee General Comment No 5;16 and
- UN CRPD Committee General Comment No 7.17
- 1.4 The NIHRC further advises on the UK Government commitment in Protocol Article 2(1) to ensure there is no diminution of rights, safeguards and equality of opportunity in the relevant section of the Belfast (Good Friday) Agreement as a result of the UK's withdrawal from the EU. This is given effect in UK law by section 7A of the EU (Withdrawal) Act 2018. In addition, Section 6 of the Northern Ireland Act 1998 provides that the NI Assembly is prohibited from making any law which is incompatible with Protocol Article 2. Section 24 of the 1998 Act also provides that all acts of the Department should be compatible with Protocol Article 2.
- 1.5 The NIHRC welcomes the opportunity to respond to the Department of Health's consultation on the reform of adult social care. The NIHRC has sought to highlight relevant human rights standards and principles where they may be of assistance in developing the new adult social care strategy. The NIHRC will provide some general comments on the consultation document referencing, where relevant, examples from the 48 proposed actions.

2.0 Human Rights Standards

2.1 Social care engages a range of rights outlined in the ECHR. This includes the right to life (Article 2), the prohibition on torture, cruel, inhuman and degrading treatment (Article 3), the right to liberty (Article 5), the right to

¹⁶ CRPD/C/GC/5, 'UN CRPD Committee General Comment No 5: Living Independently and Being Included in the Community', 27 October 2017.

¹⁷ CRPD/C/GC/7, 'UN CRPD Committee General Comment No 7: Participation of Persons with Disabilities Including Children with Disabilities, Through Their Representative Organisations, In the Implementation and Monitoring of the UN CRPD', 9 November 2018.

private and family life (Article 8), and the prohibition of discrimination (Article 14).

- 2.2 Social care further engages several rights outlined in international treaties which have been ratified by the UK. Article 12 of UN ICESCR protects the right to the highest attainable standard of physical and mental health. In the context of the latter right, Article 2 of the UN ICESCR requires that the UK "takes steps... to the maximum of its available resources, with a view to achieving progressively the full realisation... [of this right] by all appropriate means". The UN ICESCR Committee clarifies that "such steps should be deliberate, concrete and targeted as clearly as possible towards meeting the obligations" contained within this right". 18 These steps should also be taken "expeditiously and effectively as possible" towards fulfilment of the right. 19 Furthermore, "any deliberately retrogressive measures... require the most careful consideration" and "need to be fully justified" and "in the context of the full use of the maximum available resources". 20 The UN ICESCR Committee also clarifies that "the guarantee that the right will be exercised without discrimination of any kind" should be given "immediate effect".21
- 2.3 Consideration should also be given to Article 12 of the UN ICCPR which protects the right to liberty of movement and freedom to choose one's residence.

¹⁸ E/1991/23, 'UN ICESCR Committee General Comment No 3: Nature of States Parties' Obligations', 14 December 1990, at para 2.

¹⁹ E/1991/23, 'UN ICESCR Committee General Comment No 3: Nature of States Parties' Obligations', 14 December 1990, at para 9; E/C.12/2000/4, 'UN ICESCR Committee General Comment No 14: The Right to the Highest Attainable Standard of Health', 11 August 2000, at para 30.

²⁰ E/1991/23, 'UN ICESCR Committee General Comment No 3: Nature of States Parties' Obligations', 14 December 1990, at para 9.

²¹ E/C.12/2000/4, 'UN ICESCR Committee General Comment No 14: The Right to the Highest Attainable Standard of Health', 11 August 2000, at para 30.

2.4 The UN CRPD compels States to ensure that persons with disabilities are supported to live in the community on an equal basis with others. Article 19 requires that States:

recognise the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.
- 2.5 Further relevant guidance is found in the UN Principles for Older Persons which recognise that older persons:

should be able to enjoy human rights and fundamental freedoms when residing in any shelter, care or treatment facility, including full respect for their dignity, beliefs, needs and privacy and for the right to make decisions about their care and the quality of their lives.²²

2.6 The UN Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care recognise that "[a]Il persons have the

²² A/RES/46/91 'UN Principles for Older Persons', 16 December 1991, at Article 14.

right to the best available mental health care, which shall be part of the health and social care system"²³ and that "[e]very patient shall have the right to be treated and cared for, as far as possible, in the community in which he or she lives".²⁴

- 2.7 The NIHRC welcomes the Department's vision for the future of a "human rights based system of service provision", ²⁵ however notes the limited reference to specific rights within the consultation document. The NIHRC recommends that the human rights-basis of service provision encompasses the full range of internationally accepted human rights standards, which the UK has signed and ratified.
- 2.8 A human rights-based approach enables rights-holders to exercise and claim their rights and enhances the capacity of duty bearers who have a legal obligation to respect, protect, promote and fulfil human rights.²⁶
- 2.9 The FREDA principles helpfully demonstrate how a human rights-based approach can be applied in practice.²⁷ They are comprised of the following elements:
 - Fairness individuals should have a say in matters which impact their human rights.
 - Respect an obligation to refrain from interfering or undermining a person's rights.
 - Equality all forms of discrimination should be eliminated and those

²³ A/RES/46/119 'UN Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care', 17 December 1991, at Principle 1(1).

²⁴ A/RES/46/119 'UN Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care', 17 December 1991, at Principle 3.

²⁵ A/RES/46/119 `UN Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care', 17 December 1991, at Principle 3.

²⁶ UN Office of the High Commissioner for Human Rights, 'Frequently Asked Questions about a Human Rights Based Approach to Development and Cooperation' (OHCHR, 2006), at 15.

²⁷ NI Public Services Ombudsman and the NI Human Rights Commission, 'Human Rights Manual' (NIPSO and NIHRC, 2017).

that face the biggest barriers should be prioritised.

- Dignity a person must be recognised, respected and protected as a rights holder and as a unique and valuable human being with an individual personality, distinct needs, interests and privacy.
- Autonomy a person should be allowed to make free and informed decisions about how they wish to live their lives.
- 2.10 The NIHRC recommends that the Department of Health adopts a human rights based approach to the development of a new social care strategy. In addition, to the ECHR, UN ICCPR and UN ICESCR, this strategy should adopt and, for the purposes of benchmarking, utilise the FREDA Principles.
- 2.11 A human rights-based approach also involves ensuring effective participation. This requires genuine opportunities to be offered at every stage of the process design, development, implementation, monitoring and evaluation. It also requires consideration to be given to accessibility and to reasonable accommodation, which should be established by consulting with those you are seeking to engage with.
- 2.12 Article 4(3) of the UN CRPD provides useful guidance as to what effective participation requires. It states that "in the development and implementation of legislation and policies... and in other decision-making processes... States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their

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²⁸ European Network of National Human Rights Institutions, 'We Have the Same Rights: The Human Rights of Older Persons in Europe' (ENNHRI, 2017), at p.49.

representative organisations". ²⁹ The participation should be "meaningful" and occur in a "timely manner". ³⁰

2.13 The NIHRC recommends that the Department of Health ensures effective participation in any further steps taken in developing implementing, monitoring and evaluating this strategy.

3.0 Resourcing

- 3.1 The consultation document advises that "estimated costings and an economic impact assessment for the proposed actions will be developed during the consultation period" ³¹ and that "these costings, impact assessments as well as the availability of funding will inform the future strategy".³²
- 3.2 The NIHRC recalls the obligations to respect, to protect and to fulfil human rights and to maximise available resources, as identified within human rights treaties including Article 2(2) of the UN ICCPR, Article 2(1) of the UN ICESCR and Article 4(2) of the UN CRPD.
- 3.3 The effective allocation of resources is a key element in the enjoyment of human rights and requires States not only to distribute existing resources, but also to effectively mobilise resources within a country, including through fiscal reform.³³

²⁹ Article 4(3), UN Convention on the Rights of Persons with Disabilities 2006.

³⁰ CRPD/C/GC/7, 'UN CRPD Committee General Comment No 7: Participation of Persons with Disabilities Including Children with Disabilities, Through Their Representative Organisations, In the Implementation and Monitoring of the UN CRPD', 9 November 2018, at paras 11 and 22.

³¹ Department of Health, 'Consultation on the Reform of Adult Social Care' (DoH, 2022), at 5.

³² Department of Health, 'Consultation on the Reform of Adult Social Care' (DoH, 2022), at 5.

³³ UN Human Rights Office of the High Commissioner, 'Realising Human Rights Through Government Budget' (OHCHR, 2017).

- 3.4 The UN ICESCR Committee has previously raised concerns about the impact of the UK's fiscal policy on its capacity to "collect sufficient resources to achieve the full realisation of economic, social and cultural rights for the benefit of disadvantaged and marginalised individuals and groups".³⁴
- 3.5 Further, the UN ICESCR Committee states that "economic policies, such as budgetary allocations and measures to stimulate economic growth, should pay attention to the need to guarantee the effective enjoyment of the Covenant rights without discrimination".³⁵
- 3.6 The NIHRC recommends that the Department of Health assesses the level of resources necessary and, with the NI Executive, ensures that the maximum available resources are utilised and ring fenced for the development of this strategy.
- 3.7 The NIHRC further recommends that the Department of Health maintains a participatory process in the development of the budget relating to the proposed strategy and engages in meaningful consultation with those affected by the strategy and their representative organisations.

4.0 Monitoring and Data Collection

4.1 Effective monitoring is essential to ensuring human rights compliance and is a recurring requirement of human rights standards.³⁶ For monitoring to be

³⁴ E/C.12/GBR/CO/6, 'UN ICESCR Committee Concluding Observations on the Sixth Periodic Report of the UK of Great Britain and NI', 14 July 2016, at para 16.

³⁵ E/C.12/GC/20, 'UN ICESCR Committee General Comment No 20: Non-discrimination in Economic, Social and Cultural Rights' 2 July 2009, at para 38.

³⁶ E/C.12/GC/20, 'UN ICESCR Committee General Comment No 20: Non-discrimination in Economic, Social and Cultural Rights', 2 July 2009, at para 41; 'UN CEDAW Committee General Comment No 6: Effective National Machinery and

effective it "should assess both the steps taken and the results achieved" and "national strategies, policies and plans should use appropriate indicators and benchmarks, disaggregated on the basis of the prohibited grounds of discrimination".³⁷

- 4.2 Comprehensive monitoring requires a State to "establish and/or strengthen effective national machinery, institutions and procedures, at a high level of Government, and with adequate resources, commitment and authority".³⁸
- 4.3 The consultation document sets out that there will be a phased and incremental approach to the implementation of the proposed actions over the next ten years.³⁹ However, it does not outline how the implementation of the strategy will be monitored. The NIHRC also notes that many of the proposed actions will rely on cooperation with civil society organisations and the private sector. When delegating to private entities or civil society organisations this should be in the confident knowledge that they are appropriately resourced and best placed to take on the responsibility, including comprehensively trained on human rights obligations. The Department of Health should ensure that human rights considerations are embedded within its procurement processes as required by the Procurement Policy Note on Human Rights. 40 This should include ensuring that a due diligence process is adhered to when awarding contracts and requiring external agencies to demonstrate their compliance with human rights standards.

Publicity', 1988, at para 1(b); CRC/GC/2003/5, 'UN CRC Committee General Comment No 5: General Measures of Implementation of the UN CRC', 27 November 2003, at para 45.

³⁷ E/C.12/GC/20, 'UN ICESCR Committee General Comment No 20: Non-discrimination in Economic, Social and Cultural Rights', 2 July 2009, at para 41.

³⁸ 'UN CEDAW Committee General Comment No 6: Effective National Machinery and Publicity', 1988, at para 1(b).

³⁹ Department of Health, 'Consultation on the Reform of Adult Social Care' (DoH, 2022), at 5.

⁴⁰ Department of Finance, 'Procurement Policy Note PPN 05/21 Human Rights in Public Procurement' (DoF, 2021).

- 4.4 The NIHRC recommends that in drafting the strategy, the Department of Health develops a clear and realistic timeframe for delivery, using appropriate benchmarks and indicators for each agreed action. This should include provisions for regular reporting to the NI Committee for Health, and an annual report on progress.
- 4.5 The NIHRC recommends that the Department of Health ensures that outsourcing of responsibilities to private entities or civil society is subject to a human rights-based procurement process and will be monitored for human rights compliance.
- 4.6 The NIHRC recommends that the Department of Health ensures that external agencies, particularly civil society organisations, are appropriately resourced to ensure their long-term sustainability in the provision of care.
- 4.7 The NIHRC notes the proposal to adopt a regional approach to data collection in relation to social care staff. ⁴¹ It is the NIHRC's view that robust disaggregated quantitative and qualitative data of those who engage with social care services is essential to effectively implementing law and policy in this area. For example, the UN CRPD Committee has found that to fulfil the right to independent living it is necessary to "collect consistent quantitative and qualitative data on people with disabilities, including those still living in institutions". ⁴²
- 4.8 The NIHRC recommends that the Department of Health commits to consistently collect, monitor and publish robust data that is comprehensively disaggregated and offers an opportunity for comparison across time and jurisdictions.

⁴¹ Department of Health, 'Consultation on the Reform of Adult Social Care' (DoH, 2022), at 41.

⁴² CRPD/C/GC/5, 'UN CRPD Committee General Comment No 5: Living Independently and Being Included in the Community', 27 October 2017, at para 38(g).

5.0 Strategic Priority 1 - Sustainable Systems Building

- 5.1 The NIHRC recognises the concern that "current procurement, contracting and monitoring processes can drive a short term, cost focused system of service provision with a focus on the transactional time for task arrangements rather than a personalised outcomes model of care". This is inconsistent with a human rights based approach to social care embedded within the FREDA principles. As suggested in the Power to People report, "the care sector is not the right place for a 'profit maximisation' business model". He had a suggested in the Power to People report, "the care sector is not the right place for a 'profit maximisation' business model".
- 5.2 The NIHRC notes the proposals set out in Actions 6 and 7 in relation to regionally consistent tariff setting for adult social care services and increased powers of inspection and regulation in relation to overhead and management costs and levels of profit. 45 As outlined on page 32 of the consultation document, it is important that any regulated level of cost "would be flexible enough to accommodate smaller scale providers who cannot offer economies of scale but can provide added value in other ways". 46 The NIHRC welcomes more regional consistency in terms of social care costs, but notes that this must allow scope for person-centred care planning to address the specific support requirements of each individual.
- 5.3 The NIHRC also welcomes the assertion that "agreed regional bandings would have to reflect the true cost of providing the model of care that is being commissioned".⁴⁷ This should fully consider the cost of care delivery

⁴³ Department of Health, 'Consultation on the Reform of Adult Social Care' (DoH, 2022), at 28.

⁴⁴ Expert Advisory on Adult Care and Support, 'Power to People: Proposals to Reboot Adult Care and Support in NI' (DoH, 2017), at 64.

⁴⁵ Department of Health, 'Consultation on the Reform of Adult Social Care' (DoH, 2022), at 33.

⁴⁶ Department of Health, 'Consultation on the Reform of Adult Social Care' (DoH, 2022), at 32.

⁴⁷ Department of Health, 'Consultation on the Reform of Adult Social Care' (DoH, 2022), at 33.

that is human rights compliant and supports the full realisation of the rights of those being supported.

- 5.4 The NIHRC recommends the Department of Health ensures that decisions on cost bandings as part of the tariff setting exercise are informed by human rights standards and principles that centre on the dignity of those availing of social care services.
- 5.5 The NIHRC notes that there is currently a level of inconsistency in the availability of social care based on geographical setting,⁴⁸ which risks leaving certain individuals less able to realise their rights as a result of their location.
- 5.6 The UN ICESCR Committee makes clear that:
 - the exercise of ... [UN ICESCR] rights should not be conditional on, or determined by, a person's current or former place of residence; e.g. whether an individual lives or is registered in an urban or a rural area ... or leads a nomadic lifestyle.⁴⁹
- 5.7 The NIHRC therefore welcomes the proposed Action 5, which will reform how adult social care is planned and delivered within the new Integrated Care System model. Included in the list of outcomes and objectives is the intention to ensure "equitable access to publicly funded services across localities, types of need and financial means". ⁵⁰ This should give full consideration to the rurality of NI, assessing and rectifying any discrepancy in support options between urban and rural settings.

⁴⁸ Expert Advisory on Adult Care and Support, 'Power to People: Proposals to Reboot Adult Care and Support in NI' (DoH, 2017), at 62.

⁴⁹ E/C.12/GC/20, 'UN ICESCR Committee General Comment No 20: Non-discrimination in Economic, Social and Cultural Rights', 2 July 2009, at para 34.

⁵⁰ Department of Health, 'Consultation on the Reform of Adult Social Care' (DoH, 2022), at 31.

- 5.8 The NIHRC further welcomes the proposal set out in Action 1 which will consolidate legislation to provide a cohesive framework for the delivery of social care.⁵¹
- 5.9 The NIHRC recommends that the Department of Health ensures that it is made explicit that the principles guiding the implementation of future legislation operate within a human rights based framework, which incorporates the full range of international human rights standards ratified by the UK.
- 5.10 The NIHRC recommends that the Department of Health ensures that any future legislation is accompanied by a Human Rights Impact Assessment that takes account of all the UK's international human rights obligations.

6.0 Strategic Priority 2 - Valuing the Workforce

6.1 The Universal Declaration of Human Rights protects the rights of those who work to "just and favourable remuneration ensuring for [themselves] and [their] family an existence worthy of human dignity". The right of everyone to the enjoyment of just and favourable conditions of work is further recognised in the UN ICESCR as well as through other international and regional human rights treaties. ⁵² Article 7 of the UN ICESCR specifically protects the right to "Fair wages and equal remuneration for work of equal value".

⁵¹ Department of Health, 'Consultation on the Reform of Adult Social Care' (DoH, 2022), at 16.

⁵² See Article 5, UN CERD; Article 11, UN CEDAW; Article 32, UN CRC.

- 6.2 While the minimum wage is the minimum that an employer is required by law to pay an employee, a living wage is one that affords a decent standard of living for the worker and their family. This includes food, water, housing, education, health care, transportation, clothing, and other essential needs, including provisions for unexpected events.⁵³ The right to an adequate living wage is stressed in the Preamble to the International Labour Organisation's Constitution.⁵⁴
- 6.3 The UN ICESCR Committee comments that "the notion of a fair wage is not static, since it depends on a range of non-exhaustive objective criteria, reflecting not only the output of the work but also the responsibilities of the worker".⁵⁵
- 6.4 Care work is "an essential, skilled and professional occupation". ⁵⁶ Care workers play a vital role in protecting and promoting the rights of those who avail of their services yet they "receive amongst the lowest wages in the labour market". ⁵⁷
- 6.5 The UN ICESCR Committee further comments that:

[i]n setting minimum wages at the sector or industry level, the work performed in sectors predominantly employing women, minorities or foreign workers should not be undervalued compared with work in sectors predominantly employing men or nationals. It is particularly important to ensure that the job evaluation methods

⁵³ Global Living Wage Coalition, 'The Anker Methodology for Estimating a Living Wage'. Available at: https://www.globallivingwage.org/about/anker-methodology/

⁵⁴ International Labour Organization, 'Constitution of the International Labour Organisation', 1 April 1919.

⁵⁵ E/C.12/GC/23, 'UN ICESCR Committee General Comment No 23: Right to Just and Favourable Conditions of Work', 7 April 2016, at para 10.

⁵⁶ Expert Advisory on Adult Care and Support, 'Power to People: Proposals to Reboot Adult Care and Support in NI' (DoH, 2017), at 54.

⁵⁷ Department of Health, 'Consultation on the Reform of Adult Social Care' (DoH, 2022), at 53.

used to align or adjust sectoral or occupational minimum wage schemes are not inherently discriminatory.⁵⁸

- 6.6 The NIHRC notes that the vast majority of care workers are women.⁵⁹
- 6.7 The NIHRC recommends that in assessing appropriate wage levels for social care workers, the Department of Health considers whether the current rates of pay reflects an inherently discriminatory evaluation of the value of social care work.
- 6.8 The NIHRC welcomes the proposal to improve the pay, terms and conditions of the lowest paid in the social care workforce, but recommends that, at a minimum, wages should be set at a living wage level.
- 6.9 Article 7 of the UN ICESCR also protects the right to "safe and healthy working conditions". It is the NIHRC's view that the identification and adequate funding of safe staffing levels in social care is essential to the health and safety of the workforce.
- 6.10 The NIHRC welcomes the proposal to develop a model which will identify safe staffing levels in social care settings.
- 6.11 The NIHRC recommends that this is determined in consultation with service providers and is allocated the necessary funding.

⁵⁸ E/C.12/GC/23, 'UN ICESCR Committee General Comment No 23: Right to Just and Favourable Conditions of Work', 7 April 2016, at para 10.

⁵⁹ Expert Advisory on Adult Care and Support, 'Power to People: Proposals to Reboot Adult Care and Support in NI' (DoH, 2017), at 53.

- 6.12 The NIHRC welcomes the inclusion of training and education of the workforce within proposed Action 10,60 however notes the absence of specific reference to training in human rights standards and principles. Ensuring that staff are trained in applying human rights standards is not only important in promoting the professional development of the social care workforce, but is essential in ensuring that human rights are realised in practice and embedded within the social care system. This was previously raised by the NIHRC in its report 'In Defence of Dignity', which recommended that "[n]ursing home staff, managers and homeowners should receive human rights training developed in collaboration with health care staff and human rights experts".61 It is also in line with recommendations put forward in the Commissioner for Older People for NI's report, 'Home Truths', which argues that "human rights should be an essential component of practitioner dialogue" and that "all staff in care settings, commissioners of care, social care workers, and regulators must receive training on the implications of human rights for their work".62
- 6.13 The NIHRC recommends that the Department of Health includes within the strategy a commitment to comprehensive human rights training for all social care staff. This training should be mandatory and be subject to periodic review and evaluation.

7.0 Strategic Priority 3 - Individual Choice and Control

7.1 Article 3 of the UN CRPD states that the general principle of "respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons", while Article 19 emphasises

⁶⁰ Department of Health, 'Consultation on the Reform of Adult Social Care' (DoH, 2022), at 38.

⁶¹ NI Human Rights Commission, 'In Defence of Dignity: The Human Rights of Older People in Nursing Homes' (NIHRC, 2012), at 71.

⁶² Commissioner for Older People for NI, 'Home Truths' (COPNI, 2018), at 30.

that persons with disabilities are not obliged to live in any particular living arrangement.

7.2 The UN CRPD Committee defines independent living as meaning "individuals with disabilities are provided with all necessary means to enable them to exercise choice and control over their lives and make all decisions concerning their lives". ⁶³ It has confirmed that:

[i]ndividualised support services must be considered a right rather than a form of medical, social or charity care. For many persons with disabilities, access to a range of individualised support services is a precondition for independent living within the community. Persons with disabilities have the right to choose services and service providers according to their individual requirements and personal preferences, and individualised support should be flexible enough to adapt to the requirements of the "users" and not the other way around.⁶⁴

7.3 The UN CRPD Committee also confirms that:

individual choice...is not limited to the place of residence but includes all aspects of a person's living arrangements: the daily schedule and routine as well as the way of life and lifestyle of a person, covering the private and public spheres, every day and in the long term.⁶⁵

7.4 The former UN Special Rapporteur on Torture and other Cruel, Inhuman or Degrading Treatment or Punishment, Juane E Méndez previously highlighted

⁶³ CRPD/C/GC/5,' UN CRPD Committee General Comment No 5: Living Independently and Being Included in the Community', 27 October 2017, at para 16(a).

⁶⁴ CRPD/C/GC/5,' UN CRPD Committee General Comment No 5: Living Independently and Being Included in the Community', 27 October 2017, at para 28.

⁶⁵ CRPD/C/GC/5,' UN CRPD Committee General Comment No 5: Living Independently and Being Included in the Community', 27 October 2017, at para 24.

that in the health care context, "choices by people with disabilities are often overridden based on their supposed 'best interests," and "serious violations and discrimination against persons with disabilities may be masked as 'good intentions' of health professionals".⁶⁶

7.5 The CoE Committee of Ministers also recognises that:

older persons have the right to respect for their inherent dignity. They are entitled to lead their lives independently, in a self-determined and autonomous manner. This encompasses, inter alia, the taking of independent decisions with regard to all issues which concern them, including those regarding their property, income, finances, place of residence, health, medical treatment or care, as well as funeral arrangements. Any limitations should be proportionate to the specific situation, and provided with appropriate and effective safeguards to prevent abuse and discrimination.⁶⁷

- 7.6 Additionally, the UN ICESCR Committee recognises the importance of people's involvement and participation in their own health-related decision-making and also wider planning of policies and services. This includes those groups who face barriers to effectively engage in consultation processes.⁶⁸
- 7.7 The NIHRC welcomes the proposals set out under strategic priority 3.
- 7.8 The NIHRC recommends that the Department of Health, as part of the development of a regional strategic 'In Control' action plan,

⁶⁶ A/HRC/22/53 'Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Juan E Méndez', 1 February 2013, at para 61.

⁶⁷ CM/Rec(2014)2, 'CoE Committee of Ministers, Recommendation to Member States on the Promotion of Human Rights of Older Persons', 19 February 2014, at para 9.

⁶⁸ E/C.12/2000/4, 'UN ICESCR Committee General Comment No 14: Right to the Highest Attainable Standard of Health', 11 August 2000, at para 54.

considers the inclusion of those who face barriers to engagement in consultation processes.

- 7.9 The NIHRC notes that in order for an individual to effectively exercise choice and control, their options must be presented in a way that is accessible to them.
- 7.10 The NIHRC recommends that the proposed legislative duty on Health and Social Care Trusts to provide information and advice on care and support options includes a requirement that this is tailored to a range of communication requirements. For example, through the provision of language translations, large print, easy read and audio versions. This will require appropriate resource allocation.
- 7.11 Within the health and social care system, certain individuals, particularly those with complex communication requirements have been assessed as being unable to live in a community setting. Article 19 of the UN CRPD "extends the right to live independently and be included in the community to all persons with disabilities, regardless of their level of intellectual capacity, self-functioning or support requirements".⁶⁹
- 7.12 The UN CRPD Committee's General Comment No 5 describes institutionalised settings as having defining elements, such as:

obligatory sharing of assistants with others and no or limited influence over by whom one has to accept assistance, isolation and segregation from independent life within the community, lack of control over day-today decisions, lack of choice over whom to live with, rigidity of routine irrespective of personal will and preferences, identical activities in the

⁶⁹ CRPD/C/GC/5, 'UN CRPD Committee General Comment No 5: Living Independently and Being Included in the Community', 27 October 2017, at para 21.

same place for a group of persons under a certain authority, a paternalistic approach in service provision, supervision of living arrangements and usually also a disproportion in the number of persons with disabilities living in the same environment. Institutional settings may offer persons with disabilities a certain degree of choice and control, however, these choices are limited to specific areas of life and do not change the segregating character of institutions.⁷⁰

- 7.13 The NIHRC acknowledges the need for careful planning and safeguarding procedures in promoting community based care options, but notes that there have been significant ongoing delays in the resettlement of people with learning disabilities and mental health needs into the community. The NIHRC welcomes that a number of the proposed actions within the consultation document support the deinstitutionalisation of social care. However, there is room for improvement.
- 7.14 The NIHRC recommends that, within the strategy, the Department of Health includes specific action on the deinstitutionalisation of care through the lens of the UN CRPD. This should be completed as a matter of urgency.
- 7.15 The NIHRC notes that measures implemented during the COVID-19 pandemic impacted the choice and control of many of those receiving social care support. For example, the Commissioner for Older People for NI expressed concerns of possible breaches of human rights as a result of older people in care homes being denied visits from families for many months.⁷¹ These restrictions, and the resulting isolation, had a negative and sometimes

⁷⁰ CRPD/C/GC/5, 'UN CRPD Committee General Comment No 5: Living Independently and Being Included in the Community', 27 October 2017, at para 16(c).

⁷¹ Commissioner for Older People for NI, 'Press Release: Commissioner says denial of care home visits a breach of human rights', 10 March 2021.

traumatic impact on the physical and mental wellbeing of care home residents.⁷²

7.16 The NIHRC recommends that the Department of Health adopts the recommendations from the COVID-19 Inquiry in relation to the management of the pandemic in care homes, ensuring that learning is disseminated across the sector and that a human rights based plan is in place for any future outbreak. This learning should be incorporated into the future strategy to ensure that the isolation experienced during the COVID-19 pandemic is prevented in any future pandemic or societal emergency.

8.0 Strategic Priority 4 - Prevention and Early

Intervention

- 8.1 The NIHRC welcomes the inclusion of a chapter on prevention and early intervention. The right to non-discrimination is essential to human rights law,⁷³ yet in practice, inequality leaves many individuals with a lower level of human rights protections.⁷⁴ Prevention and early intervention are key to addressing the issues which can lead to an individual requiring health and social care services with particular regard given to those who face higher levels of marginalisation and discrimination.
- 8.2 The consultation document importantly highlights that there should be "an emphasis on the provision of services that recognise and tackle root causes

⁷² Committee for Health, 'Inquiry Report on the Impact of COVID-19 in Care Homes', 1 February 2021, at para 14.

73 E/C.12/GC/20, 'UN ICESCR Committee General Comment No 20: Non-discrimination in Economic, Social and Cultural Rights', 2 July 2009.

⁷⁴ For example, in 2022 there was a gap of seven years in male life expectancy between the most and the least deprived areas. *See* Department of Health, 'Health Inequalities Annual Report' (DoH, 2022).

of social care need. This would include services which recognise and seek to ameliorate the impact of poverty and social deprivation".⁷⁵

- 8.3 The NIHRC recommends that specific provision for these services is guaranteed within the future strategy in close consultation with the relevant services providers. This will require the appropriate allocation of resources and clear monitoring mechanisms.
- 8.4 The NIHRC notes the absence of reference to transitional care in this chapter. While the consultation is focused on adult social care, there needs to be a seamless transition from children's to adult social care services, including clear communication between the relevant agencies. A loss of continuity in care has the potential to be a disruptive experience whereas a well-managed transition can prevent the escalation of identified issues and the need for crisis intervention.
- 8.5 The NIHRC recommends that the Department of Health ensures that the future strategy includes provision for those who are transitioning into adult social care services.
- 8.6 The NIHRC recommends that, as part of introducing the offer of preventative/support visits for anyone aged over 75 by an appropriately trained professional, the Department of Health incorporates learning from the application of the scheme in Denmark and ensures that there are appropriate guidelines and quality assurance indicators.

9.0 Strategic Priority 5 – Supporting Carers

9.1 The UN CRPD Committee confirms that States have an obligation to:

⁷⁵ Department of Health, 'Consultation on the Reform of Adult Social Care' (DoH, 2022), at 57.

provide adequate support services to family carers, so they can in turn support their child or relative to live independently in the community. This support includes respite care services, childcare services and other supportive parenting services. Financial support is also crucial for family carers who often live in situations of extreme poverty, without the possibility of accessing the labour market. States parties should also provide social support to families and foster the development of counselling services, circles of support and other adequate support options.⁷⁶

- 9.2 The NIHRC welcomes the proposed legislative duties to sustain, promote and protect social wellbeing for service users and family carers in the provision of adult social care services.
- 9.3 The NIHRC recommends that the Department of Health ensures that the proposed legislative duties include legislative provision for the right of carers to access respite care services.
- 9.4 The preamble to the UN CRC states that "children, for the full and harmonious development of his or her personality, should grow up in a family environment, in an atmosphere of happiness, love and understanding". The NIHRC notes that in circumstances where a child is required to spend a significant amount of their time in a caring role their development may be hindered.
- 9.5 A number of protected human rights within the UN CRC may be engaged in the case of children who are carers. In particular in this context, Article 3 of the UN CRC must be given due weight. It states that:

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⁷⁶ CRPD/C/GC/5, 'UN CRPD Committee General Comment No 5: Living Independently and Being Included in the Community', 27 October 2017, at para 67.

- 1) In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.
- 2) States Parties undertake to ensure the child such protection and care as is necessary for his or her well-being, taking into account the rights and duties of his or her parents, legal guardians, or other individuals legally responsible for him or her, and, to this end, shall take all appropriate legislative and administrative measures.
- 9.6 Also of relevance is Article 12 of the UN CRC which provides that:
 - 1) States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.
 - 2) For this purpose the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law.
- 9.7 The NIHRC recommends that, as part of the review of the Caring for Carers strategy and development of a new strategic approach, the Department of Health adopts a human rights based approach with specific consideration to rights of child carers, including the right to participation, as protected by the UN CRC.

10.0 Strategic Priority 6 – Primacy of Home

10.1 As outlined in previous sections of this submission, individual autonomy and the ability to live independently in the community are key to the fulfilment of human rights within social care. The NIHRC therefore welcomes the

proposals, set out under Strategic Priority 6, which aims to support people to live well independently in their own homes. The NIHRC particularly welcomes the removal of any set limits on the amount or cost of a service someone may receive and views this as an important measure in promoting the dignity and autonomy of those requiring social care support. As with most proposals contained within the consultation document, this will require a commitment to the necessary levels of adequate funding.

- 10.2 The NIHRC notes that the proposal requiring the Regulation and Quality Improvement Authority and commissioning Health and Social Care Trusts to ensure that, in places of residential care, the care on offer is in line with the philosophy outlined on pages 81 and 82 of the consultation document. The philosophy of care indicates that care homes should protect and promote the right of residents to private and family life, as per Article 8 of the ECHR. As outlined under 'human rights standards', there are a number of human rights engaged in adult social care and it is a legal requirement under section 6 of the Human Rights Act for public authorities to act in a way that is compatible with ECHR rights. It is vital that social care staff are fully informed of all of the human rights obligations that apply in the provision of social care. Human rights training for all social care staff will be essential to ensuring that staff understand what this means in practice.
- 10.3 The NIHRC recommends that the Department of Health ensures that the philosophy of care clearly states that it is grounded in human rights and that staff must act in full compliance with ECHR rights, as per the Human Rights Act.
- 10.4 The NIHRC welcomes the measures proposed to reduce the possibility of any care home resident having to move home because of a change in their care needs.⁷⁷ It is essential that staff involved in any potential decision to compel

⁷⁷ Department of Health, 'Consultation on the Reform of Adult Social Care' (DoH, 2022), at 85.

a resident to move to an alternative care home understand the potential rights implications of the decision.

- 10.5 In the case of *Watt v the United Kingdom* (2010), the European Court of Human Rights (ECtHR) found that Article 2 ECHR was engaged in a case in which an elderly resident was involuntarily transferred from one care home to another home. While the ECtHR found no violation in this instance, it was "persuaded that a badly managed transfer of elderly residents of a care home could well have a negative impact on their life expectancy as a result of the general frailty and resistance to change of older people".⁷⁸
- 10.6 The ECtHR further held that while there was no violation, Article 8 of the ECHR was also engaged as the transfer gave rise to stress and distress which could have had an impact on the applicant's health.⁷⁹
- 10.7 The NIHRC recommends that the measures proposed to reduce the possibility of any care home resident having to move home are monitored as part of the Regulation and Quality Improvement Authority's inspections of care homes. Safeguards should also be in place to prevent distress to those who are forced to move home because of a closure decision made by the Regulation and Quality Improvement Authority.
- 10.8 The Department is proposing that, where a notice to leave has been given, the resident will be given a right to appeal and independent advocacy would be made available to the resident and family carer in such a process.⁸⁰

⁷⁸ Watts v UK (2010) ECHR 793, at para 88.

⁷⁹ Watts v UK (2010) ECHR 793, at para 97.

⁸⁰ Department of Health, 'Consultation on the Reform of Adult Social Care' (DoH, 2022), at 85.

- approach, ⁸¹ while access to justice is protected within regional and international human rights mechanisms. ⁸² Along with the right to access the justice system, this also includes the right to clear and effective complaints mechanisms when accessing statutory care services. ⁸³ This applies not only to a decision in relation to a care home resident having to move home, but to decisions made throughout the social care system. For example, the UN CRPD Committee has held that "States Parties must...ensure that all decisions concerning living independently in the community can be appealed" ⁸⁴ and that "[s]upport to enable living independently in the community shall be enforceable as a right and an entitlement". ⁸⁵
- 10.10 The NIHRC recommends that the Department of Health ensures that the strategy includes a clear, expeditious complaints mechanism that is accessible and includes a transparent and meaningful process by which to appeal decisions. The Strategy should include a commitment that comprehensive, fully accessible information on these processes is available to those availing of social care services and their carers.
- 10.11The NIHRC welcomes the provision of independent advocacy services to those who have been given notice to leave their place of residence. The NIHRC notes that the consultation document in some instances suggests that the strategy will "provide independent advocacy for service users and

⁸¹ European Network of National Human Rights Institutions, 'We Have the Same Rights: The Human Rights of Older Persons in Europe' (ENNHRI, 2017), at 69.

⁸² See Articles 6 and 13, ECHR; Article 3, UN ICCPR; Article 13, UN CRPD.

⁸³ European Network of National Human Rights Institutions, 'We Have the Same Rights: The Human Rights of Older Persons in Europe' (ENNHRI, 2017), at 54.

⁸⁴ CRPD/C/GC/5 'UN CRPD Committee General comment No 5: Living Independently and Being Included in the Community', 27 October 2017, at para 81.

⁸⁵ CRPD/C/GC/5 `UN CRPD Committee General comment No 5: Living Independently and Being Included in the Community', 27 October 2017, at para 81.

family carers",⁸⁶ while other instances it indicates that this will be available "where a person would otherwise be unable to participate in decisions about their care and where there are no informal advocates such as family members available".⁸⁷

- 10.12 The NIHRC is aware that those in receipt of social care may be reluctant to complain for a variety of reasons.⁸⁸
- 10.13The NIHRC recommends that the Department of Health ensure that fully accessible, independent advocacy services are available to everyone supported within the social care system.

⁸⁶ Department of Health, 'Consultation on the Reform of Adult Social Care' (DoH, 2022), at 16 and 69.

⁸⁷ Department of Health, 'Consultation on the Reform of Adult Social Care' (DoH, 2022), at 47 and 49.

⁸⁸ European Network of National Human Rights Institutions, 'We Have the Same Rights: The Human Rights of Older Persons in Europe' (ENNHRI, 2017), at 54; Equality and Human Rights Commission, 'Close to Home: An Inquiry into Older People and Human Rights in Home Care' (EHRC, 2011) at 83.

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