

**Department of Health and
Social Care**

**Best Practice on Care
Coordination for People with a
Learning Disability and Long-
Term Conditions**

Report

April 2020

Department of Health and Social Care

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Contents

1	Executive Summary.....	3
2	Introduction.....	7
3	Context.....	7
3.1	Definition of learning disabilities	7
3.2	Prevalence of people with a learning disability	8
3.3	Links between learning disability and long-term conditions.....	9
3.4	Poor health of people with a learning disability.....	9
3.5	Reasons for health inequalities	10
3.6	Government responses to health and care needs of people with a learning disability	11
4	Methodology.....	13
5	Good health and wellbeing from the perspective of people with a learning disability and long-term conditions	14
5.1	Barriers to achieving good health and wellbeing	15
5.2	Enablers of good health and wellbeing.....	16
6	What is care coordination?.....	17
6.1	Co-ordinated care packages and pathways, that reduce fragmentation between services.....	18
6.2	Co-ordinator/care and support navigator/key worker/liaison role.....	22
6.3	Coordinated care through whole systems, strategic commissioning	30
7	Other approaches to improving the health and wellbeing of people with a learning disability.....	34

8	Further Considerations – An IPC Perspective: Care coordination and empowering people with learning disabilities and long-term conditions	37
8.1	Mental Capacity Act and Deputyship.....	38
8.2	Advocacy.....	39
8.3	Strengths based approach	40
8.4	Attitudes, behaviours and culture	42
8.5	Flexible service provision	44
8.6	Digital solutions	45
9	Recommendations	46
	References	49
	Appendix One.....	53
	Appendix Two.....	54

1 Executive Summary

It is widely acknowledged that people with a learning disability experience poorer health than the general population and too many people with a learning disability die prematurely. The deaths reviewed by the University of Bristol Norah Fry Centre for Disability Studies (2017) show that compared with the general population, the median age of death is 23 years younger for men and 29 years younger for women and is often for avoidable reasons.

Government responses to the health, care and support needs of people with a learning disability and long-term conditions are written into the NHS Ten Year Plan (2019):

“Across the NHS, we will do more to ensure that all people with a learning disability, autism, or both can live happier, healthier, longer lives”. (chp 2, 2.31). Core principles include promoting progression and independence using a strengths-based approach, enabling choice and control and personalised care planning. The National Service Model, referred to in the LGA, ADASS, NHS England 2015 report, includes a commitment to overcome barriers and improve health outcomes for people with a learning disability and long-term conditions. The model emphasises the role that local care and support navigators can take to co-ordinate care as well as encouraging mainstream health services to make reasonable adjustments and provide extra support to help overcome the difficulties and risks that people with a learning disability experience.

People with a learning disability and long-term conditions are clear about the **things that help them to stay healthy and well**. Our focus group participants identified the following protective factors, which are fundamentally the same for all of us: relationships; activities/social life; time out/relaxing; keeping well; sense of security; sense of acceptance/understanding from others; sense of freedom, independence, choice; making a contribution.

When it comes to **barriers** to achieving good health and wellbeing people spoke about:

- Information about help not being readily available or easy to understand and poor signposting;
- Cut backs in support hours, eligibility thresholds which are too high and inflexible benefit rules;
- Difficulties with the way help is offered and provided, including poor communication, unhelpful processes, inflexible responses;
- Shortcomings in staffing including high turnover, lack of training, not enough time;
- System fatigue, barriers feeling unsurmountable, people giving up.

Conversely **enablers** were identified as:

- Professionals and services listening and communicating effectively
- Staff being respectful and working alongside the person and their carers
- Staff having the right training and qualifications
- People having the right attitudes
- Support from professionals and others eg advocates, key workers, community

Care coordination is one of the core principles that underpins the transformation of care and support services in this country. One of the main recommendations in the Second Annual Report of the Learning Disability Mortality Review (LeDeR) Programme (University of Bristol, May 2018) is to improve the coordination of care and this report is to fulfil the action agreed by the Department of Health and Social Care:

“We agree that coordinating care across and within health and care services is a crucial determinant of outcomes. We will be reviewing best practice on care coordination to identify approaches that work best for people with a learning disability with two or more long-term conditions” (DHSC and NHSE, September 2018, p 11)

What do we need to do to ensure care coordination contributes to improving the health and wellbeing of people with a learning disability?

Value the diversity of roles that contribute to care coordination

There is no ‘one size fits all’ approach to care coordination. The different levels of need experienced by people with learning disabilities ranging from mild to moderate, severe or profound means that the type and amount of care co-ordination will vary. It is important to recognise that this type of work is carried out by a multitude of people. These include health and social care staff such as social workers who work directly with people with learning disabilities; health and social care staff in other non-learning disability roles such as hospital workers; personal assistants and family members; as well as others with job titles that include the word ‘coordinator’, ‘facilitator’ or ‘key worker’.

Use person-centred, co-productive approaches

For care coordination to be successful and contribute to improving health and wellbeing outcomes, people with a learning disability should be at the centre of decision making about their own lives and in the development of new initiatives.

- At an individual level, the principles of the Mental Capacity Act to protect and empower people to have as much control over their lives as they can should be adhered to, including when care and welfare deputyships are in place
- All forms of advocacy should be supported and resourced to give people information they can understand, to help them express what they want, secure their rights, represent their interests and obtain the services they need to maximise their chances of having good health and wellbeing. This means sufficient financial investment should be given to advocacy organisations as well as giving time and space for self advocacy or advocacy by a trusted individual eg family member or friend
- Pathways and services should be coordinated in a flexible way around the needs and wishes of the person
- A strengths-based approach should be employed at all times recognising the capacity, skills, knowledge and potential that individuals possess and can be built on throughout their lives
- Initiatives to improve health and wellbeing should be co-produced to ensure they are appropriate and will appeal to the people they are aimed at (e.g. health and wellbeing videos being co-produced by North Wales Together)

Improve organisational standards, systems and processes – services need to demonstrate commitment to standards for delivering care, for example, those developed for providers working with people with Profound and Multiple Learning Disabilities (Care Management Group, 2017) and quality assure/performance manage adherence to these. Systems and processes should be streamlined, for example a single point of access, so that the person only needs to tell their story once; integrated assessment and planning, with all the relevant individuals feeding in and listening to the aspirations of the person as the starting point; multidisciplinary teams so care and support is experienced as being well coordinated and seamless and health and wellbeing goals are embedded and monitored as part of the care plan.

Make workforce training and development a priority - Whether staff are working in a direct care management role, health promoting role or health liaison role, this diverse workforce would benefit from training and development to ensure they have the right knowledge, skills and behaviours to maximise the positive influence they can have on improving health and wellbeing for people with a learning disability, whether their disability is mild, moderate, severe or profound.

- Excellent guidance is in place (Skills for Care, Health Education England and NHS England (2019), identifying twenty-five capabilities divided into 5 domains (one of which is health and wellbeing) and arranged in tiers of complexity depending on individual roles. The guidance gives the desired learning outcomes for each topic and links to key references and documents that will be valuable to those planning training or curriculum content. Employers should build in capability training to enable people who have roles that include care coordination to perform better
- A raft of guidance is available on improving access to health services, for example how to increase take up of annual health checks and other screening programmes, the importance of being on the GP register and having a Summary Care Record with details of reasonable adjustments needed.
- There is also advice and guidance on the more specialised needs of people with Profound and Multiple Learning Disabilities (PMLD)
- Staff should be encouraged to embrace new ways of working including digital. There are many examples of good practice in health promotion, early intervention and care management, including the use of digital technology (e.g. Maldaba's My Health Care App), health facilitator roles (eg Leeds and York NHS Trust) and easy read materials (e.g. MacIntyre) which should be more widely shared amongst the workforce across the UK
- Training needs to bring about culture change and shift negative attitudes and behaviours. Training must promote and instil positive values and behaviours in the workforce like active listening, being respectful, communicating clearly, working in partnership so positive and trusting relationships are built between people with a learning disability and those who support them. The quality of the relationship is a key factor in improving their health and wellbeing.
- Training and sharing of best practice needs to be available to family members who are often providing a significant amount of care and support, including the coordination role

Acknowledge and support the vital role played by family members who in many cases will be the primary carer (and care coordinator) of the person with a learning

disability. One way to do this is to ensure that they have a **carer assessment** to identify and support their own needs which could be financial or about their own health and wellbeing (both physical and mental). 'Caring for the carer' will indirectly support and improve the health and wellbeing of the person with a learning disability.

Embed strategic integrated commissioning for a whole systems approach. Local authority (including social care, housing, public health) and health commissioners should agree joint commissioning objectives that address the broad range of factors that contribute to the health inequalities experienced by people with a learning disability. These include social determinants such as poverty, poor housing conditions, unemployment; unhealthy lifestyles and barriers to accessing healthcare.

2 Introduction

This report has been written for the Department of Health and Social Care (DHSC) to highlight examples of best practice, as well as the challenges and barriers to providing effective care coordination for people with a learning disability and long-term conditions, to improve their health and wellbeing. The Learning Disabilities Mortality Review (LeDeR) Programme which reviews the deaths of people with a learning disability has highlighted the profound and persistent health inequalities that people with a learning disability experience. In the most recent review (University of Bristol, 2018), a number of recommendations were made including the need to improve the coordination of care within and across health and care services.

The purpose of this report is to provide a body of evidence and ideas on care coordination to support future guidance on good practice. Our research has included a review of the literature; engagement with commissioners and providers across the UK to identify live examples of innovative practice; and most importantly a listening exercise to ensure the views of people with a learning disability and long-term conditions and their families and carers are at the centre of policy and practice moving forward.

Whilst the Government response to the LeDeR Second Annual Review (May 2018), p11 focuses on a model of care co-ordination that requires “*a local, named care coordinator*”, based on National Institute for Clinical Excellence (NICE) Quality Standard 142 (NICE 2017); whilst gathering evidence of best practice it became apparent that there are different models and approaches to care coordination which are equally important and hence have been included in this report.

3 Context

3.1 Definition of learning disabilities

Learning disability is a term that can be complicated to define and has been much debated over the years. At its simplest, it has been expressed by the British Institute of Learning Disabilities (2011) as a general term that refers to individuals who find it hard to learn, understand and communicate.

Internationally, three criteria are regarded as being required to be met before a learning disability can be identified or diagnosed. These are:

- Intellectual impairment (IQ)
- Social or adaptive dysfunction combined with IQ
- Early onset

In other words, a learning disability includes the presence of:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- A reduced ability to cope independently (impaired social functioning);
- Which started before adulthood, with a lasting effect on development.

The causes of learning disability include genetic factors, infections before birth, brain injury or damage at birth, brain infections or brain damage after birth. For many who are diagnosed with having a general learning disability, the cause remains unknown, (British Institute of Learning Disabilities 2011).

Mencap's website (no date) describes different types of learning disability, which can be mild, moderate, severe or profound. In all cases a learning disability is lifelong. The different levels of need means that the type and amount of care co-ordination will need to be flexibly delivered.

It can be difficult to diagnose a mild learning disability as the individual will often mix well with others and will be able to cope with most everyday tasks. However, they may need support in other areas of their life such as filling out forms.

People with a severe learning disability or profound and multiple learning disability (PMLD), will need more care and support with areas such as mobility, personal care and communication. People with a moderate learning disability may also need support in these areas, but not definitely.

3.2 Prevalence of people with a learning disability

There is no definitive record of the number of people with a learning disability in England. However, it is possible to estimate figures using a variety of different sources. Improved neonatal care means that more babies are surviving with profound and multiple disabilities. Whilst there are health inequalities which are shortening lives, more people with a learning disability are also living into older age and experience the challenges of ageing.

It is estimated that approximately 1.5million people in the UK have a learning disability. There is no definitive record; we know the numbers of those receiving long term social care, the number receiving disability benefits and the number on GP registers but these won't include everyone, especially those with mild types of learning disability who may be managing independently or supported informally by family.

In terms of children, according to the most recent Government statistics (Public Health England, updated January 2020):

In 2018, 67,765 children in England had a statement of special educational needs (SEN) or an Education, Health and Care (EHC) plan and were identified as having a primary SEN associated with learning disabilities, including:

- 28,241 children identified as having a Moderate Learning Difficulty (MLD), a reduction of 31% from 2010
- 29,492 children identified as having a Severe Learning Difficulty (SLD), an increase of 17% from 2010
- 10,032 children identified as having a Profound Multiple Learning Difficulty (PMLD), an increase of 16% from 2010

3.3 Links between learning disability and long-term conditions

People with a learning disability are at increased risk of having a long-term condition. This can be defined as something that cannot, at present, be cured but it can be controlled by medication and other therapies. It is an illness lasting longer than a year that will often worsen with time. Examples include diabetes and heart disease (Skills for Care 2018). Other significant underlying long-term conditions with physical manifestations that are associated with people with a learning disability include cerebral palsy, epilepsy, diabetes, visual and hearing impairments.

Additionally, people with a learning disability have substantially higher rates of major mental health conditions and dementia than other people and also higher rates of common mental disorders such as anxiety and depression (Public Health England 2016). Fifty percent of people with autistic spectrum disorders also have a learning disability.

3.4 Poor health of people with a learning disability

The following facts and figures are from a study carried out by Emerson and Baines in 2011:

Coronary heart disease is a leading cause of death among people with a learning disability (14–20%).

Almost half of all people with Down Syndrome are affected by congenital heart defects.

Respiratory disease is possibly the leading cause of death for people with a learning disability (46–52%), with rates much higher than for the general population (15–17%).

The prevalence of epilepsy among people with a learning disability is at least 20 times as high as for the general population.

Increased rates of diabetes among adults with a learning disability have been reported in a population-based study undertaken in the Netherlands.

Approximately 40% of people with a learning disability are reported to have a hearing impairment.

Studies from Australia and the USA indicate that people with a learning disability may have increased prevalence of osteoporosis and lower bone density than the general population. Fractures can occur with only minor injury and can be multiple.

Hypothyroidism is relatively common among people with Down Syndrome, prevalence increasing with age.

One in three adults with a learning disability and four in five adults with Down Syndrome have unhealthy teeth and gums.

The prevalence of psychiatric disorders is 36% among children with a learning disability, compared to eight per cent among children without a learning disability.

Challenging behaviours are shown by 10–15% of people with a learning disability.

Prevalence rates for anxiety and depression among adults with a learning disability vary widely, but are generally reported to be at least as prevalent as in the general population and higher among people with Down Syndrome.

There is some evidence that the prevalence rates for schizophrenia in people with a learning disability are approximately three times as great as for the general population.

The prevalence of dementia is higher among older adults with a learning disability than in the general population (22% vs 6% aged 65+).

3.5 Reasons for health inequalities

It is widely acknowledged that people with a learning disability experience poorer health than the general population and too many people with a learning disability die prematurely. A report published in 2018 by University College London's Institute of Health Equity (IHE) found that two out of every five (40%) children with a learning disability remain undiagnosed and that adults with a learning disability will die 15-20 years sooner on average than the general population - that's 1,200 premature deaths each year.

The latest mortality rate indicator statistics (NHS Digital 2019) suggest that between 2015 and 2018 people identified with a learning disability aged 0 to 74 years were between 3.9 and 4.2 times more likely to die in the period than would be expected for people with broadly the same characteristics in the general population.

Emerson and Baines (2011) suggest some of the reasons underlying the health gap are:

- Increased exposure to common social determinants of poorer health such as poverty, poor housing conditions, and unemployment.
- Increased risk arising from genetic and biological factors associated with the learning disability.
- Communication difficulties and reduced health literacy.
- Personal health risks and behaviours for example, poor diet, low levels of physical activity, leading to increased risk of obesity and diabetes.
- Difficulties in accessing health care and health screening, including scarcity of services, poor understanding of needs due to difficulties with communication, and potentially diagnostic overshadowing where the physical symptoms are seen to be issues arising from their learning disability.

3.6 Government responses to health and care needs of people with a learning disability

The approach to delivering health and social care in England has undergone significant change over the last decade. The Putting People First Concordat, published by the Department of Health in 2007, stated a shared vision and commitment to transform adult social care through a programme of reforms. The key principles underlying the Government's vision for improved outcomes for people with health, care and support needs can be summed up as:

- Enabling choice and control
- Tailoring support
- Coordinating care
- Building community capacity – early help and prevention

The Health and Social Care Act (2014), which has been described as the biggest reform of care and support since 1948 reinforces the commitment to 'improving lives' rather than 'services'. The principles above are now enshrined in law, placing a duty on health and social care authorities to work with communities to enhance people's independence, wellbeing and citizenship; to enable choice and control through use of personalised care planning and personal budgets and to take an integrated approach to commissioning and delivering health, care and support services.

The changes described above apply to the whole of adult social care. In addition, a number of policy and guidance documents have been published that relate specifically to people with a learning disability, outlining best practice.

The overall approach has been to move away from providing care for people with a learning disability and long-term conditions in long stay hospital and residential homes towards an approach that promotes independent living in the community, and the right to an 'ordinary life'. People with a learning disability at all levels of complexity should be able to access the spectrum of services from universal through to long-term specialist interventions, as and when needed throughout their lifetime.

A significant policy driver that emerged at about the same time as 'Putting People First' (Department of Health 2007) was the government programme Valuing People Now (Department of Health 2010) which focused on improving lives for people with a learning disability in three core areas - health, housing and employment.

In terms of improving healthcare, an emphasis was placed on the following priorities:

- greater leadership in the NHS and local councils
- annual health checks
- involvement of people with a learning disability and their families in checking and planning services
- increased use of acute liaison nurses and health facilitators
- making reasonable adjustments
- use of tools such as patient passports and communication books

By 2010 some progress had been made, as evidenced in the Department of Health's summary report (2010) which showed:

- an increase in key posts such as strategic health facilitators
- matrons in the hospital with individual case management responsibility, acute liaison nurses, primary and secondary healthcare facilitators
- significant progress in improving people's access to mainstream health services
- an increase in the number of annual health checks for people with learning disabilities

However, the report acknowledged that there was still a long way to go, for example, although health checks had increased, over half of people eligible had not had one and concerns were raised about the lack of understanding of people who work in the health service about the needs of people with a learning disability, how to communicate effectively and how to make "reasonable adjustments."

The pace of change accelerated again in 2015, with the launch of the Transforming Care programme, a multi agency programme with NHS England as one of the partners. This national programme embodies the same core principles of independence, prevention and early intervention, choice and control/personalisation, co-ordinated care, living in the community/close to home, better health and wellbeing.

The vision, as set out in Building the Right Support (Association of Directors of Adult Social Services et al 2015) is that:

"Children, young people and adults with a learning disability and/or autism have the right to the same opportunities as anyone else to live satisfying and valued lives, and to be treated with dignity and respect. They should have a home within their community, be able to develop and maintain relationships, and get the support they need to live healthy, safe and rewarding lives".

Association of Directors of Adult Social Services, Local Government Association and NHS England (2015) p4

Forty-eight transforming care partnerships have been leading the implementation of a national service model, which includes a range of new community services. However, the lack of any direct reference to Transforming Care and Building the Right Support in the NHS Ten Year Plan means it is unclear whether there is continued commitment to implementing the model.

The best practice service model (LGA, ADASS, NHS England (2015) states that:

"Care and support should be person-centred, planned, proactive and coordinated – with early intervention and preventative support based on sophisticated risk stratification of the local population, person-centred care and support plans, and local care and support navigators/keyworkers to coordinate services set out in the care and support plan" p25

It also emphasises the importance of 'good care and support from mainstream health services', highlighting annual health checks, health action plans and hospital passports,

liaison workers, quality checkers and reasonable adjustments as methods that can help overcome barriers and improve health outcomes for people with a learning disability.

The Equality Act 2010 states that all public sector organisations must be accessible to disabled people as well as everybody else. Public Health England (2016) has published guidance for health care teams to ensure that they are alert to the particular needs of people with a learning disability for example:

- clear, simple and possibly repeated explanations of what's happening and of treatments
- help with appointments
- help with managing issues of consent in line with the Mental Capacity Act 2015

The Green Light Toolkit, is a set of free to access resources, produced by the National Development Team for Improvement (2015) that includes an audit framework and a database of best practice examples of reasonable adjustments made by services to enable people with a learning disability to access mainstream support.

4 Methodology

IPC followed a number of key lines of enquiry, to investigate good practice, beginning with a literature review of published material and then seeking out materials that were available but not published that DHSC and national agencies were able to provide, as well as through our own contacts in local areas.

We used the literature review, as well as suggestions from DHSC and other leading learning disability organisations and our own contacts to identify local case study areas that were demonstrating good practice and innovation. We interviewed key individuals involved in care coordination from local authorities and their partners (see appendix one) to tease out barriers, enablers, challenges and how they can be overcome to improve support and access, for example through key working models.

A key aim of the project was that it should be informed by people with learning disabilities and their families and carers. We worked with Learning Disability England (LDE) to run four focus groups around the country during February 2019. Three of the groups were facilitated by self advocacy organisations in Sunderland, Lewisham and Northallerton with support from LDE, a fourth group was run by LDE in Halifax. In total, thirty two people attended; these included people with learning disabilities including people with PMLD and a range of long-term conditions and autism, family members and carers, with a mix of ages, gender and ethnic backgrounds. See appendix two for detailed findings.

The final part of the project was to draw all the information together into this report which aims to provide a body of good practice evidence and ideas on care coordination, identifying key characteristics of successful support and recommendations on how it can be implemented.

5 Good health and wellbeing from the perspective of people with a learning disability and long-term conditions

It is important to start by outlining what people with a learning disability themselves see as the key factors that make them healthy and well. The feedback we got from the focus groups that included people with a range of types of learning disability and long term conditions as well as parents and carers is summarised below. Full details are in Appendix One:

Relationships	<p><i>“having friends and relationships”</i></p> <p><i>“being in a good loving relationship”</i></p> <p><i>“being around good people”</i></p>
Activities/social life	<p><i>“having hobbies, activities”</i></p> <p><i>“going to the gym”</i></p> <p><i>“seeing friends, going to clubs, socialising, going for a walk, going to the park, nature”</i></p> <p><i>“time to do everyday ordinary things”</i></p> <p><i>“going to pubs and restaurants, disco, golf, bowling, dance class being involved in performing arts”</i></p>
Time out/relaxing	<p><i>“respite breaks and holidays”</i></p> <p><i>“listening to music”</i></p> <p><i>“learning how to relax and not be anxious”</i></p> <p><i>“time for yourself to do what you want when you want”</i></p> <p><i>“break in routine”</i></p> <p><i>“chill out time (man cave)”</i></p>
Keeping well	<p><i>“holistic balance (nutrition, mental health, physical health, medication, medical support”</i></p> <p><i>“physical and mental health to do what you want to do”</i></p> <p><i>“mindfulness to help good mental health”</i></p> <p><i>“eating healthy, exercise”</i></p> <p><i>“good information/instructions around medication”</i></p> <p><i>“attending medical appointments, having a health check, eye and ear tests, dentist, going to doctors/hospital”</i></p>
Sense of security	<p><i>“having a job and earning money”</i></p> <p><i>“having your own place”</i></p> <p><i>“security for the future (longer term needs)”</i></p>
Sense of acceptance / understanding from others:	<p><i>“being accepted by people – being yourself and not having to ‘fit in’</i></p> <p><i>“mixing in with mainstream society”</i></p> <p><i>“feel welcomed, accepted, wanted”</i></p> <p><i>“being listened to and being understood”</i></p>

Sense of freedom, independence, choice:	<p><i>“having choices in life – what I do, where I go is my choice”</i></p> <p><i>“encouragement/good support to try new things”</i></p> <p><i>“being able to do the things that make me happy”</i></p>
Making a contribution	<p><i>“speaking up and being involved in self advocacy”</i></p> <p><i>“delivering training and quality checking services”</i></p> <p><i>“being part of and giving back to my community and helping others”</i></p>

From this starting point, we can consider what role care coordination and other approaches can play in enabling people to achieve good health and wellbeing.

5.1 Barriers to achieving good health and wellbeing

We know that people with a learning disability often face barriers in accessing health and care services and in living healthily. These include:

- Not recognising signs and symptoms that need investigating, resulting in delayed diagnosis and poorer prognosis
- Diagnostic overshadowing
- Lack of understanding of the Mental Capacity Act
- Lack of understanding about learning disability and autism
- Difficulty with navigating the NHS – eg making and attending appointments including for routine screening programmes, dental care, and other services that support healthy lifestyles eg weight loss, smoking cessation, sexual health.
- Those with long-term conditions may struggle to manage medication, treatment regimes and outpatient appointments.

The people who participated in our focus groups were very clear about ‘what gets in the way’ of getting the right kind of support for their health and wellbeing. The key themes that emerged are summarised below

Finance

Cut backs in support hours, eligibility thresholds and inflexible benefit rules were all mentioned as barriers:

“only being able to work for 16 hours or I lose benefits”
“Universal credit – making people go into debt”
“lack of realistic finance”

Lack of information

Information about help is not readily available or easy to understand and signposting can be poor:

“not sure where places are”
“not knowing where to go or who to ask for help”
“endless loop of being sent to different services that are not suitable”

Difficulties with the way help is offered and provided

This includes poor communication, unhelpful processes, inflexible responses (not having choice or control):

“not being listened to”

“being treated like a child”

“decisions being made without me”

“not being trusted to make the right choices”

“not allowing risks”

“lack of flexibility in care options, especially if circumstances change”

Staffing

Shortcomings in staffing was mentioned frequently:

“lack of knowledge from so called professionals”

“untrained staff”

“turnover of staff – often don’t get the same one and this stops them from knowing you and you from knowing them”

“sometimes staff don’t have a lot of time to see you so have to rush off, or they can’t make it to the appointment”

System fatigue

Sometimes the barriers feel insurmountable and carers feel they can’t go on:

“having to fight for everything is too much to cope with”

“sometimes people have to jump through hoops and end up giving up”

“just being too worn out to look for help and support”

5.2 Enablers of good health and wellbeing

Conversely, people were positive about the key characteristics of successful support that can help them stay healthy and well:

Professionals and services listen and communicate effectively:

“listen to everyone, carers and other professionals involved in cases to improve outcomes”

“people, services, staff who listen to me”

“having people, especially professionals explain things in a way I understand. Explain it like a story to me”

Staff are respectful and work alongside the person and their carers:

“being respected. Recognising the things I am capable of”

“work in partnership, valuing the views of carers”

“staff knowing where the boundaries are – not overstepping them”

“my home feeling like my home – not the staff’s home”

“not ignoring you or telling you what to do or holding ignorant views”

Staff have the right training and qualifications:

“make sure the person has the right experience/qualifications to deal with the task in hand”

“Give good training to staff, delivered by experts with experience”

People have the right attitudes:

“no bullying or taking the mick”

“good support, not bossy or controlling”

“helpful staff – I decide but they help me get what I want”

“knowing that people who support me have my best interests at heart and respect my decisions”

“people being aware of my abilities, talents, skills”

“being understanding, able to listen and offer advice, particularly when I’m upset”

Support can be from professionals and from others:

“having an advocate and being a self advocate”

“being able to stick up for self and others”

“having a good key worker”

“specialist help like speech therapist”

“good community support from family and friends”

“colleagues at work looking out for each other”

Support can include:

“someone to manage finances, staff, training of staff, takes the stress away”

“advice about healthy food. How to stay safe. Being in control. Somebody to help me exercise”

Other things that are important:

“one place to go for help and advice”

“other parents with similar experiences who understand”

“knowing your way around the system”

“people listen to us and keep us informed at every stage”

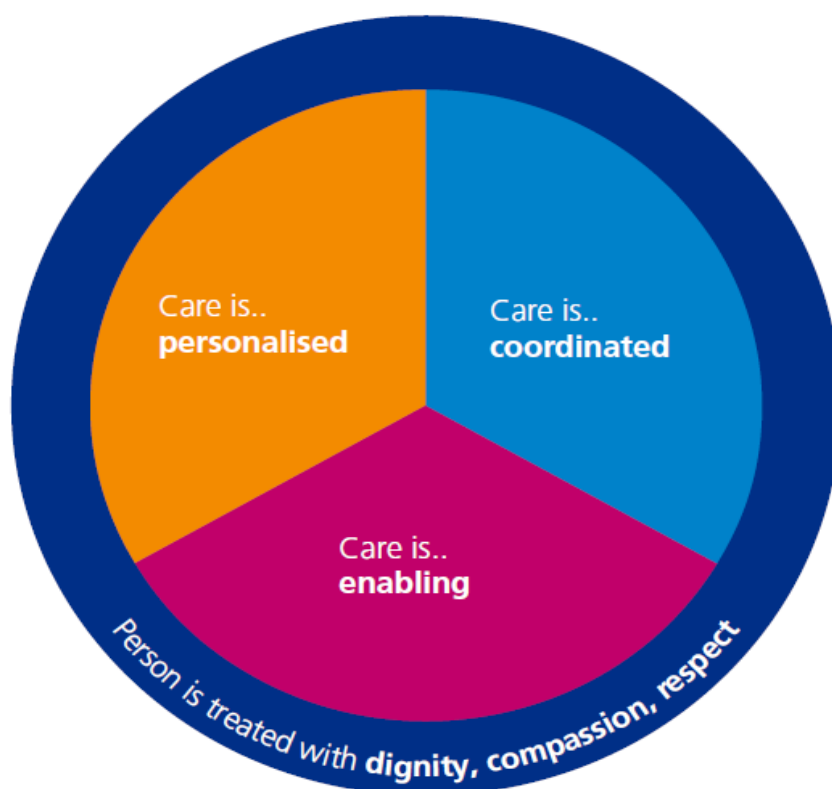
“Don’t expect us to keep chasing professionals for answers, remember we are the experts when it comes to our families!”

6 What is care coordination?

Care coordination is important because:

- It can help to improve the quality of life and health and wellbeing of people with a learning disability
- It supports the objective of reducing the health gap between people with mental health problems, learning disabilities and autism and the population as a whole
- A personalised care and support approach often involves multiple providers, plans, appointments, interventions as well as personal budgets and the responsibility for paying for services. This level of complexity can be difficult to manage, coordination is needed to make it work

Care coordination is one of the core principles that underpins the ongoing transformation of care and support services in this country, both for adults generally and for people with a learning disability and long-term conditions specifically. This is illustrated in the Health Foundation’s (2014) circle of person-centred support:



We have identified three main approaches to care coordination:

- Co-ordinated care via joined up pathways and packages of care
- Co-ordinator/care and support via a navigator/key worker/liaison role
- Co-ordinated care through whole systems, strategic commissioning

6.1 Co-ordinated care packages and pathways, that reduce fragmentation between services

For the individual, a personalised care and support system means co-ordinated health and social care that is planned and organised around their needs (which may be mild, moderate, severe or profound) and preferences. It means joined up and seamless services that:

“address an individual’s full range of needs, taking into account health, personal, family, social, economic, mental health, ethnic and cultural background and circumstances. It recognises that there are other issues in addition to medical needs that can impact on a person’s total health and wellbeing”

Department of Health, 2009

According to the Institute for Public Policy Research North (2014 p18)

“The purpose of whole person care is to coordinate services around an individual with a stronger emphasis on care provided outside of acute settings”.

This type of approach is characterised by having a single point of contact for accessing services and only having to tell your story once. It avoids 'system clash' and promotes early intervention. A study of NHS examples of co-ordinated care for people with long-term conditions backs this up, demonstrating positive outcomes, including empowerment of patients and carers, improved quality of life, and high staff satisfaction (Goodwin et al 2013).

6.1.1 Education Health and Care (EHC) Plans for children and young people

EHC plans were introduced as part of the Children and Families Act 2014 as a statutory duty for local authorities and Clinical Commissioning Groups (CCGs). Their purpose is to combine information about a range of needs that children and young people up to the age of 25 may be experiencing and outline an integrated, multi-agency response. The Council for Disabled Children (2017) has produced good practice examples of plans which contain the following elements:

- aspirations of the child/young person and their parents/carers
- special educational needs (SEN)
- health needs
- social care needs related to their SEN or disability
- outcomes sought for the child or young person, linked to aspirations
- special educational provision required
- health provision reasonably required by the learning difficulties or disabilities which result in the child or young person having SEN
- Social care provision which must be made for a child or young person under 18 resulting from section 2 of the Chronically Sick and Disabled Persons Act 1970 (CSDPA)
- Any other social care provision reasonably required by the learning difficulties or disabilities which result in the child or young person having SEN (including any adult provision)

The plan includes the name and role of the professionals that have contributed and will be responsible for ensuring that the interventions are delivered. The underlying principles echo those of the Health and Social Care Act 2014, i.e. encouraging independence and progression, enabling choice and control through use of personalised care planning, the option to have a personal budget and a co-ordinated approach to delivering health, education, care and support services.

6.1.2 Care Programme Approach (CPA)

The Care Programme Approach was introduced in the early 1990s in response to a lack of effective care coordination for people with mental health problems.

The CPA meant that anyone experiencing severe mental health problems and who met one or more criteria, should have their care co-ordinated under the Care Programme Approach which covers assessment, planning and reviewing mental health care needs.

One of the criteria set out in the original guidance which should lead to getting care coordinated in this way was if the person had a learning disability. Although CPA has

been in place for nearly thirty years, recent research suggests that the implementation of the CPA for this group has been fragmented and services are not working together in partnership (Kelly 2017). A key finding was that the CPA is being effectively implemented for people who are deemed to present with a risk to themselves or others. However, if a service user does not present with a high risk, they are not provided care through the CPA. Kelly recommends that alternative service user led care planning frameworks should be used instead.

6.1.3 Examples

Integrating care from an early age in Conwy, North Wales

The Conwy Early Years Child Development Centre provides co-ordinated care for children aged 0-5 with complex disabilities. The centre, based on the same site as the special school for 3-19 year olds - Ysgol y Gogarth and the Children's Disability Service, enables families to access support from a range of disciplines. A multi agency panel including a community paediatrician, clinical psychologist, speech and language therapist, physiotherapist, specialist teacher, educational psychologist, and social worker meet regularly to consider referrals, carry out holistic assessments and decide on interventions. Person centred planning is key and parents and carers are fully involved with every aspect of care delivery, which promotes confidence and independence in supporting their child.

Having an integrated team on the same site as the school with staff employed by the Health Board and the Local Authority based together and delivering co-ordinated care is successfully setting in motion a vision of developing potential and enabling progression from the very beginning of a child's life, however complex their needs.

The full case study is available here: <https://ipc.brookes.ac.uk/publications/children-disabilities-conwy.html>

Avoiding the cliff edge between children and adults healthcare in Devon

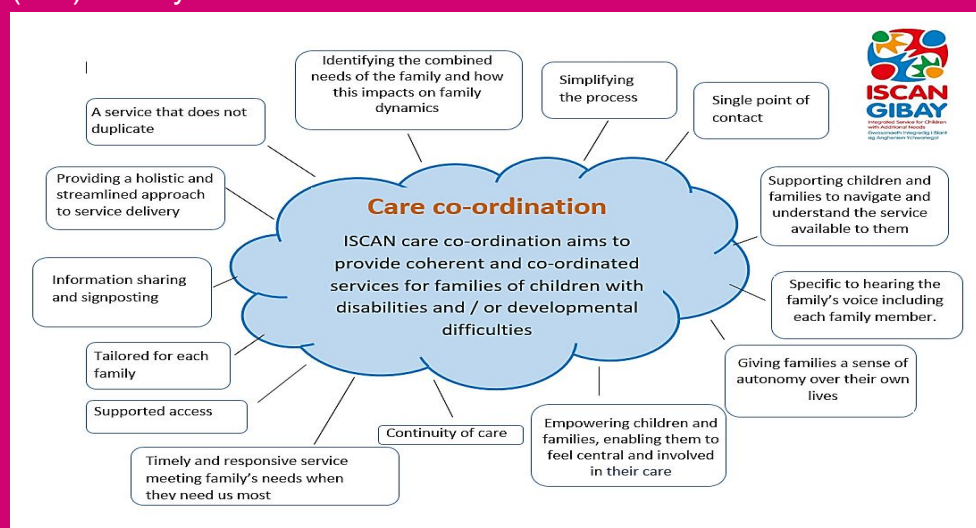
The Royal Devon and Exeter NHS Foundation Trust, are easing transition between children's care and adults' by taking an 'umbrella of care' approach. Up to age 18, the paediatrician has been the lead professional in the young person's care, being the first port of call for medical advice and able to refer to other specialisms in a timely and seamless way. The usual process has been to discharge a young person to the care of their GP when they turn 18, leaving them without a trusted specialist to refer to and breaking the continuity of care they had experienced previously.

The Trust has recently piloted a new pathway whereby the young person is transferred from the care of a paediatrician directly to an adult physician, experienced in looking after adults with a range of complex needs and managing sensitive issues like palliative care and shared decision making with families. Feedback from the pilot has been positive from young people and their families.

Integrated Service for Children with Additional Needs (ISCAN), in Gwent, Wales

A new Care Coordination Service, delivered by three sector teams each made up of a Care Co-ordinator and Family Support Worker, has been established in Gwent. This service, which is available to children who have multi-agency complex needs, provides the family with a single point of contact, co-ordinates services involved with the child and facilitates integrated assessment and planning (IAP) in the most complex cases.

The development of the new service has been led by parents. A parent and professional care coordination forum was established and parents were able to express their frustrations with being given the 'run around' as they saw it, when they tried to get help for their children. Agencies recognised that they had been working in silos, resulting in duplication of services, long waiting lists and poor outcomes for children. Together parents and professionals came up with a charter of key principles that became the blueprint for a new approach to service delivery. The Gwent Children and Families Partnership Board approved the use of Integrated Care Fund (ICF) money to fund the care coordination model.

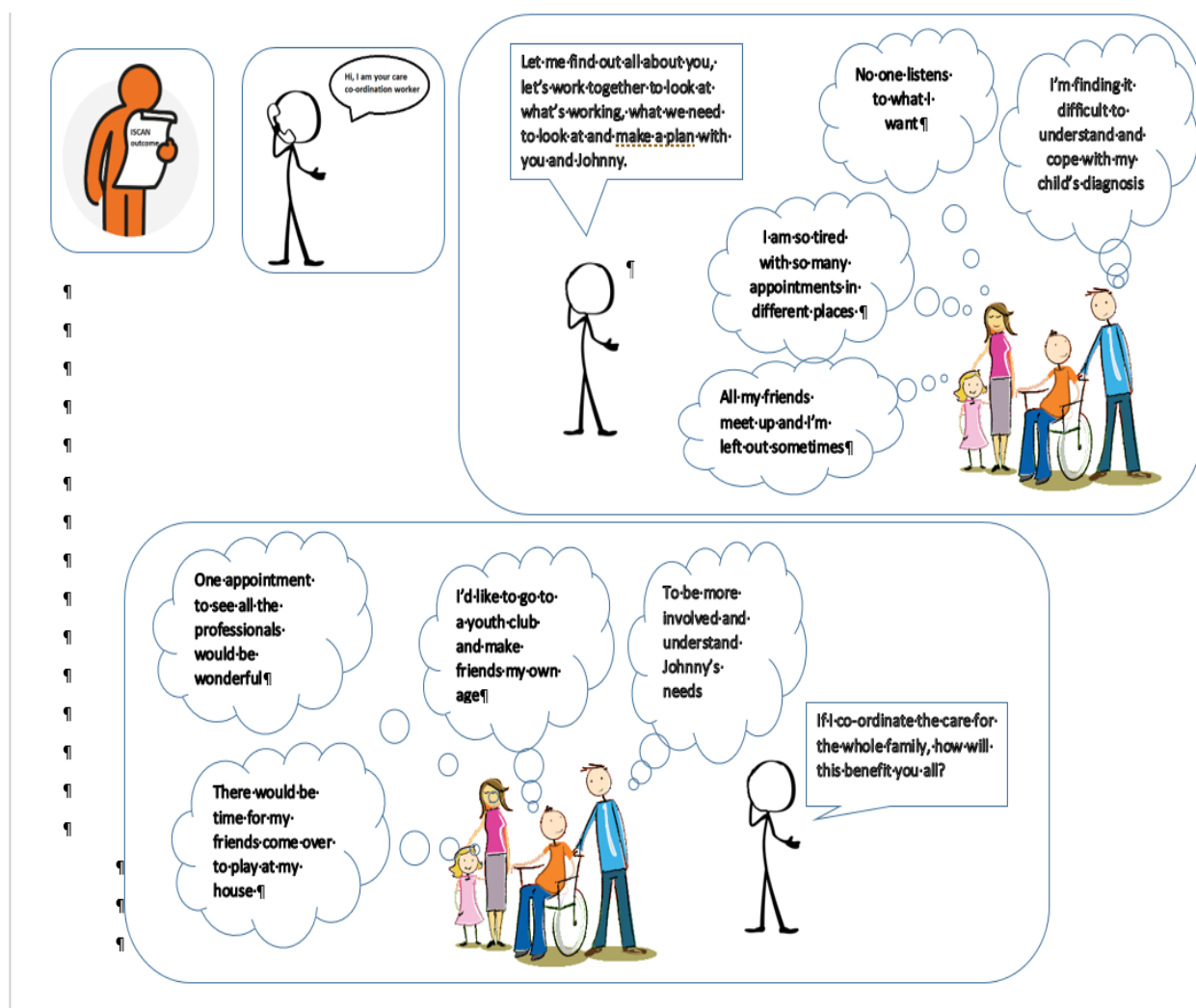


Key aims for the service are:

- Fewer children waiting on multiple statutory agency waiting lists
- More children receiving an integrated assessment and planning service
- Earlier intervention on a multi-agency basis
- Improved relationships with families who are in receipt of a co-ordinated and integrated assessment process
- More effective use of scarce agency resources as planning is not done in silos but on a shared and agreed basis
- More empowered families resulting in greater resilience

It is still early days to be able to measure benefits and impact of the developments, but one of the things they will be measuring is the cost of professionals' time saved through not having to invest in care coordination activities over and above their core roles; as well as the impact on the health and wellbeing of children with additional needs and their families.

The full case study is available here: <https://ipc.brookes.ac.uk/publications/children-additional-needs.html>



These three examples, taken from children's services illustrate a number of key principles that underpin successful care coordination, such as:

- A single point of access to a range of services, so that the child/young person and their parents/carers only need to tell their story once
- Integrated assessment and planning, with all relevant professionals feeding in and listening to the aspirations of the child/young person and their parents/carers as the starting point
- A flexible approach which means pathways and services are coordinated around the needs and wishes of the child/young person and their parents/carers especially at times of transition

6.2 Co-ordinator/care and support navigator/key worker/liason role

This model of care coordination focuses on the creation of a specific job role that might include all or some of the following functions:

- leading the care planning process

- facilitating joined up working between different professionals and agencies, especially between health and social care
- providing links to mainstream health services for example to investigate symptoms facilitate access to preventative initiatives eg screening programmes, health advice, appointments or medication
- support management of long-term conditions
- support with healthy lifestyles, eg diet, physical activity
- provide advocacy and help with navigating services
- work with universal services to help them make reasonable adjustments so they are more accessible to people with a learning disability

The following diagram from Health Education England (2016) illustrates the multi-faceted nature of the role. It is also important to acknowledge that the job role will vary according to the level of need of the individual.



Having a key worker who can help an individual with a learning disability and their family/carers to navigate and co-ordinate services is recommended by the National Institute for Clinical Excellence in Standard 142 (2017).

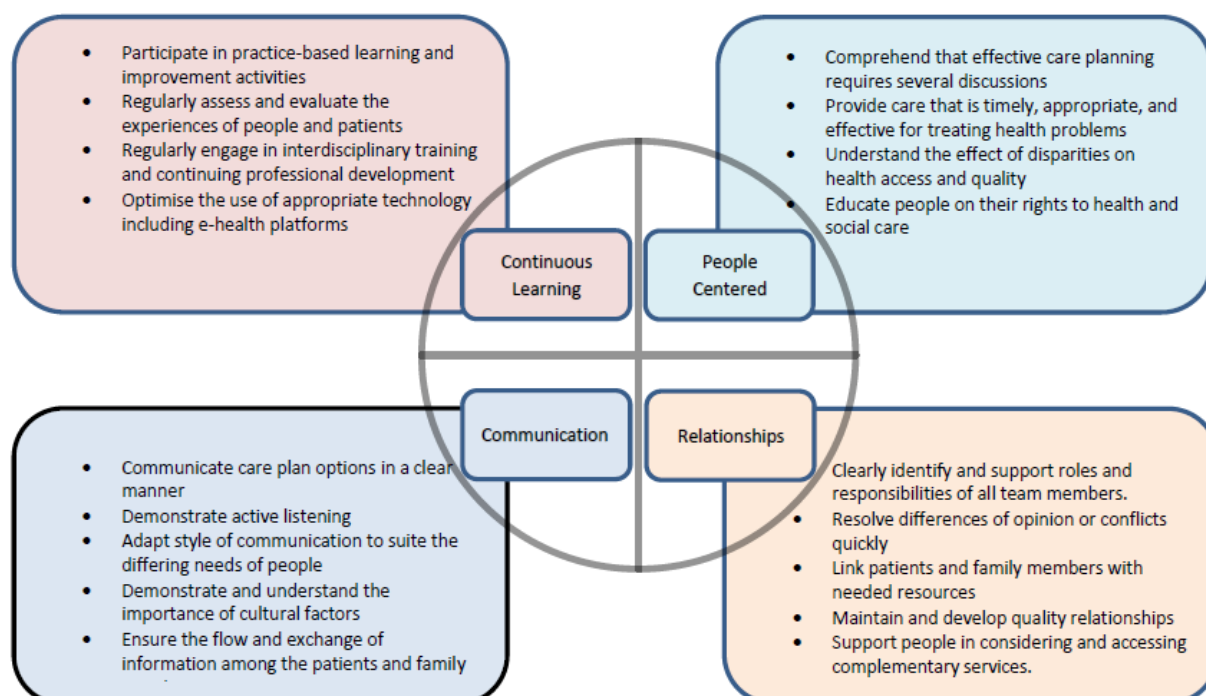
“A key worker (also known as a care or case coordinator, (or a Care Programme Approach care coordinator) is the central point of contact for the person with learning

disabilities, their family members and carers, and the services involved in their care. They are responsible for helping the person and their family members and carers to access services and for coordinating the involvement of different services. They ensure clear communication between all people and services and have an overall view of the person's needs and the requirements of their care plan. They ensure that services communicate regularly with the person and their family members and carers, in a suitable format."

Training and Skills required for this role

Care coordination is a core function in the role description for a 'lead practitioner in adult care', described in Health Education England (HEE)'s guidance on care roles (no date). Tasks relating to health and wellbeing needs are also considered essential such as supporting people to make and attend medical appointments and implement the advice that medical professionals give.

HEE has recently supported the testing and development of a care coordination model in the West Midlands (no date), to explore the **key competences** needed for the multiple roles that include co-ordinated care (see diagram below). The model is not intended for any single occupational group; its aim is to capture the principles that cross all professions and staff levels and that consequently provide a 'common model' for all staff groups. The model was tested across four test sites and the findings used to support approaches to supporting integrated care transformation across the West Midlands. HEE's Care Navigation Competency Framework (2016) is another useful tool for determining the education and training that might be needed to support people in these roles.



More recently, Skills for Care, Health Education England and NHS England (2019) have published a *Core Capabilities Framework for Supporting People with a Learning Disability* which builds on the 2016 document, outlining the capabilities that a whole workforce, across both health and social care, need to have to successfully enable people with a learning disability to reach their fullest potential and live meaningful lives.

The framework has also been extended to provide increased focus on improving health outcomes and avoiding premature mortality. *Domain B, Health and Wellbeing*, outlines key capabilities and learning outcomes that practitioners require to enable them to effectively support:

- physical and mental health
- people with a learning disability and autism
- health equality and reasonable adjustments
- people with Profound and Multiple Learning Disabilities (PMLD)

Whether staff are in roles specifically related to care coordination or in more generic health and social care jobs, training to improve health and wellbeing priorities should equip them to do the following (p43):

- be able to provide and support people to populate health passports, health action plans, hospital traffic lights or hospital passports and books and understand how these can provide important information about a person's communication and care needs and any potential hazards such as a risk of choking, known allergies and epilepsy
- be able to advise on and implement reasonable adjustments to enable the health needs of people with a learning disability to be met
- identify and set out actions which may support the uptake of annual health checks and population of the GP learning disability register
- promote and support healthcare co-ordination and collaborative working by health and social care professionals

Best practice guidance on annual health checks

The Department of Health 2010 'Valuing People' Programme highlighted the need to improve the number of people with a learning disability having an **annual health check**. Ten years later this remains a primary objective and is one of the few national indicators related to the health and care of people with a learning disability that is monitored by local authorities. NICE Quality Standard 142, Statement 1, (2017), gives a clear steer on best practice:

- *"This should involve the person with a learning disability and a family member, carer, care worker, GP or social care practitioner (as appropriate) who knows them. It should include:*
- *a review of any known or suspected mental health problems and how they may be linked to any physical health problems*
- *a physical health review, including assessment for the conditions and impairments that are common in people with a learning disability*
- *a review of all current interventions, including medication and related side effects, adverse events, interactions and adherence for both mental health and physical health conditions*
- *an agreed and shared care plan for managing any physical health and mental health problems (including pain)*

- *Healthcare professionals should take into account the communication needs of people with a learning disability*
- *They should make reasonable adjustments and provide support if needed for people who have limited or no speech, who have difficulty with English, or who have other communication needs.*
- *Communication with the person and their family members, carers or care workers (as appropriate) needs to be in a clear format and in a language suited to the person's needs and preferences”.*

The Royal College of General Practitioners website (2020) has produced a comprehensive toolkit to support all those involved in co-ordinating and delivering the check. It includes an Annual Health Check Resources Guide ([Annual Health Check resources guide](#)) and the following:

- Pre Health Check questionnaires
- [Go Prepared for the Annual Health Check](#). Hertfordshire Adult Disability Service's guide for carers, family members and friends of people with a learning disability to go prepared for an Annual Health Check. This checklist should be reviewed two weeks prior to an Annual Health Check
- [Annual Health Check – pre-health check questionnaire for people with a learning disability](#)
- [Annual Health Check action plan template](#)
- [Example of a Health Action Plan for an adult with Down's Syndrome](#)

More guidance on improving health

Another very helpful guidance document for social care staff which would be an essential training tool for care co-ordinators and others supporting people with a learning disability that focuses particularly on improving health was produced by the National Development Team for Inclusion (NDTI) and Voluntary Organisations Disability Group (VODG) in 2017. The Guide highlights practical steps that include ensuring people with a learning disability are:

- on the GP learning disability Quality and Outcomes Framework (QOF) register
- get annual health checks
- have additional information on their Summary Care Record that says what reasonable adjustments they need

People with Profound and Multiple Learning Disabilities (PMLD)

As long ago as 2000, a network that had been established to raise awareness and promote the interests of People with Profound and Multiple Learning Disabilities highlighted the need to improve health:

“Various studies of the health needs of children and adults with PMLD demonstrate a high prevalence of severely underweight individuals, a higher prevalence of epilepsy, a high risk of pressure sores, a disproportionate amount of respiratory infection and a generally higher level of health care needed (Hutchinson 1988). In contrast, health care has been reported as poor. In one study of a group of people with PMLD who

were given a health check, 92% were found to have a previously undetected but treatable condition (Meehan 1995)”.

Mencap and Foundation for People with Learning Disabilities, 2000, p20)

It is interesting that over twenty years ago parents who contributed to the report were calling for a care coordination role to support them:

“Children with PMLD and their families receive services from a wide range of agencies, reflecting the diversity of their needs. They are often confused and frustrated in their attempts to make sense of this system. There is an urgent need for co-ordination by providing a single point of access to services via a single key-worker”. (p12)

They also recommended that children and adults with PMLD should have annual health checks and should be given priority in establishing the use of health facilitators.

Moving on in time, a recent publication developed by a partnership of organisations (Care Management Group (Cmg), PMLD Link, The Sensory Project and Choice Support, 2017) provides important **service standards** designed to improve the quality of services and outcomes for individuals. In terms of promoting health and wellbeing, recommendations include:

“Staff receive high quality training and competency assessment in all aspects of the physical and psychological needs of the people being supported. This includes postural care training, relevant medical/health training and mental health awareness training

The organisation ensures staff have an understanding of the significance of common health conditions on the (high rates of) mortality of people with profound and multiple learning disabilities. Staff will demonstrate timely/early intervention to prevent escalation or in response to all health concerns and by routine monitoring of an individual’s holistic health; they will ensure the people they support have Annual Health Checks and an accurate and up to date Health Action Plan.

The service has good knowledge of local support and services available to support the person’s health needs and maximise access to these as relevant e.g. access to community based sport and leisure activities”.

6.2.1 Examples

Leeds and York Partnership NHS Trust, Health Facilitation Team and ‘Get Checked Out’ website

A new Health Facilitation Team has been established by the Leeds and York Partnership Trust to improve access to health services and promote healthy lifestyles.

The team offers free accessible information on their ‘Get Checked Out’ website to support people with a learning disability access their annual health check and other screening programmes, for example cancer awareness, as well as signpost to other ‘helpful services. Their easy read, colourful resources encourage people to get

healthy and stay healthy through simple messages – ‘eat well’, ‘be active’, ‘get checked out’ ‘stay well’. They also train non learning disability professionals and healthcare students so they are more responsive to people with a learning disability who use their services. This includes training and supporting ‘Get Me Better Champions’, people with a learning disability who work in different roles to help improve the services that are provided by Leeds Teaching Hospitals Trust.

For more information: <https://www.getcheckedoutleeds.nhs.uk/>

Acute Liaison Nurse role

R works as an Acute Liaison Nurse covering hospitals in Wakefield, Dewsbury and Pontefract. The role was created to improve the experience of people with a learning disability when they go into hospital and includes training nurses and consultants on the needs of people with a learning disability and the kinds of reasonable adjustments and support that may be required; offering guidance on best interest decisions; and training community support staff on particular procedures that may be needed on an ongoing basis post discharge.

Over the years, R has helped to implement a range of initiatives that are contributing to better healthcare for people with a learning disability in hospital. For example, the VIP card which is carried by people with a learning disability gives a quick picture of the person including any long-term conditions and medication. If they are admitted to hospital they can be flagged up straight away for a visit from the Acute Liaison Nurse to assess what extra support they may need. Each unit now has a ‘learning disability champion’ who offers advice to clinical staff on treatment and care. A patient experience group has been established and regularly feeds back on ways to improve care for people with a learning disability. The group has also produced easy read leaflets on topics such as blood collection and how to make a complaint.

Beyond the acute sector, the role is also instrumental in making links with other parts of the health and social care sector. In terms of prevention and early intervention, R has worked closely with the strategic health facilitator to get local GPs proactively offering annual health checks.

The manager of the local supported living service speaks highly of the role: “it helps everyone get together and communicate.”

Named Social Worker Pilot: Camden Learning Disability Service

The Department of Health and Social Care (DHSC) initiated the Named Social Worker (NSW) pilot to build an understanding of how a named social worker can help to improve outcomes for individuals with a learning disability, autism and mental health conditions. Phase 1 ran from October 2016 to March 2017 and Phase ran 2 from October 2017 to March 2018. An evaluation of phase two found that there was a positive impact across three levels: on the individuals engaged in the pilot, on the named social workers themselves and on the wider system in terms of better cross-service coordination (Social Care Institute for Excellence, 2018).

Camden Learning Disability Service was part of phase one and has continued to embed the approach. All people with a learning disability who are supported by the service who live in supported living or residential care now have an 'always allocated' named social worker with the aim of delivering practice based on long-term relationships. In addition, each supported living project has a link with a health professional who gets to know the people living in the project and is able to offer advice to the named social worker or staff team on health matters.

One of the benefits of the new ways of working has been to establish better knowledge of and links to community resources, including those that can support people with learning disabilities to live healthily. For example, a social worker was able to link a client to a mix of learning disability specific and mainstream opportunities that support healthy lifestyles and enhance wellbeing:

- Somerstown community centre exercise classes
- Ability Bikes at Regents Park, free service for people with a learning disability and physical disabilities, 8 adapted bikes available for hire
- Fleetwell swimming club for people with a learning disability
- Mind 'healthy minds' projects – exercise sessions, gardening and walking tours
- Kentish Town City Farm – volunteering opportunities, riding therapy

Another consequence of the named social worker approach has been an increase in skills and knowledge, resulting in social workers having greater confidence to advocate for the people they work with and bring their voices to the fore (SCIE, 2018). This has positive benefits for care coordination. For example, in Camden, a named social worker was able to step in quickly and prevent an 'unsafe' hospital discharge which would have resulted in the care home ending the placement. By liaising with the local learning disability health team, a package of care was put in place enabling the person to return safely to the care home.

Family Transition Project Coordinator, Denbighshire and Conwy, North Wales

This new project is a partnership between the Betsi Cadwaladr University Health Board (BCUHB), Denbighshire and Conwy Child and Adolescent Learning Disability Service (CALDS) and a specialist learning disability third sector organisation, Conwy Connect.

The coordinator will work as a bridge between young people, their families, the third sector and statutory health and social care services. In doing so, the aim is to test whether this approach leads to better individual development outcomes for young people and their families and especially, those with the most complex health and social care support needs.

A key element will be raise awareness of local pathways and opportunities for young people alongside specialist provision which have the benefit of allowing the young person to continue their learning and development in their home community. The learning from the post will be drawn upon to inform transition policy and practice in the region based on the experience of young people and their families.

Transitions Planning Wellbeing Officer, Gwynedd, North Wales

A new post has been created as part of the Gwynedd County Council Learning Disability Service focusing on wellbeing. The role is holistic in nature and will address the social, emotional and physical wellbeing of individuals. They will facilitate effective working across health and social care for the most complex individuals during their key transition periods. As part of this process, this officer will promote the identity, cultural and language needs of the individuals, which can become secondary when accessing services outside Wales e.g. education services.

The officer will prioritise:

- Supporting adults who require additional support during key transition periods in their life, for example, early adulthood, mid-life and later life.
- The role will also support adults who are experiencing key transitions due to a change in their health or social needs. For example, due to a change in training, education or employment opportunities.
- The aim of this project will be to further map the transition support/wellbeing needs of individuals
- A key output will be the development of a transitions toolkit / handbook for practitioners and for individuals accessing support (and their families)

These examples demonstrate the variety of roles that include facilitation or coordination of care and support both within health care settings and the community. Having a dedicated role helps to raise awareness of what extra support or reasonable adjustments might be needed to improve the health and wellbeing of people with a learning disability. This includes making sure they get the best out of education, health and social care services particularly at times of transition, as well as helping them to access opportunities in the community that will positively impact on their health and wellbeing, such as exercising and volunteering.

The Skills for Care, Health Education England and NHS England (2019) *Core Capabilities Framework* is also a very useful reference point for identifying key competences that can be embedded into both single worker approaches and wider care and support roles.

6.3 Coordinated care through whole systems, strategic commissioning

Commissioning services for people with a learning disability is complex as many people have a wide range of needs that can be the responsibility of a number of services including primary care, acute care, specialist learning disability services and general health and wellbeing services, commissioned by clinical commissioning groups and local authorities.

Best practice guidance from the Royal College of General Practitioners and Royal College of Psychiatrists (2013 p1) on how to reduce the health inequalities of people with a learning disability is clear that:

“CCGs need to work closely with Local Authorities, who have lead responsibility for commissioning social care services for people with a learning disability and family carers and Public Health Services. Social factors such as poverty, discrimination, unemployment, housing and social isolation adversely affect the health of people with

a learning disability. It is important for health and social care commissioners to develop joined up, person centred services which meet people's needs and are cost effective"

Care coordination via joint commissioning is about thinking holistically at a systems level across health and social care and potentially broader eg linking in employment, housing and the voluntary sector, aligning resources or pooling budgets to enable multi-disciplinary approaches that address needs holistically and embed personalisation, co-production and community based support in the design and delivery of local services.

6.3.1 Local Area Coordination

Local Area Coordination is a long-term, integrated, evidence-based approach to supporting people with a disability, mental health needs, older people and their families/carers, within a specific locality. It works alongside people to:

- Build and pursue their personal vision for a good life,
- Stay strong, safe and connected as contributing citizens,
- Find practical, non-service solutions to problems wherever possible, and
- Build more welcoming, inclusive and supportive communities.

Instead of focusing on deficits, the local area coordinator helps people focus on their own vision for a good life, building on their assets and relationships. Coordinators act as an accessible, single point of contact supporting children and adults within their community. Originating in Australia, the approach is currently being implemented in 11 areas in England and Wales in collaboration with the Local Coordination Network Community Interest Company. For more information on the core characteristics see Local Area Coordination Network website: <https://lacnetwork.org/>

According to the Local Area Coordination website, there is a growing body of evidence on the outcomes for individuals, community and the service system. These are coming from evaluations on the active programmes in England and Wales.

The wider outcomes include:

- Reductions in referrals/visits to GP, A&E, adult care, mental health and safeguarding services; avoided housing evictions
- Reduced dependence on day services and better health outcomes
- Relationship developments across neighbourhoods leading to increased community capacity
- Independent Social Return on Investment (SROI) evaluations in Leicestershire (2017) Derby City (2016) and Thurrock (2015) Councils have shown at least £4 return for every £1 invested
- Swansea University (2016) Significant cost benefit of between 2:1 – 3:1 (plus cautious cost saving estimate of £1.2 million in 1st year of operation with 3 Coordinators)
- Contribution to system reform and culture change through cross system partnerships

People themselves report:

- Feeling less isolated through valued, informal, support relationships
- Increasing capacity of families to continue in caring role
- Improved access to information
- Improved access to specialist services, communities
- Support into volunteering, training and employment

6.3.2 Examples

Salford's whole system approach

Salford local authority and clinical commissioning group's joint approach is often identified as good practice. The National Audit Office (2015) found that it was one of the few areas that had managed to make progress in transforming care services for people with a learning disability, in response to the Department of Health (2012) Winterbourne View Concordat.

Salford has developed a holistic community-based model of care, drawing upon the principles in the Department of Health (1993 and revised 2007) guidance, the outcome of a project group chaired by Professor JL Mansell. This seminal work outlines the core principles that remain true today including the need for a joined-up approach that incorporates commissioning, care management and specialist support so that packages of care are integrated and that responsibility is held not only by health and social care, but more broadly to include other agencies such as housing and education.

A key finding from the Audit Report has been that developing robust local services for people with a learning disability and challenging behaviour takes time. Salford local authority and clinical commissioning group (previously the primary care trust) have worked together for over a decade to develop a single service. They have:

- developed a shared culture, with the service user at the centre of their delivery model, based upon mutual support and a commitment to giving people meaningful lives, rather than just getting them out of hospital;
- implemented a joined-up health and social care management and commissioning structure with a pooled budget;
- co-located health and social care commissioners and a multidisciplinary specialist learning disability community team of social workers, occupational therapists, speech therapists, nurses, psychologists, psychiatrists, physiotherapists and trained carers (community teams work with providers at short notice to maintain placements, when a service user's behaviour might otherwise lead to hospital admission or readmission);
- ensured that people with a learning disability are supported to communicate their views and reduce challenging behaviour, through accessing mainstream leisure, health and social services, but supported by the multidisciplinary team.

A joint approach to health, social care and housing in Moray, North East Scotland

Only 15.2% of people with a learning disability in Scotland rate their health as very good, compared with 52.5% of the general population. People with a learning disability have as many health conditions at age 20 and over, as the rest of the population aged 50 and over. (Scottish Learning Disability Observatory, 2011).

In the light of these statistics, local leaders within health, social care and housing recognised that whole system change was needed. Working with Alder, they embarked on a programme of transformation, underpinned by the 'progression model' with the aim of enabling people with a learning disability to progress to the maximum degree of independence possible at each stage of their lives. Key changes that have been introduced include:

- Joining up health and social care funding: 'one population, one budget'
- Culture change across the wider system of care and support that emphasises outcomes
- Multi-disciplinary assessment combining health and social needs
- Social workers re-connecting with social work, moving away from care management
- Investment early on, working towards independence longer term
- A new market shaping strategy to ensure providers are delivering care in line with self-directed support principles
- Contract monitoring includes overseeing individual support plans and health objectives, eg checking that support workers are working alongside people with a learning disability to implement the physiotherapy exercises they have been given by health professionals
- Moving away from traditional residential homes to new arrangements that promote independence, eg building new, bespoke housing for people with autism and challenging behaviour where they are managing their own tenancies with a support team around them has led to fewer assaults on staff, better staff retention and reductions in medication. The housing project is seen as a centre of excellence

The Integrated Services Manager acknowledges that there is more work to be done to see people with a learning disability as 'citizens that need extra support' rather than a marginalised group who require separate services. All too often they are still not having a positive experience when they access mainstream healthcare and can find themselves excluded from community activities.

Adopting a whole system approach is perhaps the most ambitious response to improving the lives of people with a learning disability but one that has the potential to make the biggest difference at a population level. Both Salford and Moray have found that it requires sustained commitment over many years by health and social care as well as other agencies to transform their models of care.

7 Other approaches to improving the health and wellbeing of people with a learning disability

Whilst the purpose of this report is to look at models of care coordination and how they can improve health and wellbeing, in the course of our evidence gathering we have identified other examples of good practice from both the statutory and community and voluntary sectors that are worth highlighting.

North Wales Together: *Seamless Services for People with a Learning Disability Transformation Programme, 2019-2021*

This Welsh Government funded Transformation Programme in North Wales is supporting new and innovative ways of promoting health and wellbeing for example through the use of assistive technology.

Wrexham and Denbighshire are setting up groups and purchasing Fitbits for participants, to promote healthy lifestyles and increase people's awareness and motivation around personal well-being and fitness.

Mobile interactive projection equipment has been purchased for people to use in supported living and day opportunities in Anglesey. The system uses motion activated games, music and social activities to increase social interaction, physical activity and wellbeing of people with a learning disability. The project will also develop bespoke person-centred apps for individuals to use with the equipment.

Health and wellbeing videos, one in English and one in Welsh are being created for use across the North Wales region. The films will combine the physical and mental aspects of wellbeing and will seek to promote a person centred perspective. The coproduction process will bring together citizens and health professionals and will incorporate information about health & wellbeing, annual health checks, national health screening, community engagement and social prescribing. The films will include innovative graphics to encourage citizens to be fully aware and engaged in all matters relating to their health & wellbeing.

'Making Sense' Community Interest Company is working with professional artists to create **sensory parcels** for people with a learning disability containing sensory objects, sounds and smells along with suggestions for sensory interactive activities and trips. Working in partnership with local museums and galleries the organisation is enabling creative exploration of the arts to enhance health and wellbeing.

For more information on any of these initiatives: <https://northwalestogether.org/>

(At the time of writing some of these projects are being delayed or adapted due to the social isolation measures being implemented during the coronavirus pandemic).

Making sure people with a learning disability get all the right health checks

In 2015, Derbyshire County Council asked Derbyshire Healthcare Foundation Trust to develop some information for providers setting out all the different health checks and screening appointments people with a learning disability should have, including

Annual Health Checks. The aim was to make it easier for providers to ensure that they supported people appropriately to attend these appointments.

The checklist was circulated to all the learning disability providers commissioned by Derbyshire County Council, and was shared across the East Midlands.

The Schedule can be found here:

https://www.ndti.org.uk/uploads/files/Schedule_of_expected_health_appointments_for_Adults_with_Learning_Disabilities_1docx.pdf

Public Health England (PHE) Health Charter for Social Care Providers

The Charter, published in 2017, encourages providers to pledge their commitment to helping people with a learning disability access good healthcare and lead a healthy lifestyle. Actions include:

- providing ongoing training to staff on basic health and wellbeing issues including pain recognition and the implications of specific syndromes and health conditions
- providing information on health and wellbeing that is accessible to people with a learning disability
- making sure support is available from someone who can, if necessary, advocate on behalf of the individual so that people can attend and benefit from all types of health appointments
- promote access to screening tests by: – helping staff and the people we support to understand their importance – working in partnership with clinical services to ensure support is available before, during and after screening checks

The Charter can be found here:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/656670/Health_charter_social_care_2017.pdf

Mencap ‘Don’t Miss Out’ campaign to increase the number of people with a learning disability on GP registers

Mencap has produced easy read guides, videos and posters to encourage people with a learning disability to join the GP Register. Their website points out that anyone of any age and any level of disability can join the learning disability register and get extra support. They recommend joining early so that adjustments and support are put in place before a person starts using adult services. Their website also has guides on hospital passports, summary care records and flu vaccines and a helpful Health FAQs section.

For more information: <https://www.mencap.org.uk/advice-and-support/health/dont-miss-out>

Share’s Live Well Feel Great! Project

Share provides training and employment support to disabled adults including adults with a learning disability. The Healthy Living Co-ordinator at Share has been raising awareness of the importance of health checks, including annual health checks, with the students Share supports. She talks the students through the different health checks, why they happen, how regularly, how appointments are made, and asks when their last check-ups were. She also supports people to get their health

passports completed as she has found this is a great resource that can be used at health appointments.

The Coordinator has worked hard to get the students active, supporting them to take part in a variety of sports and physical exercise, and eating well by understanding what's on their plate, cooking simple, healthy meals for themselves, and knowing how to choose healthy food options.

Inclusive sessions involving sport and exercise are on offer every week, including yoga, zumba, chair-based exercise, movement dance and cycling. Many of these activities are not always widely available or accessible for people with a learning disability and hence are popular among the students – both from a physical and social perspective.

For more information: <https://www.sharecommunity.org.uk/news/mayors-award-shares-healthy-living-project>

Using technology to improve care coordination: My Health Guide app

The App uses a variety of pictures, sound and text to help individuals better manage their healthcare and communicate with their support network. Users of the app, developed by Maldaba, experience better outcomes such as reduced readmissions and hospital appointments, more stable daily patterns, and more effective communications. Service providers are able to give better quality support which includes more efficient information sharing and better coordination of health appointments and regimes.

For more information: https://www.maldaba.co.uk/case_studies/my-health-guide/

Voluntary Organisations Disability Group (VODG) events to tackle health inequalities

Staying Healthy conference, February 2020 explored a wide range of initiatives to support people to lead active and healthy lives and offered delegates the opportunity to reflect on how to promote a culture and practices that support a healthy lifestyle.

For example:

- Downs Syndrome Association Healthy Living App
- Sense Arts and Wellbeing Programme for disabled people with complex needs
- VODG 'Good Food Matters' resource
- Breast screening and bowel screening easy read guides
- Public Health England report on making reasonable adjustments to obesity and weight management services for people with a learning disability

<https://www.vodg.org.uk/event-roundups/staying-healthy-event-roundup/>

Leading for Better Health conference, October 2019 explored how leaders can foster an organisational culture, systems and practices that reduce health inequalities experienced by people with learning disabilities. Useful resources include:

- MacIntyre's suite of health related materials
- National Autistic Society's resources and strategies for supporting people with autism to look after their health

- VODG's 'Tackling Health Inequalities' - a discussion paper setting out what social care providers believe can help or hinder efforts to tackle health inequalities.
- Collaborating across systems – an overview of initiatives that are being trialled in the South-West to promote increased uptake of flu jabs and annual health checks and better recognition of when a person's health is deteriorating.

https://www.vodg.org.uk/news/leading-for-better-health-event-roundup/?utm_source=Publicate&utm_medium=embed&utm_content=page-not-found-vodg&utm_campaign=Staying+healthy+roundup+%28social+share%29

8 Further Considerations – An IPC Perspective: Care coordination and empowering people with learning disabilities and long-term conditions

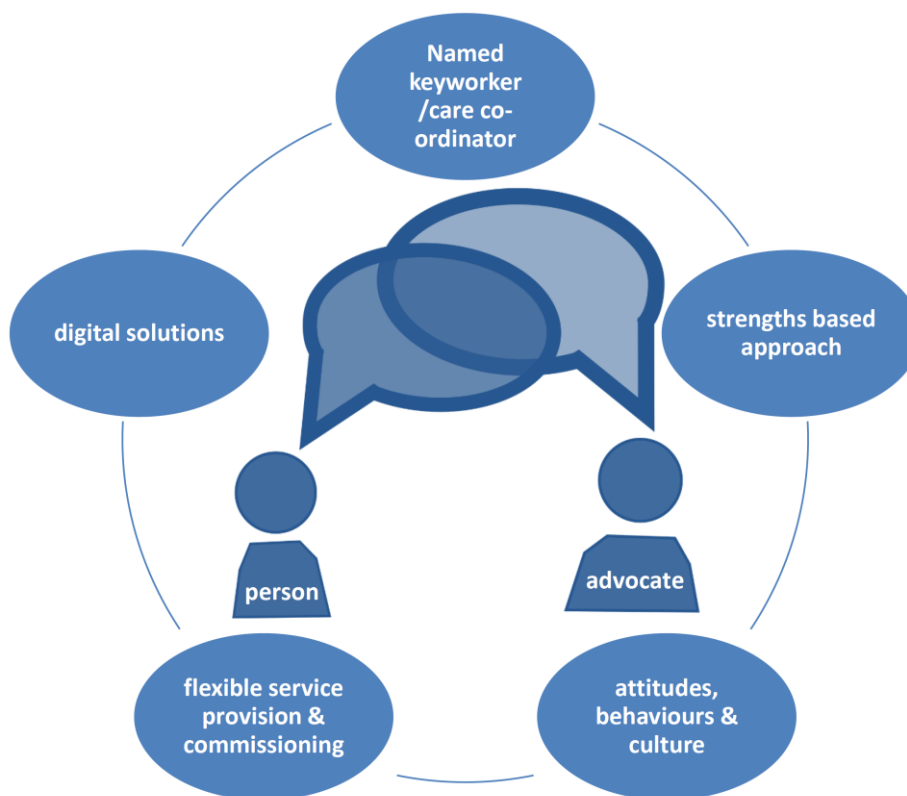
Improving the health and wellbeing of people with a learning disability and reducing health inequalities and premature mortality is not something that can easily be fixed.

The key principles for transforming care and support for people with a learning disability such as personalisation, care coordination, enabling choice and control, are well established principles that have been around for some time. The good practice examples demonstrate that there are some interesting and innovative approaches being developed, both operationally and strategically. However, as our focus group participants pointed out, the challenges are real and can feel like little progress has been made.

At its most basic care coordination is the gathering of and sharing of information and decision making with the person, their family and/or paid carers, and other professionals and/or services. At the heart of care coordination must be the person and their most trusted advocate who could be a family member, paid carer or other professional. A key function of care coordination is to ensure that all the information is gathered and made accessible to the person with a learning disability and shared among all those involved and that decision making always involves the person with a learning disability and enabling this to happen often necessitates involving their most trusted advocate. It is often the trusted advocate who 'translates' the information into ways that the person with learning disabilities can understand. It is also the trusted advocate who is often best placed to support the person with a learning disability to communicate their views.

It is important to acknowledge that in many cases it will be a **family member** who is the main carer, a role that will encompass day to day hands on delivery of care, care coordination (liaising with professionals, coordinating health appointments and regimes, enabling access to health checks and screening programmes, etc); advocating for and supporting the person to have as much autonomy and control of their life as possible. It is vital that the family member who carries out this role is supported. One way to do this is to ensure that they have a **carer assessment** to identify and support their own needs which could be financial or about their own health and wellbeing (both physical and mental). 'Caring for the carer' will indirectly support and improve the health and wellbeing of the person with a learning disability. For more information on local authority carer assessments: <https://www.nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/carers-assessments/>

What enables person centred care coordination?



8.1 Mental Capacity Act and Deputyship

The Mental Capacity Act 2005 is a law that protects vulnerable people over the age of 16 around decision-making. It says that:

- Every adult, whatever their disability, has the right to make their own decisions wherever possible.
- People should always support a person to make their own decisions if they can. This might mean giving them information in a format that they can understand, for example this might be easy read information for a person with a learning disability or explaining something in a different way.
- But if a decision is too big or complicated for a person to make, even with appropriate information and support, then people supporting them must make a 'best interests' decision for them.

Supporting someone to make decisions about their lives, including about their care and support, needs to be part of care co-ordination. Whoever is responsible for care coordination, should follow the principles in the [Mental Capacity Act Code of Practice](#) which includes four main points to help someone make a decision:

- Provide relevant information
- Communicate in an appropriate way
- Make the person feel at ease
- Support the person

After all steps have been taken to support someone to make their own decision, if the person is assessed as lacking capacity to make that particular decision, then a ‘best interests’ decision must be made. When a best interests decision is being made, the person must still be involved as much as possible.

Mencap and BILD’s [Involve Me](#) resources offer some creative ways to ensure people remain at the heart of decision making. There are guides and a video to show how the preferences of people with PMLD can be captured and used to influence decisions about their lives, even if they lack capacity to make the decision themselves.

In some situations, families may be granted **personal welfare deputyship orders** to enable them to make a wide range of decisions about a vulnerable individual’s medical and social welfare including:

- their day-to-day care, including diet
- consenting to medical and dental treatment
- the person’s care arrangements
- leisure or social activities they should take part in

The Code of Practice governing the making of these orders suggests that these should only be granted in the most difficult cases. However, three recent test cases brought to the Court of Protection by parents of individuals with a learning disability argued that more consideration should be given to the importance of their ongoing role in supporting the interests of their children after they had reached the age of 18. The cases were upheld and may result in many more families taking on a care and welfare role, including care coordination and making decisions that impact on health and wellbeing.

8.2 Advocacy

Advocacy has been described as:

“Taking action to help people say what they want, secure their rights, represent their interests and obtain services they need. Advocates and advocacy schemes work in partnership with the people they support and take their side. Advocacy promotes social inclusion, equality and social justice”

National Development Team for Inclusion (NDTI) website

There are different types of advocacy, including:

- Self-advocacy – people advocating for themselves
- Peer advocacy – people advocating for those defined in a similar way
- Professional advocacy – people who are paid as skilled representatives to speak on behalf of a person, such as Independent Mental Capacity Advocates (IMCAs)
- Representational advocacy – people who represent the interests of another on a voluntary basis (such as citizen advocacy)
- Family advocacy – families explicitly advocating for their family member

Principles and standards for delivering advocacy can be found in NDTI's Advocacy Charter (2018) and the Advocacy Quality Performance Mark (2018) both on their website.

Advocacy plays an important role in enabling people with a learning disability to have choice and control about how they live their lives so that care can be co-ordinated in line with their aspirations. Professionals and services need to ensure that when there is a 'trusted advocate' involved, that they always include this person as part of the communication pathway outlined in the support plan.

8.2.1 Examples

Oxfordshire Family Support Network – family advocacy

Oxfordshire Family Support Network (OxFSN) provides independent information, advice and support by families for families of people with a learning disability. Set up by family carers who wanted to use their experience to help others in the same situation they strive to improve the lives of people with a learning disability and their families.

"We have a small team of Family Advocates who are all family carers of children or adults with a learning disability. Each advocate has skills in different areas – and, while none of us claim to 'know it all' if we don't know the answer to your query then we will know someone who probably will and can signpost you in the right direction".

OxFSN has also produced the "Getting a Life" series of guides to help young people and their families to plan for the future, by using person centred thinking techniques. The guides contain useful tips and advice on subjects that include: education, money matters, social care, finding the right support, becoming an adult, health and well-being, finding work/volunteering and somewhere to live.

Sunderland People First – professional advocacy

Sunderland People First is a community interest company based in the North East of England. Established for over twenty years, their aim is to improve people's lives and champion the rights of people with a learning disability.

As well as running self-awareness and self-advocacy courses, people with a learning disability can get involved in a range of activities including quality checking NHS services to assess how well they are meeting the needs of people with a learning disability; sitting on care and treatment panels as experts by experience to contribute to care and treatment reviews; delivering training sessions on disability awareness, hate and mate crime and personal assistant training.

8.3 Strengths based approach

The Care Act 2014 requires local authorities to "consider the person's own strengths and capabilities, and what support might be available from their wider support network or within the community to help in considering 'what else other than the provision of

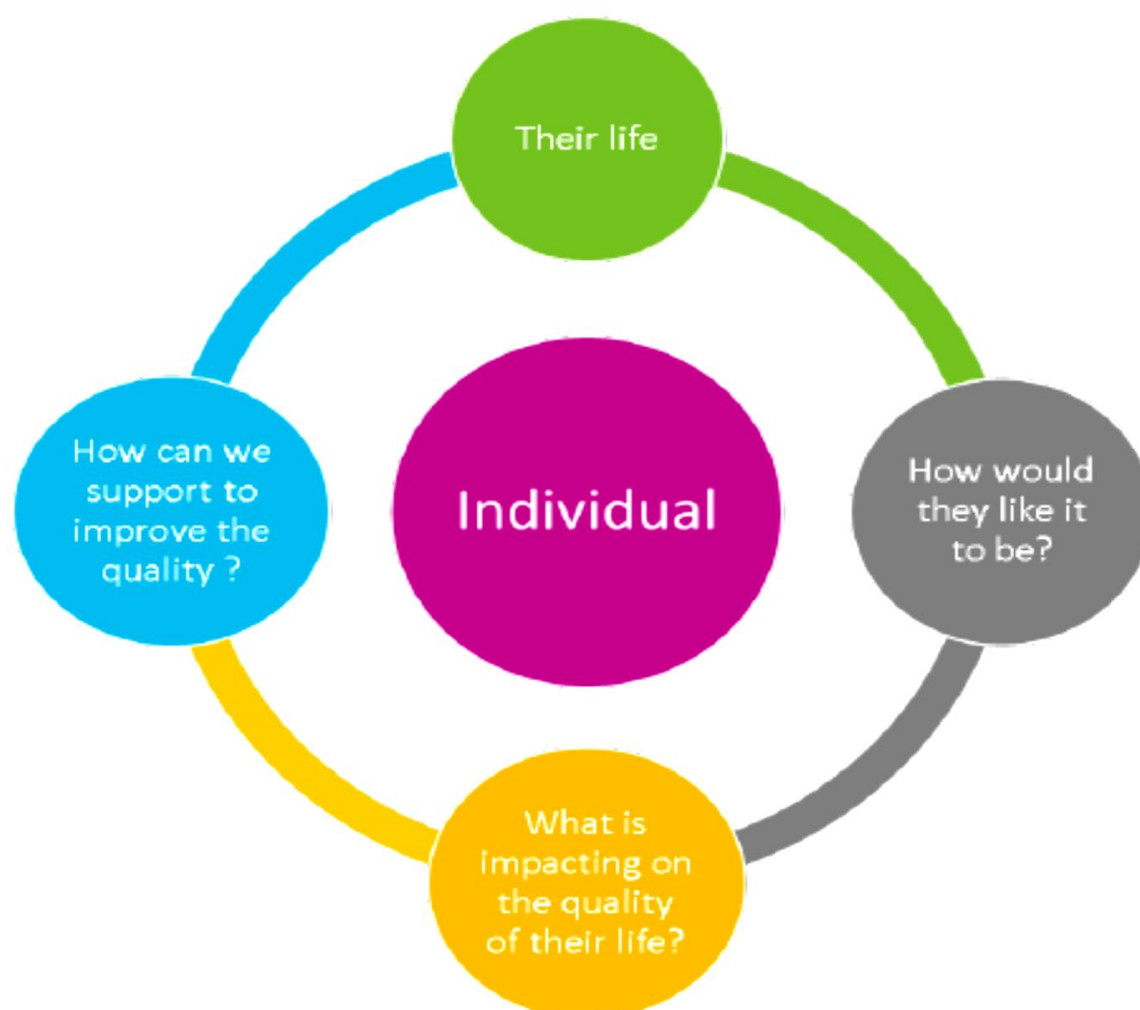
care and support might assist the person in meeting the outcomes they want to achieve”.

Care planning and coordination therefore needs to be done collaboratively – involving professionals, providers and the person’s own network including friends, family, advocates to gain a holistic picture of the individual’s life and co-produce a way to maximise quality of life and good health and wellbeing.

Recently published guidance on strengths based social work (Department of Health and Social Care, 2019) emphasises that

“A strengths based approach explores, in a collaborative way the entire individual’s abilities and their circumstances rather than making the deficit the focus of the intervention....It shifts the focus to the positive attributes of individual lives and of neighbourhoods, recognising the capacity, skills, knowledge and potential that individuals and communities possess.” (p24) and see diagram below.

As a participant in one of our focus groups put it: *“People being aware of my abilities, talents and skills.”*



8.3.1 Example

Preparing for adulthood assessment: Richard's story

“Richard is a 23 year old man with Down's syndrome. He had been referred to our Preparing for Adulthood Team for an initial assessment. Prior to our first meeting I thought about the best environment to meet. I was aware that if he came to our office he may find the buzz slightly intimidating. Instead I decided to meet him at home. I remember the first thing we spoke about was our mutual love of Arsenal football club. It is easy to become too focused on filling in a form and forgetting who the form/life belongs to. Without the barriers of paperwork Richard spoke quite candidly about many of his aspirations, including his desire to one day become a chef. Within the first couple of meetings we had bonded quite well.

Richard told me of his mixed experience at college and the lack of support when it came to working out what to do next. Working with the college's SEN team, we explored a suitable employment pathway. Initially Richard appeared quite shy and reserved, we managed gradually to break the ice and as his self-assurance grew he started to express additional outcomes he hoped to achieve such as going out by himself and having a girlfriend. Signing up for a catering internship at a local hospital had a profound effect as he became so much more vocal and his body language changed, he now holds his head high and can maintain eye contact for longer”.

Why is this intervention strengths based?

- The professional focuses the interview on Richard, his life and priorities
- The intervention goes beyond filling out a form, being inquisitive about Richard and his personal outcomes, not only ticking boxes on his needs
- The intervention promotes Richard's wellbeing, in a holistic way. Not limiting the intervention to the presenting need but establishing a meaningful and trustworthy relationship and enquiring and listening to what is important for him

Adapted from Strengths-based approach: Practice Framework and Practice Handbook, (DHSC 2019).

8.4 Attitudes, behaviours and culture

Few would argue against ways of working with people with a learning disability that promote choice and control, inclusivity and empowerment. However, putting it into practice may require a shift in attitudes and behaviours. People with a learning disability and their carers in our focus groups were very vocal about the sort of attitudes and behaviours that were not supportive, for example:

“not being listened to”

“being treated like a child”

“decisions being made without me”

“not being trusted to make the right choices”

“not allowing risks”

“lack of flexibility in care options, especially if circumstances change”

“endless loop of being sent to different services that are not suitable”

Conversely, they highlighted the key characteristics of more helpful interactions and relationships:

“being respected. Recognising the things I am capable of”

“work in partnership, valuing the views of carers”

“staff knowing where the boundaries are – not overstepping them”

“my home feeling like my home – not the staff’s home”

“not ignoring you or telling you what to do or holding ignorant views”

“people, services, staff who listen to me”

“having people, especially professionals explain things in a way I understand. Explain it like a story to me”

Whether care is co-ordinated by a key worker or by multi-disciplinary teams working closely together, it is unlikely to deliver effective outcomes unless there is positive rapport and trusting relationships between all parties. Continuity of staff, having adequate time together as well as skills in motivational interviewing and facilitating strength-based conversations, enhance the experience and are more likely to result in positive health and wellbeing outcomes.

The following example highlights how two providers have changed attitudes, behaviour and hence culture from silo working to close collaboration and the positive impact this has had on the health of the people they support.

Changing the culture - co-ordinated working between health and social care in North Yorkshire

A small residential care home for young adults with a learning disability and complex health needs in North Yorkshire run by United Response, exemplifies the importance of close interaction and collaboration to establish trust and mutual respect which is the basis for providing co-ordinated care. Over the years social care staff have established a close working relationship with health professionals from the Harrogate Learning Disabilities team (Tees, Esk and Wear Valleys NHS Foundation Trust). This enables them to deliver a seamless and co-ordinated service that responds to an individual’s full range of needs and contributes to the overall health and wellbeing as well as the longevity of residents.

“We are a social care provider – we aren’t nursing or health care assistants – the staff are support workers. However with the support and the way we work together with the team of learning disability health professionals around us – it works really well in terms of maintaining a very high standard of supporting people with their health needs.” Service Manager

Key elements of this approach include:

- Early identification of potential problems by support staff on the look out for signs and symptoms
- Health staff manage ‘episodes of care’, responding quickly to any concerns highlighted by care home staff

- They intervene early to prevent problems from escalating, bringing in specialists from their multi-disciplinary team including occupational therapists, physiotherapists, speech and language therapists, dieticians
- They always communicate with the individual to establish what is important for them, offering choice and control eg not imposing specialist equipment, especially if quality of life may be better without it
- They provide clear and detailed discharge reports to support staff so they know what to look out for and when to re-refer. This helps the staff to feel valued and enables them to report back accurately
- If equipment is to be provided such as wheelchairs, moulds, sleep systems and slings, support staff are trained in how to use it
- Health professionals deliver in house training and coaching to staff to help develop their knowledge and skills, for example providing clear visual guidance designed like a place mat on what to do if someone is choking

Health staff believe that care coordination works well between them because there is strong leadership by the care home manager and the workforce is stable and know the residents well.

8.5 Flexible service provision

The following two examples illustrate how providers have adopted a flexible and creative approach to enable care to be coordinated in accordance with the individual's wishes.

Working in partnership with people with a learning disability to provide flexible support by using Individual Service Funds (ISFs)

Individual Service Fund (ISF) provide flexible support because the service provider holds the personal budget as a 'managed account' and works with the person to design, develop and manage the best possible support, altering it with minimal fuss when changes are needed.

New Key provides support to people living in supported living accommodation in Bristol, Torquay, Totnes and Kingskerswell. People who use the service include people with physical disabilities, autism or learning difficulties. New Keys helps people to live independently and assists them to live the lives they want. They support people to achieve outcomes in managing their own money, making friendships, finding work, managing their home, finding and attending local groups, exercising and cooking skills.

The following case example illustrates their flexible approach to care and support using an ISF to improve health and wellbeing outcomes:

"A person with high anxiety that we support requires support throughout the day to mitigate falls risks, provide reassurance and ensure his safety. He regularly has Reiki sessions from the same practitioner, who he trusts and relates well to, he has had this treatment regularly for two years and it has a hugely calming effect for him. Instead of paying £15 per hour for the support worker to be there when this happens, the ISF is

used to fund a DBS for the Reiki therapist, and potentially any training (e.g. first aid) and she fulfils the support function whilst giving him Reiki, she charges £10 per hour and usually does two hours a session. We are able to use the ISF to fund two or three sessions a week saving £10 support costs per session. (Based on 2 sessions a week over 52 weeks this would deliver a saving of approximately £1040 per annum)”

Flexible approach to end of life care

Providing end of life care to people with a learning disability can be challenging and hospitalisation may be seen as the easiest option, despite the fact that most people would prefer to die at home. The manager of a large supported living provision in Central Lancashire describes how they effectively co-ordinated care to enable a resident with a profound learning disability to stay in her home and have the most dignified death possible.

“Following a Continuing Healthcare Assessment, an agency was commissioned to provide support. We challenged this as the agency staff did not understand JT and they sent different staff each day. We ensured that the agency was removed and our own staff provided all her support up to and including the time of her death. The staff understood JT and her needs as they changed.

Staff ensured that JT's health and social care needs were met properly by ensuring multi-disciplinary team working was effective and referrals and communication to the following people were made: GP, oncology, district nurses, 111 practitioners, priest.

A referral was made to the LD team for the other residents. We asked for help in telling people that JT was dying and that they were supported to understand their feelings.

JT was able to remain at home in the supported living provision surrounded by the people who cared for her. Family were encouraged to be part of house. JT was given appropriate pain relief and other medical procedures in her home instead of being in a hospital where she would not have had the one to one support from people she knew.

Staff felt supported and were able to provide the best care for JT. Staff feel confident in supporting people in end of life care. Family were thankful for the opportunity to become a bigger part of her remaining life. The other tenants had the opportunity to say goodbye to their friend JT. The fear of death and being taken away to die was reduced for the other older tenants.

Family and JT's best friend felt that JT had received the best support possible”.

8.6 Digital solutions

Advances in technology mean that there are now a range of digital solutions including personalised websites and apps that are accessible to people with a learning disability and their advocates for storing and sharing all relevant information. They are designed to help the person co-ordinate their care and make informed decisions, with all relevant information being fed in by professionals.

Digital Solution – RIX Wiki – Accessible and secure personal websites

The RIX Wiki is a uniquely accessible, web-based multimedia communication & planning tool developed by RIX Research & Media at the University of East London. RIX Wikis have been developed with and for people with a learning disability, their families, carers, and support professionals.

Wikis are simple, accessible, secure and easy to build personal websites. They can be used to create multimedia person-centred plans that use pictures, words, video and sound to capture the voice, skills, aspirations and needs of the individual.

Wikis give ownership of the planning process to individuals and families, facilitating genuine collaboration between people with learning disabilities, trusted advocates and professionals.

9 Recommendations

From the evidence that we have compiled during this rapid review of best practice, it is clear that well-coordinated care at all levels from strategic, whole system approaches to key worker roles on the ground can play an important part in improving health outcomes for people with learning disabilities and long-term conditions.

Some models have grown organically, shaped by local needs and circumstances and innovative practitioners e.g. the ISCAN service in Gwent or New Key in the South West of England. Others have been driven nationally such as education health and care plans, named social worker pilots or imported from abroad e.g. local area coordination. All are underpinned by the changes to care and support that have been evolving over the last couple of decades such as personalisation, choice and control, progression and independence.

What do we need to do to ensure care coordination contributes to improving the health and wellbeing of people with a learning disability?

Value the diversity of roles that contribute to care coordination

There is no 'one size fits all' approach to care coordination. The different levels of need experienced by people with learning disabilities ranging from mild to moderate, severe or profound means that the type and amount of care co-ordination will vary. It is important to recognise that this type of work is carried out by a multitude of people. These include health and social care staff such as social workers who work directly with people with learning disabilities; health and social care staff in other non-learning disability roles such as hospital workers; personal assistants and family members; as well as others with job titles that include the word 'coordinator', 'facilitator' or 'key worker'.

Use person-centred, co-productive approaches

For care coordination to be successful and contribute to improving health and wellbeing outcomes, people with a learning disability should be at the centre of decision making about their own lives and in the development of new initiatives.

- At an individual level, the principles of the Mental Capacity Act to protect and empower people to have as much control over their lives as they can should be adhered to, including when care and welfare deputyships are in place
- All forms of advocacy should be supported and resourced to give people information they can understand, to help them express what they want, secure their rights, represent their interests and obtain the services they need to maximise their chances of having good health and wellbeing. This means sufficient financial investment should be given to advocacy organisations as well as giving time and space for self advocacy or advocacy by a trusted individual eg family member or friend
- Pathways and services should be coordinated in a flexible way around the needs and wishes of the person
- A strengths-based approach should be employed at all times recognising the capacity, skills, knowledge and potential that individuals possess and can be built on throughout their lives
- Initiatives to improve health and wellbeing should be co-produced to ensure they are appropriate and will appeal to the people they are aimed at (e.g. health and wellbeing videos being co-produced by North Wales Together)

Improve organisational standards, systems and processes – services need to demonstrate commitment to standards for delivering care, for example, those developed for providers working with people with Profound and Multiple Learning Disabilities (Care Management Group, 2017) and quality assure/performance manage adherence to these. Systems and processes should be streamlined, for example a single point of access, so that the person only needs to tell their story once; integrated assessment and planning, with all the relevant individuals feeding in and listening to the aspirations of the person as the starting point; multidisciplinary teams so care and support is experienced as being well coordinated and seamless and health and wellbeing goals are embedded and monitored as part of the care plan.

Make workforce training and development a priority - Whether staff are working in a direct care management role, health promoting role or health liaison role, this diverse workforce would benefit from training and development to ensure they have the right knowledge, skills and behaviours to maximise the positive influence they can have on improving health and wellbeing for people with a learning disability, whether their disability is mild, moderate, severe or profound.

- Excellent guidance is in place (Skills for Care, Health Education England and NHS England (2019), identifying twenty-five capabilities divided into 5 domains (one of which is health and wellbeing) and arranged in tiers of complexity depending on individual roles. The guidance gives the desired learning outcomes for each topic and links to key references and documents that will be valuable to those planning training or curriculum content. Employers should build in capability training to enable people who have roles that include care coordination to perform better
- A raft of guidance is available on improving access to health services, for example how to increase take up of annual health checks and other screening programmes, the importance of being on the GP register and having a Summary Care Record with details of reasonable adjustments needed.

- There is also advice and guidance on the more specialised needs of people with Profound and Multiple Learning Disabilities (PMLD)
- Staff should be encouraged to embrace new ways of working including digital. There are many examples of good practice in health promotion, early intervention and care management, including the use of digital technology (e.g. Maldaba's My Health Care App), health facilitator roles (eg Leeds and York NHS Trust) and easy read materials (e.g. MacIntyre) which should be more widely shared amongst the workforce across the UK
- Training needs to bring about culture change and shift negative attitudes and behaviours. Training must promote and instil positive values and behaviours in the workforce like active listening, being respectful, communicating clearly, working in partnership so positive and trusting relationships are built between people with a learning disability and those who support them. The quality of the relationship is a key factor in improving their health and wellbeing.
- Training and sharing of best practice needs to be available to family members who are often providing a significant amount of care and support, including the coordination role

Acknowledge and support the vital role played by family members who in many cases will be the primary carer (and care coordinator) of the person with a learning disability. One way to do this is to ensure that they have a **carer assessment** to identify and support their own needs which could be financial or about their own health and wellbeing (both physical and mental). 'Caring for the carer' will indirectly support and improve the health and wellbeing of the person with a learning disability.

Embed strategic integrated commissioning for a whole systems approach. Local authority (including social care, housing, public health) and health commissioners should agree joint commissioning objectives that address the broad range of factors that contribute to the health inequalities experienced by people with a learning disability. These include social determinants such as poverty, poor housing conditions, unemployment; unhealthy lifestyles and barriers to accessing healthcare.

Institute of Public Care
March 2019, updated March 2020

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Appendix One

The following organisations contributed to this report:

Learning Disability England
Sunderland People First
Lewisham Speaking Up
Mencap Northallerton
Halifax self advocates group
United Response
Self Directed Futures
New Key
Heath and Social Care, Moray Council
Choice Support
Camden Learning Disability Service
Royal Devon and Exeter NHS Foundation Trust
Harrogate and District Community Learning Disability Service
MacIntyre
Conwy Council
Aneurin Bevan University Health Board
Gwent County Council
Betsi Cadwaladr University Health Board
Sparkle
North Wales Together Programme Team

Appendix 2

Feedback from People with a Learning Disability and Long Term Conditions and their Families and Carers

Analysis of focus groups organised by Learning Disability England in February 2019

1 Participants

- **Sunderland People First** – 20th Feb, 7 people attended

Autistic people, self advocates with range of support & some with complex health needs invited (bias to people living with family or alone)

- **Lewisham Speaking Up** – 27th Feb, 6 people attended

Self advocacy group members plus Parliament reps

- **Northallerton, Mencap** – 20th Feb, 9 people attended

Family members predominantly invited but mixed group including some self advocates & a member of CLDT

- **Halifax** – 27th Feb

Self advocates invited mostly people who live in supported living

2 Questions and responses

2.1 What does good health and wellbeing mean to you?

Relationships: “having friends and relationships”; “being in a good loving relationship”; “being around good people”

Activities/social life: “having hobbies, activities”; “going to the gym”; “seeing friends, going to clubs, socialising”; going for a walk, going to the park”; “time to do everyday ordinary things”; “going to pubs and restaurants”; “disco, golf, bowling”; “dance class”; “having banter”; “nature” “being involved in performing arts”

Time out/relaxing: “respite breaks and holidays”; “listening to music”; “learning how to relax and not be anxious”; “time for yourself to do what you want when you want”; “break in routine”; chill out time (man cave);

Keeping well: “holistic balance (nutrition, mental health, physical health, medication, medical support”; physical and mental health to do what you want to do”; mindfulness to help good mental health”; “eating healthy, exercise”; good information/instructions around medication”

Sense of security: “having a job and earning money”; “having your own place”, “security for the future (longer term needs)”

Sense of acceptance/understanding from others: “being accepted by people – being yourself and not having to ‘fit in’; “mixing in with mainstream society”; “feel welcomed, accepted, wanted”; “being listened to and being understood”

Sense of freedom, independence, choice: “having choices in life – what I do, where I go is my choice”; “encouragement/good support to try new things”; “being able to do the things that make me happy”

Making a contribution: “speaking up and being involved in self advocacy”

2.2 What helps you keep healthy and well?

Qualities/attributes of support: “good support that is consistent, appropriate and dependable”; “good support - not bossy or controlling”, “helpful staff – I decide, but they help me to get what I want”; “people, services, staff who listen to me”, “Understanding the way I communicate”; “good person centred planning to achieve what you want in life”; “flexible and reliable support”; knowing that people who support me have my best interests at heart and respect my decisions. Being treated equally. Having consistency. Everyone supports me in the right way. People being aware of my abilities, talents, skills. Having the same staff. Respect. Support to be independent

People who can support:

Informal: “good community support from family and friends” “voluntary support groups”; colleagues at work looking out for each other”; “neighbours” “community support (food banks, charities)”, “street pastors”; “church”; “carers centre”, teachers, personal trainer

Health and social care professionals: “specialist help like speech therapist”, “well trained support workers”; “good support from community learning disability team staff”, “having a good key worker”; “dietician”; “PAs”, doctor, dentist, chemist

What they can support with: “someone to manage finances, staff, training of staff, takes the stress away” (carer)

“Advice about healthy food. How to stay safe. Being in control. Somebody to help me exercise”.

Other things that are important: “one place to go for help and advice”; “other parents with similar experiences who understand”, “knowing your way around the system”; “people listen to us and keep us informed at every stage”. “Don’t expect us to keep chasing professionals for answers, remember we are the experts when it comes to our families!” (all from carers)

Importance of choice: “choosing staff that support me. Choosing where I live and who I live with. Being able to make my own choices. Information to make choices.

2.3 What is most important in how professionals and services work with you?

Listening and communication

“When I was allowed to have a say”

“Asked me questions”

“Listen to everyone, carers and other professionals involved in cases to improve outcomes” (carer)

“Having people, especially professionals, explain things in a way I understand. Explain it like a story to me”.

“Good communication, letting us know things in advance”

“Listened. Took my views into consideration. They learned what works best for me”.

“Gave me information that was easy to understand”

“Spoke to me and explained what was going to happen”.

Respect

“Being respected. Recognising the things I am capable of”

“Work in partnership, valuing the views of carers”

“Treat us with respect”

“That they respect what you want from them”

“staff knowing where the boundaries are – not overstepping them”

“My home feeling like my home – not the staff’s home”

“general respect, manners and principles – you are paid to support me”

“Be more considerate of our needs” (carers)

Staff have the right training/qualifications and attitudes

“Gave good training to staff, delivered by experts with experience”

“Make sure the person has the right experience/qualifications to deal with the task in hand”

“Having knowledgeable staff and professionals”

“Having staff and professionals that give you good advice”

“Professionals being mature”

“Happy, friendly, had good banter, professional, welcoming”

2.4 Are you or your family the care co-ordinator?

Yes – me, mum, dad, sister, husband, wife, microboard¹

What makes it work?

“They know me. They understand me”; “Being honest with each other”; “Trust, confidentiality”; “Being realistic - no empty promises”

From carers:

“Family input, joint approach, I am in charge, me making it work from necessity, good communication with staff who are flexible, controlling finances to do what he wants”

What stops it being possible?

“Budgets/funding, time; not making reasonable adjustments”; “Not being listened to”;

¹ a small group of committed family and friends ‘circle of support’ (min 5 people) who join together with the individual to create a non profit society to help the individual plan his/her life, advocate for what they need, monitor services, connect to his/her wider community, do fun things together (Velacanada website)

“Decisions made without me”; “Family members being overbearing”; “Lack of imagination”; “Not being trusted to make the right choices”; “Not being taken seriously”; “Not allowing risks”; “Not understanding my disability”; “Not being flexible”; “Not being truthful about choices made”; “Misleading information”

From carers:

“Lack of flexibility in care options especially if circumstances change”; “Lack of realistic finance”; “Commissioners”; “Organisational roles”; “Not getting personalised care”; “Having to fight for everything is too much to cope with”; “No joint working”; “No respite”; “Cuts”; “Lack of carers to choose from”

2.5 Does someone else co-ordinate your care?

Patient liaison nurse at City Hospitals
Carers centre

What makes it work?

“having a dedicated member of staff. Having one place/person to go to”; “They provide easy read information”

2.6 What gets in the way (of getting the right kind of support or services)?

Finance

“Budget cuts”; “lack of realistic finance”; “cutbacks – cuts to support hours, charging for support”, “eligibility”

The Benefits system

“Sometimes the system doesn’t include people, ie Universal Credit”; “Only being able to work for 16 hours or I lose benefits”; “Universal credit – making people go into debt”

Staff

“Lack of staff”; “staff not trained properly”; “hidden agenda by professionals”, “lack of knowledge from so called professionals”; “social workers sometimes”; “bad support staff”; “untrained staff”; “sometimes social workers won’t access your need”

Families

“Families can be overprotective and treat their children like kids”; “Families stopping people with learning disabilities from working”

Problems with accessing help

“Not sure where places are”; “ area you live”; “not knowing where to go or who to ask for help that is available”; “endless loop of being sent to different services that are not suitable”; “incorrect signposting”

Difficulties with the way help is offered and provided

“Gatekeepers can sometimes be the barrier”; “service hours are usually based on a work week 9am-5pm basis”; “complicated information”; “difficulties with communication”; “meeting areas are not always suitable”; “having to make phone calls”; lack of available advocacy”; “Jargon”, “not being listened to”; Lack of understanding of individual needs”; “organisational roles”; “commissioners”, “service providers – sometimes”; “lack of

regular reviews of the care package”; “not understanding what help is needed when caring for more than one person in the house with very different needs”; “You don’t get the right feedback”

System fatigue

“Sometimes people have to jump through hoops and end up giving up”; “Just being too worn out to look for help and support”;

2.7 What is the most important message?

“Don’t butt in when I’m talking. Make sure services/professionals speak directly to the person”

“Look at what can be achieved rather than the obstacles”

“That vulnerable people aren’t excluded by society but are valued for their skills, talents and experiences”

“I would make sure that staff are listening to people with learning disability and understanding their needs”

“everyone could lead the life that they choose with the correct support where needed”

“people with learning disabilities would not need specialist services because all people with disabilities would be accepted and catered for”