

A uniform approach: competency framework and toolkit for Learning Disability Acute Liaison Nurses

Literature review

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Introduction

Changing Our Lives is a rights based organisation. We work alongside disabled people to make an ordinary life achievable for all. Since the beginning of the organisation we have worked alongside people with learning disabilities and their families to tackle health inequalities. Our work rests on the social model of disability, and we know that access to good quality healthcare not only reduces the risk of premature death and improves health outcomes, but also improves people's quality of life.

In our work to reduce health inequalities, we have long championed the role of the learning disability nurse as one of a range of measures to dismantle the barriers to good healthcare that people with learning disabilities face. Through our Quality of Health reviews in acute hospitals we have lobbied for acute liaison nurse posts to be put in place, and through our books we have highlighted best practice in learning disability nursing¹ and the impact that learning disability nurses have from the perspective of the people they work with².

Changing Our Lives have been commissioned by NHS England to develop a competency framework for learning disability acute liaison nurses. Throughout this literature review we will refer to these nurses as ALNs. Learning disability nurses themselves have written about the ALN role³. However, in Changing Our Lives, we know that some people with learning disabilities face greater barriers to accessing good healthcare than others.⁴ We also know that some people with learning disabilities are more likely to experience poor health or die prematurely than other people with learning disabilities.

We decided at an early stage that our work would focus first on 4 priority groups of people who were either least likely to have had support from an ALN, most likely to experience poor health outcomes in hospital or least likely to be included in work like this about access to healthcare. Our priority groups are:

¹ Changing Our Lives (2020a) Best practice and challenges in learning disability nursing 2020: Putting the learning disability improvement standards for NHS Trusts into practice. https://changingourlives.org/wp-content/uploads/2022/09/ nhsibestpracticeandchallengesinldnursing2020-.pdf

² Changing Our Lives (2020b) Resetting the Narrative: What learning disability nursing means to me - Stories from people with a learning disability, autistic people and their family members https://changingourlives.org/wp-content/uploads/2022/09/resettingthenarrative2020_1.pdf

³ Health Education England *Project report: understanding the who, where and what of learning disability liaison nurses* https://learningdisabilitynurse.co.uk/real-nurses/gwen-moulster-obe-review-of-liaison-nursing

⁴ Changing Our Lives (2023) *Small Margins: Working with people with a learning disability and autistic people from minority ethnic communities* https://changingourlives.org/wp-content/uploads/2023/03/Small-Margins.pdf

- People with the label of profound and multiple learning disabilities
- People from minority ethnic communities
- People whose care is labelled as 'complex' or 'challenging' by professionals
- People who have lower support needs and are likely to attend hospital without a paid or family carer.

This literature review was carried out in 2023 near the beginning of the *Uniform Approach* project. As this is not a research project, and Changing Our Lives is not an academic organisation, it is not intended to be a full academic literature review. However, we intended to learn from the findings of researchers who have studied hospital care for people with learning disabilities in England, to find out what is already known about the barriers people face, and to guide our thinking about what is important to include in our work towards developing the competency framework.

We searched for academic studies about people with learning disabilities in acute hospitals. We only included studies that were based fully or partly in England. We included national reports about health inequalities such as the latest annual *LeDeR* report. We also read some grey literature relevant to this work, such as reports written by nurses themselves. While setting up our advisory group for this project, and having initial conversations with professional stakeholders, we asked them to send us any literature they felt would be useful to include.

In this literature review we refer to 'health inequalities' and 'health outcomes'.

Health inequalities are when some groups of people don't get the same chance at having good health that other groups of people get.

Health outcomes are things that we can measure to tell us about what happens to someone's health as a result of something they do, or something that happens to them.

We aimed to answer the following questions:

- 1. What health inequalities do people with learning disabilities face in acute hospitals?
- 2. What affects health outcomes for people with learning disabilities in hospitals?
- 3. Do some people with learning disabilities face different health inequalities to each other?
- 4. Do acute liaison nurses change the health outcomes that people with learning disabilities have?

Findings

What health inequalities do people with learning disabilities face in acute hospitals?

10 years ago, the Confidential Inquiry into the Deaths of People with Learning Disabilities (CIPOLD)⁵ found that people with learning disabilities in the South West of England died significantly earlier than non-disabled people and called for a national review of deaths. Since then Learning from Lives and Deaths - people with a learning disability and autistic people (LeDeR)⁶ has consistently found that people with learning disabilities die earlier and face poorer health outcomes than non disabled people. The most recent LeDeR report found that people with learning disabilities are more likely to die in hospital than non-disabled people. People with learning disabilities are also more likely to go to hospital for health conditions that can and should be treated at home or in the community, such as asthma or diabetes, meaning that some people with learning disabilities are admitted to hospital unnecessarily.

Louch et al (2021)⁸ did a scoping review of patient safety outcomes for people with learning disabilities in acute hospitals. They found that people with learning disabilities experience poorer patient safety outcomes in hospital, but also found that since the earliest national reports, such as *Healthcare for All* in 2008, there has been very little change in the health inequalities that people with learning disabilities face.

Many of the reports we read said that people with learning disabilities' basic care and safety needs were not being met in hospitals. For example, people were receiving inadequate support with eating, using the toilet and accessing medication, and were getting an inferior quality of diagnosis and treatment for their health conditions.⁹

For Ramsey et al (2022) this lack of basic care showed the extent to which people with learning disabilities were valued or respected:

⁵ Heslop et al (2013) The Confidential Inquiry into the deaths of people with learning disabilities (CIPOLD) https://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf

⁶ White et al (2022) Learning from Lives and Deaths - People with a learning disability and autistic people (LeDeR) report for 2021. https://www.kcl.ac.uk/research/leder

⁷ NIHR (2020) Themed review: Better health and care for all. Health and care services for people with learning disabilities https://evidence.nihr.ac.uk/themedreview/better-health-and-care-for-all/

⁸ Louch et al (2021) Exploring patient safety outcomes for people with learning disabilities in acute hospital settings: a scoping review https://bmjopen.bmj.com/content/11/5/e047102.long

⁹ Bradbury-Jones et al (2012) Promoting the health, safety and welfare of adults with learning disabilities in acute care settings: a structured literature review https://onlinelibrary.wiley.com/doi/10.1111/jocn.12109 AND Tuffrey-Wijne et al (2013) Identifying the factors affecting the implementation of strategies to promote a safer environment for patients with learning disabilities in NHS hospitals: a mixed-methods study https://pubmed.ncbi.nlm.nih.gov/25642531/

'Some organisations arguably seemed to come to accept standards of care that would be otherwise deemed unacceptable. This included the management of distress and relief, symptom interaction, physical and mental health concerns, and pain.'10

Williamson et al (2021) found that people with learning disabilities were more likely to be admitted to hospital with COVID-19 and to die from COVID-19 than non-disabled people.¹¹ Courtenay and Cooper (2021) commented on this study and said that the experiences of people with learning disabilities who were subject to blanket DNACPR orders in the pandemic, as well as the fact that people with learning disabilities were not prioritised for COVID-19 vaccination, demonstrate the stigma and prejudice that people with learning disabilities face.¹²

Baksh et al (2021) looked at people with and without learning disabilities who were admitted to hospital with COVID-19. They matched the two groups so that they were similar in age, sex, ethnicity and severity of illness. They found that people with learning disabilities had a 56% increased chance of dying from COVID-19 after being admitted to hospital compared to non-disabled people and that they were significantly less likely to be given treatments like respiratory support, intubation or going to intensive care.¹³

How should this inform the work of ALNs?

- ALNs need to think and act strategically to tackle health inequalities that have existed for many years. It is not enough for them to work on an individual basis to relieve the effects of those inequalities day-to-day.
- ALNs need to work collaboratively with primary and community care teams to
 ensure continuity of care for conditions that can be treated in the community and to
 be part of the work to avoid unnecessary admissions to hospital.
- ALNs should work to embed a good standard of basic care for people with learning disabilities in hospital settings. This cannot be done just by the ALN, but should be expected of all hospital staff.

¹⁰ Ramsey et al (2022) Systemic safety inequities for people with learning disabilities: a qualitative integrative analysis of the experiences of English health and social care for people with learning disabilities, their families and carers https://pubmed.ncbi.nlm.nih.gov/35090463/

¹¹ Williamson et al (2021) Risks of COVID-19 hospital admission and death for people with learning disability: population based cohort study using the OpenSAFELY platform https://www.bmj.com/content/374/bmj.n1592

¹² Courtenay and Cooper (2021) COVID-19: People with learning disabilities are highly vulnerable, they must be prioritised and protected https://pubmed.ncbi.nlm.nih.gov/34261641/

¹³ Baksh et al (2021) Understanding inequalities in COVID-19 outcomes following hospital admission for people with intellectual disability compared to the general population: a matched cohort study in the UK https://bmjopen.bmj.com/content/11/10/e052482

• The work of ALNs should be values-based and embedded in human rights. It should focus not just on the practical aspects of supporting people with learning disabilities, but should challenge stigmatising attitudes and discriminatory cultures.

What affects health outcomes for people with learning disabilities in hospitals?

Many of the studies we read spoke about how the attitudes of mainstream staff in hospital towards people with learning disabilities led to poorer quality care. Pellerboer-Gunnink et al's (2017) systematic review found many examples of doctors and nurses who held discriminatory beliefs about people with learning disabilities, seeing them as 'difficult', 'aggressive', 'uncooperative' or having equally damaging stereotypes about people with learning disabilities being 'childlike', 'funny' or 'bizarre'.¹⁴ As well as these fundamentally ableist attitudes towards people, many other studies and reviews we read found that mainstream staff in hospitals felt a lack of confidence in caring for people with learning disabilities, or stepped back from situations and treatments for fear of getting something wrong.¹⁵ Unfortunately, this uncertainty can be self-fulfilling, as studies also showed that professionals who had previous experience of working with people with learning disabilities were less likely to have stigmatising attitudes towards them.¹⁶

Studies that we read also showed a lack of knowledge among mainstream healthcare staff about the rights of people with learning disabilities and the laws that protect those rights. Understanding of the *Mental Capacity Act (2005)* or of reasonable adjustments, outlined in the *Equality Act (2010)* was low among staff at all levels of seniority within hospitals.¹⁷

This lack of knowledge and understanding mean that many of the interventions that have been put in place to improve the health of people with learning disabilities are not being done in a systematic way so that they benefit all people with learning disabilities all of the time. Flagging people with learning disabilities when they come into hospital was mentioned in many studies as a measure which either was not done or was done inconsistently. Hospital passports are designed and filled in differently in different places, and even good hospital passports are not always used or read by staff in

¹⁴ Pellerboer-Gunnink et al (2017) Mainstream health professionals' stigmatising attitudes towards people with intellectual disabilities: a systematic review https://pubmed.ncbi.nlm.nih.gov/ 28198094/

¹⁵ LeDeR (2022), Ramsey et al (2022), Bradbury-Jones et al (2012), NIHR (2020), Mimmo et al (2019) Partnerships for safe care: A meta-narrative of the experience for the parent of a child with Intellectual Disability in hospital https://onlinelibrary.wiley.com/doi/epdf/10.1111/hex.12968

¹⁶ Pellerboer-Gunnink et al (2017)

¹⁷ Tuffrey-Wijne et al (2013), CIPOLD (2013)

¹⁸ Tuffrey-Wijne et al (2013), CIPOLD (2013), Louch et al (2021), NIHR (2020)

hospitals.¹⁹ Ramsey et al (2022) found that people with learning disabilities and their families were concerned that hospital passports or communication books were temporary solutions that did little to address the systemic issues people with learning disabilities face.

Responses to health inequalities for people with learning disabilities often happen in a patchwork way, with different professionals and campaigners designing their own solutions to these deep-seated problems. We looked for evidence that showed if any interventions such as flagging or hospital passports improved health outcomes for people with learning disabilities but we did not find any.

One study found that people with learning disabilities who had their Annual Health Check were less likely to have an emergency admission to hospital than people who didn't have their Annual Health Check.²⁰ This suggests again that good healthcare in the community is important. The link between hospital care and primary care or community care was highlighted in a number of studies, showing that good links are helpful for improving health outcomes for people.²¹ Tuffrey-Wijne et al (2013) found that barriers between organisations, such as between GPs and hospitals had an impact on the quality and safety of care that people with learning disabilities got in hospital.²²

Communication between healthcare staff and people with learning disabilities was also important for the care people in hospitals got. Many studies highlighted the fact that mainstream staff were not skilled in communicating with patients with learning disabilities, which has an impact on a range of health outcomes such as how well pain is managed, how health conditions are diagnosed or how well patients understand their treatment.²³ The *Accessible Information Standard*²⁴ says that people are entitled to have information about their healthcare in a way that they understand, and mainstream staff should have the resources and training they need to be able to establish communication with patients.

Many studies found that family carers and paid care staff supported communication between patients and mainstream healthcare staff.²⁵ Carers were found to have a positive impact on people's health outcomes as they often have a wealth of knowledge about a

¹⁹ Louch et al (2021), Ramsey et al (2022)

²⁰ Cuccu et al (2020) Linked data analysis of learning disability health checks and emergency hospital admissions in the Kent Integrated Dataset https://onlinelibrary.wiley.com/doi/full/10.1111/jar.12799

²¹ LeDeR (2022), NIHR (2020)

²² Tuffrey-Wijne et al (2013)

²³ Louch et al (2021), Ramsey et al (2022), Bradbury-Jones et al (2022), Mimmo et al (2019)

²⁴ NHS England (2016) *Accessible Information Standard* https://www.england.nhs.uk/about/equality-frameworks-and-information-standards/accessibleinfo/

²⁵ Louch et al (2021), Ramsey et al (2022), Tuffrey-Wijne et al (2013)

person's communication and health needs. In many studies, carers were found to be helping with basic care like eating, hygiene and patient safety. People and families often felt that having a carer who knows the person well involved was really important for good care. However, Tuffrey-Wijne et al (2013)²⁶ found in their study of 6 NHS Hospitals in the South of England that carers were "used as an extra pair of hands but not appreciated for their insight". For Louch et al, the input of carers highlighted gaps in services that still posed a risk for people with learning disabilities who don't attend hospital with a regular carer.

"We found a range of evidence that suggested families and carers regularly 'prop' up services ... and that without this 'prop', the outcomes for patients with learning disabilities may well be poorer."²⁷

In Mimmo et al's (2019) meta-narrative of the experience of parents and children with learning disabilities in hospital, parents described being expected to provide essential care for their children, to the extent that they were ignored by healthcare professionals.²⁸

How should this inform the work of ALNs?

- ALNs cannot be seen as the only specialists with the skills to provide good healthcare to people with learning disabilities. This only worsens the stigma and lack of confidence that some mainstream healthcare staff have in treating people with learning disabilities.
- ALNs should be instrumental in designing and delivering robust training within their Trust about reasonable adjustments and the Mental Capacity Act and in auditing the outcomes of this training to ensure it is embedded in mainstream staff teams.
- Although the design and evaluation of interventions such as flagging and hospital passports are not only the responsibility of ALNs, they should be involved in research that finds evidence-based solutions to health inequalities, and they should be implementing evidence-based interventions in hospitals where they work.
- Learning Disability Awareness training by ALNs should include tips for establishing communication with patients with learning disabilities, and they should support different wards and departments in setting up plans for how they will meet the requirements set out in the Accessible Information Standard.
- ALNs should ensure that paid and family carers are aware of their services and should be skilled in facilitating the sharing of knowledge between paid and family carers and mainstream healthcare staff.

²⁶ Tuffrey-Wijne et al (2013)

²⁷ Louch et al (2021)

²⁸ Mimmo et al (2019)

Do some people with learning disabilities face different health inequalities to each other?

As mentioned above, many studies we read said that carers are important for improving health outcomes of people with learning disabilities, and people with learning disabilities who go to hospital without a regular family or paid carer are likely to face barriers to communication and to getting good levels of basic care with things like eating, hygiene, diagnosis and treatment. Without someone to advocate for them, many people with learning disabilities were shown to have difficulty navigating the hospital system or speaking up for their needs and wishes.²⁹

Across the population as a whole, people who live in the North East and North West of England have the highest rates of poor health or disability that limits their day to day life and are most likely to be unpaid carers.³⁰ We can see similar trends for people with learning disabilities, as LeDeR shows that people with learning disabilities in the North West of England were the most likely to die avoidable deaths, and over 50% of people with learning disabilities died in areas that are rated as the most deprived in England.

White British people were overrepresented in *CIPOLD* and are still overrepresented in *LeDeR* annual reports. This suggests that these reviews are missing data from people with learning disabilities from minority ethnic communities. This makes it harder for us to understand the health inequalities facing people with learning disabilities from minority ethnic communities. Despite these gaps, the latest LeDeR report showed that Black and Asian people with learning disabilities die younger than white people with learning disabilities, and a themed review by the NIHR found that people from minority ethnic communities face additional health inequalities compared to white British people.³¹ A recent report from the Commission on COVID-19, Ableism and Racism showed that disabled people from minority ethnic communities faced multiple barriers to good health related to both their disability and ethnicity, and that they experienced increased discrimination and disruption when accessing health services during the height of the COVID-19 pandemic.³² A recent Race and Health Observatory Report³³ found that people from minority ethnic communities faced barriers to good healthcare related to both their disability and their ethnicity. It was noted that experiences were better when dealing with

²⁹ CIPOLD (2013), Louch et al (2021), Ramsey et al (2022), Bradbury-Jones et al (2012)

³⁰ Office for National Statistics (2023) The geographic divide in general health, disability and unpaid care: Census 2021 https://www.ons.gov.uk/visualisations/censushealthdisabilitycare/

³¹ NIHR (2020)

³² Commission on COVID-19, Ableism and Racism (2023) *A spotlight on injustice* https://www.vodg.org.uk/resource/a-spotlight-on-injustice-the-final-report-from-the-commission-on-covid-19-ableism-and-racism.html

³³ Umpleby, K et al (2023) We deserve better: Ethnic minorities with a learning disability and barriers to healthcare. Race and Health Observatory Report https://www.nhsrho.org/publications/we-deserve-better-ethnic-minorities-with-a-learning-disability-and-access-to-healthcare/

a healthcare professional who had a good understanding of learning disabilities, or someone who knew the person well. Many people felt that a learning disability nurse would be helpful, but people rarely had experience of meeting one.

People with the label of profound and multiple learning disabilities are likely to face significant health inequalities. Williamson et al (2021) found that people with severe or profound learning disability were at higher risk of hospital admission or death than people with mild to moderate learning disability.³⁴ People with severe learning disabilities are also much more likely to have epilepsy than the general population, and Tyrer et al found that health needs that many people with the label of profound and multiple learning disabilities have, such as PEG feeding and mobility difficulties, were associated with much lower life expectancy than people with learning disabilities who did not have additional health needs.³⁵

The way that people's care needs are labelled and viewed has an impact on the quality of care that they get. Pellerboer-Gunnink et al's (2017) systematic review showed that mainstream healthcare staff had negative preconceptions of people based on labels like 'challenging behaviour'. Ramsey et al found that people whose care was labelled 'complex' received standards of care that would be unacceptable for other people without the label, and that the label of 'challenging behaviour' meant that some people with learning disabilities were considered "too difficult to care for" and discharged from services.³⁶

There also seems to be a difference in the health inequalities for children with learning disabilities compared to adults with learning disabilities. Zylberstein (2023)³⁷ found that over transition from childhood to adulthood, people with learning disabilities had fewer planned admissions to hospital and more unplanned admissions to hospital. This may suggest that there is less collaborative working between community teams and acute teams for adults, or that adults with learning disabilities are being admitted to hospital for health conditions that could be treated in the community. However, many studies found that children with learning disabilities face health inequalities compared to children with out learning disabilities.³⁸

³⁴ Williamson et al (2021)

³⁵ Tyrer et al (2022) Health needs and their relationship with life expectancy in people with and without intellectual disabilities in England https://pubmed.ncbi.nlm.nih.gov/35682186/

³⁶ Ramsey et al (2022)

³⁷ Zylbersztejn et al (2023) Trends in hospital admissions during transition from paediatric to adult services for young people with learning disabilities or autism: Population-based cohort study https://pubmed.ncbi.nlm.nih.gov/36394000/

³⁸ Mimmo et al (2019)

How will this affect the work towards the competency framework?

- Our priority groups for this work will be people from minority ethnic communities, people with profound and multiple learning disabilities, people whose care is labelled as 'complex' or 'challenging' and people who may attend hospital alone.
- We will ensure our work considers all areas of England as far as possible.
- We will look at the differences between adult and children's care in hospitals to see if there is good practice that can be incorporated.

Do acute liaison nurses change the health outcomes that people with learning disabilities have?

When people with learning disabilities and family carers had contact with an ALN they tended to speak positively about them in reports that we read, and when examples of good healthcare practice were highlighted in the literature, there was often an ALN involved.³⁹ Many reports about the health inequalities people with learning disabilities face speak about the importance of the ALN role and call for more ALNs in hospitals. However, there is very little research that specifically looks at the impact that the ALN role has on health outcomes.⁴⁰ Sheehan et al, in an audit of 9 hospital trusts and 6 mental health services found that patients in trusts where there was an ALN had some better access to reasonable adjustments such as hospital passports, but it was not possible to tell if ALNs were driving this, or if trusts that place importance on the safety of people with learning disabilities are more likely to appoint an ALN.⁴¹ One difficulty in building a picture of the effectiveness of ALNs is that the role is enacted so differently in different areas.⁴²

In their scoping review, Louch et al mention a study in which a specialist learning disability team developed a learning module that made mainstream nurses feel more confident in caring for people with learning disabilities.⁴³ However, in children's care, Oulton et al (2019) found that ALNs were valued by hospital staff, but not shown to improve staff capacity or confidence, how children and young people were valued or their safety and access.⁴⁴ Nurses in this study identified that the culture of the trust is important, as is how the ALN role is valued by senior leadership. Tuffrey-Wijne found similar.

³⁹ Ramsey et al (2022)

⁴⁰ CIPOLD (2013), LEDER (2022), Bradbury-Jones et al (2012), NIHR (2020)

⁴¹ Sheehan et al (2016) An audit of the quality of inpatient care for adults with learning disability in the UK https://bmjopen.bmj.com/content/6/4/e010480

⁴² Kupara (2023) in Mafuba, K (ed) *Learning and Intellectual Disability Nursing Practice*, Health Education England (see note 3)

⁴³ Louch et al (2021)

⁴⁴ Oulton et al (2019) Learning disability nurse provision in children's hospitals: hospital staff perceptions of whether it makes a difference https://pubmed.ncbi.nlm.nih.gov/31182066/

"The main enablers were the learning disability liaison nurse (LDLN), provided that this role was properly supported by senior management and carried sufficient authority to change practice; and ward managers who facilitated a positive ward culture and ensured consistent implementation of reasonable adjustments."

The presence of the ALN is not enough, ALNs must also be seen as a useful resource for improving practice across mainstream healthcare teams. An NIHR themed review quotes a study in which 14 doctors were interviewed and said that they struggled to provide good quality care to patients with learning disabilities, but that half made little use of reasonable adjustments and few made use of specialist learning disability nurses.⁴⁵

How should this inform the work of Acute Trusts and ALNs?

- Acute Trusts and ALNs should gather data that can be used to demonstrate the
 efficacy of the ALN role, identify gaps where practice can be improved and
 highlight good practice that can be shared with other trusts.
- The forthcoming competency framework should be used to make the role of the ALN role clearer and more consistent across the whole of England.
- Acute Trusts should embed the work of ALNs into their strategic plans for patient safety and reducing health inequalities.
- There is a need for leadership development and opportunities that enable strategic leadership roles within ALN teams working at the highest levels of Acute Trusts.

⁴⁵ NIHR (2020)

Conclusion

The health inequalities faced by people with learning disabilities are not only related to their treatment in hospital, and are not only the responsibility of the ALN. However, the literature shows that there are inequalities related to the way people with learning disabilities are kept safe and treated well in hospital that must be addressed. We also know that these inequalities impact upon different people with learning disabilities differently. There is some evidence to suggest that the ALN role can play an important part in improving safety and quality of care.

Changing Our Lives will use this literature review to guide our work in *A Uniform Approach* to develop a national competency framework for Acute Liaison Nurses. We will focus on the experiences of people with learning disabilities and families from our priority groups and in all 7 areas of England.

This project is closely focused on the skills, knowledge and attributes needed to make the ALN role as effective as it can be. However, this is not a role with the scope or responsibility to fix the many issues that currently exist in healthcare for people with learning disabilities. Our work will acknowledge the wider health landscape, and the support needed for the ALN role from other health professionals. It will also acknowledge the rights of people with learning disabilities to get a good standard of care from all health professionals.

An Easy Read summary of this literature review will be made available on Changing Our Lives' website.