

Our Charter of Ambition and Rights for Personalisation

Peer Support Network



projectart works

Published November 2018

Introduction

We need compassionate collaboration to keep a person-centred approach at the heart of care. This Charter has been created by people with complex support needs, parents, siblings, support workers, councillors, commissioners, campaigners and legal specialists. It puts personalisation back into the picture of social care and our community. There are many ways in which personalisation can and should happen. This Charter is the voice of the Project Art Works Peer Support Network and is underpinned by legislation from the Equality Act 2010, Care Act 2014, Health & Social Care Act 2012 and the Children and Families Act 2014. It outlines legal rights that people with complex support needs, their families, carers and health and social care practitioners can call on when making decisions about care and influencing change.

Make Change

Statement on behalf of Mandy (parent carer and member of the Peer Support Network)

“We call for:

- the ethos of personalisation to be fully understood acknowledged and supported,
- personalisation to be promoted circulated and offered willingly,
- personalisation to be tailored uniquely to each individual and delivered proudly,
- all individuals to have choice and control over their lives so that they may be content and live fulfilled lives.”

What is Personalisation?

- Personalisation puts individuals in control of planning and implementing systems of care and support that are designed and tailored to meet their own unique needs
- Personalisation is about starting with what individuals want and not what services are able to provide
- Personalisation is not about fixing the person, it's about fixing the environment
- Personalisation is living the life you want to live
- Personalisation puts individuals at the centre of any decision making process about their care, support, social life, health, family life and much more
- Personalisation also means making universal services such as transport, housing, education and culture accessible to all citizens

Charter Guide

The Charter shares ambitions relating to Support, Community, Housing and Health & Wellbeing. Each ambition is divided into three areas.

Ambition

Each ambition has been shared by a person with complex support needs, a brother, sister, parent, carer or support worker. The ambitions provide a snapshot of the conversations shared at the Peer Support Network Summit held in July 2018 at Project Art Works which asked the question 'What are our aspirations for Personalisation?'

How do we get there?

The recommendations following each aspiration represent the views of the Peer Support Network and have been drawn directly from conversations between families, support workers and health and social care practitioners who attended the July 2018 Summit. They outline how, together with councillors, commissioners and decision makers, we can achieve these ambitions.

Legal Guidance

Here you will find key information drawn from legislation relating to person-centred care and personalisation compiled by Community Care Lawyer, Carolyn Hunnisett. A toolkit containing further legal guidance to support the ambitions, useful links and places to go for support is available to download from: projectartworks.org/networks/charter

Support



I NEED SPECIALIST
SUPPORT TO THRIVE



Support

"I want to understand how I can use a Personal Health Budget (PHB) and I want it to be structured in a way so that it does not limit my life choices and quality of support"

- Bring together families who have experience in managing PHBs to share their experiences
 - Stop families from fighting the same battles over and over again
 - Transparency around the budget and what it can pay for
-

Personalisation is at the heart of the Care Act 2014, which requires there to be universal information and advice available locally to help people understand how to access care. It describes how local authorities should work with providers of care and support to develop services to meet people's needs and preferences.

The Health and Social Care Act 2012 gives commissioners a duty to promote the involvement of individual patients in decisions relating to their care and to extend the use of personal budgets.

The Children and Families Act 2014, Education, Health and Care Plans (EHCP) offer families personal budgets so that they have more control over the type of support they get.



"I want support during the transition from school to adult life including access to information on the full scope of what is available to me"

- Create a map of how to get to an end goal by asking a series of personal questions
 - Services work collaboratively to share information
-

The Care Act 2014 places a duty on local authorities to conduct transition assessments for children, children's carers and young carers where there is a likely need for care and support after the child in question turns 18 and a transition assessment would be of 'significant benefit'.

If an Educational, Health and Support Plan (EHCP) is in place, this is a legal document under the Children and Families Act 2014 which should look holistically at the needs of a young person going forward. If an assessment has not been conducted you have a legal right to appeal.

"I want people involved in decisions about my care to be better informed about complex needs and disability rights to ensure that I am not discriminated against"

- Identify training needs across services including health and social care in line with Equality Act 2010
 - Provide training and awareness raising sessions in all council offices
-

The Equality Act 2010 should offer protection for people with disabilities and their carers, to ensure they are not discriminated against. Health and social care professionals are required to keep up with Continuing Professional Development (CPD). They should not work in an area that means they are acting beyond their scope and practice.



"I want a personalised support plan that fully takes into consideration my needs and ambitions for my life"

- Involve families in the process of designing a support plan as well as health and social care professionals
 - Understand that support is a lifeline
-

In compliance with the Care Act 2014, a personalised support plan should be an holistic approach that should take account of a person's needs and wants in the context of their life, environment and social setting.

Under the Children and Families Act 2014, children with Special Educational Needs (SEN) are entitled to an Education, Health and Care Plans (EHCP) for meeting their education, health and social care needs, which can run from birth to age 25.

"I want continuity of record keeping which is easy to access so people know my situation"

- Implement systems that put continuity at the heart of personalisation
 - Identify key accountable record holders
-

There is currently a massive culture shift to realising that health and social care information/assessment should be joined up and non repetitive. More recent legislation such as the Children and Families Act 2014 have created documents such as EHCPs.

Community

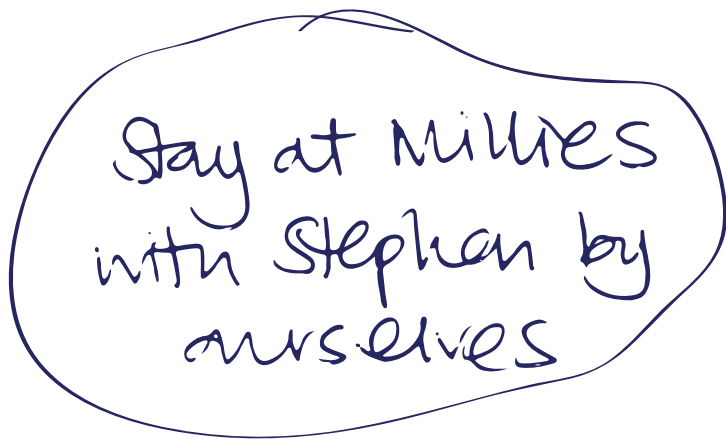




Visit old
friends in old
college



Community



"I want my son to be involved in community events"

- The council and community networks work together to devise a set of recommendations for events to make them accessible
 - Approach businesses to provide advice on inclusive programming
 - Set up a social media network
-

If participation in community events is identified as a need under the principle of the Care Act 2014, as an adult this should be facilitated to promote social inclusion. Under the Children and Family Act 2014 this should be facilitated as part of a child or young person's EHCP.

"I want higher visibility and integration of people with learning disabilities in community life"

- Develop new shared and integrated spaces within the community for informal information sharing
 - Identify key spaces for provision such as day centres and residential living within towns and communities rather than on the outskirts
 - Provide training for community and service providers to understand the benefits of integration and how they can implement change
-

Personalisation is the central principle of the Care Act 2014, which enshrines in law the duty to prevent, reduce and delay people's need for formal services, including considering the role of communities and local networks and resources in helping people stay independent for longer.



"I want community services including the police force to be personalised so we know the people and not the organisation"

- Create safe structures such as the Safe Place Scheme
-

Disability Engagement Officers are in place within the Police force to raise their knowledge and understanding, and create awareness in physical and learning disabilities. DEOs act as a point of contact for disabled communities and individuals, building relations to increase trust, confidence and encourage reporting of crime.

"I want to ensure people are valued as part of their community and that people overcome their fear of difference through enlightened understanding"

- Put people ahead of general stories to avoid stereotyping
 - Think about how and when we use labels and how this may shift our perception of each other. E.g. 'learning disabled or neurodiverse'
-

The Equality Act 2014 promotes inclusion with people with disabilities. For instance by ensuring employers offer reasonable adjustments so disabled people can become part of the workforce. That housing and access to public buildings consider the needs of disabled people. That clubs do not exclude certain protected characteristics.



"I want more exposure for people from a young age to people with learning disabilities to change the idea of 'normal'"

- Run services for people with learning disabilities in the heart of communities, in our shared public spaces, on the Pier and in parks
 - Develop a more integrated approach to education
 - Deliver Makaton training in mainstream school
-

The Equality Act 2010 promotes inclusion with people with disabilities. With access requirements to public buildings and facilities, traditional barriers are being removed. However, it is a societal shift that still needs work and advocacy to change attitudes. The Act says schools mustn't discriminate against a pupil because of their disability. This is unlawful under the Act. In some situations, schools must also take positive steps so that disabled pupils can access and participate in the education and other activities they provide.

Housing

Be near to my family
and see them regularly





Housing



“I want to live independently at home with skilled support as and when I need it”

- Separate care and housing services
- Separate tenancy agreements from care agreements
- Ensure housing is personalised and secure through community presence that supports social care provision

Local authorities are under a duty to assess your social and health care needs in line with the person centred approaches in the Care Act 2014. Daily equipment and adaptations need to be provided if they meet your needs. You are not required to cover the cost if the minor adaption is less than £1,000. If the adaptations cost more than £1,000 you can apply for a Disabled Facilities Grant.

“I want a choice of housing options within my community for my sister so she can live near her family”

- Shift the default away from large-scale residential care home model of living and a one size fits all approach to care
- Protect units within the community for supported living
- Housing associations to work in partnership with people who have complex needs
- Provide proactive information about rights related to housing and specialist resources (e.g. Disabled Facilities Grant etc.)
- Research models of housing and establish a specialist housing advisory group that informs housing projects, councils and private providers

Under the Care Act 2014, if an assessment identifies this is a need for a person this should be facilitated as much as possible.





“My daughter would crumble if she moved from home, she needs someone to help her understand different options for the future”

- Support and guidance on how to develop housing situations i.e. mortgage transfer, supported living and house conversions to allow people to live how they want to live

The Local Authority must provide free information and advice about options available to people in the community such as housing and provision of care. An occupational therapist can see if there are aids or adaptations to the home to prevent unnecessary moves. The Local Authority can assess the needs of any carers (Care Act 2014) if that would help facilitate loved-ones staying at home.

“We want people to have their skills assessed periodically and be given the opportunity to move onto new housing opportunities and to develop new skills”

- Fully consider housing in person-centred planning
- Information sharing via a specialist housing summit

The Local Authority has a legal responsibility, under the Care Act 2014, to review care plans to make sure needs and outcomes continue to be met over time. If anything has changed, the authority must carry out a new assessment. You have the right to request a review of your care and support plan.



Health and Wellbeing



I want
choice and
control

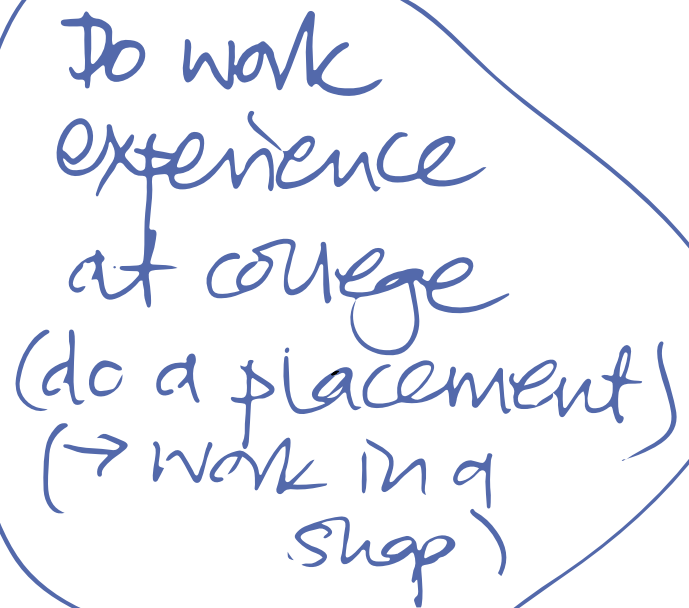


Health and Wellbeing

"We need Health and Social Care to have a better understanding of complex support needs"

- Provide awareness raising experiences to care and medical staff through a regional programme
 - Provide guidelines in-line with legislation to support sector to better understand disability
 - Ensure continuity of GPs, social workers and health professionals so people are not meeting strangers
-

The Equality Act 2010 offers protection for people with disabilities and their carers, to ensure they are not discriminated against. Health & social care professionals need to ensure that they are working within their professional codes of conduct and meeting their competencies. They should not work in an area that is beyond their capabilities and means they should not act beyond their scope and practice. Education and training is necessary for professionals to better understand complex support needs. Advocacy organisations and specialist charities can highlight and promote the lived experience of individuals with complex support needs and their carers.



To work
experience
at college
(do a placement)
(→ work in a
shop)

"I hope my daughter has an occupation, she is healthy, happy, loved and has support to do as she wishes... she has her dream job"

- Support to go about setting up a business and an understanding of the financial implication on generating income (e.g. if in receipt of ESA/ PIP)
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The Equality Act 2010 promotes inclusion with people with disabilities. For instance by ensuring employers offer reasonable adjustments so disabled people can become part of the workforce.

The use of a personal budget could assist an individual to access work, by providing a personal assistant. A person may be entitled to Access to Work grants to support paid work.

"I want somewhere to meet up in the winter in the evening so I don't feel so isolated"

- Approach businesses and the Council to provide advice on inclusive programming
 - Set up a social media network
-

As an adult under the Care Act 2014 if the criterion is met and this is an identified need this should be facilitated in the plan. There is a growing awareness of the isolation that can be experienced by disabled people. The Red Cross is part of the Jo Cox Commission on Loneliness where MPs, policy makers and 13 leading organisations have come together to expose the growing crisis of loneliness



"We need preventative health services"

- Provide Annual Health Checks with appropriate support to make sure people can be assessed
 - Enable access to leisure services for increased physical and mental wellbeing
-

In line with the Care Act 2014, needs that are well supported with continuity of care through person-centred planning should minimise reliance on reactive and emergency services. There is still some way to go for the NHS not to be a reactive service. However with the concept of person-centered care planning this should be evolving and is very much on the current agenda for the NHS.



Peer Support Network

The Peer Support Network at Project Art Works brings together people who have complex needs, families, carers, support workers, commissioners and providers to share their knowledge and experience.

Each forum explores the lived experience of disability, celebrating best practice and also working constructively with providers to identify and find solutions to gaps in services, information and provision. The network includes:

- Bi-monthly catch-ups
- Network Summits
- Information sharing and signposting
- Training and skills sharing

Network members are encouraged to work together to achieve successful personalised pathways for the people they care for and support.

About Project Art Works

Project Art Works is the UK's leading visual artist-led organisation working with people who have complex needs and the people, systems and services that support them. We run a regular year-round programme from our studios in Hastings and in the region for adults, young people, children and families. We also collaborate with major cultural venues from across the UK through exhibitions and other inclusive cultural events. Since 1997 Project Art Works has collaborated with thousands of people who have complex support needs and we continue to offer advocacy and friendship to them and their families.



Designed by Amy Mock

Images contributed by the Peer Support Network and Project Art Works

projectart works

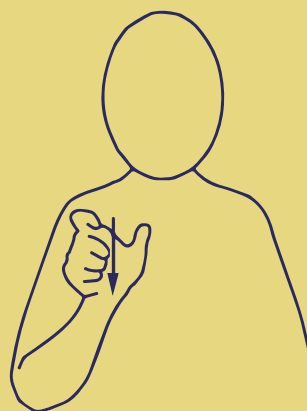
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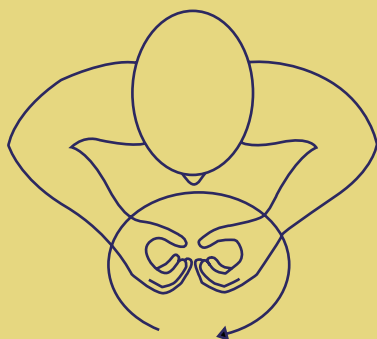
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#PeerSupportNetwork



care



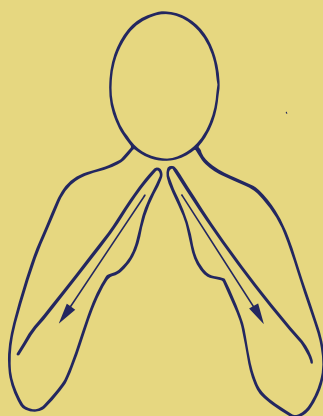
people



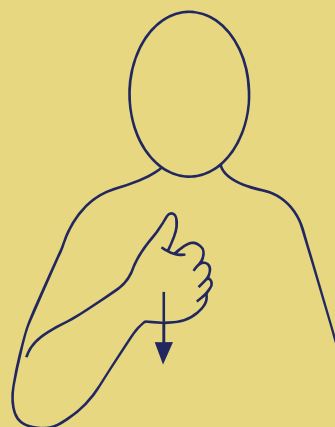
community



worker



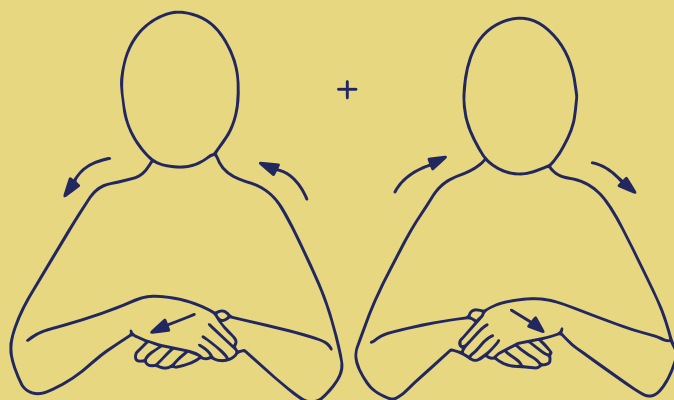
house



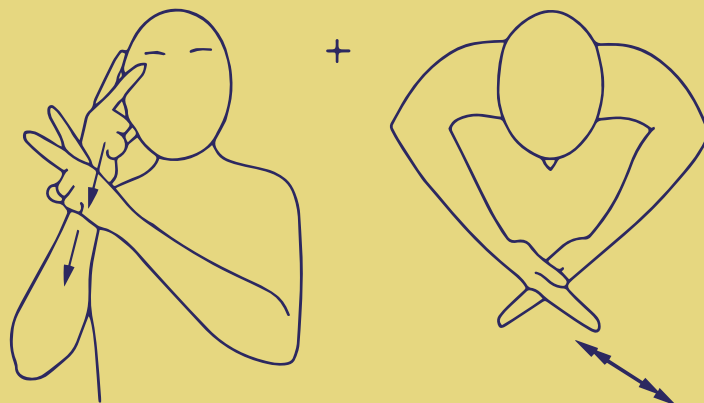
healthy

Makaton Signs

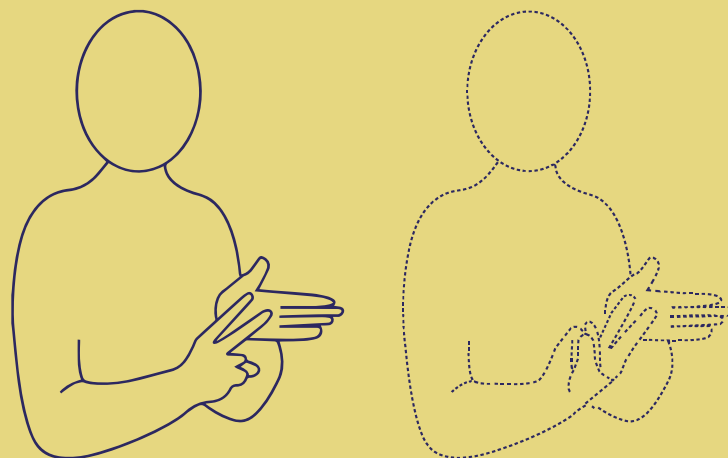
Makaton Signs



comfortable



social care



plan

My notes and ambitions...

[illegible]

My notes and ambitions...

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