


HERIOT WATT UNIVERSITY

UKRI Arts and Humanities Research Council

# Designing the future of care with seldom-listened-to people

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**Cover** *This drawing comes from the* **Empowering children to shape the future of research on social inequality, health and wellbeing** *project where year 4 and year 5 pupils of Pennyman Primary Academy and year 5 pupils from Dormanstown Primary Academy, working with graphic artist Julian Lawrence and poet Bob Beagrie, created collective poems and comic strips pertaining to their understandings of health and wellbeing.*

# Executive summary

## Overview

Our projects are carried out in the context of persisting health inequalities which determine whether people lead healthy lives. The overarching lesson from our ten projects that span the UK, is that it is both possible and indeed vital to co-design the future of health and care with seldom-listened-to individuals and communities if we are to succeed in improving health and care for everyone. Whilst professionals often perceive this as challenging, we find that creative and humanities-based approaches help facilitate the process of co-designing health and care supporting seldom-listened-to individuals and communities to fully engage. Although each of the projects has its own distinct focus and unique findings, we collectively demonstrate the positive impacts of this approach for individuals, communities, and stakeholders, across the life course. We coined the term, **Health Labour**, to represent the burden on the individual and those associated with the individual to access and navigate care. Our projects outlined ways to enhance the accessibility of care by taking this co-design approach. The lessons learned are transformative to the future of health and care.

## Key enablers of good care for all

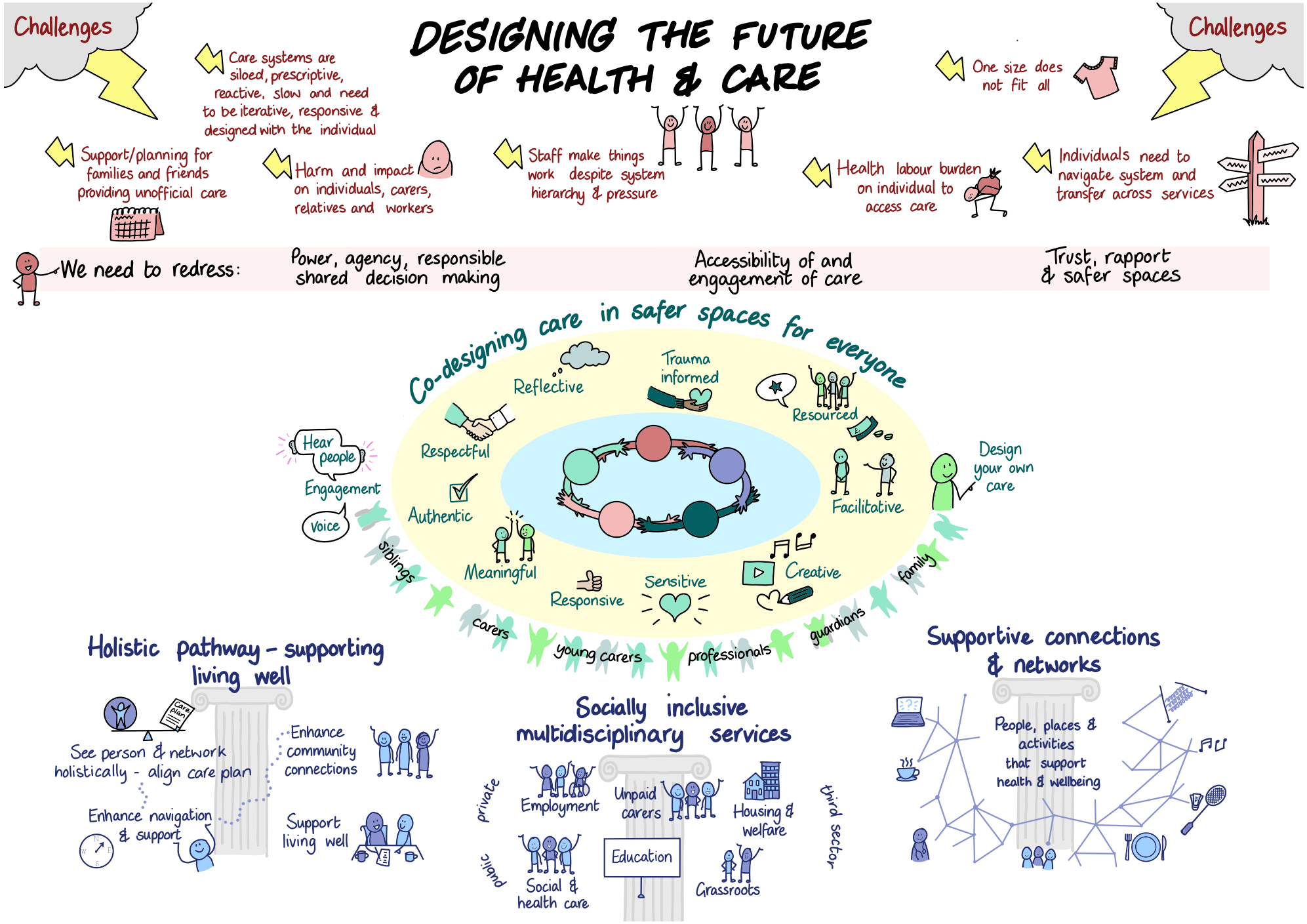
Through working with seldom-listened-to people, communities and stakeholders we have established a shared vision of what constitutes the key enablers of good care for all across the UK. These are:

- **Holistic care pathways** incorporating personalised care pathways, community connections, proactive prevention and comprehensive support addressing physical, mental, emotional, and social factors in health and wellness and foregrounding individual agency.
- **Socially inclusive multidisciplinary services** that represent the diverse social and cultural needs of the community and coordinate services across disciplinary and sector boundaries.
- **Supportive connections and networks** available to aid access to a broader network of support and support systems.
- **Co-designed care in safer spaces** that is developed collaboratively with individuals and communities.

## Recommendations

To realise these enablers we make the following recommendations to enhance care for both those who receive and deliver care. We recommend:

- **Reimagining care** to promote a human rights approach. Care needs to be flexible and responsive, integrated in the person's life, and be part of a person's everyday routine. Information gathering and information sharing should be authentic, unencumbered, and supported, with multidisciplinary professionals equipped to work with their recipients of care and within the system.
- **Enhancing communities and connections**, involving wider networks and support systems, co-creating communities of interest and communities of care, and harnessing what is positive and supportive for people's lives to better promote and support wellbeing and living well.
- **Establishing a proactive approach to care across the life course.** Anticipating future needs, fostering future-ready environments, and enhancing knowledge and understanding of care and living well in accordance with people's specific needs.
- **Equipping staff and organisations to deliver effective care.** Staff should be equipped to honour each person's uniqueness and biography, organisational systems should support recognition of each person's preferences and needs, and there needs to be respect and cognizance of differences.
- **Improving decision making to better support agency** by working with individuals to establish a meaningful dialogue using techniques such as creative methods to ensure engagement and that information upon which decisions are made is accurate and representative. Enhancing transparency around factors which influence decision making and noting that transition points require particular attention. Emphasising the importance of meaningful and effective discussions about options so that recipients can engage with their care.




*An illustration capturing the key messages and recommendations from this policy brief, created live during a workshop with the AHRC cohort by Clare Mills from 'Listen, Think, Draw.'*

# Introduction

Health inequalities affect individuals, communities and populations across the UK and determine the opportunities people have to lead healthy lives. Health inequalities have been increasing in the UK since 2011 and the Marmot Strategic Review of Health Inequalities (2010) set out a policy agenda to reduce inequalities through action across all social determinants of health[1]. In 2024 a Health Foundation report projected inequalities would persist until 2040[2]. They affect life expectancy, quality of life, the health conditions that people may experience, the care that is available, and whether the care is appropriate for the person's needs. Some individuals are not prioritised by care services and/or the care services may be unable to prioritise them. Many factors may play a part, for instance particular illnesses may be prioritised over others thereby creating a hierarchy of illnesses. There may be social, economic, gender and ethnicity health inequalities, and these prioritisations and inequalities may be influenced by factors including place, resource, and training. In addition, while there is a focus on the individual with the condition those in the wider network can be neglected. There are examples of resourcefulness and creativity to enhance access to social and health care, for instance, community fundraising for medical equipment. However, framing access to care as something that depends on the individual's or community effort can unintentionally place responsibility on the need for resilience rather than addressing the need for broader structural change. These inequalities in care can impact on health, quality of life, and the ability to live well, not only for the individual, but also their families and the wider community.

Securing better health and wellbeing across society through addressing health inequalities brings huge challenges. Designing the future of health and care to reduce health inequalities is fundamental to achieving our aspirations for a fairer and more just society that benefits us all. Many studies evidence the need for collaboration and co-production between services and communities to achieve positive change. But currently, many people who experience health inequalities come from seldom-listened-to communities and are not included in discussions about the design of health and care services. Professionals often perceive including seldom-heard individuals in the design of their care as challenging: traditional methods of capturing views, such as surveys, interviews, and focus groups, are often not accessible or culturally appropriate ways in which to engage and capture the critical perspectives of seldom-listened-to communities. Creative methods offer alternative approaches that bring to the fore the value of lived experience and root individual and community perspectives at the heart of the process.
This brief demonstrates that it is possible to work with individuals and communities to produce rich, insightful and valuable data that can inform change. And not only do these approaches produce fresh insights that can help improve health and care services by reducing health inequalities, the experience of engaging with creativity and culture in this way has many additional positive impacts on the wellbeing of participants.

[1] Marmot, M., Allen, J., Goldblatt, P., Boyce, T., McNeish, D., Grady, M., & Geddes, I. (2010). *Fair society, healthy lives: The Marmot review. Institute of Health Equity.* Accessible: www.instituteofhealthequity.org/resources-reports/fair-society-healthy-lives-the-marmot-review

[2] Raymond, A., Watt, T., Douglas, H. R., Head, A., Kypridemos, C., & Rachet-Jacquet, L. (2024). *Health inequalities in 2040: Current and projected patterns of illness by deprivation in England. The Health Foundation.*
Accessible: www.health.org.uk/reports-and-analysis/reports/health-inequalities-in-2040

# *Hopes Before Birth*

## By The Awesome Foursome (Dormanstown)

*Though I am not yet born,*
*I hope to live a long life*
*With loving friends and family,*
*With support whatever I do.*
*When I escape from this tunnel of horror,*
*I will need love and care to survive*
*The outside world.*

*Though I am not yet born,*
*I should have freedom to grow,*
*To learn, to play, to rest, to sleep*
*In a shelter, warm and comfortable.*
*To live without cruelty,*
*To be free to marry whoever I want.*

*Though I am not yet born,*
*To survive, I need food and water*
*If I want to be strong and healthy;*
*Then, set my own path in life.*
*I fear greed, temptation and neglect.*
*I will need a cosy cot, warm clothing*
*And kindness in my life.*
*I should have the right to make my*
*Own mistakes,*
*And find my own happiness!*

*This poem was written by year 4 and year 5 pupils of Pennyman Primary Academy and year 5 pupils from Dormanstown Primary Academy, working with poet Bob Beagrie. This was as part of the '**Empowering children to shape the future of research on social inequality, health and wellbeing**' project.*

# *It's 2048: A letter to the future*

## By Louise Wallwein

*Dear NHS,*

*Happy 100th Birthday. I am really glad that the powers that be listened.*

*As you can see this is a forest hospital you stand in. There are trees in every corridor. Each nook and cranny. Each cupboard sends out the sound of bird song.*

*People now look forward to visiting or coming to get their lumps and bumps sorted out. Doctors and nurses are now trained in traditional medicine. Everyone is relaxed. People heal. Babies are born by the beautiful pound. People die surrounded by fresh clear air after a party with their loved ones.*

*Everyone is paid a fair wage. Security giards have been retrained as holistic guides. Everything run on time because more time is give.*

*The food people eat is grown on the ground. Patients are cared for when they leave the hospital. There are many hospitals designated to meet the needs of the whole community. Each within walking distance*

*It has been so successful that young people want to train to become doctors.*

*This is a poem from the **NHS 75/150: Looking Back, Looking Forwards** project that illustrates the hopes for the future of the NHS by Louise Wallwein who participated in that study.*

# Underpinning research

The findings in this brief synthesise key points from ten projects across the UK from Kent in southeast England to the Highlands and Islands in Scotland. All of the projects are partnerships between communities, community organisations, and universities. They use creative methods to engage and explore seldom-listened-to individuals' and groups' visions for the future of health and social care (**https://simhw.hw.ac.uk/projects/arts-and-humanities-research-council-funded-projects-exploring-the-future-of-health-and-social-care/**). The projects worked with a wide variety of people including:

- children who have siblings experiencing life-limiting conditions to understand their perspectives on wellbeing and care and to offer advice to those who care for them;
- women, trans men, non-binary, and gender nonconforming people with energy limiting conditions (ELC), including dedicated work with LGBTQIA+ people and Muslim women to imagine what better futures of health and social care would involve for themselves as they age, and for people diagnosed with these conditions in the future, along with health care professionals who support people with ELC;
- members of the public living with endometriosis to co-create novel approaches to communicating pain, and a pain communication toolkit;
- older autistic people with learning disabilities (aged 50+), autistic people without learning disabilities (aged 50+), and social care and health practitioners to co-produce a vision of what happy and healthy ageing looks like;
- community members to consider the history of rural health and care in the Highlands and Islands to address what health and care in rural and island Scotland should look like in the future;
- diverse communities in Greater Manchester including older people, LGBTQIA+ people, young people with mental health experiences and Caribbean and African communities to discuss the future of health and care;
- children living in areas of high deprivation in the South Tees region to express and communicate their perspectives on social inequality and health and wellbeing;
- people from the African-Caribbean Community to discuss folk story, folk song, and mental health and to develop a mental health toolkit;
- underserved members of Kent Communities including young people, new mothers, older adults, and migrants to capture the lived experiences of community members and be part of the conversation around the future of mental healthcare and research;
- local community organisations from Manchester University NHS Foundation Trust, including both patients and staff, to explore the realities of community ward care.

## What do we mean by care and care systems?

Our projects envisage care as supporting individuals and their wider networks with both social and health care needs. This includes people and services that support individuals to live well and includes mental and physical health. We recommend that care is holistic, person and community-centred, culturally sensitive, collaborative, preventative, proactive, safe, respectful, and trauma-informed.

We use the term 'care systems' to recognise the connections between services that rely on services across disciplinary and sector boundaries, including social care, housing, employment, education, charities, grassroots organisations led by people with lived experience, community organisations, health services including the NHS, private provision, and the voluntary sector.

## What is living well?

Living well is understood differently by people in different contexts. Broadly it means that the person is living a fulfilled life. Living well encompasses both mental and physical health, managing health conditions and maintaining health behaviours. It includes social connection, positive relationships, meaningful activities, and a sense of purpose. In this brief, living well acknowledges the broader structural inequalities within society. It includes wider networks, for instance, siblings of those with life-limiting conditions.

## How do we include seldom-listened-to people in design?

Our projects are testament to the value of using creative methods to support discussion and design of services. Creative methods can enable exploration of thoughts, feelings, and visions for the future in ways that are inclusive, enjoyable and rewarding. As a result, important new insights can be obtained to inform health and care services.

# Key challenges




*This drawing is by Dr Letizia Bonanno from the* **INTERACT: Imagining the future of mental healthcare in Kent** *project illustrating community members having conversations about mental health and the future of the NHS.*

We identified 3 key challenges across the projects.

## 1. Power, agency, and effective and responsible shared decision making.

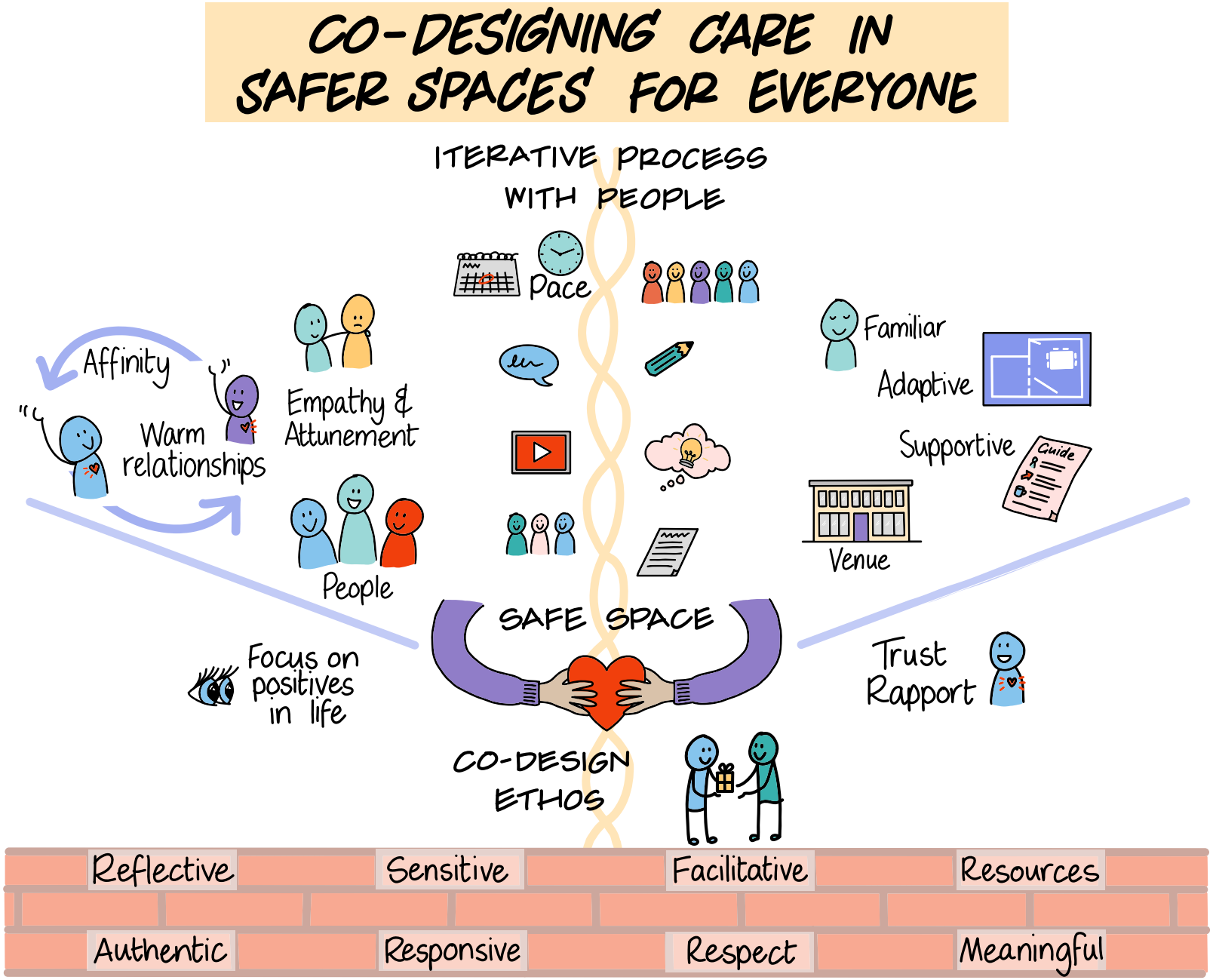
Traditionally, power in the care system has not been held by the recipients of care. Our projects have highlighted the need for, and how to, include seldom-listened-to people and groups within decision making using creative methods. Our projects recommend creating safer spaces so that people feel comfortable and are able to fully engage with services so that they have agency in their own care.

## 2. Accessibility of and engagement with care.

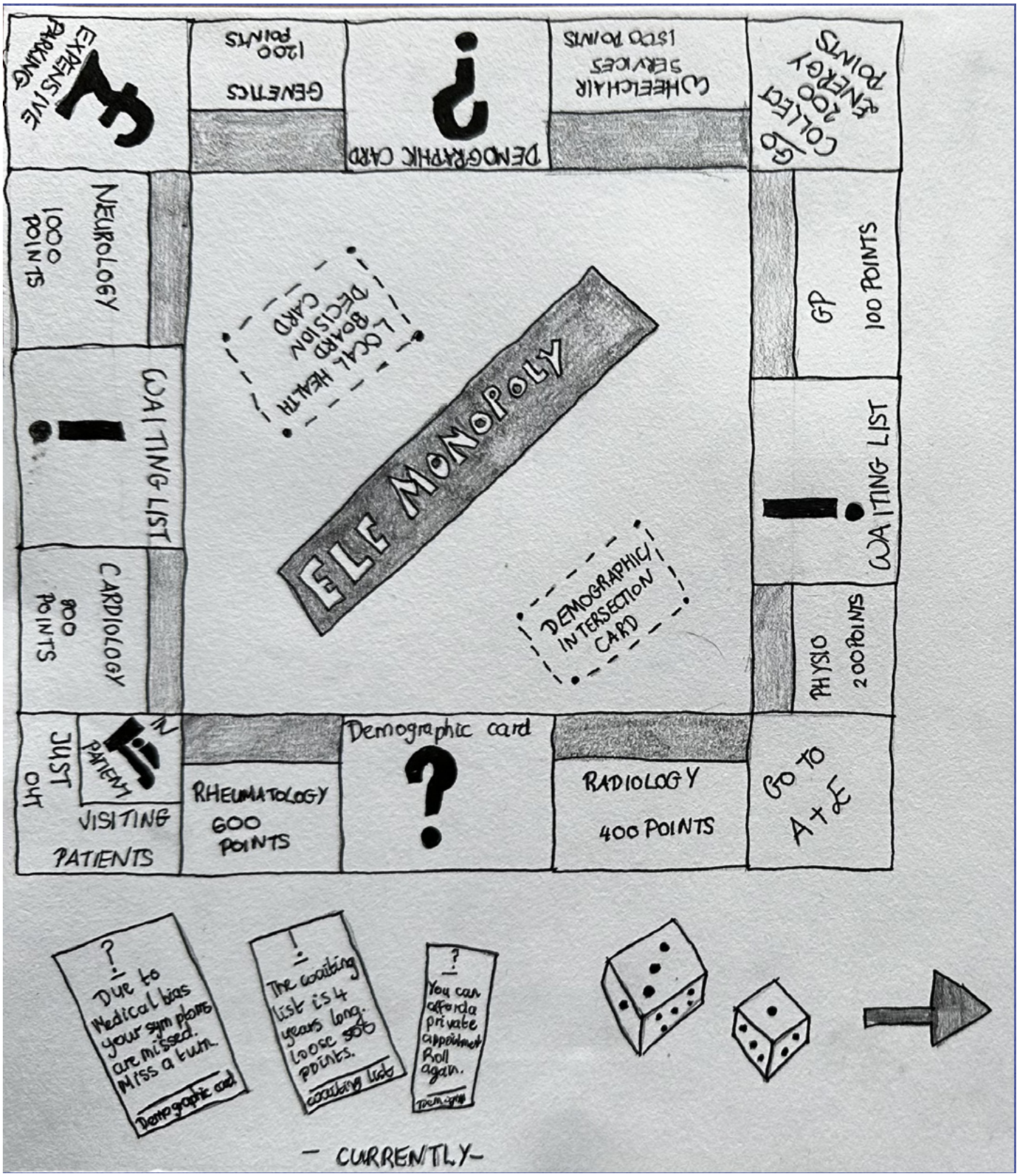
Care can be inaccessible to many people living in the UK which can result in disengagement from care, not seeking out care in the first place, and/or inadequate care. There can be a burden on the individual and those associated with the individual to access and navigate care which can result in what we coin as Health Labour. We define Health Labour as the cognitive, emotional, time and energy resource required to navigate health and social care services and to self-advocate for health and care needs. Health Labour is unacknowledged and without compensation. It can result in an inequality in the amount of effort to maintain health and wellbeing. As a result, the demands of Health Labour can have adverse effects on people's health and wellbeing and on their capacity to participate in social and cultural life. In our projects we noted that Health Labour included a burden on the individual to navigate complex and disconnected services, and on both practitioners and individuals to ensure information is shared between providers and carers. The burden increased particularly during transition points, staff changes, or when multiple services were involved. Our projects outlined some ways to make care more accessible and highlighted the need to include user experience in the design of services.

## 3. Trust, rapport, and safer spaces.

Building trust and rapport with individuals and the system takes time and, in some cases, may need to be rebuilt after experiences of iatrogenic harm and trauma, which must be recognized and addressed. It is of vital importance to co-create safer spaces for people to engage with services. Safer spaces are fluid and require adaptation across time and circumstance.




*This illustration is part of the* **Ageing, Health, and Social Care: The meaningful engagement of autistic people with learning disabilities in supported living services in Scotland** *projectand was created live during a meeting where the researchers on the project discussed what co-designed care in safer spaces means for autistic older people. This illustration is by Clare Mills from 'Listen, Think, Draw.'*




*Healthcare Monopoly' by Fern from the* **Imagining Better Futures of Health and Social Care with and for People with Energy Limiting Conditions** *project. "Accessing healthcare with an Energy Limiting Condition can feel like landing on a monopoly board. The system doesn't always recognise that people are not homogenous resulting in multiple barriers to overcome while simultaneously running out of energy and resources in a quest for medical help".*

# Key recomendations

## Designing the future of health and care with seldom-listened-to people

From these challenges we make a number of recommendations and identify what is required for good care:

- **Holistic care pathways** incorporating personalised care pathways, community connections, proactive prevention and comprehensive support addressing physical, mental, emotional and social factors in health and wellness. Holistic care pathways aim to foster individuals to have their own agency by linking them to services and resources that promote a higher quality of life, encompassing social engagement, mental health support, physical activity, and personalized wellbeing initiatives.
- **Socially inclusive multidisciplinary services** that represent the diverse social and cultural needs of the community. A multidisciplinary service would coordinate medical specialists, social care services, housing, employment and benefits, education, services across disciplinary and sector boundaries, including grassroots organisations led by people with lived experience, community organisations, health services including the NHS, private provision, charities, and the voluntary sector.
- **Supportive connections and networks** that are available at the right time and right place to support when required. These can include people with similar conditions, similar needs, or similar experiences, and people with understanding and knowledge. Supportive connections would aid access to a broader network of support and support systems.
- **Co-designed care in safer spaces** that are developed collaboratively with the individual. Safer spaces are dynamic, context dependent, accessible, and trauma informed. Care is co-designed with the recipient of care.




*This image is from the frontpage of the* **Using Philosophical Dialogues with Children to Understand Care and Wellbeing for Siblings of those with Life-Limiting Conditions** *project recommendations leaflet. The children outline what they need from doctors, teachers, nurses, parents and anyone else who might care for them. This illustrates the importance of considering the whole network of people involved in care.*

**To enable these we recommend the following:**

## Care is reimagined

a. **Care is part of everyday routines:** Identify issues, and discuss health and care as part of the normal routine

   i. Be flexible and responsive about the location, timing, and delivery of care, for instance include online and asynchronous options. Professionals can conduct assessments and share information in familiar environments for recipients such as schools, hospices or hospitals. For example, visiting day centres that support autistic people, people with learning disabilities, or dementia. Peer support could be accessible within a hospice environment. This could alleviate the Health Labour on both the care recipients and their broader support network, fostering more authentic interactions with individuals and family members.

b. **Equip professionals** to work with people with varying communication, cognitive, sensory, and cultural needs. Ensure that staff understand how to work with the individual, how best to engage with them, and how best to gather and share information.

c. **Enhance information gathering:** Employ creative methods to capture experiences, to information gather, and to support decision making with individuals (including children). This can include a wide range of solutions including utilising technology, such as AI and robotics to enhance data collection.

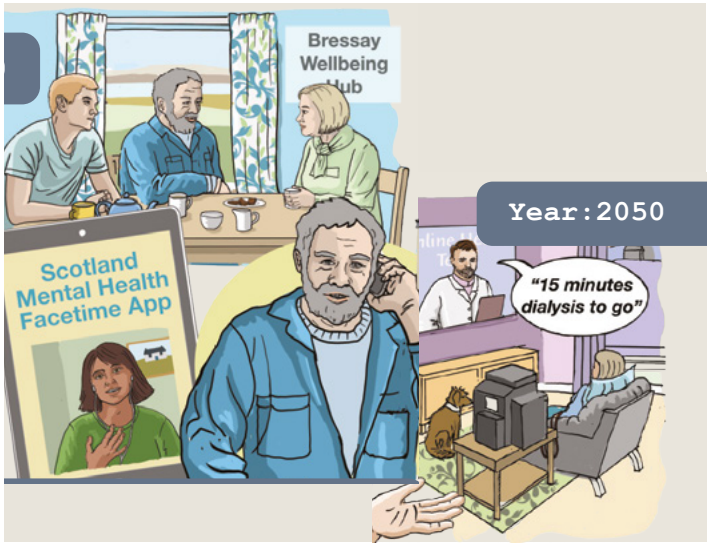
d. **Improve data sharing:** Develop secure data sharing portals so that data and information can be more easily shared with recipients and providers of care.

e. **Develop a new discourse of care:**

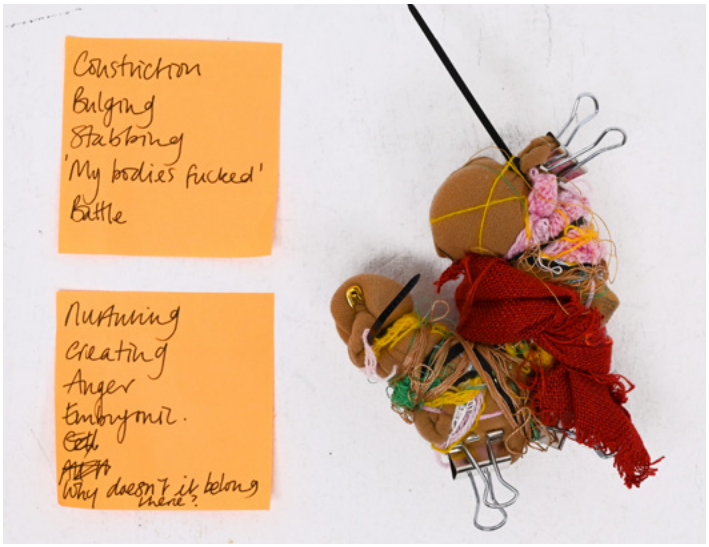
   i. **Shift perceptions:** Promote a human rights approach. Care is often perceived and portrayed as a burden and costly, which can lead individuals to think of themselves as a burden.

   ii. **Address hierarchies of illness and inequalities in access to support for those who need it:** There can be a hierarchy of illnesses with conditions such as energy limiting conditions, endometriosis, period pain and other gynaecological conditions, coming lower down in the hierarchy. Likewise, there are well-established gender and ethnicity health gaps that impact these illness hierarchies. Furthermore, those in the wider network can be neglected. People reported that their experiences were dismissed or not believed by health care professionals, leading to their needs not being prioritised and a lack of access to appropriate care. People may feel like imposters, believing that they do not deserve care and resources because their condition or situations aren't viewed as a priority. This can discourage them from seeking or engaging with care.

   iii. **Support living well:** Services were reported to prioritise treating specific symptoms or pursuing a cure, rather than helping individuals and their networks to live well. This approach placed a significant psychological, emotional, and practical burden on individuals, especially when they were expected to articulate negative experiences without clear resolutions. Discussions about the broader impact of the illness were often avoided if no definitive treatments existed, further alienating individuals from services. Additionally, services frequently focused on the person with the illness, neglecting the care needs of others in their network, such as siblings of those with life-limiting conditions. This lack of holistic support could contribute to disengagement from care, or a sense that their needs are not important.




*These illustrations are from* **Rural Health and Care: Past, Present and Future**, *created by Heather Christie a Shetland based Artist. She developed the illustrations from completed story stems by people who live in the Highlands and Islands of Scotland, about how future care can be embedded into the everyday.*




*This is a participant visualisation of how endometriosis feels from the* **Making the invisible, visible: co-creating novel approaches to endometriosis pain communication** *project.*



*This image is of Iceberg Productions conducting an interview with one of the older autistic people who contributed to the documentary as part of* **Ageing, Health, and Social Care: The meaningful engagement of autistic people with learning disabilities in supported living services in Scotland** *project.*

## Enhance community and connections to better support living well, health, and wellbeing

Actively working within the community can bring to light and reveal the wider context of the individual's layered identities. This highlights community connections and can support the individual's agency in their care. Support can be gained from people and relationships, places, and activities. Relationships can be with family, carers, practitioners, members of the public, and can be intergenerational. Activities that develop intergenerational conversations and support cultural identities, and that provide opportunities for expression and community building, may in turn support wellbeing.

a. **Promote and support wellbeing** by harnessing what is positive and supportive, including relationships, connections, places, previous successes, and activities. These can support engagement, assessment, delivery, and maintenance of health and care, both for the individual and for their wider network. For instance, a coffee shop or a sporting club may hold particular relevance for an individual, not only regarding going there but also the memories and connections that it activates for the person.

b. **Co-create communities and communities of care** to support living well, health, and wellbeing and dying well in the case of palliative care. Relationships are important in supporting wellbeing, health, and care, supporting access to care, and reducing isolation. It is, therefore, important to develop these with community members rather than to impose them. For instance, bringing together community organisations and harnessing folk story and folk song to support and affirm identities, well-being, and positive mental health.

c. **Involve wider networks:** Health and ill-health impacts not only the person with the condition but also their wider network. Ensuring that support systems are in place and accessible both for the individual and their wider network is crucial to ensure dignity, agency, and living or dying well. Individuals reported that friends and family were relied upon and there was uncertainty about their future if support became unavailable, for example, an autistic adult with learning disabilities who is ageing and their parents are ageing themselves. Another example would be for someone who is in palliative care and wishes to return home will require a care plan that considers the impact on the wider family network.

## Support proactive care: plan for care, enhance navigation to care and support, and support understanding

Working with people, using approaches suitable for them, to imagine the futures of care, and care and support options.

a. **Plan for lifespan care:** Implement proactive care strategies that anticipate future needs and give clear information about how this can be planned. For some individuals, such as autistic adults with learning disabilities, it was challenging for them to envisage what their needs might be, placing themselves in an abstract future, and identifying what they might want their future care to look like. It is important to consider the future and to share information in accessible formats so that everyone can both make informed decisions about their care.

b. **Foster future-ready environments** that are suitable for the individual in their context:

   i. Homes could be built/selected to be future ready and/or adapted ahead of a crisis point.

   ii. If someone owns their own home, and can stay in their own home, plan how it can be adapted to support living within the home.

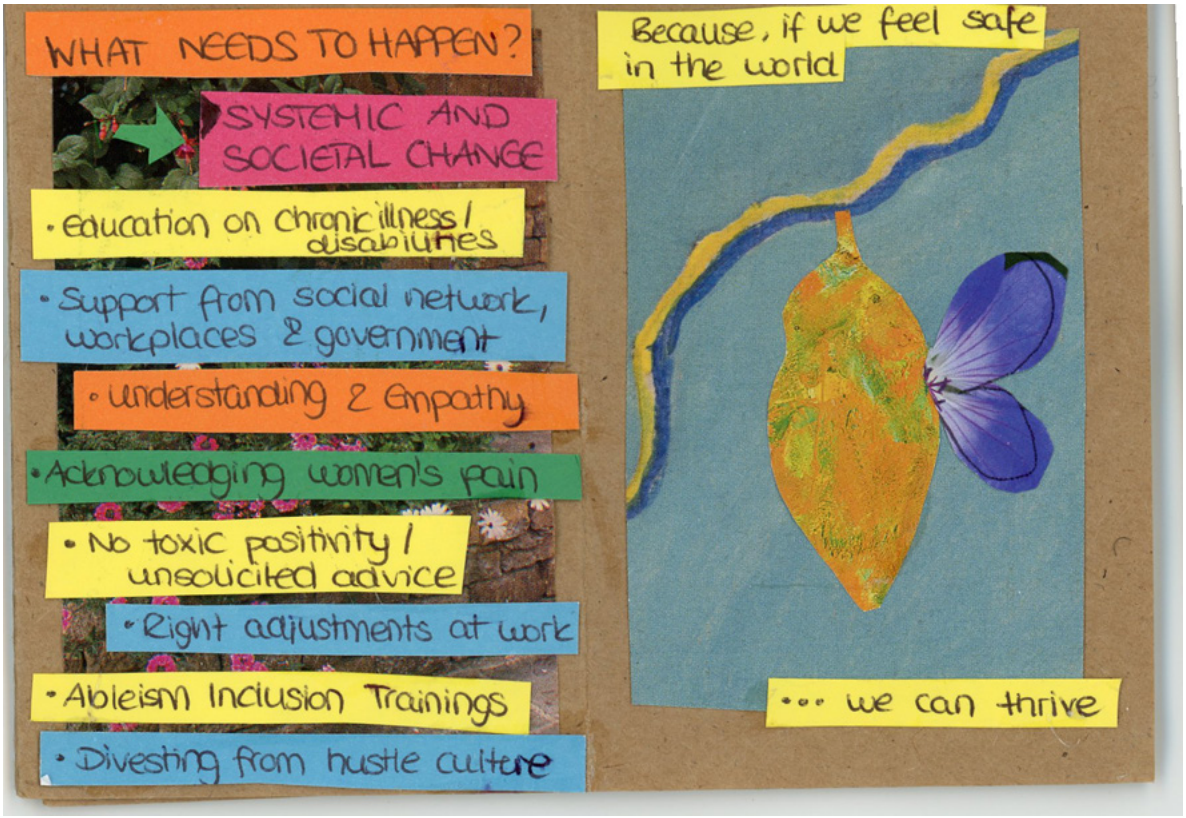
   iii. Support and care should be in place before a crisis.

   iv. Consider activities, places, and people that are supportive to wellbeing.

c. **Enhance knowledge and understanding.** Provide clear information about what to expect from care and enhance understanding about what good care and living well looks like in relation to the individual's circumstances, condition and experience.

   i. Individuals may have no experience of care or support. Information could be shared in a meaningful way including through videos and testimonials that could be co-created with people with lived experience. People could have the opportunity to experience different care options before needing care to help them better decide on what care will suit their needs.

   ii. Communities could be better utilised so that people know what to expect. Networks could be formed to formally and informally give advice; they can also provide peer support.




*"What Needs to Happen," by Aylin from the* **Imagining Better Futures of Health and Social Care with and for People with Energy Limiting Conditions** *project. This extract is from a zine produced during a workshop seeking to visualise and creatively express participants' experiences as Muslim women with energy limiting conditions.*

# *Buccleuch Lodge Jigsaw*

*Piece by piece we are put back together,*
*bones and pride restored,*
*slotted neatly next to one another,*
*in a setting of caring yellow walls*
*that look out to tendered gardens,*
*amongst the tranquillity of lowered volume*
*from a TV set, and the slow squeaky wheels*
*of a tea trolley gently rolled past,*
*a semi-circle of wing back armchairs,*
*and a light touch of a hand on a shoulder,*
*a bended whisper in an ear*
*calls time for physiotherapy,*
*or ability tests that stretch independence,*
*and provide support for living,*
*until bit by bit a picture forms,*
*showing Buccleuch's guests preparing*
*to be in their own homes.*

*Written by Helen Harrison with words and ideas provided by staff and patients at Buccleuch Lodge*

*This poem by Helen Harrison from the* **Home from Home: Building Independence in Community Health Settings** *project. Staff and patients were asked questions like: what makes a home comfortable? How do you make yourself comfortable in your life, and what are the things that you have in your life that give you comfort?*

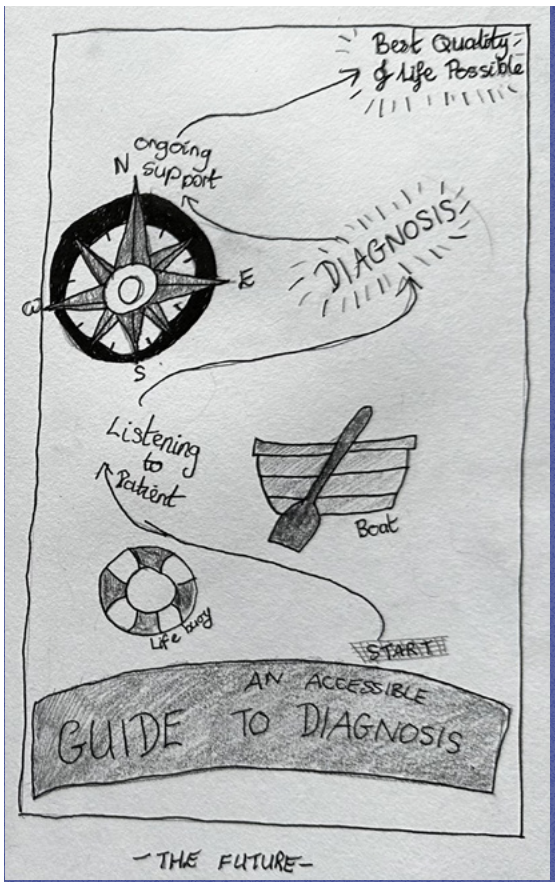
# *Linstead Market*

## *A song of struggle, strength, and healing across generations.*

*Carry me ackee go a Linstead Market*
*Not a quatty would sell.*
*Carry me ackee go a Linstead Market*
*Not a quatty would sell.*

Chorus: *Oh Lord! Not a mite, not a bite,*
*What a Saturday night!*
*Lord! Not a mite, not a bite,*
*What a Saturday night!*

*This traditional folk song reflects struggle, resilience, and community life. The* **Re-igniting Windrush folk song and stories to improve African-Caribbean mental health disparities** *project workshop found traditional folk songs support African-Caribbean mental health by fostering cultural identity, emotional healing, and strong support networks, promoting well-being, belonging, and cultural pride across generations.*




*'An Accessible Guide to Diagnosis' by Fern from the* **Imagining Better Futures of Health and Social Care with and for People with Energy Limiting Conditions** *project: "Hopefully in the future a clear, accessible, linear pathway will replace this, with a focus on the end goal being each patient having the optimal quality of life in their individual circumstances."*



*This photograph is of the 'Caribbean Social Forum' and 'Everyone's a Singer' project participants that were part of the* **Re-igniting Windrush Folk Song and Stories Project to improve African-Caribbean mental health disparities.**

## Equip organisations to work effectively

Individuals reported often feeling identified by their current health condition rather than as a person in their own right. This was especially challenging when they had co-occurring and comorbid conditions, as one condition could overshadow another, affecting their presentation, assessment, and care plan. Individuals reported feeling that they are often homogenized into groups, with the diversity of their characteristics and experiences being overlooked. Individuals reported that their experiences were not fully understood and that they were not easy to explain in words.

a. Staff can co-create a book with the individual about their life which would be used to train and inform staff to:

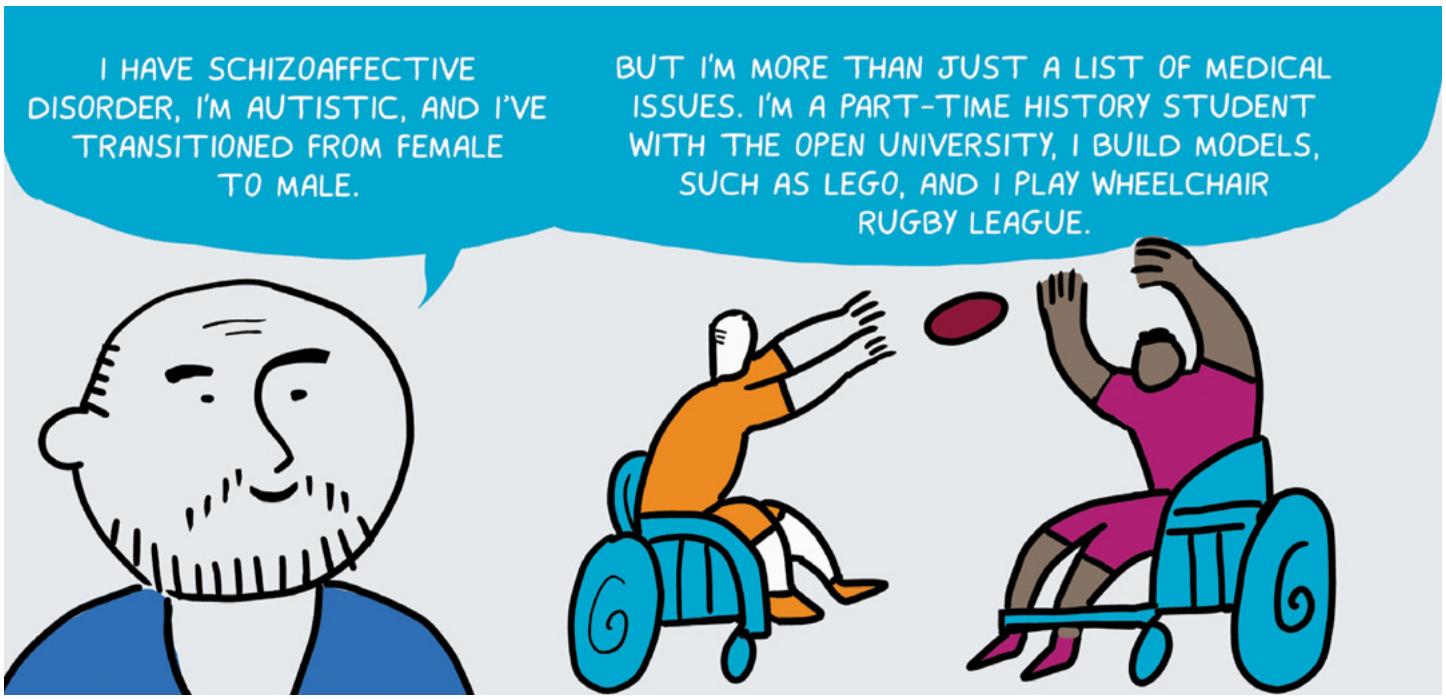
   i. **Better support strengths** and positive behaviours to enable the person to better address challenges. Treating an illness is important; however, it is also about supporting living as well as possible particularly when no treatments may be available. This must go hand-in-hand with supporting people to address challenges to living well with their conditions.

   ii. **See the person** and not a collection of health conditions.

   iii. **Take into account people's biographies and individuality**, their experiences of care, health, and challenges that they may have faced which may influence their views of services and service provision. Barriers may include being concerned about being disbelieved and a fear of hostility when accessing care. These factors can affect engagement with care.

   iv. **Be respectful and cognisant of culture and differences** and challenge intersectional and institutional forms of discrimination that patients may encounter in health and social care services

   v. **Align plans that support recognition of individuals' preferences and needs.** One size does NOT fit all, and individuals' needs can change and fluctuate due to contextual and temporal factors.




*This is part of 'Oliver's Story' from the* **NHS 75/150 : Looking Back, Looking Forwards** *project with artwork created by Darryl Cunningham.*

## Improve decision making to better support agency

Decisions about care and the design of care have not traditionally been made by recipients of care. Decisions about care are often made by care professionals who are constrained by managers, local authorities, and governments who make decisions that affect many aspects of care delivery. Providers may limit eligibility, pathways, and the nature of care due to constraints out with their control. Care tends to be organised and funded by age group, and by specialities. Decision making and options available can vary between specialities and between regions. For instance, options may be available before age 18 but not after, and different care packages may be available pre- and post-retirement age. These differences in service provision can be difficult for the recipient of care to navigate.

Our research raised questions about what constitutes an informed decision and how to ensure each actor has agency, especially when there is limited knowledge about care options. Our studies emphasised the importance of meaningful and effective discussions about options so that recipients can engage with their care.

This can include:

a. **Enhanced engagement** ensuring that there is a dialogue with the individual to allow for meaningful decision-making. This can include **information presented about potential options** in a way that allows individuals to engage with the information and make informed decisions, and **creative methods** to engage with recipients of care.

b. **Enhanced information** upon which decisions are made. Ensure that data used to make decisions is representative of the people about whom decisions are being made.

c. **Transparency** around what influences decisions.

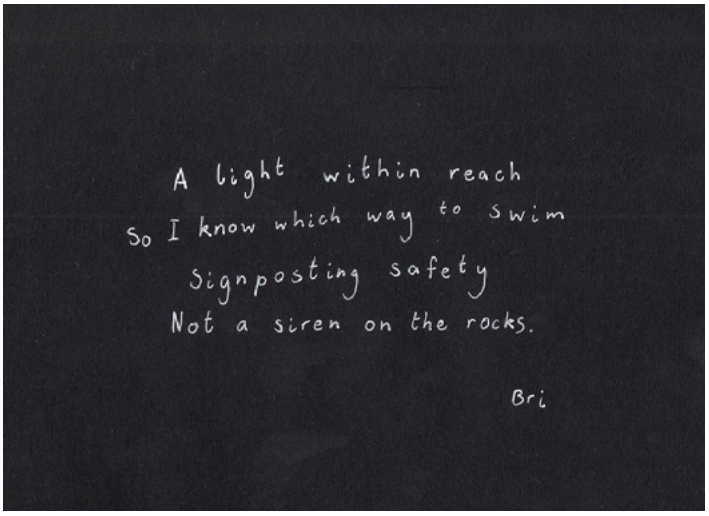
d. **Clarity around transition points** and how they are managed for instance at life stages (e.g. child to adult services), and between specialities (e.g. oncology and mental health services).

# Conclusion

This brief demonstrates that using arts and humanities approaches to work with seldom-listened-to individuals and communities produces rich, insightful and valuable data that can shape and inform the design of health and care services to reduce health inequalities and secure better outcomes across society. People across the UK from seldom-listened-to communities reported that the experience has had a profound impact on them and that they will take this experience forward into their ongoing health journeys. Stakeholders have been able to reach new audiences and start relationship-building. Researchers, artists, health professionals and policymakers involved in the work have been affected by the personal stories of people involved.

The creative outputs capture the critical perspectives of seldom-listened-to individuals and communities on their hopes and fears for the future of health and care. These outputs will be a resource to inspire and promote further work in this area well beyond the end of the funded projects. Importantly, while each project has its own focus and unique findings, the cross-cutting themes and findings across projects were strong and compelling enough for us to have identified key enablers of good care that addresses health inequalities as: holistic care pathways; socially-inclusive multidisciplinary services; supportive local connections and networks; and co-designed care in safer spaces. We have distilled the evidence gathered in each project to produce a collective set of recommendations that will support the realisation of these enablers. These focus on reimagining care; enhancing communities and connections; establishing a proactive approach to care across the life course; equipping staff and organisations to deliver effective care; and improving decision-making to better support agency. Our recommendations set out the specific ways in which staff, organisations, stakeholders, and policymakers can place seldom-listened-to individuals and communities at the heart of the design of the future of health and care. While each project has its own focus and unique findings, a common lesson emerges: the need to design **with** seldom-listened-to individuals. This approach leads to services that are designed for and by the people who use them, resulting in enhanced engagement with the longer-term aim of better outcomes and reduced health and care inequalities.






*'A Light Within Reach' by Bri from the* **Imagining Better Futures of Health and Social Care with and for People with Energy Limiting Conditions** *project. This extract is from a zine called 'Another Future is Possible'. This zine is a collection of artworks made during a series of creative workshops exploring possible future healthcare for those with Energy Limiting Conditions.*


































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