

# Learning Disability and Autism Strategy 2019 – 2021

Issue Date: 18 <sup>th</sup> February 2020	Page 1 of 16	Filename: STWOLDA	Issue No: 1.0
Author: Debbie de Jonge	Authorised by: Integrated Governance Committee		Copy No:

## Contents

Executive Summary .....	3
Learning Disability Improvement Standards .....	3
Trust Values and Strategic Priorities .....	4
1.0 Introduction .....	6
2.0 Background .....	7
2.1 What do we mean by the term learning disability?.....	8
2.2 What do we mean by the term autism? .....	9
3.0 Context.....	9
3.1 National Context .....	9
3.2 Local context.....	10
4.0 Delivery of CCC Learning disability and/or autism Strategic Objectives 2019-2021 .....	11
4.1 Objective 1: Respecting and protecting rights .....	11
4.2 Objective 2: Develop our workforce to better understand the needs of people with learning disabilities and their families for all staff and volunteers working within the Trust .....	12
4.3 Objective 3: Work in partnership with individuals with a learning disability and /or autism, their families, advocates, self-advocates and carers to improve the patient experience and journey in our hospital and community services .....	13
4.4 Objective 4: Care for carers, relatives and friends of people with learning disability and/or autism .....	13
4.5 Objective 5: Improve communication to ensure appropriate information is collected and shared between healthcare staff, patients, carers and family members.....	14
4.6 Objective 6: Develop and maintain collaborative systems wide partnerships .	14
4.7 How will we measure success? .....	14
4.8 Monitoring and compliance .....	15
5.0 Key Documents .....	15

Issue Date: 18 <sup>th</sup> February 2020	Page 2 of 16	Filename: STWOLDA	Issue No: 1.0
Author: Debbie de Jonge	Authorised by: Integrated Governance Committee		Copy No:

## Executive Summary

The purpose of this document is to set out a three year strategic plan for Clatterbridge Cancer Centre NHS Foundation Trust (CCC) to deliver high quality person-centred care for people living with a learning disability and /or autism and cancer and their carers/families.

This strategy builds on the work that we have undertaken to date to improve the care of those people living with a learning disability and /or autism and cancer and their carers/families.

It sets out the journey we will take over the next three years to ensure we continue to improve patient outcomes, patient experience and partnership working to provide excellence cancer care for people with a learning disability and/or autism.

## Learning Disability Improvement Standards

CCC has integrated the National NHS Improvement Learning Disability Improvement Standards (2018) into six local key strategic objectives to improve care for people living with with a learning disability and /or autism and cancer and their carers/families.

Our objectives are:

1. Respecting and protecting rights
2. Develop our workforce to enable them to better understand the needs of individuals living with a learning disability and /or autism and cancer
3. Work in partnership with individuals with a learning disability and /or autism, their families, advocates, self-advocates and carers
4. Care for carers, relatives and friends of people with learning disability and/or autism
5. Improve communication to ensure appropriate information is collected and shared between healthcare staff, patients, carers and family members

Issue Date: 18 <sup>th</sup> February 2020	Page 3 of 16	Filename: STWOLDA	Issue No: 1.0
Author: Debbie de Jonge	Authorised by: Integrated Governance Committee		Copy No:

## 6. Develop and maintain collaborative system wide partnerships

We will deliver these objectives by working in partnership with our patients, carers, families, advocates, self-advocates, staff, community groups and partner organisations to deliver services that support the wellbeing of all involved, promoting delivery of integrated care, maximising the impact of available resources.

### Trust Values and Strategic Priorities

The care delivered will reflect the Trust values of;

- ✓ achieving excellence,
- ✓ putting people first,
- ✓ being passionate about what we do,
- ✓ looking to the future,
- ✓ always improving our care,

The objectives will reflect the Trust strategic priorities of;

- ✓ Delivering outstanding care as locally as possible
- ✓ Retaining and developing our outstanding staff
- ✓ Investing in research and innovation
- ✓ Collaborative leadership to deliver better patient care
- ✓ Be enterprising
- ✓ Maintaining excellent quality, operational and financial performance

Issue Date: 18 <sup>th</sup> February 2020	Page 4 of 16	Filename: STWOLDA	Issue No: 1.0
Author: Debbie de Jonge	Authorised by: Integrated Governance Committee		Copy No:

# Clatterbridge Cancer Centre NHS Foundation Trust

## Our Learning Disability and Autism Strategy

### Our Mission

- To improve health and wellbeing through compassionate, safe and effective cancer care

### Our Values

- Putting people first
- Achieving excellence
- Passionate about what we do
- Always improving our care
- Looking to the future

### Our Vision

To provide the best cancer care to the people we support.

#### 1. Using feedback to improve and develop our services

- Use lots of different ways to get feedback: patient stories, surveys, focus groups etc.
- Develop and support our learning disability ambassadors to help us collect meaningful feedback
- Create an easy read information pack and make sure that people understand their rights
- Learn from complaints and positive stories
- Actively listen to what people tell us about their needs. Use health passports and create good reasonably adjusted plans for individuals

#### 2. Teaching and developing our staff and volunteers

- Develop our workforce, recruit and train our staff to understand the needs people with learning disabilities and autism
- Work in partnership with people who have a lived experience to co-deliver training
- Grow the number and role of the learning disability ambassadors
- Ensure that in everything we do our staff and volunteers protect and respect people's rights
- Ensure our staff use the reasonable adjustments 'flag' in patient records and notes
- Develop a buddy system across the trust

#### 3. Raise awareness of cancer and improve knowledge about cancer treatments across the trust

- Co-produce and provide accessible information in a variety of formats
- Develop a carers network or forum or support group
- Use our communication resources to create a social media campaign
- Develop a targeted awareness and publicity campaign, using newspapers and radio
- Promote awareness and increase knowledge by supporting roadshows and events for people with learning disabilities, their families and carers

### The learning disability improvement standards for NHS trusts

**Standard 1.**  
Giving people their rights

**Standard 2.**  
Involving people and listening to them

**Standard 3.**  
Making sure we have the right staff with the right training

co-production

## 1.0 Introduction

Most people will have met or cared, either professionally or personally, for someone with a learning disability and /or autism.

Covering the period 2019 to 2021, this strategy sets out our plan by which we will drive improvements for patients with a learning disability and /or autism and cancer s for whom care is often complex and admission to hospital challenging.

To achieve this will require strategic planning, commitment and leadership at all levels within our organisation , coproduction with service users , advocates, self-advocates and carers and the contribution of our entire workforce.

As a Trust we believe it is important to work in partnership with individuals with a learning disability and /or autism, their families, advocates, self-advocates and carers people using co-production.

This means people with a learning disability, people with autism and people with both a learning disability and autism, and their families, working together with health and social care professionals, providers of services, to change people's lives for the better. To co-produce is to make something together.

This will enable us to have first-hand experience of improving the cancer patient journey and patient experience for individuals with a learning disability and /or autism living with cancer and their carers/families.

We will make the most of the resources and money we have available through work, which focuses on the shared priorities and principles identified during co-production.

As we progress, the care we offer individuals with a learning disability and /or autism living with cancer living and the support given to their carers/families, will be exemplary.

The Clatterbridge Cancer Centre NHS Foundation Trust Executive leads for learning disability and/or autism are:

- Director of Nursing and Quality and,

Issue Date: 18 <sup>th</sup> February 2020	Page 6 of 16	Filename: STWOLDA	Issue No: 1.0
Author: Debbie de Jonge	Authorised by: Integrated Governance Committee		Copy No:

- Head of Safeguarding.

Also integral to delivery of the learning disability and/or autism strategy will be:

- Individuals with a learning disability and /or autism, their families, advocates, self-advocates and carers
- Clinical Specialist for Additional Needs,
- Safeguarding Team ,
- Consultants in Psychological Medicine
- Community Learning Disability Facilitators,
- Education Champions,
- Estates and Environment Leads,
- Medical Staff and Allied Health Professions (AHPs), Senior Nurses including Ward Managers and Matrons.

## 2.0 Background

More people are surviving cancer than ever before, but we know that we can save even more lives by catching more cancers early and starting treatment fast.

One in every two people in this country will be told they have cancer at some point in their lives.

The NHS Long Term Plan (NHS England 2018) aims to save thousands more lives each year by dramatically improving how we diagnose and treat cancer. This will include improving our national screening programmes, giving people faster access to diagnostic tests, investing in cutting edge treatments and technologies, and making sure more patients can quickly benefit from precise, highly personalised treatments as medical science advances.

However, we know some people with learning disabilities, autism or both encounter difficulties when accessing NHS services and can have much poorer experiences than the general population (Heslop et al 2103; Tuffrey-Wines et al 2013: Allerton and Emerson 2012).

Issue Date: 18 <sup>th</sup> February 2020	Page 7 of 16	Filename: STWOLDA	Issue No: 1.0
Author: Debbie de Jonge	Authorised by: Integrated Governance Committee		Copy No:

In 2017-18, patients with learning disabilities had lower rates of cancer screening than patients without a learning disability. The difference was most pronounced in cervical screening, with 31.2% of patients with learning disabilities having a cervical screening compared to 73.2% of those without a learning disability.

52.5% of patients with learning disabilities received a breast cancer screening, compared to 68.0% of those without a learning disability.

Although there was an increase in those patients with learning disabilities receiving colorectal cancer screening (from 68.6 % in 2014-15 to 77.8 % in 2017-18), the rate was still significantly lower for those patients with learning disabilities (77.8 %) than those without (83.7 %) (NHS Digital 2019).

Several inquiries and investigations have also found that some NHS trusts and foundation trusts are failing to adequately respect and protect people’s rights, with devastating consequences for them and their families.

Skills deficits in the NHS workforce mean people’s needs are sometimes misunderstood or responded to inappropriately.

People with learning disabilities, autism or both and their families and carers should be able to expect high quality care across all services provided by the NHS. They should receive treatment, care and support that are safe and personalised; and have the same access to services and outcomes as their non-disabled peers.

Our vision is to provide the best cancer care to the people we support regardless of disability.

## 2.1 What do we mean by the term learning disability?

The term learning disability is used to describe an individual who has:

- A significantly reduced ability to understand new or complex information, or to learn new skills (impaired intelligence); and / or
- A reduced ability to cope independently (impaired adaptive functioning); which started before adult-hood and has a lasting effect on development

Issue Date: 18 <sup>th</sup> February 2020	Page 8 of 16	Filename: STWOLDA	Issue No: 1.0
Author: Debbie de Jonge	Authorised by: Integrated Governance Committee		Copy No:



(Department of Health, 2001).

*Please note: the term learning disability should not be confused with the term learning difficulty which is used in education as a broader term which includes people with specific learning difficulties such as dyslexia (Emerson and Heslop, 2010).*

## **2.2 What do we mean by the term autism?**

The term autism is used to describe a lifelong developmental condition that affects how a person communicates with, and relates to, other people. Autism also affects how a person makes sense of the world around them. It is a spectrum condition which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. About 50% of people with a diagnosis of autism also have a learning disability.

## **3.0 Context**

### **3.1 National Context**

Information from a range of sources consistently reports that people with learning disabilities in England die much younger than the general population (13 to 20 years younger for men with learning disabilities; 20 to 26 years younger for women with. As with the general population, the median age of death for people with learning disabilities is increasing.

More than three times the number of people with learning disabilities dies than would be expected when taking into account age and sex. The three most common causes of death for people with learning disabilities are circulatory diseases (22.9% of deaths), respiratory diseases (17.1%) and neoplasms (cancers) (13.1%). (PHE Learning Disability Observatory report 2015)

Our learning disability and autism strategy is aimed at individuals with a learning disability and /or autism living with cancer regardless of their age and has used the following national policies as the framework for structuring development activity over the next three years;

- ✓ NHS Improvement Learning Disability Improvement Standard's (2018)

Issue Date: 18 <sup>th</sup> February 2020	Page 9 of 16	Filename: STWOLDA	Issue No: 1.0
Author: Debbie de Jonge	Authorised by: Integrated Governance Committee		Copy No:

- ✓ Learning Disability Mortality Review Programme (LeDeR) Annual Report (2017-18),
- ✓ The NHS Long Term Plan (2018)
- ✓ The Care Act (2014)
- ✓ Building the Right Support (NHS England 2015)
- ✓ Mental Capacity Act (2005)

### 3.2 Local context

The Clatterbridge Cancer Centre NHS Foundation Trust is one of the largest NHS specialist cancer treatment facilities in the UK – employing 919 staff and providing more than 220,000 treatments and appointments to over 30,000 patients a year.

Based in Wirral and Liverpool, CCC serves a population of 2.3 million across Merseyside, Cheshire, North Wales, the Isle of Man and parts of Lancashire: providing an outstanding level of care; cutting-edge cancer treatments; a comprehensive network of off-site clinics and multi-disciplinary teams throughout the region, and a supportive environment committed to providing cancer patients and their carers/families with advice and support.

The Trust is currently undergoing considerable change and transformation and in May 2020, CCC will be expanding their services as we open our new hospital in Liverpool.

During 2017-2018, the Trust cared for 34 patients with a learning disability and diagnosis of cancer; 2 of whom had an inpatient stay and 32 who attended for cancer treatment as an outpatient.

At CCC we have already made significant progress in improving care for those individuals living with a learning disability and /or autism and cancer and their carers/families as noted in our achievements to date:

- Coproduction of this strategy with Cheshire and Merseyside service users, advocates, carers and family members
- Flagging system alert added to Meditech(patient electronic record)

Issue Date: 18 <sup>th</sup> February 2020	Page 10 of 16	Filename: STWOLDA	Issue No: 1.0
Author: Debbie de Jonge	Authorised by: Integrated Governance Committee		Copy No:

- Committed to an ‘Open Visiting’ culture which supports carer access in the hospital outside of normal working hours to enable them to be with the person with a learning disability and /or autism.
- Communication links between all members of the multi-disciplinary team, the patient, their family and carers; commenced on admission to hospital (or before, should the patient be an elective admission) and continues throughout their stay.
- Employment of a Clinical Specialist for Additional Needs whose role is to support patients with learning disability and /or autism and their carers during their cancer treatment journey
- Use of the Risk Assessment and Reasonable Adjustment Care Plan (RA) to provide individualised care for patients with a learning disability and /or autism; available on Meditech
- Development and delivery of a learning disability and /or autism awareness training programme for all levels of staff
- Established partnership working with our volunteer agencies, local self-advocates and advocacy groups, community learning disability facilitators, patient’s carer and their families.

## 4.0 Delivery of CCC Learning disability and/or autism Strategic Objectives 2019-2021

### 4.1 Objective 1: Respecting and protecting rights

#### CCC will:

- Treat all patients ,carers/relatives with dignity and respect
- Clearly identify people requiring the provision of reasonable adjustments, record, and the adjustments that are required, and regularly audit their provision.

Issue Date: 18 <sup>th</sup> February 2020	Page 11 of 16	Filename: STWOLDA	Issue No: 1.0
Author: Debbie de Jonge	Authorised by: Integrated Governance Committee		Copy No:

- Ensure appropriate social care assessments are timely and undertaken in line with Care Act (2014) requirements
- All patients will be assumed to have mental capacity in the decision making process unless proven otherwise.
- Work together with patients who lack mental capacity to ensure a best interest decision is made on their behalf by a suitable advocate.
- Ensure all clinical staff understand and follows legislation relating to Mental Capacity Act 2005/Deprivation of Liberty Safeguards and any decision made is communicated effectively to the patient’s relatives/ carers and colleagues within the multi-professional environment
- Participate in internal mortality reviews and the national Learning Disability Mortality Review (LeDeR) process, learning and acting on findings from investigations

**4.2 Objective 2: Develop our workforce to better understand the needs of people with learning disabilities and their families for all staff and volunteers working within the Trust**

**CCC will:**

- Deliver learning disability and autism awareness training sessions for all clinical and non-clinical staff, including volunteers to the Trust staff in conjunction with people with learning disabilities and/or autism and their families.
- Implement training and education at appropriate levels for ‘Learning disability/autism champions’ across the Trust.
- Develop staff confident in their roles are able to champion excellent practice and challenge any aspects of care that might not be in our patient’s best interest

Issue Date: 18 <sup>th</sup> February 2020	Page 12 of 16	Filename: STWOLDA	Issue No: 1.0
Author: Debbie de Jonge		Authorised by: Integrated Governance Committee	Copy No:

**4.3 Objective 3: Work in partnership with individuals with a learning disability and /or autism, their families, advocates, self-advocates and carers to improve the patient experience and journey in our hospital and community services**

**CCC will:**

- raise awareness of cancer and improve knowledge about cancer treatments across the Trust
- use feedback from patients with a learning disability and /or autism and their carers/relatives to inform the patient journey and improvements in our cancer pathways
- Endeavour to carry out the wishes of our patients wherever possible
- Strive to ensure all our patients are given support to communicate their wishes in the decision making process.
- Keep patients length of stay to the minimum required and endeavour to assist the patient back to their usual abode.

**4.4 Objective 4: Care for carers, relatives and friends of people with learning disability and/or autism**

**CCC will:**

- Support carers/relatives in their role ensuring they receive better information and advice; allowing carers/relatives to be true partners in delivery of care, involved in decision making and participating in social activities.
- Coproduce a feedback form specifically designed for patients with a learning disability and /or autism and their carers/relatives on discharge to capture feedback on patient experience.
- Aim for patients, carers and relatives to be able to speak freely with any member of staff caring for the patient and for any staff member to be able to respond with confidence, knowledge and understanding.
- The Trust welcomes the friends and carers of patients with learning disability and/or autism in all areas of the hospital. It is committed to

Issue Date: 18 <sup>th</sup> February 2020	Page 13 of 16	Filename: STWOLDA	Issue No: 1.0
Author: Debbie de Jonge	Authorised by: Integrated Governance Committee		Copy No:

an ‘Open Visiting’ culture which supports carer access in the hospital outside normal working hours to enable them to be with the person with a learning disability and/or autism.

**4.5 Objective 5: Improve communication to ensure appropriate information is collected and shared between healthcare staff, patients, carers and family members**

**CCC will:**

- Raise awareness of the profile of learning disability/autism and focus of the Learning disability and autism Strategy
- Ensure partners communicate and celebrate achievements.

**4.6 Objective 6: Develop and maintain collaborative systems wide partnerships**

**CCC will;**

- Benchmark the Trust against the national NHS Improvement learning disability improvement standards
- Coproduce an action plan with individuals with a learning disability and /or autism, their families, advocates, self-advocates and carers in response to the NHS Improvement standards benchmarking
- Continue to actively engage and work in partnership with individuals with a learning disability and /or autism, their families, advocates, self-advocates and carers in the Transforming Cancer Care project
- Engage individuals with learning disability and/or autism in research projects in partnership with our Trust research partners

**4.7 How will we measure success?**

Success of this strategy will be indicated by year on year delivery against agreed actions, the NHS Improvement Learning Disability Improvement standards and feedback from our service users, advocates, carers and families.

We will also report on the following indicators:

Issue Date: 18 <sup>th</sup> February 2020	Page 14 of 16	Filename: STWOLDA	Issue No: 1.0
Author: Debbie de Jonge	Authorised by: Integrated Governance Committee		Copy No:

- The number of patients with a diagnosis of learning disability and/or autism
- Feedback from people with learning disability and/or autism and their carers/family
- Uptake of and compliance with mandatory learning disability/autism awareness training
- Patient led assessment of clinical environment (PLACE) audit
- Number of care plans with a reasonable adjustment flag and relevant hospital passport in place
- Audits as indicated
- Celebrate and report success stories

#### 4.8 Monitoring and compliance

Delivery of the Trusts Learning Disability and Autism Strategy will be undertaken by the Trust learning disability champions in conjunction with Cheshire and Merseyside Confirm and challenge group.

The Trust learning disability champions consist of a variety of named clinical and non-clinical staff from each directorate across all Trust sites including volunteers who will be supported via the Matrons and Clinical Specialist for Additional Needs to deliver on this work to ensure progress across the Trust.

Progress will be monitored by the Safeguarding Committee on a quarterly basis and reported to the Trust Board via the Trusts Integrated Governance and Quality Committees.

Update and progress of work against the national NHS Improvement learning disability improvement standards will be presented in the Trusts Annual Quality Account.

#### 5.0 Key Documents

NHS Digital Published Jan 2019 Health and Care of People with Learning Disabilities: 2017-18 Health Care: Palliative Care, Cancer Screening and Condition Prevalence

Issue Date: 18 <sup>th</sup> February 2020	Page 15 of 16	Filename: STWOLDA	Issue No: 1.0
Author: Debbie de Jonge		Authorised by: Integrated Governance Committee	Copy No:

NHS Improvement Learning Disability Improvement Standard's (2018)

Learning Disability Mortality Review Programme (LeDeR) Annual Report (2017-18),

The NHS Long Term Plan (2018)

The Care Act (2014)

Building the Right Support (NHS England 2015)

Mental Capacity Act (2005)

Issue Date: 18 <sup>th</sup> February 2020	Page 16 of 16	Filename: STWOLDA	Issue No: 1.0
Author: Debbie de Jonge	Authorised by: Integrated Governance Committee		Copy No: