



**Blackpool Teaching
Hospitals**

NHS Foundation Trust

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| Title: Guidelines for the provision of Learning Disability Adapted Dementia Screening | | Version Number: 1 |
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| <p>Blackpool Teaching Hospitals NHS Foundation Trust aims to design and implement services, policies and measures that meet the diverse needs of our service, population and workforce, ensuring that they are not placed at a disadvantage over others. The Equality Impact Assessment Tool is designed to help you consider the needs and assess the impact of your policy in the final Appendix.</p> | | |

CONTENTS

| | | |
|-------|--|----|
| 1 | Purpose | 3 |
| 1.1 | Philosophy and Health Need | 3 |
| 2 | Target Audience | 3 |
| 3 | Guideline | 3 |
| 3.1 | Blackpool Integrated Community Learning Disability Team | 3 |
| 3.1.1 | Blackpool Learning Disability Team Adapted Dementia Screening and Support | 4 |
| 3.2 | Benefits of Prospective assessment | 4 |
| 3.2.1 | Assessment | 4 |
| 3.3 | Proactive Screening for people diagnosed with Down's Syndrome | 5 |
| 3.3.1 | Overview of Assessment Tools Currently utilised by Blackpool Integrated Learning Disability Team in the Dementia Screening Process | 5 |
| 3.4 | Monitoring following Dementia Diagnosis | 5 |
| 3.5 | Referral Pathway..... | 6 |
| 4 | Attachments | 6 |
| 5 | Procedural Document Storage (Hard and Electronic Copies) | 6 |
| 6 | Locations this Document Issued to..... | 6 |
| 7 | Other Relevant / Associated Documents..... | 6 |
| 8 | Supporting References / Evidence Based Documents | 7 |
| 9 | Consultation / Acknowledgements with Staff, Peers, Patients and the Public | 7 |
| 10 | Definitions / Glossary of Terms | 8 |
| 11 | Author / Divisional / Directorate Manager Approval..... | 8 |
| | Appendix 1: Dementia Health Screening Assessment..... | 9 |
| | Appendix 2: Equality Impact Assessment Form..... | 14 |

| | | |
|---|------------------------------|---|
| Blackpool Teaching Hospitals NHS Foundation Trust | | ID No. CORP/GUID/483 |
| Revision No: 1 | Next Review Date: 01/01/2022 | Title: Guidelines for the provision of Learning Disability Adapted Dementia Screening |
| <i>Do you have the up to date version? See the intranet for the latest version</i> | | |

1 PURPOSE

1.1 Philosophy and Health Need

The aim of this guidance is to ensure that people with learning disabilities have access to adapted dementia screening where appropriate and in turn access appropriate health and social care support to enable them to be at their optimum health. The guidance will also enable staff in acute and primary care settings to identify eligible people and make contact with the Learning Disability team to ensure they are known and followed up accordingly.

Increasing lifespans and advances in healthcare have contributed to an ageing population that is dependent on others in terms of care and support. This particularly applies to older persons who develop dementia, a disease characterised by confusion, loss of memory and loss of adaptive skills.

People with a learning disability have an increased risk of developing dementia across the lifespan. Individuals with a diagnosis of Down's syndrome have a specific additional risk of developing early onset dementia of the Alzheimer's type

Early assessment and diagnosis means that people who have a learning disability can access other health and social care services and interventions that are appropriate to their level of need. This is particularly important given that in recent years there has been growing evidence from a series of reports and inquires that the health service is not commissioning or providing services in a way that adequately meets people with learning disabilities health needs and that people with a learning disability will die from a cause which could have been prevented (CIPOLD, 2013).

2 TARGET AUDIENCE

These guidelines apply to the practice of staff within the Integrated Learning Disability Team (Adults) in the provision of health and social care and support. They also apply to all staff that has healthcare interactions for patients with Learning Disabilities in the Blackpool locality aged 18 years plus and registered with a Blackpool or Cleveleys general practitioner, in the provision of general healthcare and support of people with a learning disability in order to facilitate access to specialist assessment as needed.

3 GUIDELINE

3.1 Blackpool Integrated Community Learning Disability Team

The team is made up of Health and Social Care Professionals from Blackpool Teaching Hospitals NHS Foundation Trust and Blackpool Council who work together to provide a service to adults with a learning disability. A range of services are offered through referral to the team that includes:

- Joint health and social care assessments of an individual's needs;
- Identification of services and support systems to meet individual need;

| | | |
|---|------------------------------|---|
| Blackpool Teaching Hospitals NHS Foundation Trust | | ID No. CORP/GUID/483 |
| Revision No: 1 | Next Review Date: 01/01/2022 | Title: Guidelines for the provision of Learning Disability Adapted Dementia Screening |
| <i>Do you have the up to date version? See the intranet for the latest version</i> | | |

- Development of care and support plans alongside the person and other relevant people;
- Specialist consultation and advice to other health, social care and provider agencies thus promoting equal access to all available services for people with a learning disability;
- and comprehensive assessment in the assessment of adults with Learning Disabilities who may be at high risk of dementia or who present with a dementia profile.

3.1.1 Blackpool Learning Disability Team Adapted Dementia Screening and Support

The Dementia screening service has been set up by Blackpool learning disability partnership to help meet the needs of local people with learning disability who need to access adapted dementia assessment. Services include proactive dementia screening for persons with a diagnosis of Down’s syndrome and reactive screening for persons who have a diagnosis of Learning Disability without a diagnosis of Down’s syndrome.

3.2 Benefits of Prospective assessment

There are many known health risks for people with a diagnosis of Down’s syndrome, with many treatable illnesses having symptoms which mimic the types of decline associated with the onset of dementia. An effective proactive dementia screening process is able to help identify these types of problems which may include memory and behavioural change, and/or physical or mental health concerns which will benefit from early treatment. Early changes associated with dementia in people with Down’s syndrome can often relate to behaviour or personality rather than memory functioning. For this reason, assessments that explore executive functioning are important to consider, especially in terms of establishing baseline measurement when a person is still healthy and well.

3.2.1 Assessment

Due to the varied levels of cognitive and functional ability in people with a diagnosis of intellectual disability comparison with ‘peer related norms’ is not possible. Therefore, any assessment of decline needs to be personalised to each individual with their own ‘baseline’ of best ability being the comparison when concerns arise.

Published in 2015, the British Psychological society (BPS) and Royal College of Psychiatrists “Dementia and People with Intellectual Disabilities: Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia” (BPS, 2015) recommends that the following be taken into consideration when conducting comprehensive assessment of dementia in adults with a learning disability:

- File review and systematic history-taking from the person and multiple informants across settings and services, who have known the individual for a significant period of time.
- Physical and mental state examinations.

| | | |
|---|------------------------------|---|
| Blackpool Teaching Hospitals NHS Foundation Trust | | ID No. CORP/GUID/483 |
| Revision No: 1 | Next Review Date: 01/01/2022 | Title: Guidelines for the provision of Learning Disability Adapted Dementia Screening |
| <i>Do you have the up to date version? See the intranet for the latest version</i> | | |

- Cognitive examinations.
- Other investigations to evaluate present functioning.
- Screening for other sources of decline e.g. thyroid problems; hearing loss; Urinary Tract Infection (UTI) infections.

3.3 Proactive Screening for people diagnosed with Down’s Syndrome

As part of the proactive screening service individuals with a diagnosis of Down’s syndrome are offered a ‘baseline’ assessment when they reach the age of 30 years. Screening includes completion of a ‘health checklist’ (see Appendix 1), that includes checking that annual health checks are being completed and also screens for symptoms of conditions that are known to commonly be associated with Down’s syndrome e.g. thyroid problems; hearing difficulties. If such symptoms are noted then a referral to the appropriate agency is made e.g. General Practitioner (GP); Community Learning Disability Nurse (CLDN).

Future periodic screening is also then offered from aged 50 (unless notified of significant changes earlier) and based upon individual need in order to explore any changes that have occurred in the interim period. Changes that indicate a concern of a dementia will trigger a referral to the Memory Assessment Team for formal diagnosis.

Young people in transition with a diagnosis of Down’s syndrome will be identified by the transitions worker and details added to the data on the dementia screening service.

Referrals of adults new to the Blackpool Area with a diagnosis of Downs Syndrome will be added on the dementia screening service.

3.3.1 Overview of Assessment Tools Currently utilised by Blackpool Integrated Learning Disability Team in the Dementia Screening Process

Following consideration of the British Psychological Society and the Royal College of Psychiatrists “Dementia and People with Intellectual Disabilities: Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia” Blackpool Integrated Learning Disability Team utilises the following methods of data collection when completing learning disability adapted memory assessment. Due to the variability in presentation of clients with a learning disability the type of assessment used may vary dependant on ability.

3.4 Monitoring following Dementia Diagnosis

A programme of regular monitoring and reassessment should be established once there is a suspicion that a person has dementia. This enables the progression of the disease to be described and suitable medical, psychosocial and environmental interventions to be put in place. The nature of the monitoring will be agreed and recorded in the individual’s health and social care plan. In some instances bespoke training packages are delivered to families and/or staff teams in order to demonstrate practical steps which can increase independence and promote longer term well-being.

| | | |
|---|------------------------------|---|
| Blackpool Teaching Hospitals NHS Foundation Trust | | ID No. CORP/GUID/483 |
| Revision No: 1 | Next Review Date: 01/01/2022 | Title: Guidelines for the provision of Learning Disability Adapted Dementia Screening |
| <i>Do you have the up to date version? See the intranet for the latest version</i> | | |

Any diagnosis of Dementia is made by the Memory Service following screening from the Integrated Learning Disability Team. Memory Assessment Service (MAS) may offer the individual pharmaceutical intervention through access to their own specialist psychiatrist.

Memory Assessment Service discharge back to the General Practitioner for ongoing review of pharmaceutical intervention. Any outcomes of assessment will be shared with the Learning Disability Team.

The Integrated Learning Disability Team are a Multi-Disciplinary Team who are able to provide individuals diagnosed with Dementia with access to Learning Disability specific Psychiatry, Psychology, Speech and Language Therapist (SALT), Nursing, Social Care and Occupational Therapist (OT).

Individuals receive an annual Care Act Assessment Review which may trigger referrals to any of the above specialist services. Referrals may also be accepted from other areas if concerns regarding a change in needs occurs. Changes may include behavioural presentation, declining feeding ability, mobility concerns etc.

3.5 Referral Pathway

The Learning Disability Team operate an open referral system. Referrals can be made in person, by phone or letter. Information relating to evidence of learning disability is required at point of referral in addition to information around the reason for the referral.

The Learning Disability Team operates Monday to Friday, between the hours of 09.00 hours to 17.00 hours. To contact the team, please call 01253 477803.

| 4 ATTACHMENTS | |
|-----------------|--------------------------------------|
| Appendix Number | Title |
| 1 | Dementia Health Screening Assessment |
| 2 | Equality Impact Assessment Form |

| 5 PROCEDURAL DOCUMENT STORAGE (HARD AND ELECTRONIC COPIES) |
|--|
| Electronic Database for Procedural Documents |
| Held by Procedural Document and Leaflet Coordinator |

| 6 LOCATIONS THIS DOCUMENT ISSUED TO | | |
|-------------------------------------|--------------------------------|-------------|
| Copy No | Location | Date Issued |
| 1 | Intranet | 08/01/2019 |
| 2 | Wards, Departments and Service | 08/01/2019 |

| 7 OTHER RELEVANT / ASSOCIATED DOCUMENTS | |
|---|--|
| Unique Identifier | Title and web links from the document library |
| | |

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|--|------------------------------|---|
| Blackpool Teaching Hospitals NHS Foundation Trust | | ID No. CORP/GUID/483 |
| Revision No: 1 | Next Review Date: 01/01/2022 | Title: Guidelines for the provision of Learning Disability Adapted Dementia Screening |
| Do you have the up to date version? See the intranet for the latest version | | |

| 8 SUPPORTING REFERENCES / EVIDENCE BASED DOCUMENTS |
|--|
| References In Full |
| Dementia: supporting people with dementia and their carer's in health and social care. CG42, Nov 2006, last Update Sept 2016. See pgs. 9, 10,12-13, 16-17, 20, 23, 26 and 28. https://www.nice.org.uk/guidance/cg42 |
| Mental Health Foundation – Need2Know: Peer Support - in mental health and learning disability, Aug 2012 https://www.mentalhealth.org.uk/publications/need2know-briefing-peer-support |
| Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) 2013. http://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf |
| Royal College Nursing (RCN) - Meeting the health needs of people with learning disabilities: RCN guidance for nursing staff, 2013. https://www.rcn.org.uk/professional-development/publications/pub-003024 |
| 2015, Dementia and people with intellectual disabilities: guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia. <i>British Psychological society, Royal Society, Royal College of Psychiatrists.</i> |
| Foundation for People with Learning Disabilities (FP) authors Christine Towers and Cindy Glover - Talking Together: Facilitating peer support activities to help people with learning disabilities understand about growing older and living with dementia, 2015. https://www.mentalhealth.org.uk/learning-disabilities/our-work/getting-the-right-support/talking-together |
| Mental health problems in people with learning disabilities: prevention, assessment and management NG54, Sept 2016. See pgs. 13-14, 18, 31 and 33. https://www.nice.org.uk/Guidance/NG54 |
| NICE Bites/Specialist pharmacy Service Oct/Nov 2016: No 91. Mental health problems in people with learning disabilities. https://www.sps.nhs.uk/articles/nice-bites-mental-health-problems-in-people-with-learning-disabilities-and-challenging-behavior-and-learning-disabilities/ |
| Royal College Nursing (RCN) - The Needs of People with Learning Disabilities: What pre-registration students should know 2017. https://www.rcn.org.uk/professional-development/publications/pub-005769 |
| Advances in Mental Health and Intellectual Disabilities, 11(4), 2017, pp.134-44. - Aging with intellectual and developmental disabilities and dementia in Manitoba (Abstract). |

| 9 CONSULTATION / ACKNOWLEDGEMENTS WITH STAFF, PEERS, PATIENTS AND THE PUBLIC | | |
|---|--|-------------------------------|
| Name | Designation | Date Response Received |
| Vivien Banner | Learning Disability Nurse | September 2017 |
| Anna Southerland | Locum Clinical Psychologist | January 2017 |
| Dagmar Hartshorn | Locum Clinical Psychologist | July 2017 |
| Yvette Griffin | Community mental health nurse. Fylde Coast Memory Assessment Service | August 2017 |
| Mrs C Smith | Parent /Carer | May 2017 |

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|--|------------------------------|---|
| Blackpool Teaching Hospitals NHS Foundation Trust | | ID No. CORP/GUID/483 |
| Revision No: 1 | Next Review Date: 01/01/2022 | Title: Guidelines for the provision of Learning Disability Adapted Dementia Screening |
| Do you have the up to date version? See the intranet for the latest version | | |

| 10 DEFINITIONS / GLOSSARY OF TERMS | |
|---|-------------------------------------|
| BPS | British Psychological society |
| CLDN | Community Learning Disability Nurse |
| GP | General Practitioner |
| LD | Learning Disability |
| MCA | Mental Capacity Act |
| MDT | Multi-Disciplinary Team |
| MAS | Memory Assessment Service |
| OT | Occupational Therapist |
| SALT | Speech and Language Therapist |
| UTI | Urinary Tract Infection |

| 11 AUTHOR / DIVISIONAL / DIRECTORATE MANAGER APPROVAL | | | |
|--|---|-------------------|--|
| Issued By | Liz Russell | Checked By | Michelle Sowden |
| Job Title | Team Manager Community Learning Disability Team | Job Title | Head of Mental Health & Learning Disability Services |
| Date | October 2017 | Date | October 2017 |

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|---|------------------------------|--|
| Blackpool Teaching Hospitals NHS Foundation Trust | | ID No. CORP/GUID/483 |
| Revision No: 1 | Next Review Date: 01/01/2022 | Title: Guidelines for the provision of Learning Disability Adapted Dementia Screening |
| <i>Do you have the up to date version? See the intranet for the latest version</i> | | |

APPENDIX 1: DEMENTIA HEALTH SCREENING ASSESSMENT

Dementia Health Screen Checklist

| | |
|--|--|
| Information – including referral details | |
| Assessment Baseline completed on (if applicable) | |
| Personal details Name | |
| DOB | |
| Address | |
| Completed by | |
| Information source | |
| How long have they known the person | |
| Does the person have a diagnosis i.e. Downs Syndrome | |
| Next of kin | |
| Address | |
| Home telephone | |
| Mobile | |
| Any family history of Diabetes, dementia, heart disease, stroke, epilepsy | |
| Capacity and consent - Has the person consented to this assessment? | |
| Is the assessment being completed in the person's best interest? | |
| Does the person consent to the nurse obtaining a patient summary from their GP | |

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|--|------------------------------|---|
| Blackpool Teaching Hospitals NHS Foundation Trust | | ID No. CORP/GUID/483 |
| Revision No: 1 | Next Review Date: 01/01/2022 | Title: Guidelines for the provision of Learning Disability Adapted Dementia Screening |
| Do you have the up to date version? See the intranet for the latest version | | |

APPENDIX 1: DEMENTIA HEALTH SCREENING ASSESSMENT



**Blackpool Teaching
Hospitals**
NHS Foundation Trust

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Medication

| Name of drug | Strength | Frequency | Route | Prescribed for | Other |
|--------------|----------|-----------|-------|----------------|-------|
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |

Medical conditions with a diagnosis

| Condition | Yes | No | Consultant | Last appointment | Drug therapy |
|----------------------------|-----|----|------------|------------------|--------------|
| Diabetes | | | | | |
| Epilepsy | | | | | |
| Cardio vascular conditions | | | | | |
| Alcohol dependence | | | | | |
| Illegal drug dependence | | | | | |
| Urinary retention / UTIs | | | | | |
| Constipation | | | | | |
| Mental health condition | | | | | |

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|--|------------------------------|---|
| Blackpool Teaching Hospitals NHS Foundation Trust | | ID No. CORP/GUID/483 |
| Revision No: 1 | Next Review Date: 01/01/2022 | Title: Guidelines for the provision of Learning Disability Adapted Dementia Screening |
| Do you have the up to date version? See the intranet for the latest version | | |

APPENDIX 1: DEMENTIA HEALTH SCREENING ASSESSMENT



**Blackpool Teaching
Hospitals**
NHS Foundation Trust

Blackpool Council

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|---|--|
| Communication - How does the person communicate -? | |
| Who does the person live with? | |
| How does the person display pain – Is there a pain assessment tool in place | |
| Life changes – Environmental, personal, change of staff change in routine/activities any recent physical illness. | |

| Health checks | Yes | No | Last appointment | Details | Outcomes / results |
|-------------------------------|-----|----|------------------|---------|--------------------|
| LD health check | | | | | |
| Eye health check / impairment | | | | | |
| Hearing check / impairment | | | | | |
| Blood test | | | | | |
| Urinalysis | | | | | |
| | | | | | |

| | |
|---|--|
| Mobility - Difficulty with mobility or coordination – describe – how long for | |
| Difficulty with depth and perception – Describe – how long for | |
| Does the person have access to a downstairs bathroom / wet room? | |
| Are there aids and adaptations fitted or requires | |

| | | |
|--|------------------------------|---|
| Blackpool Teaching Hospitals NHS Foundation Trust | | ID No. CORP/GUID/483 |
| Revision No: 1 | Next Review Date: 01/01/2022 | Title: Guidelines for the provision of Learning Disability Adapted Dementia Screening |
| Do you have the up to date version? See the intranet for the latest version | | |

APPENDIX 1: DEMENTIA HEALTH SCREENING ASSESSMENT



**Blackpool Teaching
Hospitals**
NHS Foundation Trust

Blackpool Council

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|--|--|
| Has the person ever had an OT assessment – Who with – outcome | |
| Has the person ever had a physio assessment – who – outcomes | |
| Skin integrity - Is the person skin integrity a cause for concern – describe | |
| Eating and drinking - | |
| Does the person have a special diet – describe | |
| Has the person had a SALT assessment – with who – outcome | |
| Are there eating and drinking guidelines in place – date last reviewed | |
| Does the person suffer from reoccurring chest infections? | |
| Does the person cough when eating or drinking | |
| Has the person lost weight in the past 12 month? | |
| Sleep pattern - Describe sleep pattern including any recent changes to usual routine | |
| Behaviour - Describe any changes to patterns of usual behaviour either emotionally or socially | |

Other health professionals involved at present

| Profession | Yes/No | Name | Contact details | Last seen |
|------------|--------|------|-----------------|-----------|
| Nursing | | | | |
| Psychology | | | | |
| Psychiatry | | | | |

| | | |
|--|------------------------------|---|
| Blackpool Teaching Hospitals NHS Foundation Trust | | ID No. CORP/GUID/483 |
| Revision No: 1 | Next Review Date: 01/01/2022 | Title: Guidelines for the provision of Learning Disability Adapted Dementia Screening |
| Do you have the up to date version? See the intranet for the latest version | | |

APPENDIX 1: DEMENTIA HEALTH SCREENING ASSESSMENT



| Profession | Yes/No | Name | Contact details | Last seen |
|-----------------------|--------|------|-----------------|-----------|
| SALT | | | | |
| Physiotherapy | | | | |
| Occupational therapy | | | | |
| Dietetics | | | | |
| Mental health team | | | | |
| Hospital / consultant | | | | |
| Extensive team | | | | |
| Other | | | | |

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| Any other information / concerns not discussed. | |
| Date DLD completed and by whom - | |
| Action agreed - | |
| Completed by | |
| Date | |

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|--|------------------------------|---|
| Blackpool Teaching Hospitals NHS Foundation Trust | | ID No. CORP/GUID/483 |
| Revision No: 1 | Next Review Date: 01/01/2022 | Title: Guidelines for the provision of Learning Disability Adapted Dementia Screening |
| Do you have the up to date version? See the intranet for the latest version | | |

| APPENDIX 2: EQUALITY IMPACT ASSESSMENT FORM | | | | | |
|--|--|---|-----------------------|-----------------|------------|
| Department | Adult & Long Term Conditions | Service or Policy | Learning Disabilities | Date Completed: | 10/10/2017 |
| GROUPS TO BE CONSIDERED Deprived communities, homeless, substance misusers, people who have a disability, learning disability, older people, children and families, young people, Lesbian Gay Bi-sexual or Transgender, minority ethnic communities, Gypsy/Roma/Travellers, women/men, parents, carers, staff, wider community, offenders. | | | | | |
| EQUALITY PROTECTED CHARACTERISTICS TO BE CONSIDERED Age, gender, disability, race, sexual orientation, gender identity (or reassignment), religion and belief, carers, Human Rights and social economic / deprivation. | | | | | |
| QUESTION | RESPONSE | | IMPACT | | |
| | Issue | Action | Positive | Negative | |
| What is the service, leaflet or policy development? What are its aims, who are the target audience? | This pathway is to ensure early assessment leading to diagnosis of people who have a learning disability can enhance access to other health and social care interventions that are appropriate to their level of need. | No action | Positive | | |
| Does the service, leaflet or policy/ development impact on community safety • Crime • Community cohesion | This pathway helps to protect vulnerable people with learning disabilities and dementia by identifying their needs for support at an early stage. With the provision of adequate and timely support, these individuals will be less susceptible to being targeted in criminal activities. Community cohesion will also be enhanced through the support of the vulnerable members of the community. | No action | Positive | | |
| Is there any evidence that groups who should benefit do not? i.e. equal opportunity monitoring of service users and/or staff. If none/insufficient local or national data available consider what information you need. | For the pathway to be implemented fully, work is required to identify all people in the Blackpool area who have Down's Syndrome, and all people with learning disabilities who are starting to experience dementia. More information from GP practices, education services and care providers may be necessary. | Information being gathered from GP practices, education and care providers is on-going. | Positive | | |
| Does the service, leaflet or development/ policy have a negative impact on any geographical or sub group of the population? | Implementing the pathway, and offering regular dementia assessments, may make some people with Down's Syndrome anxious about developing dementia. | No action | Positive | | |
| How does the service, leaflet or policy/ development promote equality and diversity? | As some standard tests for dementia do not provide a reliable assessment for people with Down's Syndrome and other learning disabilities, this pathway ensures that the correct tests are used for this client group so that dementia can be identified as quickly and as accurately in people with Down's Syndrome and other learning disabilities as in people without these diagnoses. A deterioration in cognitive impairments may not be identified as quickly in people with Down's Syndrome as in people without any learning disabilities; this pathway ensures that people with Down's Syndrome will be offered regular assessments so that changes can be identified quickly and reliably. | No action | Positive | | |
| Does the service, leaflet or policy/ development explicitly include a commitment to equality and diversity and meeting needs? How does it demonstrate its impact? | The pathway ensures that people with Down's Syndrome and other learning disabilities who start to develop dementia are identified at an early stage and can be given the treatment and support that they require in the same as people without any learning disabilities. | No Action | Positive | | |
| Does the Organisation or service workforce reflect the local population? Do we employ people from disadvantaged groups | The Trust currently promotes positive "discrimination" for people with learning disabilities and other disabilities in recruitment policy and practices. | No Action | Positive | | |

| | | |
|--|------------------------------|---|
| Blackpool Teaching Hospitals NHS Foundation Trust | | ID No. CORP/GUID/483 |
| Revision No: 1 | Next Review Date: 01/01/2022 | Title: Guidelines for the provision of Learning Disability Adapted Dementia Screening |
| Do you have the up to date version? See the intranet for the latest version | | |

| APPENDIX 2: EQUALITY IMPACT ASSESSMENT FORM | | | | |
|--|---|-----------|----------|--|
| Will the service, leaflet or policy/ development i. Improve economic social conditions in deprived areas ii. Use brown field sites iii. Improve public spaces including creation of green spaces? | The pathway will ensure that people with learning disabilities and dementia receive good quality, professional care and treatment at an early stage. An example of this may be the contribution of the pathway to people with learning disabilities and dementia being prescribed memory-enhancing medication which will delay the deterioration in their functioning and allow them to have a more independent, productive and better quality of life for longer. By receiving appropriate care and treatment when required, this will help to improve the economic situation of people with learning disabilities and dementia and of their families. | No Action | Positive | |
| Does the service, leaflet or policy/ development promote equity of lifelong learning? | The pathway will enable people with learning disabilities and dementia to continue to develop their skills as long as possible. When people are diagnosed with dementia, medication can help to protect their ability to learn and remember. Behavioural interventions and memory aids can also support people with dementia to find new ways to access and retrieve information, so that they can function more effectively for as long as possible. | No Action | Positive | |
| Does the service, leaflet or policy/ development encourage healthy lifestyles and reduce risks to health? | The pathway supports the early identification and treatment of dementia, to help people stay well and function well as long as possible. Where people have other health conditions, an early diagnosis of dementia will ensure that their ability to manage their other health conditions and they can be given additional support to do this when they require it. | No Action | Positive | |
| Does the service, leaflet or policy/ development impact on transport? What are the implications of this? | People with dementia experience impairments in their ability to orient themselves to place and to remember and recognize routes. Early diagnosis and treatment can delay these impairments. Dementia assessments and monitoring cognitive impairments can help to determine when additional support is required with transport. | No Action | Positive | |
| Does the service, leaflet or policy/development impact on housing, housing needs, homelessness, or a person's ability to remain at home? | The pathway aims to help people with learning disabilities and dementia remain as independent as possible for as long as possible. It will also help to determine what type of accommodation and level of support is most appropriate. | No Action | Positive | |
| Are there any groups for whom this policy/ service/leaflet would have an impact? Is it an adverse/negative impact? Does it or could it (or is the perception that it could exclude disadvantaged or marginalised groups? | This pathway will have an impact on people with Down's Syndrome, their families and care providers. As outlined above, there are many advantages to regular assessments and early diagnosis. However, regular assessments for dementia may cause anxiety and distress. Receiving an early diagnosis of dementia may cause distress earlier than a later diagnosis. | No Action | Positive | |
| Does the policy/development promote access to services and facilities for any group in particular? | The pathway promotes access to the Learning Disability Service and to the Psychology team for people with Down's Syndrome and for people with learning disabilities whose presentation has recently changed. It also promotes access to Psychiatry and to the Memory Assessment Service. | No Action | Positive | |

| | | |
|---|------------------------------|---|
| Blackpool Teaching Hospitals NHS Foundation Trust | | ID No. CORP/GUID/483 |
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| APPENDIX 2: EQUALITY IMPACT ASSESSMENT FORM | | | | |
|--|--------------------------------|---------------------|-----------|---------------------------------------|
| Does the service, leaflet or policy/development impact on the environment | 1. Meetings 2. Appointments | No Action | Positive | |
| 1. During development 2. At implementation? | | | | |
| ACTION: | | | | |
| Please identify if you are now required to carry out a Full Equality Analysis | | | No | (Please delete as appropriate) |
| Name of Author: Signature of Author: | Liz Russell | Date Signed: | | |
| Name of Lead Person: Signature of Lead Person: | Vivienne Banner | Date Signed: | | |
| Name of Manager: Signature of Manager | Michelle Sowden | Date Signed: | | |

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| Blackpool Teaching Hospitals NHS Foundation Trust | | ID No. CORP/GUID/483 |
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