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‘services’ – it’s about having a life.”**



Day opportunities for people with learning disabilities

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V1.0

1. INTRODUCTION

Historically, day services and the opportunities they offer have been a key source of support for people with learning disabilities (PWLD) and their families. The people who draw on them are a very diverse group, with different interests, aspirations and levels of independence. Individuals classified as having a ‘mild to moderate’ learning disability generally have less need for support, whereas those categorised with a ‘severe’ learning disability, or with ‘profound and multiple’ learning disabilities, tend to require higher levels of support respectively. Some PWLD may also have physical and/or mental health issues, sensory and communication impairments, and behaviours that others find challenging.

As PWLD are living longer, more adults with learning disabilities are also requiring access to day services and opportunities that are appropriate for older adults and older people; for adults who reach retirement age, these may be provided by learning disability or by older people’s services.

Day services also enable family carers of PWLD to work, train, study and/or have a break. Changes in day services and provision of day opportunities therefore have important implications for this group too.

1.1 Policy background

At the turn of the century, major new strategies for PWLD were launched in the UK. These included: *The Same As You?* in Scotland (Scottish Executive, 2000), *Valuing People* in England (Department of Health, 2001), *Fulfilling the Promises* and related guidance and policy in Wales (Learning Disability Advisory Group, 2001; Welsh Assembly Government, 2004, 2007), and the *Equal Lives* review in Northern Ireland, also known as the Bamford review (Northern Ireland Executive, 2005, 2012). Each of them highlighted the need to modernise day services provision.

In *Valuing People*, the vision was that PWLD in England would have ‘new opportunities’ to live ‘full and independent lives as part of their communities’ (Department of Health, 2001: 2). The White Paper noted that, while progress had been made in closing large institutions and developing services in the community, there was still some way to go. One of the major problems it listed was that day services were ‘often not tailored to the needs and abilities of individuals’ (Department of Health, 2001: 2). Based on the four key principles of rights, independent, choice and inclusion, *Valuing People* included a five-year programme to help local councils transform day services by 2006. The intention was to move away from large, segregated day centres and instead provide more community-based activities, including opportunities for PWLD to engage in paid work. Through person-centred planning and direct payments, individuals would have personalised support and means to exercise more choice and control over their lives, and live more independently.

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Six years later, ahead of refreshing its policy, the government published a consultation and discussion document called: *Valuing People Now: From Progress to Transformation* (Department of Health, 2007a). The document contained five ‘big’ priorities, one of which was a continued focus on: ‘what people do during the day (and evenings and weekends)’ (Department of Health, 2007a: 11). In a pivotal development, it proposed ‘moving away from the concept of day services modernisation and instead having the policy objective of supporting people to live the lives that they want as equal citizens in their communities - in other words social inclusion’ (Department of Health, 2007a: 12). The message it gave was to ‘Stop thinking about “day services modernisation” and instead work on people getting better lives in their communities by using person centred planning, with access to work as the main starting point’ (Department of Health, 2007a: 22). It went on to explain that:

‘6.1.4 Valuing People proposed ‘day services modernisation’ in relation to services provided by adult social services departments. We now think that this term is unhelpful. It encourages people to think about buildings rather than outcomes. Some authorities have used this policy to justify cuts in services. For others, small day centres have replaced big ones, but what people do with their time has hardly changed.

6.1.5 Changing this picture means that people and organisations responsible for adult social services, employment, education, leisure and community development will need to work better together in the future’ (Department of Health, 2007a: 23).

The document suggests that the starting points to achieving this are first, effective person-centred planning and second, forward planning.

The resulting strategy, *Valuing People Now: a new three-year strategy for learning disabilities. Making it happen for everyone*, was published two years later (Department of Health, 2009a, 2010a). With it, responsibility for the funding and commissioning of social care for adults with learning disabilities was transferred from the NHS to local government (Department of Health, 2010b). *Valuing People Now* affirmed the guiding principles of the original policy. Taking a human rights approach, it emphasised the need to improve the social inclusion of different groups of PWLD, particularly people with more complex needs, people from black and ethnic minority groups and ‘newly arrived communities’, and people with autistic spectrum conditions (Department of Health, 2009a).

The refreshed strategy also reframed the original priorities (Whitehead *et al.*, 2008). One of the stated objectives was that:

‘all people with learning disabilities and their families will... have a fulfilling life of their own, beyond services, that includes opportunities to study, work, and enjoy leisure and social activities; be supported into paid work, including those with more complex needs; [... and] have the opportunity to speak up and be heard about what they want from their lives – the big decisions and the everyday choices. If they need support to do this, they should be able to get it’ (Department of Health, 2009a: 16-17).

In line with the preceding consultation and discussion document, the strategy makes no reference to the redesign of ‘day services’ as such, focussing more generally on improving the social inclusion of PWLD.

At the same time, the government published a sister strategy, called *Valuing Employment Now*, for getting more PWLD into jobs (Department of Health, 2009b). This strategy was focussed on people with moderate and severe learning disabilities, who were recognised to have benefitted the least from previous initiatives. The long-term goal was to increase the aspiration of people to work and to ‘increase radically’ the number of people in employment by 2025 (Department of Health, 2009b: 14). To this end, the strategy noted that local authorities would be encouraged to refocus some of their budget for adult day services to supported employment.¹ Likewise, Learning Disability Partnership Boards would also be encouraged to review day service modernisation plans, to ensure that ‘they have employment at their heart’ (Department of Health, 2009b: 15, 47, 49).

The publication of *Valuing People Now* and *Valuing Employment Now* signalled a shift in the policy spotlight in England away from the form of day services, and towards the goals of equalising opportunities, and improving social inclusion, by diversifying and mainstreaming provision for PWLD. In subsequent years, day services have been less prominent in policy, becoming part of a more complex landscape of social care and support. They have continued to evolve at different rates, and in different ways. In England, and across the rest of the UK, day services provided exclusively in large, dedicated, day centres have been replaced by a range of day opportunities in smaller centres and/or the wider community. These services are now often provided by different organisations in a locality.

1.2 Aims of this evidence review

This evidence review was conducted as part of an IMPACT demonstrator project carried out in partnership with two providers of day services for adults with learning disabilities in England. The review aimed to locate and summarise published evidence on approaches to the provision of day services and associated day opportunities for this group in the UK. It focussed on three topics of interest to the two sites:

1. Emerging models of, and innovations in, day services for PWLD.
2. Strategies used to promote the co-design and co-production of day services for PWLD.
3. Strategies used by day services to promote the skills and employment of PWLD.

¹ ‘Supported employment’ was initially developed in the USA (Beyer and Robinson, 2009). The term has since been used to describe various approaches to supporting disabled people into employment. While supported employment was intended to help people with moderate to severe learning disabilities to engage in paid work, it has been used more generally for PWLD and other disabilities.

2. METHODS

For the purposes of this review, an inclusive definition of ‘day services’ and ‘day opportunities’ was used, to capture the range of developments in progress across the UK. The review encompassed adults with learning disabilities (all classifications), reflecting the diversity of people who draw on the day services in the two sites.

Searches for relevant publications were conducted in October 2024. The searches covered academic and grey literature containing insights from research, practice-based knowledge and people’s lived experience of adult social care.

Research studies were primarily located through searching titles and abstracts listed in the following databases: CINAHL, Medline, SocINDEX, Social Policy and Practice, and Web of Science core collection (Arts and Humanities Citation Index; Emerging Sources Citation Index, Social Sciences Citation Index). These searches were supplemented using Google Scholar and Google search engines for both academic and grey literature. Additional searches were also conducted for reports on the websites of relevant organisations. Some works were also identified through backward- and forward-citation searching.

Different variations and combinations of search terms were tested and adapted for the above sources. The terms used were: learning disabilities, learning difficulties, learning disorders, intellectual disabilities, intellectual impairments, developmental disabilities, special needs, mental retardation, mental handicap, mental deficiencies; autism, autistic disorders; day services, day opportunities, day activities, day centres, day care; modernisation, models, innovations, novel, design, redesign, improvement, development, planning, change, transformation, organisation, reorganisation, delivery, consultation, culture, centre-based, community-based, peer-led, programme; codesign, coproduction, co-delivery, delivery, empowerment, power sharing, participation, involvement, shared, joint; skills, work, employment, jobs; social inclusion, aspirations; unpaid carers, family carers. Alternative forms and/or spellings of these terms were used where appropriate.

To be eligible for inclusion in the review, publications needed to contain discrete evidence relating to adult social care in the UK, on one or more of the topics of interest. Publications were excluded if they were published before 2006. This date was chosen to dovetail with a major review conducted for Social Care Institute for Excellence (SCIE) that was published in February 2007 (Cole *et al.*, 2007).

After screening titles and abstracts, candidate texts were read to check their eligibility and relevance. Relevant findings and insights from the final selection of publications were noted and are summarised in this report. While the report describes policy and evidence from across the UK, the overview of developments in day services in section 3.1 focuses mainly on England, where the IMPACT demonstrator project is set (the devolved nations having their own distinct policies).

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2.1 Limitations

The content of some of the publications was broader than the remit for this review and in these cases only relevant sections were reviewed. Various types and sources of evidence were also included. For these reasons, and because of time constraints, the quality of the evidence was not assessed.

Some of the studies examined day services for multiple groups, not only PWLD. In these cases, it was not always easy to distinguish if evidence related to PWLD or other groups. While every effort has been made to focus on material relating to PWLD, there may be some conflation in the analysis.

The search strategies were designed to find evidence on strategies and opportunities for PWLD linked to day services (including services in transition), but not how these same strategies and opportunities operate independently of this context. For example, there is a wider literature on how PWLD access and experience employment and participate in activities in the community, but this report does not extend to these works, or to more general works on the social inclusion of PWLD.

3. FINDINGS

After screening, 46 publications were found to contain relevant content pertaining to one or more of the topics of interest. Some of the publications were about PWLD in general, while others focussed on specific groups of PWLD, such as adults with mild to moderate learning disabilities, adults with higher support needs, older adults with learning disabilities, and people often described as having behaviours that challenge others.

The publications included a mix of articles in peer-reviewed journals (n=19), and reports in the grey literature (n=26). The remaining item was a PhD thesis (which was also linked to one of the articles). The reports included works by, or on behalf of, organisations representing PWLD, professional organisations, government bodies and non-governmental organisations in the UK. Four of the reports were linked to a programme of work by Healthcare Improvement Scotland (Healthcare Improvement Scotland) called the ‘New Models for Learning Disability Day Support Collaborative’ (Healthcare Improvement Scotland, 2020, 2021a, 2021b, 2022). Evidence was found relating to all parts of the UK, especially England and Scotland.

Ten of the publications were either purely literature reviews or contained reviews that were conducted as a part of a wider piece of work (Scottish Executive, 2006; Cole *et al.*, 2007; Beyer and Robinson, 2009; Department of Health, 2011; Slevin *et al.*, 2011; Innes *et al.*, 2012; Scottish Government, 2012; Healthcare Improvement Scotland, 2020, 2021b; Ryan *et al.*, 2024). These reviews varied in terms of their aims, geographical coverage and population/s of interest. While a few were similar in scope to the present review, none were an exact match. Nonetheless, they were useful sources for this review and some sections of this report draw heavily on them, with updates provided where appropriate.

Information on the characteristics of the 46 publications included in the review is provided in Appendix 1.

3.1 Overview of developments in day services in England and the rest of the UK

In the literature, ‘traditional’ day services were generally characterised as older, institutional forms of centre-based and segregated provision. They were contrasted with emerging alternative, flexible and more personalised forms of support, that enabled PWLD to participate in activities of their choice, in various ordinary community settings. This is illustrated by the following account of the ways in which day services have developed over time:

‘Since the late 1980s a wide range of community-based alternatives to ‘traditional’ day services have emerged in the UK. These include a range of employment-related support, access to adult and continuing education, use of leisure and recreational

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services, befriending schemes and other forms of more generic ‘without walls’ provision that operate outside of day centres’ (Cole et al., 2007: 4).

Following the introduction of *Valuing People* in 2001, Mencap commissioned research to examine the life experiences and services used by PWLD in England (Emerson and Hatton, 2008). The study found that, in 2003/4, 39% of all PWLD in England were attending a day centre. This figure was higher for people with profound and multiple learning disabilities (66%) and people with severe learning disabilities (49%), than for people with mild to moderate learning disabilities (24%) (Emerson and Hatton, 2008: 9). It also found that 28% of people with mild to moderate learning disabilities had some form of paid employment, compared to 10% of people with severe learning disabilities and 0% of people with profound and multiple disabilities (Emerson and Hatton, 2008: 8).

In 2012, Mencap carried out further research in response to growing concerns about the de-commissioning of day services not being accompanied by the provision of suitable alternatives (Mencap, 2012). Data from 151 local authorities in England were examined, along with responses from a survey of the experiences of 280 PWLD and their family carers, and 194 professionals who supported them (Mencap, 2012: 2). The research found that, in the past three years, 32% of local authorities had closed day services; of these, 20% did not say they had provided replacement services, or they just cited personal budgets as an alternative. The research also found that 57% of PWLD who were known to social services were not receiving any day service provision at all, compared to 48% in 2009/10; others were accessing day services less often (Mencap, 2012: 2, 2-3). A large proportion of the respondents had experienced the closure of a day service (29%), shortened opening hours (16%), and increased charges for transport or attending (50%). Their rates of attendance had declined, and many no longer attended due to the changes (41%). A quarter of the respondents now spent less than one hour outside their home each day and they reported feeling lonely (28%) and isolated (27%) (Mencap, 2012: 2). The report concluded:

‘In recent years, government policy has encouraged local authorities to modernise day services, to make them more ‘person-centred’. Mencap welcomes this, as there are still too many day services that are outdated and fail to provide meaningful activities. However, Mencap believes that often modernisation of day services has been driven by a desire to save money and, as such, has failed to improve day services as was originally intended. Changes to day services are often justified as giving people more choice and the opportunity to access services in the community, but these can be empty words used to disguise a cut’ (Mencap, 2012: 6).

In the same year, a separate survey of day centre staff (n=123) in the UK (except Northern Ireland) also found evidence that day centres were being closed, or eligibility criteria changed, reducing access to this option for some PWLD (Needham, 2012, 2013a, 2013b).

A subsequent study examined trends in access to day services by PWLD across the devolved nations of the UK (Hatton, 2017). While acknowledging that their definitions of day services varied, it found that, over the period 2010/11 to 2015/16:

‘Overall, there seems to be a consistent drop in the number of adults with learning disabilities accessing building-based day centres across most parts of the UK, with the exception of Northern Ireland. In contrast, there are less consistent increases in the number of adults with learning disabilities accessing alternative daytime support options’ (Hatton, 2017: 111).

Examination of data in Scotland found that, in 2014/15 compared to 2011/12, use of building-based day centres:

‘are decreasing, both in the number of people accessing them at all but also in the amount of time each person spends at the building-based day centre. Alternative day opportunities, both in terms of number of people accessing them or the amount of time they spend, are remaining static over this time period. It is unknown whether similar trends are evident in other parts of the UK’ (Hatton, 2017: 113).

In 2021, a review of developments in day services in Scotland also found evidence that cuts in public spending had led to reductions in support options and choice for people with a mild to moderate learning disability (Healthcare Improvement Scotland, 2021b). Drawing on work by Fraser Allander Institute, the review noted that the impact of the cuts varied by locality and level of support required. Employability and community inclusion services were particularly impacted. Cuts to mainstream services (e.g. libraries and community clubs) also had an indirect impact because they were used by PWLD (Healthcare Improvement Scotland, 2021b).

More recently, in February 2023, Mencap Cymru and the Learning Disability Consortium undertook a national survey of PWLD and their parents/carers, examining the impact of the Covid-19 pandemic on their access to day services in Wales (Mencap Cymru, 2023). It had 293 responses. Before the pandemic, respondents had between them a total of 718 hours of day service support each week. At the time they completed the survey, this had dropped to 296 hours. Three-quarters of the respondents (73%) had experienced some form of cut to the hours of day service support they received (Mencap Cymru, 2023: 3).

Another review of day opportunities and respite/short break services in Wales following the Covid-19 pandemic was conducted by the Association of Directors of Social Services Cymru

(Chick and Pavia, 2023). While PWLD were only one of several groups encompassed by the review, the report concluded with a comment on the pace of change, noting that:

‘Many examples of service reform observed have resulted from gradual, evolutionary changes, rather than revolutionary reform. This has enabled a gradual change to the offer of service with additional service components being added through changing relationships with local communities and partner agencies.

Evolutionary reform is likely to be less controversial than revolutionary change.

However, where services are no longer sustainable in their present form or are substandard or sub optimal, it may be necessary to bring about rapid and large-scale change. Where this is the case, such a process must be carefully and sensitively managed, embracing the principles of co-production.

Developing new models whilst serving existing users presents challenges associated with parallel running of services. This has obvious capacity and financial implications’

(Chick and Pavia, 2023: 28).

The next section of this report focusses on the alternative models of day services to have emerged in the UK, summarising what is known about the relative effectiveness and/or lived experience of them in improving the social inclusion of PWLD.

3.2 Alternative models of, and innovations in, day services

As is shown below, alternative forms of day services and the day opportunities they offer have been variously described as being place-based (e.g. ‘dispersed’ or ‘community-based’ models), user-led (e.g. self-advocacy and peer support models), delivery-based (e.g. partnership models), and scheme-based (e.g. employment support models). These models often overlap and are not mutually exclusive. With this caveat in mind, this section outlines the different models that have been distinguished in the literature to date. The findings have been organised by different groups of PWLD, and are generally summarised chronologically, around key developments in policy and research.

3.2.1 Day opportunities for PWLD in general (non-specific groups)

In 2006, a sub-group of *The Same As You?* National Implementation Group for the Scottish Executive carried out a review of existing research on buildings-based day centres and alternative day opportunities, namely employment, education, volunteering, art, and leisure. It found that ‘systematic evaluation is needed to establish the availability, use and outcomes of these services “with and without walls”’ (Scottish Executive, 2006: 15).

The same sub-group also carried out a survey examining the views of PWLD on day services. Responses were received from 169 people. It found that, for some people, the provision of new day opportunities had led to significant and dramatic improvements in their lives. For

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example, some felt that they were more included in their communities, that they had greater choice and independence, that services were more flexible, and that smaller groups meant they had more choice and chance to be heard. However, other people were still attending the old day centres. Generally, the respondents also still wanted real jobs for real pay, more training, and more choice and individualised support (Scottish Executive, 2006).

In the same year, the Scottish Consortium for Learning Disability also conducted a survey of 605 PWLD and autism spectrum disorders in Scotland (Curtice, 2006). Nearly three-quarters of the respondents thought they had enough opportunities to do the things they wanted to and 80% thought there were enough places they liked going to in their areas. Many people were doing activities that took place in both disability and mainstream groups. People with communication difficulties were more disadvantaged in making friends. Overall, the research found evidence of increased variety in the day services and day opportunities provided since *The Same As You?* was introduced in 2000.

One study investigated whether PWLD in a smaller day centre had a higher rate of interaction with staff, and more positive interactions, compared to a larger day centre (Skea, 2007). Interactions were observed in two day centres in England over an eight-month period. The research found that there was a higher rate of interactions in the smaller day centre, and that the ‘overwhelming majority’ of interactions observed in both centres were regarded as positive as opposed to neutral or negative (Skea, 2007: 48).

Another publication contained comparative evidence from an otherwise unpublished evaluation of a pilot project for a new community-based, dispersed model of day services that was set up as an alternative to the traditional day centre model in Scotland (Simpson, 2007). The study included interviews with 19 PWLD who had previously been long-term attendees at a traditional day centre (their level/s of learning disability was unclear). It found that, while many of the activities offered were not new, the staff ratio was better, enabling people to attend with up to three others; the service was also more responsive to individual preferences and gave people more autonomy and control. People who drew on the service were more satisfied with the new arrangements compared to the day centre, and their families and staff had noticed they were too. However, the PWLD seemed to want to carry on with what they were doing and had not yet developed aspirations to do something else. It also noted that dispersed services were more vulnerable to staff absences and cutbacks compared to centralised services.

In 2007, a major evidence review on community-based day activities across the UK was carried out for SCIE (Cole *et al.*, 2007). Drawing on earlier work by Simons and Watson (1999), the review referred to four types of initiatives to have emerged since the 1980s: performing arts schemes – these may be time-limited and often aim to promote citizenship; community activities – where local amenities (e.g. leisure centres, shops, cinemas) are used for outreach activities from a local base to promote community presence and inclusion;

relationship schemes – these help people to build friendships and relationships in the wider community through befriending, leisure and workplace schemes; comprehensive strategies – these are initiatives that attempt to open up an array of opportunities, such as through the Changing Days² project (Cole *et al.*, 2007: 5, paraphrasing Simons and Watson (1999)).

Based on their review, Cole and colleagues (2007: 15) identified eight key conditions for change when modernising day services. These were: partnership with people and their families; leadership; cultural change in services; person-centred planning with and for people; individualised funding and direct payments; ‘smart’ commissioning; staff development; and community capacity building.

In the *Valuing People Now* consultation and discussion document (Department of Health, 2007a), the government suggested various strategies for how local authorities could develop day services to improve the social inclusion of all PWLD (see Box 1).

Box 1: How day services can be developed to help achieve social inclusion for PWLD

- *work in partnership with the employment, education and leisure sectors, using resources flexibly between sectors and linking into local strategic partnerships and local area agreements;*
- *prioritise making support for person centred planning available to people in receipt of traditional day services – and direct payments and individual budgets;*
- *make sure young people with learning disabilities (including those at special schools) get equal access to the entitlement to work experience for children and young people in schools and colleges. Work with independent supported employment agencies to help this happen;*
- *prioritise change for people with high support needs and people from black and minority ethnic communities who currently use traditional day centres;*
- *think beyond nine to five working days and include evenings and weekends – but also recognise that for people living with their families, existing day centre hours provide important breaks for both the family and the person themselves;*
- *have an objective that no young person leaving school and college in the future goes into a segregated day service or centre;*
- *invest in specialist employment support agencies but see Jobcentreplus as the main resource to help people to find jobs;*
- *develop partnerships with major employers to help find paid employment – with public services leading by example;*
- *recognise the importance of planning for people who are past the retirement age and may want things other than work;*

² This was a joint project between The Kings Fund and the UK National Development Team. It was set up to develop and evaluate alternatives to traditional day centres and ran from 1994 to 2000.

- *establish a local outcome (e.g. within three years) that no day centre should be segregated. Only invest in integrated facilities and have a de-commissioning strategy for traditional services.*

Source: *Valuing People Now* consultation and discussion document (Department of Health, 2007a: 24).

As Graham (2010) notes, *Valuing People Now* promoted a human rights approach, placing more of an emphasis on rights, independent living, control and inclusion. However, she is critical of how this discourse has shaped the everyday lives of PWLD who draw on day services, and whether it reflects their values and priorities. In a similar vein, a detailed qualitative study of PWLD making mundane choices showed how they were not necessarily more in control or empowered by having a basic menu of choices offered to them (Hollomotz, 2014). Others have also been critical of how the modernisation agenda has, in their view, led to ‘enforced collectivities’ being replaced by ‘enforced individualism and isolation’ (Roulstone and Morgan, 2009: 343).

One other study examined the views of 18 PWLD, 36 carers and six care staff linked to six day centres in an area of Scotland (Campbell, 2012). It found that the day services were highly valued by PWLD and carers. The participants particularly valued the friendships, activities and security of the centres. Most of the participants who expressed a view about what to keep and what to change about day services said they preferred to keep things as they were. The study concluded that any changes to services should be responsive to needs and aim to achieve outcomes that are valued by PWLD and their families.

3.2.2 Day opportunities for people with mild to moderate learning disabilities

In 2020-22, Healthcare Improvement Scotland carried out a programme of work to support the redesign of day services for PWLD in Scotland (Healthcare Improvement Scotland, 2020, 2021a, 2021b, 2022). This programme included two reviews of the literature, each published in summary form (Healthcare Improvement Scotland, 2020, 2021b).

The first review examined the international and UK literature on models of day services for people with a mild to moderate learning disability (Healthcare Improvement Scotland, 2020). One of the questions addressed by the review was ‘What are the different models of day support services and their outcomes for people with a mild to moderate learning disability?’ (Healthcare Improvement Scotland, 2020: 3). The following definition of day services was used:

‘Day services for people with mild to moderate learning disability vary in their function, structure and setting (centre/community based). Building or centred [sic] based services are increasingly being redesigned to offer alternative opportunities in the community that are more flexible, personalised and provide fuller opportunity to

participate in community life. These alternative opportunities can include sport and leisure, further education and support with gaining employment’ (Healthcare Improvement Scotland, 2020: 3).

The review found 11 relevant publications, most of which related to the UK. It identified three alternatives to the traditional model of day services for people with a mild to moderate learning disability: self-advocacy/peer advocacy groups; employment support; and partnership-based initiatives. However, it noted that the evidence on how effective these models of support are compared with traditional day services was ‘relatively limited’ (Healthcare Improvement Scotland, 2020: 1).

The three models are summarised below. Where appropriate, additional information from the literature has been added to update and expand the findings of the Healthcare Improvement Scotland review on these approaches.

Self-advocacy/peer support groups

Self-advocacy and peer support groups (and peer-advocacy) involve PWLD coming together to form their own support groups, which meet in community venues, to advocate for themselves and each other (Healthcare Improvement Scotland, 2020). The Healthcare Improvement Scotland review cited evidence from one study (Power *et al.*, 2016) that peer advocacy provided PWLD with vital opportunities for social interaction and informal learning in the community at a time when other services and support were in decline (Healthcare Improvement Scotland, 2020). To expand on this finding, Power and colleagues stated that peer advocacy provided PWLD with opportunities for ‘re-collectivising but in a more bespoke, flexible, community-based and user-led manner, thus filling some of the residual spaces left by personalisation’ (Power *et al.*, 2016: 190). They observed that the self-led ethos of peer advocacy can offer people an opportunity to self-build their own pathways to a life in the community based on their own aspirations, needs and abilities. However, they also caution that peer advocacy may not fill the gap left by service reductions completely, and that peer-advocacy may not be sustainable without paid facilitators (Power *et al.*, 2016).

The present review also found a more recent publication on the topic of peer support and self-built networks. In a qualitative study, Nind and colleagues (2021) examined how PWLD had responded to changes in day services provision in four sites in England and Scotland, focussing on peer-learning. They found:

‘...the change from attending building-based day care to navigating a diverse ‘market’ of social care options made high demands on the skill, knowledge, confidence and agency of people with intellectual disabilities and their allies. We found evidence of people learning from peers and non-peers in established community learning cultures, such as self-advocacy and disability rights

organisations. We saw learning too in emergent learning cultures in new form social care settings and some old ones in transition’ (Nind et al., 2021: 1566).

The authors observed that some opportunities for peer learning were missed, especially when organisations were ‘in transition’ from buildings to dispersed settings. For example, in one case, people who used the service were not involved in the redesign process, resulting in inequalities in participants’ uptake of activities, with some people having no more than one or two activities per week (Nind et al., 2021: 1561-1562).

In much earlier review of research and survey of practice in the UK, Cole and colleagues (2007) found evidence that self-advocacy groups were leading some innovative and successful projects, which had increased people’s social and leisure opportunities, and provided information on what was going on locally. However, it was also noted that partnerships with these groups was ‘fragile’ because of their insecure, short-term contractual and funding arrangements (Cole et al., 2007: xi).

Employment support

The second alternative model of day services identified by Healthcare Improvement Scotland was what it referred to as ‘employment support’ (Healthcare Improvement Scotland, 2020: 4). This includes a distinct approach widely known as ‘supported employment’, which was initially developed in the USA (Beyer and Robinson, 2009). While supported employment was developed to help people with moderate to severe learning disabilities to engage in paid work, it has been used more generally for people with mild to moderate learning disabilities, as well as autism and other disabilities.

Two other forms of targeted employment support were also identified and briefly described in a follow-up review by Healthcare Improvement Scotland. These were ‘transition to open employment’ programmes that help young people with learning disabilities to compete for jobs in the open market, and schemes that provide support for people with disabilities to pursue entrepreneurship and self-employment (Healthcare Improvement Scotland, 2021b: 22).

In their review, Healthcare Improvement Scotland found some evidence that supported employment was an effective model of employment support for people with mild to moderate learning disabilities (Healthcare Improvement Scotland, 2020: 2, 4-5). The nature of this approach and existing evidence on this model is described in more depth in section 3.4 below.

Partnership-based initiatives

The third and final alternative model of day support services identified by Healthcare Improvement Scotland was partnership-based initiatives (Healthcare Improvement Scotland, 2020). This finding was derived from an earlier evidence review and practice

survey, which found various examples of partnership working between councils and partners in the community, such as businesses, churches and faith groups, pressure groups, public facilities, transport services, housing planners and others (Cole *et al.*, 2007: 85-85).³ It also found that, where there was very good practice in the progression to individualised, community-based solutions, partnership was part of the service culture. Conversely, a lack of effective partnerships between services and departments was identified as a barrier to the development of community-based day activities (Cole *et al.*, 2007: xviii, 37).

The Healthcare Improvement Scotland review describes one evaluation of a partnership-based initiative, namely the ‘Time to Connect’ project (Healthcare Improvement Scotland, 2020: 6). This was a partnership between several organisations, including Timebanking UK. The project helped PWLD who lived in traditional care settings to increase their participation in, and contribution to, community life. The evaluation⁴ of the project included participants from six localities in England. It found positive outcomes for residents. These included more choice over activities and where these took place, better social connections, less isolation, and improved wellbeing and confidence. Care and support staff were also found to have more positive attitudes regarding what people could achieve given the opportunity.

The importance of partnership working was recognised in other publications identified by the present review (e.g. Scottish Executive, 2006; Cole *et al.*, 2007; Healthcare Improvement Scotland, 2022; Chick and Pavia, 2023). For example, one report examined the impact of the Covid-19 pandemic on innovation and transformation in day opportunities and respite/short break services for PWLD and other groups in Wales (Chick and Pavia, 2023). It recommended that local authorities and their partner organisations review their provision and commissioning strategies (Chick and Pavia, 2023: 7). Some local authorities were recognised to be ‘making concrete moves towards rethinking services’ (Chick and Pavia, 2023: 18). One was in the process of ‘scoping a review of its day service’ with a view to ‘engaging with hard-to-reach groups’ (Chick and Pavia, 2023: 18). Another was ‘...developing localism and a community assets-based model as part of a wider Live Well approach. The idea here is that people live in communities and a range of opportunities exist within specific localities’ (Chick and Pavia, 2023: 18). While acknowledging these positive developments, the report suggests that engagement with a wider range of local authority provision and agencies ‘would enable greater connectivity with local communities, the most effective use of local resources and the efficient use of public money’ (Chick and Pavia, 2023: 29-30). The authors add that:

³ The Healthcare Improvement Scotland (2020) report actually cites a different publication, but it is not a review and there is no mention of partnership approaches. This appears to be an error in the Vancouver numeric referencing system, as the adjacent reference by Cole and colleagues (2007) is a review and it does contain a brief section on partnership approaches, hence it has been substituted here.

⁴ This summary is based on the Healthcare Improvement Scotland (2020) review - it was not possible to locate a copy of the original evaluation and independently review it.

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‘This approach requires effective collaboration within and between agencies. Social services would require the development of partnership approaches with other directorates and departments within the local authority, as well as relationships and, potentially contracts, with other agencies that provide services within its locality. These are challenging tasks, but the potential rewards are great and would potentially provide greater choice and a far more integrated models of service, that will continue to make a difference to the lives of many living in communities across Wales’ (Chick and Pavia, 2023: 30).

It should be noted that, while the above publications tended to discuss partnerships between organisations involved in the commissioning and delivery of day services, there was also some reference to partnership working with families (e.g. Cole *et al.*, 2007). This was in relation to both the redesign of provision at a service level, and the process of co-producing a person’s support with them and their family. This is discussed later in this report, in section 3.3 on the co-design of day services.

Other approaches

The second Healthcare Improvement Scotland review examined three supplementary topics: culture change and impacts on inequalities following the move to community-based day services; staff empowerment and autonomy, including transferable learning from dementia and other areas of care; and ‘examples of emerging practice from the learning disability sector relevant to co-design/production, employability, working differently’ (Healthcare Improvement Scotland, 2021b: 6). The findings that are directly related to PWLD are summarised below or elsewhere in this report.

Staff empowerment and autonomy were recognised to be requirements for service transformation, enabling staff and managers to change roles and mindset, problem-solve, be creative and flexible, take positive risks, and ‘delegate “permission to innovate”’ (Healthcare Improvement Scotland, 2021b: 36-37). Service transformation also required support from leaders at the highest levels; this could include support to develop and redefine staff and workforce composition, and to change budgeting or commissioning arrangements, to better respond to needs at a local level (Healthcare Improvement Scotland, 2021b: 12). The present review noted that staff development was also identified as one of eight key conditions for change (Cole *et al.*, 2007: 15). It was seen to be vital if staff are to understand the changing nature of their role and feel confident in their abilities to deliver a new service (Scottish Executive, 2006: 88).

One of the case study examples included in the Healthcare Improvement Scotland review was from South Lanarkshire in Scotland (Healthcare Improvement Scotland, 2021b: 14). Here, an experience lab was used to help prepare for moving from a day care centre service

to a model that supports and facilitates PWLD to access lifestyle choices in the community. The lab methodology involved staff, people who used the service, carers and research staff. Other examples of approaches identified by Healthcare Improvement Scotland included the use of storytelling, ethnographic and drama-based methods.

The potential of self-directed support was recognised. However, the review observed that this had not been realised because of two barriers: a limited availability of services (constraining choice) and insufficient support to enable people to make informed choices about support and care (Healthcare Improvement Scotland, 2021b: 10).

The Healthcare Improvement Scotland review also briefly described examples of initiatives for PWLD in Scotland and the UK. They included four ‘social connectedness’ projects: an intergenerational and multi-ability supper club; a social network of current and former students from a college; a community garden and supper club; and a befriending project supported by volunteers from the local community (Healthcare Improvement Scotland, 2021b: 26).

The report also provided two examples of ‘activity redesign’, along with evidence of their benefits (Healthcare Improvement Scotland, 2021b). One of these was a ‘Yoga for me’ scheme in Wales, which provided yoga classes that were adapted, person-centred and delivered by specialist instructors. An evaluation found that participants particularly enjoyed the mindfulness element of the class (Healthcare Improvement Scotland, 2021b: 28). The other was of the Shared Lives scheme, which includes day support for PWLD who live in a care provider’s own home as a family member. An evaluation found some positive benefits in terms of choice and control of daily activities and a sense of belonging. The present review also identified a more recent study that included some Shared Lives participants. It found that these participants were living an ordinary life, and were part of their community, but the authors queried whether it was appropriate for people to still be using some segregated day activities as an integral part of the scheme rather than accessing mainstream activities (Ryan *et al.*, 2024: 49).

Finally, the Healthcare Improvement Scotland review also included two examples of digital tools for empowerment (Healthcare Improvement Scotland, 2021b: 35-36). One was a digital personal communication ‘passport’ designed with family carers of people with profound and multiple learning disabilities to express their interests, help maintain social contacts, aid care planning, train carers and to interact with others in a range of environments. The other was a digital app called ‘Human Rights Town’, the development of which was led by PWLD, which aims to empower people to recognise and realise their human rights in everyday situations.

The present review found information about other models and initiatives in the literature, including some evidence relating to people who were not covered by the Healthcare

Improvement Scotland programme of work (which was concerned with people with mild to moderate learning disabilities). This is discussed below.

3.2.3 Day opportunities for PWLD with higher support needs

In *Having a Good Day?*, Cole and colleagues (2007) observed that, historically, services have found it hard to provide the level of support needed for people with higher support needs to access opportunities in the community. The authors queried whether some of the new provision being developed at the time would serve as a community base or simply act as smaller, relocated, day centres for this group (Cole *et al.*, 2007: 77). One of the challenges to providing person-centred planning and individualised support packages was the costs of support and freeing up budgets from existing services. PWLD were also relying on these services as a contingency while trying other options, such as employment. Some examples of strategies being used to provide access to day opportunities for this group were identified, such as the use of personal assistants to help link into community resources, and a buddy scheme for younger people (Cole *et al.*, 2007: 76-78).

In December 2007, the *Valuing People Now* consultation and discussion document stated that, overall, progress was being made in implementing policy (Department of Health, 2007a). However, it found evidence that progress for people with high support needs and those from minority ethnic communities (see section 3.2.7 below) was less than for others (Department of Health, 2007a: 9). In discussing next steps for people with complex needs, the document advised that there are three important principles (see Box 2).

Box 2: Principles for delivering *Valuing People Now* for people with complex needs

- *start with person centred planning, direct payments and individual budgets for people with the most complex needs – rather than thinking they cannot work. By definition, the more complex a person’s support needs, the more individualised support has to be;*
- *it is good practice and it works to start with the people with the most complex disabilities first. For example, action on what people do during the day, which will involve changing day services, should start with planning for people with the most complex needs rather than leaving them until last;*
- *think what additional services and supports are needed so that people with the most complex needs can be included with everyone else. Do not start by assuming and planning separate services. For example, new ways of working will need places and resources where people with high levels of personal care needs can be supported properly throughout the day and evening.*

Source: *Valuing People Now* consultation and discussion document (Department of Health, 2007a: 49).

Following the publication of *Having a Good Day?* (Cole *et al.*, 2007), two of the authors were involved in an action research project in England promoting citizenship for people with high support needs (Swift and Mattingly, 2009). Entitled ‘*A Life in the Community*’, this two-year

project sought to improve day opportunities for up to 40 PWLD, working with four partners from the third sector. It also aimed to develop the capacity of these organisations to support this group and make greater use of mainstream services and facilities. Thirty-four people were recruited, of whom four dropped out or died over the course of the project. The project’s partners were encouraged to work ‘creatively to find local solutions to the problems faced by people with high support needs’ (Swift and Mattingly, 2009: 17). Various strategies were adopted. They included person-centred approaches, circles of support, advocates, individual funding and community connectors. Outcomes were measured in relation to individual’s aspirations. Around half of the participants achieved one or more of their goals and a few people achieved all of them (Swift and Mattingly, 2009: 7-8). Most of the good outcomes were about the development of relationships rather than doing activities (Swift and Mattingly, 2009: 12). Small organisations from the third sector were adjudged to be well-placed to support people with high support needs. This project also led to the publication of associated guides for commissioners and care managers on the role of community connectors (Wightman, 2009), and on implementing better daytime services for this group (Foundation for People with Learning Disabilities, 2009).

In response to concerns that not enough was being done to address the needs of adults with profound intellectual and multiple disabilities, a review of good practice in services was undertaken by Professor Jim Mansell for the government (Mansell, 2010). The review examined all aspects of people’s lives and support systems, including day activities and employment. The resulting report noted that some people were being denied access to day activities because they were deemed ‘too disabled’ for staff to cope (Mansell, 2010: 6). It argued that:

‘New models of providing services in a person-centred way should make us raise our sights. Examples of good practice show that, in general, the ‘personalisation agenda’ (...) – the framework of person-centred planning and highly individualised services, increasingly funded through individual budgets, is providing what people need and want’ (Mansell, 2010: 8)

The report goes on to highlight the key elements of (all) good services: individualisation, person-centred, families treated as experts, quality of staff relationships with the disabled person, sustained packages of care, and cost-effectiveness.

Mansell’s review also identified some specific obstacles to increasing the number of people adults with profound intellectual and multiple disabilities in meaningful activities outside the home, including work, education and leisure activities (Mansell, 2010: 28). The report notes that there is evidence that the imaginative use of personal assistants and individual budgets can enable this (Mansell, 2010: 28-29). It also recognises that access to these opportunities may be sessional and that, as traditional day centres are replaced with alternative opportunities, a local base where people can access different activities is still

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provided by local authorities. South Lanarkshire is cited as an example of such a model (Mansell, 2010: 29).

3.2.4 Day opportunities for PWLD and behaviours that challenge others

Earlier, in 2007, Mansell chaired a group that produced a report for commissioners of services for PWLD and so-called behaviours that challenge others (Department of Health, 2007b). The Mansell report (as it became known) recommended that this group of PWLD should have access to alternative day services that offer good support, as well as supported access to education, employment and other day opportunities. It also recommended that service planning and delivery should be highly individualised, to meet the widely differing needs of people in this group. It cites evidence from the United States that the availability of a day service is associated with successful community placements for this group. It adds that people with behaviour that challenge others are most likely to benefit from small-scale, alternative day services providing supported employment or innovative leisure or educational activities. The report recommends that commissioners purchase day care in these kinds of services rather than large day centres, and that they take a lead in developing a much wider range of alternative models for this group (Department of Health, 2007b: 17).

The present review identified three other publications with information on alternative day services for PWLD and behaviours that challenge others. One article described the development of a new person-centred day opportunity and supported lifestyle service in London, England (Carnaby *et al.*, 2010). The Flexible Response Service (FRS) support model was developed to improve the social inclusion of people with behaviour that challenge other and complex needs. Part of the philosophy of the service is to get to know people well and the environments that can stimulate challenging behaviours, and how to plan and mitigate for these by developing staff competencies. The article included a plan to evaluate the service but there was no evidence presented of its effectiveness to date.

A rapid review of services and support for two relevant groups of people was also located, including people with intellectual disabilities and/or mental health problems who display behaviour that challenges others (Slevin *et al.*, 2011). The review covered the international literature, and the analysis focussed on the evidence relating to Northern Ireland. One of the questions addressed by the review was: ‘What day opportunities meet the needs of people who challenge and how effective are these?’ (Slevin *et al.*, 2011: 1). Based on the analysis of evidence from 11 publications, it found that day opportunities for this group ‘needs to be widened to a range of services beyond traditional day centres to include education, vocational training, work experience, paid employment, voluntary work, social and leisure activities’ (Slevin *et al.*, 2011: 3, 98).

Finally, a recently published study focussed on older adults with learning disabilities who also had behaviour that challenges others (Ryan *et al.*, 2024). The participants, who were

aged 40 years or above, were involved in a range of activities in day centres, day activity hubs and their wider communities. The authors found that the day centres used by one person were ‘unappealing venues’ where people spent the day in a room with the television on, ‘clearly bored at times’ (Ryan *et al.*, 2024: 50). Conversely, the hubs:

‘were more dynamic, with thoughtful staff, an inviting atmosphere and a good range of activities to choose from. There was a sense of community and belonging and of sustained relationships that were important to participants’ (Ryan *et al.*, 2024: 50).

However, the authors observed that it was difficult to tell whether people genuinely enjoyed attending the hubs or were just filling time; this was compounded by a lack of activities specifically targeted at older adults with learning disabilities (Ryan *et al.*, 2024: 50).

3.2.5 Day opportunities for older adults and older people with learning disabilities

The other group included in the review by Slevin and colleagues (2011) was older people with intellectual disabilities (ID).⁵ This aspect of the review also covered the international literature and focussed on Northern Ireland in the analysis. Although this review did not examine day opportunities directly, the report contains some points of interest. Based on a review of 17 publications, the authors found that ‘There is a lack of alternative day opportunities for older people with ID’ (Slevin *et al.*, 2011: 90). They suggest that:

‘Development of high quality older person day-care, respite and recreational services for older people with ID within both ID services and mainstream older people’s services should be put in place and used’ (Slevin *et al.*, 2011: 13).

Two small primary studies on the impact of actual and potential changes in day services on older adults with learning disabilities were identified. One study examined changes in the frequency of activities in the community for 15 older adults aged 38-63, who also had higher needs, two years after the closure of two small day service facilities they attended in an area of England (Leyin and Kauder, 2009). It found that, overall, the closure of the facilities did not result in a significant increase in community activities in the sample. The time that people had previously spent in specialist day services had not been used to develop social inclusion. For individuals who had made some small gains, this was considered by the authors to be a poor return for the number of hours released by the closure of the facilities.

The other study examined the views of 16 older adults with learning disabilities on the day services they attended (Judge *et al.*, 2010). The participants were aged between 41 and 64 years and had been recruited from three day centres in two local authorities in Scotland. At the time, they were required to retire from using day services when they reached the age of

⁵ The age range of the participants in the studies included in the review was not stated but is likely to have been around 40 years and above. In the wider literature, PWLD aged 40 and above are sometimes referred to as ‘older adults’ and sometimes as ‘older people’.

65. The study found that the participants were looking for a wider range of leisure options than were available. The participants valued activities that were purposeful and meaningful. They enjoyed being active and occupied, and they saw the day centre as a social hub and a community. They wanted continuity and did not want major change in lifestyle at 65. They also wanted to maintain their independence and autonomy for as long as possible and stay living in their own home. The participants expressed confusion and varied understanding of the concept of retirement. The authors concluded that the policy of ending day service attendance for older people with learning disabilities at age 65 could have negative implications for those who did not wish to retire from the service then.

A systematic review on older people with an intellectual disability further highlighted the trend for services for PWLD to be provided by specialist provision as they age, despite the wider shift towards independent living and community inclusion (Innes *et al.*, 2012). This review also identified a concern about the lack of daytime activities for PWLD after they reach retirement age.

3.2.6 Day opportunities for PWLD and autism

The culture of a day service was examined in a PhD study that was subsequently published (Redmore, 2021, 2024). Taking a phenomenological approach and using ethnographic methods, the study examined the lifeworld of one person: a 27 year old man with profound learning disabilities and autism, who attended two day services on weekdays. The participant’s interactions with staff and his peers in one of the day services was observed over time. The service had a base with facilities that were used by some PWLD for most of their activities during the week, whereas others used it more as a meeting place. The study showed how the participant contributed to the service culture and what facilitated this.

3.2.7 Day opportunities for PWLD from black and ethnic minority communities

In 2006, a review carried out for the Scottish Executive noted that little was known about how PWLD from black and ethnic minority communities experience day services (Scottish Executive, 2006: 18). The review by Cole and colleagues for SCIE (Cole *et al.*, 2007) found that some provision for black and ethnic minority groups had evolved from advocacy and mapping projects that had been set up to reach them. However, in general, the authors struggled to find examples of initiatives for this group. They also observed that, at the time, some self-advocacy meetings were being held in a segregated base and queried if this ‘clubhouse’ model was really shifting power and control into the hands of people with learning disabilities (Cole *et al.*, 2007: 54). In 2009, *Valuing People Now* (Department of Health, 2009a) also recognised that progress had been slow for this group and that they were one of the groups at greatest risk of social exclusion. More recently, Ryan and colleagues have highlighted a need for research on the experiences of people from diverse ethnic backgrounds (Ryan *et al.*, 2024).

3.2.8 Day opportunities and family carers

Day services were recognised to benefit family carers of PWLD, providing them with a break from caring and time to have independent lives of their own. Family carers were also recognised to help support PWLD into employment, for example, by helping with transport (Cole *et al.*, 2007). However, despite this, it was noted that the needs and rights of family carers are rarely considered when designing day services (Cole *et al.*, 2007). The need to include family carers in consultations over changes in day services and/or to involve them in the design of day services was highlighted in the literature (e.g. Scottish Executive, 2006; Cole *et al.*, 2007; Scottish Government, 2012).

None of the publications really examined which models of day services work well from both the perspective of PWLD and their family carers. However, one study did develop a ‘family and community support model’ to help older adults with learning disabilities and their ageing family carers to remain together in the family home for longer (Taggart and Hanna-Trainor, 2017a, 2017b). The model included an element on ‘reshaping services’, which was about providing ‘age-appropriate’ day opportunities (Taggart and Hanna-Trainor, 2017a: 12, 2017b: 71). It also included an element about recognising the needs of older adults with learning disabilities who themselves become carers for their ageing parents (Taggart and Hanna-Trainor, 2017a: 12, 2017b: 71).

3.3 Co-design and co-production of day services

When *Valuing People* was published in 2001, the government recognised that the success of the programme would depend on the ‘active involvement of people with learning disabilities and their families in redesigning services’ (Department of Health, 2001: 77). This message was not repeated in the *Valuing People Now* consultation and discussion document (Department of Health, 2007a) or the final strategy (Department of Health, 2009a), which focussed more on the policy end goals and less on the role of specific services in delivering them. However, the associated delivery plan for the strategy for 2010-2011 did include a short chapter entitled ‘Co production – the key to delivering *Valuing People Now*’ (Department of Health, 2010a: 17). It emphasised the importance of a partnership approach at national, regional and local levels, the involvement of PWLD and family carers, and the active engagement of all relevant agencies (Department of Health, 2010a: 19).

In the wider literature, while there were allusions to PWLD and their families being involved to varying degrees in the design of day services, there were very few worked examples of how this had happened in practice. Where examples were given, there was very little detail. For instance, there were passing references to PWLD and their families being involved as partners on steering groups, reference groups and boards of management (Cole *et al.*, 2007: xi), and as representatives on planning groups (Scottish Executive, 2006: 23). Interestingly, the second Healthcare Improvement Scotland review also sought examples of co-design to

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inform its programme of work but widened the scope of its searches to include transferable learning from research on dementia and other contexts, presumably because of the lack of exemplars relating to PWLD and their families (Healthcare Improvement Scotland, 2021b).

A more relevant and in-depth discussion of the nature and value of co-production in the context of day services was found in a report on the future of day services in Wales (Mencap Cymru, 2023). The report included useful insights from a conference where co-production was discussed. The presentations included a talk by some people involved in running a co-produced day service in Rhondda Cynon Taff in south-east Wales; however, the design and operation of the service were not described in the report.

One other example of co-production was found, which did have a little more detail, including evidence of PWLD being involved in setting up and running a social enterprise. This was a case study of ‘creative decommissioning’ of day centres in Thurrock, England, at the turn of the century (Bunt and Leadbeater, 2012: 48-50). The authors describe how the then Director of Adult Social Care, the Service Manager for provider services, and a network of people who used the service, came together and ‘redesigned a more effective, personalised alternative to institutional care’ (Bunt and Leadbeater, 2012: 48). The process led to the closure of all its multipurpose day centres and ‘the development of a specially created social enterprise run by and for service users – Thurrock Lifestyle Solutions – to provide more targeted, personalised support for adults with learning disabilities’ (Bunt and Leadbeater, 2012: 50). The authors note that the process was successful but ‘contentious’ and ‘hard fought’ (Bunt and Leadbeater, 2012: 50).

Other references were made to examples of co-production that were under development at the time. For example, one of the objectives of the Healthcare Improvement Scotland programme of work was about the co-design and co-production of day services, but this was work in progress (Healthcare Improvement Scotland, 2021a, 2022). Similarly, a review of practice in Wales briefly described two projects that were ‘developing co-production approaches’ (Chick and Pavia, 2023: 23). In one of the projects, groups of PWLD were being supported to pool their direct payments to model and commission services for themselves. In the other project, a local authority was looking to ‘expand and enhance the application of co-production approaches’ by focussing less on the nature of the activities being undertaken and more on the relationships and connections engendered, and learning from the experience (Chick and Pavia, 2023: 23-24).

The rest of this section examines how the co-design and co-production of day services has been conceptualised in the literature, what it requires, and the gaps in understanding on the topic. A list of potential resources and tools for co-designing services with PWLD and other disabilities is also provided in Appendix 2.

3.3.1 Conceptualisations of co-design and co-production

Various terms were used in the literature to describe the different ways in which PWLD and their families have been, or could be, involved in shaping day services at a service level (as opposed to being involved in planning their own personal day activities). For example, the terms ‘consultation’, ‘partnerships’, ‘engagement’, ‘co-design’ and ‘co-production’ were all used but seldom defined. Various values, principles and behaviours associated with co-design and co-production were also mentioned. These included ‘equity’, ‘power and control’ and ‘teamwork’ (Mencap Cymru, 2023: 5). Co-design and/or co-production were also recognised to bring benefits to individuals in terms of providing a way of building self-esteem and creating moments that people value as they make choices (Mencap Cymru, 2023: 5). Conversely, where they are not adequately involved when new projects start up or traditional day services change, then PWLD miss out on opportunities to learn (Nind et al., 2021).

Some concepts were also used in ways that differed from how they are used in other contexts. For example, some of the publications referred to a lack of consultation with PWLD and their families regarding the changes made to day services in their localities (e.g. Mencap, 2012: 4). Here the use of the term ‘consultation’ was linked to the legal duty of local authorities to consult with people who draw on services. However, in the wider literature on approaches to involving people in their care and the development of services, here ‘consultation’ is generally conceptualised as a weaker form of involvement. This is commonly represented by the ‘ladder of co-production’, where ‘co-production’ is the top rung and strongest form of involvement, immediately followed by ‘co-design’, ‘engagement’, ‘consultation’, ‘informing’, ‘educating’, and ‘coercion’ is the bottom rung and the weakest form of involvement ([TLAP website](#)).⁶ The importance of this distinction between relatively active and passive forms of involvement, and working on an equal basis, is illustrated by the following quotation from a member of one of the teams involved in phase 2 of the Healthcare Improvement Scotland Collaborative project:

‘It shouldn’t be the case of us taking what people say and doing what we think is best, we’ve been doing that for the last 30 years and it hasn’t worked so we work together, we listen to each other and then we co-design the ways to move forward together’ (Healthcare Improvement Scotland, 2022: 9).

A lack of understanding of what ‘co-production’ means, how it works, and how it can be mis-understood, was highlighted in one report (Mencap Cymru, 2023: 5). It recommended to the Welsh Government that a national definition and standard for co-production and

⁶ Other versions of the ladder of co-production exist, depicting similar hierarchies of involvement. For example, an alternative top to bottom hierarchy is: devolving, co-producing, involving, consulting, informing (Whaley et al., 2019: 6)

asset-based community development is established to ensure that power is shared and so that people understand co-production is not simply about consultation. It also recommended that local authorities and organisations that provide day services are given a duty to explain how they have co-produced changes (Mencap Cymru, 2023: 8).

3.3.2 Requirements for the co-design and/or co-production of day services

Co-design and/or co-production were recognised to take a lot of time and practice, especially for people not used to being asked what they think (Cole *et al.*, 2007; Chick and Pavia, 2023; Mencap Cymru, 2023). They require support workers to have the necessary skills and capacity to listen (Healthcare Improvement Scotland, 2021a; Chick and Pavia, 2023; Mencap Cymru, 2023), clear and effective communications (Cole *et al.*, 2007; Bunt and Leadbeater, 2012; Healthcare Improvement Scotland, 2021a, 2022; Chick and Pavia, 2023), and a willingness to share power and control (Mencap Cymru, 2023).

It was also suggested that service redesign should involve the wider community as well as PWLD and their families (Healthcare Improvement Scotland, 2021a: 7), and that support was needed for families to adjust to the growing independence of PWLD and positive risk taking (Mencap Cymru, 2023: 5).

Finally, it was acknowledged that co-production can lead to ‘unrealistic goals, wanting to achieve things that are not possible’ and the need for everyone to understand that choices can be limited by resources (Mencap Cymru, 2023: 6).

3.3.3 Tools and resources for co-design

Various resources with information about working with people with disabilities to co-design and co-produce services were found when executing the search strategies. Although they lie outside the scope of this report, in that they are not necessarily specific to PWLD and/or the UK and/or the redesign of day services, some examples are listed in Appendix 2 because of their potential transferability.

3.4 Skills and employment

3.4.1 Day services and supported employment

When *Valuing People* was published, the government noted that, at the time, less than 10% of PWLD in England had jobs (Department of Health, 2001: 7). One of its objectives was to enable more people to participate in all forms of employment, ideally paid work (Department of Health, 2001: 26). Commenting on the role of day services in promoting the employment of PWLD, the government noted that some day services had been slow to develop links with supported employment services and the wider community (Department of Health, 2001: 77). It added that ‘modernising day services will involve developing and

strengthening links with local supported employment schemes, and with providers of further and community education and training for disabled people’ (Department of Health, 2001: 78).

By 2006, progress at getting PWLD into employment was still slow. In England, the government recognised that there was a lack of focus of day centres on employment-related activities (Department for Work and Pensions, 2006). PWLD were still reliant on day centres, where there was often little if any opportunities to move into employment (Department for Work and Pensions, 2006). In Scotland, a review found variation in how good day centres were at helping people find work (Scottish Executive, 2006). A few centres had employment teams and were helping people into work using supported employment methods, such as vocational profiling, job matching and on the job support (Scottish Executive, 2006). However, PWLD were still wanting real jobs, for real pay, and more training (Scottish Executive, 2006).

In 2007, a major review of research and survey of practice in the UK examined the role of day centres in supporting people into paid work (Cole *et al.*, 2007). It found that ‘day centres vary greatly in the emphasis they place on helping people to find paid work’ (Cole *et al.*, 2007: 31). Where day centres were helping people, they were informed by a model known as ‘supported employment’. These findings are supported by the present review. In the literature, supported employment is sometimes positioned as an alternative to, and separate from, day services, and sometimes as an integral part of what day services facilitate. As Cole and colleagues (2007) observed, this may reflect the extent to which there are other agencies working to improve employment outcomes for PWLD in an area - they found that where there was little supported employment provision, or they were at capacity, day services were taking a more active role in preparing people for work; staff were also developing new skills and taking on new employment related roles as part of day services modernisation. The authors added that ‘The picture is patchy, however, and the role of day services in relation to employment does not appear to have a strategic push in many areas’ (Cole *et al.*, 2007: 47). It is also likely that funding arrangements have been a factor in them being positioned as ‘alternatives’ for individual placements.

In Wales, a statement on policy and practice for PWLD included a section on the relationship between employment and day services (Welsh Assembly Government, 2007: 30-32). It stated that, prior to retirement age, PWLD should have equal access to training schemes and lifelong learning opportunities, to help them secure employment. It noted that staff needed to become more skilled at working with PWLD to be more effective at supporting them into work. It endorsed supported employment as being an effective model, requiring well-trained job finders and job coaches. It also noted that there were other routes to employment and that day services should provide meaningful and rewarding activities that reflect people’s interests and help them to develop confidence, independence and skills. In

the statement, the Welsh government also recognised that day services should continue to offer the same to PWLD when they reach retirement age, and that this group should also still have access to lifelong learning opportunities.

A subsequent review of the UK and international literature on supported employment found evidence that people were more satisfied with activities in supported employment and spent more time in purposeful and meaningful activities, compared to in day services (Beyer and Robinson, 2009: 26, 30). It also identified a lack of social skills as a factor in job loss (Beyer and Robinson, 2009: 22). Two approaches had been developed to address this. One focused on changing social behaviour of people with learning disabilities, the other on co-workers acting as bridging agents to help with social integration. Advocacy was found to be a less useful approach compared to teaching disabled workers social skills (Beyer and Robinson, 2009: 24). The authors concluded that supported employment was ‘worthwhile at an individual and societal level’ and that much could be done to improve employment rates for PWLD (Beyer and Robinson, 2009: 79-80). Another study found that people with learning disabilities in supported employment had better emotional well-being compared to those in employment enterprises and day services (Beyer *et al.*, 2010).

In *Valuing Employment Now*, the government acknowledged that 65% of PWLD would like a paid job; however, only 10% of people known to social services had one (Department of Health, 2009b: 12; Department of Health, 2009c). The strategy included the goal of ‘radically’ increasing the number of people with moderate and severe learning disabilities in employment in England by 2025, with as many jobs as possible being at least 16 hours a week (Department of Health, 2009b: 14). The government also aimed to close the gap in employment rates between PWLD and disabled people as a whole – with the latter rate standing at 48% (Department of Health, 2009b: 14). Accordingly, local authorities were encouraged to shift some of the current spending on adult day services to supported employment. Learning Disability Partnership Boards were also encouraged to review day services modernisation plans to ensure that they had employment at their heart (Department of Health, 2009b: 15, 47, 49).

In 2011, the government published a review of the evidence base on strategies for getting PWLD into employment (Department of Health, 2011). The report examined the evidence on three approaches: supported employment, self-employment and social enterprises. It found that supported employment was the most effective. It was described as ‘an evidence-based and personalised approach to support people with significant disabilities into real jobs, where they can fulfil their employment aspirations, and achieve social and economic inclusion’ (Department of Health, 2011: 17). It added that the jobs can be provided by different types of employers across the private, public and third sectors, and that support can also come from various sources, including day services (Department of Health, 2011: 19).

In an article published in 2011, Melling and colleagues reflected on how supported employment for people with learning disabilities has developed in the UK since 1997 (Melling *et al.*, 2011). The authors observed that supported employment had helped people with mild and borderline learning disabilities into employment but there was little evidence that it had helped people with higher support requirements (Melling *et al.*, 2011: 29; see also Cole *et al.*, 2007). They concluded that ‘Adult day services, special schools and colleges still show little progress in moving people with higher support needs through into paid employment’ (Melling *et al.*, 2011: 29).

In the same article, Melling and colleagues cite evidence from two studies that compared the net cost of a supported employment place with that of one in a local authority day service. One of the studies, set in North Lanarkshire, showed that the net cost of the former was 48% of the latter.⁷ The other was of the Kent Supported Employment service (Kilsby and Beyer, 2011). It estimated the annual cost of a supported employment place to be £7,811 compared to £12,792 for a place with day services, over the 12-month period April 2010 to March 2011. A more conservative estimate was also provided, which suggested a potential saving of £2,540. The authors acknowledge uncertainties in the analysis, and point out that the saving is only achievable if the more costly service is replaced by the less costly one (Kilsby and Beyer, 2011: 4).

Around the same time, the Scottish Government also recognised that supported employment was cheaper and more beneficial for PWLD than day services, but that still only a minority were in paid work (Scottish Government, 2012: 5, 19).

A subsequent mapping of the employability landscape for PWLD in Scotland, where a Supported Employment Framework was introduced 2010, found that it was available in 26 of 32 local authority areas (McTier *et al.*, 2016). There was a growing trend of supported employment services being transferred from social work to employability and economic development departments (McTier *et al.*, 2016). The overall employment rate of PWLD in Scotland was estimated to be between 7% and 25% (McTier *et al.*, 2016: 54). The authors concluded that:

*‘Supported employment services in Scotland are estimated to have supported up to 2,000 people with a learning disability in Scotland in 2014/15, with an overall 16 hours/job outcome rate of 28% and a cost per 16 hours/week job outcome of £14,000’ (McTier *et al.*, 2016: 55).*

Only small numbers of PWLD were thought to be engaged in mainstream employability programmes (McTier *et al.*, 2016: 55).

The authors of the same report examined the views of providers and other stakeholders on what helps the effective delivery of the Supported Employment Framework in Scotland.

⁷ It was not possible to locate the study, which was by Beyer (2008).

They found that a person-centred and a long-term approach were key. Other factors found to be helpful at the five different stages of the framework were identified. These included: a need to work with parents and carers (stage 1); in-depth and thorough vocational profiling, and good quality work and placements in real work environments (stage 2); high quality job matching and provision of support for employers (stage 3); maintaining a strong relationship with employers (stage 4); and ensuring PWLD and employers have access to specialist support and aftercare, which remains in place as long as it is required (stage 5) (McTier *et al.*, 2016: 44-47).

As noted earlier in this report, the first Healthcare Improvement Scotland review found that supported employment was the most successful model of employment support accessed by people with mild to moderate learning disabilities (Healthcare Improvement Scotland, 2020: 4-5). The review cited evidence from small observational studies showing that PWLD in supported employment had better quality of life and community integration than similar adults attending day services and employment enterprises (Healthcare Improvement Scotland, 2020: 2, 5). It also found that personalised approaches in supported employment, for example, vocational profiling, peer mentoring, and ongoing support, were associated with higher satisfaction and better employment outcomes (Healthcare Improvement Scotland, 2020: 2). However, the second Healthcare Improvement Scotland review further noted that people with mild to moderate disabilities felt that there was less support available following cuts in services and changes in eligibility criteria, which had particularly impacted employability and community inclusion services (Healthcare Improvement Scotland, 2021b: 9).

A recent review of the delivery of supported employment in Scotland (for all groups, not just PWLD), found high variation in access, ranging from 2% to 60% (Scottish Government, 2021: 5). The cost of the service was also found to vary from £57 p.a. to £17,795 p.a. (Scottish Government, 2021: 5). The review found there was no data on the access rates for PWLD or people with autism (Scottish Government, 2021: 5). It highlighted the need to address the variation in rates and lack of transparency in data. One of its recommendations was also that Scottish Government explore how to use ‘anchor’⁸ institutions to increase the number of jobs available for PWLD and autism (Scottish Government, 2021: 40). It notes that NHS England has developed a Learning Disability Employment Programme and that the Senedd had recently recommended the same to Welsh Government (Scottish Government, 2021: 40).

⁸ ‘Anchor’ institutions include larger employers, such as the NHS, Local Authorities, universities, colleges and other public sector providers.

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3.4.2 Barriers to employment for PWLD

In Wales, a recent review of day opportunities and respite/short break services for all groups following the Covid-19 pandemic recommended that local authorities and their partner agencies examine how to remove barriers to employment and consider directly employing people themselves (Chick and Pavia, 2023: 7).

In the rest of the literature reviewed, factors that had negatively influenced employment rates for PWLD included: welfare benefit disincentives (Cole *et al.*, 2007: 10; Beyer and Robinson, 2009: 40); an absence of mainstream funding for supported employment (Beyer and Robinson, 2009: 40); lack of social skills training (Beyer and Robinson, 2009: 22); reductions in public sector workforce and funding (Melling, 2011: 31); employment not being seen as a priority for people with moderate and severe learning disabilities (Melling, 2011: 31); lack of specialist employment support provision for matching people to jobs (Melling, 2011: 31); employer attitudes (Healthcare Improvement Scotland, 2021b: 10-11); and low expectations of PWLD (Healthcare Improvement Scotland, 2021b: 22).

4. CONCLUSION

Existing research has shown that, over time, the historical model of day services for PWLD being provided in large and segregated day centres has declined. It has been replaced by a more varied range of alternative day opportunities in the community, and employment opportunities in the workplace, that are arranged on a more individualised basis. With this shift, the role of day services has diversified, acting as both a provider and a facilitator of (alternative) day opportunities and/or employment in different settings, working in conjunction with a wide range of council departments, agencies and organisations across sectors.

Surveys have shown that PWLD who have accessed day opportunities in the community generally have positive experiences. However, while there were references to several initiatives across the UK, there were not many published evaluations of these schemes. As a result, there is limited evidence on the nature, appeal, effectiveness, and experience of different models of or types of day opportunities for different groups of PWLD and their family carers, at an individual, programme, service, or population level.

Similarly, while there was growing recognition in the literature of the need for day services to be co-designed and co-produced with PWLD and their family carers, there was very little research on the nature and extent of these practices. Some of the publications on self- and peer-advocacy suggested that some PWLD were coming together to design and arrange the delivery of day opportunities for themselves, but in general there was little evidence on how this was happening in practice, what helped the process, and what benefits were realised. Nor were any substantial worked examples published, explaining how different groups of PWLD have been involved in the co-design and co-production of day services.

A more substantial evidence base was found on supported employment for PWLD. Research has shown that this approach is effective for PWLD and people with other disabilities, and that being in employment helps with social and economic inclusion. However, it has also shown that supported employment has benefitted people with mild to moderate learning disabilities more than those with higher needs, for whom it was originally intended. And for PWLD as a whole, the rate of people in employment is still a lot less than the rates for disabled people generally, and data is lacking to track trends and the impact of policies.

Gaps were noted in the literature on the preferences and experiences of some specific groups of PWLD who access day services, and the effectiveness of strategies for promoting their social and economic inclusion. These groups include people from black and ethnic minority communities, older adults as they approach retirement age when they may no longer be eligible for the same day services they have received as a person with learning disabilities, and PWLD who also have behaviours that challenge others. There was also little evidence on how changes in day services for PWLD have affected family carers.

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Finally, some of the more recent publications included in the review provided insights into the ways in which the Covid-19 pandemic had impacted PWLD and their family carers. For example, there was evidence that people’s access to day opportunities had been negatively impacted and that family carers had experienced increasing care demands and stress. There was also recognition of the innovative delivery of services by the third sector and community organisations during the pandemic (e.g. Healthcare Improvement Scotland, 2021b: 11), although this was largely undocumented and unevaluated.

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APPENDICES

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Appendix 1: Publications included in the review

1st author	year	source	title	region	notes/links
Beyer	2009	Report	A Review of the Research Literature on Supported Employment	UK, International	
Beyer	2010	J App Res Intell Dis	A comparison of quality of life outcomes for people with intellectual disabilities in supported employment, day services and employment enterprises	Wales (south)	
Bunt	2012	Report	The Art of Exit	UK, International	Includes case study of ‘creative decommissioning’ (Thurrock, England)
Campbell	2012	J Intell Dis	Changing day services: do you agree?	Scotland	
Carnaby	2010	Brit J Learn Dis	A flexible response: person centred support and social inclusion for people with learning disabilities and challenging behaviour	England	Re: PWLD and ‘challenging behaviour’
Chick	2023	Report	Review of Day Opportunities and Respite/Short Break Services: the impact of the COVID-19 pandemic on service innovation and transformation May 2023	Wales	Post-Covid-19 pandemic
Cole	2007	Report	Having A Good Day? A study of community-based day activities for people with learning disabilities	UK	Landmark review for SCIE published in Feb 2007
Curtice	2006	Report	How Is It Going? A survey of what matters most to people with learning disabilities in Scotland today	Scotland	
Department for Work & Pensions	2006	Report	Improving Work Opportunities for People with a Learning Disability	UK?	
Department of Health	2007b	Report	Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs	England	Re: people with higher support needs (profound intellectual and multiple disabilities)
Department of Health	2011	Report	Increasing the Numbers of People with Learning Disabilities in Employment. The evidence base – best practice guidance for local commissioners	England	
Emerson	2008	Report	People with Learning Disabilities in England	England	
Graham	2010	Brit J Learn Dis	How the tea is made; or, the scoping and scaling of ‘everyday life’ in changing services for ‘people with learning disabilities’	England	

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1st author	year	source	title	region	notes/links
Hatton	2017	TLDR	Day services and home care for adults with learning disabilities across the UK	UK, national comparisons	
Healthcare Improvement Scotland	2020	Report	Evidence Summary: new models for Learning Disability Day Support Collaborative	Scotland, UK, International	Re: people with mild to moderate learning disabilities. See also the supplementary review by Healthcare Improvement Scotland (2021b)
Healthcare Improvement Scotland	2021a	Report	New Models of Learning Disability Day Support Collaborative (Phase 1)	Scotland	
Healthcare Improvement Scotland	2021b	Report	New Models of Learning Disability Day Support Collaborative (Phase 2). Scoping review summary.	Scotland	Follow-up to Healthcare Improvement Scotland (2020) review on three related topics; includes transferable learning
Healthcare Improvement Scotland	2022	Report	New Models for Learning Disability Day Support Collaborative – phase 2	Scotland	
Hollomotz	2014	Brit J Social Work	Are we valuing people's choices now? Restrictions to mundane choices made by adults with learning difficulties	England?	
Innes	2012	Maturitas	Caring for older people with an intellectual disability: a systematic review	International	Re: older people with intellectual disabilities and unpaid carers
Judge	2010	J Pol & Prac Intell Dis	Activity, aging, and retirement: the views of a group of Scottish people with intellectual disabilities	Scotland	Re: older people with intellectual disabilities
Kilsby	2011	Report	A Financial Cost:Benefit Analysis of Kent Supported Employment: a framework for analysis	England	
Leyin	2009	TLDR	Social inclusion: life after 'day services'	England?	
Mansell	2010	Report	Raising Our Sights: services for adults with profound intellectual and multiple disabilities	England?	Re: people with higher support needs (profound intellectual and multiple disabilities)
McTier	2016	Report	Mapping the Employability Landscape for People with Learning Disabilities in Scotland	Scotland	
Melling	2011	TLDR	Supported employment for people with learning disabilities in the UK: the last 15 years	England?	

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1st author	year	source	title	region	notes/links
Mencap	2012	Report	Stuck At Home: the impact of day service cuts on people with a learning disability	England	
Mencap Cymru	2023	Report	The Future of Day Services	Wales	
Needham	2012	Report	What is Happening to Day Centre Services? Voices from frontline staff	UK (not N. Ireland)	
Needham	2013a	BMC HSR	Personalized commissioning, public spaces: the limits of the market in English social care services	England	
Needham	2013b	Crit Soc Pol	Personalization: from day centres to community hubs?	England	
Nind	2021	Disability & Society	Learning from each other in the context of personalisation and self-build social care	UK (England, Scotland)	
Power	2016	J Intell Dis	Peer advocacy in a personalized landscape: the role of peer support in a context of individualized support and austerity	England?	
Redmore	2020	Thesis (PhD)	Day service culture from the perspective of autistic adults with profound learning disabilities	England	See also Redmore (2024)
Redmore	2024	Brit J Learn Dis	Day service cultures from the perspectives of autistic people with profound learning disabilities	England	Based on Redmore's (2020) PhD thesis
Roulstone	2009	Social Policy & Society	Neo-liberal individualism or self-directed support: are we all speaking the same language on modernising adult social care?	England	
Ryan	2024	HSDR Res	Improving support and planning ahead for older people with learning disabilities and family carers: a mixed-methods study	England	Re: older people with learning disabilities and 'behaviours that challenge others'
Scottish Executive	2006	Report	Make My Day!	Scotland	
Scottish Government	2012	Report	The Same As You? 2000-2012: consultation report	Scotland	
Scottish Government	2021	Report	Review of Supported Employment within Scotland: findings and recommendations	Scotland	
Simpson	2007	J Pol & Prac Intell Dis	Community-based day services for adults with intellectual disabilities in the United Kingdom: a review and discussion	Scotland	

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1st author	year	source	title	region	notes/links
Skea	2007	Ment Health & Learn Dis Res & Prac	Quality of staff - service user interaction in two day centres for adults with learning disabilities	England	
Slevin	2011	Report	A Rapid Review of Literature Relating to Support for People with Intellectual Disabilities and their Family Carers when the Person has: Behaviours that Challenge and/or Mental Health Problems; or they are Advancing in Age	International?	Re: people with higher support needs and PWLD who are older
Swift	2009	Report	A Life in the Community	England	
Taggart	2017a	Report summary	Supporting Older Adults with a Learning Disability and their Ageing Family Carers: a family and community support model: executive summary	Northern Ireland	Re: PWLD who are older. See Taggart & Hanna-Trainor (2017b) for full report
Taggart	2017b	Report	Supporting Older Adults with a Learning Disability and their Ageing Family Carers: a family and community support model: full report	Northern Ireland	Re: PWLD who are older. See Taggart & Hanna-Trainor (2017a) for executive summary of the report

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Appendix 2: Examples of tools and resources for co-designing and co-producing services from the wider literature

During the review, various tools and resources were found relating to the co-design and co-production of services with PWLD and/or other people with disabilities. Some examples are included in this appendix. See the reference section for full bibliographic details and links to the individual resources.

1st author	year	title / source / link	country
Alfred Health	UD	A guide for accessible co-design: tips for designing with people who have diverse ways of thinking, communicating, and sharing ideas.	Australia
Aswad	2022	Towards an inclusive co-design toolkit: perceptions and experiences of co-design stakeholders.	Ireland
Department of Health	2011	Increasing the numbers of people with learning disabilities in employment. The evidence base – best practice guidance for local commissioners. Annex: supported employment and job coaching: best practice guidelines	UK
Foundation for People with Learning Disabilities	2005	Shaping the future together. A strategic planning tool for services supporting people with learning disabilities.	UK
Foundation for People with Learning Disabilities	2009	Life in the community. Better daytime opportunities for people with higher support needs. A briefing note for commissioners and care managers from the FPLD.	UK
Healthcare Improvement Scotland ihub (website)	2020-2022	New models for Learning Disability Day Support Collaborative. The website has various tools and resources, including: mapping tools, journey mapping, design personas. https://ihub.scot/improvement-programmes/people-led-care/collaborative-communities/new-models-for-learning-disability-day-support-collaborative/	UK
Healthtalk.org (website)		Learning disabilities and the health service catalyst film. This film was developed as a resource to help with service improvement initiatives. https://healthtalk.org/experiences/service-improvement/learning-disabilities-health-service-catalyst-film/	UK
Heerings	2022	Ask Us! Adjusting experience-based codesign to be responsive to people with intellectual disabilities, serious mental illness or older persons receiving support with independent living.	The Netherlands
Humanly	2018	Big Plans: a guide for meaningfully engaging people with learning disabilities in the development of their plans.	UK
Jarrett	2023	Building with butterflies: the role of design and art in co-creating new identities for services. Conference workshop abstract.	UK

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1st author	year	title / source / link	country
Kuznetsova	2011	Commissioning care in the 21st century: improving outcomes for people with learning disabilities.	UK
Love	2002	Day services modernisation toolkit. Part 1. See also Whitehead <i>et al.</i> , (2003).	UK
McNeish	2016	Building bridges to a good life: a review of asset based, person centred approaches and people with learning disabilities in Scotland.	UK
Miller	2024	Changing culture not just process: community led support in action.	UK
Moriarty	2007	Practice guide: the participation of adult service users, including older people, in developing social care. Published in: Stakeholder Participation SCIE Guide 17 series.	UK
National Development Team for Inclusion	UD	Commissioning effective employment supports (for people with learning disabilities and people with mental health problems): a practical review tool for commissioners.	UK
National Involvement Network	2016	Putting the Charter into practice: feedback from organisations that have signed up to the Charter for Involvement.	UK
National Involvement Network	2019	Charter for Involvement.	UK
NHS	2019	Core capabilities framework for supporting people with a learning disability.	UK
NHS England	2023	Supporting people with a learning disability and autistic people to live happier, healthier, longer lives. Bitesize guide for local systems.	UK
Purple Orange	2021	Guide to co-design with people living with disability.	Australia
Raman	2022	Enabling genuine participation in co-design with young people with learning disabilities.	UK
Research in Practice	2023	A brighter social care future: co-producing the evidence to make five key changes. Sharing power as equals.	UK
Rice	2014a	Working with outcomes: the practitioner experience. Experience lab, case study 1.	UK
Rice	2014b	How to run an experience lab: developing social care and support.	UK
Scottish Commission for Learning Disability (SCLD)	2019	Developing a learning disability strategy: guidance, suggestions and questions for developing a local learning disability strategy.	UK
Scottish Government / Digital Scotland	UD	The Scottish approach to service design: how to design services for and with users.	UK
Think Local Act Personal (TLAP)	UD	Two co-production journeys: ADASS West Midlands and ADASS East of England.	UK

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1st author	year	title / source / link	country
Towers	2014	Evaluation toolkit for providers. An assessment tool and action plan for organisations to improve the quality of life for people with learning disabilities as they grow older.	UK
Whitehead	2003	Day services modernisation toolkit. Part 2. See also Love <i>et al.</i> , (2002).	UK
Wightman	2009	Connecting people: the steps to making it happen.	UK