Evaluation Toolkit for Providers

An assessment tool and action plan for organisations to improve the quality of life for people with learning disabilities as they grow older

foundation for people with learning disabilities

Association for **Real Change**

Written by Christine Towers, Foundation for People with Learning Disabilities.

Contents

Introduction

The number of older people with learning disabilities is expected to increase significantly over the next 15 years, and as a consequence there will be a greater requirement for health and social care for this group of people. One analysis suggests that by 2030 there will be a 14% increase in the number of adults aged 50+ using social care services for people with learning disabilities and within this group, a 164% increase in the number of adults aged 80+ using these services. This translates as a rise from 1,990 people in 2011 to 5,000 in 2030.

The Association for Real Change (ARC) and the Foundation for People with Learning Disabilities are working in partnership to produce resources and information for provider organisations to enable them to meet these challenges. Both organisations have a long history of raising awareness about the issues affecting people's lives as they grow older and providing solutions.

ARC has developed a series of Real Change Challenges. They are a call to providers and others within the sector to improve the quality of existing services to help make a real difference in the lives of people with learning disabilities. They are also an opportunity to showcase and promote positive changes and good practice. The first area looked at was the provision of services for people with a learning disability who are growing older. This topic had previously been explored by the author of the Challenge, Cally Ward, in the publication 'Prepared for a Positive Future?' (1998).

The Foundation has a long history of developing good practice in relation to older people with learning disabilities and their family carers. To celebrate its golden anniversary the Foundation delivered the Growing Older with Learning Disabilities (GOLD) development programme which covered a range of projects including health, end-of-life care, inclusion, friendships and where people live. This work was presented in a report, 'Today and Tomorrow' (2002), which influenced policy and practice over the next decade. The Foundation then delivered the Older Family Carers Initiative, followed by the Mutual Caring project.

Aims of the Evaluation Toolkit

The Evaluation Toolkit should be used in conjunction with the Real Change Challenge: improving the quality of life for people with learning disabilities as they grow older, written by Cally Ward for ARC.

The aims of the Evaluation Toolkit are to enable providers to:
- understand which values, knowledge and skills need to be in place to support people as they grow older so that their lives are as happy, healthy and fulfilling as possible;
- assess how well they are doing in relation to supporting people to have a good life;
- draw up and deliver an action plan to improve the support provided to people as they grow older;
- access relevant resources to achieve best practice.

RED - we are not doing this
AMBER - we do this some of the time
GREEN - we do this all of the time

RED AMBER GREEN
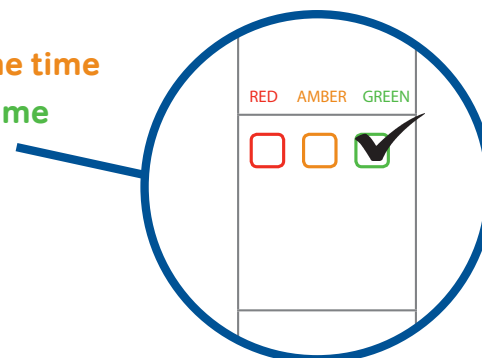
How to use the Evaluation Toolkit

Every organisation is different and therefore the Evaluation Toolkit should be seen as a flexible resource that can be adapted to your work.

Co-production
Better outcomes will be achieved when the evaluation is an open process and includes discussions with people with learning disabilities, their family and friends, staff and managers. Trustees or board members may need to be involved, and you may want to discuss some aspects of the evaluation with other people, such as commissioners or members of the community health team.

The evaluation will be more robust if all these different voices are included and the action plan, outlining the next steps, is co-produced.

Indicators
For each of the eight outcomes set out in the Real Change Challenge, a number of indicators have been produced. These are the key indicators for meeting that outcomes but your organisation may wish to add additional ones to reflect the nature of your work or service. Each indicator can be marked as red, amber or green. This rating will help the organisation to gain an overview of how they are doing and to identify priority areas for introducing changes.

Reflection
On the page opposite the indicators for each outcomes there is a space for reflections using three questions:
• How are we doing?
• What is stopping us achieving best practice?
• What do we need to change to achieve best practice?

You will have gathered information on 'how are we doing?' through your discussions about each indicator and your assessment against the traffic-light assessment.

A discussion in relation to the second and third questions helps to identify barriers and the changes needed to move things forward. The information gathered from these questions can be used to inform the action plan at the end of the Evaluation Toolkit.

Resources
For each indicator there is a short list of resources that offer practical support to achieve the indicators. Some of the resources have been produced for people with learning disabilities, some for front-line staff and others for managers. Most of the resources are available on the website and are free; it is indicated where there is a charge.

Action plan
In the final section of the Evaluation Toolkit there is a suggested format for an action plan. In this you can note what needs to be achieved against each outcome, how this will be done, who will be involved and a timescale for achieving it. It also suggests setting a review date. The best action plans will result from everyone being involved in developing them and having responsibility for their delivery. People with learning disabilities and family carers may be keen to be involved, for example, in delivering training or having responsibility for checking that the changes are delivered.

Feedback
We would welcome feedback from organisations about how they have used the Evaluation Toolkit. Please email fpld@fpld.org.uk to tell us about your experience of using it or ideas for developing it further.

Developing the EvaluationToolkit

We worked with a number of provider organisations to pilot the Evaluation Toolkit in supported living services, a residential care home and in day opportunities.

The feedback below is from Vibrance, who work in 10 local authority areas providing a range of services across housing and community support.

"We found the toolkit to be very flexible; it could be used in a range of ways, from very informally up to a formal audit where evidence was seen and checked.

Also it could be used with individual service users to identify needs and provide evidence for additional resources they may require as a result of ageing and the often associated health issues.

Both our managers involved in the pilot thought the toolkit could be effectively used with staff teams to encourage critical reflection and shared problem solving.

The toolkit encouraged staff to be open and honest about how their service was supporting people as they got older.

It provided opportunities to identify good positive practice within the services and, as a result, staff seemed comfortable in being honest about areas where they were experiencing difficulties.

Not all of the indicators in the outcomes applied to all settings but we thought there was a substantial core number that would apply regardless of the setting and that services could if they wished choose those outcomes to measure themselves against.

We found the outcomes provided a comprehensive measure of how any service is responding to individuals' needs as they age.

Our managers found the 'Resources' section very useful."

Sue Warren
Quality Manager at Vibrance

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

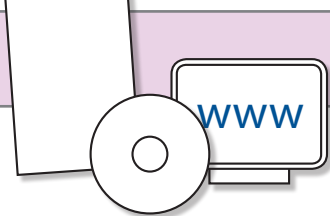|		RED	AMBER	GREEN
a	Staff have training and are supported to work in a person-centred way, thinking about what works for the person they are supporting and what is important to them. This includes an understanding of how getting older may affect people and using this knowledge to help people make changes in their lives. People with learning disabilities and their families are involved in co-producing this training.	☐	☐	☐
b	Every person has person-centred information that support staff are familiar with, such as a one-page profile, relationship map, life story, what makes a good day or bad day, what we like and admire about someone, a communication passport.	☐	☐	☐
c	People we support are asked about the kind of person they like to be supported by and this information is used to recruit and organise staff (their circle of family and friends is involved in this process). This is checked when recruiting someone new to reflect a person's changing needs.	☐	☐	☐
d	At least every 3 months we check with people we support (and their circle of family and friends) whether they think they are getting good support. This includes finding out whether the support feels right for their age.	☐	☐	☐
e	Staff are given supervision and mentoring in their job that enable them to enjoy their work and have development opportunities. Through personal development we aim to encourage staff to stay in the organisation so that they get to know people and recognise changes over time.	☐	☐	☐

Reflection	Resources
How are we doing?	**Person-centred approaches and older families**, Foundation for People with Learning Disabilities (2005): **www.learningdisabilities.org.uk** **Peer Professional Supervision Project,** Association for Real Change (2014): **www.arcuk.org.uk** £ **Helen Sanderson Associates'** website provides information on training and resources on person-centred planning: **www.helensandersonassociates.co.uk**
What is stopping us achieving best practice?	
What do we need to change to achieve best practice?	

* £ Indicates a resource that requires payment

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

		RED	AMBER	GREEN
a	Staff receive training and have an awareness of their responsibilities under the Mental Capacity Act and use the Code of Practice to guide decision-making.	☐	☐	☐
b	Everyone's person-centred plan has information about how to best support them in decision-making and is used throughout their adult life to build confidence to make choices. The person, with their circle of family and friends, is involved in developing their own plan and in decision-making.	☐	☐	☐
c	Staff regularly provide opportunities for the people they support (and their circle of family and friends) to talk about what is working or not working for them, including where they live. In this way they have the opportunity to talk about their changing needs in informal conversations rather than being limited to formal situations, such as an annual review.	☐	☐	☐
d	People we support are given opportunities to make decisions about treatments they want or do not want to receive (including advance decisions to refuse treatment), end-of-life planning and funeral arrangements.	☐	☐	☐
e	We know about the variety of accessible information that is available, for example Easy Read information about health and housing choices, and make this available to help people understand choices and make decisions. We also put information we produce into accessible formats.	☐	☐	☐

Reflection	Resources
How are we doing?	**Mental Capacity Act Audit Tool**, Association for Real Change helps organisations assess whether staff have understood their MCA training: **www.arcuk.org.uk** **The Mental Capacity Act 2005 Guidance for Providers**, Care Quality Commission (2011), explains the duties and responsibilities placed on registered care providers by the Act: **www.cqc.org.uk**
What is stopping us achieving best practice?	**Involve Me**, a Mencap project aimed at finding ways of involving people with profound and multiple learning disabilities in decision-making and consultation: **www.mencap.org.uk/involveMe** **Helen Sanderson Associates' decision-making agreement tool** provides ideas about how to support someone in their decision-making: **www.helensandersonassociates.co.uk**
What do we need to change to achieve best practice?	**Thinking Ahead: a planning guide for families**, Foundation for People with Learning Disabilities (2013), Section 1, 'Making Decisions': **www.learningdisabilities.org.uk**

3 My health is maintained as I grow older

		RED	AMBER	GREEN
a	We support people to look after their health, by eating well, exercising and having health checks, **throughout** their adult life to reduce the risks of health-related problems in later life.	☐	☐	☐
b	People have an annual health check (where they are supported by someone who knows them well), a health action plan and hospital passport which set out how they are best supported to look after and maintain their health and receive medical treatment.	☐	☐	☐
c	People are given the additional support they need to attend health appointments, including screening and outpatient appointments and during hospital stays. Where we are not able to give this support, we advocate to ensure it is provided.	☐	☐	☐
d	Staff receive training and are aware of the ageing process, for example, the menopause, sensory loss, loss of mobility and short-term memory and changes in appetite. We use the skills of community learning disability teams and other health professionals to ensure people get the right healthcare.	☐	☐	☐
e	Staff receive training and are aware of the early signs of dementia. People who are seen as having an increased risk of dementia are supported to have a baseline assessment so that changes can be assessed against it.	☐	☐	☐
f	Staff receive training and are aware of the signs of depression and other mental health problems associated with getting older.	☐	☐	☐

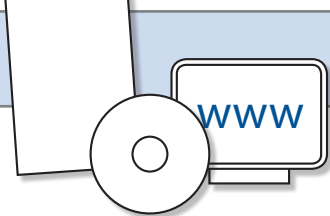| Reflection	Resources
How are we doing?	**Easy Health**, Easy Read health information and leaflets **www.easyhealth.org.uk** **Dementia and People with Learning Disabilities,** Royal College of Psychiatrists (2009): **www.rcpsych.ac.uk**
What is stopping us achieving best practice?	**Supporting Derek,** a resource book and DVD for staff, Joseph Rowntree Foundation (2010): **www.jrf.org.uk** **Books Beyond Words**, a series of books that tell stories in pictures to help people with learning and communication difficulties to understand their experiences: **www.booksbeyondwords.co.uk** £ **Seeability** provides training and information about eye care and vision for people with learning disabilities: **www.seeability.org**
What do we need to change to achieve best practice?	**Dignity in Health Care for People with Learning Disabilities,** Royal College of Nursing (2013), provides guidelines written for nurses but is useful when advocating for good healthcare. **Feeling Down: Looking After My Mental Health,** Foundation for People with Learning Disabilities (2014): **www.learningdisabilities.org.uk/mentalhealth**

4 I feel safe and secure in my own home

		RED	AMBER	GREEN
a	We support people who live at home with their families to think about the future and to have a plan in place should an emergency arise following the illness or death of a family carer.	☐	☐	☐
b	People know they have a choice to stay in their own home where physical and environmental changes can be made and support adapted, involving other professionals and organisations such as occupational therapists and independent living centres.	☐	☐	☐
c	People know they can chose to move if their current housing is no longer what they want. They are given information about alternatives, such as extra-care housing.	☐	☐	☐
d	Staff show an understanding that, as people get older, they may feel less safe in their home or less confident doing tasks such as cooking or having a shower, and this is reflected in support plans.	☐	☐	☐
e	Advice is sought from professionals, such as occupational therapists, to adapt ways of doing things around the home. Support planning is used to identify how people can maintain independence, confidence and dignity in daily activities.	☐	☐	☐
f	We are familiar with assistive technology options that are available (e.g. call alarms, gas detectors, and fall detectors) and support people to consider using these and give ongoing support if they decide to do so.	☐	☐	☐
g	People are supported to maintain, furnish and decorate their home environment so that it feels comfortable, warm and safe, e.g. outside lights, storage space to avoid floor clutter and warm blankets.	☐	☐	☐

Reflection	Resources
How are we doing?	**Thinking Ahead: a planning guide for families,** Foundation for People with Learning Disabilities (2013), a guide which providers could signpost families to, or use with them, to plan for the future. It includes a section on making an emergency plan: **www.learningdisabilities.org.uk**
What is stopping us achieving best practice?	**Hft** provides information about personalised technology (also called assistive technology) to help people do everyday things more easily, live more independently and stay safe. They plan technology to meet a person's specific needs following an assessment: **www.hft.org.uk** **Housing and Support Alliance** provides information about different kinds of housing and support and how to make these work to meet people's needs: **www.housingandsupport.org.uk/home**
What do we need to change to achieve best practice?	**Getting equipped to tackle forgetfulness: Equipment, gadgets and technology to help people with dementia,** Foundation for Assistive Technology (2011): **www.fastuk.org**

5

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

		RED	AMBER	GREEN
a	Staff have an understanding that people's levels of activity vary greatly in later life; some people remain very active and enjoy taking up new activities whilst others want to slow down. They also understand that people may have varying levels of energy day to day and week to week.	☐	☐	☐
b	We provide support in a flexible way that can accommodate people having more or less energy at different times so that they can vary what they do from week to week. This includes having agreements in place with other support providers that enable people to stay at home when they are feeling unwell or tired.	☐	☐	☐
c	Staff receive training and use their learning to adapt the way activities can be done so people can still take part in a meaningful way and feel safe whilst doing them (e.g. preventing falls). This may involve allowing more time, finding different means of travelling or finding someone to accompany them.	☐	☐	☐
d	The planning of support includes looking at new ways of being involved in the community. This may be doing activities that are not specifically for people with learning disabilities, giving them the opportunity to meet a wider group of people who are in their later life, for example, through a walking group or lunch club.	☐	☐	☐
e	We know about and encourage the use of community resources and activities available for older people and people with dementia.	☐	☐	☐

Reflection	Resources
How are we doing?	**National Association for Providers of Activities for Older People** provides resources and training to increase activity opportunities for older people: **www.napa-activities.co.uk**
What is stopping us achieving best practice?	**Activities to Share** offers a wide range of products and activities for older people, including those with dementia and learning disabilities: **www.activitiestoshare.co.uk** **Active Support Handbook**, Association for Real Change (2013), a resource for support providers explaining the idea of Active Support, which aims to fully involve people in what is happening in their lives: **www.arcuk.org.uk/publications**
What do we need to change to achieve best practice?	**Connecting People, the steps to making it happen** (accompanying DVD available), Foundation for People with Learning Disabilities (2009): **www.learningdisabilities.org.uk/publications**

6 I am still in contact with the people who are important to me – my family, my friends and the community I live in
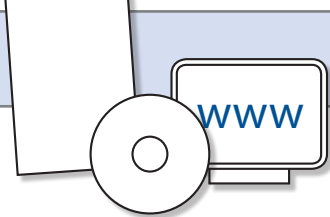
		RED	AMBER	GREEN
a	Staff have training and understand the importance of people being supported to be in contact with family and friends and the potential impact of diminishing social networks as people get older. People with learning disabilities and family carers are involved in delivering this training.	☐	☐	☐
b	Staff know the important people in the lives of the people they support and use tools such as relationship maps and life stories.	☐	☐	☐
c	We look for the best ways of supporting each person to maintain and develop their relationships; detailed guidelines are drawn up about how to support someone to maintain as much independence as possible to do this, e.g. using an adapted phone, giving privacy.	☐	☐	☐
d	There is an understanding that it may be harder for a person to go out to meet with family, friends and people in the community. We support people to invite their friends and family to their home for a cup of tea or a meal and to enjoy activities together or to arrange for community groups to meet at their home e.g. a singing or church group.	☐	☐	☐
e	We map what is available in the community for older people, e.g. groups and places where older people meet informally, and volunteering opportunities.	☐	☐	☐

Reflection	Resources
How are we doing?	**Thinking Ahead: a planning guide for families**, Foundation for People with Learning Disabilities (2013), Section 3, 'Building friendships and support networks': **www.learningdisabilities.org.uk**
What is stopping us achieving best practice?	**Friends and Neighbours,** Association for Real Change (2010), trainer's manual about social inclusion: **www.arcuk.org.uk/publications** £
What do we need to change to achieve best practice?	**Dementia and people with learning disabilities,** Respond, a training pack on the importance of supporting relationships for people with learning disabilities who develop dementia: **www.respond.org.uk/shop** £

7

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

		RED	AMBER	GREEN
a	We support people throughout their adult life to talk about loss and bereavement so that they feel comfortable with the subject. This will make it easier to share feelings in later life when a sense of loss is likely to grow.	☐	☐	☐
b	Staff have training and an understanding of the process of loss and bereavement. They realise that people will need time to react and respond and may express their feelings in different ways.	☐	☐	☐
c	Staff are aware that people experience a sense of loss regarding skills, sensory awareness and mobility as well as at the death of loved ones. Opportunities are offered for people to talk one to one or with their peers.	☐	☐	☐
d	Day to day, support staff talk to people about their family and friends, including those who have moved away or died. When family or friends move away they find ways for the person to keep in contact. If someone dies, they find ways to support the person to remember and commemorate them.	☐	☐	☐
e	We are aware of available resources and make use of professionals such as community nurses, who can advise staff or work directly with the people we support.	☐	☐	☐
f	We support people to decide whether to attend funerals of family and friends. We encourage families to talk with their relative about who they would like to attend their funeral to ensure their friends are not excluded.	☐	☐	☐

Reflection	Resources
How are we doing?	Breaking Bad News, a website providing guidance on how to support someone with learning disabilities to deal with bad news: **www.breakingbadnews.org**
What is stopping us achieving best practice? £	Books Beyond Words, a series of books that tell stories in pictures to help people with learning and communication difficulties to understand their experiences: **www.booksbeyondwords.co.uk** £
What do we need to change to achieve best practice?	

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

		RED	AMBER	GREEN
a	People are given opportunities, throughout their adult years, to put together information about their life in a format they can enjoy (photos, memory boxes, video clips etc). People are supported to use these and/or to share them with others so that they can remember their past life and celebrate important moments.	☐	☐	☐
b	We support people to make a plan about what they would like to happen when they die, including organ donation, funeral service and ways of being remembered. It is recognised that this is a sensitive topic requiring a lot of time and should be broached before the person is facing their own death.	☐	☐	☐
c	We support people whenever possible to decide whether to make a will. This may include making decisions about to whom they would like to leave significant objects.	☐	☐	☐
d	We support people who are nearing the end of their life to have an end-of-life care plan and invite family, friends, support staff and the relevant health professionals to contribute their thoughts and be involved in their care as appropriate.	☐	☐	☐
e	We know about specialist resources for end-of-life care, such as hospices. We advocate for the best end-of-life care with health professionals, including hospital staff.	☐	☐	☐

Reflection	Resources
How are we doing?	**We're Living Well but Dying Matters**, a film produced by CHANGE for Dying Matters and the national End of Life Care Programme, about including people with learning disabilities in discussions around death, dying and bereavement: **www.dyingmatters.org**
What is stopping us achieving best practice?	**Books Beyond Words, 'Am I Going to Die?'**, a book about a man with a terminal illness, with guidelines at the back for carers and supporters to talk with a person: **www.booksbeyondwords.co.uk** £
	Dying Matters, Foundation for People with Learning Disabilities (2005), a workbook for staff and managers to help them address the needs of people with learning disabilities who are dying: **www.learningdisabilities.org.uk**
What do we need to change to achieve best practice?	**Palliative Care for People with Learning Disabilities Network** provides information and resources: **www.pcpld.org.uk**

Action Plan: example

Outcome: 1 I am supported by people who see the real me and know me well

What we need to achieve	How	Who	When	Review date
We have good person-centred support plans for everyone but we want to make sure we are recording changes as people grow older.	Introduce 'what makes a good day/bad day' to make sure we know what is changing to make a person's day go well.	Operational manager to run a training session on how to use the tool. Keyworkers and PAs to talk with people to collect information.	Introduce in April and update as part of 3-monthly checks of support plans.	In 6 months' time to see whether we have gathered the information we need.
Our recruitment attracts the candidates that people we support want as they grow older.	Everyone has a written profile of the kind of person they want to be supported by. These are developed with the person and people who know them well.	HR and managers to agree how the profile information will be used in recruitment. Line managers to mentor keyworkers and PAs to develop profiles with people they support.	March to September	Review after each round of recruitment.
Staff have a better understanding of what good support looks like.	Involve tenants in staff training. Discuss this at tenants' meetings. Support 3-4 tenants to go to staff teams to talk about their experience of receiving support.	HR to set up recruitment and payment process. Lead manager for service-user involvement to attend tenants' meetings, support recruitment of trainers and delivery of training.	Tenants' meetings in May.	Review in annual appraisal and development process.

Action Plan

Outcome: **1** **I am supported by people who see the real me and know me well**

What we need to achieve	How	Who	When	Review date

Action Plan

Outcome: **2** **I am involved in making the important decisions in my life**

What we need to achieve	How	Who	When	Review date

Action Plan

Outcome: **3** **My health is maintained as I grow older**

What we need to achieve	How	Who	When	Review date

Action Plan

Outcome: **4** **I feel safe and secure in my own home**

What we need to achieve	How	Who	When	Review date

Plan **Action Plan**

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

What we need to achieve	How	Who	When	Review date

Action Plan

Outcome: **6** **I am still in contact with the people who are important to me – my family, my friends and the community I live in**

What we need to achieve	How	Who	When	Review date

Action Plan

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

What we need to achieve	How	Who	When	Review date

Action Plan

Outcome:

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

What we need to achieve	How	Who	When	Review date

The Foundation for People with Learning Disabilities (the Foundation) is one of the UK's leading learning disability charities, and as part of the Mental Health Foundation has over 60 years' experience in helping people with a learning disability live their life to the full.

The Foundation strives to fight stigma and discrimination, improve policies and services, and give people with learning disabilities and their families the information and support they need to lead fuller, more independent lives through a wide range of research and development projects.

Part of

mental
health
foundation

**Colechurch House
1 London Bridge Walk
London SE1 2SX
United Kingdom**

Phone:
0207 803 1100
Email:
fpld@fpld.org.uk
Website:
www.learningdisabilities.org.uk

Association for Real Change is a leading umbrella body representing service providers in the learning disability sector across the UK. We exist to improve the quality of life for people who have a learning disability by supporting anyone who is involved in the planning or delivery of support and services.

We are committed to sharing our learning and experience. We provide guidance, information and consultancy; support with workforce development, including qualifications, training, publications and disclosures; opportunities to network and representation at local, regional and national levels.

In promoting best practice we work collaboratively with others such as the Department of Health, Skills for Care, Big Lottery Fund and Comic Relief.

**The Association for Real Change
Marsden Street
Chesterfield
Derbyshire S40 1JY**

Phone:
01246 555043
Email:
contact.us@arcuk.org.uk
Website:
www.arcuk.org.uk

changing
lives