

VIEWS FROM PRACTICE

‘A Mistake’: A Practitioner view of the revised Continuing Healthcare (CHC) policy in Wales for the learning-disabled population.

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Introduction

The revised NHS Continuing Healthcare (CHC) Framework for adults in Wales² came into force in November 2021. The Framework should have been ‘*proper and appropriate consultation*’³ including a three-month consultation process with the Welsh Government’s the *Consultation Guidance for staff*⁴ stipulating (among other things) that: (1) *Consultation and engagement are essential to effective policy making and delivery: there should be no unpleasant surprises for our stakeholders when final proposals are published* and (2) *public bodies engage early, regularly, and imaginatively: consult widely and openly*. Neither are evident in the process that led to the 2010 Framework’s publication. Adequate consultation did not happen – a failure that will be deleterious to the learning-disabled population and in consequence, the disadvantages the experience already acknowledged by Welsh Government will be perpetuated.

The 2021 Mistake Consultation

The ‘*Draft Continuing NHS Healthcare: The National Framework for Implementation in Wales*’ (Draft for Consultation 29 May to 21 August 2021⁵) was shared widely through a network of local authority social work practitioners. However, practitioners and others who attempted to feedback on the draft were advised that the use of the word ‘consultation’ was a *mistake*. The refusal to accept feedback was emphatic; the consultation was closed as one *had happened* two years previously,⁶ in 2019. I suggest in this brief paper that it is a mistake not re-launch the consultation to ensure that all stakeholders involved in this practice area day to day were able to fully contribute following Covid-19 impact and lack of progress made to date.

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² [National framework for NHS Continuing Healthcare | GOV.WALES](#) Accessed 11/9/2021

³ The Welsh Ministers are under a duty to make a Regulatory Impact Assessment Code (Section 76 of GOWA 2006).

⁴ [dp-1431-11-16-english.pdf \(senedd.wales\)](#) accessed 12/9/2021.

⁵ <https://gov.wales/sites/default/files/consultations/2021-03/draft-consultation-document.pdf> (accessed 7/7/21).

⁶ <https://gov.wales/draft-national-framework-continuing-nhs-healthcare> (accessed 7/4/2019).

A History of Disadvantage

The detriments to the learning-disabled population's access to CHC and not having needs appropriately assessed have been previously highlighted; by Welsh Government⁷, Wales Audit Office⁸ as well as the social and health care regulators within Wales (HIW/CIW⁹). Disadvantage in accessing CHC was highlighted as far back as 2013 by Wales' Audit Office (WAO)¹⁰. WAO concluded that the CHC arrangements for learning-disabled people were inadequate, and '*specific guidance on how the framework should be applied to people with a learning disability is missing*'. In response to the criticisms, the following actions were triggered:

- 1) A Public Accounts Scrutiny Committee was established by Welsh Government. It further evidenced concerns, in particular, the potential detriment to the many 'joint' funded individuals; and concluded: '*closer examination is required of jointly funded cases for individuals with a learning disability. We are currently working with the Local Health Boards to undertake that exercise*'.¹¹
- 2) The Director General and Chief Executive for the NHS in Wales directed all Health Boards to review those who may have been treated less favourably¹² through the CHC process.
- 3) Welsh Ministers issued the current guidance in June 2014¹³ as a response to the criticisms evidenced, this included reference to learning disability.

The Joint Inspection¹⁴ of learning disability services in 2016 noted significant on-going difficulties with interpretations and practice of the 2014 CHC Policy; despite all of the above recommendations and actions. A recommendation from Inspectors to Welsh Government was; *Policy makers should consider the Continuing Health Care process and its application for people with learning disabilities, to determine if any improvements to the process can be made (Page 13)*. The Welsh Government has not addressed the above recommendation, but it did commission the Welsh Institute for Health and Social Care to undertake a 'Scoping

⁷ National Assembly for Wales Public Accounts Committee 'Implementation of the National Framework for Continuing NHS Healthcare: Follow-up Report March 2015' <http://www.assembly.wales/laid%20documents/cr-ld10163%20-%20report%20of%20the%20public%20accounts%20committee%20%20-%20%20implementation%20of%20the%20national%20framework%20for%20continuing%20nhs%20health/cr-ld10163-e.pdf>.

⁸ Implementation of the National Framework for Continuing NHS Healthcare, Auditor General for Wales, 13 June 2013 (page 10).

⁹ <https://careinspectorate.wales/sites/default/files/2018-03/160628overviewen.pdf>

¹⁰ Implementation of the National Framework for Continuing NHS Healthcare, Auditor General for Wales, 13 June 2013 (page 10).
https://www.audit.wales/sites/default/files/Implementation_of_the_National_framework_for_Continuing_NHS_Healthcare_English_2013_14.pdf.

¹¹ National Assembly for Wales Public Accounts Committee 'Implementation of the National Framework for Continuing NHS Healthcare: Follow-up Report March 2015' <http://www.assembly.wales/laid%20documents/cr-ld10163%20-%20report%20of%20the%20public%20accounts%20committee%20%20-%20%20implementation%20of%20the%20national%20framework%20for%20continuing%20nhs%20health/cr-ld10163-e.pdf> (accessed 25/1/16).

¹² Welsh Government's Director General and Chief Executive for the NHS in Wales Dr Andrew Goodall Letter (9th February 2015) Consistent and Fair Implementation of the Framework for Continuing NHS Healthcare in Wales.

¹³ Continuing NHS Healthcare The National Framework for Implementation in Wales June 2014
<https://gov.wales/sites/default/files/publications/2019-04/continuing-nhs-healthcare-the-national-framework-for-implementation-in-wales.pdf> (accessed 30/12/16)

¹⁴ <https://careinspectorate.wales/sites/default/files/2018-03/160628overviewen.pdf> (accessed 12/9/2021).

Review' of the CHC Policy and this was published in 2017¹⁵ but its recommendations have been ignored.

On-going Disadvantage

In 2018, both the Wales Audit Office and the Welsh government published policy papers that failed to address the disadvantages that each had separately been instrumental in highlighting. Welsh Government contributed to further confusion through The *Improving Lives Programme*¹⁶ of 2018. This is a specific learning disability policy which failed to offer any clarity for improving this area, furthermore, it suggests that the Welsh Government's own CHC policy is *impeding service development: Welsh Government funding rules on Continuing Health Care, for instance, mean that if an individual is eligible for it (CHC), a joint package of care cannot be provided.*¹⁷

This interpretation of eligibility for CHC suggests it is a distinct disadvantage, yet the reality of not having complex health needs appropriately assessed, reviewed and co-ordinated is potentially the greatest detriment. This is contrary to the objective of appropriate assessments and the principles in the 2014 CHC Framework that aimed to improve the situation for the learning-disabled population. In 2013, Wales Audit Office triggered the review that led to the 2014 CHC Framework. The Wales Audit Office review of commissioning arrangements for people with learning disabilities¹⁸ has highlighted the LHB's commissioning responsibilities. However, this appears to have been limited to the 'strategic intent' of joined up commissioning. Any reference to the role of CHC needs to play in joint commissioning is missing, obfuscated or merely not understood.

As demonstrated in a 2015 Serious Case Review, the risks of health inequalities and preventable conditions are very real.¹⁹ Focussed attention on the growing disparities in accessing *healthcare* per se, highlighted by both the Learning Disabilities Mortality Review Programme (LeDeR)²⁰ and Covid-19²¹ is yet to explore the impact of misapplying the CHC Policy on preventable deaths. Can it really be possible that Clements' (2020)²² conclusion; *'Neither the Department of Health and Social Care / NHS England nor the Welsh Government / NHS in Wales have the slightest interest in this issue'*, is the uncomfortable reality? The

¹⁵ WISCH Scoping Study on CHC – Report for Welsh Government · December 2016 published 5th April 2017 <http://wihsc.southwales.ac.uk/news/en/2017/apr/05/scoping-study-continuing-healthcare-published/> (accessed 16/4/17).

¹⁶ Learning Disability Improving Lives Programme (June 2018) <https://gov.wales/newsroom/health-and-social-services/2018/learning-disability/?lang=en> (accessed 29/6/18).

¹⁷ Learning Disability Improving Lives Programme (June 2018) page 4 <https://gov.wales/newsroom/health-and-social-services/2018/learning-disability/?lang=en> (accessed 29/6/18).

¹⁸ Wales Audit Office 2018 Strategic Commissioning of Accommodation Services for Adults with Learning Disabilities <http://www.audit.wales/strategic-commissioning-learning-disabilities> - authorities will need to increase investment by £365 million in accommodation in the next twenty years to address both a growth in the number of people with learning disabilities who will need housing, and the increase in the number with moderate or severe needs. P.8 and Population projections show that the number of people with a learning disability will increase in the future, and those aged over 65 and those with a moderate or severe learning disability will rise significantly P.10 (accessed 1/9/18).

¹⁹ <https://suffolksp.org.uk/assets/SCR-Case-James-091015.pdf> The first recommendation included: *reviews should always consider whether an assessment for continuing health care is required.*

²⁰ Learning Disabilities Mortality Review (LeDeR) Programme 4 May 2018, University of Bristol Norah Fry Centre for Disability Studies NHS England.

²¹ <https://phw.nhs.wales/news/new-report-confirms-people-with-learning-disabilities-at-increased-risk-of-death-from-coronavirus/> accessed 11/9/2021.

²¹ <https://www.theguardian.com/society/2020/nov/19/covid-19-deaths-must-prompt-better-healthcare-learning-disabilities> (accessed 19/11/20).

²² <http://www.lukeclements.co.uk/nhs-continuing-healthcare-young-people-r-jp-v-nhs-croydon-2020/>.

Welsh Government was advised of the gaps in CHC Policy for this population as far back as 2013 by the WAO. Practitioners observe that there has been no perceptible change in eligibility, but continued detriments to this population.

Practice Discussion

Health and social care resources have diminished in the decade prior to COVID-19; austerity was aimed to *shrink and dismantle*²³ the state, the impact on disabled people has been well documented by the profession²⁴. As a Social Worker, observing the diminishing resources it is practice knowledge that informs my views and opinions in this area. There has been no interest nor attempt to understand the challenge for practitioners negotiating the demands of the process. I suggest the struggle for CHC entitlement for the learning-disabled population, as the *problem(s) of greatest human concern*²⁵. As noted, significant recommendations have been ignored during the previous policy's implementation, despite many recommendations for improvement. Consideration of complex health needs, the legal obligations and consequential CHC eligibility should be seen as fundamental to prevention of inequality and the promotion of health equalities for this population across the life-course. Practitioners interested in CHC have long articulated how continuing healthcare seems to fail and negatively impacts the lives of the learning-disabled population. Throughout their lifespan the learning-disabled population is more likely to need support and intervention from both health and social care; therefore. The limited progress in achieving social and health equalities across both areas appears to have contributed to the 'parallels of inequity'²⁶ exposed as a result of the COVID-19 pandemic.

Any correlation between the *impact* of the legal limits of local authority legislation and legal duties of the NHS has been long missing in policies, as discussed above. The layers of bureaucracy are ever-present and practitioners from both health and social care are observably frustrated by the CHC processes and policy obfuscation.

*People with learning disabilities are much more likely to die from coronavirus. And black and Asian people with learning disabilities are even more likely to die from coronavirus. This isn't because the virus targets people with learning disabilities. It is because society fails to do enough to support the health and wellbeing of those at the sharp end of structural and health inequalities.*²⁷

²³ D. Whitfield (2012), In Place of Austerity: Reconstructing the economy, state and public services.

²⁴ See Ann James in <http://www.lukeclements.co.uk/the-impact-of-the-pandemic-on-disabled-people-so-much-more-than-covid-19/>.

²⁵ Schon, D.A. "Knowing-in-action: The new scholarship requires a new epistemology," 1995, Change, November/December, 27-34 and <https://www.ricktorseth.com/donald-schon-the-swamp/> (accessed 20/9/21) "There is a high, hard ground overlooking a swamp. On the high ground, manageable problems lend themselves to solution through the use of research based theory and technique. In the swampy lowlands, problems are messy and confusing and incapable of technical solution. The irony of this situation is that the problems of the high ground tend to be relatively unimportant to individuals or society at large, however great their technical interest maybe, while in the swamp lay the problems of greatest human concern. The "leader" is confronted with a choice. Shall she remain on the high ground where she can solve relatively unimportant problems according to her standards of rigor, or shall she descend to the swamp of important problems where she cannot be rigorous in any way she knows how to describe."

²⁶ C P Jones (2014) Systems of Power, Axes of Inequity: Parallels, Intersections, Braiding the Strands https://www.researchgate.net/publication/265648266_Systems_of_Power_Axes_of_Inequity_Parallels_Intersections_Braiding_the_Strands (accessed 13/12/2020).

²⁷ <https://www.theguardian.com/society/2020/nov/19/covid-19-deaths-must-prompt-better-healthcare-learning-disabilities> (accessed 19/11/20).

Health Inequalities

The COVID-19 pandemic highlighted society's injustices, the detriment to the learning disabled population suggests the mortality rate is six times that of the wider population²⁸ in the UK. Injustices in healthcare for this population must also be seen by the continued failures in the consideration of CHC eligibility, the lack of progress in recommendations and the continued detriment observed by social workers in this area. As the COVID-19 pandemic continues, Welsh Government's own Programme for Government June 2021²⁹ is to 'tackle health inequalities'.

The coronavirus pandemic has shown our health service at its best, but it has also created extraordinary pressures on staff and services. We want to create a 21st century NHS by investing in the post-Covid recovery, tackling health inequalities³⁰

Conclusions

Continuing NHS Healthcare obligations for the learning-disabled population needs to be considered from an equality and human rights perspective. The 2021 Policy is likely perpetuate the preventable and often predictable healthcare omissions. As noted above, it is contradictory to the programme for Welsh Government. Past detriments to Learning-disabled citizens and their struggle to access their rights to robust assessments, reasonable adjustments and funding persist. Any focussed attention has been absent from this area and is long overdue.

The inequity experienced by learning disabled people in the pandemic mirrors the inequity that is manifest in previous policy and practice with this area for this population. The 2021 CHC Framework³¹ fails to mention *health inequalities*, let alone how it will respond the long established concerns on how the policy is implemented for this population. Continued failure through a policy that ought to be mitigating the adverse impact of health inequalities and discrimination looks like a national cognitive dissonance³², by Policy and decision makers in Wales Post COVID-19.

Welsh Government has missed an opportunity and seems to be perpetuating health inequalities for this population. I conclude by advocating that consideration of complex health needs and consequential CHC eligibility needs now to be fundamental to prevention of inequality, addressing the 'history of disadvantage', and the promotion of health equity for this population across the life-course.

'Achieving health equity requires valuing all individuals and populations equally, recognising and rectifying historical injustices, and providing resources according to need'³³

²⁸ <https://www.gov.uk/government/news/people-with-learning-disabilities-had-higher-death-rate-from-covid-19> (accessed 12/11/20).

²⁹ <https://gov.wales/sites/default/files/publications/2021-06/programme-for-government-2021-to-2026.pdf> (accessed 25/6/2021).

³⁰ <https://gov.wales/sites/default/files/publications/2021-06/programme-for-government-2021-to-2026.pdf> (accessed 12/10/2021).

³¹ <https://gov.wales/national-framework-nhs-continuing-healthcare> Accessed 11/9/2021.

³² C Travis and E Aronson (2016) in Mistakes Were Made (but not by me) Why we justify foolish beliefs, bad decisions and hurtful acts.

³³ C P Jones (2014) Systems of Power, Axes of Inequity: Parallels, Intersections, Braiding the Strands https://www.researchgate.net/publication/265648266_Systems_of_Power_Axes_of_Inequity_Parallels_Intersections_Braiding_the_Strands (accessed 13/12/2020).