

Real Change Challenges



The Real Change Challenge:

**Improving the quality of life for
people with learning disabilities
as they grow older: A Challenge
for Providers**

By Cally Ward



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Foreword

The ageing of people with learning disabilities is a huge social and medical success story; one which is to be celebrated. Today's older people with learning disabilities are the first generation to survive beyond childhood and adulthood into older age. But increased longevity is not without its challenges for individuals, families and services. It is crucial that these additional years are as happy, healthy and fulfilling as possible. The ARC Real Change Challenge directly addresses these challenges and provides guidance on how growing numbers of people with learning disabilities can be supported to age successfully.

The current generations of older people with learning disabilities, and their families, have lived through, and have had to adapt to, radical shifts in both policy and practice. Many have done it with no professional help. It is now widely accepted that support for younger adults should be based on their basic right to independence, participation, choice and control. And services have increasingly been organised around these goals *regardless* of the level of learning or physical disability.

This Challenge forcefully makes the case for continuing this approach into later life. It is essential that the age discrimination, so widespread elsewhere in society and in many older people services, is not incorporated into provision for older people with learning disabilities. The first step to preventing this is to ensure that all health and social care professionals are armed with the necessary tools to ensure support continues to maximise independence and participation *regardless of age*. Need and aspiration should determine support not chronological age.

Despite the unprecedented period of austerity families and services are experiencing, there is much that can be achieved through greater awareness and a change in attitude towards people with learning disabilities as they age. The Challenge provides clear guidance to service professionals on how to make an already good news story an even better one. It sets out practical steps on how to ensure that the life expectancy of people with learning disabilities continues to improve (it is still lower than the general population) and how to ensure that these extra years of life are healthy, happy and fulfilled. If followed they offer the opportunity for service professionals to offer older people with learning disabilities, and their families, the chance to age successfully and enjoy a better quality of life.

Carol Walker

Professor of Social Policy, University of Lincoln

Today's older people with learning disabilities are the first generation to survive beyond childhood and adulthood into older age... It is crucial that these additional years are as happy, healthy and fulfilling as possible.



Improving the quality of life for people with learning disabilities, as they grow old: A Challenge for Providers

Older people with learning disabilities are a growing and diverse group. People find themselves growing older in many different places, with a range of different needs, experience and aspirations.

The number of people with learning disabilities over 60 will increase by nearly 40% between 2001 and 2021². By 2030 the number of adults 70+ using social care services for people with learning disabilities will more than double.³

A key question that must be asked is what sort of lives will these older people with learning disabilities have and how and where will their support needs be met?

How can we ensure that the needs of all these older people with learning disabilities are understood so they can have a successful old age; remaining healthy, active and engaged, with as much control and choice in their lives as possible? This presents a challenge for us all and a very specific set of challenges for learning disability providers.

The aim of this ARC document is to identify what learning disability providers must do to meet the Real Change Challenge of improving the quality of life for people who have a learning disability as they grow older.

This will mean:

- Supporting the people *currently* in services to age well.
- *Planning for the future* and engaging with those people currently living in the community with their families – the potential ‘customers’ of the future.

Since the early 1990’s there has been a growing interest in ageing and people with learning disabilities, including ARC’s *Preparing for a Positive Future* project. An extensive body of research is available but it is not clear how much this has impacted on the way that providers deliver support to the older people with learning disabilities in their care.

¹ Emerson E. & Hatton C. (2008) *Estimating the Future Need for Adult Social Services for People in England*. Lancaster University Centre for Disability Research

² Emerson E. & Hatton C. (2011) *Estimating Future the Needs for Social Care among Adults with Learning Disabilities in England: An Update Improving Health and Lives*. Learning Disability Observatory www.improvinghealthandlives.org.uk

³ Kerr D. (2007) *Understanding Learning Disability and Dementia: Developing Effective Interventions*. Jessica Kingsley Press

The good news is that people with learning disabilities are living longer. The bad news is that their needs are in danger of being misunderstood, overlooked, or poorly met.

Diana Kerr ³

At what age are people with a learning disability considered to be 'old'

This is an important question. Often chronological age, the number of birthdays you have had, is used to gatekeep access to care and support.

'Old' can be a very elastic concept – anything from the 50's through to 75 plus. Most people admitted to residential care for the elderly are usually 85 plus!

Chronological age is **not** a useful indicator of a person's aged related needs.

- Some people in their 50's, with chronic health conditions can feel prematurely old and have restricted lifestyles.
- Some people in their 80's and 90's can be robust and have very active lifestyles.
- Sadly, many people with learning disabilities have high levels of unmet health needs because they have not received good health care over the years. This means they approach later life at a real disadvantage and develop problems earlier than the rest of the population.

- Some groups of people with a learning disability are at particular risk of ageing prematurely and developing conditions associated with old age much earlier in life. For example, people with Down's Syndrome.

For these reasons we are defining 'old' in terms of people with learning disabilities, from the age of 50, with a key focus on age related change.



Challenging issues include:

- People with learning disabilities express fear and concern about what lies ahead as they grow older.
- People are disadvantaged because they have very little choice and control in their lives about where they live, and who and how they are supported.
- Concern over the inappropriate use of older peoples' residential and nursing homes has been highlighted.⁴
- Support staff or care workers lack basic information about the ageing process and how it can affect people with a learning disability. Many health needs go unmet because staff do not know what to look for.
- Ageist attitudes exist in learning disability services.⁵ The attitudes of individual staff to the older people they support can make a big difference and stop them from:
 - Accessing the health care they need
 - Trying out new activities and leisure pursuits
 - Remaining in their own home if their needs change
 - Staying in touch with the people that are important to them.
- A recent European study called ageism **'the most widespread and enduring discrimination of them all'**.⁶

⁴ Thompson D. et al. (2004) *People with Intellectual Disabilities Living in Generic Residential Services for Older People in the UK*. Journal of Applied Research in Intellectual Disabilities. Vol 17. No 2 pp 101 -107

⁵ Walker C., Ryan T. and Walker A (1996) *Fair Shares for All: Disparities in Service Provision for Different Groups of People with Learning Difficulties Living in the community*. Pavilion Publishing

⁶ ELSA (2002) *Health, Wealth and Lifestyles of the Older Population in England*. www.ifs.org.uk/ELSA/publications

The Challenge: Meeting the needs of people growing older in your services today



Many of the issues that were identified as critical in the 1990's in relation to ageing and people with learning disabilities are still critical today. However, the legislative, regulatory and policy context has shifted dramatically. The consolidation of a rights based approach to policy and an emphasis on the personalisation of services has meant that as providers you have had to pay attention to how you deliver personalised support to the people in your care.

My Home Life⁷ highlights the importance of developing 'relationship centred care' which enables a culture in services for the individual older person where voice, choice and control are accentuated.

- **Maintaining identity:** see who I am
- **Sharing decision making:** involve me
- **Creating community:** connect me

There is a focus today on achieving outcomes for people rather than focusing on service or policy inputs. A focus on **outcome statements** or '**I statements**' are a precursor for learning disability providers to think about developing how you are going to enable those outcomes to happen for the people you support!

Delivering these outcomes, and offering real change in peoples' lives, is the challenge for learning disability providers, both now and in the future.

The Growing Older Resource and Evaluation Toolkit

To accompany this challenge and achieve real change for individuals as they grow older the Association for Real Change and the Foundation for People with Learning Disabilities have worked in partnership to develop an evaluation toolkit designed specifically to help organisations deliver the eight Outcome Statements outlined overleaf. Together, the toolkit and challenge form the Growing Older Resource for support providers.

The toolkit has been designed to be used in conjunction with the challenge and to help providers better understand the values, knowledge and skills they will need to have in place to deliver an action plan to improve support. Included are ideas for resources to help achieve best practice and a number of key indicators linked to each statement that will help organisations assess how well they are doing and identify priority areas for introducing changes.

⁷ For more information on My Home Life see www.myhomelife.org.uk

The outcome statements



Real Change Challenge:
Outcome statements



1. I am supported by people who see the real me and know me well.
2. I am involved in making the important decisions in my life.
3. My health is maintained as I grow older.
4. I feel safe and secure in my own home.
5. I am still doing the activities that are important to me, and trying new things if I want to.
6. I am still in contact with the people who are important to me – my family, my friends and the community I live in.
7. I am well supported when the people that are important to me move away or die.
8. I can celebrate my life and am coming to terms with my own approaching end of life.

1

I am supported by people who see the real me and know me well

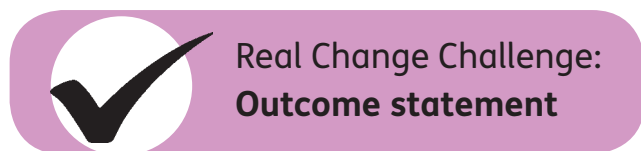
- The everyday encounters that people have with the people that support them are the biggest determinate of the way they experience their lives, hour by hour and week by week. Continuity of staff is something that people value and is at the centre of relationship-centred care.
- Older people with learning disabilities need to be supported by staff that treat them with respect and dignity; talking to them rather than at them or over them. This has implications for staff training and development and needs to explore with staff how they 'see older people' and how their underlying assumptions about old age can impact on the way they work.
- Using person-centred planning tools is at the heart of getting to know someone well. This ranges from a one page personal profile, which provides a quick summary of the person, to the more detailed life story work that can enable staff to see the person as a whole and understand important aspects of their history and relationships.

When I did the life map with Annie I suddenly realised that there were whole periods of her life that I just did not know about. It was a bit scary because I thought I knew her quite well.

Support Worker



Real Change Challenge:
Outcome statement



2 I am involved in making the important decisions in my life

- As people grow older and their needs change they can find themselves having to make big decisions about where to live, health treatments and whether to make a will. Older people with learning disabilities are no different.
- Even if a person is deemed to lack the capacity to make an important decision their best interest should always be at the centre of the decision making process. Staff need to be fully aware of their responsibilities under the MCA Code of Practice and have the skills to fulfil them.





Real Change Challenge: Outcome statement

3 My health is maintained as I grow older

Help you stay healthy. Give you the right support. Look in my health book. Staff job is to help you speak at the doctors.

Betty, GOLD group member

Make sure people take the right medication. Sometimes they forget. I speak up for myself. I don't want another epileptic fit in the bath.

Roger, GOLD group member ⁸

- Supporting people with learning disabilities to maintain their health is one of the most vital ingredients of ageing well and staying independent in later life.
- For providers there is an important *preventative* agenda that needs to be put in place for *all* the people you support. It is simply never too soon to start with the lifestyle and dietary needs of the people you support as the research evidence has painted a bleak picture of poor diets, obesity and sedentary lifestyles that puts people at risk of developing a range of health related problems in later life.
- Staff in learning disability services need some basic understanding of the ageing process: e.g. sensory loss, the menopause for women, changes to bones. By being aware of these changes they can be identified early and people offered the right support. This has implications for staff training, and for opportunities to work with mainstream elderly services.

⁸ Thanks to the GOLD group for giving up their time to talk about their experiences of ageing and what it meant for them. The GOLD group have been meeting since 1998 and have produced a DVD about getting older and resources about dementia. For more information contact Noelle Blackman at Respond. www.respond.org.uk

4 I feel safe and secure in my own home

- For those growing older in the family home the worry for them and their families is what will happen in the future? An unplanned transition from your own home into alternative accommodation and support can be a terrifying ordeal. Providers need to work with families who are growing older together to plan for a smooth transition to new arrangements.
- The fear of losing their home when they get older is something that many people with learning disabilities express. A decline in health can often be a catalyst for 'moving on'. But 'moving on' into alternative models of supported accommodation like extra-care housing or Shared Lives or Home Share could also be a positive choice if people get the right support to make that happen.
- As providers you need to proactively plan for the age related changes of the people you support. For people to be enabled to 'age in place' it is important that their current home is adapted to enable them to do so.
- Creating an 'enabling environment' includes changes to the physical environment and creative use of assistive technology. But it also includes having staff with the knowledge and understanding and empathy to support a person as their needs change in later life.



Real Change Challenge:
Outcome statement

We helped to develop a service for one of the people who moved out of the long stay hospital. Bernadette had no contact with family for many years until just before she moved out when they were informed about her move. She moved into a house with two other people and was supported to make contact with her family again. An annual birthday party brought the family together. When one of the people she lived with died, and one moved into nursing care, rather than fill the vacancies we worked with her family and care manager to develop an individual support package. We employed a couple as housekeepers/ live in carers and provided support on their days off. In November, the family took over the direct employment of the staff. We continue to stay in touch and at her last birthday party in February, 30 family members attended – many from Ireland. Bernadette will go and visit them in Ireland again this summer, as she has done for the last 9 years. Bernadette is 93 and very well and content!

CEO Provider

5 I am still doing the activities that are important to me, and trying new things if I want to

Eileen is an older woman who has been in residential care more or less all her life. Over the years she has acquired a reputation for having some behaviour that is challenging. She wants to pick up everything on the floor or pavement she sees and can get very angry when anyone tries to stop her. Now we have found her a job where she picks up litter on the beach. She loves this job.

Team leader

- Older people with learning disabilities should not be ‘retired’ from the activities they enjoy doing purely on the basis of their chronological age! Keeping active and engaged is one of the best ways to stay well. John, an older man with learning disabilities and a member of the GOLD group, reminds us - “**Just because we are getting on doesn’t mean we can’t do things**”.⁹
- Age should not exclude people from trying out new activities. Providers need to support people to take part in a range of activities that keep them connected to the communities they live in. Older people with learning disabilities can make an important contribution to the communities they live in as volunteers. Some older people with learning disabilities have had their first opportunity to work in later life because the provider that supported them had an innovative approach to meeting personalised needs!
- For other older people with learning disabilities the age related changes they are experiencing make it harder to be involved in the community. As providers you must consider an approach to active support that can enable them to take up new hobbies round the house as well as helping them maintain their skills and independence in the home for as long as possible, in the face of disabling health conditions.



**Real Change Challenge:
Outcome statement**

⁹ Ward C. (2012). *Perspectives on Ageing with a Learning Disability*. Joseph Rowntree Foundation

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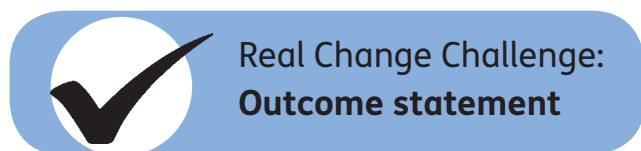
I am still in contact with the people who are important to me – my family, my friends and the community I live in

- Providers must work proactively to keep people connected to family and friends and other important people in their lives! Constructing relationship maps for the people you support is a helpful way to do this.
- Keeping in touch can be done by encouraging people to keep a birthday book and send cards, to a more sophisticated form of communication like the telephone or using Skype. Supporting visits to and from family and friends is important.
- Finding new and innovative ways of keeping people connected to their communities even when they develop significant aged related health problems is one of the major challenges providers face. The possibility of developing the use of Direct Payments or Personal Health Budgets for people in residential or nursing homes is an exciting one!



Real Change Challenge: Outcome statement

When Edna first joined the GOLD group she was living in her own flat with support. She had a lot of bad luck with falls, developing dementia and having a stroke. For the past six years she has been living in a nursing home. The people Edna met through the GOLD group are her only visitors. They keep an eye on her care, making sure she gets regular baths and doesn't spend every day in bed. Because Edna had had little opportunity to get out for several years she had a lot of savings. The GOLD group arranged for this money to pay for a Personal Assistant to spend one-to-one time with Edna and to take her out. The same PA has supported Edna for three years and they are both now familiar faces in the local community.



7 I am well supported when the people that are important to me move away or die

- For many older people with learning disabilities loss has been a prominent feature in their lives. The challenge for providers is to recognise and address it. Work on reminiscence and life story work can be a positive way of helping people reconnect to their past and provide a greater understanding for the people that support them.
- In recent years there has been a greater recognition of the need to find ways of supporting people with learning disabilities through the bereavement process. Staff must have a good understanding of loss and bereavement and how grief is expressed in the people they support and they must feel confident to deal with it.



8 I can celebrate my life and am coming to terms with my own approaching end of life

- Supporting the person at the end of their life is a demanding but important role. Staff must have good training and support to enable them to be effective and deal with their own emotions. In a service that has invested in life story work and in dealing effectively with loss and bereavement, supporting people to 'have a good death' will be greatly enhanced.
- Staff must work as part of a multi-disciplinary team; health professionals including the palliative care team, family and friends. This team will need to support the person through issues like: how and when they are told bad news; making important decisions about treatment options; where they would prefer to die. All decisions must keep the person at the centre of assessment and planning and focus on their best interest and preferred options, and feed into the development of a person centred End of Life Care Plan.
- If the person lives in a shared house then the people they live with will need to be supported to understand what is happening and to deal with their own emotions. If they have a good relationship with the person then it will be important to involve them in the person's care if that is appropriate. They can also be involved in planning any funeral arrangement or celebrations of the person's life and this can offer a positive way of helping them through the bereavement process.



Real Change Challenge:
Outcome statement

Actions to deliver outcomes: **Inform, prepare, equip**

Undertake an age related risk audit of the people you support.

Develop a range of age related policies and protocols to enable you to think through and plan appropriately for:

- Supporting someone to age in place – (including environmental audits and the use of personalised technology, living with dementia and end of life care).
- Supporting someone to make a smooth transition into alternative support service if appropriate.
- Supporting the specific needs of high risk groups of people; ensuring people with Down's Syndrome have appropriate health checks as recommended by the Royal College of General

Practitioners, and baseline assessments for Alzheimer's from the age of 30.

Develop a clear workforce strategy for supporting age related transitions including:

- Staff recruitment and retention
- Staff training and development.

Develop personalised solutions for the people you support in partnership with them, family and friends and other key stakeholders.

Develop an outward looking culture in your organisation.

Mapping local resources in the area and forming strategic partnerships with a range of services and organisations across older people's services, health and social care and the third sector.

Implications for staff training and development

- Exploring attitudes to ageing and combating any age discriminatory practices.
- Use of person centred planning tools – including life maps and life story work.
- Staff awareness of their responsibilities under the Code of Practice of the MCA.
- Training in the ageing process and age related risks – including some of the specific risks associated with some people with learning disabilities.
- Getting the best from health services on behalf of the people you support.
- Creative use of reminiscence and life story work.
- Creating enabling environments as peoples' needs change, including the creative and personalised use of assistive technology.
- How to support people through the bereavement process.
- Community connecting and mapping.
- Working with families and friends to develop Circles of Support.
- Dementia.

The Challenge: Opportunities for providers in the future!



Providers are facing an austere economic environment with the risk in the future of further contraction in public funding. This is particularly acute when it comes to funding the changing support needs of older people with learning disabilities as their comparative costs of care are higher than their non disabled peers.

The challenge for providers in the future is to be proactive and forward thinking

The challenge for providers in the future is to be proactive and forward thinking, forging out a leadership role across the health and social care sector when it comes to championing the care and support needs of older people with learning disabilities.

One of the things that learning disability services as a whole must do is to stop thinking in terms of 'the' transition (between childhood and adulthood) and start to develop a life-course approach which focuses on a series of transitions, including the transition into older age and later life. This later life transition requires the same forward planning, joined up approach as earlier transitions.

The demographic challenge of an ageing learning disability population is set to increase dramatically. The experience of supporting people as they age in learning disability services to date has been described as only the tip of the iceberg. Learning disability providers must make your ageing populations a priority group.

It is important to recognise that the experience, complexity of need and aspirations of many of those reaching old age in the future will be different from the people of today, many of whom have been in long stay provision for a considerable part of their lives.

The majority of adults with learning disabilities live with their families in the community. Significant numbers of these families are growing older together. Providers have an opportunity to proactively reach out to these families and provide them with domiciliary support in their own homes to enable them to continue to live together. This provides an opportunity to build up relationships of trust and help families to begin to plan for the future by exploring a range of personalised options for alternative arrangements when parents can no longer provide the main support.

I am working with 62 different Local Authorities and they all have a slightly different take on what constitutes a 'good life' for an older person with learning disabilities and how to get it!

There must be a range of accommodation and support options in the community for people as they age. People and their families need to be involved in these local conversations now!

One of the problems identified by research has been the lack of cohesion between learning disability and older people's services, health and social care.

This has led to a fragmented approach to delivering care and support to older people with learning disabilities, at both a national and a local level, and an unresolved debate about whether people should be supported in specialist or generic services, which has not been helpful on the ground.

Arrangements for funding support have tended to be done on an adhoc basis rather than with a clear commissioning strategy in place, one that has been coproduced with a range of stakeholders and with a focus on personalised solutions.

The 'dementia challenge' for learning disabilities providers is a considerable one. Not only are people with Down's at high risk of developing early onset Alzheimer's; but people with learning disabilities as a group carry a higher than

average risk of developing dementia than the rest of the population.

There are staff development issues and environment factors to plan for but many providers start from a position of strength because of the strong tradition of delivering person centred support that already exists in learning disability services. Providers need to be outward facing and open to developing strategic partnerships. There is great potential for joint working and joint training initiatives between older peoples' dementia services and the learning disability sector.

Learning disability providers are in a strong position to take a proactive leadership role at a local level and work with commissioners and other stakeholders to both identify the needs of older people in the area, and develop person centred pathways for individuals through local services and out into their community.

This is the only way people with learning disabilities will make a successful transition into later life, remain healthy, active and engaged, with as much control and choice in their lives as is possible, and we must all take up the Challenge to deliver this!



Real Change Challenges

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