Deinstitutionalisation: A human rights-based examination of Scotland's progress in ending institutions, from Coming Home to universal practice

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Executive summary

The Coming Home Implementation Report (CHIR) emphasizes the inherent right of all individuals, particularly those with learning disabilities and/or autism, to reside within their local communities in Scotland. It strongly advocates for the cessation of inappropriate placements in institutional settings, highlighting a national commitment to a zero-tolerance policy. While being clear on its vision, the CHIR fails to acknowledge legislation or policy that could help them deliver a human rights based approach, for example, the report refers to ‘placements’ where it should, if adhering to Article 19 of the Convention of the Rights of Persons with Disabilities (CRPD) and the Social Care (Self-Directed Support) (Scotland) Act 2013, be discussing home-ownership or tenancies. This report will avoid the use of language that undermines independent living as the goal, unless it is used to demonstrate the incompatibility of policies and/or data generation with Article 19. This report assesses Scotland's progress toward deinstitutionalisation, using identified human rights indicators, highlighting data that could be used to measure progress against the CHIR, or with some change, could evolve to measure progress. Priority was given to evaluating data representing people on the Dynamic Support Register including adults who were living outwith Scotland and those whose support networks were deemed to be at high risk of failure.

Methodology

The research employed a mixed-methods approach. This involved the analysis of a range of publicly available data sets, with the aim of measuring the deinstitutionalisation process. Within the scope of the project funding, we prioritised data generated by the Scottish Government or by other statutory bodies such as Public Health Scotland and Health and Social Care Partnerships or Integration Joint Boards. The research also incorporated qualitative data from data sets, published reports, and the Coming Home Implementation Report to assess progress, and also to evaluate the Scottish Government’s planned policy and funding interventions in this area. This approach was supplemented with interviews throughout the research process with key stakeholders including duty-bearers, researchers and representatives of third sector organisations. Publicly available commentary on data lay outwith the scope of the project though attempts were made to incorporate as much as possible where direct and explicit reference to CIHR was established (for

example, the Stakeholder Submission on Common Concerns[1]). Our aim in evaluating data, was to determine to what extent the data a) evidenced successful implementation of the CIHR and b) evidenced that Article 19 of the CRPD was being upheld in practice for adults with learning disabilities and/or autism.

Findings

The findings of this research suggest that Scotland's existing structures, policies and interventions are currently inadequate in relation to realising a human rights based process of deinstitutionalisation. It is clear that people continue to live in accommodation that is institutional, inappropriate, and not in the area that they would call home. The CIHR itself would not, if implemented in full, fulfil the terms or vision of Article 19 of the CRPD. Furthermore, the key interventions proposed in the CHIR have not been fully implemented. The dynamic support register is operational but limited. The framework to support the register is still in a phase of implementation, and the Community Living Change Fund has, according to the latest available figures, been largely unspent. Of particular concern is evidence of the spend that appears to contravene the CRPD guidelines on deinstitutionalisation.

Recommendations

There is a clear need for increased transparency of data relating to the deinstitutionalisation process, and of the people who continue to be impacted. This data should be collected and published using defined human rights indicators. The use of public funds to support this process should be made transparent, and again be measured using human rights indicators. The CIHR has influence and should be remastered and fully aligned with the terms and vision of Article 19 of the CRPD and the Social Care (Self-Directed Support) (Scotland) Act, 2013.

Conclusion

In conclusion, this research underscores the urgent need for Scotland to intensify its efforts toward deinstitutionalisation, ensuring it aligns with the fundamental human rights of individuals with learning disabilities and/or autism. The report reveals significant gaps in data, and both the strategy and implementation of policies intended to support people in living within their communities, rather than in

[1] Stakeholder Submission on Common Concerns - Coming Home Implementation Report

placements or institutional settings. To achieve the goal of deinstitutionalisation, it is critical for Scotland to not only enhance the transparency and accountability in the use of public funds and data but also to rigorously apply human rights indicators in measuring progress. An accountable and committed governmental and societal push towards inclusive community living is required in order to realise Scotland's commitment to human rights and the dignity of all its citizens.

Introduction

The Coming Home Implementation Report (CHIR) states that people with learning disabilities and/or autism, alongside everyone in Scotland, have a right to live in a home within their local community, and commits to a zero-tolerance approach to inappropriate placements[2]. While being clear on its vision, the CHIR fails to acknowledge legislation or policy that could help deliver a human rights based approach, for example, the report refers to 'placements' where it should, if adhering to Article 19 of the CRPD and the Social Care (Self-Directed Support) (Scotland) Act 2013, be discussing home-ownership or tenancies. The CHIR acknowledges a major form of rights violation in Scotland, requiring urgent attention: many live in institutions such as hospitals and care homes, live outwith their area, and some live outside their nation home of Scotland. Our report aims to deliver a rigorous understanding of the current state of deinstitutionalisation in Scotland, and the extent to which authorities such as Health and Social Care Partnerships (HSCP) take a rights-based approach. This is of particular concern given the historic lack of rights realisation for people who have learning disabilities and/or autism.

Our overall aim was to work with identified human rights indicators to assess Scotland's progress on deinstitutionalisation. We have carried out interviews with civil society actors who have expertise in supporting people with learning disabilities and/or autism towards independent living, and in human rights and rights indicators. We spoke to academics, Scottish Government, and Integration Authorities about their commitments to, and progress in delivering the Framework to learn more about progress in fulfilling the Framework. These exploratory interviews helped us:

Consider new forms of data to measure human rights progression

Identify where data exist that could be used to measure against human rights

[2] Coming Home Implementation Report

indicators

Assess how meaningfully the human rights of individuals are taken into account in the process of deinstitutionalisation

We also deliver here the results of desk-based research seeking data sources that could contribute to evidencing the Scottish Government and HSCP's progress in meeting the CHIR's ambitions. Data produced by government and statutory bodies were prioritised, rather than publications that commented on data. This then enabled us to consider how accessible and available data sources are, as well as evaluate the extent to which they were adequate in evidencing the implementation of Coming Home, or fulfilling the terms and vision of Article 19 of the CRPD. We also identify a) where indicators cannot be evidenced, and b) where publicly available data sources provide partially evidenced information but are insufficient to explicitly inform the indicator (for example, data cannot be disaggregated to reveal information about people who have learning disabilities and/or autistic people). This report delivers a synthesis of publicly available government-produced data in Scotland that can help us learn about the success of the CHIR.

This report includes as a supplement, a section assessing Structure-Process-Outcome indicators relating to Article 19 of the CRPD as applied to the individuals within the scope of the Coming Home implementation plan. Throughout the report we deliver an assessment of to what extent it is possible to develop a Scotland specific set of human rights indicators to assess progress on deinstitutionalisation using available data, and what changes would be required to do so more rigorously.

This report further includes:

A map of government and statutory data sources (data available up to April 2024) that will include:

A review of data that could be used to measure progress against the CHIR, or with some change, could evolve to measure progress.

An assessment of to what extent Scotland has the structures in place with regards to law and policy, whether the correct processes are in place to support effective implementation, and whether outcomes for people deliver the principles of the Report/Framework and fulfil a human rights-based approach. This assessment will suggest adjustments to commitment, effort and results as required.

An assessment of the framework proposed to support the Dynamic Support Register.

An exploration of the Community Living Change Fund.

The report will begin with a brief overview of the exploratory interviews (though their contribution is represented throughout the report) before turning to what we can learn from publicly available data.

Exploratory Interviews

We carried out exploratory interviews during the project with a range of experts in the field. To date we have interviewed:

1. Dr Sheena Jones – Mental Welfare Commission
2. David Jack and Chirsty McFadyean - Fraser of Allander Institute
3. Dr Anne MacDonald – University of Glasgow and author of ‘Coming Home A Report on Out-of-Area Placements and Delayed Discharge for People with Learning Disabilities and Complex Needs’
4. Lorne Berkely – Scottish Commission for People with Learning Disabilities
5. Two civil servants from The Scottish Government
6. A civil servant Public Health Scotland
7. A Head of Service for a Health and Social Care Partnership
8. We also thank Dr Sam Smith – C-Change Scotland, for her review of a draft version of the report and her insightful and valuable feedback.

This provided us with expertise and sense-checking of our approach and data sources. We would like to state our thanks to each participant for their time and expertise. We would also like to thank the Scottish Government, who in addition to providing us with their time, also provided a copy of the Dynamic Support Register.

We also attended a meeting of the Scottish Human Rights Commission ‘Deinstitutionalisation Spotlight Project Group’, who further provided expertise and sense-checking. We would also like to thank the members of this group for their time and support.

Data and Analytical Capabilities

This section reviews the publicly available data that relates to where adults with a learning disability or autism live, where that accommodation is considered a ‘placement’. Thus, this data does not capture independent living whether that be home ownership or tenancies. The decision to prioritise evaluation of this data, was based on feedback from the funder and interviews and aimed to focus on those living furthest from the realities of independent living. Further research on adults not captured by this data is required. Further some covers institutions such as hospitals and some features adults who categorised as requiring urgent attention. Each sub-section describes the data before progressing to a review of what the data can tell us.

4.1 From the Care Inspectorate: Type and Quality of Care Services in Scotland

This was downloaded on the 8th April 2024 and was published on the 29th February 2024. Also mentioned in brackets in this section, are data relating to the period 2021/22 downloaded on the 8th February, 2024. The 2024 data captures 10,952 (11,709 recorded in 21/22) providers of care including private, local authority and charity-run services. The majority were focused on childcare (mostly child minding) and these were removed prior to analysis. It may be that some of these services (for example East Park in Glasgow) do accommodate people who have recently moved from child to adult designation, but it was not possible to determine this from the data.

After removing services designated for children, 3691 (down from 3799 in 21/22) care services for adults remained.

A minority of adult services provided residential support, and this was indicated by them reporting a specific number of bedrooms, and the number of beds within bedrooms. Removing the 2,745 services that did not specify bedrooms resulted in removing services that included housing associations, and providers identified as support services, and care at home (we will though look at the complaints against these services). Further, all the remaining 946 (996 in 21/22) adult services provided a minimum of 2 beds and therefore it is assumed, that residences with a single occupant have become excluded from a deeper dive into the data.

Of the 946 adult services with beds, 92% have 6 beds or more (down from 94% in 21/22) with a range of 2 to 180 beds recorded. While the data shows the main designation category, they also have a variable that includes ‘all areas of provision’. It was challenging (for an experienced data scientist working for over 90 minutes) to identify all services that included ‘learning difficulties’ (the language used in the dataset) and/or ‘autistic spectrum disorder’; but these resulted in the data featuring in

table 1. Note that while there has been a reduction in services between 2021/22 and 2024, the number of services that provide beds suitable for adults with a learning difficulty and/or autism has risen during this period.

Of the 345 (323 in 21/22) adult services reported suitability for people with learning disabilities, services ranged from 2 rooms to 150. Figure 1 represents the range, and the size of residences that accommodate 2 people or more (available at end of section 4, page 19. Note on service in 21/22 and 2024 provided 150 beds and is excluded because it would make the data harder to read). What is clear from this data is that even when people have their own rooms, they are living beside many other people. It is not possible to ascertain how many of these adults would be considered in an appropriate placement, but they are people who do no have home ownership or tenancies and so do not live independently. It is also not possible from this data to consider the structure of the property (for example, whether people share corridors or actually have living spaces that feel unconnected to others), however, the organisations are named and with more time, some greater learning could be achieved.

Table 1: Main Designation of Adult Services Reviewed by the Care Inspectorate with beds

Main Designation of Service	Number of services in 2021/22	Number of services that included ‘learning difficulties’ as part of their provision in 2021/22	Number of services that include ‘Autistic Spectrum Disorders’ as part of their provision in 2021/22	Number of services in 2024	Number of services that included ‘learning difficulties’ as part of their provision in 2024	Number of services that include ‘Autistic Spectrum Disorders’ as part of their provision in 2024
Acquired Brain Injury	4	2	0	5	2	1
Alcohol Dependency	3	0	0	5	0	0
Alcohol Related Brain Injury	9	1	0	11	1	2
Autism Spectrum Disorders	7	7	7	10	10	10

Blood Borne Viruses	1	0	0	1	0	0
Drug Dependency	3	0	0	6	1	0
Hearing Impairment	1	1	1	1	1	0
Learning Difficulties	141	141	64	131	131	69
Mental Health Problems (other than dementia)	48	9	8	44	17	10
Neurological Condition (other than dementia)	9	3	2	7	1	1

Older people - dementia	339	75	5	344	76	4
Older people - frailty	403	72	3	351	73	4
Physical disability or illness	22	12	3	27	18	7
Visual Impairment	2	0	2	2	2	1
Palliative Care	0	0	0	2	0	0
Total	996	323	95	946	333	109

There is no data about suitability of the placement or person-led choice around the suitability of the placement. There is data about the quality of the provision with scores given for quality of:

9. Information
10. Care and Support
11. Environment
12. Staffing
13. Management & Leadership

Further scores are generated for

14. Support and well-being
15. Care and Support Planning
16. Setting
17. Staff Team
18. Leadership and
19. Covid 19

Here scores range from 1-6 with no indication which part of the range is considered poor or excellent, and no information on whether middle figures (3 and 4) are part of a graduation or considered to be neutral. Caution is therefore needed when interpreting this data and it is has limited use until the Care Inspectorate map the numerical points to a qualitative label. We are aware of the ratings used by the Care Inspectorate in their standard inspection methodology, where a rating of 1 represents Unsatisfactory and 6 represents Excellent and it is likely the same qualitative labels may apply here. Qualitative labels are not however available in the data set itself and this is therefore a data gap. A scan of the data shows that few services are earning scores of 1 or 6 and so it is assumed that few services are either very poor or excellent.

Recommendation: This data is publicly available in excel format which has the benefit of column labels that can be expanded to provide more detail. This is required for people to meaningfully access the data without having to consult other documents that explain the content and variables. Some column heads are very clear, and so the column heads for the quality of provision should improve and explain what the data represents.

Where numbers indicate a graduated response, the qualitative indicator (poor, good, excellent) should be available in order for the data to be clearly understood.

Short answer data were provided for placements/institutions that were considered to fall below the health and social care standards on at least one measure. The number of places identified has fallen over recent years: from 279 in 2021/22, to 189 in 2022/23 and most recently 117 adult services were recorded as falling below standards. A quick analysis of these data revealed that around one third of all adult services were required to improve provision in the following areas:

20. The most common change required was around training staff including ensuring that support tasks were observed and or supervised by senior staff to ensure best practice was followed (36 adult services of 117).
21. Having person centred care plans, reviewing these at least every 6 months, involving people or their representatives in care plans and for care plans to anticipate need were required for 20 adult services.
22. Nineteen adult services were required to improve their auditing processes to ensure that they had an accurate and complete record for scrutiny by outside agencies and were able to show progress toward improvement plans.
23. Ensuring that there were adequate daily activities to stimulate people were identified as needing work at 17 adult services and included inside and outside activities.
24. Further 13 adult services had to demonstrate how decisions around care and support were made in participatory ways.
25. Ten services were required to ensure that they had adequate staffing levels; 10 were required to demonstrate correct use of medication and 10 had to demonstrate higher standards of cleanliness.

The requirements were often date specific and used the Health and Social Care Standards which focus heavily on participation from people living in these settings and if useful, their representatives to establish personal standards for good quality of life. It is positive that participation is explicitly stated within requirements for change. Some requirements also flagged the need for services to be committed to constant improvement of provision.

It would be possible to do some analysis on the kinds of requirements for change by the service provider category, and by the size of the service (number of beds, number of staff).

The kinds of Health and Social Care Standards breached do tell us that a human rights lens is being applied by the Care Inspectorate with choice and participation

featuring in both the standards, and the narrative captured in the 2023/24 data. This will be explored in the separate document around human rights indicators.

4.2 NHS Delayed Discharge Data

This data was collected on the 8th February 2024 and is further ‘dated’ by the NHS to the 6th February 2024. The data itself was extracted on the 1st November 2023 and includes data up to June 2023.

The data shows some worrying trends and is captured in charts 1-4 at the end of this section. These charts capture people aged 18-74 and do not include ‘patients’ who died or those transferred to other hospital facilities. In the data, the number of delayed bed days is ‘attributed to the calendar month when they occurred’. This is calculated from the person’s ready for discharge date to either their discharge date within the specific calendar month, or the end of the calendar month for people who are still ‘in delay’. Further, ‘The average daily number of beds occupied is calculated by dividing the total monthly number of delayed discharge bed days by the number of days in the calendar month’.

There are 3 codes used on the charts. ‘Standard’ is the first code and includes people discharged from hospital to home, to home with support, and to placements including care homes and other placements that offer ‘intermediate care’. As stated elsewhere in the report, care homes and placements do not deliver the terms of vision of Article 19 of the CRPD. ‘Delays for standard reasons’ include delays that relate to health and social care, or patient and family. The two codes ‘9-AWI’ and ‘9-other’ are not defined in the dataset.

Chart 1 shows the trend across Scotland for delayed discharge. The number of bed days were fairly stable at 40,000 and then dropped to 20,000 at the first Covid-19 lockdown and have steadily risen since to a current rate of around 50,000. In terms of the average number of days of delay, this was fairly stable at 1500 and then dropped to 750 at the first Covid-19 lockdown. Across Scotland the number of days have steadily risen to 2000.

Chart 2 shows that the increase is more stable in the ‘standard’ group which we believe includes people who are waiting for an appropriate placement, though from the data available we cannot know the size of this sub-population, or how much their experiences are contributing to the steady increase in the number of delays. As stated above, there is no clarification of who is included in the Code 9 AWI and ‘9-other’ but their increases are not as dramatic.

Chart 3 may be more illuminating. The black line represents people who are discharged to a placement and while it was fairly stable at 600 people experiencing discharge delays, with a drop to around 250 during the first Covid-19 lockdown, the number of people experiencing discharge delays is steadily increasing back to 600

people. This does seem to indicate that the Coming Home Implementation is not succeeding for adults who require placements (noting again that the ambition of a placement may be in line with CHIR, bit does not fulfil Article 19 of the CRPD). Again, the data does not enable us to understand how many of these people have a learning disability and/or autism, or how their experiences feed into these patterns. Neither does it tell us why discharge is delayed. To adequately assess Coming Home from a human rights-based approach, this data is needed and should be made public.

Finally, the data can be explored by local authority and by NHS board. Chart 4 captures each local authorities' performance against the Scottish average. There does appear to be a trend towards greater issues the further away a person lives from the central belt, or from a city, but this analysis has not been completed.

4.3 NHS Scotland Annual Complaints Summary

We accessed this data for 2022-23. It covers complaints against primary care provision (general practice; dental; ophthalmic and pharmacy services disaggregated to whether the provision is board managed or delivered by independent contractors) and prisons. Forensic placements (for example, a non-sentence placement in the State Hospital) are not included or cannot be detected from the data. There is some data on NHS Special Boards including Public Health Scotland which received 17 complaints during this period. It cannot be determined what these complaints were related to or how they were resolved. This data is not able to even partially determine whether human rights indicators have been met.

4.4 Inpatient Census, 2022

Part 1 Mental Health & Learning Disability Inpatient Bed Census

Part 2 Out of Scotland NHS Placements

This data captures all 'patients occupying a psychiatric, addiction or learning disability inpatient bed in a NHS hospital in Scotland on the census data (as at 23:59 on 11th April 2022). The information also includes trends from previous years were available. This data was downloaded on the 23rd February 2024. We could not find a rationale for why data after April 2022 has not been made available. In order to better understand the implementation of Coming Home and to assess the extent to which a human rights-based approach has been used, this data needs to be available.

The data tends towards including psychiatric, addiction and learning disability beds as a single category and of course, is describing 'beds' rather than 'people' and so effectively de-humanises adults. There is though some valuable data within the dataset. For example, Table 2 breaks down occupancy by 'ward type', and rows that

relate specifically to adults with a learning disability and/or autism are highlighted. This does not mean that the other rows do not include people with learning disability and/or autism. Note, that data from 2020 and 2021 is not included and it is assumed (and not explicitly stated within the dataset) that this is due to the Covid-19 pandemic.

Table 2: Number and Occupancy Rates for Psychiatric, Addiction or Learning Disability Beds by Ward Type

Ward Type	Number of beds by ward type					Occupancy rates by ward type - %				
	2016	2017	2018	2019	2022	2016	2017	2018	2019	2022
Acute	1543	1525	1331	1352	1132	87	88	86	88	87
Intensive psychiatric care	133	139	144	133	126	80	76	87	78	87
Rehabilitation (non-addiction)	371	318	311	378	336	89	81	85	85	89
Addiction wards	54	72	40	44	41	76	82	83	102	73
Continuing care/long stay	490	500	402	239	274	73	74	68	86	84
Perinatal	12	10	12	12	*	100	90	100	92	83
Forensic (non-LD)	382	391	410	399	356	90	88	90	90	90

Forensic (LD)	80	82	79	68	79	88	91	85	88	81
Dementia wards	818	795	814	858	619	86	86	87	75	77
Young people/children	50	54	54	54	54	96	70	98	87	87
Learning disability unit	177	179	170	190	150	90	90	87	77	88
Eating disorder	22	22	22	22	*	82	95	55	82	70
Admission & assessment	-	-	173	161	183	-	-	89	91	93
Other (please specify)	122	118	113	12	-	82	83	76	92	-

Note: there is no information on what the symbols '-' and '*' indicate

Some tentative conclusions to be drawn from Table 2:

There are fewer people using beds (calculated by multiplying number of beds with occupancy rates) in wards in 2022 (64 in forensic (LD) and 132 in learning disability unit) compared with 2016 (70 in forensic (LD) and 159 in learning disability unit). That said, the figures from the interim years make it difficult to conclude that there is a downward trend. Further the data relating to other ward 'types' also generally shows similar reductions in numbers and percentages when comparing 2016 to 2022. It is possible that the Coming Home implementation is detectable, but equally plausible from the data available, that some other factor is impacting across ward-types.

There is data about the formal (79%) or informal status (21%) of people at admission by ward type, and most admissions to wards that are specifically designated for adults with a learning disability. There is also data about the formal status of people (88%) versus informal status (12%) on the census date, suggesting that people admitted informally may become formal presumably after a period of assessment.

There is no data about formal or informal status at admissions or at census for the forensic (LD) ward type. There may be issues around choice and control within this data but the data available cannot illuminate further.

More concerning data is derived around the average (median) length of stay (in days) by ward type, see Table 3.

Table 3: Average length of stay in Scottish NHS wards by ward type

Ward Type	Average length of stay in days				
	2016	2017	2018	2019	2022
Acute	41	41	36	40	47
Intensive psychiatric care	65	57	54	57	66
Rehabilitation (non-addiction)	770	840	537	582	695
Addiction wards	13	7	7	7	7
Continuing care/long stay	1463	1255	1170	1318	694
Forensic (non-LD)	861	832	779	922	1046
Forensic (LD)	1709	1371	1398	1451	1395
Dementia wards	205	206	204	269	165
Learning disability unit	840	1401	447	779	1564
Eating disorder	90	85	88	100	68

The average length of stay for adults on forensic (LD) wards over the 5 years captured (noting there is no data for 2020 or 2021) is 1,464.8 days which is equivalent to 4.01 years. The minimum average was captured in 2017 and 1,371

days is equivalent to 3.75 years. The value for 2022 which should have been impacted by Coming Home implementation is 1,395 days equivalent to 3.82 years.

The average length of stay for adults on learning disability unit wards over the 5 years captured (noting there is no data for 2020 or 2021) is 1,006.2 days which is equivalent to 2.76 years. The minimum average was captured in 2018 and 447 days is equivalent to 1.22 years. The value for 2022 which should have been impacted by Coming Home implementation is 1,564 days equivalent to 4.28 years.

Unlike the other data explored in this section which does not distinguish between placements which should be considered institutional, the data here relate to institutional placements.

The data set also reports on gender, ethnicity (only 5 categories), marital status, dependents, employment status and age but the data is not presented in a way that allow for specific ward types to be analysed by these characteristics.

There is some data on the 'reason patient was admitted to inpatient facility'. Learning disability is listed as a reason (other reasons are therapeutic/clinical crisis; diagnostic; rehabilitation; self-inflicted injury; other type of psychiatric admission; no additional detail).

Table 4: Number of people admitted to inpatient facility, NHS Scotland for reason 'learning disability', 2016-2022

Reason for Admission	2016	2017	2018	2019	2022
Learning disability	140	131	112	107	65

This runs counter to Professor Sir Gregor Smith, the Chief Medical Officer's declaration in the forward of the Coming Home Implementation Report that institutional and hospital care for people with a learning disability would need to be based on a clinical issue, and not their learning disability or any challenging behaviour for this would be an indication that a placement is not meeting their needs. It is important to note that the data from 2016-2019 occurs prior to his statement and the 2022 data is in part, about using legacy labels. There is a trend towards lower numbers year on year. Still, in 2022 the value should be 0, if the Coming Home implementation had impacted according to the vision. For example, the report states in the vision that "The core commitment made here is a zero-tolerance approach to

inappropriate placements for people with learning disabilities."[3] It has been stated before but it is imperative to be clear, that the CHIR, in explicitly discussing placements, is falling far short of the right to independent living and Article 19 or the CRPD.

Related data that could be of value records the number of adults who use a consultant who specialises in learning disability (overall decline from 162 adults in 2016 to 109 in 2022). Further there is data regarding the number of adults who are subject to other legislation (for 2022 only) including Adults with Incapacity (Scotland) Act, 2000, though this data is not disaggregated by whether a person does, or does not have a learning disability and/or autism.

There is data about the number of patients treated outwith but funded by NHS Scotland with a learning disability/autism diagnosis, all years available are captured in Table 5.

Table 5: Patients treated outwith but funded by NHS Scotland

Patient Category	2014	2016	2017	2018	2019	2022
Learning disability/autism	35	33	27	65	40	33

The difference between 2014 and 2022 is very small and while there are some significant fluctuations in the years between, there is no evidence that Coming Home implementation is reducing the number of people with a learning disability and/or autism being treated outwith Scotland. There is no information about whether these adults have chosen to be treated outwith Scotland, or what kind of support and information they may have had to make a choice had it been offered.

4.5 Carers Census Data

[3] Coming Home Implementation Report (p.23)

This data was collected in 2021 and 2022. It was downloaded for use in this report on February 9th, 2024.

According to the data 1,090 adult with a learning disability; 1,240 adults with an autism spectrum disorder (their language) and 130 adults with a learning disability and physical disability receive unpaid care. The total captured is 2,460 adults. Their care may be considered ‘appropriate’ and there is no information within this dataset about whether these adults have chosen to be supported by unpaid care, or what kind of support and information they may have to make a choice had it been offered. Perhaps also relevant, 44% of unpaid carers have incomplete support plans, equating to 12,150 people. Again, it is difficult to derive much meaning from this data (including how many of these unpaid carers are supporting an adult with learning disabilities and/or autism) but there is also a lack of evidence that this provision is adequate, appropriate, or supported.

The data is presented in tables and figures and has information about the support needed by unpaid carers which includes needed breaks, emotional support and training. It would be useful if this data could be provided for analysis.

4.6 Learning Disability Inpatient Activity Resource

This data was last published on the 30th January and covers 2016/17 to 2022/23 data around inpatients to psychiatric hospitals or certain care homes with a learning disability. We downloaded this data on the 1st March 2024.

Data is available in 9 different tables. There is interesting information about age, sex and deprivation that is provided in some tables but as it is not linkable to data around length of stay for example, it cannot be used for analysis. The only information that really pertains to the Coming Home report and implementation relates to the length of stay and features in Table 6.

Interestingly the years most impacted by Covid-19 2019-2022 are reported on here. In 2022/23 91 adults with a learning disability were in a psychiatric hospital or certain care home (their language) for over a year, and a further 37 for over 3 months. The data shows that there is a trend across most categories for less people over the years. The lack of transparency over the range of lengths of stay captured by the 365+ days category is worrying.

Table 6: Inpatients with learning disabilities: Length of stay in psychiatric hospitals and certain care homes

	Years

Length of stay - days	2016/17	2017/18	2018/19	2019/20	2020/21	2021/22	2022/23
Less than 1	4	2	1	0	1	2	1
1-7	8	10	9	9	4	4	7
8-29	13	10	7	10	14	6	3
30-90	16	28	12	14	20	12	4
91-365	52	43	42	26	38	38	37
365+	145	116	122	107	84	100	91

4.7 Public Health Scotland's Scottish Health Service Costs

This data is a summary for financial year 2022 to 2023. The data is extensive and covers data from costs of linen services, to property services, to running theatres. In total, 59 separate excel files were downloaded to determine if there was information pertaining to adults with a learning disability and/ or autism and that could add evidence to this report. Of these only four appeared to provide data that could contribute to understanding the costs associated with the care of adults with a learning disability and/or autism in institutional settings. The data is not illuminating but is captured in tables 7-10 in order to easily show what is available. It may be valuable if collated across various years to note any changes in expenditure. This is beyond the scope of this report.

In file r300s-22_23, tab R350 provided data extracted into Table 7 at end of section. It shows healthcare expenditure for people with learning disabilities. All guidance around the data suggests that it covers health rather than health and social care so would include dental, district nurse visits etc rather than meet the focus of this report around community living and full participation in choices about a quality life.

In file R020LS: Hospital Running Costs by Patient Type, there is data about 9 institutions described as 'Learning disabilities hospitals'. The data on costs features in Table 8. This data does not deliver much meaning for this report, but it is a snapshot of the data available by year, and other years could be sourced and added

together to make a new dataset. Once this is constructed, trends over time could be examined and this could become meaningful if the operation of each institution was better understood. Similar expenditure data exist for long-stay hospitals by NHS board, but this data does not disaggregate to hospital type or patient category.

Table 9 data is extracted from R040LS-22_23.xlsx and captures speciality group costs for inpatients in long stay specialities. Though the data does not disaggregate to cover adults with learning disabilities and/or autism, it does list seven of the hospitals categorised as ‘learning disabilities hospitals’ in R020LS. The data does not help inform this report but a deeper dive that compares the proceed years may offer some insight. File R720 examines overall staff costs by a number of categories including learning disabilities. As this data does not disaggregate to actual service or describe the people supported, it has very limited value and has not been reported here.

Taken from file d040-x-d040LS-x-22_23.xlsx, another version of R040LS brings data together for a number of services supporting adults with learning disabilities, see Table 10.

4.8 Social Care Dataset: Guidance Document

This document published by Public Health Scotland, provides the background for what data should be available and was most recently published on the 31st October 2023, and downloaded by the team on March 8th 2024. That is, what is described in this section is the framework that covers what data should be collected, but isn’t. The framework is only partially useful: often can be disaggregated to those with a learning disability but not whether someone has, or also has a diagnosis of autism. The parts of the framework that could be relevant to assessing implementation of the Coming Home report are detailed below.

This data has not been available/published since 2019. On the (SCLD) website, it is reported under a ‘2024 update’ that the Scottish Government is currently undertaking a review of the Learning Disability Statistics Scotland (LDSS, which see below, is an interesting set of data) data collection and publication. What follows is a review of the potential of this data, should it be made available.

Data on all people who have been assessed and access social worker/support worker services including community care, home care, housing support, receive self-directed support, live in a care home, or access learning disability services should be represented.

Section 2 on Client Information should record:

26. 2.3 the Client/service user group, that uses the Key to Life definition of learning disability (2.3c) and a separate category (2.3k) of autistic spectrum disorder.
27. 2.4 whether the person lives alone
28. 2.5 support from an unpaid carer
29. 2.8 type of housing
30. 2.11 learning disability statistics Scotland (LDSS)

Section 3 covers self-directed support, section 4 covers home care/reablement and section 6 covers care homes. Section 8 covers learning disability statistics Scotland (LDSS) in more detail and includes diagnosis, out of area placements, area client resides in and priority to return data. This then, is highly relevant data.

Specifically, analysis of the following data could shed some light on Coming Home implementation.

Section 3.6 records SDS (Self-directed support) contribution towards social work support; housing; independent living; health; client; other and not known. An increase in independent living funding might be anticipated if Coming Home implementation has impacted. With data in 3.7 and 3.8, a picture about need, and who is delivering support, could emerge.

Section 4 on housing seems to describe the housing but doesn't cover how large the accommodation is, whether a person is sharing spaces or how much choice they have/had in selecting the accommodation. It does not cover where the accommodation is, how well people can connect to the community or how easy it is for friends and family to visit. Participation, control and decision making are not covered. Sub-section 4.10 provides some data on reablement, an intensive and focused care package that aims to improve independence. It can be used to help people navigate daily living after a hospital (or institutional living) stay for example. There is a particular code (4) for clients with learning disabilities. There is not a separate code for adults with autistic spectrum disorders and it is unclear whether they are subsumed into code 4, or into code 5 which relates to mental health needs.

Section 6 on care homes includes respite (a term I thought had been discontinued), self-funded placements and partially or fully funded placements (regardless of whether the adult is living within or outwith their partnership area). It does not cover placements funded by an NHS board. As well as information about admission and discharge dates which an analyst could use to determine length of stay, sub-section 6.8 on type of admission covers respite, intermediate and long-term care. There may not be enough information to determine if the care home is an institution, but it is likely to be and so long-term care judgements are at odds with the vision of the

Coming Home report and would not fulfil the terms or vision of Article 19 of the CRPD. Sub-section 6.12 covers client type so analysis could be done on the above isolating the data that relates only to people with a learning disability (again, people with autistic spectrum disorders are hidden by the coding used).

Section 8 examines the spend on adults with a learning disability and sub-section 8.3 provides codes for someone who has a learning disability only; someone who has an autism spectrum diagnosis only; someone who has both and not known. Sections 8.4 to 8.6 offer basic but useful data.

31. 8.4 whether the person lives within or outwith the area
32. 8.5 area they reside in with codes for the 32 local authority areas plus codes for England, Northern Ireland and Wales
33. 8.6 whether the person is or is not a priority to return.

The following sections cover employment, education and volunteering which could be an indicator that someone is connected to their community (though this conclusion would be drawn with caution) and 8.15 covers whether a person has access to advocacy (and if so, from whom).

4.9 Coming Home Dynamic Support Register

This document outlines the planned data capture towards better understanding progress towards Coming Home implementation and in particular, reducing the number of adults on an inappropriate placement. We have access to version 2 dated September 2023, and we gained access on the 15th March, 2024.

There are four tabs to the reporting instrument. The first two contain information about those who need urgent attention, or are out of area (and considered a priority). A sub-sample of the data for these two groups of adults are returned to Public Health Scotland (PHS). More information is captured for those with urgent status (DSR Red & Amber) than with Out of Area OoA Status and this section will focus on these, and clarify where data is not captured for those with OoA status.

Most columns indicate that drop down menus are available. These were not functional for the writers of this report (this was attempted on two different computers; and by opening in Firefox and Chrome). Therefore, while the following section is very useful and hopeful in terms of potential data capture, how the data can be operationalised is still poorly understood.

The first column indicates the priority level of the adult with seemingly two levels: ‘Red URGENT: In Hospital (IH)’ and ‘Amber: Enhanced Monitoring (EM) (note, this was one column where the drop-down function was operating). This data can be linked to anonymised ID, personal identity codes and CHI data as well as date of

birth. Thus, there is capacity to link this data to other sources of information potentially.

The tab enables data completers to indicate if the person has previously been on the register which could enable those with a legacy of issues to have different priority status. Staff leads and mental health officers are named which may help with communication flow and with accountability, though it does raise questions about who would have sight of this data as this presumably a) would increase chances that an adult is identifiable and b) makes information about colleagues publicly available. This data is collected for adults living OoA and is not part of the sub-set sent to PHS.

The dataset seeks information about whether the person considers themselves to have any other physical, mental health conditions or illnesses expected to last 12 months or more. To answer this question with integrity, a professional completing the form would need to engage with and be led by the person which is consistent with a human rights-based approach and full participation. There then follows 11 (out of 49) questions around equalities monitoring, which is a sizeable chunk of the data capture. This data is collected for adults living OoA and only sex information is shared with PHS.

It was positive to see information requests around funding and host authorities. This should enable better understanding of the proximity of a placement to their home community. For example, a person could be out of area but actually live in a village one mile away from ‘home’ across a authority boundary. This information is collected for adults living with OoA AND part of the submission to PHS.

There are a couple of data points collected for people considered red or amber, that are not collected on the Out of Area (OoA) tab and not shared with PHS. One is a column labelled ‘bed type’ but it’s not clear what that will gather as no drop-down boxes are supplied. It could mean what kind of accommodation, or whether the accommodation is multi-occupancy. It is this detail that is needed. The form collects data on where a person came from, and this again provides useful context. Adding ‘reason for move’ might also be of value. The other column not included in the OoA tab is ‘Support arrangement person admitted from’. Again, a drop-down icon sits next to this column head, but does not inform us of the different levels of data and it is unclear what information will be captured here.

There are four questions pertaining to delayed discharge: ‘Is the person delayed discharge’; ‘delayed discharge code’ (note, drop down menu did not work); ‘date clinically ready for discharge’; and ‘length of delay (days)’. Measuring delays in days provides data at the most disaggregated level and can be categorised into categories if useful for analysis (for example clustered into ‘delayed less than a year, delayed between 1-2 years). Thus, data will be available to avoid the current practice of grouping adults delayed for more than 10 years into a single group. The data may still be presented in this way, but that would be a choice that can be evaluated. This

data is not shared with PHS but could be engineered from the data that is provided, by calculating the difference between the date that data is submitted and the ‘Date clinically ready for discharge’ column. Sharing the ‘length of delay (days) data would be more immediately transparent and accessible to a broader set of data users.

On the DSR – Red & Amber tab and Out of Area tab there is further information collected not shared with PHS. On both tabs there is data: ‘Context for inclusion/further details’; ‘Date of last register review meeting’; and ‘legislation status’.

On the DSR – Red & Amber tab this data (paragraph directly above) is collected within a sub section called ‘Action Monitoring’. Further, for those adults considered in an inappropriate placement that needs urgent attention or has enhanced monitoring the following data is collected (but not for Out of Area adults, nor is it shared with PHS).

34. Funding Status
35. Housing Status
36. Support Package Status
37. Workforce Status
38. Required to facilitate discharge
39. Action being taken
40.

And in a sub section called ‘Forward Planning’ the following data is collected for adults with DSR – Red Amber status only:

41. Anticipated discharge date
42. Destination Integration Authority
43. In area?
44. Type of accommodation
45. Service specification agreed
46. Date accommodation available
47.

With all columns, it appears that a drop-down menu will be available but we cannot access it so cannot see the levels at which this data will be collected and cannot comment on the functionality of the data.

The final two columns of data collected for adults with DSR – red & amber and OoA status should provide valuable data on participation and choice. With a sub section title of ‘Individual and Family Choice’, the two columns are:

48. Person’s preference
49. Family/friend/advocate/welfare guardian comment

Note that on the OoA status tab, as well as the ‘Person’s Preference’ there is a column with more limited capture of ‘Family/friend/advocate comment’.

The information shared with PHS is limited, and more limited for adults who live OoA compared with adults with red & amber status. See Table 11 (end of this section) for data to be included in the PHS submission. Figure 1: Availability of beds by the number of services that provide residential support for adults with learning disabilities and/or autism.

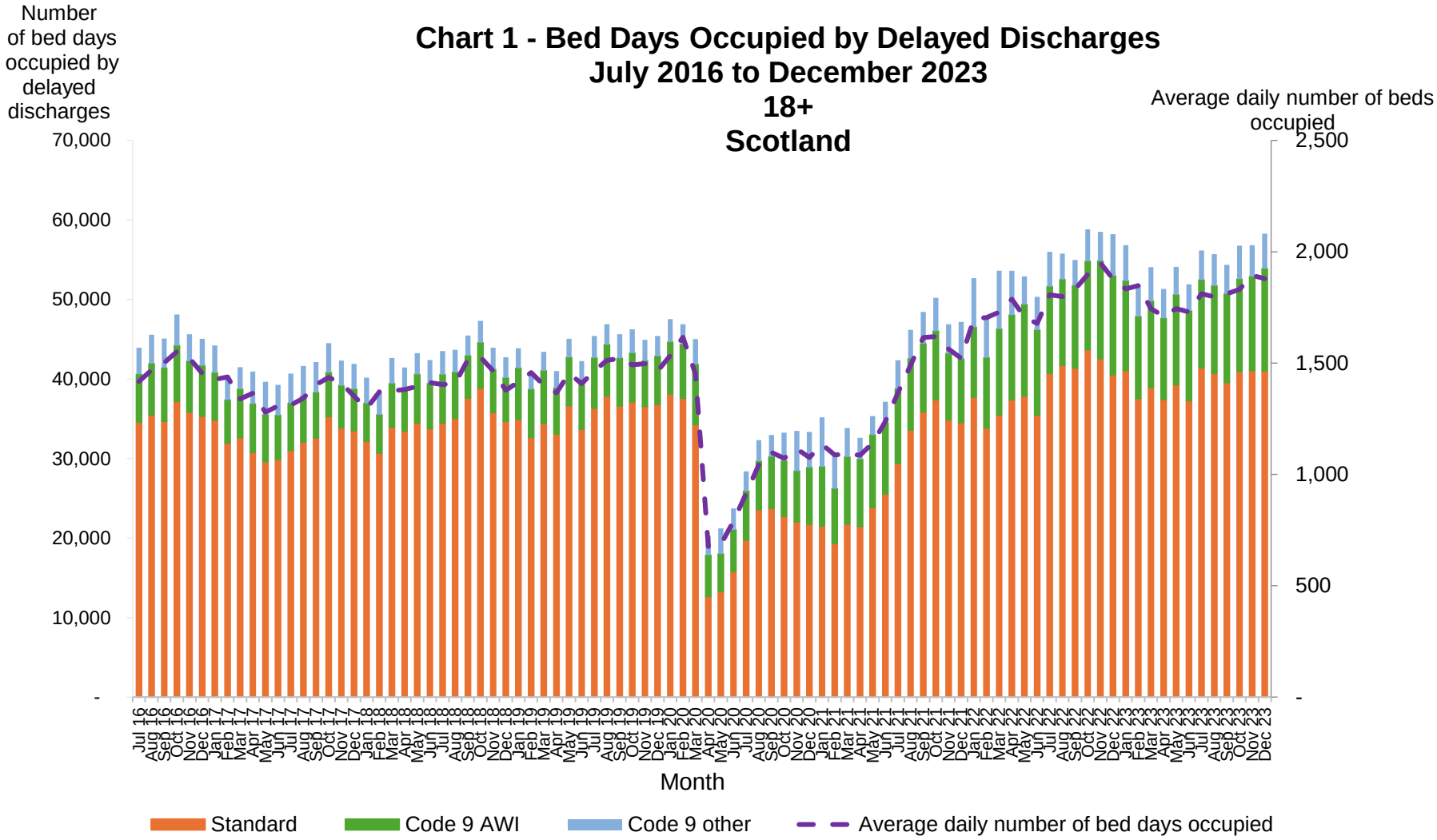
Chart 1 - Bed Days Occupied by Delayed Discharges
July 2016 to December 2023
18+
Scotland
Number of bed days occupied by delayed discharges
Average daily number of beds occupied
70,000
60,000
50,000
40,000
30,000
20,000
10,000
-
2,500
2,000
1,500
1,000
500
-
Month
Standard
Code 9 AWI
Code 9 other
Average daily number of bed days occupied

Chart 2 - Delayed Discharges at Census by Delay Reason
July 2016 to December 2023
18+
Scotland

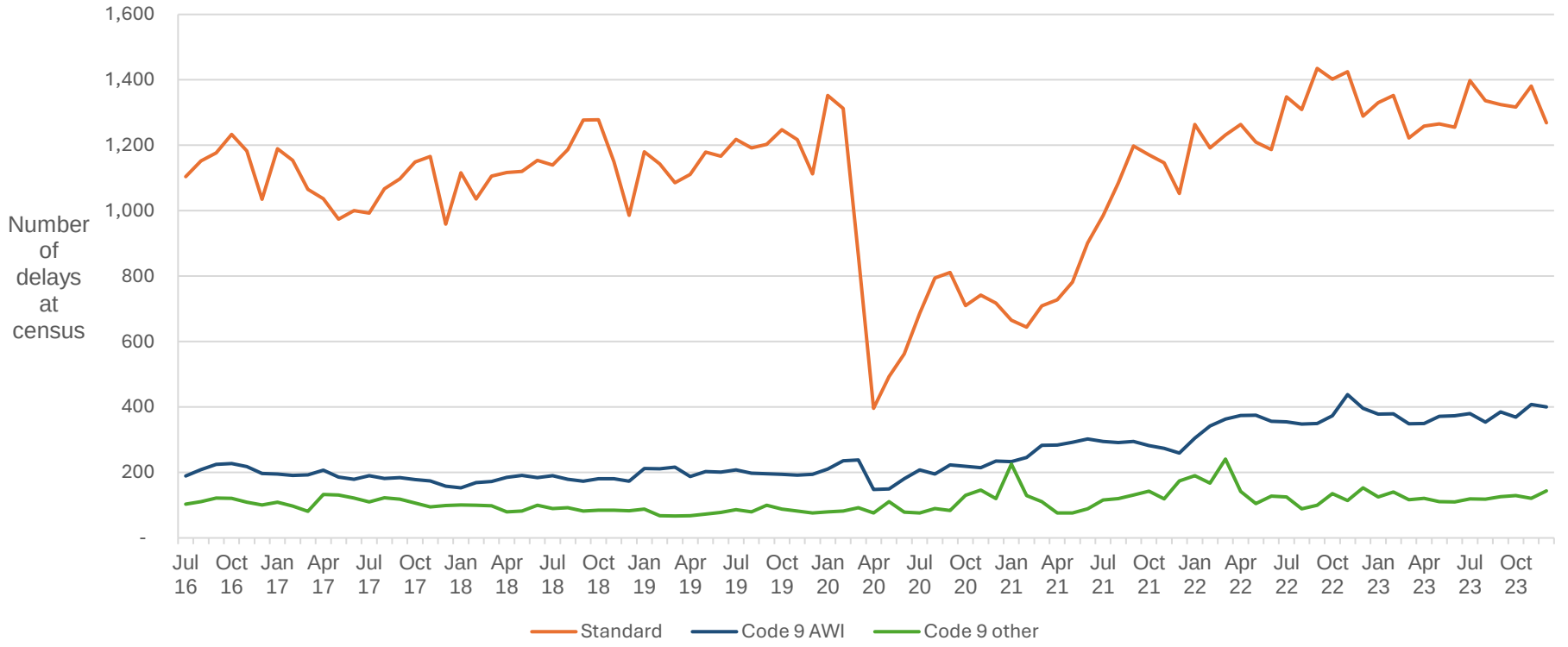

Chart 3 - Number of discharges from hospital following period of delay to Home or to Placement, 18+
July 2016 to December 2023
Scotland

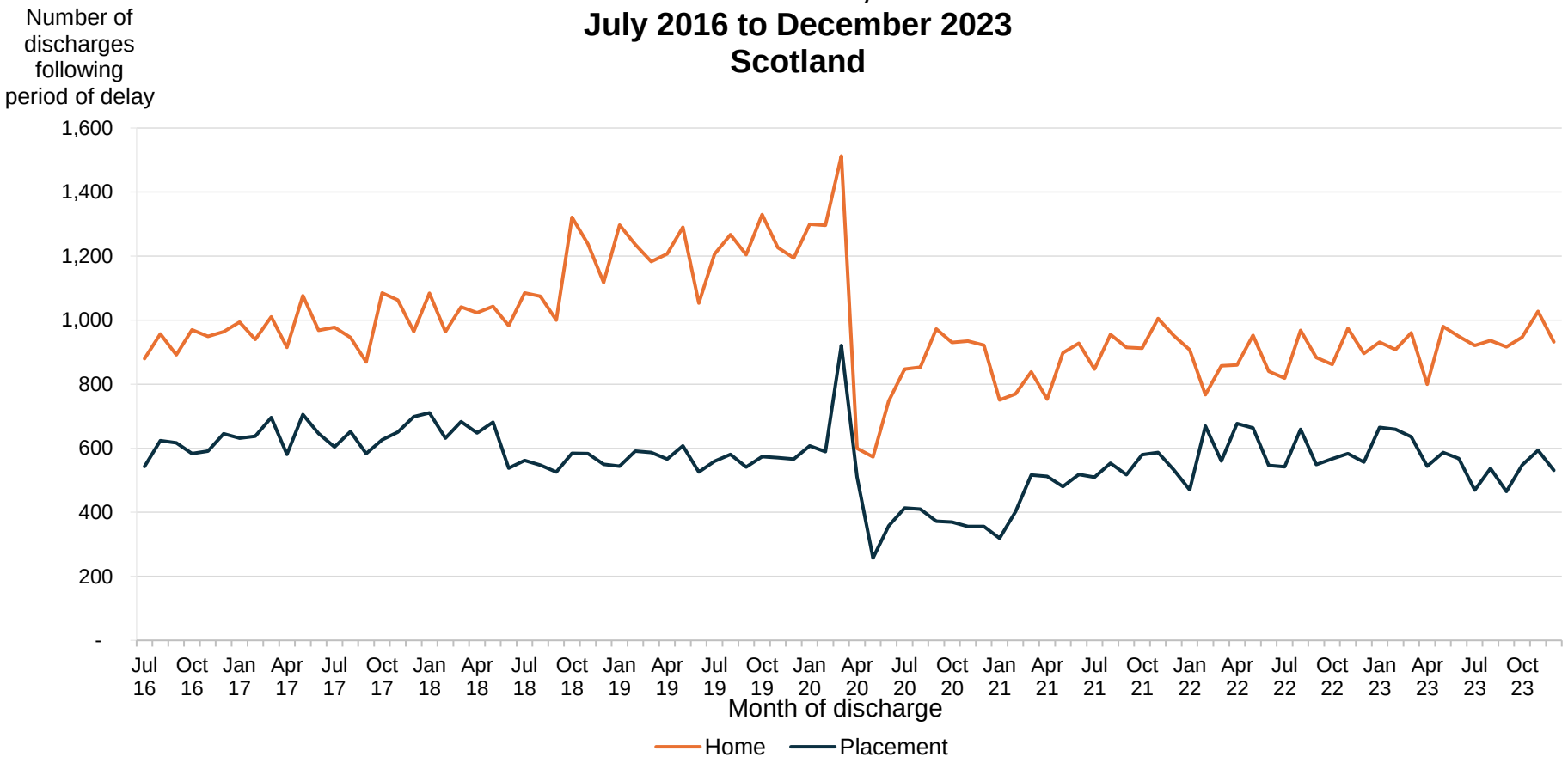

Chart 4 - Delays at monthly census point per 100,000 18+ population[1], by Local Authority, December 2023

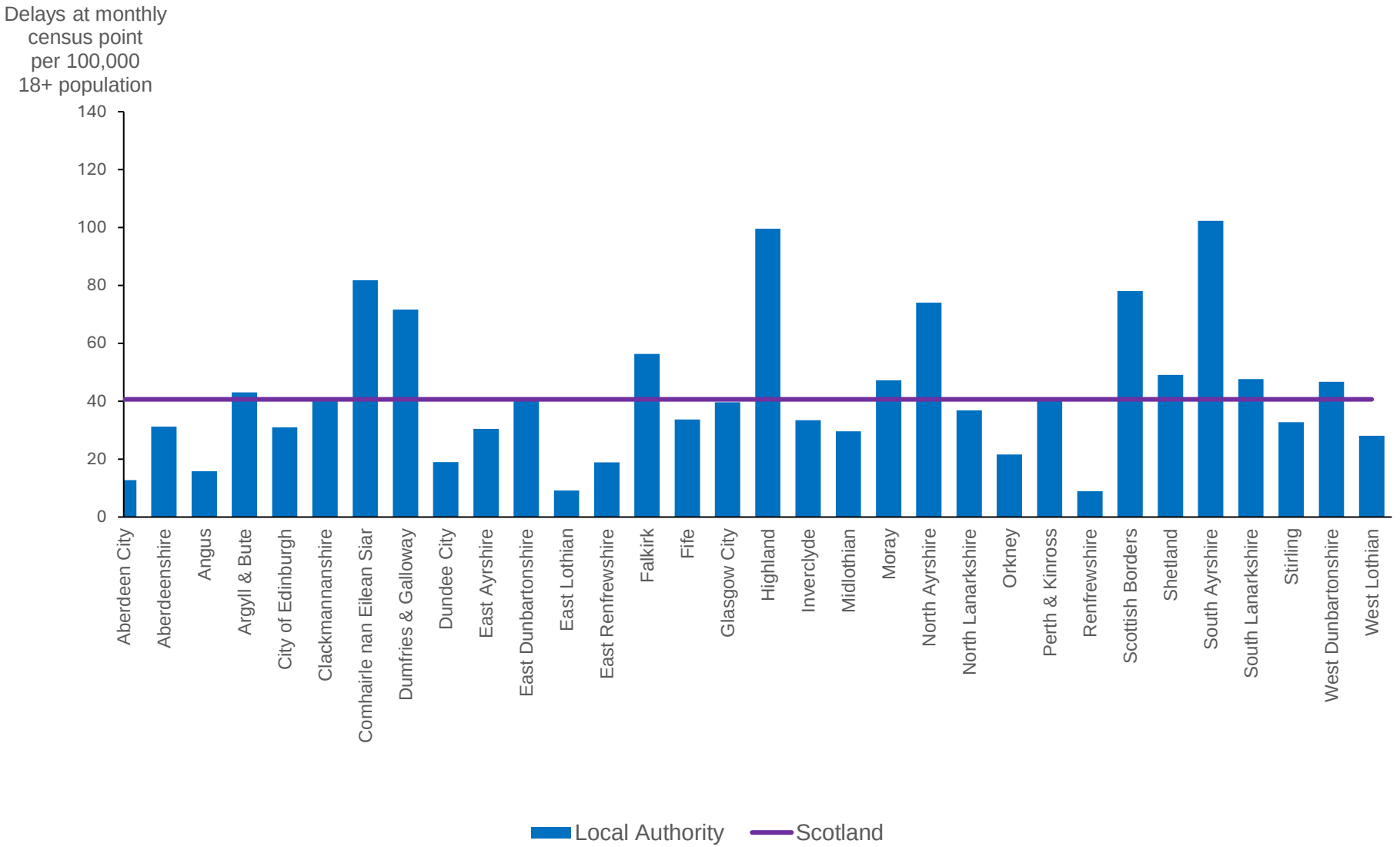

Table 7: R350 Provision of Healthcare: Learning Disabilities Services

NHS Board	Inpatients			Outpatients			Day Patients			Community Learning Disabilities Team			Resource Transfer	Total	
	Expenditure £000	Weeks	Cost per week £	Expenditure £000	Attendance	Cost per attendance £	Expenditure £000	Attendance	Cost per attendance £	Expenditure £000	Population	Cost per population £	Expenditure £000	Expenditure	% of all Scot. Expenditure
Ayrshire & Arran	-	-	-	184	484	380	-	-	-	3,366	368,690	9.13	11,847	15,397	5.4
Borders	-	-	-	-	-	-	-	-	-	-	116,020	-	-	-	-
Fife	10,273	1,198	8,573	345	877	394	-	-	-	1,339	374,730	3.57	13,273	25230	8.8

Greater Glasgow & Clyde	10,543	1,591	6,625	99	374	265	-	-	-	19,151	1,185,040	16.16	52,929	82722	28.8
Highland	4,510	321	14,038	102	421	242	-	-	-	1,625	324,280	5.01	11,068	17305	6.0
Lanarkshire	6,911	952	7,256	-	-	-	-	-	-	3,029	664,030	4.56	27,411	37351	13.0
Grampian	3,626	471	7,694	376	469	803	-	-	-	4,077	586,530	6.95	18,725	26805	9.3
Orkney	-	-	-	10	9	1,056	-	-	-	33	22,540	1.47	592	635	0.2
Lothian	15,727	1,760	8,935	1	30	20	-	-	-	5,679	916,310	6.20	14,187	35594	12.4
Tayside	10,036	1,518	6,611	154	630	244	1,862	3,717	501	3,290	417,650	7.88	8,498	23839	8.3

Forth Valley	4,921	835	5,896	242	1,561	155	-	-	-	1,676	305,710	5.48	7,607	14446	5.0
Western Isles	338	-	-	-	-	-	-	-	-	-	26,640	-	361	699	0.2
Dumfries & Galloway	1,313	185	7,081	-	-	-	-	-	-	1,073	148,790	7.21	4,181	6567	2.3
Shetland	-	-	-	-	-	-	-	-	-	232	22,940	10.13	-	232	0.1
Totals or Averages	68,198	8,833	7,721	1,512	4,855	311	1,862	3,717	501	44,589	5,479,900	8.35	170,679	286,820	100

Table 8: Learning Disabilities Hospital Running Costs by Patient Type

Hospital	Average staffed beds	Inpatients			Outpatients - Consultants			Day patients			Total Expenditure
		Expenditure £000	Weeks	Cost per week £	Expenditure £000	Attendance	Cost per Attendance	Expenditure £000	Attendance	Cost per Attendance	
Lynebank Hospital	25	9873	1094	9025	332	847	392	-	-	-	10205
GGPCD LD Partnership	24	6776	1063	6375	-	-	-	-	-	-	6776
Lochview Hospital	19	4711	798	5901	195	1279	153	-	-	-	4906
Strathmartine Hospital	18	5909	756	7815	47	205	230	1574	2857	551	7531

Kirklands Hospital	12	4564	536	8508	-	-	-	-	-	-	4564
Acorn House, Dumfries	10	653	70	9314	-	-	-	-	-	-	653
Learning Disabilities Service Healthcare Houses	6	1649	312	5286	-	-	-	-	-	-	1649
Elmwood	-	-	-	-	376	469	803	-	-	-	376
Hawkhill Day Hospital	-	-	-	-	-	-	-	287	860	334	287

Table 9: R040LS: Speciality Group Costs – Inpatients in Long Stay Specialities

Hospital	Discharges	Inpatient weeks	Direct Cost per Inpatient Week							Total allocated cost per inpatient week£	Total costs: Cost per inpatient week				
			Medical and Dental £	Nursing £	Pharmacy £	AHPs and others £	Other direct care £	Theatre £	Laboratory £		Gross £	Income ACT £	Income other £	Net £	Group index
Lynebank	11	1,094	326	4,667	186	900	6	-	4	3,099	9,188	-27	-137	9,025	197
GGPCD LD Partnership	19	1,063	399	4,031	113	560	4	-	17	1,703	6,827	-	-452	6,375	139
Lochview	12	798	226	3,653	88	517	4	-	12	1,463	5,963	-	-63	5,901	129
Strathmartine	4	756	87	5,259	34	460	0	-	5	2,311	8,156	-	-341	7,815	171

Kirklands	12	536	616	4,326	47	5	0	-	85	3,437	8,516	-	-8	8,508	186
Acorn House	272	70	4	9,436	36	72	6	-	-	2,942	12,497	-3	-3,180	9,314	203
Learning disabilities service healthcare houses	3	312	113	3,276	67	205	-7	-	0	1,652	5,306	0	-20	5,286	115

Table 10: R040LS: Speciality Group Costs – Inpatients in Long Stay Specialities April 2022-March 2023

File name: d040-x-d040s-x-22_23

Hospital	Average staffs	Occupied bed	Average Occupancy	Discharges	Average staff numbers	Direct cost per inpatient week	Total Direct costs	Total allocated costs	Total costs		
									gross	Income	net

	beds	s day	Ratio %																			
					Medical &	Nursing	Medical &	Nursing £	Pharmacy	AHPs and	Other	Theatre £	Laborator	Expenditu	Cos t per	Expenditu	Cos t per			Income	Income			
NHS Fife	25	7658	82.8	11	2.14	98.41	326	4667	186	900	6	-	4	6662	6089	3390	3099	10052	9188	-29	-150	9873	9025	114
Lyneba nk Hospital	25	7658	82.8	11	2.14	98.41	326	4667	186	900	6	-	4	6662	6089	3390	3099	10052	9188	-29	-150	9873	9025	114
NHS Greater Glasgow &	36	11139	85.1	35	6.19	133.93	402	4165	94	539	4	-	17	8308	5221	2739	1721	11047	6942	-	-504	10543	6625	84

Clyde																							
Gartnavel Royal Hospital	12	3698	85.5	16	1.94	44.64	409	4433	58	496	3	-	17	2861	5417	928	1757	3790	7174	-	-23	3767	7130	90
GGPCD LD Partnership	24	7441	84.9	19	4.25	89.29	399	4031	113	560	4	-	17	5447	5124	1810	1703	7257	6827	-	-481	6776	6375	80
NHS Highland	7	2249	89.7	5	2.19	60.06	864	8918	265	355	37	-	1	3355	10442	1186	3690	4540	14132	-1	-112	4427	13780	174

New Craigs Hospital	7	2249	89.7	5	2.19	60.06	864	8918	265	355	37	-	1	3355	10442	1186	3690	4540	14132	-1	-112	4427	13780	174
NHS Lanarkshire	12	3755	85.7	12	2.44	41.86	616	4326	47	5	0	-	85	2724	5079	1844	3437	4568	85116	-	-4	4564	85088	107
Kirklands Hospital	12	3755	85.7	12	2.44	41.86	616	4326	47	5	0	-	85	2724	5079	1844	3437	4568	85116	-	-4	4564	85088	107
NHS Grampian	9	3299	99.0	17	2.19	59.50	539	6293	39	692	1	-	0	3565	7564	210	445	37775	80009	-24	-124	3626	76994	97

Royal Cornhill Hospital	9	3299	99.0	17	2.19	59.50	539	6293	39	692	1	-	0	3565	7564	210	445	37775	80009	-24	-124	36269	76944	97
NHS Lothian	40	11957	82.5	27	15.84	82.78	827	5166	99	156	-4	-	3	10670	6246	4947	2896	156117	91443	-2	-71	155445	91000	115
Royal Edinburgh Hospital	33	9463	79.5	17	13.09	62.66	866	5683	102	128	-2	-	3	9165	6779	4267	3157	134332	99336	0	-60	133772	98922	125
St John's	1	310	100.0	7	2.34	-	4678	2683	215	668	-9	-	6	365	8239	164	3713	5229	119	-1	-5	5223	1118	149

Hospital																		52				18	
Learning Disabilities Service Healthcare Houses	6	2184	96.1	3	0.41	20.12	113	3276	67	205	-7	-	0	1140	3654	515	1652	16555	530606	0	-6	16449	52866	67
NHS Tayside	29	9448	88.6	18	1.68	115.95	219	4396	33	294	1	-	7	6681	4950	2981	2208	96622	71559	-28	-304	93300	69122	87
Strathmartine	18	5293	82.4	4	0.37	76.96	87	5259	34	460	0	-	5	4420	5845	1747	2311	61	81	-	-258	59	78	99

Hospital																	67	56			09	15	
Carseview Centre, Dundee	12	4155	98.0	14	1.31	38.99	387	3296	32	82	2	-	10	2262	3810	1233	2078	34955	58888	-28	-46	34203	57633	73
NHS Forth Valley	20	5843	80.4	19	1.24	67.62	236	3636	92	496	4	-	12	3735	4475	1240	1486	49975	59600	-	-54	49211	58966	74
Lochview Hospital	19	5589	79.7	12	1.13	65.19	226	3653	88	517	4	-	12	3593	4500	1168	1463	47611	59633	-	-50	47111	59011	74

Forth Valley Royal Hospital	1	254	100.0	7	0.11	2.43	444	3251	171	32	-2	-	12	142	3908	72	1985	214	5893	-	-4	210	5791	73
NHS Dumfries & Galloway	12	1298	29.1	279	-	22.21	3	5911	84	44	10	-	6	1123	6057	418	2253	1541	8310	0	-228	1313	7081	89
Acorn House, Du	10	491	13.5	272	-	13.47	4	9436	36	72	6	-	-	670	9555	206	2942	877	12497	0	-223	653	9314	118

mfries																							
Midpark Hospital	2	807	100.0	7	-	8.74	2	3767	112	27	12	-	9	453	3929	211	1835	664	5763	0	-5	660	5723	72
Scotland Totals or Averages	190	56646	81.6	423	33.91	682.32	465	4791	97	416	3	-	13	46823	5786	18954	2342	65777	81128	-85	-1550	64142	79226	100

Table 11: Comparison of data to be shared with Public Health Scotland from the Coming Home Dynamic Support Register: Adults with Red & Amber status compared with adults with Out of Area status.

Column Head/Data Captured	Submitted to PHS (Red & Amber Status)?	Submitted to PHS (Out of Area Status)?
DSR Category	Yes	Yes
Anon ID	Yes	Yes
Date of Birth	Yes	Yes
What is the Person's Sex?	Yes	Yes
Funding Authority	Yes	Yes
Host Authority	Yes	Yes
Date Admission/Placement Began	Yes	Yes

Is the Person Delayed Discharge?	Yes	
Delayed Discharge Code	Yes	
Date Clinically Ready for Discharge	Yes	
Inclusion Category	Yes	

Framework to support the register

The following section explores the framework to support the Dynamic Support Register. This will explore and evaluate the progress of each component to the proposed framework, and consider its applicability in terms of data that could capture human rights progress and realisation.

5.1 Background

The Coming Home Implementation Report (CHIR) proposed a framework to support the use of the Dynamic Support Register (DSR). The report stated that this was required as "Without a framework to support the use of the Register, it may be ineffective in facilitating the broad systemic change required to address." [4]

The CHIR proposed the following three components to the framework:

50. Complex Support Needs Pathway
51. Peer Support Network
52. National Support Panel

The purpose of this following section is to explore and evaluate the progress of each component to the proposed framework.

5.2 Complex Support Needs Pathway

The 'Complex Support Needs Pathway' was proposed to include "person-centred steps to avoid service breakdown and subsequent admission to hospital or being placed out-of-area". In addition, the pathway was proposed to include the steps to plan for discharge from hospital or from out-of-area placement in order to help facilitate a return home.[5] The pathway would provide 'timescales and milestones' and 'incorporate the various standards from a range of already existing legislation, guidance documents and good practice reports, including from NICE, the Care Inspectorate, SSSC, the Royal College of Psychiatrists, and the Mental Welfare

[4] Coming Home Implementation Report (p.45)
[5] Coming Home Implementation Report (p.45)

Commission, into one pathway'.[6] This pathway contains elements of participation and empowerment, depending on what 'person-centred' meant in practice, a clear indicator for accountability in the form of timescales and milestones, and greater legality if these 'timescales and milestones' were tied to legislation. The pathway could employ indicators based on Article 19 of the CRPD to ensure and demonstrate that key components, such as accountability, choice, and control (which are poorly evidenced in publicly available data) are being met, and that individuals' human rights are being upheld. Beyond its transformative and rights-realising potential, the pathway could also serve as a data source to evidence a human rights-based approach.

From conversations with stakeholders, we are aware of the existence of a draft pathway; however, this pathway is not currently published or, to our knowledge, in use, and no publicly available data was found in relation to its existence.

5.3 Peer Support Network

The Peer Support Network was proposed "to facilitate practitioners coming together to learn and share best practice, and to get support when planning services for individuals with particularly complex care needs". The proposed network would draw from the expertise and experience of "clinicians, commissioners, social care providers and family members from around Scotland,"[7] but not from people with learning disabilities and/or autistic people themselves. Given the need for systemic change, the omission of the people whose lives are most directly impacted and influenced by practice, appears glaring, and is not compliant with the CRPD committee guidelines, which calls for earmarked budgets to support the development of a wide range of support including peer-to-peer networks of support.[8]

Since the publication of the CHIR, the Scottish Government have "Worked with partners to understand the role and purpose of a Peer Support Network in order to design a model that provides value and allows for genuine collaboration across Scotland,"[9] and according to the LDAN consultation paper they are "establishing a

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[6] Coming Home Implementation Report (p.45)
[7] Coming Home Implementation Report (p.46)
[8] Annotated outline of Guidelines on Deinstitutionalization of Persons with Disabilities, including in emergency situations. Endorsed at the CRPD 25th Session (16 August-14 September 2021)
[9] Breakdown of the progress of the Coming Home Implementation report from February 2022: FOI release

Practitioner Peer Support Network through Healthcare Improvement Scotland (HIS)."[10] In an update to the Health, Social Care and Sport Committee, the Minister for Social Care, Mental Wellbeing and Sport, Maree Todd MSP, stated that the Network will be launched "as soon as recruitment has completed."[11] Once more, through conversations with stakeholders, we are aware of this network being launched; however, the research found no current publicly available data relating to the network, including on the HIS' 'practitioner peer support/networks' website.[12] Whilst the Network may not provide rich data in itself, it has clear potential to further embed rights-based approaches if the network is established, using the detail of Article 19 and the CRPD as a framework. This would require mandatory training on the CRPD for all members of the network. The CHIR also suggested that "Local areas may wish to consider appointing a dedicated "change champion,"[13] i.e. an individual with expertise in the needs and challenges faced by people with learning disabilities in the area who is then able to collaborate more widely via the Peer Support Network. The report found no evidence of the creation of this role. We have been informed that a change champion may have been created in NHS GGC but we found no public evidence of the creation of this role.

5.4 National Support Panel

The final component of the proposed framework to support the register was the National Support Panel. The Panel was proposed to be "established as a national body who will work on behalf of the Scottish Government and Local Authorities to ensure that the Register is achieving positive outcomes for people with learning disabilities who are currently in hospital or living in out-of-area placements."[14] This would involve the Panel working with "HSCPs and partner organisations by providing support and expertise for their decision making and solutions for individuals in a collaborative forum." The Panel would provide 'checks and balances' to ensure standards of care that took place in the 'most suitable environment', and "to understand and hear from families and individuals about their individual

[10] Learning Disabilities, Autism and Neurodivergence Bill: Consultation (p.82)
[11] Letter to Convenor of Health, Social Care and Sport Committee from Maree Todd MSP (NPN)
[12] Practitioner peer support/networks
[13] Coming Home Implementation Report
[14] Coming Home Implementation Report (p.47)

circumstances." This Panel would be representing a significant data source, as it would provide insight into the circumstances and barriers faced by the people who would access it.

The Short Life Working Group (see Appendix 1 for membership) created on the instruction of the Scottish Government with a remit to "undertake a joint focused piece of work in relation to delayed discharge for people with learning disabilities and/or enduring mental health conditions,"[15] recommended in the CHIR that the Panel should "be backed with statutory powers in order to support their function, including the authority to require any information that enables the panel to carry out their role, as well as powers to make placements and/or require funding of a support package." Data relating to the progress of this panel was drawn from the Learning Disabilities, Autism, and Neurodivergence Bill (LDAN) consultation.[16] This highlighted that the scoping work was 'progressing', but that the Panel is not currently in existence.

The LDAN consultation set out three possible options for the foundation of the proposed panel.[17]

Option A: Legislative Panel Conducting Individual Reviews within Defined Parameters This option would require relevant public bodies to participate in individual case reviews heard by the panel by law. This panel would consist of "sector experts who have current knowledge of the Scottish approach to complex care, and who are committed to a human rights-based approach. We would recruit or appoint people with lived experience, housing and social work expertise to the Panel. The panel will likely also need legal and clinical expertise."

The second option 'Option B: Legislative Panel Conducting Peer Reviews of Local Processes', which would "consist of a group of experts who could provide checks and balances through a model of peer reviews. It would be made up of a 'bank' of expert members, including people with lived experience, who could be brought in to conduct peer reviews of the work and processes of Health Boards, Local Authorities and Integration Authorities in relation to this population." This option would be legislative but would not consider individual cases and may struggle "to create a culture of fully open and reflective practice within a legislative context."

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[15] Coming Home Implementation Report (p.15)
[16] Learning Disabilities, Autism and Neurodivergence Bill: Consultation
[17] Learning Disabilities, Autism and Neurodivergence Bill: Consultation (pp. 85-89)

The third option ‘Option C: Non-legislative Panel Conducting Peer Reviews of Local Processes’, would “would work in the same way as the Panel described in Option 2, however, it would not be legislative.”

Given the context of the need for systemic change, and the historic lack of rights-realisation for people with learning disabilities and/or autistic people, it would appear crucial that a panel would have legislative powers. Furthermore, the involvement of people with lived experience, which each option recognises, is crucial. Considering that “There is not currently a way for people with learning disabilities and complex care needs who are facing inappropriate hospital stays or out-of-area placements to have their case reviewed by experts,”[18] and the historic and ongoing systemic failure to realise human rights, Option A appears the most appropriate given its proposed legislative power, and its remit to hear individual cases. Properly implemented, this could, therefore, meet the requirement of the State to “provide individualized, accessible, effective, prompt and participatory pathways to access to justice for persons with disabilities who wish to seek redress, reparations and restorative justice, and other forms of accountability.”[19] However, given that the panel remains at the scoping/consultation stage, its creation is not certain, and if created, not likely to be in operation in the near future.

5.5 Senior Government Coming Home Senior strategy group

In response to a Freedom of Information request regarding the progress of the Coming Home Implementation report, the Scottish Government stated that they, alongside COSLA, had established a senior strategy group “who are advising us on developing the panel recommendation before it is formally established.”[20] The Senior Strategy group was also referenced by Kevin Stewart, the then Minister for Mental Wellbeing and Social Care, in response to a Parliamentary question.[21] Details of the group’s membership and or its meetings were not found on the Scottish Government’s website. An online search using the term ‘Scottish Government's coming home senior strategy group membership’ yielded information on one

[18] Learning Disabilities, Autism and Neurodivergence Bill: Consultation (p. 84)
[19] CRPD/C/5: Guidelines on deinstitutionalization, including in emergencies (2022) (p.17)
[20] Breakdown of the progress of the Coming Home Implementation report from February 2022: FOI release
[21] Parliamentary question reference: S6W-14284

member - a CEO of an organisation that provides care and support for people with learning disabilities, autism and complex care needs. Once more, we are aware of other members of this group through conversations with stakeholders. Publishing information regarding the membership and remit of this group, would improve transparency and offer possible data of participation and empowerment of people with learning disabilities and/or autism, their families, and DPOs.

5.6 Summary & Recommendations

From the publicly available data, there is no evidence of the Complex Needs Pathway being in operation, and no data relating to the work or impact of the Peer or Practitioner Peer Support Network. As made clear by the LDAN consultation paper, the National Support Panel is still the subject of discussion and proposal, and, therefore, does not exist in any operational form.

The CHIR cautioned that “Without a framework to support the use of the Register, it may be ineffective in facilitating the broad systemic change required to address this long-term and challenging issue.”[22] This is of concern as the Dynamic Support Register is operational but without the support of the framework that was proposed. Whilst progress has been observed in relation to the framework, the current environment speaks to the current unrealised potential of the full implementation of key components of the Coming Home Implementation Report. Each component further offers potential to promote, and evidence a rights-based approach.

53. Clarification, and timeframes are required from the Scottish Government on the progress of both the Complex Needs Support Pathway, and the Practitioner Peer Support Network.
54. The use of indicators, based on Article 19 of the CRPD, to be incorporated into the Pathway.
55. Alignment throughout and commitment to independent living, e.g. remove placements as part of the strategy.
56. Ensure that there are platforms for participation, and for expert voices with lived experience of institutional care, of having a learning disability and/or autism are heard and inform all decisions.

[22] Coming Home Implementation Report (p.45)

57. The proposed National Support Panel to be created, have legislative powers, and to provide people with learning disabilities and/or autism in hospital and inappropriate placements access to have their case reviewed by a panel of experts.
58. The Scottish Government to publish details on the membership, purpose and information relating to meetings such as agendas and minutes, of the Senior Government Coming Home Strategy Group.
59. Each component, if implemented, to be monitored and reported on using human rights indicators and frameworks. These should incorporate the CRPD Committee guidelines,[23] and the already available indicators by the European Union Agency for Fundamental Rights (FRA)[24] and the Office of the United Nations High Commissioner for Human Rights (OHCHR).[25]

[23] CRPD/C/5: Guidelines on deinstitutionalization, including in emergencies (2022)
[24] Implementing the UN Convention on the Rights of Persons with Disabilities: Human rights indicators
[25] Human Rights indicators on the Convention on the Rights of Persons with Disabilities in support of a disability inclusive 2030 Agenda for Sustainable Development

Community Living Change Fund

This section explores the Community Living Change Fund, as an indicator of how much commitment there has been to progressing the vision of the Coming Home Implementation Report.

6.1 Background

A key proposal of the Coming Home Implementation Report (CHIR) was the creation of the Community Change/Living Change Fund. This led to the allocation of £20m to Integration Authorities in February 2021,[26] which could be held in reserve for three years. The end date for the money to be spent is the 31 March 2024. Its stated purpose is:

"to drive the redesign of services for people with learning disabilities and complex care needs. The goal is to provide high-quality, local, community-based services where, regardless of complexity of need or behavioural challenge, people's right to live a full and purposeful life, free of unnecessary restrictions can be realised."[27]

According to the CHIR, the fund's intended use is to support people with a learning disability[28] to:

60. be discharged from hospital quicker, and not face any unnecessary delays to their discharge;
61. come home back to their local area if they have been inappropriately placed out of Scotland;
62. deliver better connection to their communities through an increase in local community service provision for adults who have been placed in inappropriate or institutional out-of-area placements;

[26] Coming Home Implementation Report
[27] Coming Home Implementation Report (p. 50)
[28] Coming Home Implementation Report (p. 50 states that "although this could be extended to support people with enduring mental health conditions where this was deemed appropriate.")

63. receive better services through redesign of existing provision that is better tailored to the specific needs of the person.[29]

The fund carries the aim “that by March 2024 out-of-area placements are only made through individual family choice and people are only in hospital for genuine short-term assessment and treatment.”[30] The use of the fund is, therefore, a key source of data, as its use should theoretically contribute to the meeting of this aim.

6.2 Allocation of the fund

The fund was allocated on the basis of “an established combination of health and local government formulae (a mix of relevant GAE and NRAC) to Health Boards, for onward distribution to Integration Authorities.”[31] The guidance highlights that this was seen as ‘the fairest method’, having considered other options including making the fund open to local bids, and determining allocation “based on the scale of the delayed discharge and out of area cases.” The eventual allocation is detailed in Table 14 below. This led to the allocation of the fund to at least one Integration Authority - Shetland - that did not have any people in delayed discharge from hospital or inappropriately placed outwith Scotland (although there may be people from this area still placed inappropriately out of area) at the time the fund was released.[32] This raises questions regarding the decision to base allocation not on the scale of delayed discharge and out of area cases, and whether the chosen funding approach was indeed the fairest method.

6.3 Guidance of the use of the fund

The guidance relating to this fund was made available to the research team following a meeting with the Scottish Government. In terms of its public availability, it was difficult to source, and the guidance was eventually found online published by Dumfries and Galloway HSCP (we could not source it through searches of other HSCPs).[33] The guidance, issued in March 2021 supplied by the Director of Mental Health and Social Care to IJB Chief Finance Officers, NHS Directors of Finance, and LA Directors of Finance provides more detail regarding a set of principles that the

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[29] Coming Home Implementation Report (p. 50)
[30] Coming Home Implementation Report (p. 51)
[31] Community Living Change Fund Guidance
[32] Shetland Islands Council information on use of Community Living Change Fund
[33] Community Living Change Fund Guidance

fund should adhere to, and reiterates that the fund should be used by March 2024. These principles (see Appendix 2) should be "signed off by representation from NHS Boards, local authorities, third sector providers and service users."[34]

The CHIR provides four case studies that showcase interventions and system changes that, considering their inclusion in the report, can be considered to be examples of best or improved practice. In response to the CHIR, a group of DPO's and human rights organisations examined these case studies, highlighting areas in each that were not in compliance with the CRPD. In the case of Teviot Court, the submission stated that the design did in fact appear to "to meet the criteria for institutional provision as defined by the CRPD."[35] Publishing these case studies could influence integration authorities. As the case studies were identified explicitly as not delivering a right-based approach, the CHIR is creating a misleading environment where practice that is not rights-respecting could therefore be replicated by Integration Authorities when using the fund.

6.4 Monitoring of the fund

In respect to monitoring of the use of the fund, the guidance states that:

"The use of each Integration Authority's share of the £20m should be recorded in their annual financial statement and the outcomes delivered detailed in their annual performance report. Where the funding has been carried over in reserves, this must be earmarked separately and reported to the Scottish Government through the quarterly monitoring."

Whilst we are aware from conversations with stakeholders that this takes place, the quarterly monitoring reports submitted to the Scottish Government are not publicly available. Publication of all monitoring related to the fund could provide data relating to the use of the fund and increase transparency and accountability. This could also ensure the sharing of best practice amongst individual Integration Authorities. The guidance builds on information in the CHIR which states that informal monitoring "will also be carried out collaboratively and co-operatively through partners such as the

[34] Community Living Change Fund Guidance
[35] Stakeholder Submission on Common Concerns - Coming Home Implementation Report

Social Work Scotland Learning Disability Network."[36] The research found no evidence of this informal monitoring.

6.5 How has the fund been spent to date?

In order to ascertain how and on what the fund has been spent, and in the absence of publicly available monitoring data, we selected five Integration Authorities to focus on. Glasgow City was selected due to it being the recipient of the largest share of the Community Living Change Fund, and East Renfrewshire as it was mentioned as 'hosting' learning disability services on behalf of Glasgow City. We then decided to focus on Western Isles, Clackmannanshire and Stirling, and East Dunbartonshire as, according to Public Health Scotland's 'Insights into Learning Disabilities and Complex Needs: Statistics for Scotland',[37] these HSCP have the highest rates of people on the Dynamic Support Register in Scotland. As the fund was made available in February 2021, we looked at annual accounts and performance reports for the years 2020-2021, 2021-2022, 2022-2023 (the latest available). Due to difficulties in locating the figures relating to the CLCF, we omitted Glasgow City and Western Isles from this search. We found little recorded spending of the CLCF within any of the three HSCPs sampled and the data we could find features in Table 12.

Table 12: Annual accounts

Integration Authority	2020-2021	2021-2022	2022-2023
East Renfrewshire	£ 295,000	£ 295,000	£ 254,000
Clackmannanshire & Stirling	£ 512,000	£ 512,000	£ 512,000
East Dunbartonshire	£ 350,000*	£ 341,000	£ 341,000

[36] Coming Home Implementation Report (p.54)
[37] Insights Into Learning Disabilities and Complex Needs

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* Figure appears as £0.35m in annual accounts of 2020-21, but is recorded as £341,000 in subsequent accounts without evidence of spend.

The terminology used to refer to the fund in accounts was inconsistent. East Renfrewshire used the terms ‘Learning disability community living change fund’ in 2020-2021 and 2021-2022, and ‘Community Living Change Fund’ in 2022-2023. Clackmannanshire and Stirling consistently used ‘Community Living Fund’, and East Dunbartonshire used ‘Community living Change fund’ in 2020-2021, and ‘community living charge’ in the subsequent two reports. This reduced transparency and made information more difficult to find.

Timeline of fund

As noted above, guidance was issued by the Scottish Government to representatives of IJB’s, NHS, and Local Authorities in March 2021. In conversations with stakeholders, it was highlighted that the CHIR itself was published almost a year later in February 2022. This was noted as being an important detail as Integration Authorities may have been waiting for the publication of this report before commissioning spending of the fund. As figure 2 below illustrates, this may in effect have reduced the window available for Integration Authorities to use the fund and may be a contributing factor to the lack of spending of the CLCF shown below in Table 14. However, beyond conversations with stakeholders we found no publicly available data that provided insight on this.

Figure 2 Timeline of fund and guidance

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Given the lack of apparent spending of the fund, and the fact that the publicly available data regarding how much of the fund has been spent only goes up to March 2023, it is difficult to draw firm conclusions as to the impact of the fund. Data regarding the use of the fund is needed to understand its use and introduce a level of transparency and accountability. As is demonstrated in this report, to ascertain the spend of this fund to date, an individual would have to access each individual Integration Authority’s annual accounts, which do not provide information beyond any spend (as a figure), and any reserve held. This piecemeal approach reduces transparency and accountability. Furthermore, this makes it challenging to understand any impact on the deinstitutionalisation process.

From conversations with stakeholders and as raised by Shetland Council (who are not the Integration Authority specifically but reported publicly on the use of the fund), there is “an ongoing difficulty to identify sustainable funding beyond 2024 when the Community Living Change Fund expires”.[38] The sustainability of interventions and actions arising from the use of the fund is therefore unclear. We are further aware from conversations with stakeholders of instances of reserves from the CLCF being carried over past the scheduled end of the fund in March 2024, however we found no publicly available data relating to this.

Refurbished accommodation

In one authority, evidence was found of proposed use of the fund to purchase and refurbish vacant NHS multi bed accommodation.[39] More recent publicly available documents provided detail of the purchasing, rationale and plans for this.[40] This report provided an update on longstanding plans to resettle people with a learning disability who have been resident in the authority’s “last remaining NHS longer stay unit..” According to this report, the identified building had previously been used, as a longer stay unit before being closed in 2017. In 2021, having been vacant since its closure, it was purchased and has since undergone refurbishment. A service provider has been appointed and was scheduled to open in March 2024. These plans, part of a resettlement strategy were “further enhanced with the publication of the Scottish Government Coming Home implementation report 2022, and the £20 million fund to take forward redesign across Scotland.”[41] Whilst we were not able to ascertain the level of spend, we are able to confirm that it was purchased and redesigned using at least part of the share of the CLCF.[42].

6.6 Annual Performance Reports

An expectation of the fund is that outcomes are recorded in IJB/HSCP annual performance reports. Given the fund was recorded as being carried over, there is no requirement to publish outcomes. We decided to search these reports for evidence of the intention to use the fund, or for evidence of processes of planning. East

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[38] Shetland Islands Council information on use of Community Living Change Fund
[39] Glasgow City Integration Joint Board: 22.09.21
[40] Meeting of East Renfrewshire Health and Social Care Partnership Agenda Item 12 (p.81)
[41] Meeting of East Renfrewshire Health and Social Care Partnership Agenda Item 12 (p.85)
[42] Glasgow City IJB Directions Annual Report 2021-22

Renfrewshire referenced the fund in their 2020-2021 report, stating that “We had also planned to meet some refurbishment costs for work within our Learning Disability in-patient units, however this work was delayed at the start of the pandemic; this work is now on hold and will be incorporated as part of the work supported by the Community Living Change Fund.”[43] This work was not evidenced latterly in outcomes. East Renfrewshire’s 2022-2023 report references the CLCF’s allocation, and a ‘community and inpatient redesign group’ which was chaired by both ‘inpatient and community colleagues’, but that does not include people with lived experience, or DPOs.[44] Therefore the decision making behind East Renfrewshire’s spend is not participatory and thus, does not meet the standards of using a human rights-based approach.

Clackmannanshire and Stirling reference a commitment to the delivery of the Coming Home Report in 2021-2022,[45] but no specific mention of outcomes related to the CLCF. We could not access their performance report for 2022-2023. East Dunbartonshire made no specific reference to the fund in any of their performance reports that cover the period of the fund.

Table 13: Evidence of potential use of CLCF

Integration Authority	2020-2021	2021-2022	2022-2023
East Renfrewshire	✓	X	✓
Clackmannanshire & Stirling	X	X	N/A
East Dunbartonshire	X	X	X

The annual performance report of Clackmannanshire & Stirling HSCP also could not be found on the HSCP’s landing page (which holds the previous annual performance

[43] East Renfrewshire HSCP Annual Performance Report 2020-21
[44] East Renfrewshire HSCP Annual Performance Report 2022-23
[45] Clackmannanshire & Stirling Health & Social Care Partnership Annual Performance Report 2021-2022

reports)[46]. The link cited in IJB annual accounts for 2022-2023 is at the time of writing, broken.[47]

The lack of evidence of the fund being used by these Integration Authorities led us to look more widely at the use of the fund nationally. To do this, we searched the 2022/2023 annual accounts of all IJBs/HSCPs to see how much of the fund was held in reserve. Table 14 below details the allocation of the CLCF to each Integration Authority and the figure that was held in reserve as of their last published annual accounts.

Table 14: Allocation of CLCF and balance as of March 2023 (figures in bold denote no spend)

Integration Authority	Share allocated	Allocation in £	Balance as of March 2023
Aberdeen City	4.4 %	£ 876,523	£ 876,523
Aberdeenshire	4.1 %	£ 814,809	£ 612,000
Angus	2.0 %	£ 391,750	£ 332,000
Argyll & Bute	1.5 %	£ 300,701	£ 240,000
City of Edinburgh	9.6 %	£ 1,924,542	N/A
Dumfries & Galloway	2.5 %	£ 496,841	£ 400,000
Dundee City	3.1 %	£ 613,010	£ 613,000

[46] Clackmannanshire & Stirling HSCP Annual Performance Report landing page
[47] Clackmannanshire & Stirling Integration Joint Board Annual Accounts 2022-2023

East Ayrshire	2.3 %	£ 461,122	£ 149,000
East Dunbartonshire	1.7 %	£ 340,669	£ 341,000
East Lothian	1.7 %	£ 345,525	£ 346,000
East Renfrewshire	1.5 %	£ 294,805	£254, 000
Falkirk	2.8 %	£ 568,512	£ 596,000
Fife	6.7 %	£ 1,333,946	£ 1,339,000
Glasgow City	13.7 %	£ 2,739,050	N/A
Highland	4.1 %	£ 814,627	N/A
Inverclyde	1.6 %	£ 319,813	£ 292,000
Midlothian	1.6 %	£ 312,385	£ 309,000
Moray	1.6 %	£ 319,463	£ 319,463
Na h-Eileanan Siar (Western Isles)	0.5 %	£ 96,589	N/A
North Ayrshire	2.6 %	£ 513,041	£ 513,000
North Lanarkshire	6.5 %	£ 1,298,332	£ 1,298,000
Orkney Islands	0.4 %	£ 81,141	£ 0 (spent in 2021-2022)
Perth & Kinross	2.5 %	£ 504,878	£ 475,000

Renfrewshire	3.5 %	£ 696,756	£ 697,000
Scottish Borders	1.9 %	£ 377,966	£ 377,966
Shetland Islands	0.4 %	£ 77,972	£45, 929*
South Ayrshire	2.0 %	£ 409,720	£ 371,000
South Lanarkshire	5.8 %	£ 1,161,818	£ 681,000
Stirling & Clackmannanshire	2.5 %	£ 512,079	£ 512,000
West Dunbartonshire	1.8 %	£ 356,726	N/A
West Lothian	3.2 %	£ 644,888	£ 645,000
Total		£ 20,000,000	£ 14,068,466

*This figure relates to the balance as of 31st March 2024. This figure was not publicly available but was shared following a request for information.

From the figures that we have available, the total allocation of the CLCF we were able to trace was £14,068,466 (this is £20million minus the allocation given to West Dunbartonshire, Western Isles, Highland, Glasgow City, and Edinburgh City). We are aware of individual spend of the fund from within this group, as is shown in the case of the refurbished accommodation, so it is important to note that the absence of the figure does not necessarily mean that the fund has not been spent.

The total held in reserve as of March 2023 of the figures found was £14,068,446. As of the same date, the total traceable spend was £1,433,585. This suggests that the vast majority of the CLCF was unspent going into the final year of the fund.

Table 15: Allocation, amount held in reserve and spending of CLCF

Total Allocation where figures were available	£14,068,466

Total held in reserve as of March 2023	£12,634,881
Total spend of CLCF from available figures as of March 2023	£1,433,585

6.7 Missing data

As can be seen from Table 14, we were unable to trace the balance of a number of the allocations. Some accounts carry an aggregated figure in respect to 'earmarked reserves', which may explain this.

NHS Highland have a lead agency approach to integration, where NHS Highland lead on adult services.[48] We could not ascertain the figure of spend. The Shetland Island's annual accounts mention the receipt of the fund in their 2021 accounts[49]. Neither the 2021-2022,[50] nor the 2022-2023[51] appear to carry a figure, though they do have figures regarding combined earmarked reserves, where the CLCF funding may be.

The difficulty in ascertaining these figures again underlines the need for publication of data by the Scottish Government regarding the use of the fund.

6.8 Transparency

Continuing from the inconsistency of terminology noted above, we continued to find a range of terminology used in respect to the CLCF. The CHIR itself uses both Community Living Change Fund, Community Change Fund, and for the purposes of the report, 'the fund'. In annual accounts we found the CLCF referred to as 'community living change plan', 'community living change fund', 'community living fund', 'community living change', and 'community living charge'.

The example of Midlothian illustrates how this is problematic in terms of accessing information. The CLCF was referred to as the 'community support fund' in the annual

[48] What is Integration? Audit Scotland
[49] Western Isles HSCP Annual Report 2020
[50] Shetland Islands Integration Annual Accounts 21/22
[51] Shetland Islands Integration Annual Accounts 22/23

accounts for 2022-2023.[52] We followed the term back in the accounts and found its use in 2021 as a 'movement' in reserves, i.e., the money had been received that financial year. This figure from 2021 (£312,000) corresponds with the allocation of the CLCF so is taken to be the same. Taking this approach of cross-referencing terms and figures was time-consuming and confusing for researchers who have subject knowledge and research expertise. The lack of transparency could, therefore, be considered a barrier to access and in turn, accountability.

6.9 Accessibility of reports

Formats of the publicly available reports varied greatly (which is permitted as per the Scottish Government guidance[53]). Some reports required the user to download word documents to access, which places a further step required by anyone wishing to access them. Glasgow City's HSCP provided a clear landing page from which annual performance reports and summaries dating back to 2016-2017 could be accessed.[54] Performance reporting, as noted in the Scottish Government's Annual Performance Statutory Guidance, "is essential for open, transparent and effective public service provision and reports will be of interest to supported people, carers and wider local communities." The guidance highlighted that these reports should be available online, and that "the integration authority should ensure that these are as accessible as possible to the public." Whilst the Scottish Government has produced a 'Health and Social Care Integration Annual performance reports: guidance Easy Read Version',[55] the annual performance reports we accessed did not provide an easy read version. Gathering this data was an extremely time-consuming and challenging task due to the absence of a central database where annual accounts are clearly located.

The link to Western Isles' HSCP from HSCP Scotland are currently broken as of 27th March 2024.[56] This contradicts the Scottish Government's call for the Health and Social Care Scotland website to host key documents, that are up to date, on the Health and Social Care Scotland website.[57]The Health and Social Care Scotland website hosts key documents from all of Scotland's integration authorities, including

[52] Midlothian Integration Joint Board Accounts 22/23
[53] Health & Social Care Integration Annual Performance Reports 2014
[54] Glasgow City HSCP Annual Performance Reports
[55] Annual Performance Reports Guidance
[56] Western Isles HSCP Annual Report 2020
[57] Health & Social Care Integration Annual Performance Reports 2014 (p.5)

strategic plans and performance reports. This should be kept up-to-date. It is also worth noting that whilst this website links the user to annual performance report (and other information), it does not carry a link to the annual accounts. Adding these links would improve transparency.

It is also worth noting that whilst the HSCP Scotland website carries links to individual HSCP annual performance report (and other information), it does not have a link to individual annual accounts. Adding these links would greatly improve accessibility of this information, in addition to improving transparency.

6.10 Principles of local use of the Community Living Change Fund

The principles guiding the use of the fund (see Appendix 2) are of interest as they suggest elements of a human rights-based approach within the use of the fund. Four principles in particular stand out: Locality based, Transparency, Collaboration, Involvement, Human Rights.

Locality based

Locality based – the locality aspects must include input from users and carers and the public. Partnerships should develop plans with the people who best know the needs and wishes of this cohort. Such a bottom-up approach should maximise the contribution of local assets including volunteers and existing community networks. These links should be made at both a practice and strategic level.

The research has found no publicly available evidence to date of input from ‘users’ or carers. Whilst this may occur, as shown in Table 13, there was minimal reporting of outcomes relating to the fund, or participatory processes relating to planning in the selected annual performance reports we accessed.

Transparency

Transparency – there must be a ‘single version of the truth’ with regard to cost and activity data so that the totality of the resource (financial and assets) is used to best effect

Whilst most annual accounts carry evidence of the figure received as part of the CLCF, the inconsistent use of the terminology, and the absence in searches to date of the figure in some annual accounts, contradicts this principle.

Involvement

Partnerships should take a co-production, co-operative, participatory strength-based approach, ensuring human rights are central to the design and delivery of new ways

of working – delivering support and services based on an equal and reciprocal person-centred relationship between providers, users, families and communities.

Whilst this may take place, the research has to date found no evidence of this in terms of publicly available data.

Human Rights

Human rights - partnerships should adopt a human rights-based approach. Taking a human rights-based approach empowers people to know and claim their rights. It increases the ability of organisations, public bodies and businesses to fulfil their human rights obligations. It also creates solid accountability so people can seek remedies when their rights are violated. The PANEL principles are one way of breaking down what a human rights-based approach means in practice. PANEL stands for Participation, Accountability, Non-Discrimination and Equality, Empowerment and Legality.

Whilst the call to adopt a human rights-based approach is welcome, there is little evidence of rhetoric meeting reality in respect to the CLCF. This principle is not grounded in any of the specifics of the relevant human rights. For example, it does not highlight the key right of independent living, nor provide detail as to what that means in practice. This omission may create an environment where money is spent in direct contravention of the requirements of Article 19.

For all stakeholders to be empowered to use a human rights-based approach, support in the form of training would be an obvious first step. As there is currently no statutory training regarding human rights, the expectation that a human rights-based approach will be applied, appears flawed. There would, furthermore, be an expectation that public services who engage with people with a learning disability and/or autism would have training on the CRPD. As noted in the LDAN consultation, whilst training may be available to public sector professionals “to help them better understand and communicate with people with learning disabilities and neurodivergent people”,[58] there is no statutory requirement to undertake this training. Furthermore, the LDAN consultation highlights that training available may not have been developed by people with lived experience. The current environment is, therefore, one where “people who work in public services, such as in the NHS or social care, the police and prisons, can choose to do training or not, if it is available

[58] Scottish Government Learning Disabilities, Autism and Neurodivergence Bill: Consultation (p.30)

to them. It is also not available consistently across different public services or delivered to a set standard; it can therefore vary in quality and effectiveness."[59]

6.11 Summary & Recommendations

The Community Living Change Fund was presented as a key tool in realising the aims of the Coming Home Implementation Report. This report has found little evidence of the fund being spent, and whilst it is expected that this has taken place in the past year, the lack of activity and transparency is concerning. During the time since the fund has been issued, people have continued to be kept in hospitals when they should have been discharged and have been continued to live and be placed in inappropriate placements. Placements cannot fulfil the terms or vision of Article 19 of the CRPD and so the CHIR even if implemented in full (there is little evidence to show it has impacted at all) would not deliver a human rights based approach as it did not truly aspire to independent living, or to participatory and informed decision making. Where the fund has been carried over, the reasons for such allocation should be transparent. Furthermore, the future of interventions resultant of the fund is unclear, due to uncertainty over the funding landscape post-fund.

65. Integration authorities to publish reports outlining their use of the fund, and the processes followed, including any engagement with people with lived experience, their families, and disabled people's organisation.
66. Uniform use of terminology in all reporting to increase transparency and accessibility.
67. Co-produced easy-read versions of all annual performance reports to be published.
68. HSCPs to host annual accounts and performance reports on their website. Scottish Government publications to embed links to these reports.
69. Statutory training in human rights in order to ensure that those tasked with delivering a human rights-based approach are empowered to do

[59] Scottish Government Learning Disabilities, Autism and Neurodivergence Bill: Consultation (p.30)

so. Similarly, training to be made widely available for people with lived experience, their families and carers.

70. Research into the impact of both the fund, and, if it is not continued or replaced, the impact of the removal of funding.
71. Publication of publicly available and accessible reports that provide clear explanation and examples of how the use of the fund meets the requirements of human rights, specifically the CRPD guidelines.

Appendices

Appendix 1 - Membership of ‘short life working group (SLWG)’

- Jane O’Donnell, Convention of Scottish Local Authorities (COSLA) (Joint Chair of SLWG)
- David Williams, Scottish Government (Joint Chair)
- Cleland Sneddon, Society of Local Authority Chief Executives (SOLACE)
- Hugh McAloon, Scottish Government
- Julie Murray, Chief Officer East Renfrewshire & member of Integration Joint Board Chief Officers (IJB CO) Network group
- Duncan McIntyre, Midlothian Council, on behalf of Social Work Scotland
- Clare Thomas, COSLA (Co-chair workstream 1)
- Brian Slater, Scottish Government, (Co-chair workstream 1)
- Gillian Barclay, Scottish Government, (Chair workstream 2) COSLA and Scottish Government Officials

Appendix 2 - Principles of local use of the Community Living Change Fund

72. Leadership-the budgets in scope (hospital inpatients and delays, community supports and the cost of placements) have all been delegated to Integration Authorities, so they should take the lead in developing proposals.
73. Partnership – the use of the Fund should take cognisance of the expertise within different sectors including health, social work, social care support, housing and the voluntary sector. Integration Authorities should take an inclusive and collaborative local approach through their Strategic Planning Groups that seeks out and takes into account the views of non-statutory partners in the assessment of priorities and delivery of innovative ways to deliver better outcomes.
74. Locality based – the locality aspects must include input from users and carers and the public. Partnerships should develop plans with the people who best know the needs and wishes of this cohort. Such a

bottom-up approach should maximise the contribution of local assets including volunteers and existing community networks. These links should be made at both a practice and strategic level.

75. Best use of resources – the funding represents a small percentage of the total currently spent on delayed discharges and out of Scotland placements so must be able to improve the use of that resource while seeking to optimise the sustainable use of the total resource envelope.
76. Transparency – there must be a ‘single version of the truth’ with regard to cost and activity data so that the totality of the resource (financial and assets) is used to best effect.
77. Flexibility – makes better use of all resources (financial and human) in a flexible way, supporting staff to work across organisational boundaries focussing on the best care and support to meet the needs of the individual.
78. Collaboration –partnerships should take a collaborative approach, working together with neighbouring partnerships to develop area plans where this delivers better outcomes.
79. Involvement – Partnerships should take a co-production, co-operative, participatory strength-based approach, ensuring human rights are central to the design and delivery of new ways of working – delivering support and services based on an equal and reciprocal person-centred relationship between providers, users, families and communities.
80. Visionary – focused on providing better outcomes for people to live their lives as independently as possible, incorporates clinical expertise to support people in the community.
81. Human rights - partnerships should adopt a human rights-based approach. Taking a human rights-based approach empowers people to know and claim their rights. It increases the ability of organisations, public bodies and businesses to fulfil their human rights obligations. It also creates solid accountability so people can seek remedies when their rights are violated. The PANEL principles are one way of breaking down what a human rights-based approach means in practice. PANEL

stands for Participation, Accountability, Non-Discrimination and Equality, Empowerment and Legality.

Appendix 3: Qualitative Data from the Care Inspectorate 2024.

Table 16 features the Health and Social Care Standards (HSCS) that were identified as falling below acceptable threshold at 117 adult services in 2023/24. The table features thematic areas identified in the reports as well as the standard breached. Providing the thematic code helps illustrate how some standards are used in diverse ways to challenge service providers to improve, for example HSCS 1.15 and 3.14. Further themes including participation, medication, activities and choice that are linked to several HSCS. Further analysis could link to earlier years but as it is unclear whether someone with a learning disability and/or autism are actually resident in each service, analysis could lead to more information but no new understanding.

Where an issue was identified, adult services were typically given a date by which to rectify the issue. Most services had multiple breaches recorded sometimes related (for example often several HSCS were cited that related to daily activities or to better auditing instruments), and sometimes unrelated (for example HSCS relating to diverse issues for example a single service having inadequate safeguards around medication and requiring improved maintenance of buildings and gardens).

Table 16: Health and Social Care Standards (HSCS) Identified as Falling Below Acceptable Threshold in 2023/24.

Thematic area covered	Health & Social Care Standards Required	Number of institutions where issues identified
Outcome focused care plans	My personal plan (sometimes referred to as a care plan) is right for me because it sets out how my needs will be met, as well as my wishes and choices." (HSCS 1.1)	2
Wellbeing	I am fully involved in assessing my emotional, psychological, social and physical needs at an	2

	early stage, regularly and when my needs change (HSCS 1.12)	
Up to date care plans	'My future care and support needs are anticipated as part of my assessment' (HSCS 1.14)	4
Hydration	My personal plan (sometimes referred to as a care plan) is right for me because it sets out how my needs will be met, as well as my wishes and choices (HSCS 1.15)	1
Privacy	My personal plan (sometimes referred to as a care plan) is right for me because it sets out how my needs will be met, as well as my wishes and choices (HSCS 1.15)	1
Anticipatory/end of life planning	My personal plan (sometimes referred to as a care plan) is right for me because it sets out how my needs will be met, as well as my wishes and choices (HSCS 1.15)	2
Up to date care plans	My personal plan (sometimes referred to as a care plan) is right for me because it sets out how my needs will be met, as well as my wishes and choices (HSCS 1.15)	20
Risk assessments complete	My personal plan (sometimes referred to as a care plan) is right for me because it sets out how my needs will be met, as well as my wishes and choices (HSCS 1.15)	3
Goals and aspirations recorded	My personal plan (sometimes referred to as a care plan) is right for me because it sets out how my needs will be met, as well as my wishes and choices (HSCS 1.15)	1
Daily activities	My personal plan (sometimes referred to as a care plan) is right for me because it sets out how	2

	my needs will be met, as well as my wishes and choices (HSCS 1.15)	
Accident	My care and support meets my needs and is right for me (HSCS 1.19)	2
Hydration/nutrition	My care and support meets my needs and is right for me (HSCS 1.19)	3
Communication	My care and support meets my needs and is right for me (HSCS 1.19)	1
Up to date care plans	My care and support meets my needs and is right for me (HSCS 1.19)	6
Up to date medication records	My care and support meets my needs and is right for me (HSCS 1.19)	5
Adequate staffing	My care and support meets my needs and is right for me (HSCS 1.19)	1
Individual choice	My needs, as agreed in my personal plan, are fully met, and my wishes and choices are respected". (HSCS 1.23)	1
Daily activities	My needs, as agreed in my personal plan, are fully met, and my wishes and choices are respected". (HSCS 1.23)	1
Personal and oral care	My needs, as agreed in my personal plan, are fully met, and my wishes and choices are respected". (HSCS 1.23)	2
Staff training	'Any treatment or intervention that I experience is safe and effective' (HSCS 1.24)	7

Medication is correctly administered	'Any treatment or intervention that I experience is safe and effective' (HSCS 1.24)	4
Cleanliness	'Any treatment or intervention that I experience is safe and effective' (HSCS 1.24)	1
Daily Activities	I can choose to have an active life and participate in a range of recreational, social, creative, physical, and learning activities every day, both indoors and outdoors' (HSCS 1.25)	17
well-being	I can choose to have an active life and participate in a range of recreational, social, creative, physical, and learning activities every day, both indoors and outdoors' (HSCS 1.25)	3
Staff training	I can choose to have an active life and participate in a range of recreational, social, creative, physical, and learning activities every day, both indoors and outdoors' (HSCS 1.25)	2
Incorporate person’s perspective	I can choose to have an active life and participate in a range of recreational, social, creative, physical, and learning activities every day, both indoors and outdoors' (HSCS 1.25)	5
Daily activities	I can choose to spend time alone (HSCS 1.26)	1
Well-being	If my independence, control and choice are restricted, this complies with relevant legislation and any restrictions are justified, kept to a minimum and carried out sensitively (HSCS 1.3)	2
Meals	I can choose suitably presented & healthy meals and snacks including fresh fruit and vegetables, and participate in menu planning (HSCS 1.33)	5

Meals	I can enjoy unhurried snack and mealtimes in a relaxed and atmosphere as possible.' (HSCS 1.35)	4
Meals	My meals and snacks meet my cultural and dietary needs, beliefs and preferences". (HSCS 1.37)	3
Available snacks	I can drink fresh water at all times (HSCS 1.39)	1
Care plans should be anticipatory	‘My future care and support needs are anticipated as part of my assessment’ (HSCS 1.4).	3
Daily activities	I get the most out of life because the people and organisation who support and care for me have an enabling attitude and believe in my potential (HSCS 1.6)	4
Anticipatory care plans	"I am supported to discuss significant changes in my life, including death or dying, and this is handled sensitively" (HSCS 1.7)	3
Agency	'I am recognised as an expert in my own experiences, needs and wishes' (HSCS 1.9).	2
Care plans include life history	'I am recognised as an expert in my own experiences, needs and wishes' (HSCS 1.9).	1
Communication tools	I can access translation services and communication tools where necessary and I am supported to use these." (HSCS 2.10)	1
Family involvement, 6-month reviews	‘My views will always be sought, and my choices respected, including when I have reduced capacity to fully make my own decisions.’ (HSCS 2.11)	1

Accessible care plans	'I am fully informed about what information is shared with others about me' (HSCS 2.14).	1
Up to date care plans	I am fully involved in developing and reviewing my personal plan, which is always available to me' (HSCS 2.17)	4
Relationships	I am supported to manage my relationships with my family, friends or partner in a way that suits my wellbeing.' (HSCS 2.18)	2
Independence	'I take part in daily routines, such as setting up activities and mealtimes, if this is what I want' (HSCS 2.21)	1
Daily activities	'I can maintain and develop my interests, activities, and what matters to me in the way that I like' (HSCS 2.22).	4
Mealtimes	'I can maintain and develop my interests, activities, and what matters to me in the way that I like' (HSCS 2.22).	1
Privacy	If I need help with medication, I am able to have as much control as possible' (HSCS 2.23)	1
Advocacy	' I am supported to understand and uphold my rights' (HSCS 2.3)	1
Advocacy	I am supported to use independent advocacy if I want or need this' (HSCS 2.4).	1
Menus/activities use accessible format	'I receive and understand information and advice in a format or language that is right for me' (HSCS 2.9).	4

Outcome oriented	My personal plan (sometimes referred to as a care plan) is right for me because it sets out how my needs will be met, as well as my wishes and choices' (HSCS 3.07).	1
Communication	'I can understand the people who support and care for me when they communicate with me' (HSCS 3.12)	1
Staff training Including for staff who do not have English as a first language (1), supervision (13) and using reflective and best practice (3)	'I have confidence in people because they are trained, competent and skilled, are able to reflect on their practice and follow their professional and organisational codes' (HSCS 3.14)	36
Medication correctly administered	'I have confidence in people because they are trained, competent and skilled, are able to reflect on their practice and follow their professional and organisational codes' (HSCS 3.14)	3
Hydration/nutrition	'I have confidence in people because they are trained, competent and skilled, are able to reflect on their practice and follow their professional and organisational codes' (HSCS 3.14)	2
Audit of changes	'I have confidence in people because they are trained, competent and skilled, are able to reflect on their practice and follow their professional and organisational codes' (HSCS 3.14)	3
Adequate staffing levels (including recruitment)	'My needs are met by the right number of people' (HSCS 3.15)	10

Adequate staffing levels	People have time to support and care for me and to speak with me (HSCS 3.16)	3
Adequate staffing levels	'I am confident that people respond promptly, including when I ask for help.' (HSCS 3.17)	2
Hydration/nutrition	'I am supported and cared for sensitively by people who anticipate issues and are aware of and plan for any known vulnerability or frailty' (HSCS 3.18)	1
Anticipatory care plans	'I am supported and cared for sensitively by people who anticipate issues and are aware of and plan for any known vulnerability or frailty' (HSCS 3.18)	1
Staff training	My care and support is consistent and stable because people work well together (HSCS3.19)	3
Reporting incidents	'I am protected from harm, neglect, abuse, bullying and exploitation by people who have a clear understanding of their responsibilities' (HSCS 3.20)	2
Up to date care plans	‘I am protected from harm because people are alert and respond to signs of significant deterioration in my health and wellbeing, that I may be unhappy or may be at risk of harm’ (HSCS 3.21)	1
Staff training	‘I am protected from harm because people are alert and respond to signs of significant deterioration in my health and wellbeing, that I may be unhappy or may be at risk of harm’ (HSCS 3.21)	1
Incidents reported	‘If I might harm myself or others, I know that people have a duty to protect me and others,	1

	which may involve contacting external agencies' (HSCS 3.24).	
Respect for belongings	I have agreed clear expectations with people about how we behave towards each other, and these are respected.' (HSCS 3.3)	1
Audits	I benefit from a culture of continuous improvement with the organisation having robust and transparent quality assurance processes (HSCS 4.1)	2
Communication	'I experience high quality care and support based on relevant evidence, guidance and best practice'. (HSCS 4.11)	3
Staff training	'I experience high quality care and support based on relevant evidence, guidance and best practice'. (HSCS 4.11)	4
Improvement plans	'I experience high quality care and support based on relevant evidence, guidance and best practice'. (HSCS 4.11)	2
Appropriate use of medication	'I experience high quality care and support based on relevant evidence, guidance and best practice'. (HSCS 4.11)	10
Risk assessments	'I experience high quality care and support based on relevant evidence, guidance and best practice'. (HSCS 4.11)	1
Privacy and choice with regard to shared rooms	'I experience high quality care and support based on relevant evidence, guidance and best practice'. (HSCS 4.11)	2

Adequate staffing	My care and support is provided in a planned and safe way, including if there is an emergency or unexpected event'. (HSCS 4.14)	1
Staff training/staff updates	My care and support is provided in a planned and safe way, including if there is an emergency or unexpected event'. (HSCS 4.14)	2
Accurate record keeping	My care and support is provided in a planned and safe way, including if there is an emergency or unexpected event'. (HSCS 4.14)	2
Notifiable events reported	‘I benefit from a culture of continuous improvement, with the organisation having robust and transparent quality assurance processes’ (HSCS 4.18).	1
Improvement plan	‘I benefit from a culture of continuous improvement, with the organisation having robust and transparent quality assurance processes’ (HSCS 4.18).	2
Audit of changes	I benefit from a culture of continuous improvement, with the organisation having robust and transparent quality assurance processes'. (HSCS 4.19)	19
Observe staff practices	I benefit from a culture of continuous improvement, with the organisation having robust and transparent quality assurance processes.' (HSCS 4.19)	4
Quality assurance	I benefit from a culture of continuous improvement, with the organisation having robust and transparent quality assurance processes.' (HSCS 4.19)	1

Complaints	If I have a concern or complaint, this will be discussed with me and acted on without negative consequences for me' (HSCS 4.21).	2
Accidents reported	'I use a service and organisation that are well led and managed' (HSCS 4.23).	4
Recruitment	'I am confident that people who support and care for me have been appropriately and safely recruited' (HSCS 4.24).	4
Staff training	I am confident that people are encouraged to be innovative in the way they support and care for me (HSCS 4.25)	1
Access to socio-historic data in care plans	‘I experience high quality care because people have the necessary information and resources’ (HSCS 4.27)	2
Up to date care plans	‘I experience high quality care because people have the necessary information and resources’ (HSCS 4.27)	7
Care plans use respectful language	I experience care and support where all people are respected and valued (HSCS 4.3)	2
Participation in service improvement plan	'I can be meaningfully involved in how the organisations that support and care for me work and develop' (HSCS 4.6).	2
Participation	I am actively encouraged to be involved in improving the service I use, in a spirit of genuine partnership' (HSCS 4.7)	13
Participation	‘I am supported to give regular feedback on how I experience my care and support and the	5

	organisation uses learning from this to improve.' (HSCS 4.8)	
Environment improvement plan	'I experience a high quality environment if the organisation provides the premises' (HSCS 5)	1
refurbishment	I can use an appropriate mix of private and communal areas, including accessible outdoor space, because the premises have been designed or adapted for high quality care and support". (HSCS 5.1)	1
Access to technology	'If I experience 24 hour care, I am connected, including access to a telephone, radio, TV and the internet.' (HSCS 5.10)	1
Maintenance	I can independently access the parts of the premises I use as the environment has been designed to promote this". (HSCS 5.11)	8
Maintenance	The premises have been adapted, equipped and furnished to meet my needs and wishes." (HSCS 5.16)	4
Environment (including dementia-friendly design (3))	'My environment is relaxed, welcoming and free from avoidable intrusive noise and smells.' (HSCS 5.18)	8
Access to technology	'My environment is relaxed, welcoming and free from avoidable intrusive noise and smells.' (HSCS 5.18)	1
Private bathrooms	'My environment is relaxed, welcoming and free from avoidable intrusive noise and smells.' (HSCS 5.18)	1

Maintenance	I experience an environment that is well looked after with clean, tidy and well maintained premises, furnishings and equipment' (HSCS 5.22)	7
Décor enhances wellbeing	'I am able to access a range of good quality equipment and furnishings to meet my needs, wishes and choices' (HSCS 5.23)	1
Cleanliness	'I experience an environment that is well looked after with clean, tidy and well maintained premises, furnishings and equipment.' (HSCS 5.24)	10