Our support, our lives: joining up the public services used by disabled people

Alissa Davies March 2015



About Scope

Scope exists to make this country a place where disabled people have the same opportunities as everyone else. Until then, we'll be here. We provide support, information and advice to more than a quarter of a million disabled people and their families every year.

Being able to choose where and how you live has an enormous impact on your quality of life, your sense of independence and your self-esteem. Yet often disabled people struggle to find and afford the support they need to enjoy an independent life. This makes it harder for disabled people to access education and employment, as well as opportunities to develop wider friendships and social lives, or become leaders in their communities. Joined up support is crucial in overcoming these barriers and ensuring independence is achievable for all disabled adults.

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1. Executive summary

Joined up support can make it easier for working-age disabled people to live independently – to enjoy family life fully, participate in and contribute to their community, access education and training opportunities, find and stay in employment.

Integrated care for disabled adults is possible. Many of the structures and processes needed already exist. Nationally and locally these structures are starting to transform support for older people.

Is it right that when we talk about integrated care, we think primarily – sometimes exclusively – of older people,¹ and of how to meet rising demand and support people better in later life? Working-age disabled people under 65 are a third of social care users² and are likely to be more intensive users of health services than the general population.³

Public awareness of the relationship between the NHS and social care is growing. All political parties have pledged to bring health and social care closer together, and some initiatives to incentivise this are already in place.

The full potential of integrated support is yet to be realised for disabled adults. Scope believes this is an opportunity the next Government cannot afford to miss. Where integration between different public services happens, it's crucial that it reflects the needs of the 6.1 million working-age disabled adults in the UK.⁴

About this report

Our interest is in how service integration can improve the quality of support disabled people get. Sections 3, 4 and 5 of this report look at how health and social care integration can work better for working-age disabled people in the care system. Although better coordination across health and social care may deliver efficiencies, this is unlikely to address the significant underfunding of social care.⁵ Section 6 of this report applies key lessons and themes from integrated care and disabled people's definitions of independent living to a wider range of public services (including employment support).

¹ For example http://www.publications.parliament.uk/pa/ld201213/ldselect/ldpublic/140/140.pdf and http://services.parliament.uk/bills/2013-14/care/stages.html

² HSCIC: Community Care Statistics 2013/14 http://www.hscic.gov.uk/catalogue/PUB14397

³ The NHS does not collect data on how disabled people use health services, but local evidence suggests that disabled adults are intensive users of health services. See Appendix A.

⁴ DWP: Family resources survey 2013/13. https://www.gov.uk/government/collections/ family-resources-survey--2

⁵ LGA and ADASS (2014): councils face a £4.3bn funding gap for social care funding by 2020. http://www.local.gov.uk/media-releases/-/journal_content/56/10180/6660933/NEWS

Integrated support from health and social care services

- Poor co-ordination across health and social care makes it harder for disabled adults to live independently, participate in society or contribute to the economy
- Yet disabled adults are not seen as a priority in current integrated care initiatives, or identified as a key group for future integration plans
- Existing integrated care initiatives have massive untapped potential in relation to disabled adults
- There is a financial, demographic and socio-economic case for making sure integrated care works for disabled adults
- The next Government can realise the full potential of integrated care through:
 - A national strategy on independent living for all disabled adults with a strong focus on joined up support
 - New incentives which reward councils and Clinical Commissioning Groups (CCGs) that transform support for disabled adults
 - A longer-term approach to the benefits of supporting disabled adults to live independently throughout their lives

Integrated support beyond health and social care

- Integrated support for disabled people throughout their lives means they can learn, work, thrive and fulfil their potential.
- Integrated support for disabled adults needs to reflect all the barriers to living independently – this means looking beyond health and social care and towards a wider range of services and transformation models across national and local government (including councils, CCGs and other local agencies).
- Disabled adults have diverse needs, aspirations and expectations from services, and different definitions of independent living from, for example, older people. This means disabled adults will not always automatically benefit from solutions designed for other groups. Equally there are big differences between different disabled adults which suggests that sophisticated solutions are needed.
- Scope has developed ten principles for integrated support to help national and local services make sure integration proposals work for disabled adults.
- Throughout 2015 Scope will be running a series of roundtables to inform Government thinking about how to deliver integrated support for disabled adults.

2. Methodology

For this report, Scope carried out desktop analysis of the impact of current integrated care initiatives on working-age disabled people, based on a qualitative review of:

- National planning guidance and Department of Health data on the Better Care Fund
- Local Better Care Fund Plans, local Joint Strategic Needs Assessments and local Joint Health and Wellbeing Strategies
- Local Government Association profiles of the Integrated Care Pioneers
- The national prospectus for Integrated Personal Commissioning

Scope ran interviews and two focus groups with disabled adults in early 2015, exploring their experiences of coordination across health and social care services.

This analysis forms the basis of a series of recommendations on how the next Government can realise the full potential of integrated care for disabled adults. It has also been used to identify a number of key issues and areas for further exploration across the wider integrated support agenda.

Additionally, this report draws on Scope's Better Care Project research⁶, a year-long study conducted between April 2014 and March 2015, funded by the Department of Health. The research provides a detailed picture of working-age disabled people's (aged 18-64) recent experiences of the social care system, and how far services support disabled people to live, work and participate in their communities.

The project included two focus groups with younger and older disabled adults, 15 in depth interviews with social care users and a survey with over 500 responses. Relevant key quantitative findings on integration from the research are included in this report on page 11, and have informed our recommendations. Many of the quotes in this report come from this research.

3. Why it is important that integrated care works for disabled adults

Moves by national and local government to integrate care are driven by three main factors. First, to make better use of public resources in the context of rising demand for health and social care. Second, to improve outcomes for people who use services.⁷ Third, to address the incompatibility of a health system that is free at the point of use with a social care system that is rationed and means-tested.⁸ Integrated care must work for disabled adults if these objectives are to be achieved.

We cannot afford a poorly joined up care system that creates barriers to disabled people participating in their communities or contributing to the economy. The number of disabled adults needing care and support is growing and demand is rising. Addressing this is a financial imperative for local authorities and Clinical Commissioning Groups (CCGs), particularly in the wider context of pressures on their budgets.

Until now, the drivers behind integration have mostly been considered in the context of the ageing population. The needs of working-age disabled people have largely not been seen as central to the debate. This is partly because health data on disabled adults is comparatively weak. However, disabled adults are a demographic group who do not always have the same needs and life goals as older people.

While there is a lack of robust health data, the evidence which is available – primarily demographic, financial and socio-economic – strongly indicates that disabled adults should become a priority group for integrated care, alongside older people.

The number of disabled adults who need care and support is growing

The numbers of disabled adults needing care and support is growing in two directions. Firstly, more disabled children with complex needs are living into adulthood due to medical advances and improved access to health services.⁹ Secondly, adult life expectancy is growing for some groups.¹⁰

⁷ Kings Fund (2014): http://www.kingsfund.org.uk/publications/making-integrated-care-happen-scaleand-pace

⁸ Barker Commission (2014): A new settlement for health and social care: http://www.kingsfund.org.uk/ sites/files/kf/field/field_publication_file/Commission20Final2020interactive.pdf

⁹ CeDR (2009): Estimating future numbers of adults with profound multiple learning disabilities in England – http://base-uk.org/sites/base-uk.org/files/[user-raw]/11-07/dh_103200.pdf

¹⁰ Life expectancy for people with Downs Syndrome doubled from 20 in 1980 to 49 in 2002. Life expectancy for people with Cystic Fibrosis increased from 14 in the 1980s to 50 in 2014.

The number of disabled adults needing social care is projected to rise by 9.2 percent between 2010 and 2020.¹¹ This includes disabled adults whose parents can no longer support them because of an increase in their own health and social care needs, and disabled adults who are experiencing early symptoms of ageing.¹²

⁴⁴I depend on my parents for a lot more than your average twentysomething year old would. I do dread the day their own ailing health gets the better of them.³⁷ Caitlin, 26

A financial imperative for local authorities and the NHS

More disabled adults needing care and support, in a climate of shrinking budgets and short-term funding settlements, presents significant financial challenges for local authorities and the health service. Since 2010 social care spending has fallen by £3.5bn (14 percent), but the number of people needing support has grown by 12 percent.¹³

Tackling this gap is an immediate and pressing need for councils and Clinical Commissioning Groups (CCGs). Average social care spending per head is higher for disabled adults than it is for older people. **Disabled adults are a third of social care users and their support already represents just under half of all social care expenditure.**¹⁴

Data on health spending on disabled adults is limited and disabled adults come into contact with the health service in different ways (see page 10). However, data from areas that have analysed total costs across health and social care suggests this pattern of higher spending per head is also true for health services. Detailed modelling of annual costs across the whole care system in Hammersmith and Fulham found that spending per head was highest for disabled people under 75 with learning disabilities and physical disabilities.¹⁵



11 Based on estimations in Tables 10 and 11 in Personal Social Services Research Unit (2013): Implications of setting eligibility criteria for adult social care at moderate needs level. http://www.pssru.ac.uk/archive/pdf/dp2851.pdf

12 For example, adults with Downs Syndrome are more likely to develop younger-onset Alzheimer's. http://www.alz.org/dementia/down-syndrome-alzheimers-symptoms.asp

- 13 ADASS Budget Survey (2014): http://www.adass.org.uk/adass-budget-survey-2014/
- 14 HSCIC: Community Care Statistics 2013/14. http://www.hscic.gov.uk/catalogue/PUB14397

15 McKinsey analysis (2014): integrated data sets for Hammersmith and Fulham. http://integration.healthiernorthwestlondon.nhs.uk/section/what-approach-should-we-takeGiven that reducing costs is a key driver of integrated care, it is essential that national and local government understand the full picture of spending and patterns of demand for all their service users. Otherwise, we risk creating a joined up care system that is not financially sustainable.

The fact that the number of disabled adults is growing – and growing due to improved life expectancy – also creates a much longer-term financial challenge. Young disabled adults are likely to use health and social care services throughout their lifetime. The real benefits (and savings) from a joined up care system therefore only become clear when you look at support for disabled adults throughout their lives.

Recommendation

 Councils and CCGs model how disabled adults use health and social care services over their whole life to understand the short-term and long-term financial pressures, benefits and incentives. This should be supported by a national framework and guidance from the Department of Health (DH), the Department for Communities and Local Government (DCLG) and NHS England.

What is living independently?

¹¹Independence is about living life to the full and making the most of what I have. Living life and being part of it, not watching life pass by because of a lack of support. That is not living, it is existing.¹¹ Katy, 43

¹¹Independence isn't doing everything for myself but is being in control of how I live and what I do, whether that's at home or work or out and about.¹¹ Elizabeth, 34

Pen portraits: how disabled people use care and support¹⁶

Amy

I'm single and in my early 40s. I've been blind since childhood. Then I became deaf in my late twenties.

I went to a good university and have had a successful career. Now I own my own home in London – a long way away from my family in the North East.

For the last 20 years I've employed a range of Personal Assistants who can give me the tailored support I need to live independently. The people I've employed over the years have changed as my work, social and personal care needs have changed. At the minute I'm working long hours and travelling a lot so I need a PA who is prepared to do that.

I need support to communicate and with personal care. My condition also causes me to lose balance and that means sometimes I have accidents at home and at work. I don't think I see my GP as often as I should – it's usually not the same person, they often talk like I'm not there and it feels like a waste of time repeating the same information again and again.

As I get older, I'll start to need more support from the NHS and care services. Recently I developed a thyroid problem that isn't yet under control. This leaves me very tired and makes things difficult at work. I'm determined to stay in my own home though.

Charlotte and Mandy

My sister Mandy is in her late 50s. Mandy has Downs Syndrome and autism. Sometimes Mandy's behaviour requires active management and support – especially when she's scared, upset or things change suddenly without any notice.

Throughout her life Mandy has been in and out of residential care homes and in-patient hospitals, mostly paid for by the NHS. That's not ideal because Mandy is scared of doctors, hospitals and care workers.

Mandy tells me that she would really like to live with family. That hasn't been possible since our parents got older and died. I live far away, have my own children living at home and don't have the time, space or money to support her properly. That makes me feel really guilty.

Mandy has a limited social life and only occasionally gets taken out by staff. I see Mandy as often as I can but she lives on the other side of the country.

16 These pen portraits have been developed based on interviews and focus groups with disabled people with a range of different impairments.

John

I'm 23 and I left [residential college] last summer. I have Cerebral Palsy, use a powered wheelchair that I control with my left hand. I can't speak so I use my iPad to communicate.

At college I got lots of support from staff who showed me that with the right support I could be in control. They helped me learn, provided personal care and helped me take my medication and go to doctors' appointments. That's really important for me as I get lots of chest infections. Everything was joined up around me.

I started planning what would happen when I left college in my first year. I knew I wanted to live in a house with friends, away from home, and see if I could find a job – like everyone else my age!

The college staff and my mum tried to work with social services and the NHS to get me into supported living. But there wasn't anything suitable back home and they refused to look at things near college. I ended up having to choose between living with my parents or going into a care home for older people. The thought of a care home terrifies me, so I went home.

I'm not leading the life I want. I'm isolated, angry and I can't get out of the house except with my parents. It's making me depressed and my chest infections are getting worse. I want to be independent, but it just doesn't feel like the care system is set up for people like me.

Not supporting disabled adults to live independently costs money

The country as a whole will face even greater costs if the care system fails to support disabled adults to fulfil their potential in society. When the right support is not provided or support is not joined up, disabled adults find it much harder to work, learn, volunteer, build and maintain relationships and save for older age.

Scope's Better Care research asked over 500 disabled adults about what independence means to them and the role of support in helping them live independently. While disabled adults all have different definitions of independence, consistent themes emerged as key features of independent living, including: choice and control, family life, relationships, participating in society, working, learning, and overall wellbeing.

Disabled adults have very high aspirations around independence and see support as central to achieving these aspirations. Two-thirds (66 percent) of disabled adults surveyed said that social care is very important for work, job seeking, volunteering and study. Sixty nine percent of disabled adults aged 18-35 said that social care is important for building new relationships and meeting new people and 50 percent said they need support working and looking for work.

The care system is not doing enough to help disabled adults achieve these aspirations. Just 18 percent of disabled adults surveyed said that social care supports them to live as independently as possible and 55 percent said social care never supports their independence.

As a society we do not usually expect 20 year olds to want the same things from life as 80 year olds. A one-size-fits-all approach to integrated care which assumes the same solutions work for all groups is unlikely to succeed, given the range and breadth of disabled adults' aspirations.

Recommendation

 The next Government makes better support for disabled adults to live independently a key priority for councils and the NHS throughout the next parliament.

This could be achieved immediately by:

- Adding an explicit objective on independent living for disabled adults to the NHS Mandate for 2015/16.¹⁷ This would introduce a specific requirement for NHS England to promote independent living for disabled adults.
- Strengthening the national outcomes frameworks for health and social care¹⁸ (see page 23) so the performance of councils and NHS services is measured based on how well disabled adults are supported to live independently
- Revising the national policy framework for the Better Care Fund and any future integrated care initiatives (see section 5) so they provide clearer incentives for councils and NHS services to support disabled adults to live independently.

Ben's story

"I live with my parents – I always have apart from the few years I was at college. I've wanted to live independently for a long time. I spoke to my social workers about this repeatedly.

I was on the council's housing list for about 12 years and in 2013 I finally found a flat. I contacted social services and asked how I could change my support. I'd tried doing it before I found somewhere, but they said "you can't until you find somewhere to live." Eventually they assessed me and came up with a care package that was, just, utterly ridiculous. They were only going to fund an hour in the morning to get me up – nothing during the day at weekend, nothing in the evenings, nothing overnight.



So lots of arguments ensued. The council wouldn't help me. They shunted me onto the NHS. The NHS turned me down for continuing healthcare. Now they've changed their mind, but I still don't know when I'm going to be able to move in. I've been paying for a flat for over a year that I haven't even slept in.

The attitude of social services was "well, this is the support you've got and you've just got to make do – get on with it." And when you're in chronic pain, holding down a job, facing the biggest change of your life starting to live on your own, the last thing you want to be doing is spending your time arguing about the support you need.

It's had a massive impact – not just on me, but on the people I care about. I'm on anti-depressants. I was off work with depression, I've nearly lost my job. I've ended a relationship as a result. I've had screaming rows with my parents because I was so stressed.

If I'd known what it would do, I wouldn't ever have started down that road. I can absolutely see why so many disabled people end up in residential care or living with their parents. I never thought living independently would be this hard in a million years."

Disabled adults need a joined up care system that supports independent living

From the perspective of the health and care system, disabled adults who use services fall into two broad groups: those who use social care services on an ongoing basis but rarely use health services, and those who regularly use both types of services. Joined up care needs to work for both groups. The care system must focus on making it easier to live independently as well as on improving health outcomes and making savings.

Care which is poorly joined up has a negative impact on the lives of disabled adults who regularly use health and social care services. Our research uncovered numerous examples of disabled adults who are unable to access services as a result of poor join up across health and social care.

Both health and social care professionals and disabled adults find the differences between health and social care confusing and sometimes get caught in the middle of disputes over who is responsible for arranging and paying for their care.

⁶⁶ There seems to be a big mix up in what you can have, and you can't buy NHS services with a social care package. That's out of the question. They saw bipolar as the mental health condition that health should deal with and Lupus as a social care element that I needed care for. They couldn't bring the two together as a package.⁹¹ Reagan

Time and again disabled adults are repeatedly asked to give the same information to different professionals. This is frustrating and disempowering. Disabled adults highlighted waste and unnecessary duplication in the care system, for example in assessments and care planning across social care and NHS continuing healthcare.

⁶⁶ Different people phone up and ask exactly the same question that someone asked you three weeks ago. And it's like – talk to each other! I shouldn't be sitting there and telling person B that person A has already come and done the assessment. That's not my responsibility.⁷⁷ Ben Delays putting social care support in place create avoidable demand for the NHS – particularly for mental health services – and other services like the criminal justice system. 57 percent of disabled adults surveyed told us they need social care services to better support their mental health and emotional wellbeing.

⁴⁴ If my social worker is not available then the police take up the slack, and that may mean being put into a police cell for many hours, making you feel like a criminal and ultimately making your suicidal crisis worse, and then you lose hope in the system and then you may not ask for help the next time you need it.³¹ Sophie, 45

Sometimes disabled adults end up accepting support that is not appropriate for their age, needs or aspirations because it is a struggle to get any support agreed at all. Inappropriate or insufficient support has a negative impact on disabled people's mental health.

This is a particular issue during the transition from children's to adults services and makes it harder for young disabled people to plan for the future, and achieve their aspirations.

⁶⁶Some of the services when moving from child to adult services were very difficult to understand, with each service blaming the other for a lack of information. Now in adult services it feels like if we don't accept one of the limited choices, then it's a case of take it or leave it. We're not offered a resource that is more suited to us.⁹⁹ Mhairi, 19

Many young disabled people told us they felt the care system was not set up to meet their needs or support them to achieve their goals. More than half of social care users surveyed who were aged 18-35 said they want help with working or job-seeking, but only around one in seven are currently getting support for these activities.

Disabled adults need a joined up care and support system that supports them to live fulfilling lives rather than acting as a barrier to living independently, participating in society and contributing to the economy.

4. Existing integrated care initiatives are not going far enough

Three major initiatives for joining up health and social care services already exist – the Better Care Fund, Integrated Care Pioneers and Integrated Personal Commissioning (see below).

These initiatives have created new structures, mechanisms and ways of working that are essential building blocks for a joined up care system. Alongside this, the Care Act 2014 has put independence at the heart of the social care system through the wellbeing principle. Whenever they make decisions, councils are legally required to promote the wellbeing of adults, including their ability to contribute to society and the economy.¹⁹

Better Care Fund²⁰

National

- Pooled budgets
- 1 year for 2015/16
- 151 areas
- Focused on reducing hospital admissions

Testing and gathering

people's needs

evidence on new ways of

coordinating care around

Integrated Care Pioneers²¹

- Local
- 14 areas since 2013
- 11 new areas from 2015

Integrated Personal Commissioning²²

- Individual personal budgets for health and care
- 8 demonstrator sites
- Testing new financial incentives
- 3 years from April 2015

21 NHS England: Integrated Care Pioneers. https://www.england.nhs.uk/2013/11/01/ interg-care-pioneers/

22 NHS England: Integrated Personal Commissioning http://www.england.nhs.uk/2014/07/09/ipc-prog/

¹⁹ The Care Act 2014: section 1. http://www.legislation.gov.uk/ukpga/2014/23/section/1/enacted 20 NHS England (2014): Better Care Fund – revised planning guidance.http://www.england.nhs.uk/ wp-content/uploads/2014/07/bcf-rev-plan-guid.pdf

While these changes could radically transform the care system for disabled adults, Scope's analysis indicates that much more needs be done. Full details of our analysis of the programmes can be found in Appendix B.

Current integrated care initiatives can do more to improve outcomes for disabled adults

So far the biggest focus has been on joining up services for older people who are at risk of needing acute health services. However, the Better Care Fund and Integrated Care Pioneers have significant untapped potential in relation to disabled adults. Integrated Personal Commissioning is also a substantial opportunity for disabled people to have more choice and control over their support.

The Department of Health and NHS England should grasp these opportunities and extend the benefits of existing integrated care initiatives to disabled adults by:

- revising the national policy framework for the Better Care Fund;
- using Integrated Care Pioneers and Integrated Personal Commissioning to test different ways of supporting disabled adults to live independently.

The Better Care Fund

Scope's analysis of the Better Care Fund's national policy framework²³, guidance²⁴ and the 91 local Better Care Fund plans approved in October 2014²⁵ indicates that the fund is largely focused on reducing hospital admissions for older people. This is particularly problematic given that Disabled Facilities Grant funding and Care Act implementation funding for all social care users is included in the Better Care Fund.

Only 14 of the 91 local Better Care Fund Plans approved in October 2014 include schemes that are specifically aimed at disabled adults.²⁶

The majority of these 14 schemes focus on adults with learning disabilities – the second highest demographic group in terms of social care spending²⁷ – with barely any focus across the schemes on adults with physical impairments or mental health conditions.

²³ LGA: Better Care Fund information: http://www.local.gov.uk/home/-/journal_content/56/ 10180/4096799/ARTICLE

²⁴ NHS England (2014): Better Care Fund – revised planning guidance. http://www.england.nhs.uk/wp-content/uploads/2014/07/bcf-rev-plan-guid.pdf

²⁵ Scope analysis of data provided by the Department of Health. See Appendix B.

²⁶ Scope analysis of Department of Health data: Oldham, Sheffield, Stockport, Sunderland, Bath and North East Somerset, Bristol, Swindon, Wiltshire, Barnsley, Durham, Havering, Islington, Norfolk and Rutland.

²⁷ HSCIC: Community Care Statistics 2013/14 – 32 of national social care expenditure is on support for adults with learning disabilities. http://www.hscic.gov.uk/catalogue/PUB14397

The focus on older people is driven by the national policy framework, guidance and payment by results metric on non-elective hospital admissions. The Better Care Fund is a one year programme for 2015/16 and local areas were asked to provide evidence of annual savings. This makes it harder for local areas to focus on the longer-term benefits of joined up care for disabled adults.

Local plans mainly focus on outcomes that are more relevant to older people such as reducing hospital admissions and preventing delays in people leaving hospital.²⁸ This reflects the national supporting metrics and recommended local metrics. **Two of the four national supporting metrics for the Better Care Fund**²⁹ **(on admissions to residential care and**



Only 14 of 91 local Better Care Fund Plans include schemes that are specifically aimed at disabled adults

nursing homes and hospital discharges) only apply to older people. Only three of the nine recommended local metrics³⁰ for the Better Care Fund are relevant to disabled adults.

Some disabled adults are still likely to benefit from new types of universal services being used to supplement formal care packages, for example electronic health monitoring devices. However often services that support disabled adults to live independently (such as education, employment support and travel) have not been included in local Better Care Fund schemes, are not age-appropriate or are simply unavailable.

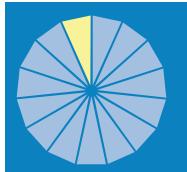
This is a missed opportunity – more can be done to promote the wellbeing and independence of disabled adults.

28 Public Accounts Committee (2015): Planning for the Better Care Fund, pg 3. http://www.publications.parliament.uk/pa/cm201415/cmselect/cmpubacc/807/807.pdf 29 See Appendix B. NHS England (2014): Technical Guidance for the Better Care Fund http://www.england.nhs.uk/wp-content/uploads/2014/08/bcf-technical-guidance-v2.pdf 30 Ibid: see Appendix B

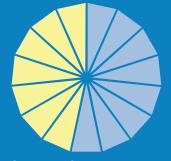
Integrated Care Pioneers

Scope's analysis of the first wave of Integrated Care Pioneers revealed a similar focus on transforming support for older people. **Only one of the 15 Integrated Care Pioneers has a specific scheme to improve support for disabled adults**.³¹ Only four of 15 local Better Care Fund Plans in Integrated Care Pioneer areas include schemes to improve support for disabled adults.³² As with the Better Care Fund, adults with learning disabilities are almost universally seen as a higher priority than other groups of disabled adults, such as adults with physical impairments or mental health conditions.

This is surprising given that six of the Pioneers identify disabled adults as a priority in their Joint Health and Wellbeing Strategies³³ and eight Pioneers highlighted disabled adults as a key demographic in their Joint Strategic Needs Assessment.³⁴ The narrow focus on older people could be easily addressed: seven of the 15 Integrated Care Pioneers have schemes that could benefit disabled adults but do not yet apply to disabled adults,³⁵ for example around personal budgets.



Only one of 15 Integrated Care Pioneers has a specific scheme to improve support for disabled adults



Seven of 15 Integrated Care Pioneers have schemes that could benefit disabled adults but do not yet apply to disabled adults

³¹ Worcestershire

³² Barnsley, Stoke and North Staffordshire, Waltham Forest and West Norfolk. Local plans for Stoke and North Staffordshire and Waltham Forrest were not included in Department of Health data on the 91 plans approved by October 2014.

³³ Cornwall and Isles of Scilly, Islington, Kent, South Devon and Torbay, Southend on Sea and Stoke and North Staffordshire

³⁴ Barnsley, Kent, Leeds, Southend on Sea, South Tyneside, Stoke and North Staffordshire, Waltham Forest, East London and the City and West Norfolk.

³⁵ Barnsley, Cheshire, Greenwich, Islington, Kent, Leeds, North West London and Southend on Sea.

Integrated Personal Commissioning

Scope's analysis of the national prospectus³⁶ and eight demonstrator sites³⁷ suggests Integrated Personal Commissioning has real potential to improve support for disabled adults who regularly use health and social care services.

Four of the eight demonstrator sites will develop blended personal budgets for young disabled people and disabled adults across health and social care funding.³⁸ This shows that with the right national incentives and support councils and CCGs can and do focus on joining up support for disabled adults.

Four of the eight demonstrator sites will develop blended personal budgets for disabled people across health and social care funding

The care model outlined in the national prospectus for Integrated Personal Commissioning includes a number of approaches that disabled adults see as essential for choice and control, including holistic (or 'whole life') care plans, personalised support planning, independent advocacy, peer support and brokerage. The financial model also aims to 'align financial accountability to the outcomes that matter to people' so commissioners and providers are rewarded based on what works for individuals.³⁹ To ensure the success of Integrated Personal Commissioning it is crucial that these outcomes are defined in terms of independent living for disabled adults rather than benefits for the care system.

36 NHS England (2014) Integrated Personal Commissioning Prospectus. http://www.england.nhs.uk/wp-content/uploads/2014/09/ipc-prospectus-updated.pdf
37 NHS England: Integrated Personal Commissioning programme https://www.england.nhs.uk/commissioning/ipc/
38 Cheshire West and Chester, Tower Hamlets, Hampshire and the South West Consortium.
39 NHS England: Integrated Personal Commissioning programme. https://www.england.nhs.uk/commissioning/ipc/

5. How the next Government can realise the full potential of integrated care

In an uncertain financial climate, local integration plans tend to reflect national programmes. In the short-term, simple adjustments to the design of the Better Care Fund could transform support for disabled adults. In the longer-term there are important lessons that should be applied to make sure future integrated care programmes and wider systems of integrated support work for disabled adults. This report identifies action on three fronts:

- 1. Incentives and rewards for independent living
- 2. A longer-term approach to risks and benefits
- 3. Making it clearer whether schemes apply to disabled adults

New incentives and rewards for independent living

The Better Care Fund offers relatively weak incentives for local areas to develop care systems that support disabled adults to live independently, participate in society and contribute to the economy. This is evident in the payment by results mechanism, and the national and local metrics.

The payment by results mechanism

This is based on reducing avoidable emergency hospital admissions.⁴⁰ As a result, local plans strongly focus on keeping people out of hospital (who are more likely to be older people) rather than supporting people who are less likely to use acute health services (who are more likely to be disabled people of working age). It also emphasises short-term savings to the NHS budget over wider savings to the public purse. If this continues there is a significant risk that future care funding will be used to drive savings for the health budget and disabled adults will not be supported to contribute socially and economically.

Recommendation

 The Department of Health and NHS England change the payment by results mechanisms for integrated care programmes so councils and CCGs are rewarded for supporting disabled adults to live independently.

In the short term this could be achieved by incorporating existing measures from the national Adult Social Care Outcomes Framework⁴¹ and the NHS Outcomes Framework⁴² on employment of adults with learning disability (1G), employment of people with mental illness (2.5) and proportion of adults with learning disability living in their own home or with their family (1L).

Including measures on learning disability would also allow the next Government to address the lack of financial incentives for areas to develop new models of care outside long-stay hospitals for people with learning disability/autism and challenging behaviour.⁴³

Getting incentives and rewards right is crucial. In the long-term, for future integrated care initiatives or wider systems of integrated support, the next Government must develop and use a single outcomes framework across government (health, social care, education, employment, housing and welfare services) with new measures of independent living based on the barriers identified by disabled adults. This should make sure the full range of impairment types (for example physical impairments, learning disability and mental health conditions) are covered. This could build on the outcomes framework that underpins the Fulfilling Potential Strategy.⁴⁴

National and local metrics

The focus on older people emphasised in the payment by results mechanism is reinforced by the national supporting metrics and recommended local metrics for the Better Care Fund. Two of four supporting national metrics only apply to older people (permanent admissions to residential care homes and nursing homes and people living at home 91 days after hospital discharge.) Only three of nine recommended local metrics are relevant to disabled adults.⁴⁵

42 Department of Health (2015): NHS Outcomes Framework 2015/16

https://www.gov.uk/government/publications/nhs-outcomes-framework-2015-to-2016 43 NAO (2015): Care services for people with learning disabilities and challenging behaviour.

43 NAO (2013): Care services for people with learning disabilities and challenging behaviour. http://www.nao.org.uk/report/care-services-for-people-with-learning-disabilities-and-challenging-behaviour/ 44 DWP (2014): Fulfilling potential: making it happen for disabled people, pg 46-49.

https://www.gov.uk/government/publications/fulfilling-potential-making-it-happen-for-disabled-people

45 NHS England (2014): Better Care Fund – revised planning guidance. http://www.england.nhs.uk/wp-content/uploads/2014/07/bcf-rev-plan-guid.pdf

⁴¹ Department of Health (2014): Adult Social Care Outcomes Framework 2015/16 https://www.gov.uk/government/publications/adult-social-care-outcomes-framework-ascof-2015-to-2016

Recommendation

The Department of Health, NHS England and Department for Communities and Local Government measure the success of integrated care against outcomes that are relevant to disabled adults.

This could be achieved immediately by:

 Widening the supporting national metric on permanent residential care and nursing home admissions in the Better Care Fund to people aged 18-65.

 Adding existing metrics from the Adult Social Care Outcomes Framework⁴⁶ on quality of life (1A) and social contact (1L) alongside payable metrics on employment and independence.

– Bringing existing results from the Department of Work and Pensions' Life Opportunities Survey⁴⁷ and Family Resources Survey⁴⁸ on disabled people's participation in work, society and education into the national outcomes frameworks for health and social care. These questions could also be used to form the basis of new measures of people's experiences of and outcomes from integrated care.

In the longer-term the Department of Health and NHS England should also address gaps in the national outcomes frameworks for particular groups of disabled adults – particularly those with physical impairments or with high functioning autism. This could be achieved by developing a single outcomes framework across the whole care system (and potentially other national and local services) that includes a wider set of independent living outcomes for all disabled adults. The planned closure of the Life Opportunities Survey in autumn 2015 presents an ideal opportunity to review measures of independent living outcomes for disabled people across government early in the next parliament. A single national framework would ensure integrated care initiatives and wider systems of integrated support deliver for all groups of disabled adults.

A longer-term approach to risks and benefits

The benefits of integrated care for disabled adults are long-term and become clear when local areas look at costs and patterns of service use over a lifetime. This needs to be reflected in the design of integration initiatives through:

- Multi-year programmes
- A wider approach to risk stratifications and capitated budgets which takes the costs of not supporting disabled adults to live independently into account.

47 DWP: Life Opportunities Survey. https://www.gov.uk/government/collections/life-opportunities-survey 48 DWP: Family Resources Survey. https://www.gov.uk/government/collections/

family-resources-survey--2

⁴⁶ Department of Health (2014): Adult Social Care Outcomes Framework 2015/16

Multi-year programmes

The Better Care Fund is a one year programme that requires immediate, cashable savings by the end of 2015/16. In general, national integrated care programmes normally require immediately cashable savings within a year. This short-term focus encourages local areas to focus on immediate short-term savings from reducing the risk of (mostly older) people needing acute health services.

Recommendation

- The next Government provides a sustainable long-term settlement for health and social care services and protects the social care budget alongside the health budget
- The next Government should extend the Better Care Fund to 2016/17 during the spending review
- Beyond the lifetime of the Better Care Fund, we urge the Department of Health and NHS England to introduce a multi-year integration programme which lasts at least five years and does not require savings in the first year.

This would have the added benefit of providing sustainable funding for councils and CCGs so they can confidently invest in developing new models, transform existing models and implementing the cultural change needed to improve support for disabled adults

Risk stratification and capitated budgets

National risk stratification guidance for the Better Care Fund currently focuses on the risk of avoidable NHS spending.⁴⁹ This works well for older people who develop care needs in later life, but works less well for disabled adults who have wider definitions of independence and are likely to use support over much longer periods of time. The introduction of the cap on care costs in April 2016 provides an opportunity for councils and CCGs to model and track lifetime care costs for disabled adults.

Without accurate risk stratifications based on the costs of not all supporting disabled adults to participate in society and contribute to the economy, it will be harder for commissioners to create financial incentives around independent living for disabled adults. In successful integrated care systems, risk stratification data is used as the starting point for new payment systems called local 'capitated budgets' or 'year of care tariffs'(total health and social care spending per head) for population groups with different types of support needs. The aim of capitated budgets is to set up new financial incentives for all providers so they work together to support a population group (for example older people) to achieve a set of outcomes defined by commissioners (for example staying out of hospital).

The Kings Fund has highlighted capitated budgets as a key way of implementing the new models of care described in the NHS Five Year Forward View.⁵⁰ The Oldham Commission also recommended capitated budgets as a key building element of Whole Person Care.⁵¹ The Integrated Personal Commissioning demonstration sites will test capitated budgets for adults with learning disabilities, autism and mental health conditions and for disabled children and young people with complex needs.⁵² There is an opportunity to use Integrated Personal Commissioning to develop and test wider approaches to risk stratification and capitated budgets for disabled adults.

Recommendation

Risk stratifications carried out by the Department of Health, NHS England, the Department for Work and Pensions (DWP), the Treasury, the Cabinet Office and the Department of Communities and Local Government (DCLG), councils and CCGs identify the risks of not supporting disabled adults to contribute to society and the economy, as well as the risk of high care support costs.

In the short-term the Department of Health, Cabinet Office and NHS England should use the integrated care pioneers (for example Hammersmith and Fulham), emerging devolution deals (for example in Greater Manchester) and the Integrated Personal Commissioning demonstrator sites to pilot economic modelling of the full costs of not supporting disabled adults to contribute to society and the economy. This should include costs across health, social care, employment support and overall costs to the exchequer.

In the longer-term the Department of Health, NHS England, DWP and the Treasury should:

Develop a single set of nationally defined categories for risk stratification across health, social care, employment support and costs/contributions to the exchequer to help councils, CCGs and other local services jointly predict risks, costs and benefits of improved support for disabled adults. This would make it easier for local services to justify a stronger focus on better support for disabled adults to live independently.

⁵⁰ The Kings Fund (2015): Implementing the NHS Five Year Forward View: aligning policies with the plan, pg. 11. http://www.kingsfund.org.uk/publications/implementing-nhs-five-year-forward-view 51 Independent Commission on Whole Person Care (2014), pg 70. http://www.yourbritain.org.uk/ agenda-2015/policy-review/whole-person-care

⁵² NHS England (2014): Integrated Personal Commissioning prospectus, pg.8. http://www.england.nhs.uk/wp-content/uploads/2014/09/ipc-prospectus-updated.pdf

Clarify whether local schemes cover disabled adults

In a number of local Better Care Fund Plans and in the Integrated Personal Commissioning prospectus it is not clear whether disabled adults will benefit from schemes designed to improve support for people with long-term health conditions.

Recommendation

The Department of Health and NHS England should include an explicit requirement in all national guidance and planning templates for local areas to set out how they will support disabled adults to live independently. This has already been done for carers in the current Better Care Fund template and will make it clearer which local schemes are designed to improve support for disabled adults.

6. Towards a wider integration agenda

Joined up support throughout their lives means disabled people can learn, work, thrive, participate in society and fulfil their potential. As a society, we cannot afford a disjointed support system that keeps in place barriers to independent living.

So far this report has focused on the integration of health and social care services. Future plans for joined up support should apply the lessons from existing integrated care initiatives so that the full potential of the integration agenda can be realised.

However, integrated care is only one example of how national and local government are bringing together services that support the same individuals. Other current examples include the Troubled Families programme,⁵³ devolution deals⁵⁴ and community budgets.⁵⁵ It is important to consider how the wider integrated support agenda can lead to better support for the 6.1 million working-age disabled adults in the UK⁵⁶ to participate in society and contribute to the economy.

A cross-government approach is needed

Integrated support must address all the barriers to independent living. This means looking beyond health and social care and towards education, work, volunteering, welfare and housing.

The Five Year Forward View⁵⁷ and Green Paper on support for adults with learning disabilities, autism and mental health conditions⁵⁸ are a first step. But they do not go anywhere near far enough. The Government needs to look beyond new models of health and care and start looking at how holistic, joined up services can make independent living a reality for all disabled adults.

greater-manc-funding/

⁵³ Troubled Families Programme. https://www.gov.uk/government/policies/helping-troubled-families-turn-their-lives-around

⁵⁴ Devolution Deal to Greater Manchester. https://www.gov.uk/government/publications/devolutionto-the-greater-manchester-combined-authority-and-transition-to-a-directly-elected-mayor. http://www. england.nhs.uk/2015/02/27/

⁵⁵ For example, Service Transformation Challenge Panel (2014):

http://publicservicetransformation.org/images/2902929_ChallengePanelReport_acc3.pdf

⁵⁶ DWP (2014): Family resources survey 2012-3.

https://www.gov.uk/government/collections/family-resources-survey--2

⁵⁷ NHS England (2014): NHS five year forward view.

http://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf

⁵⁸ Department of Health (2015): No voice unheard, no right ignored. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/409816/Document.pdf

Recommendation

 In the next Parliament, the Government commits to a national crossdepartmental strategy for independent living for all disabled adults. The strategy should be agreed and overseen by the Inter-Ministerial Group on disability and supported by the Office for Disability Issues.

The strategy should make clear how departments including Health, Work and Pensions, Education, Communities and Local Government, along with the Treasury and Cabinet Office, will use the integration agenda to drive better support for disabled adults to participate in society and contribute to the economy. It will allow the next Government to realise the full potential of integration for disabled adults.

Further exploration of what works for disabled adults

Integrated support for disabled adults is under-researched and undermodelled in comparison to other groups, for example troubled families and older people.

As a result, there are a number of different aspects of joined up support for disabled adults and some significant issues that need further exploration. Scope will be running a series of roundtables throughout 2015 to explore where and how more joined up support would make it easier for disabled adults to live independently. The roundtables will focus on different ways of integrating support and examine the key issues for disabled people and national and local government. They are likely to cover the following issues.

Incentives and accountability arrangements

⁴⁴ It's all about promoting independence and I keep saying to people if you put in the independence it's less time in hospital, it's fewer people falling, it's less time being depressed, but they just don't seem to understand it⁷⁷ Saanvi, 54

Integrated care has highlighted the challenges of securing aligned incentives across national and local government and the consequences of a lack of data on needs, aspirations and patterns of service use for different groups of disabled adults. It is important to investigate how incentives currently operate across the different forms of support used by disabled adults and how new incentives around independent living can be introduced. This is particularly crucial given that the long-term financial benefits of supporting all disabled adults to live independently may be for the Treasury and the Department for Work and Pensions rather than councils, CCGs, the Department of Health and NHS England.

Personal budgets and direct payments

Disabled people tell us that they are often the best integrators of their own support if they are given power and control to make the system work for them. Scope has previously highlighted the benefits of direct payments in social care and recommended the use of personal budgets for specialist employment support.⁵⁹

Direct payments and personal budgets have significant potential as a way of achieving more joined up support across the services used by disabled people. 63 percent of social care users surveyed who feel they have choice and control when planning their care said that using a direct payment or alternative personal budget has helped.

However, the conditions necessary for direct payments and personal budgets to be successful need further exploration. For example, failure to uprate payments in line with inflation may undermine the potential of direct payments.

Assessments and support planning

⁴⁴I struggle with disability paperwork. In the last year I have had a DLA form, an ESA form, a Social Services assessment, a Social Services plan with a broker, I've advertised, interviewed and trained two new PAs, and had two financial assessments (one from Social Services and one, maybe even two, from the DWP). At best, these were a few days' work, at worst they take several weeks and leave me emotionally and physically exhausted. The country needs to reduce the burden of assessments on disabled and ill people.³¹ Siobhan, 38

Disabled adults have told us about unnecessary duplication within the health and care system – particularly between social care and NHS continuing healthcare. But this duplication is not confined to the health and social care system. Disabled adults also tell us that assessments and support plans are not holistic, do not reflect broader structural barriers to independent living and are not flexible enough to meet fluctuating support needs.

At the same time, coordinating assessments risks creating a single point of failure for disabled adults, so any integration needs to be carefully thought through.

Clarifying the role of extra costs payments

⁶⁶I don't have a clue what is ok to use money for any more. There is constant goal post moving.⁷⁷ Moira, 35

Disability Living Allowance (DLA) and Personal Independence Payments (PIP) are intended to cover the extra costs that disabled people face in their daily lives.⁶⁰ At the same time national and local government often expect extra costs payments to cover a wide range of support that disabled people need from different local services. For example DLA and PIP can be taken into account in means testing for social care.⁶¹ The role of extra costs payments in offsetting the extra costs of disability, as well as the difference between disability related extra costs and specialist support for disabled adults to live independently, should be further explored.

Devolution and community budgets

The devolution agenda and development of community budgets is already starting to affect support for disabled adults – particularly those who are looking for work. This is a significant opportunity to remove the structural barriers that make it harder for disabled adults to live independently.

Independent living outcomes should become a key feature of devolution deals. Given the significance of disabled adults as a demographic group and as users of public services, the needs of disabled adults must be specifically considered within the devolution agenda. This work should identify groups of disabled adults who are likely to be complex users of multiple public services across employment, social care and health, for example people with mental health conditions. It should also explore the areas where further data is needed to plan effective, local and long-term support for disabled adults throughout their lives.

Addressing market failure

⁴⁴ It was a two year struggle to get the Council to find a service to help me, because there aren't services out there. So I gave up and handed them back the money. I'm still entitled to help, but there isn't any. It's just ridiculous and embarrassing.⁷⁷ Mo

Some public and private markets do not work well for disabled adults who need more specialist support. This is a common theme Scope hears time and again across employment, social care and extra costs. Giving disabled adults choice and control over their support will not be enough to ensure effective joined up support if there are no appropriate options to choose from. It is therefore crucial to identify key areas where public service markets are not working for disabled adults, and action national and local commissioners can take to address market failure.

Ten principles for integrated support

Scope has developed ten principles for integrated support to help councils, CCGs and government departments make sure any future integration proposals work for disabled adults.

Any integrated system of support should...

- 1. Drive a focus on disabled people living independently and having greater choice and control including over budgets
- 2. Be holistic, person-centred and allow people to achieve the outcomes that matter to them
- 3. Remove genuine duplication from the perspective of disabled people using support (rather than the organisations providing support)
- **4.** Have clear and measurable benefits for disabled people, not just immediate financial benefits for the state
- 5. Prevent or reduce future support needs
- 6. Not drive up extra costs for disabled people
- 7. Make sure the right people get support and are not pushed out of the system
- 8. Be flexible so people can easily move between different types and levels of support
- **9.** Use accessible and person-centred assessments, systems and processes that consider all relevant long-term barriers and goals
- **10.** Keep national responsibility for the whole system and give local areas freedom to shape local service markets so they reflect disabled people's needs and aspirations

Recommendation

In developing new models of service integration that deliver independent living for disabled people ahead of the spending review, the next Government should adopt these principles as the basis for future decisions. This will allow national and local government to realise the full potential of joined up support for disabled adults, the public purse and the country as a whole.

Appendix A: Further evidence

Disabled adults are more likely to be regular users of health services

For example, a study of whole population data in Kent found that there are fewer younger people with multi-morbidity, but they require greater resources to meet their health and social care needs than older people.⁶² Data from Hammersmith and Fulham suggests spending per head from health and social care is higher for adults with learning disabilities and complex physical disabilities.⁶³ In Norfolk adults aged between 18 and 69 account for 68 percent of the total population with one long-term condition and 40 percent of the total population with multiple long-term conditions.⁶⁴ This is significant given that in England people with chronic long-term conditions account for 80 percent of all GPs appointments and nearly 30 percent of inpatient bed days.⁶⁵

62 Kent County Council et al: Population level commissioning for the future. http://www.nhsiq.nhs.uk/media/2514788/population_level_commissioning_for_the_future.pdf

63 North West London: Whole Systems Integrated Care Toolkit, chapter 4. http://integration.healthiernorthwestlondon.nhs.uk/section/what-approach-should-we-take-

64 Scope analysis of data in Norfolk's local Better Care Fund Plan, pg. 23. http://www.norfolkambition.gov.uk/view/NCC158187

65 World Health Organisation (2008): Caring for people with chronic conditions, pg 3. http://www.euro.who.int/__data/assets/pdf_file/0006/96468/E91878.pdf

Appendix B: Scope's analysis of existing integration initiatives

The Better Care Fund

Scope carried out a desktop qualitative analysis of the national policy framework⁶⁶ and technical guidance⁶⁷ for the Better Care Fund, alongside data provided by the Department of Health on the 91 local Better Care Fund plans approved in October 2014.

Better Care Fund Metrics

The national payment by results metric for the Better Care Fund is on total emergency admissions.

The four national supporting metrics⁶⁸ for the Better Care Fund are:

- Permanent admissions of older people (aged 65 and over) to residential and nursing care homes, per 100,000 population
- Proportion of older people (65 and over) who were still at home 91 days after discharge from hospital into reablement / rehabilitation services
- Delayed transfers of care from hospital per 100,000 population
- A locally selected metric on patient/service user experience.

The recommended local metrics⁶⁹ for the Better Care Fund are:

- The proportion of people feeling supported to manage their (long-term) condition
- Estimated diagnosis rate for people with dementia
- Proportion of patients with fragility fractures recovering to their previous levels of mobility / walking ability at 30 / 120 days

66 NHS England (2014): Better Care Fund - revised planning guidance. http://www.england.nhs.uk/wp-content/uploads/2014/07/bcf-rev-plan-guid.pdf

67 NHS England (2014): The Better Care Fund technical toolkit. http://www.england.nhs.uk/wp-content/uploads/2014/09/1-seg-strat.pdf

68 NHS England (2014): Better Care Fund – revised planning guidance.

http://www.england.nhs.uk/wp-content/uploads/2014/07/bcf-rev-plan-guid.pdf

- Social care-related quality of life
- Proportion of adults in contact with secondary mental health services living independently with or without support
- Carer-reported quality of life
- Proportion of adult social care users who have as much social contact as they would like
- Proportion of adults classified as 'inactive'
- Injuries due to falls in people aged 65 and over.

Of these recommended local metrics, only three metrics are relevant for disabled adults:

- Proportion of adult social care users who have as much social contact as they would like
- Proportion of adults in contact with secondary mental health services living independently with or without support
- Social care-related quality of life

Local Better Care Fund plans

14 of the 91 local Better Care Fund plans approved in October 2014 include schemes that are specifically aimed at disabled adults.

Local area	Title of schemes specifically aimed at disabled adults		
Oldham	Fully Integrated Health and Social Care Teams to offer joined-up assessment and care management across all adult care areas		
Sheffield	Independent Living solutions		
Stockport	Learning Disability Stability Services – intensive Support scheme for people with learning disabilities		
Sunderland	Learning Disabilities		
Bath and North East Somerset	Increased Capacity in Learning Disabilities Social Work service		
Bristol	Long-term care options for people with mental illness and learning disabilities		
Swindon	Learning disability		
Wiltshire	Developing our community services and enabling full integration of health and social care		
Barnsley	Adult learning disability transformation		
County Durham	Supporting independent living		
Havering	Learning Disabilities		
Islington	Support mitigating pressures in health care for both people with learning disabilities and older people		
Norfolk	Predictive modelling and complex need risk stratification. Supporting independence, wellbeing and self-care. Supporting good mental health		
Rutland	Learning disability		

Integrated Care Pioneers

Scope reviewed profiles and case studies,⁷⁰ local Joint Health and Wellbeing Strategies (JHWBS), Joint Strategic Needs Assessments (JSNA) and local Better Care Fund (BCF) plans for each of the 14 Integrated Care Pioneers.

	Specific schemes for disabled adults	Schemes that could benefit disabled adults	Disabled adults in JHWBS	JSNA covers disabled adults	BCF plan covers disabled adults
Barnsley	×	\checkmark	\checkmark	\checkmark	\checkmark
Cheshire	×	\checkmark	\checkmark	×	×
Cornwall and Isles of Scilly	×	×	\checkmark	×	×
Greenwich	×	\checkmark	\checkmark	×	×
Islington	×	\checkmark	\checkmark	×	×
Kent	×	×	\checkmark	\checkmark	×
Leeds	×	\checkmark	\checkmark	\checkmark	×
North West London	×	\checkmark	×	×	×
South Devon and Torbay	×	×	\checkmark	×	×
Southend on Sea	×	\checkmark	\checkmark	\checkmark	×
South Tyneside	×	×	\checkmark	\checkmark	×
Stoke and North Staffordshire	×	×	\checkmark	\checkmark	\checkmark
WELC (Waltham Forest, East London and the City)	×	×	~	~	~
West Norfolk	×	×	×	\checkmark	\checkmark
Worcestershire	\checkmark	×	\checkmark	×	×

Integrated Personal Commissioning

Scope analysed the national prospectus⁷¹ for Integrated Personal Commissioning and media announcements with details of the eight demonstrator sites.⁷² This showed that four of the eight demonstrator sites are specifically aimed at disabled adults.

Demonstrator site	Areas of focus		
Cheshire West and Chester	People with learning disabilities, including those who have mental health problems or autism		
	People who have high support needs, are in institutional settings or at risk of being placed in these settings, and/or are children and young people aged 14 and with complex/learning disability needs		
Tower Hamlets	Expand personal health budgets to: people with long-term conditions, particularly adults and children with more complex health needs including significant mental health problems; and people eligible for jointly funded continuing healthcare.		
Hampshire	Children and young people in transition (14-25 years old) with complex needs such as learning disability, mental health problems and physical conditions		
	Adults with a learning disability, including those in, or at risk of entering, an institutional setting		
South West Consortium	People with a range of multiple long-term conditions; including mental health issues; learning disabilities and children with complex needs.		
Barnsley	People with complex diabetes		
Luton	People with dementia		
Stockton on Tees	Older people with long-term conditions		
Portsmouth	Older people with multiple long-term conditions		

71 NHS England (2014): Integrated Personal Commissioning Prospectus.

http://www.england.nhs.uk/wp-content/uploads/2014/09/ipc-prospectus-updated.pdf 72 NHS England: Integrated Personal Commissioning programme Scope exists to make this country a place where disabled people have the same opportunities as everyone else. Until then, we'll be here.

We'll provide support, information and advice through our services when disabled people and their families need us. And we'll raise awareness of the issues that matter. We'll keep influencing change across society until this country is great for everyone.

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