Scottish Government (2022) Coming Home Implementation: A Report from the Working Group on Complex Care and Delayed Discharge. [1]

Stakeholder Submission on Common Concerns
July 2022

Disabled people, their families and organisations working in health and social care welcome the Scottish Government's intention to address the issue of people with learning disabilities and autistic people living in inappropriate out of area placements and hospital settings. There is widespread agreement that "The risk of human rights abuses is an urgent issue which needs to be addressed" (pg.34) and that timely concerted action is required.

Many have been engaging with this issue for years and understand that reform of the current system has the potential to create meaningful change, not just for the individuals and families affected right now, but also for those people who may require tailored support to live their good life in the future.

It is on this basis that we have adopted the role of a critical friend in our review of the report. Our aim is to ensure that plans of action are as effective as possible. This submission details serious concerns we consider need to be addressed to achieve this goal. However, we would like to highlight specific goals in the implementation plan with which the signatories to this paper broadly agree. These include:

> *"That people are only admitted to hospital for appropriate reasons. Behavioural challenge and the service breakdown that often accompanies it, are no longer a reasonable reason for admission to hospital.*
>
> *That those who are admitted to hospital do not become stuck there and have to wait for long periods of time until they can be discharged to a suitable community setting.*
>
> *That people are no longer placed in unsuitable or poor quality out-of-area placements, which do not meet their needs.*
>
> *Ensure that the needs of people with learning disabilities and their families drive the local commissioning strategy.*
>
> *Provide greater local visibility for people with learning disabilities and complex support needs, and to ensure that people do not get lost or forgotten in the system"* (pg. 57).

That said, the language used throughout the report is concerning. The term 'care' and, by extension, the terms 'complex care', 'continuity of care', etc., are contested within the disability rights movement. Such traditional terminology casts disabled people in a passive role, submitting to the will of those who provide them with 'care' (relatives, physicians, service providers, charities): 'For many disabled people the concept "care" is both patronising and oppressive'.[2]

---

[1] Coming Home Implementation report - gov.scot (www.gov.scot)
[2] Oliver, Michael, and Colin Barnes. *The new politics of disablement*. Macmillan International Higher Education, 2012, p. 66.

To provide context for our position we highlight the following:

- For every person in a hospital/Assessment and Treatment Unit or out of area placement there are equal numbers, if not more people, with similar support needs living at home with their family or being supported by a provider organisation (or a combination of both) in the community. This was the case even when the long stay hospitals were operating.[3]
- People are frequently admitted because of service failure or family crisis. These are not health issues.
- Having a learning disability and/or being autistic are not medically treatable conditions.
- An identifying characteristic of this group of citizens is that they have been singularly ill served by the health and social care system.
- The right level of support, delivered in a way that iteratively evolves to meet changing needs, and the will and preferences of the person, is foundational.

Whilst we acknowledge the good intention behind the report, many aspects within it are problematic and concerning. This relates to both the process of its creation, as well as the proposed direction of travel.

A summary of these concerns is detailed below.

Policy development Process

Despite stating 'genuine allyship is key, staying true to *nothing about us without us' (*pg.5) and referencing a Human Rights Based Approach and the **P**ANEL Principles[4] (the P standing for participation) (pg.6), there was **no** involvement of people with learning disabilities and/or autistic people, or Disabled People's Organisations in the drafting of this report.

There was also very little by way of engagement with family carers, carers' organisations, or Support Provider representative organisations such as CCPS.

As a result, the report:

- Fails to harness the wealth of knowledge and experience of disabled people and their allies.
- 'Others' people with learning disabilities and/or autistic people reinforcing the impression that they lack agency and are to be 'done to'.
- Leads to a focus on service solutions for service problems.
- Fails to outline what a good life looks like.
- Has limited scope and low aspirations.
- Fails to adhere to the Human Rights Based Approach it espouses.[5]

---

[3] Baker, Nicki, and James Urquhart. *The balance of care for adults with a mental handicap in Scotland*. ISD Publications, 1987.

[4] PANEL Principles stand for **P**articipation, **A**ccountability, **N**on-discrimination and equality, **E**mpowerment and Legality. Human Rights Based Approach | Scottish Human Rights Commission

[5] General Comment No. 5 of the CRPD Committee: 'States parties should develop transitional plans [for deinstitutionalisation] in direct consultation with persons with disabilities, through their representative

- Consistently uses medical model framing despite reference to the UN Convention on the Rights of Persons with Disabilities (CRPD) (pg.4; pg.84), which draws on the social model of disability.[6]
- Fails to provide a clear definition of what constitutes an 'institution'[7] and appears to explicitly endorse, as good practice, 'models' of support regarded as institutional, for example 'The design is 12 council tenancies in a cluster of four flats around three courtyards. This allows for efficiencies of support, provided in a town centre location.'[8]
- Locates the challenge within individuals rather than as a product of the support they receive, or the disabling environment in which they live.
- Relates to adults but uses a wellbeing model based on Getting it Right for Every Child (GIRFEC), including inappropriate and infantilising language – '*What I need from people who look after me*'(pg. 24).
- Uses case studies that locate the 'complexity' within the individual and fails to articulate a Human Rights Based or person centred perspective (see appendix 1 for more detail).
- Presents a qualified approach to independent living, 'Everybody with a learning disability and complex needs *who can,* should be able to live in their own home (pg.5); 'For those for whom housing is the appropriate outcome' (pg. 31). Article 19 of the CRPD refers to **all** persons with disabilities.[9]
- Makes no mention of Black, Asian and Minority Ethnic people. The exclusion of BAME people is particularly concerning given research from other areas of the UK

organizations, in order to ensure full inclusion of persons with disabilities in the community.' (Committee on the Rights of Persons with Disabilities, 2017: 9)

[6] The CRPD refutes the medical and charity approaches to disability by adopting a human rights model based on the inherent dignity of persons with disabilities and the recognition 'that impairments must not be taken as a legitimate ground for the denial or restriction of human rights'. CRPD General Comment No. 6, para 9.

[7] 'Although institutionalized settings can differ in size, name and set-up, there are certain defining elements, such as obligatory sharing of assistants with others and no or limited influence over whom one has to accept assistance from; isolation and segregation from independent life within the community; lack of control over day-to-day decisions; lack of choice over whom to live with; rigidity of routine irrespective of personal will and preferences; identical activities in the 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.' (Committee on the Rights of Persons with Disabilities, 2017: 4)

[8] 'Article 19 is not properly implemented if housing is only provided in specifically designed areas and arranged in a way that persons with disabilities have to live in the same building, complex or neighbourhood.' (Committee on the Rights of Persons with Disabilities, 2017: 8)

[9] 'Neither the full or partial deprivation of any "degree" of legal capacity nor the level of support required may be invoked to deny or limit the right to independence and independent living in the community to persons with disabilities.' (Committee on the Rights of Persons with Disabilities, 2017: 7)

indicates concerns regarding the intersectional risk of multiple discrimination.[10] [11]It is imperative that investigation is undertaken to see if this trend is repeated in Scotland.

- Offers unqualified support for Positive Behavioural Support (PBS), a contested approach that lacks evidence of efficacy.[12] The recent Positive Behavioural Support in the UK: A State of the Nation Report states that, 'A proportion of individuals with learning disabilities will additionally be autistic. It should be noted, however, that PBS as defined here, and in the past, is not intended for persons identifying as neurodivergent who do not have a learning disability,' (pg7). This begs the question why such an approach would be appropriate for a person with a learning disability?[13]

Furthermore

- The whole tone of the report reflects a 'special and different' approach to the group of people in question, when, as has already been outlined, the core defining characteristic is that this group of fellow citizens has been singularly ill served by the current health and social care system.

- The report appears to have been written with little or no reference to the outcomes and recommendations of the Independent Review of Adult Social Care (Feeley Review).

- There is no reference to independent advocacy, supported decision-making or Self Directed Support, key mechanisms for supporting choice and control for those drawing on social care support. This unhelpfully reinforces the impression that this group of fellow citizens sits outwith current regulatory policy and practice frameworks.

- Similarly, there is no reference made to the use of the Independent Living Fund (ILF), potentially an ideal mechanism for maximising choice and control for adult with learning disabilities and/or autistic people who are particularly discerning about how they need to be supported.

- The only peer support mentioned focusses upon professional needs (pg.46). No reference is made to disabled peoples' peer support requirements and the role that the Centres for Independent/Inclusive Living could have in providing

---

[10] Evidence indicates Black and Asian people experience greater risk of being sectioned under the Mental Health Act, and higher evidence of Restraint and Seclusion than white people in England. Institutional racism plays a part in this, where Black people are seen as more of a danger to themselves and others by medical staff, and so experience worse treatment https://www.mind.org.uk/news-campaigns/legal-news/legal-newsletter-june-2019/discrimination-in-mental-health-services/

[11] Black people are being diagnosed at autistic in higher rates, so are at an intersectional risk of experiencing multiple discrimination https://inews.co.uk/news/health/autism-more-common-higher-rates-ethnic-minorities-university-cambridge-study-933942

[12] On 'Positive Behaviour Support' – AMASE

[13] Positive Behavioural Support in the UK: A State of the Nation Rep...: Ingenta Connect

counselling and peer support to disabled people transitioning to community living.

- The current proposals appear to recognise existing service system challenges, for example the way people are coded as delayed discharge. However, instead of addressing the potentially discriminatory misuse of existing coding options through existing escalation procedures, more 'special and different' oversight mechanisms are proposed. This appears to be an attempt to address system failure by generating increasingly elaborate (and costly) institutional processes, rather than addressing the root cause.

As can be seen from the above, we have serious concerns about the process for developing the report and the proposals outlined within.

We are keen to work with the Scottish Government to ensure that the rights of people with learning disabilities and autistic people are respected, protected, and fulfilled; particularly those currently living, against their wishes, out-of-area or in hospital due to delayed discharge. The current service system has contributed to a situation where 700+ of our fellow citizens are experiencing costly, substandard support that breaches their human rights. However, we submit that by following the recommendations within the Feeley Review, and by implementing the principles and values of the National Care Service[14], Scotland can provide these fellow citizens with better opportunities to live their good life.

We believe that better is possible and that the solutions to the presenting problems require imaginative, creative, and aspirational thinking. We believe that those who operate the current system, that fails so many, would benefit from the perspective of those who use the system and from those who know and love them. Additional value would be gleaned from soliciting contributions from those who currently support people to live good full lives, despite current systems that add unnecessary complexity. Working in co-production, with support from all directly involved, would identify solutions that are person led rather than professional directed.

And so, we call on the Scottish Government to adopt a fully-fledged collaborative process, working with a wide range of stakeholders to draft a revised report, adopting a truly Human Rights Based Approach, to address the issues raised in the Coming Home Report. Fundamentally, this includes a commitment to ensure that Scottish Government funding is only spent on supports and services, including housing, that is UNCRPD compliant.

[14] Adult social care: independent review - gov.scot (www.gov.scot)

Signatories

Moira Tasker, Chief Executive
Inclusion Scotland

Inclusion Scotland
Disabled People's Organisation
Our voices ▪ Our choices

Sam Smith, Chief Executive Officer &
Ian Welsh on behalf of the
Board – C-Change Scotland

C-CHANGE
SUPPORTING GOOD LIVES

Jaqui Reid, Executive Director
Inclusion Glasgow

Inclusion!

John Dalrymple, Director
Radical Vision

RADICAL VISIONS

Jaynie Mitchell, Director
Inspiring Inclusion

inspiring inclusion

Pauline Lunn, Director
In Control Scotland

in Control® Scotland

Janine Hunt, Chief Executive Officer
Partners for Inclusion

Partners for Inclusion Group

Tressa Burke, Chief Executive Officer
Glasgow Disability Alliance

GDA Glasgow Disability Alliance
Confident Connected Contributing

Teodor Mladenov, Senior Lecturer
University of Dundee

Fiona Clarke,
Self-Advocate

Kabie Brook, Director
National Autistic Taskforce

NAT
National Autistic Taskforce
Bolder Voices, Better Practice

Sara Redmond, Chief Officer
Health and Social Care Alliance Scotland

ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

Kabie Brook, Chair on behalf of
Autism Rights Group Highland

ARGH
Autism Rights Group Highland

Fiona Dunwoodie, Chief Executive Officer
Fair Deal

Fairdeal
my support my choice

Dorry McLaughlin, Chief Executive
Scottish Autism

Rachel Birch, Sean Macaskill &
Leila Talmadge, Directors
Autistic Knowledge Development

Fergus Murray, Chair
Autistic Mutual Aid Society Edinburgh

Heta Pukki, President
European Council of Autistic People

Zoey Read, CEO, Becky Gillespie,
UK Co-ordinator, & Caroline Cole,
Lead International Special Advisor
Coalition Against Restraint and Seclusion

Terra Vance, Chief Executive Officer
Neuroclastic

Laura Bilton, Co-founder
Scottish Ethnic Minority Autistics

Richard Mills, Associate Consultant &
Adviser to the Board, AT-Autism

Clare MacGillivray, Director
Making Rights Real

Jim Elder-Woodward
Glasgow Centre for Integrated Living

Appendix 1 – Case Studies

A Human Rights Based Assessment

This assessment offers a Human Rights Based perspective on the case studies included in the Coming Home Implementation Report. The assessment explicitly adopts the position of the rights holder, using the UNCRPD for reference.

It is important to note that different perspectives can exist simultaneously and do not, and are not intended to, negate other views and opinions. This is particularly important when considering the rights holder positions of disabled people and of their family members.

Surfacing an explicitly Human Rights Based perspective aims to stimulate discussion and debate, improve policy, and practice and increase respect for, protection and fulfilment of human rights of disabled people in Scotland.

Case study 1:

Louis' Life – The view from a mother: What it is like living in Scotland with a complex and profound learning disability.

1. There appear to be two voices in the write up of this case study, a service perspective, and the voice of Louis' mother. This is most clearly highlighted in the final paragraph.

   > *'Louis' underlying needs are profound and multiple, requiring flexibility and ongoing learning for individual carers, managers, the care organisation, commissioners, Louis, and his mother, to integrate and use available resources. As Louis mother I have led the project, motivated by Louis best interests.'(Pg.10)*

   Observation: Louis' mother is a rights holder. Louis is also a rights holder. The Scottish Government and public authorities are duty bearers to both. From a human rights perspective these distinctions are important, they should not be conflated or confused.

   CRPD: Louis' voice, as a rights holder, is not present. [15]

2. Louis is described as being *'in his early thirties and lives with Complex and Profound learning disabilities and is also autistic'*. He *'had enjoyed six years of high quality of life in a care home*' living with 8 other people 'placed by their own authorities' (pg.7). He was supported by people who "understood his 'language' and needs". The home announced it was closing. The hosting Local Authority would not (or could not) due to Ordinary Place of Residence rules (the risk of incurring financial liability) support Louis and his fellow 'residents' to remain living in their home, with continuity of support.

   Observation: Louis is not described as challenging despite living with 8 people he had not chosen to live with and being supported by a large team of people. There

[15] CRPD Article 3, General principles, 1. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons.

was no separation of housing and support. Despite living arrangements many may find difficult, he thrived.

CRPD: Louis lived in a small institution[16] with 8 other disabled people he did not choose to live with. He had no tenancy rights.

3. *'A home was identified in England, 250 miles away'*. It "*specialised in 'challenging behaviour'*", Louis *'was moved there'*. *'Louis' mother had no option but to travel to visit him there'*
(pg7).

   Observation: Louis is cast in a passive role; he has no agency. Things are done to him over which he has no choice or control, nor support to exert choice and control.

   CRPD: Louis has no personal autonomy or self-determination, nor support to have such, which are fundamental to 'independent living'.[17]

4. *'Louis expressed himself through the only language left to him; destructiveness towards property, and aggression to people. Louis' challenging behaviour was managed through restraint, which was both pharmacological and physical in nature. Over three months, the cycle of restraint and protest grew' (*pg 8).

   Observation: Louis is now being described as having 'challenging behaviour'. The focus moves from the failure of the service to effectively support him, along with the trauma of losing the important people in his life; his mother, his house mates with whom he had lived a high-quality life, his knowledgeable support team who had enabled that to happen. The issue now resides with Louis with a shift to medical model framing. Professional services are engaged including clinical psychology, speech and language therapy and occupational therapy.

   'Louis' desire to return home was identified as a major factor in his distress in reports' (pg 8).

   CRPD: Louis right to physical and mental integrity was not respected and protected.[18] The use of physical and chemical restraint to respond to distress exhibited as a result of service failure to make reasonable accommodations in

[16] 'Although institutionalized settings can differ in size, name and set-up, there are certain defining elements, such as obligatory sharing of assistants with others and no or limited influence over whom one has to accept assistance from; isolation and CRPD/C/GC/5 5 segregation from independent life within the community; lack of control over day-to-day decisions; lack of choice over whom to live with; rigidity of routine irrespective of personal will and preferences; identical activities in the 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.' CRPD Article 19, General Comment 5, 16 (c).

[17] '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', CRPD, Article 19 (a)

[18] 'Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others'. CRPD, Article 17

relation to communication and sensory requirements,[19] may be considered cruel and degrading treatment.[20]

5. *'As costs rose to £6,000 per week, the local authority planned to bring Louis back to Scotland' (*pg 9*).*

   Observation: £313,000+ per year is a significant amount of public money. Used to fund a good, full life it may be considered justifiable expenditure. However, spending this amount with the effect of breaching a disabled persons' human rights may be more accurately categorised as 'misery money'. Financial imperatives rather than breaches of Louis' human rights were the driver of change.

   CRPD: Would this form of state action apply to a non-disabled person? If not, is it discriminatory?[21]

6. *'The local authority planned to bring Louis back to Scotland'. 'Louis mother objected to the plan'. 'The family and senior managers' objections were over ruled'.*
7. *'After seven weeks, Louis was admitted to the NHS Learning Disability Assessment Unit..following service breakdown and challenging behaviour. Louis remains in the unit 3 years later'* (pg 9).

   Observations: see point 3 and 4 (and repeat).
   The system fails to learn, at the expense of Louis and his family. Knowledge of how to do better (what works) is available. Louis did his best with the resources he had available to him to let people know what does and does not work for him.

   CRPD: see point 3 and 4

8. *'Louis' underlying needs are profound and multiple, requiring flexibility and ongoing learning for individual carers, managers, the care organisation, commissioners, Louis, and his mother, to integrate and use available resources' (pg10).*

   Observations: Louis is described in ways that source the issue within him, his profound and multiple needs, his challenging behaviour. This is a medical model framing. Louis, an autistic man in his early thirties lived in a 9 person institution and thrived. Louis is resilient.

---

[19] "'Reasonable accommodation' means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms" CRPD Article 2.

[20] 'States Parties shall take all effective legislative, administrative, judicial or other measures to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment or punishment'. CRPD, Article 15 (2).

[21] 'Discrimination on the basis of disability" means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation'. CRPD Article 2.

Case Study 2:

Enable

This case study details a 27 year old man inappropriately living in an acute hospital setting moving into his own home with 5:1 support at all times.

Observations: The only practical reason for 5:1 support is to administer physical restraint. The story of success should be a good full life, where one's human rights are respected protected and fulfilled.

This case study illustrates a change of venue, a service solution to a service system problem; a 'blocked bed' and 'delayed discharge'.

CRPD: 'States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds', Article 5.

'No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment', Article 15.

'Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others', Article 17.

Case Study 3:

Teviot Court, Midlothian

'The design is 12 council tenancies in a cluster of four flats around three courtyards. This allows for efficiencies of support' (pg 53).

Observations: This appears to meet the criteria for institutional provision as defined by the CRPD.

CRPD: 'Article 19 is not properly implemented if housing is only provided in specifically designed areas and arranged in a way that persons with disabilities have to live in the same building, complex or neighbourhood', (Committee on the Rights of Persons with Disabilities, 2017: 8).

'Support services provided as combined residential and support service (delivered as a combined "package") are often offered to persons with disabilities on the premise of cost efficiency. However, while this premise itself can be rebutted in terms of economics, aspects of cost efficiency must not override the core of the human right at stake', (Committee on the Rights of Persons with Disabilities, 2017: 8).

'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', CRPD, Article 19 (a).

Case Study 4:

The Richmond Fellowship Scotland: Colin's Story

It is unclear whose voice is narrating this case study. From the content it would appear to be a duty bearer.

Observation: Colin is a rights holder; his family are rights holders. The story told is a service system narration. This is important when considering where the emphasis is placed. For example, a medical model lens is used throughout to describe Colin's experience of navigating the health and social care system. This locates the issue as internal to Colin and not the disabling support he received. A significant portion of the case study is used to outline the 'complex' health issues that resulted in 'a range of behavioural concerns' (pg 64).

Little is made of the systems failures that resulted in Colin's family spending *'ten years campaigning to access the right support in the community to allow him to return home', (*pg 63*)*.

It is interesting to note that at the end of the case study, despite presumably continuing to experience lifelong health conditions, Colin is quoted as saying '*My life has changed so much for the better*', (pg 64). The resolution was not a 'cure/treatment' but better 'Colin focussed support', near his family that enabled him to:

- Have regular contact with his family
- Be part of his local community
- Exercise choice, control and independence
- Have a job
- Have friends, hobbies and a girlfriend
- Attend college.

The medical model approach fails to highlight the obligations of duty bearers to prevent the situation Colin experienced. He lived 10 years of his life away from his family and the community he knew, deprived of all the opportunities he now enjoys. This framing defines Colin's distress, as 'behavioural challenges', which need to be managed and controlled. When they are not, this in turn is used as the rationale for his continued detention in a place far from those who know and love him.

CRPD: 'States Parties to the present Convention recognize 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', Article 19.