Developing a Reablement Service for people with memory problems or a dementia living at home in Wales

Resource Document
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How to use this document

This document is divided into sections that can be used either as 'special interest' sections or as a whole development manual relevant to the requirements of a reablement provider. It focuses on individuals with memory problems or a dementia living in their own homes/sheltered accommodation in the community and does not include information on the following:

- Supporting people with memory problems or a dementia with medication administration and management.
- People with memory problems or a dementia in residential or nursing care.
- Individuals known to Specialist Learning Disabilities Services.

However the principles and values section contained within this document can be applied across different accommodation provision or service user groups. These are included in the section, ‘Vision, Principles and Values’ which should be read before the ‘Introduction’ to provide the reader with an understanding of the ethos of this document.

The document starts with an introduction followed by the sections ‘Definition of a Reablement Service for people with memory problems or a dementia’ and ‘What is Dementia?’ It is advised that providers unfamiliar with working with people with memory problems or a dementia should read this section ‘What is Dementia’ before moving onto others.

The other sections of this resource document have an overview with their own individual standard. Good practice points are also included to support the provider to achieve each standard. However this is not an exhaustive list of good practice points and providers may identify other points that they may wish to include.

Some sections of this document are cross cutting with others. It is advised that they are read in conjunction with the chosen section to gain fuller explanations.

As this document is written as a pick and mix resource, it is advised that the section ‘glossary of terms’ is read first.

This provides explanations for the reader who chooses to read selected sections rather than the whole document. Throughout this document individuals are referred to either as experiencing memory problems or a dementia. This provides for individuals who may not have a diagnosis; either out of choice or they are unable to secure a diagnosis for different reasons but will experience memory problems indicative of dementia. Some of these individuals may not go on to develop a dementia. Further information on this topic is provided in the section ‘What is Dementia’.

The term ‘informal carers’ is used in this document. It refers to people of any age who support individuals with memory problems or a dementia. Informal carers provide unpaid care compared to ‘carers’ who provide care under a contract or by virtue of a contract or as voluntary work.
The terms carer and informal carer

The term informal carer used in this document refers to unpaid carers.

The Carers Strategy for Wales 2013\(^1\) defines a carer as ‘anyone of any age, who provides care and support to a relative, friend or neighbour who is disabled, physically or mentally ill or affected by substance misuse. Unpaid carers are the single largest provider of care to people with support needs in our communities and they save the NHS and Social Services millions of pounds a year’. The Social Services and Well-being Act 2014\(^2\) defines a carer as ‘a person who provides, or intends to provide, care for an adult or disabled child. It excludes those who provide care under or by virtue of a contract or as voluntary work. The definition includes carers of all ages’.

Virtual ward

Regulars meeting held in the community to discuss individuals with memory problems or dementia known to a particular GP practice. Participants are representatives from the reablement team, the GP and any other significant professional or organisation involved with the individual and reablement. The individual being discussed is either receiving a reablement programme or maybe identified as suitable for assessment for reablement. Problems, issues and progress can be shared between all professionals.

Assistive Technology

Assistive technology is an umbrella term that refers to any device or system that supports an individual to carry out a task or activity that they are unable to carry out themselves. The device reduces the risk to the person in performing it.

Telecare - refers to devices that are linked to a call monitoring centre or a designated person via a telephone line. These devices automatically and remotely monitor and manage identified risks such as flood, gas or leaving the home sensors. Other devices include monitoring daily living patterns in an individual's home over a period of time.

Telehealth is not a specific service. It involves using telecommunication technologies to enhance, monitor and evaluate an individual's health care. Apart from using electronic communication systems and remote patient monitoring other mobile health devices are computers and tablets etc.

Telemedicine is also a term that is used to describe a range of diagnosis, management and education in health care.

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The Vision

The resource document is designed to support people in developing reablement services for people with memory problems or a dementia, offering timely support to enable individuals to relearn skills, routines and interests that are important to them to live fulfilled lives in their own homes and communities; providing information, training and reassurance to informal carers for them to have confidence to support the individual.

Whilst it is recognised that Welsh Reablement Services deliver positive outcomes for their service users, they will continue to evolve in different ways, dependent on variables such as current provision, budget and partnership arrangements and agreements. Therefore this document is not about promoting one model but rather about supporting reablement development for people with memory problems or a dementia across Wales.

Principles and Values

When setting up a reablement service for people with memory problem or a dementia the following principles and values must be agreed.

• There is knowledge and understanding of the needs of people with a memory problem or a dementia.

• Reablement promotes the equal importance of mental, emotional and physical wellbeing.

• Reablement destroys the myth that people with memory problems or a dementia cannot be supported to build on their strengths and resilience and can benefit from a degree of choice and independence.

• Reablement works in diverse and multicultural communities; recognising and responding to difference; ensuring all people with memory problems or a dementia are given the same opportunities as others to live well at home.

• The reablement workforce will see beyond the individual’s difficulties and see the person and their strengths; acknowledge and respect their knowledge and experience.

• Everyone involved in the life of an individual with memory problems or a dementia participating in a reablement programme will be encouraged and supported to believe in and sign up to its ethos.

• Governance arrangements are established and maintained for service provision.

• Informal carers, including ‘hidden’ informal carers in diverse and multi-cultural communities, will be recognised and respected for their knowledge and experiences of supporting individuals with memory problems or a dementia; participate on the basis of equal partnership in operational and strategic forums relevant to reablement; contribute to local and national ‘reablement’ strategies and be involved in the recruitment and training of staff in reablement services in their communities.
Introduction

The purpose of this resource document is to assist in providing equity in principles, values, skills and knowledge to be achieved in providing Reablement Services for people living at home in Wales with memory problems or a dementia. It is not intended to be a document to inform strategic direction. It aims to provide practical and operational support to enhance service development, including where any current provision may partly meet some or all of the standards.

Established Welsh reablement services for individuals with poor physical health will have already developed standards of good practice. There will be cross-cutting issues and themes between working with people with physical disabilities and those with poor mental health.

A reablement model enables individuals and their informal carers to achieve good outcomes supporting individuals to live independently and well at home. The model focuses on what people ‘can do’ rather than what they ‘can’t’, providing opportunities for them to identify what they want to achieve.

The increasing numbers of adults experiencing memory problems or a dementia estimated by the Alzheimer’s Society and Diverse Cymru cannot be ignored. Radical changes are required to enable them to live well at home.

Current Welsh reablement services for people with memory problems or a dementia are supporting individuals based on their needs and strengths. These services have demonstrated success in supporting individuals to become independent of services via a reablement programme. They recognise that reablement will restore and maintain existing skills for individuals who will not go on to achieve complete independence. The Position Statement on Reablement in Wales (2013) provides information on the provision and promotion of Welsh reablement services. It refers to Sustainable Social Services for Wales (Welsh Assembly Government 2011) and the Social Services and Well-being (Wales) Act (2014) promoting reablement services.

This resource document has had the benefit of contributions from individuals and informal carers with knowledge and experience of a reablement service for people with memory problems or a dementia, professionals from statutory and third sector organisations, (see appendix 1 for acknowledgements).

The methods used to compile the work can be seen in appendix 2.
Definition of a Reablement Service for individuals with memory problems or a dementia.

The following definition of a reablement service was agreed by the Social Services Improvement Agency and the Learning and Improvement Network (LIN) and published in the ‘Position Statement on Reablement Services in Wales’ (2014). 4

Services for people with poor physical or mental health or disability to help them live as independently as possible by learning or relearning the skills necessary for daily living.

This definition embraces all disabilities. It does not discriminate against any particular group. The definition puts all individuals requiring support on a level playing field to be given equal consideration for reablement.

A definition of a reablement service for individuals with memory problems or a dementia was offered by the different organisations and individuals interviewed to support the work to produce this resource document. Most felt that a fuller more specific definition was required and should reflect the role and efforts of informal carers who support the individual.

Therefore the project steering group of the Rhondda Cynon Tâf Local Authority and the Cwm Tâf University Health Board Reablement Services who were commissioned to produce this document agreed a definition.

A Reablement Service for individuals with memory problems or a dementia offers timely support to enable people to relearn skills, routines and interests that are important to them to live fulfilled lives in their own homes and communities; providing information, training and reassurance to informal carers for them to have confidence to support the individual.

What is Dementia?

Dementia is a term that describes organic decline in mental ability that interferes with daily living. Dementia has a range of different symptoms and these can vary with individuals. Dementia symptoms can start slowly and gradually get worse as dementia causes damage to brain cells.

The most common dementias are Alzheimer’s disease and vascular dementia. However, less common dementias such as Lewy Body and Pick’s disease still account for a significant amount of dementias.

Another term commonly used in reference to memory problems is Mild Cognitive Impairment (MCI) which does not present as severe enough to interfere with everyday life and can be caused by anxiety, physical illness or side effects of medication. Within this group not everyone goes on to develop dementia.

Individuals with dementia have several different kinds of memory deficits such as short term, long term and working memory. The workforce needs to know how dementia affects these different types of memory for the person so that the reablement programme is tailored to their individual needs. It is also important for staff to understand changes in performance. Individuals may struggle one day to perform tasks and routines but able to carry them out the following day.

Whatever the symptoms, it is important to seek a doctor’s advice as soon as possible, as memory problems can be caused by other medical conditions.

The College of Occupational Therapy Consultancy Service states the following; “dementia is used to describe the symptoms that occur when the brain is affected by specific diseases and conditions. Symptoms of dementia include loss of memory, confusion and problems with speech and understanding”.

Dementia can happen to anyone regardless of their age. While it is more common in older people, people in their forties, fifties and early sixties can experience it.

A diagnosis of dementia can devastate the individual, making it hard for them to accept that life will change. Even without a diagnosis, having insight of their memory problem can cause fear and anxiety.

People with memory loss or a dementia may experience some of the following: misplacing keys or money, not remembering to pay bills or to turn up to appointments, unable to prepare meals or use a domestic appliance. Other difficulties can include problems with communication, orientation, language or concentration. This can also lead to a loss of confidence, anxiety, depression, panic or anger which all in turn can make the memory worse.

People can experience feelings of devastation, feel that it is the end of life, or that they are losing a future and their independence. Have you ever thought “it won’t happen to me”? Imagine if it was you. How would you feel? How would it affect you? How would it affect the way others view you? How would you like to be supported?

An individual with a dementia experience of a reablement service,

“Getting a diagnosis early is important to get the right help but when I received mine I felt my whole life had been taken away, I didn’t have a purpose. Reablement support makes me feel more positive and the reablement workers and my family understand me.”

For her full personal account of living with dementia see appendix 3.
How can individuals live well with memory problems or dementia?

The National Dementia Vision for Wales (2011)\(^7\) states that if people with dementia and their informal carers and families, on receiving a diagnosis of dementia, are given access to appropriate information, advice and support at the right time then it is possible to live well with dementia.

Tom Kitwood discusses ‘personhood’\(^8\) and advocates individuals at different stages of dementia are able to live well and get the best they can out of their lives.

For more information and details on dementia refer to the SSIA Dementia Reablement Training Document\(^9\), the Alzheimer’s Society\(^3\) summary of the scale and impact of dementia for Wales and its factsheets such as ‘What is Dementia’.

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\(^7\) National Dementia Vision for Wales, dementia supportive communities, (2011), Welsh Assembly Government www.cymru.gov.uk

\(^8\) Dementia Reconsidered, the person come first, (1997), Tom Kitwood, Open University Press

\(^9\) Dementia Reablement Training, (2015), Social Services Improvement Agency, (SSIA), www.ssiacymru.org.uk

Rationale to support the development of a Reablement Service for people experiencing memory problems or a dementia living at home in Wales.

Welsh Local Authorities and Health Boards face numerous challenges. These include an increasing diverse population living at home in Wales. As the demographics change, and in keeping with worldwide trends, it is predicted there will be increasing numbers of individuals experiencing dementia or significant memory problems.

The reablement model recognises the barriers that exist in services and society to prevent an individual with dementia enjoying equal opportunities. The diagnosis of dementia can be seen as a ‘label’ and the person with the label can be viewed negatively.

Establishing with the person what makes a difference to them, the things that make the individual who they are, forms the basis of the reablement philosophy. Small things such as listening to music, sharing a meal, having a walk, feeding the birds, visiting friends and family, being supported to keep a job, all help a person feel ‘alive’ and ‘connected’.

The Standard

“A Reablement Service will be based on the current diverse needs of its population and future prevalence of memory problems and dementia. Its strategy, vision and ethos will ensure equal opportunities so that all individuals requiring reablement benefit from this person centred enabling approach.”

Good Practice Points

- Identify the diverse needs of informal carers of people with memory problems or a dementia, listen to and understand their views on their roles, services and information.
- Recognise and promote the facts that people with memory problems or a dementia are just like other people who have or had interests, employment, relationships but may need support in a different way.
- Destroy the myth that people with a memory problems or a dementia are beyond help.
- Enable the person to ‘recover themselves’ from dementia and to move forward. ‘Recovery’ in this sense does not mean that there is a cure. It means that individuals are enabled to ‘recover’ or ‘get back’ what they have just lost in their routines skills and interests.
- Celebrates people’s strengths and does not measure deficits.
- Shift the perception of dementia of ‘what's lost’ to ‘what the person has’ and ‘focus on their strengths’. Provide individuals with the experience of a ‘to do for themselves’ or ‘doing with’ support culture rather than the traditional ‘doing to or for’ support.
- Promote the concept of ‘living with dementia’ not ‘suffering from dementia’, ‘finding hope’ to enjoy choice and independence.
- Emphasise the need for early intervention and prevention. It has been the experience of those working in this area that people with memory problems or early dementia are the most likely to benefit from the opportunities of reablement; although it is acknowledged that a similar enabling approach is beneficial at all stages of the person’s journey.
- Engage with services who are involved with people with memory problems or a dementia to ensure referrals are received in a timely way.
- Signpost individuals, (following screening and assessment), who would not benefit from reablement,
to other community ‘enabling’ services that could help them live at home for longer.

• Delay the provision of long term support at home for individuals. This benefits individuals and is also advantageous in managing budgets in financially challenging times.

• Promote coping skills not only for daily living at home but also coping skills for social inclusion outside the home too. Reablement is about the ‘whole’ person and the whole community.
Starting up a Reablement Service for people with memory problems or a dementia.

It is advised prior to any service development, a needs analysis is undertaken. There needs to be a clear rationale and business case to demonstrate the expected outcomes.

This section is divided into subsections for easy reference, each with its own good practice points. The subsections include information on strategy, operational practices, resources, training and development. These subsections are written with equal priority for the purposes of this document.

The Standard

“All strategic plans, decisions and actions to develop a Reablement Service for people with memory problems or a dementia are based on a clear rationale. Shared vision, principles and values will be owned by all stakeholders of each partner organisation, service users and informal carers connected with the service.”

Strategy

Good Practice Points

• Establish the need for a reablement service of this type with clear strategic purpose, budgetary implications and intended outcomes.

• Refer to any local Dementia Plan/Strategy, in accordance with the National Dementia Vision for Wales, (2011)\(^7\) to provide supporting evidence and guidance in the development of this type of reablement service.

• Consider any partner organisations strategic plans for changes to their current mental health dementia pathways/services, which could impact on any developmental reablement work. Identify how any service developments could complement each other.

• Carry out a needs analysis of the demographic profile and the prevalence of dementia of all adults (not just older adults) and their informal carers, including people from all ethnic minority groups.

• Develop a business case in relation to evidencing how reablement outcomes can avoid the potential for increased costs. Consider the increasing numbers of people with a dementia or memory problem, including the impact on informal carers.

• The business case needs to detail projected resources required to develop and deliver the proposed service. Consideration is required of on-going service development costs such as recruitment and training.

• Develop performance management requirements and agree how/when data will be collected and produced. Acknowledge that different stakeholders will expect different targets and priorities.

Finance

Good Practice Points

• Establish a budget proposal which addresses potential cost benefits for service development, to include the contributions of any partner agencies.

• Consider ‘pooled budgets’ as a mechanism for any partnership working with partner agencies.

• Negotiate and establish written agreements to plan and deliver the service with the partner agencies

Resource considerations

Good Practice Points

• Consider the requirement to register with ‘The Care and Social Services Inspectorate for Wales, (CSSIW), Domiciliary Care Provision, Regulation and Good Practice’\(^10\)

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\(^7\) National Dementia Vision for Wales, dementia supportive communities, (2011), Welsh Assembly Government www.cymru.gov.uk

\(^10\) Domiciliary Care Provision Regulation and Good Practice, Care and Social Services Inspectorate for Wales, (CSSIW), www.cssiw.org.uk
Review eligibility criteria/service access so that it does not discriminate against, disadvantage or exclude individuals with memory problems or dementia including those without a diagnosis.

Engender the culture of reablement, whilst acknowledging the potential for extended assessment periods for this service area.

Review duration of an existing reablement service, for example six weeks or more, by providing clear guidelines on extension periods for people with memory problems or a dementia.

Review any existing electronic and performance management systems to support data collection, referral pathways, processes and access to shared service user records agreed by all partners.

Consider

Other in-house and external services and any potential impact this new reablement development may have on their service provision.

Routes, pathways for people accessing or already receiving a direct payment following a reablement programme.

An increase in demand for assistive technology and other equipment.

The potential for added process and capacity of installation and delivery of assistive technology equipment with providers.

The need for ‘hot desking’ when it is not feasible for the team to share one office due to reasons such as those that arise in rural areas.

Operational Implementation

Good Practice Points

Decide on who will lead the management of change.

Identify an operational group which includes meaningful membership from for example service user/ informal carer representation, voluntary groups, the Third Sector, Primary and Secondary Mental Health Services. Agree on a shared understanding of values, principles of the new service.

Invite all stakeholders to contribute to mission statements, statement of purpose etc.

Timetable regular operational, managerial and team meetings or other effective communication mechanisms to ensure success and keep abreast of service developments. Agree exception rules for non-attendance and cancellation. Regular communication is important particularly in developing a new service and to address staff deployment in wide geographical rural areas.

Minimise the layers of decision making and delegation empowering those closest to the individual with memory problems or a dementia to make effective timely decisions or to have speedy advice.

Provide clear access criteria and referral pathways.

Develop clear exit arrangements and transfer process for any on-going service provision that is required.

Ensure people with the right knowledge and skills are in key positions.

Identify ‘champions’ throughout the service from all partners with experience, enthusiasm and confidence in memory problems and dementia.

Identify an assistive technology champion who can provide an easy accessible catalogue of available products.
• Consider the appointment of a nurse role into the team. A suggestion is to work with partners to consider a system of rotation for any nurse role within the team, to include service delivery and the first point of access/referral stage.

• Consider the appointment of a Designated Lead(s) or Occupational Therapist(s) with specialist skills and experience in memory problems or dementia.

• Review any current capacity of the existing Designated Lead or Occupational Therapy service within the existing Reablement Service for physical disabilities and prepare them to be flexible to support the new service.

• Ensure the service is not ‘time and task’ orientated in its approach and allows for a ‘time to participate’ approach.

• Adopt a holistic approach. Link with community resources such as Dementia Friendly Environments, Befriending Schemes, Lifelong Learning and Digital Inclusion Services, or Community Connectors.

• Market the service to allied professionals who can identify individuals at the right time to benefit from Reablement such as primary care services, memory clinics, dementia advisors, admiral nurses and informal carer groups.

• Promote reablement intervention within the community for people with a memory problems or a dementia living at home to encourage timely referral.

• Follow best evidence; familiar surroundings of the home environment have proved to be the best method to enable individuals to reach their potential.

Training and Development

• Refer to the SSIA Dementia Reablement Training Document

As reablement services become more diverse, frontline support staff working with individuals in their own homes are expected to multi task; have knowledge and confidence to work with different disabilities. Some staff may be hesitant as they do not feel confident to work with the individuals with memory problems or a dementia.

Good Practice Points

• Complete a training needs analysis for the service workforce. Ensure consideration is given to the Care and Social Services Inspectorate for Wales, (CSSIW) Domiciliary Care Provision Regulations and Good Practice.

• Develop a competency framework to ensure staff with the appropriate skills are deployed to respond to identified needs.

• Carry out a review of any current induction and include sessions that ensure memory issues are incorporated.

• Provide opportunities for any existing or new staff to acquire specialist knowledge, experience, and confidence to make effective timely decisions so that the service gains credibility within the staff group and recipients as quickly as possible.

• Communicate to all staff the ‘good news stories’ to broaden knowledge and skills, maintain enthusiasm and interest for the new service. Invite them to share their stories.

• Consider the option of developing a ‘virtual ward’, within GP practices catchment areas so all relevant professionals can attend to discuss reablement issues and learn from each other.

• Train staff on the needs and legal rights of all informal carers for example the entitlement to a carer assessment. Work within the principles of any strategies that recognise and support informal carers.

10 Domiciliary Care Provision Regulation and Good Practice, Care and Social Services Inspectorate for Wales, www.cssiw.org.uk
9 Dementia Reablement Training (2015) Social Services Improvement Agency (SSIA) www.ssiacymru.org.uk
3 Dementia Reablement Training (2015) Social Services Improvement Agency (SSIA) www.ssiacymru.org.uk
Eligibility or access to a reablement service for people with memory problems or a dementia should promote and offer early identification. Individuals should get the right support at the right time, focusing on strengths and well-being so that they remain in control of their lives as far as possible. Access to this preventive service minimizes or delays the need for increasing support.

The Standard

“Eligibility criteria for a Reablement Service for people with memory problems or a dementia must have the underlying principles of anti-discrimination, fairness and equality to promote an individual’s rights, entitlements, independence and wellbeing.”

Good Practice Points

• Provide comprehensive guidance for referrers to the service and high quality information for people to make choices on the support they receive.

• Have clear eligibility guidance to assist the workforce to determine whether the reablement service is the most appropriate intervention for an individual with memory problems or a dementia, within a proportionate time limit.

• Be able to provide advice and information on other available statutory and community resources if it appears that reablement would not be a suitable intervention.

• Agree the type of referral system for example an open system, who can refer (including self-referrals) and what service areas can refer.

• Apply equal opportunities and ensure individuals are not excluded from assessment on the basis of diagnosis alone.

• Take into account the provisions of the United Nations Convention on the Rights of Disabled People, to which the UK is a signatory, particularly Article 19 on the right to independent living.

• Recognise the issues of discrimination in assessment and setting priorities for care and support. Refer to the protected characteristics of the Equality Act (2010). Take into account the fact that some people fall into several characteristics and may experience multiple aspects of discrimination.

• Assess the individual for their potential to identify and set goals with the designated lead or the occupational therapist to participate in the reablement programme. Do not lower your expectations of success because the individual has memory problem or a dementia.


6 Challenging the Myths, Reablement for People with Dementia Workbook, (May 2014), facilitated by Suzy England, The College of Occupational Therapy Consultancy Service.
A good reablement service is dependent on the value, skills, knowledge and confidence of the staff, from the time of first contact to leaving the service. Creating trust for full participation and viewing individuals and informal carers as experts of their situation is essential; knowing what is important to them in their situation and not the worker believing that what they know is best.

Seeing past any diagnosis of a dementia ensures understanding of the person and their strengths, current and past interests, jobs and family relationships.

This starts with a referral to the first contact to the service. In some areas this is known as the Single Point of Access (SPA). For the purposes of this document the term ‘first point of contact’ will be used. The referral then progresses onto assessment, intervention and concludes with review and service withdrawal.

Reliability and continuity of support from individual staff members is essential in delivering a reablement service for individuals with memory problems or a dementia. Continuity inspires trust and confidence. Individuals who have been discharged from hospital feeling confused, disorientated, will take longer to settle back at home and will need continuity to return to their routines.

Small teams can be more effective in providing continuity. They enable the individual and the workers to get to know each other well, preventing the reablement programme being diluted and being set up to fail by too many involvements.

All staff should:

- Work within their own professional bodies’ Codes of Practice and Ethics for Social Care Workers, Social Work, Occupational Therapy, Physiotherapy or any other therapies.
- Work within NICE (National Institute for Health and Care Excellence) quality standards and guidance and the Care Council for Wales12 where applicable.
- Understand ‘safe guarding’ of both adults and children and the responsibilities and issues pertaining to it.
- Work within the joint protocol of the multidisciplinary reablement team and their own organisation’s requirements regarding health and safety of staff for example lone working issues.
- Adhere to the Health and Safety at Work Act (1974)13
- Understand and work within the key relevant provisions of the Mental Capacity Act 2005 and its Code of Practice14 e.g. a person must be assumed to have capacity unless it is established that he/she lacks capacity. (Knowledge of the new judgement known as the ‘Cheshire West case’ 201415 is also required).
- Continue to respect the fact that you are a visitor in the individual’s home.
- Work in a person centred way with the individual and

12 www.nice.org.uk/guidance   www.cc.wales.org.uk
13 www.hse.gov.uk/legislation/hswa.htm
15 Cheshire West Case (2014) http://familylaw.co.uk/news
identify outcomes important to them and the ones they wish to achieve.

• Build a trusting relationship which enables the individual to attempt tasks.

**Referral Process**

**Good Practice Points**

The first point of contact should:

• Be staffed with individuals who have experience and knowledge of people with memory problems or a dementia.

• Ensure staff receive on-going training on memory problems and dementia. As their work does not include face to face activities, meeting people experiencing these issues is essential to broaden understanding.

• Be clear about service access/eligibility.

• Respond to referrals within the teams quality standards.

• Take time to gather the most up-to-date accurate information on the individual to inform decisions.

• Avoid stereotyping that can lead to assumptions.

• Triage referrals so that the service identified for assessment is developed around the individual.

• Have the knowledge and skills to signpost onto other agencies where appropriate, maintaining updated information on the availability of local services.

• Know when to arrange a safe alternative service when an individual needs immediate support before they can receive an assessment for a reablement programme adopting a ‘positive risk’ approach.

• Maintain and update all systems to contribute to clear and smooth pathways for service users through their reablement experience.

• Show interest and avoid intrusive questioning in any telephone conversations with referrers who are informal carers or the individual themselves.

• Demonstrate positive communication techniques. Consider possible sensory difficulties.

• Understand your duties regarding individuals’ entitlements relating to ‘preferred language’ requests

• Speak to that individual whenever it is possible to do so, to enable them to describe their situation.

• Assume the person with the memory problems or a dementia has capacity unless there are valid explanations or assessments to say otherwise.

**Assessment**

**Good Practice Points**

The Occupational Therapist or Designated Lead person should:

• Have highly specialist knowledge and experience of working with people with memory problems or a dementia.

• Clarify to the individual and informal carer, purpose of the visit, scope of the assessment and intervention.

• Provide factsheets about the service including the way personal information is used and stored. Make a judgement about the appropriateness of this for the individual to avoid any distress or confusion and whether an informal carer should be included in these conversations.

• Take time to adequately assess. Invest time in initial visits to get to know the person, their strengths and abilities.

• Assess and use the correct approach and ensure others understand and follow the techniques.

• Use valid, standardised, tried and tested assessment scales and tools for best practice in short term
intervention reablement work, (see appendix 4).

- Deal with the most urgent priorities first. Include and support the individual in breaking goals down into manageable steps so that they can contribute in measuring their own success.

- Work in partnership with other therapy services within and outside the team.

- Take time to explain to informal carers the benefits of reablement. Listen to their concerns. Inform managers if this will impact on time management.

- Provide information to the informal carer on entitlement to a carer’s assessment. (If accepted arrange with appropriate colleague to carry out this work).

- Work within the principles of positive risk taking.

- Report unsafe hospital discharges through the appropriate systems.

- Communicate what works and what doesn’t in their approaches/practices to inform best practice.

- Consider assistive technology and any other equipment first as a possible solution to a problem.

Planning

Consider

Personnel who have the responsibility for planning the rota for staff who carry out the reablement intervention in the individual’s home have different job titles in different reablement services in Wales. For example in some areas they are referred to as ‘planners’ or ‘schedulers’. Below they will be referred to as the ‘staff group who plan the service’.

The staff group who plan the service should:

Good Practice Points

- Receive training in memory problems and dementia.

- Acknowledge that not all staff will feel confident to or work effectively with people with memory problems or a dementia at the onset of the new service.

- Be able to deal with staff concerns and issues with least interruption to service progress.

- Appoint a ‘dementia’ champion within the staff group that plan the service.

- Access staff competency records to ensure that, appropriately trained staff are planned to deliver the service to meet identified individual’s needs.

- Receive information on the individual with memory problems or a dementia prior to selecting and planning staff rotas.

- Ensure consistency in deployment of staff in small teams which is critical to achieving successful outcomes.

- Know their staff well. Match up frontline support workers to compliment the needs and personality of the individual, particularly when the individual is having difficulty in engaging with some staff members.

- Book adequate introduction time for the Occupational Therapist, Designated Lead and any other nominated frontline support worker to meet with the individual before the programme starts.

- Inform line managers/therapists where sickness or unplanned leave prevents the usual staff member from attending the service user. Decisions may need to be taken in respect of finding appropriate replacement staff.

- Allow individuals and workers to have sufficient time to undertake the identified tasks.

- Provide time for the worker to read and complete the daily reports so that it does not interfere with their time spent with the individual.

- Agree service parameters with the Occupational Therapist or Designated Lead. Understand the

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circumstances which require their approval. For example adjustment of times and provision of staff can be changed.

Intervention

Consider

Personnel who have the responsibility to work with individuals in their own homes to support them to achieve their identified reablement goals have different job titles in different reablement services in Wales. For example in some areas they are referred to as ‘frontline workers’ or ‘support workers’. For the purposes of this document the title ‘frontline support workers’ is being used.

Good Practice Points

Frontline Support Workers should

- Received appropriate training to ensure they have confidence to deliver the service to an individual with memory problems or a dementia, using effective communication techniques.
- Consider and respond to any sensory issues.
- Work in a small cohort of the same staff group to enhance communication and provide continuity.
- Know that memory problems and dementia can affect individuals in different ways and previous life experiences will shape their responses.
- Aim to seek views of informal carers and keep them included.
- Recognise the intervention plan identifies what the person with memory problems or a dementia can achieve at a particular point in time and that this can change.
- Understand variability in the individual’s ability to perform tasks; that to maximise potential it should not be assumed that as the individual struggles one day they are unable to engage or manage a routine or task the next. Replacement workers will also need this information.
- Understand what is normal or usual for the individual and what triggers may cause disengagement and how to respond to this.
- Use a variety of consistent prompts so that routines can be successfully achieved by the individual. It is anticipated that prompting will decrease after sufficient repetition.
- Take time to stand back, provide supervision and be patient. Individuals with a memory problem or a dementia may take longer to interpret and carry out what is required.
- Work as a team to support and develop each other’s knowledge of memory problems or a dementia to provide a consistent reablement service.
- Receive support and establish an effective means of contact with the Occupational Therapist or Designated Lead in the delivery of the programme.
- Take opportunities in attending relevant specialist training opportunities. Identify own learning needs to improve practice and contribute to continuous professional development.
- Act as a mentor /role model for new workers to the service.
- Provide training when appropriate. Include informal carers and allow them to shadow activity.
The Frontline Support Workers should:

- Write appropriate and non-discriminatory notes at each visit to enhance communication between colleagues and informal carers. Avoid making the individual feel being ‘reported on’. If appropriate try and involve them, (the individual is entitled to access their notes). Discuss with supervisor if notes/folders are causing anxiety to individual service users.

- Read colleagues' notes discreetly to inform practice.

- Report any changes immediately and directly to the Designated Lead or Occupational Therapist in a timely way so adjustments can be made to the intervention plan if necessary.

The Occupational Therapist or Designated Lead should:

- Decide from the monitoring information from frontline support staff whether Reablement is the suitable service for the individual and whether another appropriate service is required in the short or longer term.

- Justify requests for extension of the reablement programme in a timely way.

- Monitor the individual's performance against the intervention plan.

- Set enough time to seek staff views and experiences before reviewing.

Review

Good Practice Points

The Occupational Therapist or Designated Lead should:

- Consider possible sensory difficulties.

- Take responsibility for managing the expectations of the individual with memory problems or a dementia and their informal carer. For example where clear progress has been made but there may be a reluctance for the individual or the informal carer to 'let go' of the service input. Provide clear evidence of the individual's progress and 'managed risk' to support these conversations.

- Plan for a timely review to identify whether or not a longer term service is required.

- Ensure the individual with the memory problem or a dementia is present at the review and consult with them on who else should be present (the informal carer is an important consideration for invitation).

- Invite front line staff to the review if appropriate.

- Take time to explain to the individual the nature and scope of the review.

- Carry out a review even if the individual withdraws from the service before the programme ends. A record of activities for future reference or to inform another service should be available.

- Provide copies of the review to all significant people. Do not assume that the individual with memory problems or a dementia would decline a copy or would be unable to understand the contents.
Communication in Reablement Services for people with memory problems or a dementia.

Communication is a priority to all health and social care work. Understanding, talking and working with all individuals with due respect for their individual differences and characteristics such as age or ethnicity, is essential for person centred support. Providing appropriate induction and training on memory problems and dementia for the reablement workforce contributes to this holistic approach.

All public bodies in Wales are expected to treat the Welsh and English languages on a basis of equality in relation to the delivery of services. People have the right to choose the language they wish to communicate to enable them to participate effectively. A reablement service needs to have knowledge of frameworks and strategies that promote the Welsh language.

Written information (paper or electronic) is also important. It can remain on file for years and can continue to influence actions and decisions. Similarly information sharing protocols and procedures should be in place to cover all the issues of the sharing of personal information and confidentiality. The Data Protection Act (2008) and The Welsh Assembly Government provides guidance.

This section is divided into two parts. Part one focuses on the communication of the frontline support staff working face to face with the recipients of the service. Secondly the focus is on written information which is the responsibility of the whole workforce. The standard is intended to embrace these two elements.

In face to face communication, (part one).

Good Practice Points

The frontline support staff should:

- Develop good listening, specific communication and observation skills. Be aware of own use of non-verbal communication as gestures and facial expressions can affect the individual.

- Observe individuals’ verbal and non-verbal cues to aid understanding. Individuals with memory issues may find difficulty in choosing the right words to express themselves.

- Find out about the person first. Show interest, avoid intrusiveness. Ask the person who knows them best to fill in any gaps.

- Be aware when communicating with the individual of increasing any suspicion he/she may have about the purpose of the service.

- Understand if the individual is reluctant to engage it may be due to embarrassment, fear of failing, unhappy with intrusion or lack of insight believing that there is nothing wrong.

- Use the person’s preferred name or title as a good start to successful engagement.

- Wear name badges to aid communication.

- Consider use of endearing or affectionate terms. These can be felt as demeaning by some individuals. Because individuals have memory issues avoid the tendency to be over protective / sympathetic. Use empathy.

- Invest the time to explain who you are and why you are there.

- Understand that as the condition progresses people with a dementia often revert back to their first language.

The Standard

“The barriers to effective communication for people who receive support from or who are connected with a Reablement Service for people with memory problems or a dementia will be minimised.”

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16 Welsh Language Act (1993), Welsh Assembly Government, legislation.gov.uk
• Identify the preferred language needs and preferences of the individual.

• Avoid professional jargon as it can make individuals feel powerless, inadequate and intimidated.

• Use caution in using family or friends as interpreters.

• Share any creative approaches, tips and strategies that engage the individual with the team.

• Appreciate other problems a person with memory loss may have which can affect communication such as physical pain, visual, hearing or sensory impairments.

• Do not assume an older person with memory problems or a dementia has a hearing problem. Avoid raising your voice if an individual does have a hearing impairment. Speaking in a lower tone helps.

• Speak distinctively. Keep language simple and short.

• Slow down the pace of the conversation if the individual shows signs of not keeping up with the information. Chunk up information into manageable sizes so as not to overload the individual.

• Allow an individual time to process the language being used (verbal or non-verbal). Do not be afraid of silence.

• Understand that although touch can communicate you care, some individuals with memory issues may misinterpret your intentions and make them feel threatened or vulnerable.

• Be patient. It may take a few visits to build up trust before the programme can start. Managers of the service need to exercise patience with staff in this initial period.

• Explain the terms such as assessment, intervention, review in ways that is meaningful to the individual and demystifies the reablement process.

Written communication (paper or electronic), (part two).

Good Practice Points

The workforce including its managers should:

• Develop their skills in recording information. Capture the essence of the person. Understand the triggers that cause distress. See the individual behind the label.

• Always write records sensitively and objectively, be aware that individuals with memory problems or a dementia can still retain skills and the capacity to understand the issues about their health and welfare as do their informal carers/families.

• Describe not stigmatise an individual’s behaviour when they appear challenging. Find out the reasons why a person is presenting as challenging; this behaviour is often in response to an unmet need.

• Avoid using terms that promote a perception of helplessness in the individual.
Caring for a person with memory problems, a dementia or a physical disability can have an impact on an informal carer’s physical and mental health and wellbeing.

Carers UK (2011) predict that informal carers will become even more crucial due to the increase of dementia in Wales. To understand the whole picture of informal support in Wales it is important to identify the number and needs of ‘hidden informal carers’ in its diverse and multicultural communities.

All informal carers provide an important role in supporting the individual with memory problems or a dementia to live at home. They need to be consulted in a meaningful way about reablement for the person they support.

Welsh carers’ strategies advocate the entitlement of carers’ assessments. This provides opportunity for them to reflect and demonstrate what support they give and how it affects them. The informal carer may choose to delay an assessment until after reablement is completed to capture a more accurate and up to date picture of their situation and to identify whether reablement is making a difference.

The Standard

“A Reablement Service will recognise, value and respect the role and expertise of informal carers who support individuals living at home with memory problems or a dementia and will work in partnership with them to provide person centred support.”

Good Practice Points

• Spend time talking to the informal carer on the success of investing time in the ‘stepping back’ approach and positive risk taking.

• Reassure the informal carer that the routines that the individual will relearn are the ones that have been recently lost.

• Value the informal carer’s expertise. Utilise their knowledge of the individual to contribute to a ‘person centred profile’. Include ‘triggers’ that upset or anger the individual.

• Encourage the informal carer to have a say on how support is provided.

• Acknowledge that sometimes informal carers can be apprehensive about change and managing risk. Find ways to gain their commitment to the reablement process.

An informal carer’s experience of reablement

“...In hospital my mother received a diagnosis of vascular dementia. I felt reassured as I knew then what I was dealing with. I now view memory problems differently. From the start of the reablement support in my mother’s house, the Occupational Therapist consulted me every step of the way. We discussed what worked best for my mother and I was able to voice any concerns. The support workers who came every day also included me in what they were doing. Right from the start I could see it working for my mother...”

(For full personal account of the informal carer’s experience of a reablement programme see appendix 4).

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20 Carer’s UK www.carersuk.org

• Ask informal carers for suggestions on how best to start up a conversation with the individual to build up trust.

• Acknowledge their reservations of the reablement approach before assessing the situation. Do not trivialise or undermine concerns.

• Explain the process of assessment, intervention and review; illustrate how individual strengths are balanced against perceived risks.

• Understand the needs of ‘young’ informal carers. Provide information and advice and sign post appropriately.

• Understand the issues for informal carers supporting ‘younger’ people with dementia and the needs of the individual requiring age appropriate activities important to them.

• Explain that if the person supported has the mental capacity to decide for themselves about participating in a reablement programme or not, that this decision will be respected and supported.

• Provide training and information to informal carers at intervals manageable for them.
There is a natural desire to protect individuals with memory problems or a dementia and a fear that their decisions or actions may harm and put themselves or others at risk.

A risk is the likelihood (high or low) that an individual may suffer harm from a hazard. Some common examples of concern or hazards are leaving the gas on, allowing strangers into their home or leaving the door open at night. Therefore it is understandable that informal carers and the wider public would prefer the traditional approach of ‘doing for’ as being safer and quicker to support an individual with memory problems or dementia. Positive risk taking is about weighing up the potential benefits or harm of choosing one action over another.

Within families and within support teams there will be different levels of what is acceptable positive risk taking. However there are things that can be done to minimise, prepare and manage risk to reduce the chance of a situation occurring. For example within the home environment the use of prompts and the availability of a range of different assistive technology can minimise risk inside and outside the home. Carrying out appropriate risk assessments will identify and address the associated risk issues.

Positive risk taking supports the principle that people have the right to make their own decisions. The professionals involved, support the individual in good faith, recording underpinning reasoning for the discussions and decisions made.

Legislation and frameworks assist in risk assessing, its management and decision making, maintaining an appropriate balance between the promotion of independence and the safeguarding of vulnerable adults.

Therefore this section is divided into two parts. Part one considers risk in relation to the day to day assessing and decision making of the workforce. Part two considers legislation and guidance that helps to inform and influence practice and the decision making processes.

**The Standard**

“A Reablement Service will work within the principle that a person with memory problems or a dementia does not automatically lack mental capacity to make specific decisions; when the individual does not have the autonomy to make these decisions then risk will be assessed to include strengths and abilities: the individual will be involved in decision making as far as possible so that the balance between protection and promoting independence is not compromised.”

**Assessing and decision making of the workforce that supports positive risk taking, (part one).**

**Good Practice Points**

- Give time to informal carers to talk about how risks are managed for the individual with memory problems or a dementia and explain the reablement approach.

- Provide training to the whole workforce on positive risk assessing and management.

- Clarify the risk by asking the questions advised by Sussex and Scourfield below.

  - What is the nature of the risk(s) being assessed?
  - Who is saying there it’s a risk?
  - Who is it a risk for?
  - What tools, methods or other specialist opinion is available for the assessor to analyse or quantify the risk?
Is there a legal power to act?
Whose responsibility is it to manage the risk?
Are there other information available to help analyse the risk?
What danger is there for others?
Check that documentation supports effective risk assessment and management and not negativity. Forms should focus on balancing the benefits of risk taking with any potential harm; recognising resourcefulness and potential for growth; build on strengths.
Record the underpinning reasoning for all discussions and decisions relating to risk, (important when memory fades and individuals find problems with recall).
Avoid making unnecessary changes to the home environment. Familiarity provides security and comfort particularly for individuals with difficulties with their memory. Change can cause unhappiness, loss of control and confusion.
Review risk and update issues on appropriate documentation.

The Legislation and Guidance that support decision making regarding risk, (part two).

Good Practice Points
The workforce must:
Work within ‘safeguarding’ policies, their reviews and updates for both adults and children. Understand the duties to prevent, identify and respond to abuse.
Have knowledge on the judgement known as the ‘Cheshire West Case (2014)’.
Adhere to Health and Safety regulations at work.
Work and adhere to the following principles of the Mental Capacity Act (2005) and its Code of Practice.
Adhere to the first principle of the Mental Capacity Act which is to assume an individual has capacity to make decisions or act for themselves unless it is established that they lack capacity in relation to those matters.
Take all practicable and appropriate steps before deciding that someone lacks capacity to make a particular decision. Doing this will enable a person to make that decision themselves at the time it is needed to be made.
Understand that capacity is decision specific. A decision about whether to receive a reablement programme is different to a decision on how their finances are managed.
Assess whether the person can understand the information relevant to a decision, retain the information, use or weigh that information up as part of the process of making the decision, communicate his/her decision back to the person who is making the enquiry whether by talking or any other means of communication.
All decisions made on behalf of people who lack capacity are made in their best interests and the least restrictive approach is taken. Talk to all professionals involved and those who know the person best who can advise what the person would want if they had capacity to decide for themselves.
Respect and abide by the issue that people have the right to make what others might regard as eccentric or unwise decision due to their own values, belief and preferences. Professionals cannot treat people with a dementia or a memory problem as lacking capacity for that reason.
Understand the important distinction between putting people at risk and enabling them to choose to take reasonable risks.
Involves the individual where possible in any decision making and seek their consent to make changes to issues affecting their life so that they retain choice and control and build on their strengths.

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15 Cheshire West Case  http://familylaw.co.uk/news
Assistive Technology in a Reablement Service for people with memory problems or a dementia.

Assistive technology is an umbrella term that refers to any device or system that supports an individual to carry out a task or activity that they are unable to carry out themselves. The device reduces the risk to the person in performing it. It can also be used to fulfil a monitoring function, supporting assessment and decisions around risk.

Assistive technology and telecare improves quality of life and provides individuals experiencing memory problems or a dementia with more choices on the support they receive and enhances their ability to remain living as independently as possible at home. For informal carers of individuals with a memory problem or a dementia it can provide peace of mind, reduce stress, and reassure giving them confidence that the person they support is safe.

This may offer them the opportunities to remain working, enjoy more spare time or to continue with their interests and hobbies. The benefits of assistive technology need to be promoted to the community, health, social care and third sector professionals so that individuals with memory problems or a dementia receive timely access to the technology. The Social Services Improvement Agency comment that assistive technology should be the most effective and least intrusive option and work alongside other preventive measures such as reablement.

Good Practice Points

- Support individuals to make informed choices and decisions on using suitable telecare products by providing comprehensive information.
- Gain consent from the individual with memory problems or a dementia following judgement on mental capacity to receive assistive technology.

Consider the ethical issues of privacy, stigma, autonomy and control for individuals with a memory problem or a dementia. This is important as the technology develops.

- Ensure thorough assessments are undertaken so that the technology provided is appropriate ensuring the balance between safety and privacy is achieved.
- Balance quality of life, independence, safety and the best interests of people without mental capacity to give informed consent.
- Include the needs and views of informal carers in decisions around provision of assistive technology.
- Consider the individual’s response to technology in the home and feelings they may have of being ‘watched or spied on’ particularly if they are already anxious and aware of their inability of managing their routines. Speak to people who know them best.
- Ensure that technology is not used as a replacement for human contact and the provision of person centred support.
- Monitor and review the technology to ensure it continues to be appropriate during the reablement programme. Ensure that individuals, informal carers and any other services involved understand the importance of this after reablement finishes.
- Complement assistive technology, telecare/telehealth/telemedicine provision, with any other support the individual with memory problems or a dementia receives to improve joined up working.

The Standard

“A Reablement Service should promote the benefits of assistive technology for people with memory problems or a dementia and ensure that the monitoring of individuals does not compromise the ethical issues of individualisation, choice and privacy.”

27 Written Evidence to the National Assembly for Wales, Health and Social Care Committee, (2016) Social Services Improvement Agency. www.ssiacymru.org.uk/telecare
• Appoint an assistive technology champion in the reablement team who understands the needs of people with memory problems or a dementia.

• Provide awareness training for the reablement workforce so that they understand the use of technology in context of the needs of people with memory problems or a dementia.

• Set up robust systems for effective communication between the reablement workforce and any community alarm or monitoring service whilst the reablement service is on-going. Timely feedback is necessary for evaluating the success of technology in keeping individuals safe.
A Reablement Service for individuals with memory problems or dementia may need to transfer support to other agencies following the end of a reablement programme. The Social Service and Well-being Act 2014\(^2\) provides guidance to social care commissioning teams to exercise their new duties in respect of local needs assessments. It commits to the social model of disability and engaging all relevant partners to provide person centred, outcome focussed support.

This standard considers the transfer of support to a new service.

**The Standard**

“A Reablement Service for people with memory problems or a dementia, that commissions support from another service provider must have a transfer period that ensures the least possible disruption to the individual during transition. The new service will hold and practise the underpinning core values of person centred support and promoting independence.”

**Transfer of Support to another provider**

**Good Practice Points**

Managers of the service should:

- Agree and devise a transfer process with providers

- Ensure new provider staff are given shadowing opportunities to observe experienced reablement staff delivering the programme.

- Monitor compliance and effectiveness of the transfer process.

The Designated Lead or Occupational Therapist should:

- Allow sufficient time for the transfer process to take place effectively.

- Arrange a handover of information to the new provider to include the detailed intervention plan, risk assessment and review.

- Discuss ‘the doing for themselves’ or ‘doing with’ approach with the new provider or personal assistant of a Direct Payments Scheme.

- Provide ‘triggers’ that may cause the individual to disengage with services and any personal profile of the individual to enable the new provider to do their job well.

- Alert reablement managers of any difficulties in the transfer process. A smooth transfer, providing continuity is particularly important for individuals with memory problems or a dementia to retain skills and routines.

- Provide appropriate information for the individual, informal carer and all significant others when the programme ends, (discharge letter or a final evaluation form). Include reason for referral, agreed goals and outcomes, any further assessment required and who to contact for queries or further information.

Evaluating a Reablement Service for people with memory problems or a dementia.

The huge challenge for health and social services has always been to collect meaningful information from service users and informal carers of their experiences of its services. This can be a more demanding task in reablement services for individuals with memory problems or a dementia. Therefore asking the right question is important to get an accurate picture of an individual’s experience of a reablement service. There are many ways to evaluate a service, for example, service feedback from focus groups, customer satisfaction questionnaires, surveys, learning from complaints, compliments or feedback from service users at the end of a service. The individual’s experience of a reablement programme is an important underlying principle of evaluating any service. Experiencing memory problems or a dementia should not exclude individuals from having a voice.

A performance management framework should reflect both individual and service outcomes to evaluate the service.

The Position Statement on Reablement Services in Wales (2014)\(^4\) included proposals for a suite of performance outcome measures, (see appendix 6). These align with any future National Outcome Frameworks\(^23\) and the requirements of A Framework for Delivering Integrated Health and Social Care.\(^24\)

Reporting to Care and Social Services Inspectorate for Wales, (CSSIW)\(^10\) provides another quality assurance mechanism for Reablement Services in Wales.

This section is divided into the three parts; strategic and resource implications; the evaluation of an individual’s experience of their reablement journey and monitoring that supports and informs evaluation.

The Standard

“Evaluating a Reablement Service for people with memory problems or a dementia must reflect the experiences of the individual and their informal carers; integration of service delivery of all parties; have a shared sense of priorities for an outcome based, provide a safe and effective service that promotes independence and contributes to well-being; focus on the performance of the service to deliver its strategic and operational goals.”

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\(^4\) Position Statement on Reablement Services in Wales’, Improving Social Care in Wales (collected during 2012, published 2013), Social Services Improvement Agency www.ssiarecymru.org.uk/reablement


\(^10\) Care and Social Services Inspectorate for Wales, Domiciliary Care Provision Regulation and Good Practice www.cssiw.org.uk
Strategic and resource considerations, (part one).

Good Practice Points.

- Define what outcomes are to be measured for the individual and the organisation.

- Develop systems and processes for resource and budget monitoring and to capture the economic and financial benefits of a reablement service for individuals with memory problems or a dementia.

- Create a system that specifically measures the performance of reablement services for individuals with memory problems or a dementia. This will provide evidence to justify, develop and progress this type of reablement service.

- Develop specific, measurable, achievable, realistic and time-orientated (SMART) measurable indicators that allow scrutiny, audit and inspection and measure the benefits of prevention/early intervention for the individual with memory problems or a dementia. (See appendix 6).

- Identify methods to collect information on the experiences of informal carers supporting a reablement programme.

- Develop quality standards/quality assurance processes that check the individual’s pathway through their reablement journey.

- Keep data simple and transparent.

- Encourage and motivate staff who may feel that they have no connection with data to have a vested interest in performance management. Make data available to them which is engaging, timely, meaningful, easily interpreted and open to challenge by them. The information should reflect their role, enable them to monitor their own performance and feel connected to data collection.

- Continue to progress shared indicators with partners of the new reablement service as it develops to satisfy all organisations to justify the service.

Evaluating the individual’s reablement journey, (part two).

Good Practice Points

- Understand that ‘timeliness’ is important in gathering information of the individual’s reablement experience. Deteriorating memory is an inevitable issue for them and its pace is unique to each individual.

- Devise methods to collect ‘subjective’ information from the individual’s experiences that are suitable for a person with memory problems or a dementia. For example adopt an appropriate and engaging interviewing approach and devise questionnaires that can connect with individuals with memory problems or a dementia.

- Collect dependency levels of the individual with memory problems or a dementia (pre and post intervention) by the Occupational Therapist or Designated Lead to contribute to evaluation, giving a more ‘live, human’ aspect to demonstrating outcomes. (See appendix 4)

- Gain understanding of what contributes to best practice in person centred interventions in memory problems/dementia reablement to influence and measure their identified outcomes. Aim to achieve a successful reablement experience for the individual.

- Use the informal carer’s knowledge of the individual they support and how memory problems or a dementia affect them as informal carers.

- Identify methods to capture systematic feedback from them to develop outcome measures and make changes for improvement, for example via a questionnaire. The National Audit of Intermediate Care Report (2013)\textsuperscript{25} provides examples of questions that can be used as a guide to adapt to suit informal carers and reablement.

Consider

- Focussing questions to facilitate response as the informal carer could still be leading a busy life.

- Asking informal carers about whether the reablement service was supportive to them. Finding out what it was like for them?

- Enquiring if the informal carer is providing less support to the individual following cessation of the reablement programme.

- Guaranteeing confidentiality to informal carers when they provide their evaluation. They may be concerned if the individual they support may be receiving services commissioned by the same local authority providing reablement.

Monitoring a reablement service for individuals with memory problems or a dementia to inform its evaluation, (part three).

Good Practice Points

- Understand the variability of performance in skills and routines that occurs for people with memory problems or a dementia when monitoring the individual’s progress and ability to achieve optimum levels of independence.

- Learn from the day to day practice of the memory problems/dementia reablement programme. Adjust measurement frameworks based on this evidence from service outcomes and individuals’ experiences and feedback.

- Carry out follow up reviews following the cessation of a reablement programme to assess and evaluate the benefit of this type of reablement service and whether outcomes are continued to be maintained or achieved.

- Identify effective methods and timescales to support the reviewing process. Collect qualitative feedback from the individual and or the informal carer at the end of a reablement programme and at appropriate intervals following this.

- Develop indicators to monitor and evaluate sustainability of individuals who have completed and left a reablement programme including those who receive no further support. Recognise the difficulties in monitoring so that it informs evaluation as accurately as possible. (See appendix 6).
Acknowledgements

This document uses the Rhondda Cynon Tâf Local Authority and Cwm Tâf University Health Board Reablement Services for individuals with memory problems or a dementia as a baseline for its development. Rhondda Cynon Tâf Community Services Teams and Cwm Tâf University Health Board Primary and Secondary Mental Health Care also contributed. Other contributions were from similar Reablement Services provided by Merthyr Tydfil, Bridgend, Powys and Flintshire Local Authorities and their health partners. Plans, experiences and evidence of good practice of these services supported the work.

Karen Kitch who experienced a reablement programme and Angela Nutt informal carer for her mother who also received reablement contributed to the work. Both participants worked with the Rhondda Cynon Tâf Local Authority and Cwm Tâf University Health Board Reablement Service for individuals with memory problems or a dementia.

All twenty two Local Authorities’ reablement services were invited to comment on and participate in the project. The Position Statement on Reablement Services in Wales (2013)6 and the Approach to developing a Gold Standard in reablement services’ (2012)26 were used as a reference and guide in compiling this resource document.

The Rhondda Cynon Tâf Local Authority and Cwm Tâf University Health Board Dementia and Memory Reablement Service and Social Services Improvement Agency steering group managed and supported the compilation of this resource document.

The Methods

The Methods for collecting information for the resource document were achieved by:

- Using best practice from reading materials provided by Rhondda Cynon Tâf and Cwm Tâf University Health Board Reablement Services.
- Interviewing staff carrying out different roles connected with this service above, including service user and carer experience. The Rhondda Cynon Tâf and Cwm Tâf University Health Board reablement model was used as a baseline.
- Interviewing other Welsh reablement services’ personnel in Merthyr Tydfil and Bridgend Reablement Services who agreed to share their experiences of good practice and what worked for them to inform the model. Powys Local Authority shared their ideas and plans in setting up a service in one area in their county.
- Flintshire local authority provided advice on the roles of Occupational Therapists and Designated Leads in reablement services.
- Interviewing representatives from key organisations, Ruth Crowder from the Welsh Reablement Alliance and Sue Phelps from the Alzheimer’s Society in Wales.
- Reading information on good practice on other Reablement Service models in Wales and the UK who work with people with memory problems or a dementia.
- Liaising with Cardiff and the Vale reablement services and project lead Helen Lambert who produced the Dementia Reablement Training Resource Document (2015).
- Taking direction from the steering group from Rhondda Cynon Tâf and Cwm Tâf University Health Board Reablement Service which met monthly with Social Services Improvement Agency support.
- Reporting quarterly to the Learning and Improvement Network (LIN), Wales.

4 Position Statement on Reablement Services in Wales (collected 2012, published 2014), Social Services Improvement Agency www.ssiacymru-org.uk
6 The Position Statement on Reablement Services in Wales, (collected in 2012, published in 2013) by the Social Services Improvement Agency www.ssiacymru-org.uk
Appendix 3

An individual’s experience of a reablement service for people with memory problems or a dementia.

“When I received my diagnosis I felt my whole life had been taken away from me. I asked myself what is the point, what’s left of my life? What is there for me? I wouldn’t get out of bed. I didn’t have a purpose any more.

I was working but due to the nature of my job I couldn’t afford to make mistakes. I was constantly checking my work to see if I got it right. I was also a full time mum. My life was snatched away. I had been given a death sentence. I felt inadequate. It was putting great strain on my family. My partner works and my daughter is in full time education.

There is a big gap for younger people with a dementia when they finish work. I am not ready for any day centre. I needed to find what was there for me.

As I am young having dementia some people say “I expected you to be old”, “You don’t look old enough to have it”. I am only just over 50. I know people have the image of people with dementia of being older and in a residential home.

People with dementia are not numbers or figures. People need to talk to me as they have always done not treat me like a child, never mind my age. It doesn’t matter if I can’t remember things one day to the next. Even at the end of the illness I have the right to be treated properly.

Reablement workers understand me especially when I have had a bad day. I am not as frustrated as I was, and things are better with the family as it is hard for them. They are very supportive. I understand that there is no cure for me but the support I get makes me feel more positive.

I have always cooked for my family using ingredients, cooking from scratch. I had stopped doing this but wanted to start up again. The occupational therapist has introduced me to easy recipes. My kitchen has been adjusted so that I have everything to hand such as my bread maker and equipment I need to prepare soup and make other things. I have got used to the adjustments and my new cooker has a timer to use when I will need it to remind me that I am cooking. When I get worse I will have already made the adjustments and would have got used to them. The workers prompt me so I get into routines.

Six weeks reablement for people like me may not be enough due to the memory problem. After finishing reablement a gentle reduction tapering off would be best. I would be deeper in depression if I hadn’t had the help I am having. I look forward to the reablement workers coming. They let me carry on and help when I need it. I will miss them when they finish. Maybe there should be someone calling to check if things are still going ok.

Getting a diagnosis early is important to get the right help and I am now putting my affairs in order. In the beginning I was referred to the wrong doctor, sent in the wrong direction because I was young. Due to my last job and another job I had I knew I had a problem with my memory. Not everyone is like this. They wouldn’t know what to do.

I have a social worker who has helped me to get direct payments. I have interviewed two people to support me as I am doing the cooking now I want to get a life outside. So I will have some support to go out have a coffee have a look around. I used to be really house- proud but this has slipped since I had my diagnosis but I want to start doing things again around the home so my personal assistants will support me in this too but not do it for me.

Dementia and reablement needs to be promoted more so that people get the help they need at the right time. People need to know that dementia can affect anyone and that there is help.”
Appendix 4

An informal carer’s experience of a reablement service for individuals with memory problems or a dementia in South East Wales.

“I first heard about the reablement service when my mother who is 87 and living alone had been admitted to hospital due to a urinary infection which had made her very confused. A hospital Occupational Therapist assessed her as appropriate for reablement support. Prior to this my mother did have memory problems and occasionally I got frustrated dealing with this but didn’t think a lot about dementia.

In hospital my mother received a diagnosis of vascular dementia. I felt reassured as I knew then what I was dealing with. I now view memory problems and dementia differently.

From the start of the reablement support in my mother’s home, the Occupational Therapist consulted me every step of the way. We discussed what worked best for my mother and I was able to voice any concerns. The support workers who come every day also include me in what they are doing.

Right from the start I could see it working for my mother with the right number of daily visits with a gradual withdrawing. The prompts, strategies for my mother to cope and remember, the simple things, triggers and repetition got her back to an even keel, normality within her capabilities. The support has built up her confidence. This has taken a great weight off my mind. My mother now starts to think for herself, her mind is stimulated. She can now think about preparation for meals. I feel now that not everything is lost with my mother.

Reablement staff need to have a flexible approach and patience to encourage people to do things for themselves.

Although she has vascular dementia and I know as time goes on she will get more forgetful at least we are able to accept this and often talk about it together.”

Appendix 5

Examples of standardised assessment tools:

MOTOM- Morrison occupational therapy outcome measures.

Large Allens Cognitive Level Screen - (LACL’s).

Routine Task Inventory - (RTI)

Allens Lifestyle Profiles which include, Life Types, Daily Living Activities Guide and Report, (set of assessments for both clinicians and formal carers).

Pool Activity Level - (PAL).

ACE-111

Relatives Stress Scale

Hospital Anxiety and Depression Scales - (HAD)

CMOP-E - (Canadian Model of Occupational Performance)- (Environment).

Appendix 6

Joint Performance Measures.

The following joint performance measures are taken from a possible suite of key indicators to measure the performance of reablement schemes. These were developed and agreed by The Social Services Improvement Agency and the Reablement Learning Improvement Network in their work undertaken to measure the performance of reablement schemes in Wales. They have been adapted in relation to reablement services for individuals with memory problems or a dementia to evaluate and justify service development;
measurement of the benefits of prevention and early intervention.

Suite of SMART key indicators (for measuring the benefits of prevention/early intervention of reablement for individuals with memory problems or a dementia).

- Number of referrals for a reablement service (for individuals with memory problems or a dementia) out of total number of referrals to adult social care.
- % of referrals for a reablement service (for individuals with memory problems or a dementia) as a percentage of all referrals to adult social care.
- Number of individuals who experience the reablement service for individuals with memory problems or a dementia.
- % of individuals who experience the reablement service for individuals with memory problems or a dementia.
- Number of individuals with memory problems or a dementia who leave the reablement service with no on-going home support package.
- % of individuals with memory problems or a dementia who leave the reablement service with no on-going home support package.
- Number of people with memory problems or a dementia completing a reablement programme.
- % of people with memory problems or a dementia completing a reablement programme.
- Number of people with memory problems or a dementia requiring reduced packages of support following a reablement programme.
- % of people with memory problems or a dementia requiring reduced packages of support following a reablement programme.
- Number of individuals with memory problems or a dementia requiring no change to their support following a reablement programme.
- % of individuals with memory problems or a dementia requiring no change to their support package following a reablement programme.
- Number of individuals with memory problems or a dementia requiring increased support packages following reablement programme.
- % of individuals with memory problems or a dementia requiring increased support packages following a reablement programme.
- Number of individuals with memory problems or a dementia who continue to remain independent of services following cessation of a reablement programme.
- % of individuals with memory problems or a dementia who continue to remain independent of services following cessation of a reablement programme.