



Self-building Our Lives

Social Care Research Report



[#SelfBuildingOurLives](https://twitter.com/SelfBuildingOurLives)

#SelfBuildingOurLives is a collaborative research project drawing upon the work of Andrew Power, Melanie Nind, Andy Coverdale, Hannah Macpherson and Abigail Croydon at University of Southampton, Ed Hall and Alex Kaley at University of Dundee, and a team of advisory group partners including people with learning disabilities and their respective organisations from across the UK.

The report draws on primary research we undertook in England and Scotland with people with learning disabilities, support organisations and commissioners. This was funded by the Economic and Social Research Council (ESRC): *Reclaiming social care: Adults with learning disabilities seizing opportunities in the shift from day services to community lives* (ES/P011764/1). The views expressed are those of the authors and not the ESRC.

It also draws upon the feedback from participants at a national impact event held in London on 13 November 2019 and feedback received via social media (@SelfBuildLives).

<http://selfbuildingourlives.org/>

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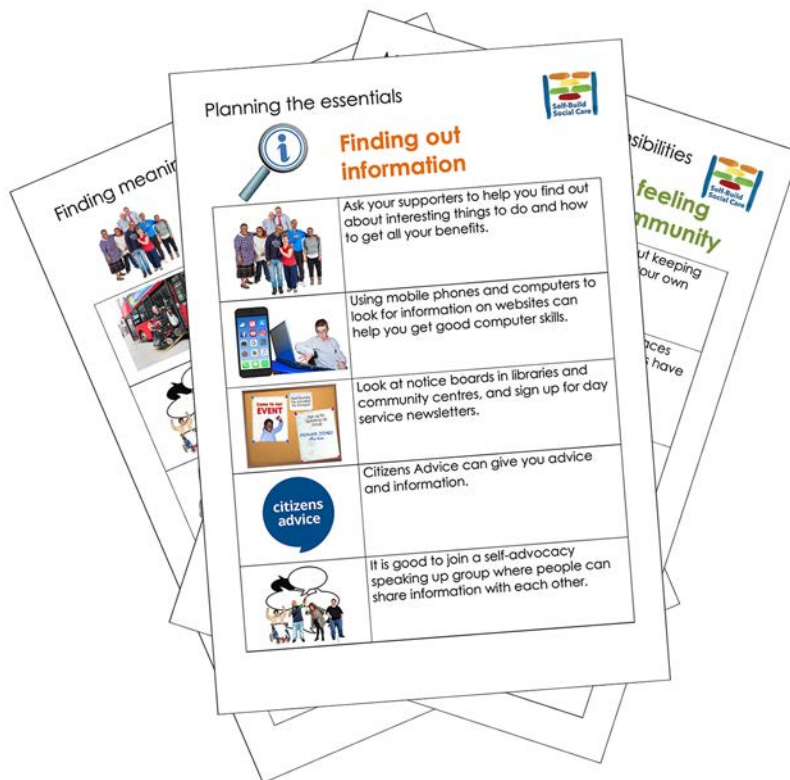
Finally, we are especially grateful to all the participants in the study and those who helped facilitate participation, including people with learning disabilities, family members, advocates, support staff, managers, and commissioners.

Cover photo: Nathan Anderson, Unsplash.

Easy Read

An Easy Read version of our resource pack for people with learning disabilities and their supporters is available to download and print at:

<https://bit.ly/34HnBwc>



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Executive summary

Social care provision is becoming more personalised for disabled people in the UK. Increasingly people in need of social care are being asked to take more responsibility for organising care, support, work and activities, what we are terming 'self-building' daily lives or 'self-build social care'. Little is currently known about how individuals with learning disabilities, and the organisations supporting them, are responding to this new situation. Researchers at the Universities of Southampton and Dundee, supported by the Economic and Social Research Council, conducted research to look at this issue.

Alongside changes in social care policy and provision there has been a long-term reduction in social care budgets and a tightening of eligibility criteria affecting the provision and sustainability of new initiatives. These changes are undermining the foundations needed to build a supported and meaningful life. Within this context, understanding how to support individuals and groups to self-build networks of support and learn to succeed in their communities remains a key challenge for commissioners, organisations and families.

The research concerns how people with learning disabilities in England and Scotland are self-building their daily lives in this context. We focused on this group as they are arguably at furthest reach from the benefits of personalisation (NDTi, 2015), however our

research should have wider relevance for social care support more generally. The aim was to find out how people with learning disabilities are experiencing and responding to changes in care and support, what learning is involved, and how support organisations are adapting to new circumstances. We did this by focusing on learning disability provision in four areas, two in England and two in Scotland (one urban and one rural in each). We spent time with 43 people with learning disabilities (24 men and 19 women; aged 18-70) using interviews, focus groups and visual methods to find out about their experiences. Two participants were Asian British and the remainder were White British. We also interviewed 39 staff at 29 organisations providing support and activities.

We found variable levels of success in self-building daily lives amongst our participants. We concluded that people with learning disabilities, like anyone requiring social care support, should not have to do it alone. Rather, to be occupied in meaningful ways, to have more of a say in shaping local networks and activities, to avoid social isolation, people need each of the 'building blocks' outlined on the next page to be in place.



Fig. 1 Building blocks for self-building daily lives

Underpinning the building blocks, we identify three enabling factors to promote successful self-building:

1. Advocacy, including self-advocacy:

Supporting this is essential, especially for the most isolated, to provide people with the skills and confidence to make their voices heard. This is a crucial step to enable people to take part in their communities.

2. Member-led involvement¹:

Involving members with learning disabilities in management and advisory roles (for example, on steering groups) can ensure support organisations create something people want and have a commitment to, and where they can learn together.

3. Social Interaction:

Facilitating opportunities for people to make and meet friends is necessary as day-centre use declines. Friendship groups and networks can foster peer-support, and help participants gain the skills and confidence to live as part of their wider communities.

These enabling factors need to be promoted and supported by policy makers, local authorities, support organisations, national learning disability and related organisations.

Finally, we outline a series of recommendations in the following pages.

¹ We refer to member-led rather than user-led to indicate that people with learning disabilities are increasingly taking active roles in support organisations rather than being passive users.

Recommendations

Our recommendations include some key priorities already outlined in the care and support statutory guidance (Department of Health and Social Care, 2020) including accessible information and preventative actions, but our research found specific failings in some cases, like provision of advocacy, and we offer specific suggestions for how to meet the responsibilities in the guidance.

5 things policy makers could do

- 1** Recognise that personalisation requires significant government investment. This would help local authorities to implement the building blocks and enabling factors identified above and sustain the support workforce required. We found that due to the limiting funding context, commissioners are unable to realise the potential of personalisation and incentivise more community-based support.
- 2** Review and address the geographical disparities in the delivery of personalisation and the availability of advocacy. This would provide a gap analysis between local authorities and aid them to develop appropriate support opportunities for different age groups and times during the week. We found significant local authority variation in social care sector provision in the areas we examined.
- 3** Ensure that ongoing independent brokerage is available as part of a person's social care entitlement. This would enable individuals and families to learn about different support options available and to make more creative choices using local assets to meet support needs. We found that independent brokerage was ad hoc and often not readily available thus creating a barrier to people taking up direct payments.
- 4** Ensure advocacy and self-advocacy opportunities reach people with learning disabilities in the most vulnerable and isolated situations. This would help people challenge inappropriate and isolating settings and care arrangements and build networks of peer-support with other self-advocates in the community. We found that statutory advocacy provision often did not meet people's needs. Some council's contracts allowed only 8 hours advocacy support per case. This was not adequate for those with complex communication difficulties or more challenging circumstances.
- 5** Ensure that people with learning disabilities are supported to have a key role in informing the quality agenda (for example, as 'Quality Checkers'). This would encourage providers to be more member-led. We found a growing emphasis on the marketing of services and support and that well-marketed organisations were not necessarily member-led or providing a high-quality experience.

10 things local authorities could do

- 1** Invest in quality advocacy and the mechanisms that aid referrals. Advocacy should be available as early as possible as a preventative measure to avoid problems arising from weak support, an absence of choice or lack of community involvement.
- 2** Ensure people with learning disabilities have access to peer-support opportunities to encourage wider community involvement, such as friendship groups, and better opportunities to remain a part of their communities (for example, through offering seed funding and business development training for organisations supporting these initiatives).
- 3** Make information about social, learning and work opportunities as well as care and support services easier to access and understand, as required under the statutory guidance, for example by offering Community, Care and Support Open Days for people with learning disabilities, and resources that are updated regularly and available in digital and non-digital formats.
- 4** Recognise the value of organisations that facilitate self-advocacy in their local areas, foster connections with them and support them financially.
- 5** Encourage neighbourhood initiatives (with housing associations) to develop more communal ways of supporting the development of skills in running a home, like a community-living volunteer scheme.
- 6** Recognise the importance of public transport when planning local social care, support and activities. Plan systematically to prevent further decay of bus services and the isolation this can bring.
- 7** Work more closely with people with learning disabilities, support organisations, parents, carers and social workers on quality and safeguarding matters, both within the community and within small support organisations. This could be achieved, for example, through supporting a forum aimed at co-production, sharing learning and boosting confidence in personalisation.
- 8** Facilitate a provider forum for knowledge and skill-sharing amongst support providers. We found that innovations in quality support often relied on a few motivated individuals. Key individuals' skillsets should be shared and successors found so that innovations and high quality support does not disappear when those individuals move on.

9 Preferentially support organisations offering sustained active engagement in work, paid or unpaid, especially those thinking innovatively about variety of placements, and about learning and progress over time in placements. Support packages could be used creatively to promote active engagement in work and to enable ongoing (not time-limited) support for people working. Community Credit Schemes could be promoted or commissioned, especially ones that partner people with learning disabilities with non-disabled volunteers. These priorities could be advertised and promoted amongst learning disability organisations.

10 Offer consistent personal support to help people navigate the complexity of direct payments and to give people confidence to use them creatively. Support the use of independent brokerage and Individual Service Funds, with commissioning by the local authority as a last resort. Recognise the ability of small organisations, especially co-operatives and micro providers, to be person-centred by virtue of their scale. Value the importance of direct relationships with support staff by facilitating and simplifying direct employment and employment through a third-party proxy.

10 things support organisations could do in co-operation with people with learning disabilities

- 1** Empower members by enabling them to seek advocacy support. At the same time, ensure that managers and staff have a good working knowledge of Human Rights and legal rights under the Mental Capacity Act, Care Act and Equality Act in particular. This knowledge is important for safeguarding, decision-making, and care planning.
- 2** Help members establish a self-advocacy group and encourage them to use their personal budgets to attend group activities and learn from their peers.
- 3** Encourage members to share their experiences and find opportunities for them to take active roles such as on steering groups where they can help shape the organisation and develop new skills. Provide support for meaningful consultation and collaboration and recognise the staff time investment required.
- 4** Enable members to choose to meet up with friends and family. Support social environments that meet people's needs for social connectedness and belonging. This will help provide more opportunities and support for people to gain confidence and skills to access their local areas safely and meet new people.
- 5** Facilitate more opportunities for peer-support and peer learning amongst members such as an individual or group mentor scheme supported by staff or experienced peers. This can give people better opportunities to remain part of their communities.
- 6** Keep transport and travel challenges in mind from the start when doing individual support planning. Be adaptable in supporting travel arrangements and consider how to enable volunteers and peers to support others with schemes like travel buddies.
- 7** Challenge traditional risk averse attitudes in the sector by developing awareness and understanding of positive risk taking through peer discussions and information and advice.
- 8** Provide opportunities for progression in roles within the organisation, including paid work opportunities that match realistic aspirations and expectations and sustain a culture of learning.
- 9** Unlock new funding opportunities by offering services (for example, producing Easy Read resources and 'Quality Checking'), which simultaneously incorporate training and education opportunities.
- 10** Foster a learning culture, remembering that local access to supportive people and schemes can be transformative, that sustained engagement within a network or scheme supports people in learning new identities, and that peer learning benefits from initial staff support to build the friendships and networks, skills and confidence that support lifelong learning.

8 things people with learning disabilities could do

- 1 Find out about your local advocacy and self-advocacy groups and ask to be involved.
- 2 Join a local friendship group or similar, if there is one in your local area.
- 3 Find out as much as you can about social, learning and work opportunities in your area as well as care and support services.
- 4 Ask for Easy Read information (or other formats) about services and opportunities if none is offered.
- 5 Speak up for your rights, and say what you want your life to be like.
- 6 Involve family and friends in your assessments and planning meetings.
- 7 Ask for support to learn to use public transport, and if there is none in your area, write to your council to tell them about the effect this has on your daily life.
- 8 Take up volunteering or work that you are interested in.

Resource Packs

For more information about things to do, check out our resource pack for people with learning disabilities and their supporters. Download at <http://bit.ly/2TDrMp8>



Resource Pack



Easy Read Resource Pack

Introduction

Social care provision is becoming more personalised for disabled people in the UK. Instead of attending local authority provided social care in day centres, people eligible for social care are being asked to take responsibility for organising their own care, support and activities. This is what we are terming 'self-building' a daily life and more widely 'self-build social care'. People with learning disabilities, like others requiring social care support, cannot and should not have to do it by themselves. Support for the building blocks and enabling factors need to be in place. We identify these in this report (see pages 32-36).

Alongside policy change, there has been a long-term reduction in social care budgets and a tightening of eligibility criteria affecting the provision and sustainability of new initiatives. Day centres, adult education centres and other services are closing or limiting availability. Understanding how individuals and groups can be facilitated to self-build their own networks of support and learn to live in the community within this context is a key challenge for commissioners, organisations and families.

Researchers at the Universities of Southampton and Dundee, supported by the Economic and Social Research Council,

conducted research to look at this issue. The original project idea was conceived in a partnership between academic researchers and local disability representative organisations across the south coast, as part of the Southampton Platform for Inclusive Research and Ideas Together (SPIRIT)². We also consulted with our national stakeholder partners, Think Local Act Personal (TLAP) and the Scottish Commission for Learning Disability (SCLD).

The research concerned how people with learning disabilities in England and Scotland are self-building their daily lives when responsibility for social care and support is handed to them. We focused on this group as they are arguably at furthest reach from the benefits of personalisation (NDTi, 2015), however our research should have wider relevance for social care support more generally. The aim was to find out about how people with learning disabilities are experiencing and responding to these changes, the learning that was involved, and how support organisations are adapting.

Our research shows that currently support for people with learning disabilities is patchy. Uneven and often unreliable provision is undermining people's confidence and ability to transition to using a personal budget to

² <https://spiritdisabilityplatform.wordpress.com>

self-build their lives. This is reflected more widely in other research on the barriers to the take up of direct payments, an integral part of personalisation, for all (Hasler and Marshall, 2013).

We identify the types of support that are needed to enable people to take up these opportunities. Examples of such support include friendship groups, mini-enterprises and neighbourhood schemes which give people the confidence to be more actively involved in their communities. Some of the people behind these initiatives shared their

experiences of the lessons they have learned and the challenges that they face. This report focuses on the conditions that are needed to make these initiatives sustainable and lifelong learning opportunities possible.

The report relates stories of people seeking to self-build their lives and of people working in organisations trying to support others to take up the opportunities available in the new landscape. The report is intended to inform policy and practice, and we hope to inspire people to make use of the ideas and examples.

Policy context

The provision of support and learning opportunities for people with learning disabilities has been transformed over the last decade. The decline in the use and availability of council-run day services, and subsequent recognition of the need for more community-led and asset-based initiatives, stems from a series of recent policy developments, starting with Putting People First 2008 and culminating in the Care Act 2014. The Care Act statutory guidance (2016) encourages co-production with citizens to help councils meet new duties. Professionals and local citizens are encouraged to share power, to design, plan, assess and deliver support together. Similarly, NHS England's (2014) Five Year Forward View refers to the need to 'harness the renewable energy in communities' in new ways.

A similar approach has been adopted in Scotland with the Christie Commission on Future Delivery of Public Services (2011) focusing on prevention. The Social Care (Self-Directed Support) (Scotland) Act 2013 stipulates that people with learning disabilities should access support from a range of providers and develop capacity to co-produce new services. In Scotland this co-production agenda is strengthened by the Community Empowerment Act (2015), which asks service providers to work closely with communities to meet needs. However, the Christie Commission advocates the continued role of government in delivering public services,

through Community Planning Partnerships in local areas.

UK Government policy has now firmly positioned choice and control, active citizenship and community capacity as the guiding principles for the future of disability support (in Scotland, in the form of the Keys to Life Implementation Strategy 2019-21). A series of guidance materials produced by national stakeholders has sought to support the implementation of this policy. Think Local Act Personal's Making It Real and Building Community Capacity projects have yielded a range of resources to showcase innovations in personalised and community-centred support. A briefing paper by Shared Lives Plus also outlines ten features of an 'asset-based area' necessary for developing strong communities and sustainable public services. More widely, the #SocialCareFuture movement (2020) has sought to challenge the negative language associated with what we call social care and champion a future where it can make a major contribution to the well-being, health and success of people, communities and our economy. According to Community Catalysts (2019), this approach is about enabling people to use their skills, interests and talents to create a life for themselves, not by themselves.

Recognising the growing interest in community-centred support, recent work on Local Area Co-ordination (Broad 2015),

Asset-Based Places (SCIE 2017) and Asset-Based Commissioning (Field and Miller 2017) provide examples of successful co-produced approaches. Providers are also encouraged to adopt these personalised and community focused approaches (NEF 2012).

We welcome the move in adult social services from institutional funding to personal budgets and the emphasis on community co-production. It offers some disabled people the chance to arrange support, gain independence and take control of their lives. While this policy direction is a welcome move for people with learning disabilities, it comes at a time when local authorities are facing significant cuts to public spending. Welfare reform has developed within a discourse of cost-efficiency and market-led provision (Roulstone and Morgan 2009). The voluntary sector has experienced significantly decreased funding (NCVO 2016). Further and adult education has been similarly affected by the changing financial context. Prior to 2015 (when the adult education budget was fixed), almost a decade of cuts had resulted in a decline in provision of adult education (SFA 2016). Moreover, cuts to provision have disproportionately affected people who are deemed 'non-productive' i.e. who are not

active contributors to the economy, who may be older, low skilled and/or digitally excluded (Appleby and Bathmaker 2006; Eynon and Helsper 2011). Consequently, many people with learning disabilities experience uncertainty as the sector changes and day centre services are not adequately replaced by alternatives. As eligibility rules are tightened, many people are deemed not to be entitled to support, so occupy an 'in-between' space – 'too able' to receive funding for care and support, but without the skills to gain employment or undertake mainstream college or community activities (Hall and McGarrol 2012).

While we recognise real potential in personalisation, and the prevention and community focus envisaged, we nonetheless remain aware of the challenging political, social and economic climate within which these policies are emerging. Our research advances a detailed account of the experiences of people seeking to self-build their daily lives with local networks in local places. It explores the capacity of support organisations to enable active community lives and lifelong learning for people with learning disabilities, amidst a decline in collectivised forms of support.

Our research

The research aim was determined through working closely with the Southampton Platform for Inclusive Research and Ideas Together (SPIRIT), and our national stakeholder partners, Think Local Act Personal (TLAP) and the Scottish Commission for Learning Disability (SCLD).

SPIRIT formed our initial advisory group, which expanded to include a range of disabled people's organisations in Scotland. The research team collaborated with the advisory-group partners throughout the project to formulate the research methods, to frame the questions to ask, to hone the methods for capturing the experiences of people with learning disabilities, and to discuss the findings and how to communicate them to others.

With this engagement, the aim became to find out about how people with learning disabilities are experiencing and responding to the changes in social care, the learning that is involved, and how support organisations are adapting to the changes.

The research comprised three phases:

- Phase 1: Area-based scoping study
- Phase 2: Research with people with learning disabilities
- Phase 3: Analysis

Phase 1: Area-based scoping study

We chose four case-study areas in the UK – two in England and two in Scotland (one urban and one rural in each). We looked at community-based day support provision in each area. We interviewed seven local authority representatives (commissioners in social care and learning disability leads) across one of the urban and two of the rural areas. We also interviewed 39 staff at 29 organisations providing a range of day and evening support and activities, as summarised in the list below.

- Voluntary work and training initiatives
- Neighbourhood group schemes
- Day services (including a day centre in transition to social enterprise)
- Peer networks
- Friendship and dating groups
- (Self-)advocacy groups
- Gardening / farm projects / enterprises

These opportunities were predominantly organised and facilitated by micro-enterprises and small charities. Micro-enterprises have been shown in other research (Needham, Allen and Hall 2015) to deliver more personalised, innovative and valued support for a similar or lower cost than larger providers. However, small-scale projects can find it hard to get started and to stay in business due to the lack of local authority contracts and the promotional resources of larger organisations.

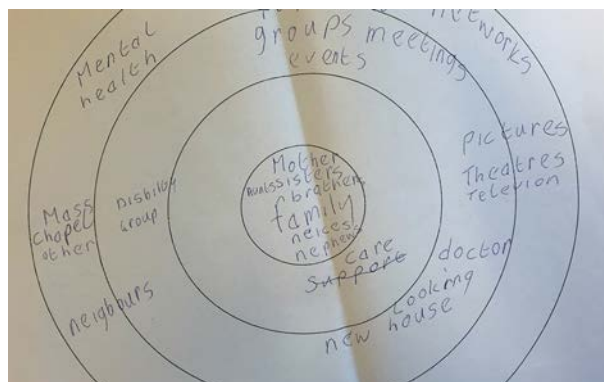
We interviewed managers at each organisation and undertook detailed observations of group activities and events, attending steering-group and management meetings over a four-month period. In addition to the above list, we undertook a one-off interview with a Theatre Group.

Phase 2: Research with people with learning disabilities

We chose two organisations in each area through which to contact people with learning disabilities. We looked at who was attending and participating in the activities that each community-focused support organisation facilitated. We spent time with 43 people with learning disabilities (24 men women and 19 women; aged 18-70) in four areas, two in England and two in Scotland (one urban and one rural in each). Two participants were Asian British and the remainder were White British.

We recognise that in using this method we are likely to have left out people who – for a range of reasons – were not accessing the kinds of community initiatives we explored. People with profound and multiple learning disabilities (PMLD) and people from ethnic minority families, for example, were less visible in these organisations’ activities. A lower uptake of health and social services by people from black and ethnic minority families is evident more generally across the UK (Fulton and Richardson, 2010). While some people with PMLD came to events, they typically attended with their own support or with family members and remained on the periphery of verbal discussions. The findings we present are largely derived from people with more mild and moderate learning disabilities and lower support needs, although large variations existed within the group.

To capture participants’ experiences we used focus groups followed by individual interviews and observation of activities. To include as many people as possible and to extend their engagement in the research, we used additional interview facilitation materials, including a circle of ‘people in my life’ and a schedule of a ‘typical week’ (see Figure 2) alongside visual representations of activities. The design and use of these materials were informed by our advisory group members.



NAME: _____

Your 'typical' week

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Morning	Cleaning Bedroom	Work 9-1 PM	Cleaning Living Room and tables	Washing	Coffee with friend	Bedroom and bathroom cleaning	make bed
Afternoon	Bank Shop Work 12-2 PM	Out for coffee with friend	Shop Work 12-2 PM	My sister	Go to visit my sister	Books Shall 13.00 to 16.00	Washing Iron
Evening	Watching TV Some time	Watching DVD	Group every 2 week	6 PM 8 PM	Go to my sister	Watching TV	Opp Washing Bedroom Shopping

Fig. 2. Examples of interview facilitation materials

Phase 3: Analysis

The data were analysed in an iterative process. Initially individual members of the research team focused on exploring a single aspect of the findings, namely:

- the landscape of care (the role of local authorities and social care initiatives in supporting self-building)
- the sustainability of voluntarism by people with learning disabilities and non-disabled people
- the lived experiences of people with learning disabilities
- evidence of informal, community and lifelong learning

Pre-set and emerging data codes from this process were later brought together and core themes were identified. The analytic process allowed us to identify the places people attended, the activities they participated in, the roles they took up, the learning they engaged in, and the issues that arose in self-building daily lives. The names of all individuals and organisations who participated have been changed to protect anonymity.

What we found: The building blocks to support community living

This part of the report shares what we learned about the experiences of people with learning disabilities who took part in our research. It considers the ‘building blocks’ needed to allow people to self-build their daily lives when they have responsibility for social care and support (see Figure 3, next page). We show the challenges in securing these building blocks and what some people are doing to address them:

Planning the essentials:

- Planning and finding support
- Finding out information
- Getting your voice heard

Managing the day to day responsibilities:

- Managing benefits and money
- Running a home
- Getting around
- Keeping and feeling safe in the community

Finding meaningful things to do:

- Spending time with friends and family
- Getting involved in disability groups
- Doing leisure activities
- Volunteering and working

Resource Packs

Companion resource packs featuring each building block are also available to use with people with learning disabilities and their supporters in discussions about self-building a community life. Download at <http://bit.ly/2TDrMp8>



Resource Pack



Easy Read Resource Pack

Fig. 3 Building a life in the community is about supporting each of the following building blocks:





Planning the essentials

First, planning support is needed. Finding information and staying up to date is key and requires enabling people to build confidence, skills and agency.



Planning and finding support

'Someone else will be watching you and they'll be thinking, oh, I might like to do that.'

What is known already

Planning daily activities and for the future is often a major concern (SCIE, 2007). Family can be important to help people to plan and find services, and to give emotional and practical support. But family support is variable. A key part of planning is finding people who can offer support and help. This might include peers who themselves require support, a citizen advocate (a person who volunteers to speak up for and support another person), family, friends, a personal assistant, support worker, or volunteer. Having independent brokerage by disabled people's organisations during the support planning process offers personal budget users the best way of achieving control to manage things for themselves and to challenge them to think about their lives (Office for Disability Issues, 2011).

What we found

Despite the potential for brokerage to enable people to plan and generate more creative ideas for support in the community, we found that this potential was still largely unfulfilled in the areas we examined. In one council, brokerage was available through the in-house council brokerage team, but a local manager of Connecting Communities argued that this team focused largely on the council framework (list of preferred providers) and was a barrier to the up take in direct payments. Acknowledging the need to address this issue, a commissioner in the same local authority felt that a peer-support and self-advocacy organisation would be better placed to provide independent brokerage:

I think what's massively missing at the moment, you know, from the [local care sector], where LD Self-Advocacy organisation could and will be fantastic at providing, is that brokerage, support brokering. Hang on a minute, you're not happy with your provider? Well, how about we help you find a new provider and help you broker something else that does work for you? Maybe there's something in there around the peer organisations doing something a bit more creatively around filling those gaps where they've identified through the peer advocacy what the problems are and fill some of those.

– Commissioner

Support planning more generally was ad hoc. Many participants talked about person centred planning no longer taking place and having limited access to a social worker or advocate. Statutory advocacy provision often did not meet people's needs. We found that some council's contracts allowed only 8 hours advocacy support per case. This was not adequate for those with complex communication difficulties or more challenging cases.

One important route to getting support to plan one's life was through accessing local neighbourhood and friendship groups. These groups offered networks of support for people to plan in a more bespoke manner, through information sharing, peer learning, and capacity building. These groups were typically organised through charitable, community interest and local-authority incentivised organisations. The peer support available in these situations was important for sharing experiences and for building the confidence and self-esteem to create wider friendships and acquaintances with all kinds of people across society. We found many examples of this type of peer support:

I recently noticed once you do something new, someone else will be watching you and they'll be thinking, oh, I might like to do that. So, you're influencing others as much as you're building up on yourself.

– Elaine, LD Self Advocacy Group

Because many of the people we spoke to were already engaged in these organisations and activities, we found that these participants had learned how to make contact, to keep in touch, and to arrange joint activities. They used skills in texting, using Facebook or WhatsApp, and local travel skills. However, the capacity to navigate community-based options cannot be taken for granted. Our participants sometimes learned from each other, but often needed people in organisations to get the learning started and sustain it.

While these groups offer much potential, the choice and provision of these groups was locally variable. As such, we found that participants' awareness and capacity to plan their daily lives, find out about the support available and how to access it was also variable.



Finding out information

'It's so tricky finding out what's on.'



Photo: Miriam Doerr Martin Frommherz, Shutterstock.

What is known already

As social care is increasingly based on making choices amongst day and evening opportunities, finding out about these can be a challenge particularly for older age groups (NICE, 2018). People with learning disabilities want information and guidance on things like benefits and support (Disability Rights UK, 2018).

What we found

Some people who took part in our research used smart phones and computers to search for information, network with friends and find out what others were doing. Use of these technologies varied however. Some people did not have access to them or the skills or capacity to use them.

The social media side of it is becoming more and more important as well, that's been really [growing], we're finding a lot of our members are actually supporting each other through things like the Facebook page and through Twitter and so on.

– Greg, Disability Rights Organisation

Many learning disability organisations produce regular printed newsletters updating their members with news and activities. These may also be sent by e-mail to reach as many people as possible. One council organised an annual Open Day for people with learning disabilities which enabled those attending to find out information about social, learning and work opportunities as well as from care and support services and other organisations (such as bus companies).

However, being part of a learning disability self-advocacy group or friendship network was the most helpful way of keeping up to date, enabling members to share information and experiences with each other. Organisations like these were also able to signpost other organisations and opportunities in the local area.

Our participants continued to rely on trusted key workers and family members to find information or provide guidance. Some talked about using volunteer centres and Citizens Advice. Social workers were seen as having local knowledge and contacts, to be able to advise and make referrals, but many of our participants were not able to access one regularly. Even with these channels, many people found it hard to keep up with changes in arrangements or schedules, or changes relating to benefits. In particular, information was not gathered in one accessible place.



Getting your voice heard

'You decide what you'll do each meeting.'

What is known already

People with learning disabilities can struggle to make their voices heard. They may have difficulties with verbal communication and information processing, and they may also have limited experience of taking control of their lives (Biesta and Teder 2007). However, through involvement in self-advocacy they can come together to speak up for themselves, become more confident and have a say about what happens in their lives. Self-advocates also listen to each other, provide support, resources and sense of community, and challenge things that work against their interests (National Forum of People with Learning Disabilities, 2011). In this way they change how they see themselves and gain greater control over their lives (Beart, Hardy and Buchan, 2004).

What we found

Participants' ability to build a fulfilling life in their communities came from gaining the confidence to make their voices heard. Building on earlier research, we found self-advocacy was key to forming the ability to speak out, make decisions and take part in discussions about their lives. Amy spoke of how her local self-advocacy group gave her the confidence to tackle issues arising in her house:

I'd go to [the agency], speak to one of the staff in charge. I'd just go across. I'd speak to the manager.

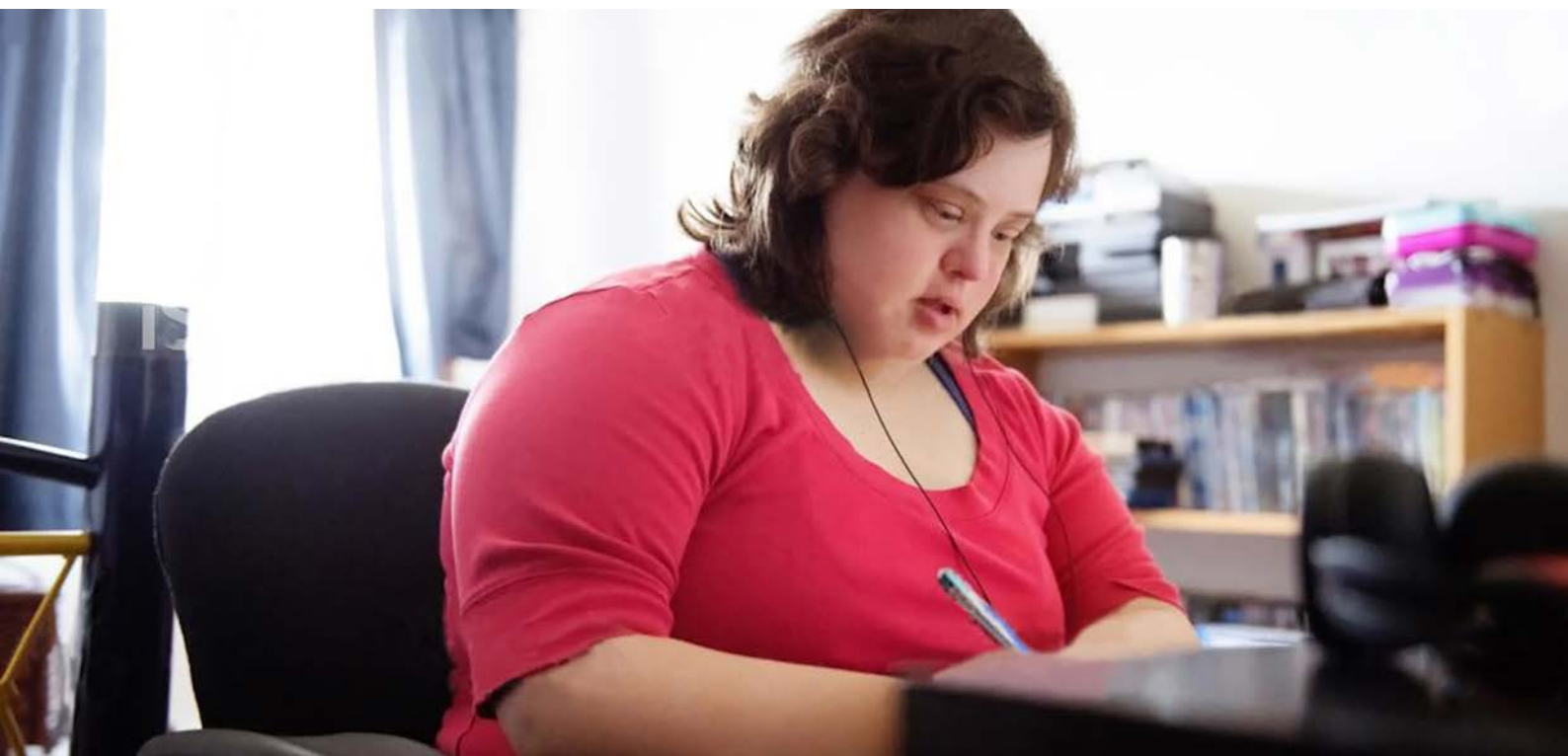
– Amy, self-advocate

Self-advocacy groups were valuable for learning. We observed people with learning disabilities supporting each other in tackling new challenges, offering emotional support, encouragement, and practical information. People were able to solve problems together and raise issues with an advocate. They learned to take on new roles as mentors, organisers and trainers while learning to speak up, make decisions and raise awareness of local opportunities and common issues. According to one of the paid advocate facilitators:

You have people around you, wherever you are that you can talk to. [Your Voice] was originally set up for people to come together and be allowed a voice. But now you guys [self-advocates] do that, but also decide yourselves what you're going to do, throughout the year, so you decide what you'll do each meeting. We've had the police, the firemen come and visit. We've had Citizens Advice.

– Brendan, paid advocate, Your Voice

Despite the potential of self-advocacy, we found that it is under real threat. Advocacy organisations in our research were struggling to maintain self-advocacy groups. One organisation was no longer able to provide staff to facilitate the group. The loss of self-advocacy and its variable availability is a major challenge to the potential of personalisation and community-based provision.



Managing the day-to-day responsibilities

We report next on what people told us about managing day-to-day, as they became more confident at home and out in the community. They spoke of learning and putting into practice a wide range of life skills and of the need to keep safe.



Managing benefits and money

'They give my mum the money and then she'll give it to me.'

What is known already

Managing money is a key skill required to live as part of the community. It contributes to being able to live more self-sufficiently. Managing benefits and money is demanding. There is a link between having a learning disability and experiencing poverty (Alcock, 2019).



Photo: Manonallard, iStock.

What we found

Our participants needed help to manage their budget, whether from family or a care manager. Many had little control over their budget but were relying on 'pocket money', typically arranged by a relative.

A small number of participants had secured paid employment (see Working and Volunteering, page 33). Most of the people we spoke to had access to some level of government welfare benefits, including Personal Independence Payment (PIP) and Universal Credit. Benefits assessments were a major concern for participants. One manager of a self-advocacy organisation stated that the transition from Disability Living Allowance (DLA) to PIP has been problematic:

[It's] an issue for members of our group because they have to then be reassessed and a lot of them are failing [eligibility assessments].

– Casey, manager, LD Self-Advocacy Group

We recorded many examples of people referring to cuts to their benefits and how this worried them. Sally had to go to a tribunal relating to her benefits re-assessment alone, without an advocate. We do not think this is acceptable:

It's horrible. Because I can't think on the spot, I take time to think of an answer and I feel pressured to get an answer quickly so therefore I mess up. It's just horrible ... My last assessment, my care manager is appealing it.

– Sally, self-advocate

One local authority had introduced charges for using day services for people on the higher rate of PIP. An advocate in the area stated that this was unfair since the higher rate was intended to meet higher disability-related costs.

Some people had taken part in money awareness training organised by their local self-advocacy organisation. Training included basic shopping skills such as comparing

prices in different shops, making a list and sticking to it, paying and checking change. According to the staff, training helped those who had taken part by improving their confidence with managing money. Not-for-profit money advice centres, where available, offered support to participants. Some talked about receiving advice and support from their local Citizen's Advice Centre, including help with welfare benefits and Universal Credit. One local authority had a money budgeting centre that offered support and advice tailored to people with learning disabilities.

As a consequence of the challenges with earning and managing money, there were lots of examples of people who did not have much money and who worried about it. Many spoke about how this shaped their experiences. Some talked about what they could not afford, including simple things like occasionally going out with friends.



Running a home

'Joan my care worker helps with managing my tenancy and with meals for the week.'

What is known already

Running a home is a key part of being in charge of your own life. More people with learning disabilities are living in ordinary houses in community settings. However, there is still some way to go to achieve more autonomous lives (Mencap, 2012).

What we found

Most of our participants lived in the community, in rented accommodation, with others in supported accommodation, or with one or both of their parents. Rented accommodation usually consisted of a social housing flat rented from the local authority or an assured tenancy with a disability housing provider.

We heard some positive stories of people living learning to live more independently:

I know how to do the washing and hang the washing, and Hoover my room and tidy up. I need to learn how to clean the bathroom.

– Rafael, self-advocate

Our participants often needed support to run a home, which was not always readily available, and in most cases was time restricted. They reported having to wait to see a care manager or support worker to address a problem. Some relied on help from siblings, or unpaid support from local relatives. Mason received help from his sister, who came to his house every Friday to help with meal preparation and the laundry. Others had no local family support.

Some participants reported that their support hours had been cut, leaving them stuck at home, watching TV:

[Staff] used to spend quite a lot of time with us lot, they used to take us out everywhere. That's a bit disappointing now because they tell us all to be independent. And I think that's wrong.

– Ian, self-advocate

One positive initiative we found was a collective neighbourhood volunteer scheme, Good Neighbours (see Case Study 1, next page) where adults with learning disabilities received support and offered peer support to each other.

CASE STUDY 1

Good Neighbours

'If someone has a problem, or is worried about something then they would talk to [others in the scheme]'

Good Neighbours is a charity set up in 2001 to support people with learning disabilities and other marginalised people to move towards greater social inclusion. There are about ten people in each Good Neighbours group, living near each other in an urban area.

Members of the group may be living in their own home, looking to move into their own home, or be living with family but hoping to be more independent. They receive practical support to establish their lives, to keep safe and become more independent. The charity aims for those involved to establish a life in which they are safe and more independent.

Each group is supported by a community worker, who also lives locally. The community worker offers flexible support, is available when needed, can intervene if a crisis arises, and is able to refer to other services if necessary. Community workers report to a central team covering a wider area, and there are administrative staff to provide support to the groups.

According to the community worker we interviewed, the group supports people to be more involved in the community, reduces feelings of isolation and loneliness, and develops people's confidence and self-esteem. Group members learn new skills, including independent travel, cooking, managing finances, volunteering and employment skills. Some members are also on the board of trustees and attend board meetings.

Good Neighbours groups meet every month with their community worker and are also invited to attend other events and meetings in the local area. These are important opportunities for members to learn something new and to meet others. They receive support from the community worker, but they also support each other, emotionally and practically, by travelling together or accompanying each other to hospital visits.

In the course of our research, an increasing number of people with learning disabilities who were no longer eligible for state-funded support were being referred to Good Neighbours, including a significant group of younger people transitioning to adult services.

Good Neighbours receives a grant from the local authority, which imposes eligibility criteria, limiting access to people not in receipt of other forms of support. Yet the charity focuses specifically on community access and social inclusion. People with practical care needs, for example, cannot access Good Neighbours, so although their care needs are provided for, they may become socially isolated.

Good Neighbours demonstrates self-building at its best. Its group members have a central role in its operation, it facilitates collective support and makes connections between individuals in communities. It focuses on members' assets and strengths to promote independent living and better quality of life, and helps people to build successful lives, supporting informal learning, independent travel, money management skills, employment, and friendships.



Getting around

'I was scared to get the bus for the first time.'

What is known already

Getting out and about on your own is an important aspect of independent living and a key goal of personalisation. To access community-based support, people need to travel more widely, yet fewer dedicated travel options like minibuses are available, and bus services are under real threat in many areas, especially rural ones (Commission for Rural Communities 2008). Problems with transport are a key challenge to the success of personalisation.

What we found

While travel training has been an ongoing focus for local authorities, significant issues remain. Our participants spoke about the importance of practising and gaining confidence in travelling independently, as much as learning the skills of planning routes and managing unexpected events. Being able to travel opened up opportunities for further learning.

The limited availability of bus services, particularly in the rural areas we studied, was a major concern for participants. Train travel, for example to see friends, was inaccessible for many on grounds of cost. For some participants, negative experiences of using public transport (for example, a lack of patience from drivers and harassment) was also a major deterrent. One parent and advocate we spoke to (James) discussed everyday difficulties that can arise when there is a change to bus routes or a cancellation. Support is sometimes needed to face these unexpected occurrences.

We did hear from participants travelling independently by bus. In many cases this was a new skill learnt after day centre closures, when participants had to access new venues and activities. It was vital to sustaining their social networks.

Because my speech is not good, that's why I was scared to get the bus for the first time, and mum took me, and then I just got the bus by myself ... So I can get the bus by myself to have a day to meet my boyfriend, now my mum trusts me.

– Sarah, self-advocate

Building the confidence to travel by bus can take time for people with learning disabilities and for families, who also need to gain confidence in someone travelling on their own. James, who had concerns over his son travelling independently, spoke of the need for technology such as a smart phone or other device to allow him to see where his son was. His son learned to use an alarm on his device when there was an unanticipated issue such as a change in a bus route.



Keeping and feeling safe in the community

‘Where you have a vulnerability sort of situation, you’ve got to be quite careful.’

What is known already

Keeping and feeling safe is important for people getting out more in their communities. Overall, the evidence suggests positive effects of individualised funding with respect to feeling safer (Campbell Collaboration, 2019). When people participate in activities and groups in the community, they will meet a range of people and encounter many different situations. Sometimes their experiences will not be positive. Companion animals such as dogs can increase people’s confidence in public situations and be catalysts for positive social interactions (Bould et al., n.d.).

What we found

Our participants showed strong awareness of the risks of harassment and the need to keep safe. Many had learned ways to avoid harassment when alone, such as staying away from large groups:

In the evening with football if I’m walking back through the park I sort of keep my distance from groups, if anything does happen to me, they’re in like the distance, a short distance between me and them, with a group of friends.

– Malcolm, self-advocate

Some participants reported that being a dog owner (or walking a relative’s dog) provided a sense of security and a different identity when out walking.

Those who regularly attended a self-advocacy group showed good awareness of safety issues and the need to be careful. In many cases local police had spoken to the self-advocacy groups about community safety. Other groups also organised sessions on keeping safe in the home and in the community. Staying safe online, which is increasingly important as people use smart phones and computers to access information and keep in touch, was also addressed at self-advocacy groups.



Finding meaningful things to do

The first building blocks concerned planning the essentials and managing daily tasks relating to a life in the community. This section deals with building a life with meaningful roles and activities. While many of our participants still attended a day service one or two days a week, most reported being involved in other activities. We report on some of the many different ways that participants were spending their time.



Spending time with friends and family

'Last Saturday there was about six, seven of us that got together.'

What is known already

Spending time and socialising with others is one of the most fundamental of our needs. People with learning disabilities often encounter major constraints to going out, meeting up, going to the cinema, eating at restaurants (Mencap, 2019).

What we found

Some participants had few opportunities to meet up with friends, especially in the evenings or at weekends. Some did not have the support to do so. Others lacked the awareness of what was available, or the confidence and voice to say what they wanted to do, find out how to do it, and arrange the necessary support and money. Some said that it was too expensive for them to go to the cinema or eat out at restaurants.

One person reported that everyone in his housing block had their own support budget and support worker, so they never did anything as a group. New build accommodation designed without communal spaces also limited socialising opportunities. Individualised contexts, support arrangements and budgets can make it hard to co-ordinate activities. In these ways, personalisation can mean living lives separately from each other.

Some participants had spouses, boyfriends or girlfriends. Some people in relationships saw their partner only once or twice a week, in some cases always accompanied by a family member or support worker. For those without relationships or family, or the ability to meet with friends independently, weekends were spent alone, stuck at home.

Our participants spoke of needing to build up their skills and confidence to meet and spend time with new people. Some lacked practical skills to keep in contact with the people they were friendly with, including competence in independent travel and in using an online social network like Facebook. Learning disability friendship groups such as Friendship MeetUps (see Case Study 2, next page) and getting out and dating clubs, where available, were an essential way for people to learn these skills. Participants talked about becoming more outgoing, more communicative and generally more confident through taking part in group activities in community settings such as nightclubs or theatre trips:

On Saturday we do our own thing, and the Friendship MeetUps members meet up on their own on Saturday nights. We go to the local bar about once a month. Last Saturday there was about six, seven of us that got together ... we arranged it.

– David, self-advocate

Participants reported they had attended with support workers or family members initially, but because of these experiences had learned over time how to make things happen and had arranged to go for a coffee together or a night out. One person had learned to drop in on an elderly neighbour and enjoy their company.

CASE STUDY 2

LD Self-Advocacy Group & Friendship MeetUps

'It helps you to be able to form relationships and you know ... help each other out if we've got any problems.'

LD Self-Advocacy Group is a charity led by and supporting people with learning disabilities to become stronger self-advocates. Founder and manager Casey promotes a 'theory of change' model of self-advocacy, describing a trajectory that starts with forming friendships, moves to learning to speak up for oneself and others, and progresses to becoming involved in the running of the organisation and its activities.

Operating across a rural county, the organisation is largely self-funded with some local authority and external funding, which has enabled the development of a member forum and various initiatives including a quality checkers service. Self-advocate Yvonne, who has a paid role running the forum, discussed the lack of core funding and the reliance on short-term projects through grants and donations.

Underpinning the ethos of the LD Self-Advocacy Group is Friendship MeetUps, which supports around 400 people with learning disabilities each year, running social and recreational activities in inclusive spaces and public venues. Most activities take place on, weekday evenings and include pub evenings and bowling which members pay for through subscriptions.

Friendship MeetUps organise information events, bringing in representatives from local authorities, services and organisations to provide information and guidance on issues such as health, transport and benefits, since members may struggle to access such information independently.

Friendship MeetUps is organised through a member-led, staff-facilitated steering group, which meets regularly to discuss feedback from club members and to plan the programme of events. Steering group members also support events, collecting subscriptions and organising activities.

Several members of Friendship Meetups described how they now arrange to meet up socially outside of the meet up programme as well as with non-disabled friends. They explained how attending Friendship Meetups brought them together and gave them the confidence and the networking and planning skills to socialise independently.

The organisation runs 'speaking up' groups nationally, enabling members to share experiences and knowledge and to problem solve key issues. One of these groups has become entirely member-led, with members taking on key roles and responsibilities with administrative support from non-disabled volunteers. A member-led management committee also engages with the strategic aims of the organisation and provides a link between the members and staff and the board of trustees.

LD Self-Advocacy Group is well recognised and respected by other organisations and providers working in the county. They provide social connections across communities, enabling peer-based support and learning opportunities and a collective voice for people with learning disabilities in the region.



Getting involved in disability groups

'I've become involved in our Friendship MeetUp steering group.'

What is known already

Getting involved in a local disability support group or with helping to design services provides meaningful activity for people with learning disabilities (NHS, n.d.)



Photo: Olesia Bilkei, Shutterstock.

What we found

Many people had gained the confidence and skills to get involved in their community from taking part in self-advocacy groups. Those who had gained these skills had been given the opportunity to take up positions on a management or steering group within their local disability support organisation.

In most cases, the organisations we spoke to were able to help members to build on these skills, by providing staff support at group meetings. A manager of one organisation talked about how having the opportunity to take part in group meetings had helped one person to take on the role of chairing the steering group:

Dennis is very much a can-do kind of person, you know... And it's really nice to see, although it's individual advocacy that these guys have maybe come to us with, but actually it's a group environment they're really flourishing within, so within the board or the steering group, you know, and actually having influence on his own group of friends as well.

– Ellie, manager, Independent Advocacy Project

We heard examples of people taking other roles, such as a campaigning role talking with children in schools about bullying. One participant, Freddie, took part in a national campaign to put an end to bullying and isolation among people with learning disabilities. As part of his role as a 'change champion', Freddie had delivered workshops across the country, speaking to schools and other organisations about the effects of bullying and what can be done to challenge bullying.

These activities were meaningful for the people involved and helped them to gain confidence in other community settings. Participating in disability organisations introduced people to active roles where they could learn incrementally. Peer-to-peer learning was taking place, with role models to follow and peers with similar experiences to share support and advice.



Doing leisure activities

'They should have more clubs open than just ... once a month.'

What is known already

Spending time on enjoyable and meaningful leisure activities is important. According to a SCIE review (2007) they enable people with learning disabilities to do things that have a purpose, develop friendships and spend time in ordinary places. Given the barriers to finding work, people with learning disabilities often have more 'free time' than the general population. Taking part in leisure activities can be an important way to avoid feeling isolated. As day centres have closed, people are having to find different ways to access leisure activities.

What we found

Many activities are freely chosen by individuals who have the will and means to do so, but different barriers affected how participants spent their time. In some areas, activities were closing down due to funding cuts and broader changes in the local area. This was a point made by Sally about her town in a rural area:

The day care is closing down, the lunch club is closing down, I don't know about everything else ... There's loads of shops closing down. It'll be a ghost town soon.

– Sally, self-advocate

For many participants there were few things to do at the weekends or evenings, due to limited availability of support, lack of budget and fears over safety when doing things alone.

These opportunity limitations remain, but as noted earlier, organisations in some areas were facilitating group leisure activities for people with learning disabilities through friendship groups and events. These ranged from performance, arts and crafts, monthly discos, to sports (indoor and outdoor) and other active occupations such as walking and gardening. They provided essential connections for participants no longer attending a day centre. Most took place in public venues, enabling links to the wider local community. While inclusion in the community was important, participants reported enjoying group activities with other people with learning disabilities. They were seen as enjoyable ways to be with their friends.

Some self-advocacy group members spoke about using texting and WhatsApp to arrange social events outside the organisation:

Some of us meet up on a Monday. We go to Go Lounge, we go to Vines or we go to the cinema. We see all different films at the cinema.

– Michael, self-advocate



Volunteering and working

'You get a shot [turn] at the till.'

What is known already

Having a job is a major goal for many people with learning disabilities. Working, whether paid or unpaid, can contribute to wellbeing and build confidence and self-esteem. And of course, paid work is a way to earn money. Paid work is one of the most difficult building blocks for people with learning disabilities to achieve. Across England, only a small proportion of people with learning disabilities (7.1%) are in paid work and 89% of this work is part time (NI Assembly 2013).

What we found

A few people referred to having a 'real job' i.e. paid work. One participant worked in a supermarket, another as a receptionist in a community centre, and another as a cleaner. Most participants did not have a paid job. Many were eager to work for financial reasons and to gain independence.

Many participants had followed 'ready for work' courses at college with the hope of eventually getting a paid job, but in many cases these did not materialise. Some reported feeling 'stuck' and bored in college, as they attended similar courses over several years. And some found it hard to learn at college, because they needed additional support or the environment was too noisy and busy. The lack of opportunities to progress into 'real' and sustained employment remains a major issue.

Participation in voluntary roles was more common and generally valued by participants. Several participants volunteered at least one day a week. Jobs included sorting clothes in a charity shop, working at a food bank, cleaning a church, helping out at a community centre, fixing up bikes, gardening, working in a bookshop, serving in a café (within a Learning Disability service site), and doing administrative tasks for the local authority. Participants had typically found volunteering and paid jobs with the help of support staff.

Most participants reported positive accounts of their volunteering work. Someone who works as a volunteer in a bookshop (see Case Study 3, next page) got to try new things:

You get a shot [turn] at the till, which is good, I've never had a shot of a till ... and I like pricing items like DVDs, books.

– Billy, self-advocate

While these skills were significant in themselves, most participants still struggled to overcome the widespread obstacles faced in transitioning to the world of paid work.

CASE STUDY 3

The Bookshop Project

'This place gave me confidence to speak to other people ... and now I've got my skills back I had when I used to work when I was younger.'

The Bookshop Project supports people with a learning disability to gain skills and experience in customer service, selling used books and CDs. This is done through a person-centred learning approach which ensures that everyone has an opportunity to learn in a way that suits them.

The Bookshop Project is a registered charity, co-founded by Frances, the development worker for the charity. The board of trustees consists of people with a personal and/or professional interest in the work of the Bookshop Project, and includes a parent of one of the volunteers, several council workers and professionals from local and national disability organisations.

The charity started as a pop-up book sale at a local cafe which ran every two weeks. But the aim was to secure a permanent premise to set up a 'proper' book shop. This occurred in September 2018, with the help of small grants from a range of charitable trusts and donations. This funding now pays for Frances's full-time salary, a part-time support worker and rent for the building. By securing a permanent base, the Bookshop Project has a visible presence in the local community, in the centre of the town, housing the bookshop, a staff room area, office, kitchen and training room. The volunteers who work there, now have important opportunities to engage with members of the community on a regular basis – talking to customers, selling books and engaging in fundraising activities on behalf of the organisation.

The Bookshop Project offers introductory training to every new volunteer. The training takes place in small groups (two or three trainees) so that staff can support volunteers individually to learn in a way that suits them. Training includes customer service skills, use of the till, pricing, health and safety at work and disability awareness training. The project also runs a peer-mentoring scheme for volunteers who have acquired the skills and experience to support newer arrivals. Peer support and the opportunity to make and meet new friends are essential aspects of the project's approach. Volunteers described to us how coming to the bookshop had helped them to feel more confident about socialising with others.

The Bookshop Project is popular; the registration of over 60 volunteers demonstrates the project's success as an organisation. However, demand for the service also highlights a lack of comparable opportunities in the area, and the extent to which the organisation is filling a gap in provision which is not being met elsewhere.

The Bookshop Project demonstrates self-building through its provision of a designated space where friendships and collectivised forms of support like peer mentoring are able to emerge, and by the ways in which it allows people to make changes to their life, by enhancing their skills in customer service and building confidence and self-esteem.

What we found out about the support sector

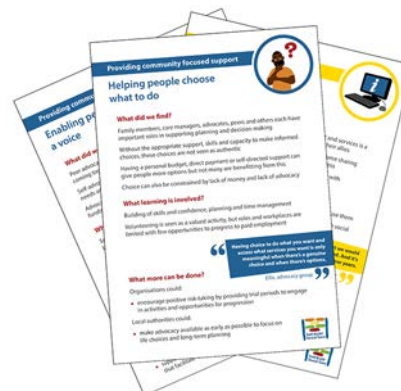
The support sector is essential for enabling people to self-build their daily lives, however we found organisations face significant challenges. Many of those in our research (primarily small voluntary and charitable organisations) are in precarious financial positions. Given the policy emphasis on enabling people to self-build their lives, government and local authorities have an important role in supporting the sector to learn, adapt and be sustainable.

We share the views of managers and other staff members, as well as commissioners, who took part in the research about the conditions that are needed to sustain their support provision and to become more member led:

- Challenges in building a sustainable support sector
- Getting people involved in taking a lead
- Managing volunteers
- Balancing family, peer and staff support
- Balancing risk and independence
- Creating a learning culture

Resource Packs

A companion resource pack is also available to guide discussions amongst commissioners and support organisations. Download at <http://bit.ly/39I55Wy>





Challenges in building a sustainable support sector

'It's about using all our resources the best way we can to ensure our sustainability.'

Most of the support organisations present in the local areas in our research were micro-enterprises and small charities. Most managers had taken financial risks, particularly at the time of setting up their organisation or initiative. Managers expressed awareness of the diverse needs amongst people with learning disabilities, related to age, degree of impairment, educational background, family support and availability of other opportunities. In effect, organisations have to be highly adaptable and offer multiple 'entry points' for people at different stages and of different abilities.

Once established, most organisations were supported by a mixed-funding model, comprised mainly of charitable and voluntary funding. Funding was often linked to specific projects; there was significant reliance on short, fixed-term grants such as Big Lottery money. These were regarded as valuable resources, but the perils of relying on this type of funding were noted by many managers. One participant stated that a sole reliance on fixed-term funding for specific projects barely allowed the organisation to cover its overheads. More generally, the short-term bidding culture put great strain on organisations, particularly as little support for business and financial skills was forthcoming from local authorities.

Other research (Needham, Allen and Hall 2015) shows that many of these micro-organisations fail. In our study, two organisations ceased operating over the period of the project, despite being heralded as models of innovation by the local authority. A market of care and support is often assumed to be present in the personalisation landscape, and personalisation has sought to create a model of funding via users' personal budgets. We found little or no support for capacity building for organisations operating within this market.

According to one of the social care commissioners, it was a real challenge for the local authority to free up resources to support preventative initiatives that organisations were seeking to sustain even though statutory guidance to local authorities emphasises the importance of prevention within personalisation:

How do we support the market or support the community to take some of these initiatives forward? Yes, I'd love to spend lots of time doing that, it's the really interesting part of the work, but some of the bigger things always over-ride.

– Commissioner

A different commissioner in the same local authority reported that they had established a local voluntary and community collaborative network as a way of bringing the sector together to work collectively on preventative work. This was described as a means of offering 'community connector' support, to link people to opportunities and to support referrals to social prescription services.



Getting people involved in taking a lead

'It's being asked to be involved, that's lovely, that's so nice.'

The importance of listening to and acting on people's experiences, views and opinions was a fundamental value embraced by many organisations. It was an important strategic priority to be more member-led. We found a range of ways that people with learning disabilities were getting meaningfully involved. Examples included opportunities to join and chair the steering group of a local support organisation to inform and plan its activities, and participation in annual feedback events.

One manager outlined both the value of people's involvement in steering their activities, and what needs to be in place to enable it to happen:

Knowing what people want from us is really, really important, so we would have people on the boards that would have a learning disability with access to advocacy. So we have the steering group, which is probably a bit more of a supported group environment that's facilitated by Hazel. It's chaired by a member of that group, and then they would look at the strategic development of the citizen advocacy, and then we try to have as much accessible [information] in that meeting as possible, so the policies are accessible, the workplans are accessible.

– Ellie, Independent Advocacy Project

The team identified three factors as essential to developing these values: (1) each contributor has access to advocacy, to build their capacity to contribute meaningfully to the group, (2) the group is supported by a paid facilitator to ensure that exchanges between contributors are meaningful, and (3) the policies for discussion are presented accessibly.

We found that organisations need to have learning cultures to be sustainable; this means that members and support workers can reflect on and solve problems together. However, we observed that learning opportunities were often missed or narrowed when transformation in services was not member-led.



Managing volunteers

'People think volunteers just go and do things. They need leaders.'

Current social care policy champions co-production with community members in providing support provision. We observed evidence of community volunteer involvement in supporting and facilitating organisations' activities. We also identified examples of people with learning disabilities taking on volunteering roles, such as helping their peers on courses or activities that they have previously undertaken.

A manager of a community credit scheme shared her experiences of developing a mentor model to support volunteers with learning disabilities. Mentors were local community members like citizen advocates who had agreed to support someone with a learning disability to volunteer. The mentors help with finding placements or offer support with networking to people who need low intensity support and pointing in the right direction. The community credit scheme had built up a network of local businesses, such as restaurants, to honour volunteering credits, which could be 'spent' in their business.

However, finding and managing community volunteers is a key challenge for support organisations. Managers spoke of the need to fund and free up staff to supervise volunteers, and some referred to the lack of resources to do this. The manager of Friendship Meetups explained:

We used to engage volunteers massively throughout our projects but they still need supervision so there's an element where as much as we could get people to volunteer lots of their time, I think realistically, expectations are that we are working with vulnerable adults and there does need to be some staff support as well in many of these areas. We do use volunteers where we can but we also do a risk assessment so there actually does need to be a member of staff involved.

– Casey, Friendship MeetUps

Another manager spoke of the need to pay volunteers if high quality involvement was expected or if the role involved a more intensive investment of time. Otherwise, she felt that it was asking too much of people.

Given the short-term nature of funding, sustaining a volunteer's involvement can be difficult. Part of the challenge is to recognise the financial and staffing demands that organisations need to invest to maintain a sustainable body of volunteers.



Balancing family, peer and staff support

'I can't do this all on my own.'

Balancing support from family, peer and staff lays the foundation for the building of successful lives in communities. As one manager stated:

It's always been about help, making sure people are as independent as possible and achieving their potential, but getting the right support to do that.

– Sandra, manager, Castlehill Resource Centre

Most of our participants had some support from family, including parents and siblings, although this was variable. Relying solely on family caregivers can strain family ties and impede the development of independence (Kings Fund, 2006). Moreover, parents cannot sustainably offer a safety net for people with learning disabilities as they age and increasingly outlive their parents.

Participants who had accessed opportunities for peer-support had formed sustainable networks of support and were resilient to these risks. We found that those people who demonstrated the greatest capacity to self-build community lives had done so through peer support found in a self-advocacy group, a steering group, or a friendship group.

It might be housing that's a problem for people, it might be relationships, it might be budgets, there are all sorts of things that affect people, social media and on-line bullying, that kind of thing. And it's an opportunity for people to come together and talk about those things that are affecting them.

– Casey, manager, Friendship MeetUps

For successful self-building, those working in social care should encourage a balance between family and peer support. In our research, many support organisations were trying to foster and facilitate peer support opportunities using paid staff facilitators. Our participants were becoming more involved in organising roles, but organisations – including member-led organisations - did not run solely by themselves.

Even with the significant benefits of peer support, almost all of our participants living independently required some paid staff support in the form of a key worker or community worker (for example, Good Neighbours – see Case Study 1, page 25). Paid staff support was typically used for help with personal care, planning meals and shopping, as well as pastoral support. This is the type of support that underpinned many participants' ability to self-build their daily lives. Finding the balance between family, peer and staff support in a co-productive manner is crucial.



Balancing risk and independence

'There's a fine line between safe and segregated.'

Balancing risk and independence is a fundamental part of social care and support delivery. Overall, the evidence suggests positive effects of individualised funding with respect to quality of life, client satisfaction and safety (Campbell Collaboration 2019).

Given the policy emphasis on connecting people with learning disabilities with the wider community and using community assets, support organisations have to work in new ways. Participating organisations were very aware of the challenges of balancing risk and independence for their members.

The friendship and community-focused groups in our research were keen to emphasise that they sought to use venues in the community for group meet-ups, including local bars, coffee shops, garden centres, parks and other public amenities. Policy emphasises inclusion within the wider community, but we found that there is still a need for inclusive and supportive spaces to be provided - in community centres, sports centres, cafés and pubs - where groups of adults with learning disabilities can meet. Limited public acceptance of people deemed to be different or who are using different forms of communication is part of the issue, but also low expectations of disabled people in society have curtailed their confidence and communication skills.

A large proportion of the increasingly diverse day service sector is not regulated by the Care Quality Commission. Some commissioners we spoke to found this problematic and had developed their own internal schemes. However, these did not cover smaller support organisations or other activities people chose to spend their personal budgets on. We included some of these types of organisations in our research. We found that managers had a healthy and well-informed attitude towards balancing risk and independence in negotiation with families and carers. Indeed, some managers considered the wider learning disability service to be highly risk averse, arguing that such caution compromises people's freedom to take part in community life.

A proactive attitude to risk was shown by most people with learning disabilities in their approach to safety in the home and community. Participants said that they accessed information through their local self-advocacy group, including visits by the police. In the course of this learning, many shared personal stories about ways that they tried to keep safe.



Creating a learning culture

'We realised that we haven't got all the skills, but we've got some good skills ... So, that invariably means coming back to the staff here and involving them.'

The new social care context explored in this research indicates that for people with learning disabilities, learning must occur outside of building-based services, in the communities in which people live and participate. The necessity to build their own daily lives from information and resources within their local community should generate multiple opportunities for learning with and from others.

The support services in the research varied in how much they purposefully, or incidentally, supported informal, peer learning. At their best they recognised that they could create a learning culture in which peer mentoring and peer learning were resources to be promoted and valued; they understood that they were part of a support system and learning network.

Learning within the self-building of daily lives happened through informal and ad hoc support among peers, through organised but unpaid peer support by volunteer mentors, and occasionally through paid peer support. Often such peer learning needed support from local services to get started. It could then become self-sustaining and support lifelong learning, enabling people with learning disabilities to enjoy long-lasting participation in which they could develop new skills and progress to take on new roles and build new identities.

Laying the foundations for self-building: What more needs to be done?

People with learning disabilities can benefit from the personalisation agenda to self-build a meaningful and fulfilling life if the right support is in place. We used the term self-build social care to denote a social care system that helps people to self-build their lives. Our research shows that currently support is uneven in availability and quality and does not enable everyone to develop their capabilities. This variability needs to be addressed before we can expect more people to feel confident to transition to using personal budgets.

Advocacy and support organisations told us that people in the most vulnerable situations were being 'left behind' in this new social care landscape, and that it was exacerbating social inequalities. We suggest that people will only choose to use personal budgets to self-build if they see examples of others like them for whom it has worked. Commissioners can only mobilise innovative support choices and help people envisage quality alternatives, if they have the capacity (funding) and power to do so. Commissioners explained how local authorities 'lack the teeth' to mobilise the sorts of radical innovations in service delivery that the policy aspires to.

This project has led us to identify the following key recommendations to encourage and support local authorities to enable more people with learning disabilities to take up these opportunities. The following foundations are thematically ordered based on the building blocks above:

- Helping people to plan the essentials
- Supporting people to manage the day to day responsibilities
- Enabling people to find meaningful things to do
- Foundations needed for a sustainable support sector

Helping people to plan the essentials

Helping people choose and plan what to do

- Making advocacy available as early as possible can help people with learning disabilities to focus on preventative choices and avoid problems that result from an absence of choices or lack of activities.
- While statutory professional advocacy is vitally important in helping people in times of crisis or major change, for the purposes of self-building community lives, the aim of all forms of advocacy should be to support people to self-advocate as far as they are able. A core goal of self-advocacy is to build a person's capacity to decide what they want and to carry out plans to achieve it. This point is echoed by the Social Care Institute for Excellence (2014).
- It is important for local authorities to ensure that people with learning disabilities have access to peer-support opportunities, in a friendship group or community circle. Many such groups facilitate peer support, including People First organisations. These have a critical role in helping people to develop the agency required to choose what to do. This is especially important in areas where day centres have closed and for people accustomed to attending them. Funding could be through direct commissioning, using a grant or agreeing to part-fund with a Big Lottery bid. As our resource for organisations that support people shows³, local charities find it difficult to fund their activities and to reach out to new members.
- Commissioners could also identify and establish a linking (brokerage) role, to facilitate more people to navigate the support landscape. Social workers could also play a role to encourage more people to use their personal budgets for group activities, but most people in our study either did not have a designated social worker or did not see one from one year to the next.

Enhancing information and communication

- Local authorities, as required under the Care Act 2014, could try to make information easier to access and understand, in different formats (not just digital) and updated regularly.
- We found that face-to-face information sharing is valued, for example, at Open Days where support providers and other organisations (such as bus companies) can share information about what they do and meet people with learning disabilities.
- Local authorities and providers can work together to create a directory of all services and activities in an area.
- Local authorities could also support greater communication and a culture of collaboration amongst support providers through a provider forum.

Enabling people to have a voice

- A key finding in this research was that the ability to build fulfilling lives in the community came when people with learning disabilities gained the confidence to make their voices heard, and from raising expectations, aspirations and awareness amongst the wider community that people have choices and the agency to make them.
- Local authority commissioners could recognise the value of and financially support organisations that facilitate self-advocacy in their local areas, and foster connections with them.

³ http://selfbuildingourlives.org/resources/organisations_that_support_people/

Supporting people to manage the day to day responsibilities

Managing benefits and money

- We recommend that support organisations refer to the Money Matters toolkit⁴, which we see as a resource for organisations to use to develop training for their members. According to the staff members leading this training, people with learning disabilities can gain confidence in managing their money.
- Policy makers could help ensure information on benefits is clear and accessible and that people with learning disabilities have access to local advice centres.

Helping people to run a home

- While local authority and housing associations have done much to provide opportunities for people with learning disabilities to get tenancies and to support life skills, this progress is under threat from cuts to social care. There is a gap for community initiatives to develop skills in running a home that are more communal, like neighbourhood schemes (see Good Neighbours in Case Study 1, page 25); participants in this study valued these where they did exist.

Supporting independent travel

- Local authorities could recognise the importance of transport when planning their social care market. They could consider systemic solutions to prevent further decay of bus services and the isolation this can bring, alongside efforts to enable people to travel independently.
- Organisations could plan with transport and travel challenges in mind from the start. They could consider how to enable volunteers and peers to support others with schemes like travel buddies.
- Bus companies should be encouraged to provide more training that recognises the specific needs of people with learning disabilities.

Balancing risk and independence

- Organisations and advocates can help people with learning disabilities learn strategies to stay safe in their homes and communities, to feel confident and have the skills to get out and about in their local areas, take up new opportunities and meet new people.
- It is challenging for local authorities to balance risk and independence in the choices and opportunities provided for people with learning disabilities, including use of self-directed support, because of underlying concerns about adult protection. Nevertheless, such concerns can constrain creative responses to support social and other meaningful activities.
- Local authorities could work more closely with parents and carers on managing risk. This may be through commissioning an organisation to provide training about managing community safety or supporting a parent and carer forum.
- Self-advocacy organisations provide much support and advice on managing community safety. Friendship groups work with people with learning disabilities and advocates to establish social and peer networks, including people and groups in the local community. These activities can reduce fear and risk and enhance feelings of safety. Local authorities could recognise and financially support these activities and promote them more widely.

⁴ <http://selfbuildingourlives.org/res/files/Money%20Matters%20Toolkit.pdf>

Enabling people to find meaningful things to do

Facilitating engagement in social activities

- Local authorities could recognise the need for commissioning peer-friendship groups in their area. This is one of the most valuable ways through which people can gain more autonomy.
- To participate in active social lives, some people with learning disabilities may need additional support with travel training, guidance on relationships, and keeping safe at night.

Volunteering and working

- There is currently a mismatch between the aspirations for work of people with learning disabilities and the opportunities available to them. Individuals will need support to gain volunteering and work placements and may need ongoing (not time-limited) support to make placements successful and sustainable. A limited range of types of placement is currently in use; support could be preferentially offered to organisations and individuals finding creative and flexible approaches to the types of roles people with learning disabilities might undertake.
- Those who wish to work may need support to gain and sustain paid employment. Local employers can play a role in providing appropriate opportunities; local authorities, public sector employers and charities can lead the way.
- Personal assistants could be encouraged and trained to support people to gain, learn and sustain a variety of types of work.

Getting people involved in disability organisations

- Support organisations of all types could develop more opportunities for people to get involved in roles that shape the organisation. A steering group, for example, can help identify the activities members of the organisation would like to do. This is key to building a sustainable and responsive support sector.

Providing opportunities for meaningful leisure activities

- While some people use weekends and evenings to relax and spend time with family and friends, others would benefit from more organised social and leisure activities, including opportunities for social evenings, days out and holidays.

Foundations needed for a sustainable support sector

We identify five additional sets of recommendations which could lay the foundations for a sustainable support sector and ensure it remains community-focused and person-led.

Supporting organisations to provide community-based support

- Local authorities could provide business development opportunities for learning disability support organisations. Personalisation policy refers to the development of a social care market, but personalisation cannot thrive by relying solely on funding from individuals' personal budgets.
- We recommend organisations could read the All Wales People First 'Self-advocacy toolkit'⁵ for self-advocacy and related organisations about ways of 'earning money', as opposed to 'getting funding'.

Getting people involved in taking a lead

- Local authorities and providers could do more to support day centres learning to become more member-led by providing time and support for meaningful consultation and collaboration.
- Transitioning organisations and innovators seeking to set up new initiatives need to involve people with learning disabilities and their allies in their planning to support mutual learning throughout the process.
- Our findings have shown that self-advocacy underpins all these processes and that funding self-advocacy makes financial sense, in that it can deliver the rewards of vibrant member-led communities that share support with each other.

Balancing family, peer and staff support

- The need for balanced family, peer and staff support underpins the key building blocks for successful self-building in communities. Local authorities could emphasise the mutually reinforcing nature of support provision from these different sources.
- Building up a network of peers in a process supported by staff can give people greater resilience and better opportunities to remain part of their communities.

Enabling organisations to manage volunteers

- We recommend that local authorities recognise the extra demands on organisational resources required to sustain the involvement of volunteers, and that support is offered for volunteer-management activities.
- We suggest that local authorities consider commissioning a local community credit scheme to help sustain involvement of community volunteers to foster learning disability volunteering.

Fostering a learning culture

- We advocate that fostering a learning culture needs to be part of ensuring that self-build care is sustainable.
- Schemes are needed to help people with learning disabilities to access routes to learning new roles and identities, to learn new skills, and to learn from and with each other and those with more experience. This learning, in informal everyday settings, requires some mediation and investment in fundamentals like self-advocacy.

⁵ <http://allwalespeople1st.co.uk/drill-toolkit-launch/>

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