

Aim: to understand the nature, scope and reach of the support local voluntary, community and faith sector (VCFS) organisations provide to people with learning disabilities in Cheshire East, and review their experience of delivering these services.

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## Introduction

### Learning Disability in Cheshire East

August 2019 (1)

Learning disability is...

*"A learning disability is a reduced intellectual ability and difficulty with everyday activities (e.g. household tasks, socialising, managing money) which affects someone for the whole of their life. People with learning disability find it harder than others to learn, understand and communicate. They may need support with everyday things, such as shopping and travel. Some physical and genetic conditions (e.g. autism, Down's syndrome, Fragile X syndrome, or cerebral palsy) can mean a person will have a learning disability. Every person's experience of a learning disability is unique to them"* (Mencap, 2018).

#### Cheshire East

There is **no definitive record of the number of people with learning disabilities in England**, but it is possible to estimate the size of the population using data on the number of people using services, national population estimates, and epidemiological research.

Estimates suggest that **in 2017 there were 10,029 people with learning disabilities in Cheshire East** (7382 adults aged 15+ and 2647 children and young people aged 0-14 years)\*.

*\*See appendix 1 for a breakdown of the estimated number of adults with learning disabilities across the different regions of Cheshire East*

#### Social Care in Cheshire East

**In 2015/16 1050 adults (aged 18+) with a learning disability were being supported by the Cheshire East Council Adult Social Care service.**

This equates to only 15% of adults with learning disabilities. Reasons for this may include:

- Eligibility criteria for specialist social care.
- Thresholds for identification post-education by social care agencies.
- Unwillingness of people with learning disabilities to identify themselves to or access specialised services.
- Lack of understanding of the impact of learning disabilities outside education.

#### GP Records

At 1567, the number of people with learning disabilities recorded by GPs in Cheshire East is considerably lower than the 2017 estimate of the total number of people with learning disabilities.

Nationally, it is estimated that **only 23% of adults with learning disabilities are identified as such on GP registers**, leaving a 'hidden' majority of 77% unrecorded.

In Cheshire East, **estimates suggest that more than 6700 people with learning disabilities are not registered as such with their GPs.**

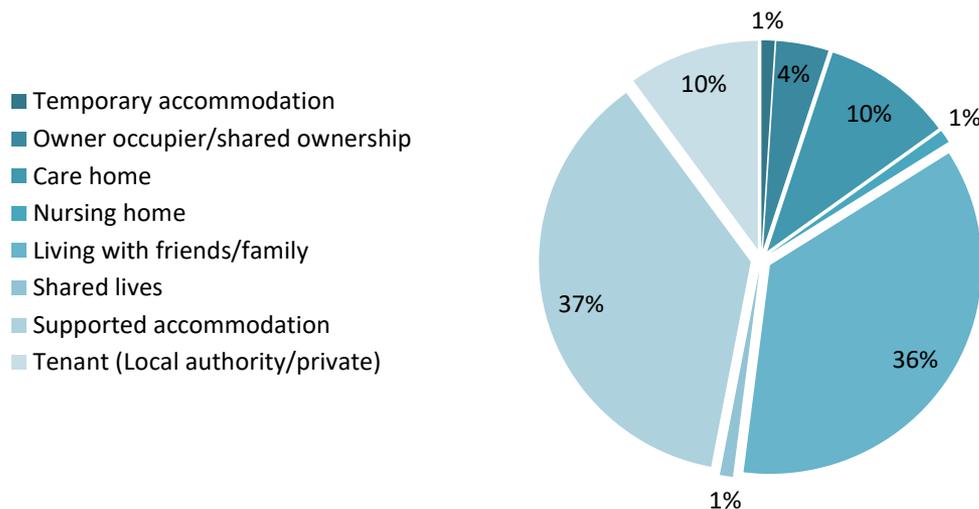
#### Accessing support

Public Health England (2016) suggest that the drop in the number of people known to services (from 2.5% of children in education to 0.6% of adults aged 20-29) indicates that **the majority of adults with learning disabilities are not accessing specialist services** designed to support people with learning disabilities.

Figures for Cheshire East provided by the Public Health Intelligence department at Cheshire East Council

**Housing in Cheshire East**

**Adults with learning disabilities receiving support from Adult Social Care in Cheshire East by type of accommodation**



**In 2019, 85% of adults of working age with learning disabilities who were receiving support from Adult Social Care in Cheshire East were living in settled accommodation, 11% were living in unsettled accommodation, and the accommodation of the remaining 4% was unknown.**

In 2015/16 the proportion of adults in settled accommodation in Cheshire East (86%) was higher than the average for England (75%), but lower than the average for the North-West as a region (89%).

**Children in Cheshire East**

The Department of Education collects information on the special educational needs (SEN) of pupils via the School Census. This excludes children educated at home and in independent schools. By combining the number of pupils with moderate (MLD) or severe (SLD) learning difficulty with those with profound multiple learning difficulty (PMLD) we can estimate the number of children with learning disabilities.

In 2018, 1050 pupils at schools in Cheshire East had SEN associated with learning disabilities, which means **the estimated prevalence of children with learning disabilities in Cheshire East is 2.0%**, lower than the rate for England as a whole (3.7%).

However, this is considerably higher than the proportion of children and young people recorded by GP practices (data for 2017/18 indicates that only 0.2% of 0-17 year olds were recorded as having a learning disability).

**Of the 1050 pupils who were recorded as having a learning disability, 77% were identified as having moderate learning difficulties.** Nearly all of these children are taught in mainstream schools.

### Inception of services

Many services were **set up by parents or carers who were unable to find the support their families needed** – whether information, activities, emotional support, or opportunities for employment.

Most have expanded their remit over the years as staff, parents and beneficiaries have identified the need for, or requested, additional forms of support, but are clear these **activities must further their primary mission**.

### Developing VCFS provision

**Providers describe the design and delivery of their services as being ‘user-led’**, by which they mean the activities and support they offer are designed to meet the needs identified or articulated by beneficiaries themselves (e.g. requests for certain kinds of activity or information; descriptions of the kinds of things they would like to learn or achieve this year).

This feedback is both elicited from beneficiaries and parents or carers (e.g. devising personal development plans; surveying parents), and gathered through more informal means (e.g. in conversation; observation) [see *Challenges: determining successful outcomes*].

The **content of their service is informed by providers’ regular, day-to-day interaction** with people with learning disabilities, and the relationships and understandings that develop (and the confidences that are shared) as a result of this rapport. Beneficiaries chat to staff about their lives, ambitions, and preferences, and providers observe users’ participation in groups or activities, becoming familiar with their different personalities, needs and concerns.

The **relatively informal nature of their relationship** with beneficiaries is central to the type of support VCFS services offer [see *Key features of VCFS support*].

While primarily user-led, **service design (particularly development and expansion) can be informed by funding opportunities**.

In some cases services have expanded on the advice of a funder who has been looking to support people with learning disabilities in a particular way. In others, development of a service has been limited by a lack of funding [see *Funding*].

*“I’ve always tried to approach [the service] from two perspectives: as a service user, and as a service provider.”*

(Provider A)

*“We did basic cooking skills [for our adults]... and they had no idea. I was shocked. I said, what do you eat? Takeaways. So it became clear we needed cooking classes, and it’s really taken off.”*

(Provider B)

*“We’ve grown with families and we’ve tried to plug the gaps... depending on what their needs have been.”*

(Provider C)

*“The children had been saying they wanted to do more arts and crafts... so when the money came up we got someone in to do craft activities.”*

(Provider F)

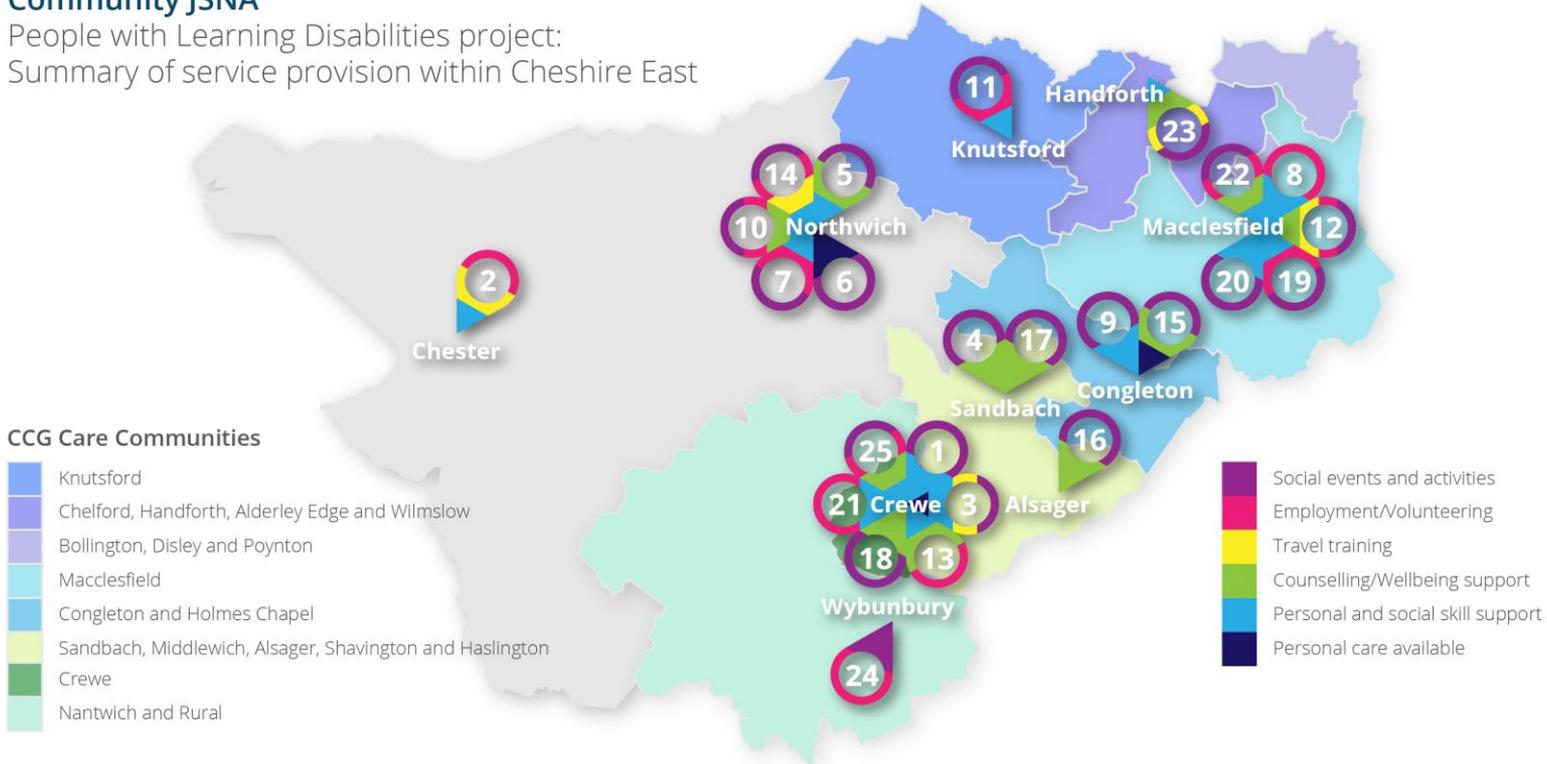
# The nature and content of local VCFS provision

## Mapping provision in Cheshire East

August 2019 (4)

### Community JSNA

People with Learning Disabilities project:  
Summary of service provision within Cheshire East



1	Autism Networks (Resource centre and venue)	9	Friends for Leisure	17	Swimming Club (Aquarius)
2	Bren Project (supported employment opportunities)	10	Grozone Community Garden	18	Swimming Club (Seahorse)
3	Central Cheshire Buddy Scheme	11	Knutsford GROW	19	Space 4 Autism
4	Cheshire Arts for Health (art and crafts activity sessions and counselling)	12	Macclesfield Community Garden Centre	20	Speaking Up Speaking Out (SUSO)
5	Cheshire Autism Practical Support (CHAPS)	13	Pathways CIC (The Alternative Solutions social prescribing service)	21	Supported Community Business (Special Needs) Ltd
6	Cheshire Centre for Independent Living (CCIL)	14	Petty Pool College	22	The Rossendale Trust
7	Cheshire Down's Syndrome Support Group	15	Ruby's Fund (Sensory Centre)	23	Time Out Group
8	Disability Information Bureau	16	Swimming Club (Alsager Swans)	24	The Wingate Centre
				25	Wishing Well - Supported Young Adults

Please note: this visual represents the primary bases of service providers within Cheshire East and does not represent their geographical reach. For further details of services and their locations, please access the full report.

## The nature and content of local VCFS provision

August 2019 (5)

### Nature and capacity of existing provision

#### Types of VCFS support for people with learning disabilities

##### Specialist

- Designed to meet the specific needs of particular groups (e.g. people with Autism).
- Offer a unique space suited to supporting the specific needs and behaviours of their users.
- Likely to be inappropriate for (and possibly frustrating to) people without those needs.

##### Generalist

- Support is tailored to the needs of people with learning disabilities (from mild or moderate to severe depending on the expertise of the provider).
- May be less suitable for (and could be disrupted by) those with additional needs (e.g. someone with a learning disability who also has sensory difficulties).

##### All inclusive

- Seek to accommodate the needs of people with mild or moderate learning disabilities alongside other users.
- Enable individuals to participate in activities they might not otherwise have access to, and to socialise with a wider range of people.
- Less closely associated with learning disability, which some users welcome.

#### What determines the capacity of VCFS services?

**Composition** - capacity is not just about numbers. For services running groups or activities, a **key determinant of capacity is the composition and dynamic of the group** (e.g. the mix of personalities and behaviours; the types of support beneficiaries require). Where a group is getting on well, providers are reluctant to disrupt that equilibrium by introducing new members, preferring instead to increase the number of groups (or replicate the service elsewhere) rather than increase the size of existing ones.

**Long-term membership** – organisations that provide ongoing support (e.g. organise regular activities, run groups, or host a hub) report that their beneficiaries tend to access the service once or twice and then, if they are happy, will continue to use the service indefinitely. Attendance becomes an important part of their routine and social life, which means services retain a large number of their users for a long time. With little turnover, the addition of new members only increases the size of their user group.

*"[Our upper age limit] was 25 but actually we've got a number over that. One must be about 45 now he's been coming so long, but it's tricky to say you can't come anymore."*

(Provider I)

*"We have to knit the group together [people] we know are going to interact well. And the trainers are very different, so it's deciding who would fit best with which groups."*

(Provider J)

*"It's only going to go one way; it's just going to keep growing."*

(Provider B)

*"It depends on the dynamics of the group... we might only have ten coming, but we say no more for the moment."*

(Provider H)

# The nature and content of local VCFS provision

August 2019 (6)

## Key features of VCFS support

Many VCFS providers have deliberately designed their day services to enable beneficiaries to access them on an ad-hoc basis; beneficiaries know the service is there, but they feel under no obligation to attend. The 'informal' nature of their relationship is central to providers' own understanding of their responsibilities regarding the well-being of the people they support, and the depth and breadth of support they offer.

### Holistic support

In practice many providers offer a greater range and depth of support than their primary focus (e.g. delivering activities; signposting to services) might suggest.

This wraparound support can include anything from supporting families in crisis (e.g. a cup of tea and a shoulder to cry on), to helping parents deal with problems at school, to supporting users to engage with statutory services (e.g. ensuring they are on waiting lists; assisting with paperwork), to texting adults who have not engaged with the service for a while to check they are ok.

### Social support

The nature of the support offered by VCFS services (e.g. organising activities; providing safe spaces in which to spend leisure time) creates opportunities for people with learning disabilities to socialise and build supportive relationships. Parents and carers similarly utilise these opportunities to expand their own informal support networks.

The informal nature of these encounters is key, as individuals are free to discuss issues that are of particular concern to them, and to develop relationships at their own speed, rather than have this determined by an external agency (e.g. on a course).

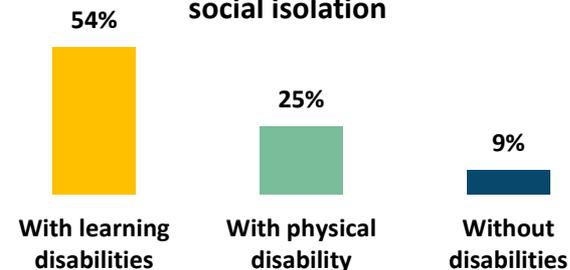
*"We've been to the foodbank for people. We're sorting someone out with a pay-as-you-go phone because he's been running up enormous bills. We're working with about ten families in crisis [so] we keep sending [our colleague] round to make sure everyone is alright, just to have a cup of coffee with them, have a phone call... If people have got problems we try to help them because that's what we're here for."*

(Provider F)

*"We encourage informal networks... we had a group of parents whose children were going bowling [with us] and they'd sit in the café and have a coffee and we later learned that they were meeting up outside as a group."*

(Provider G)

### Macdonald et al (2018) survey - % of people who reported experiencing social isolation



Research suggests social support is important because people with learning disabilities are particularly vulnerable to social isolation.

\*Source: survey exploring loneliness (Macdonald et al, 2018)

## Key features of VCFS support

### Time

At the heart of VCFS support is time – both time to sit and listen to beneficiaries and their families talk about their lives, ambitions, and the challenges they face, and time for users to familiarise themselves with services and staff and to develop confidence (in themselves; in trying new things) in an environment in which they feel comfortable and safe.

Providers see their capacity to give people with learning disabilities opportunities to develop skills, experiences and relationships in their own time as central to the philosophy underpinning their services.

### Life skills

VCFS providers of all types see helping people with learning disabilities to develop life skills as being central to their mission.

In their experience, personal development courses can be helpful in establishing the key criteria for skills (e.g. appropriate behaviours; managing money), but it is the ongoing opportunity to develop and practice these skills within a safe, supportive environment (e.g. regular attendance at a group) that is key to helping beneficiaries really understand how to complete tasks and manage situations for themselves.

### Stability during transition

Periods of change (e.g. entering adulthood; bereavement) can be extremely challenging for people with learning disabilities, and the transition from children's to adults' services is of particular concern to VCFS providers who have observed the difficulties some beneficiaries and carers face when trying to engage with stakeholders (e.g. local authorities; schools and colleges) to prepare for this event.

VCFS providers can support beneficiaries during periods of change by offering them stability, both in terms of their routine and in their social life (e.g. continuity of friendship groups; familiar faces and confidantes on the staff).

*"We used to run a 10-week personal development programme looking at appropriate dress, work, the future, how to plan a meal, how to pay for things. It was a great experience, but horrendously expensive [and] we realised we needed to keep those lessons going. So we decided to run a youth group for teens where the same lessons are repeated over and over again. And we're seeing much better outcomes."*

(Provider G)

*"What I find is that we're not perceived as 'professional', so we haven't got that 'they're going to take my child off me because I'm going to tell you how I feel'... they're not going to judge me... Having that drop-in basis and that informal approach [is really important]."*

(Provider A)

*"People come here for comfort and support. And friendship as well."*

(Provider D)

*"People become part of the [organisation's] family. If a parent comes in with an issue then we will support them, whether that's a listening ear or guidance and advice. We do a lot of advocacy. Whatever is in the best interests of the beneficiary."*

(Provider M)

# The nature and content of local VCFS provision

August 2019 (8)

## Key features of VCFS support

*"We're commissioned to work up to 18. We don't get any funding for 18+, we have to find alternative funding for that. But the decision was made to hang on to them until 21 because... they're moving from Children's to Adult services [and] one thing we can do is make sure that their friendship circle remains stable during that time."*

(Provider G)

*"A young man who visits us with a group used to stay on the mini-bus rather than come in. When we had a picnic he sat outside, but wouldn't come in. We encouraged him to come in for two minutes to start with, then he did a bit longer. Eventually he achieved 15 minutes... The idea behind the centre is to offer a place they feel comfortable."* (Provider N)

*"A parent came in the other day for the first time, absolutely in bits. [A colleague] sat with her for a while and then suggested she come back the next day for an activity. Another parent came to that event and they just got talking in the café together before it started. The next day they came in for lunch together. When they came in last week she looked like a completely different person."*  
(Provider B)

A survey of healthcare professionals found that **77% felt that the voluntary sector was best placed to provide emotional support** (Sturgess, 2019 reporting on a 2014 survey of healthcare professionals).

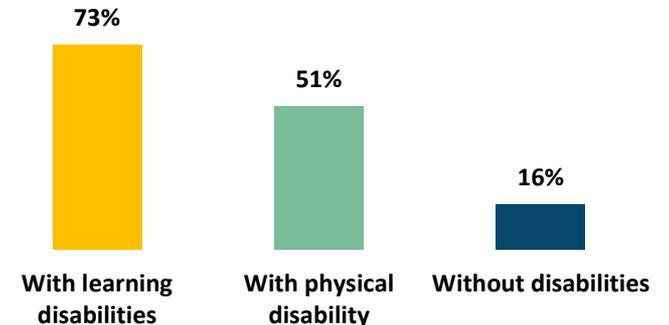
*"We tend to work a lot on the family unit, which isn't what I'd planned, but it's one of those things that's evolved. The parent, the carer, they've got to be well, mentally and physically, to look after that family unit and we've found that when the children have gone off to school, the parents are still coming to us because they're getting that support. We get it, they don't have to pretend."*

(Provider A)

### Emotional support

- Providers are very familiar with the experiences and challenges beneficiaries and their families face, both in day-to-day life and in accessing the support they need.
- The emotional support services offer is an important facet of their work, particularly when it comes to supporting carers and preventing families from reaching crisis point if they are struggling to cope.

### Macdonald et al (2018) survey - % of people who reported feelings of loneliness



\*Source: Macdonald et al (2018)

## Delivering person-centred support

### Benefits and challenges

August 2019 (9)

All the VCFS providers who participated in this project take a broadly person-centred approach to the design and delivery of their services, putting beneficiaries at the heart of their services and aiming to give them greater choice and control over their lives, be it in their housing, education, employment or activities (DoH, 2001). In order to deliver a service that can be personalised to meet the needs of individual users, providers need to be able to cater to the wide variety of needs and preferences people with learning disabilities have.

*"When I asked, 'what do you want to do?', they'd say, 'I don't know'. So we had to put tasters on or take them somewhere. Then they'd have a go and come back and say, 'oh can we go there again...' and suddenly, they've got some agency. But you've got to give them concrete tries at things to broaden [their experience]."*

(Provider D)

Research confirms providers' experience that delivering a person-centred service is resource-intensive and places a significant burden of responsibility on staff as they seek to balance what they believe to be in the best interests of their users with beneficiaries' own wishes (Clifford et al, 2018; Witso & Kittelsaa, 2018).

#### Giving people agency

Providers point out that it is not enough just to ask people with learning disabilities what they want, because if they have no experience of something they might not know if they like it or not.

VCFS organisations see their role as broadening their beneficiaries' horizons by giving them access to lots of different opportunities to help them develop a better understanding of the types of things they like to do.

*"Sometimes there is a sense that 'well they behave that way because they're X', and yes you've got to support people, but sometimes you've got to manage your own behaviour because there will be consequences. So we support young people to look at that. We set really high expectations and aspirations for them... we treat them like adults."*

(Provider M)

#### Raising expectations

Providers observed that over-supporting people with learning disabilities risks undermining their own sense of self (e.g. likes and dislikes) and the opportunities they could have to choose how they live their life and what they would like to achieve.

They are keen to raise expectations of this group, both in terms of what beneficiaries expect for and from themselves, and what other people (e.g. services; employers) expect of them as individuals (e.g. their capabilities and ambitions).

#### Challenges

Genuine person-centred care is not only about giving users the opportunity to express a preference, but also about providing the different options that will enable them to act on these choices. Providing the level of choice that would meet the needs of all beneficiaries can be challenging for VCFS providers.

## Short breaks and safe spaces

### Offering respite

August 2019 (10)

#### Safe spaces

Providers frequently stressed the need for services to be not only physically accessible, but also inviting to first-time users who may be anxious about visiting somewhere they have never been before.

They also feel that the provision of a 'safe' physical space in which to socialise with family and friends is an important means of giving carers some respite from the challenges they can face when socialising in public spaces (e.g. feeling exposed; fear of ridicule).

#### Familiar surroundings

Some providers invite external organisations to deliver services from their building. Going somewhere new can sometimes be very stressful for people with learning disabilities (and their families), so being able to access a range of services through a provider they feel comfortable with (and in a location with which they are familiar) enables beneficiaries to access a wider range of services than they might otherwise seek out if, every time they did so, they had to deal with the anxieties and logistical challenges associated with visiting a new, different place.

#### Configuring spaces

For providers who have their own facilities, the composition of space is important, because it enables them to offer a variety of activities and services, accommodate a range of users (e.g. of different ages), and allow beneficiaries a choice of environments (e.g. a lively café balanced by a quiet or sensory space).

Making their buildings welcoming spaces can be a challenge to non-specialist providers seeking to adapt their services for users with learning disabilities.

#### Carers of people with learning disability



Source: Public Health England (2016) – data from the Personal Social Services Survey of Adult Carers in England 2014/15

*“This is like a hub, everything they need, most of it will be delivered here so they don’t have to go anywhere else... if someone wants something and we’re not delivering it, we’ll get in touch with that agency and invite them to come and do a drop-in for us.”*  
(Provider B)

*“It’s the lack of creative thinking that is often a barrier to delivering services... There is a set view about what a short break is, they don’t see a family outing as a short break. Parents absolutely need a break away from their child, but they also like to do things as a family, but with that extra support.”*  
(Provider H)

## Short breaks and safe spaces

### Offering respite

August 2019 (11)

*"With short-breaks I take a really flexible approach, because some people are quite confident, they're like, 'thank goodness we've found you, here's my child, here's the problem, I'm off to have a cup of tea for a couple of hours'. Others are like, 'I've never left him before and I can't do it'.*

*I normally say we've got 4-6 weeks to work together as a threesome, the child, the parent and me. We get to know them, they get to know us. Then we say, 'right, you're going downstairs to have a cup of tea while we play upstairs'. And then it's, 'right, are you going to do your shopping?'. Often I'll send a photo of the child halfway through the session so they can relax. It's a lovely thing."*

(Provider A)

*"One of the things we hear quite a lot is that parents don't go out themselves because they can't get **babysitters**. That's a huge gap. Because it takes a slightly different person to babysit [children with additional needs]."*

(Provider G)

*We **run activities where families can get together and meet for regular days out and it's really important because the families can have days out that perhaps they wouldn't organise on their own, because it would be too much for the child and they don't want to spend £150 if they might have to leave after 10 minutes. Whereas if they come with us, they know there are a number of families in the same situation.***

(Provider C)

*"We have an individual who has profound and multiple needs, but **the [best break] for her is a cruise**. She's been on two now. She doesn't have many day-to-day interests and when she first went it was a complete shot in the dark, but it turns out she absolutely loves it. Loves the cruise, loves the entertainment, stays up until 2am. The whole thing is brilliant for her."*

(Provider O)

### Type and range of short-breaks

In Cheshire East, children's commissioned short break services are primarily youth activity groups (e.g. after school or holiday groups; weekly youth clubs), with some opportunities for one-to-one or family activity sessions.

While acknowledging that enabling beneficiaries and their carers to spend time apart is extremely important to the wellbeing of both parties, some providers feel that it would be useful to apply the principles of person-centred support to short-breaks and think more creatively about the different types of break individuals and their carers might benefit from.

For example, would they welcome regular opportunities to spend time together as a family in a 'safe' environment? Can breaks give beneficiaries the chance to spend time with different people away from home? Would beneficiaries (and their families) benefit from an opportunity to get away from the demands of day-to-day life for an extended period once a year (e.g. a family break to an activity park)?

*Note: Cheshire East Council will be reviewing children's short break commissioned services in the near future.*

**Reluctance to advertise**

A number of VCFS providers reported that they deliberately do not go out of their way to advertise their services because they would not be able to meet the demand if they attracted many more users.

If services do not feel able to advertise their services, it is likely to be difficult for potential beneficiaries, particularly those who are more socially isolated and/or not accessing the statutory services that might refer them, to find out about and access this support.

**Social media**

Social media is widely used as the primary means of communicating with existing and potential beneficiaries and carers, as well as advertising activities to potential funders and VCFS and business partners.

**Gatekeepers**

Beneficiaries find VCFS services through a variety of mechanisms (e.g. websites; social media; word of mouth), but many are referred by health or social care professionals (e.g. social workers).

Providers welcome these referrals, but observed that these gatekeepers are not always well placed to accurately describe the work of the service, particularly if they have never visited the organisation in person.

There is a risk that misrepresenting or misunderstanding the nature and content of services can deter people with learning disabilities from accessing them or, alternatively, raise expectations of the service that providers are unable to meet.

*"I always worry about the message getting to our beneficiaries [which is why] I like to speak to them directly whenever I can. I often talk to support services and tell them what we're doing, but I worry about the message getting through to the beneficiaries in its unadulterated state... So I do worry about where people with learning disabilities, with autism, where they get their information from, and how we get that message to them directly."*

(Provider R)

*"We don't want to raise awareness! We don't want anybody else coming! People say, 'do you want to advertise in our brochure?' No, we're inundated. The last thing we want to do is advertise."*

(Provider B)

*"Come and see us again and promote us – but not too much!"*

(Provider E)

*"We're very active on Facebook, we do a lot of polls in our closed group – if numbers are going down for an activity, is it the wrong day for people? Are they wanting something different?"*

(Provider J)

*"[Advertising] always frightens me because I think we're going to get bombarded and won't be able to cope."*

(Provider Q)

## Sustainability of VCFS support

### Maintaining, developing and expanding services

August 2019 (13)

*"We write to about twenty five trusts a week. You might get £500 you might get £20K – you just don't know what's coming through the door."*

(Provider B)

*"I'd prefer to do what I'm doing and do it well rather than expand and fall over."*

(Provider C)

#### Financial uncertainty

Smaller and/or newer providers face significant financial uncertainty both in terms of planning activities in the medium-term and in ensuring the longer-term future of their service.

Those relying on short-term grants, for example, are often only able to plan 6-12 months ahead because they do not know where next year's funding would be coming from.

This creates challenges for the service, not least in the recruitment and retention of staff. It also means significant time and resources are spent identifying and applying for funding.

#### Opportunities

Smaller providers with limited resources can struggle to take advantage of opportunities to develop their services, expand their range of activities, and collaborate with VCFS partners.

This limits providers' ability to expand their beneficiaries horizons, which is key to giving people with learning disabilities opportunities to develop their preferences and choose activities and goals that will have meaning to them as individuals.

#### Innovation

Providers observed that, for commissioned services, the commissioning process can be quite inflexible in its understanding of how services might support people with learning disabilities.

This limits opportunities to think creatively about the design and delivery of services and the development of new mechanisms of support.

Some new services are being developed and funded by VCFS organisations themselves in the hope that they will eventually attract the attention of commissioners, but this is not realistic for many providers, particularly smaller services.

*"We had an opportunity from [a VCFS organisation] to run their café. That would be absolutely wonderful, and it would mean our group would get paid employment, but [facilitating] that would take resources, and we can write bid after bid, but we are so under resourced that to write those bids is hard."*

(Provider D)

*"A lot of our [funding for] our main infrastructure is due to finish in November, so we're having to be very cautious at the moment until we know if it will be extended... We have lots of ideas for things we would like to do, but we daren't do anything until we know what the funding situation is."*

(Provider J)

## Sustainability of VCFS support

### Maintaining, developing and expanding services

August 2019 (14)

For larger and more established VCFS organisations, the challenge is less around maintaining their existing service and more to do with the difficulties associated with expansion.

While providers may wish to expand their service to meet increasing demand for their service, they are **reluctant to risk the financial security** (and thus the sustainability) of their organisation to do so, particularly if that expansion requires significant investment (e.g. acquiring or committing to long-term leases on new or additional buildings).

#### Expanding services

Any **expansion is also likely to require providers to take on additional staff**, many of whom will be either be professionals coming in to deliver specialist services, or in caring roles on or around the national living wage.

This can bring **additional budgetary challenges as providers find funders are often reluctant to fund staffing costs**, and, where they do, often fail to take any proposed increases in the living wage into account when calculating costs associated with staffing services over the course of a contract.

*“It gives us a conundrum as to what next, you know. If you take on more people, if you lease premises to provide more activities or cater to larger groups, it steps up your bottom line costs dramatically. You’ve then got to be pushing to fill those places. It’s a very difficult decision for, effectively, a small business to make.”*

(Provider O)

#### Gaps in commissioned funding

Providers whose services have been commissioned by the local authority or CCG can **struggle to maintain these services if they face a significant gap between the end of one contract and the beginning of the next one**. A number of providers had experienced this, with organisations having to find additional income to cover the costs themselves in the interim (e.g. applying for grants; a temporary charge for the service).

*“Some services for adults stopped last April, but new services weren’t commissioned until the end of the year... so there was this big gap. It was down to providers to decide whether or not to close the service, or if they could keep it going. In consultation with our adults, we kept it going as a paid-for service, but not everyone can afford to pay. But if we close until the end of the year a lot of those friendship groups will disappear.”*

(Provider H)

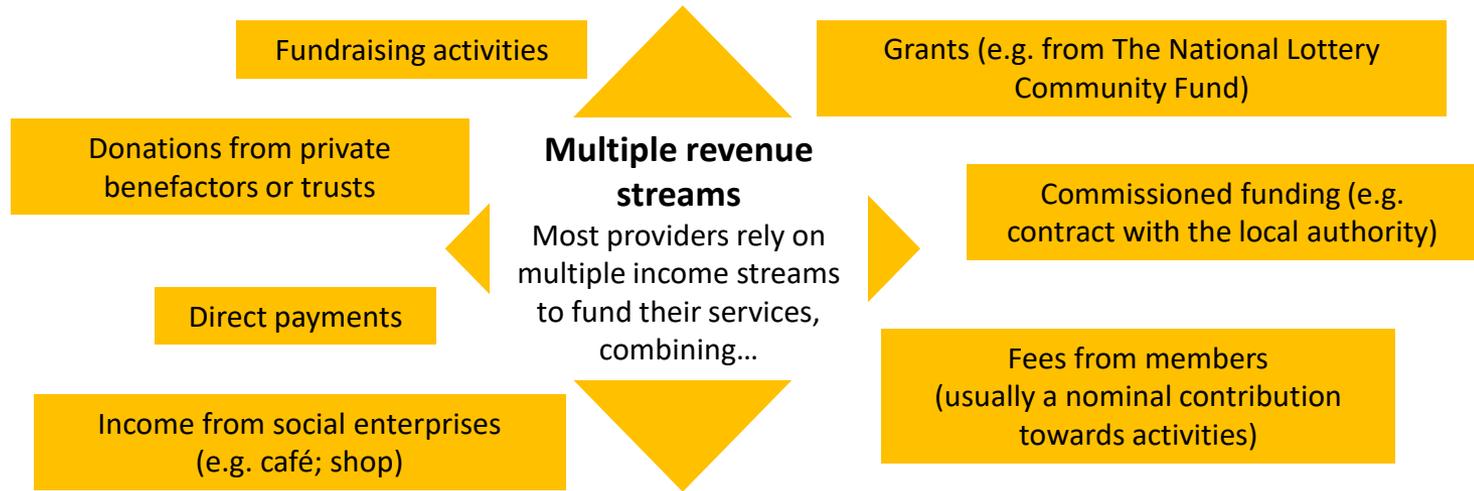
*“We’re funded for just over a year now [but] we’re well aware that we need to put more bids in now for when that ends... funding is hand to mouth.”*

(Provider T)

## Funding

August 2019 (15)

### How do VCFS services fund their activities?



*"I've always wanted to be self-sufficient. I didn't want to rely on grants because I found services would stop and start when grants ran out, and as a service user there's nothing more frustrating than trying to engage with a service and 'oh sorry, it's stopped because it's run out of funding'. I didn't want that for our families; I wanted us to be a safe [reliable] space."*

(Provider A)

*"We go on CHEST\*, but a lot of things don't fit... We're not bidding for a project, that's the last thing we want... you end up moving away from what you're here for. To me it would make sense if they commissioned the service as a whole. We shouldn't have to bid on a project – we're already doing it."*

(Provider B)

### Challenges

Providers reported having difficulty securing funding to maintain existing services (even where these were acknowledged to be successful), observing that grant-awarding bodies are more inclined to fund 'new' services than maintain existing ones (e.g. they prefer to buy new equipment than pay to maintain and insure existing equipment).

*"We haven't had a great deal of local authority funding, we quite like our outsider status, in that we're not lumped in with the statutory offer. Our beneficiaries know when they come to us they, not targets, are our main priority."*

(Provider R)

\*CHEST – local authority e-tendering portal

*What happens a lot is that social workers come to see us and say, 'that's brilliant, I know loads of people who can be referred here'... no money with it, just loads more people!"*

(Provider L)

### Frustrations

Some providers find it frustrating when local authorities and NHS services fail to acknowledge the extent to which they rely on VCFS services to help them meet their statutory obligations – particularly if they receive little financial support from these statutory bodies.

## Funding

### Delivering commissioned services

August 2019 (16)

A number of VCFS providers are reluctant, or feel unable, to apply for funding from local authorities (LA) or NHS Clinical Commissioning Groups (CCG) to deliver commissioned services.

#### Why?

Providers are often looking for funding to support the 'core' activities that will enable them to deliver their service (e.g. leasing or maintaining buildings; employing staff with particular expertise), but **much commissioned funding is project-based** and thus out of reach unless they 'create' a project specifically to access the money (which takes time and resources away from their main service).

The **process of applying for this type of funding can be onerous**. VCFS organisations have few resources and limited time to commit to applications, and the process of applying for LA/CCG funding is often much more convoluted than for other grant-awarding bodies.

The **perceived insecurity of contracts**, which is informed by providers' previous experience of seeing their own or VCFS colleagues' funding being withdrawn abruptly in the past. This was of concern because it means **beneficiaries cannot rely on services** to be there when they need them.

The **rigidity of the criteria used to assess outcomes** was cited as an example of the tendency of LA/CCGs to impose their own processes rather than engage with providers to determine the most appropriate way to deliver support. Providers were more positive about funders who pursue a more collaborative approach with grant holders (e.g. hold regular meetings to discuss progress) and allow them to be more creative in their reporting (e.g. using photos to show what beneficiaries have done).

Providers reported that **funding does not fund the 'true cost' of delivering a service**, which means providers must make up the shortfall themselves (e.g. they may be funded to run a leisure activity, but the funding does not extend to paying for staff to run the session).

*"We're a small team, none of us work full-time, sometimes we do struggle... I think there needs to be some sort of assistance with the terminology and language used by the local authority and the CCG... If you're not from a commissioning background it can be difficult to unpick the language and work out what they're actually asking you to do."*  
(Provider D)

*"Funders need to think outside the box more. I've looked at recent opportunities (to apply for commissioned funding) in Cheshire and they're very old-school, they're not innovative. It's outcome-based, which I get, but there's no consultation with [VCFS services] around how we might get there. As long as the outcome is the same, it shouldn't matter."*

(Provider D)

*"I hate the CHEST\*, I just hate the CHEST! Unless we're going for something huge, it's too complicated. They're putting too many restrictions on us, too many requests for things like cyber insurance [which is expensive]."*

(Provider F)

\*CHEST – local authority e-tendering portal

## Partnership working With VCFS colleagues

August 2019 (17)

### What prevents VCFS providers from collaborating?

Providers who rarely work in partnership with other VCFS organisations gave a number of reasons for this.

- **Differences in the levels of support** offered by different services can make collaboration challenging (e.g. if one provider offers personal care support and the other requires beneficiaries to bring their own support workers)
- Given the financial challenges many smaller providers face, there is a **fear that partnership behaviour implies that services might be combined** and may mean one (or both) of the partners will struggle to access funding in the future.
- Building relationships with other organisations **takes time away from other activities** – something most VCFS organisations can ill-afford.
- The **types of support VCFS providers offer are quite specific to the mission of their organisation** – in many cases providers see little need to collaborate with colleagues in other services.

### What works well?

#### Informal partnerships

Providers who regularly collaborate with VCFS partners usually describe these as 'informal' partnerships. These relationships have often developed because the **two services complement one another in some way** (e.g. relationships between supported employment services and VCFS services who can offer work placements or volunteering opportunities).

#### Facilitating access to other types of support

Providers who offer information and advice or activities, or who operate out of a 'hub', have often built **relationships with VCFS organisations who offer a different type of specialist support** (e.g. debt or money advice; arts activities; mental health or counselling services) by inviting them to run sessions with their beneficiaries.

These relationships have benefitted both beneficiaries (who are able to access a range of services in a familiar setting) and staff (who develop expertise in a wider range of topics and, when signposting, are able to direct beneficiaries to a person, rather than just pass on the details of the organisation).

*"People are very protective of the budgets they've got... I think that sense of competition [inhibits partnership working]... It's the funding that engenders it... everybody is on their guard all the time. [However], receiving a donation that specified [working with other VCFS organisations] has been absolutely fantastic. We've done training for them; they've done training for us. It's worked really well."*  
(Provider J)

*"Because I work with organisations in other fields I can say, 'I've got this concern about X, I've asked her to come and see you'. Then we have the autism team who come in once a month to support the coffee morning... we've had them delivering training to our staff. It's having that link."*  
(Provider A)

**VCFS providers offer unique insight**

Where commissioners are necessarily focused on meeting the needs of people with learning disabilities as a population, local **VCFS organisations are primarily concerned with supporting individuals.**

As such, providers can offer unique insight into the practices and approaches they have found most successful, and **the small, incremental changes that can make a significant improvement** to the day-to-day life of their beneficiaries (e.g. learning how to use public transport).

They can also offer valuable **feedback on the practical implications of implementing legislation** and policies intended to improve the provision of services (e.g. person-centred support).

**Best practice**

Feedback from providers suggests that the most productive VCFS-commissioner relationships develop when the **two organisations engage in dialogue** in order to design and deliver services.

These discussions **make the most of the unique knowledge of each partner** (i.e. commissioners have an overview of services across the region; VCFS organisations are 'on the ground' and in regular contact with their beneficiaries).

**Least productive**

The least productive VCFS-commissioner relationships were characterised as 'master-pupil' relationships, where the statutory lead 'hands down instructions from on high' without seeking to engage with providers and is not open to thinking more creatively about how statutory obligations might be best met.

**Commissioning constraints**

Local authority and NHS commissioners face financial and administrative challenges (e.g. reducing budgets while meeting increasing demand for services; politicised decision-making structures) that can make it difficult for commissioners to fund VCFS services as providers might wish.

*"People with learning disabilities know things and can contribute; they just might not be able to convey that to a commissioner... That's where I think [our service] could be utilised in a better way... to be a conduit between commissioners and people with learning disabilities [but at the moment we're not able to access people] at the right level to affect anything."* (Provider D)

*"I call it 'living the dream', unless you live the dream how can you know what services are required? Unless you're out there... I think it's really important for everybody to sit and work together."*

(Provider A)

*"The confusion for me with CCGs is that I still don't know how they work... Some charities seem to be getting their services commissioned, but [those opportunities] are not advertised, so how does that work?"*

(Provider B)

*"We're members of local forums, we're on the Learning Disabilities Partnership Board [but] we're a small team and very busy... It's important we're part of the conversation, but we can't attend all the time."*

(Provider R)

## Partnership working With commissioners

August 2019 (19)

### The value of involving the VCFS

Research examining collaboration between agencies in post-16 planning for young adults with learning disability found that alternatives to further education were discussed in 52% of cases when an external agency was involved.

**When non-statutory organisations were not present, alternative options were rarely discussed.**

*Source: Kaehne and Beyer (2008) cited in Kaehne (2013)*

### Visiting services

Providers feel that commissioners who visit services in person to see them in action develop a much better understanding of what the service offers, and of the needs and preferences of people with learning disabilities as individual service users.

### Personal relationships

For providers, the most successful partnerships are based on **productive personal relationships between individuals** within the different organisations who are jointly engaged in addressing the different challenges they face in delivering services.

However, one of the challenges of maintaining this collaborative working is that it can be **difficult for VCFS organisations to build long-term relationships** with statutory partners when staff regularly change roles

Providers who do not have an existing relationship with their local authority/CCG can also **find it difficult to find a 'way in'** to these organisations.

### Complexity of the commissioning process

Providers' views on the complexity of the commissioning process are consistent with the findings of a King's Fund consultation with VCFS organisations and commissioners, which noted "the complexity of the commissioning process and the difficulties associated with not having a clear understanding of commissioners' requirements and processes". They observed that **"where commissioners have taken the time to help [VCFS organisations] to understand processes, this has worked well"**.

*Source: Weeks and McKenna (2015) Submission from the King's Fund to the VCSE Review see Funding*

*"It's difficult because people change roles so much – you've just got a good relationship with someone, who has been to visit, who understands what we do, who gets it... bang, they're gone, someone new comes in and says, 'so your services, what's it all about then?'"*

(Provider O)

*"[Before] it felt like you were being brushed off all the time, it felt like you weren't important... Whereas now, meeting with [commissioners] has been very, very productive. I feel like we as an organisation, and myself, have built up a good relationship with the Council. They are two people we can work with. They know about us."*

(Provider S)

**People with learning disabilities in employment**

**Case study**

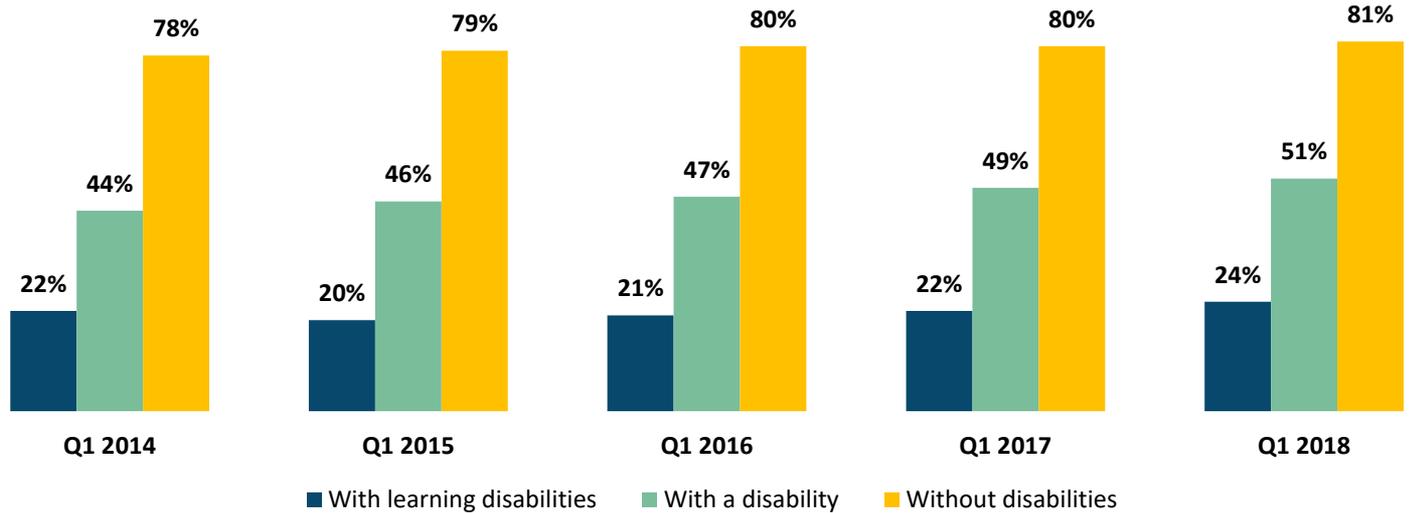
Young people hoping to work in hospitality receive extensive work-based training in an environment that simulates the conditions they will be working in, and the tasks they will be expected to perform, before they embark on external placements to ensure they are familiar with work practices and able to perform tasks to the standards (and in the time) expected by employers in the industry.

Staff then slowly withdraw support as beneficiaries become more familiar with the work. They also help employers to devise ways of supporting individuals in these roles (e.g. if they are unable to read the numbers on doors, they can use sticky notes to help them keep track of the rooms they have yet to service).

**National**

**Employment rate for people aged 16-64 (Q1 2014 - Q1 2018)\***

*\*Q1 is the period January-March*



*Source: HoC Library (2018) Learning Disability Policy and Services. Briefing Paper: 07058 Data from Labour Force Survey Microdata; ONS, Labour Market Bulletin, Table A08 (figures are estimates based on survey data)*

**Cheshire East**

**In 2018/19 12% of adults with learning disabilities were in paid employment\*.**

*\*12% of the 940 adults of working age known to services in Cheshire East (69 men and 44 women).*

*Source: Adult Social Care Outcomes Framework (ASCOF) 1e*

**Securing work placements**

Examples of best practice (e.g. advice for co-workers on appropriate language), 'success stories' (e.g. where employers have benefitted from placements), and offering significant support during the initial stages of employment were found to be the most successful strategies for securing work placements for people with learning disabilities (Kocman et al, 2018).

## Work and employment

### Models of supported work

August 2019 (21)

VCFS providers support people with learning disabilities to engage in employment work in a number of ways.

*"[On work-focused day services] They work to their own ability and speed. There is no pressure to say, 'you must produce x today', they're able to work at their own level."*

(Provider S)

*"We don't tend to talk about ongoing work because if it doesn't happen, it feels like a failure. Whereas the placement is a success on its own terms, just getting that experience... In some cases there's a genuine skills gap that doesn't make a permanent role realistic. We have greater success with ongoing voluntary work because people are aware you're volunteering your time, so greater allowances are made."*

(Provider R)

#### Internship programmes

Beneficiaries are supported to learn how to perform the tasks associated with a particular job (e.g. housekeeping; customer service) before embarking on a supported internship in that role with a partner company. Best suited to more independently able beneficiaries and can lead to a permanent employed role. Requires significant investment in job-related and life-skills training in advance of the internship.

#### Work-focused day services

Providers offer people with learning disabilities the opportunity to participate in work in a supportive environment that still operates like a professional workplace (e.g. participants are expected to dress and behave as they would in work; they may receive a nominal sum in wages). Best suited to beneficiaries who may struggle to complete tasks without significant support. Individuals who attend these services tend to stay long-term.

#### Supported work placements

Beneficiaries are supported to secure and participate in short-term placements with local businesses to develop their skills and gain experience of work. This occasionally leads to a permanent, employed role. Of value to most beneficiaries, given the right placement and appropriate support.

#### Five models of work

##### Volunteering

Beneficiaries volunteer for VCFS organisations to support their work (e.g. serving in the café). As with community projects, participants can develop new skills, meet new people and build confidence while gaining experience of work in a more supportive/less risky environment than paid employment.

#### Community projects Social enterprises

Beneficiaries participate in projects (e.g. community gardens) supported by staff and other participants, developing new skills and confidence, and broadening their experience. They meet a wide range of people with and without learning disabilities, learn to work with others and take responsibility for tasks. Of value to most beneficiaries, given the right support. Suited to beneficiaries who may struggle to complete tasks independently.

*"I think our beneficiaries' success is due to our philosophy of preparation... We have that model of developing vocational experience and employability skills, but it's [also] the travel training, the personal care... teaching them how to use a washing machine... Our job coaches will get up at 5am to support someone on breakfast services in a hotel. It's realigning the planets to get people into jobs."*

(Provider M)

*"We do personal hygiene training. It's a massive thing for people – being scruffy makes them quite vulnerable. We've done equality and diversity training, which is quite interesting with people with learning disabilities because there are quite a lot of prejudices!"*

(Provider E)

#### Tailored opportunities

VCFS providers stress that people with learning disabilities have differing types and levels of skill and aptitude and are therefore suited to different roles and working environments. Not all beneficiaries will be able to cope with the demands of permanent, paid employment, but some, given the right support, will thrive in it.

For others, volunteering offers a valuable alternative, as the nature of the volunteer relationship is very different to that of an employment contract (e.g. in terms of what is expected; the speed at which someone might need to work; the level of support they will receive).

#### Ownership

In keeping with the philosophy of empowering people with learning disabilities to make choices that have meaning for them as individuals, providers are keen for beneficiaries to take ownership of their own employment and volunteering experiences.

This includes: deciding what kind of placement they would like to try; developing a CV or portfolio they feel they own that has meaning for them so they can show employers and others what they've achieved (e.g. using photos to remind them of their activities).

#### Preparation for work tasks is key

The programmes that are most successful in achieving permanent, paid roles for their beneficiaries spend a significant amount of time (e.g. months or years) preparing individuals both for the specific tasks associated with the role they are due to perform in their internship or job, and for working life as an employee.

This wraparound support includes ensuring people can get themselves ready for work (e.g. washing; dressing; laundering uniforms) and can travel to their place of work (e.g. use public transport), as well as preparing them for the unique nature of a professional work environment (e.g. the types of behaviours that will be expected of them; the relationships they will have with managers and colleagues).

Few organisations are currently able to offer this type of preparation, with most focusing on the processes of recruitment and selection (e.g. identifying and securing appropriate work placements; supporting beneficiaries to meet with employers in interview situations) rather than on preparing beneficiaries for the work itself.

#### Partnerships with businesses

For VCFS providers, building relationships with businesses is the key to developing successful supported working opportunities and programmes. They engage with employers in a variety of ways, from participating in business-to-business groups, events and networks, to inviting employers to visit their sites in order to develop a better understanding of their work.

Providers observed that these relationships are important not only because they enable identification of, and access to, placement opportunities, but also because they break down some of the barriers that can prevent businesses from engaging with people with learning disabilities in the first place [see *Challenges: understanding learning disability*].

#### Looking beyond employment

Providers pointed out that focusing on the outcomes of work experience opportunities (i.e. whether it leads to a permanent role) risks overlooking the more immediate benefits that derive from participation in these activities in and of themselves (e.g. increased confidence; opportunities to socialise with a wide range of people; experience taking responsibility and ownership of tasks).

In addition, individuals benefit from the skills and understanding they develop as a result of engaging with the world of work (e.g. how to interact and build relationships with colleagues; understanding around concepts like equality and diversity).

To focus only on opportunities which lead to permanent employment risks excluding people with learning disabilities who may struggle without support, but who would still benefit from engaging in work in a workplace.

#### Case study

One successful approach to persuading reluctant employers to offer placements saw the provider email potential business partners a short (3 minute) film outlining what they do and what a placement would entail.

This gave the employer a lot of information about learning disability and the purpose of placements but took up very little of their time to watch.

Research by Beyer et al (2016) on supported work placements found that most people with learning disabilities who participated in placements appreciated them because they enjoyed the tasks, being treated like adults and meeting new people, and felt they were treated well by their co-workers.

*"[On conversations with funders around piloting a supported employment service] When the details emerged I didn't feel we could do it and remain true to our core mission. It was payment by results and one of the outcomes they wanted to see was 40% of beneficiaries to remain in paid work after the placement and I just thought, 'that's not realistic'. Our current figures are something like 15%, and that includes voluntary work.*

*I raised it as an issue and their response was, 'you need to seek out only the most work-ready beneficiaries', and I said, 'that's not what we do'. We offer a taste of work to anyone who wants to try it. So it never happened."*

*(Provider R)*

*“We will have those honest conversations with employers. We’ll design the job support. We won’t leave until everyone is happy. We’re constantly going back to check if there are any issues, if they need adaptations. They’re a staff member, we’re not looking for charity. We say to employers, ‘if there’s an issue, even 12 months later, come back and we will help you with it’.”*

(Provider M)

*“We’re a work-focused day service. So the guys who access our service come here to work... let’s do meaningful work, let’s have an end result. It’s all about people having that sense of pride, achieving something, doing something. There’s a uniform we all wear, which is fantastic because it creates a sense of identity.”*

(Provider E)

### Case study

**Tools providers have developed** to support beneficiaries in work include: a template with ten spaces to help someone who struggles to count to assemble packs of ten; a visual reminder of the weight an item needs to be so they can match the number on the scales to the number they need to reach.

### Practical support

Successful work placements and supported employment programmes see VCS providers working closely with beneficiaries (and any external employers) to **determine how best to support individuals to perform the work**. This requires providers to develop a comprehensive understanding of the composition of work tasks (e.g. what they entail; what challenges they might pose to someone with a learning disability), and of the employer’s expectations (e.g. how much time these tasks usually take to perform).

This enables providers to: firstly, **teach beneficiaries how to perform these types of tasks**; and secondly, anticipate and **mitigate any difficulties they might have completing them on their own** (e.g. designing an aid that would help someone to keep count if they struggle with numbers; creating a crib sheet with pictures describing the stages of a task).

### Maintaining employment

One of the main challenges people with learning disabilities face when trying to secure paid work is **maintaining their employment once support has been withdrawn**.

In providers’ experience, **the key to ensuring employment is sustainable is providing ongoing support** (of some kind) to both the employee (e.g. helping them to negotiate any training activities) and the employer (e.g. acting as a point of contact for queries to help tackle any problems before they reach crisis point).

This mentoring of both the employee and the employer needs to continue for a significant period, if not indefinitely, even if it is likely to be required infrequently.

Research exploring supported employment found that **low cost, graphic materials can facilitate individuals’ autonomy in work, and can be more helpful than verbal instruction** offered by colleagues without specialist knowledge of supporting people with learning disabilities (Becerra et al, 2018).

## Challenges

August 2019 (25)

### Understanding and accommodating learning disability

Providers strongly feel that employers and the public (including some health and social care professionals) do not understand what learning disability is, what people with a learning disability are capable of doing and understanding (and what they find challenging), and how best to adapt information, language and services to accommodate their needs.

#### Lack of experience

Providers who regularly engage with employers reported that one of the reasons businesses can be reluctant to take on employees with learning disabilities is because they lack knowledge of this type of disability. Employers are particularly concerned about doing something wrong (e.g. misunderstanding or mishandling behaviour)

This observation is consistent with research on employers' perceptions of learning disability, which found that managers perceived the barriers to work for people with learning disability to be greater than those for people with a physical disability (Kocman et al, 2018).

In contrast, providers reported that businesses who had provided placements found them valuable even if beneficiaries did not progress into a permanent job because they improved employees' and managers' understanding of learning disability, and how it can be accommodated in the work place.

#### Adapting services

Providers observed that people with learning disabilities can struggle to access statutory services, particularly information and advice, when organisations do not make allowances for their needs. Office or telephone-based services are particularly challenging as working practices are often not flexible enough to allow staff to make the necessary adaptations.

One provider cited their struggle to arrange for someone from their local authority to meet a beneficiary who had sensory difficulties (and could not attend their offices) at the provider's building as an example of the way this inflexibility can exclude beneficiaries from accessing support to which they are entitled.

#### Case study

Some providers have found that engaging with local business events and awards (e.g. applying to be local charity of the year) can be a good way to meet businesses (e.g. at awards dinners) and raise awareness of learning disability and the work of the VCFS.

*"The big gap for me is mental health services. There's no specific support. You'll get the generic package, but it isn't tailored towards people with learning disabilities. Particularly bereavement services... And helplines don't cater for people with a learning disability. There is no way, without another person, that they can access that information, but not everybody has an advocate or a carer who can help them."*

(Provider D)

*"Employers are reluctant to take on people with learning disabilities because they're terrified of doing the wrong thing, or getting themselves into trouble because they've misjudged something."*

(Provider R)

## Challenges

August 2019 (26)

### Understanding and accommodating learning disability

#### Communication

Providers were concerned that a lack of understanding of learning disability amongst some health professionals means that beneficiaries do not always have a good experience of engaging with health services, particularly when they are trying to understand explanations from professionals, or to articulate how they themselves are feeling.

They observed that beneficiaries who attended counselling, for example, reported that some **practitioners struggled to communicate with them** because they do not know what kind of language to use. A lack of knowledge of learning disability can also lead practitioners to pitch their explanation at the wrong level (e.g. treating adults as if they were children).

#### Case Study

*Book Beyond Words* was set up by Sheila Hollins to address some of the barriers faced by people who struggle with the written word when they want to talk about issues like grief, or how to manage health conditions (e.g. diabetes). The picture books can also help people with learning disabilities and health and social care professionals (e.g. doctors, social workers, therapists) to discuss topics together.

#### Mencap Treat Me Well (2017)

In 2017 Mencap asked 500 **people with learning disability** about their experience of visiting hospital.

- **75%** said their experience would be improved if staff explained things to them in a way that was easy to understand.

A survey of 500 **healthcare professionals** conducted around the same time found that:

- **37%** thought people with a learning disability received poorer quality care than the general population
- **66%** wanted more training on learning disability
- and **50%** felt that a lack of knowledge around learning disability might be contributing to avoidable deaths.

The LeDeR Annual Report 2018 (2019) found that, when compared to the general population, **average life expectancy of people with a learning disability is:**

- **23 years shorter for men**
- **27 years shorter for women.**

Public Health England (2016) have also observed that *“people with learning disabilities have more difficulty than others identifying health problems and getting treatment for them.”*

*“I think there is a misconception that people with learning disabilities won’t be as capable. Whereas they will do what other people might see as a monotonous job over and over again because they like routine. And they will stick at it and do a very good job on a regular basis.”*

(Provider S)

*“Mental health is an area that people struggle with because they don’t necessarily have the expertise. Practitioners just don’t have the sort of language to support people with learning disabilities. And it’s got to be age appropriate as well... [With employers] it’s that trepidation or nervousness, and it’s through lack of exposure if you like.”*

(Provider M)

## Challenges

### Determining successful outcomes

August 2019 (27)

#### Ambitious goals

Providers feel there is a tendency to limit the aspirations of people with learning disabilities (i.e. focus on what they are not able to do), when in fact they are capable of a great deal. VCFS services can engage their interest, help them to identify their own goals, and support them to develop the skills and behaviours that will help them to achieve these ambitions.

#### Measuring impact

Assessment of the 'outcome' of a project or service (and the criteria used to make this assessment) should acknowledge the significant impact modest improvements in confidence and skill can make to the day-to-day lives of beneficiaries, from participating in a leisure activity they had previously been reluctant to try, to socialising with peers, to learning how to use a washing machine or buy a bus ticket.

#### Giving beneficiaries a voice

Measures of success should take beneficiaries' ambitions and capabilities into account. Providers observed that the rigidity of many of the evaluation processes that are imposed on services by funders means that determination of a successful outcome is often made without reference to the expectations of beneficiaries themselves.

#### Strategic & operational partnerships

Kaehne's (2013) analysis of partnership working between statutory and non-statutory partners found that a **division between strategic and operational levels of partnership working contributes to an inability to bring about improved outcomes for service users**. This is primarily because it "leads to different 'framing' activities in the strategic and operational domains", meaning "goal setting, defining aspirations and [understanding of] positive outcomes for services users varies considerably" between the two.

#### Realistic targets

A review by Bach-Mortensen and Montgomery (2018) found that the inappropriateness of the evaluating and reporting requirements set by commissioners was often a significant barrier to the effective evaluation of VCFS services. Providers frequently cited examples of funders seeking to impose unrealistic targets of services because they did not have a good understanding of the factors that would determine the achievement (or otherwise) of these outcomes. Funders who engaged with services to determine what a successful outcome might be were more likely to achieve their objectives.

*"The fact that, by improving their functional skills, someone can send their mum a text. That's huge. You forget those little things we all take for granted."*

(Provider M)

*"For parents, if their child comes to the group and they're happy and want to come again next week, that's a good outcome. There are the formal outcomes the local authority wants to see, but actually the softer outcomes, self-confidence, participation in the community, they're more important."*

(Provider H)

*"[Measuring personal and social development can be challenging because] a lot of models are about self-reflection, which won't work with our beneficiaries."*

(Provider M)

### Access to training for VCFS staff and volunteers

#### Lack of training courses

Providers across all types and size of service identified a need for training that is tailored to supporting staff who work with people with learning disabilities. Even basic health and safety procedures (e.g. dealing with fire alarms) or medical procedures (e.g. managing diabetes) need to be adapted to ensure that they are appropriate for their beneficiaries. This kind of specialist training (i.e. training on a topic unrelated to learning disability but tailored to meet the needs of staff supporting people with learning disabilities) is scarce.

#### Lack of guidance

The lack of external training means VCFS providers often have to rely on their own staff to adapt and develop their own training programmes, but there is very little advice or guidance as to what training should include, or what criteria providers should use to determine what training staff might need.

#### Local authority/CCG

Providers who have accessed training through their local authority or CCG in the past have found this extremely valuable – particularly when it has facilitated access to specialist or medical expertise they would otherwise struggle to find (e.g. healthcare professionals advising on managing medication).

*“Sometimes we struggle with identifying and accessing training, particularly around how to keep people safe [because people with a learning disability can be vulnerable to assault], and stuff on cyber safety, because they’re on Facebook.”*

(Provider F)

*“I was really pleased to be able to access training through Cheshire East [Council]... it makes people engage better in safeguarding when they’re in a discussion. Whereas doing it online, you’re just reading something. I like to get the best training possible.”*

(Provider A)

*“Although we can use [generic] materials to deliver training, we can only use that to define the principles and then we talk as a group about how that applies to our services... some aspects of fire safety are generic, but what’s key when you’re supporting people with learning disabilities is reaction to the fire alarm, for example... [But] when you look for absolute standards [for training] it just gets pushed back to you. If you ask CQC, ‘do you have standards against which we can measure our training?’, they’ll say, ‘no, it’s up to you, whatever training you think is necessary to delivery the service, that’s what you should be delivering’. But if it turns out that for some reason your training wasn’t adequate and something has gone wrong, that will also be down to you.”*

(Provider O)

## Demand for training from other VCFS and statutory services

### Demand for training

There is a demand for training from organisations who work with people with learning disabilities but are not specialists in either learning disability or the conditions associated with it (e.g. autism; Down's syndrome; cerebral palsy). This demand was observed both by specialist providers who are asked to deliver training but do not have the capacity to do so, and by VCFS organisations who offer services to people with learning disabilities (e.g. arts organisations; social prescribing) but do not feel confident in their understanding of the disability or the adaptations they might need to make.

In 2018 Mencap launched a course for doctors focusing on law and ethics, including the Mental Capacity Act, to facilitate their understanding of, and work with, people with learning disabilities (Mencap Annual Report, 2018).

*"We're looking to deliver paid-for training. So professionals just book a place and we'll do an introduction and what it means in practice. Anybody can throw up a situation they've been dealing with and we'll go through it, giving them plans for action."* (Provider J)

### Raising awareness

Providers also feel there is an urgent need for staff who frequently encounter people with learning disabilities in the course of their work with the public (e.g. housing officers; NHS staff) to improve their understanding of, and communication with, this group [see *Challenges: understanding learning disability*].

### Delivering training

Providers who have taken steps to develop their own training for external partners have focused primarily on raising awareness of what learning disability is and on helping professionals in education and health to develop and share practical solutions for coping with some of the challenges it poses (e.g. adapting the curriculum).

Those providers who had been approached to deliver training externally but had to decline did so either because they lacked the capacity (time, resources, or expertise) to offer that service, or because they preferred to focus on delivering their existing service.

*"I haven't found any training [on learning disability] for volunteers to go on, so finding the right volunteers can be tricky. We tend to find it's people who've already had experience of dealing with those issues."*

(Provider K)

*"I'm basically a layman [re: learning disabilities], I haven't got the knowledge and skills to support people in that respect... If there was training available, I'm sure that would improve our offer to the community."*

(Provider P)

*"We have groups for teachers and teaching assistants so they can share their knowledge... If they've found something that works well for differentiating the curriculum they can pass that on."*

(Provider C)

## Challenges

### Accessing services

August 2019 (30)

#### Rural areas

Several providers observed that people with learning disabilities in more rural parts of Cheshire East are not as well served as those in towns like Macclesfield and Crewe. They suggested that a more mobile, community-based model of service delivery might be more appropriate for these areas. For example, an activity or sensory bus that visited different villages on different days to enable children with learning disabilities to participate in leisure activities without having to travel long distances.

#### Outreach

The clustering of services down the spine of the region (Crewe, Macclesfield, Congleton) not only excludes beneficiaries who may not be able to travel to these locations (whether for reasons of physical disability, or because they have difficulty using public transport), but also limits opportunities for services to reach out to people with learning disabilities (and their families) who might be isolated, not accessing statutory services, or anxious about travelling to and accessing support in unfamiliar locations.

A number of providers indicated that they would seek to expand their outreach activities if they had the necessary resources (e.g. offer support to beneficiaries and their families in their homes; enable staff to be more mobile and attend different parts of the region to signpost beneficiaries to services, offer advice, or support individuals to find work placements).

#### Transport challenges

Lack of transport was identified by many providers as a barrier to accessing day services, not only due to the location of services, but also because of difficulties with public transport. Reasons for this include: public transport does not always run late enough for beneficiaries to attend evening activities; the cost associated with using public transport or taxis; some beneficiaries are anxious about using public transport on their own.

#### Travel training

Teaching people with learning disabilities to use public transport can significantly improve their ability to act independently of their families and carers. However, travel training can be extremely resource- and time-intensive for providers. The most successful programmes see mentors modelling the necessary skills and behaviours (e.g. looking at maps or timetables; buying tickets) and then accompanying individuals or groups on trips to put their learning into practice. For providers, the key is to build beneficiaries' confidence in their ability to use the system and help them plan how they would deal with something unexpected (e.g. a cancellation).

*"I find rural areas are more difficult to set something up in, there are a limited number of venues and they're not always accessible... We'd love to have a fully-equipped bus we could take to deliver activities in the community. It's been done elsewhere, and for meeting the needs of the community it would be immense."*

(Provider H)

*"Travel training just opens so many opportunities. We do a lot of experiential training. When we go to Chester we'll use the train and the bus so people get used to it. We'll look at what personalised support training an individual needs. When beneficiaries come back to see us they'll say, 'oh I still see so-and-so, we meet to go to the pictures' – it's just reducing social isolation."*

(Provider M)

### Underestimating the support VCFS services provide to people with learning disabilities

**The ‘added value’ of the practical, emotional and social support** VCFS organisations offer to people with learning disabilities is often overlooked (or taken for granted). Providers feel that this aspect of their work is not always recognised by commissioners, nor is it taken into account when it comes to allocating funding. Yet if these services were not available, there is a significant risk that people with learning disabilities would not be able to access this kind of support elsewhere.

**Services play an important role in beneficiaries’ routine and social life** – when services are unavailable (e.g. over an extended Christmas break), beneficiaries can struggle to cope without the support and structure this regular participation offers.

### Overlooking successful outcomes

**Not acknowledging the impact small gains** (e.g. in confidence; skill; socialising) can make to beneficiaries’ independence and quality of life.

**Not taking beneficiaries’ own ambitions and capabilities into account** when determining ‘successful’ outcomes.

### Failure to publicise and accurately communicate the support offered by VCFS services

**Some popular VCFS providers are reluctant to advertise their services** because they are already at capacity (particularly specialist services e.g. those supporting people with learning disabilities alongside other conditions e.g. autism). This means people with learning disabilities in other parts of the region are unlikely to find out about them – particularly if they are not accessing statutory services either.

**There is potential for misinformation** if health and social care professionals referring into VCFS services do not have a clear idea of the type and level of support different services offer.

*“Our evaluation process involves talking to people not just about activities, but about how coming [to the group] makes them feel. Some will say ‘safe’, or ‘it means I’ve got friends’, or ‘it helps me to do things I wouldn’t normally do or was scared of...”*

(Provider G)

*“When people first register we’ve always asked ‘what do you want to get out of it?’, and we’re trying to emphasise that more and devise a system of evaluation that is more about what they want and not what the funder wants... it’s going to be impossible to compare with other data, but it seems the right way to do it.”*

(Provider L)

### Limiting opportunities to benefit from work and employment

**Seeking to secure the same employment outcomes for everyone** with a learning disability, when they have different capabilities and levels of skill, and will be more or less successful in different types of employment (e.g. volunteering; permanent paid employment; employment in a supported workplace)

**Not preparing people** with learning disabilities for work tasks before they enter placements or jobs. Ensuring beneficiaries can perform work tasks to the standards (and in the time) employers expect can require significant time and investment in training, both in work skills and in personal care.

**Lack of flexibility within employing organisations** regarding the design and composition of job roles, and a reluctance to make adaptations to roles that might facilitate the employment of someone with a learning disability.

**Fear of making mistakes** on the part of potential employers due to a lack of understanding of learning disability.

**Lack of knowledge** regarding the ways tasks and processes can be adapted for employees with learning disabilities.

### Not working in partnership where it would be helpful to do so

**Lack of VCFS partnership working** VCFS providers can lack the time to identify, and build relationships with, potential VCFS partners.

**Reluctance (or perceived inability) of VCFS providers** to apply for commissioned funding inhibits opportunities for VCFS and statutory services to work together. VCFS services that are entirely self-sufficient are under no obligation to help statutory services to meet their targets.

**VCFS providers can find it difficult to establish and maintain relationships with commissioners**, particularly if they have never engaged with them before. Both VCFS providers and commissioners are pressed for time, which limits opportunities to meet, and for commissioners to visit services.

*“A young lady who came to us about six months ago, very timid, very nervous. [Last week] her mum came to pick her up for a dentist appointment and when she dropped her back she said the dentist was completely blown away because she didn’t want her mum to come into the treatment room with her, she chatted to the dentist, did everything he asked, signed her own name on the patient form. That had never happened before and he was completely blown away by the change.”*

(Provider S)

*“It’s quite difficult to engage corporate supporters... it’s getting a foot in the door. Children with disabilities are still misunderstood.”*

(Provider C)

*“The biggest barrier I find is the lack of recognition of the need for autism-specific services... all the money goes into pan-disability, which effectively excludes most children with autism because they simply can’t cope with it. Many of our children simply don’t access short breaks because all the funding is for generic services.”*

(Provider J)

*“We’ve had people who’ve never travelled independently before but we’ve worked with them and now they can, which is huge for them. They provide peer support too. We’ve got two guys who get the bus, walk the same route, but they walk fifteen feet apart because they haven’t had much opportunity to do things on their own in life. Still keep an eye on each other, just walk separately.”*

(Provider E)

### Lack of knowledge about learning disability

**Lack of knowledge about learning disability amongst the public** (including employers) e.g. what people with learning disabilities can do/find challenging. This can lead to a reluctance to engage with people with learning disabilities for fear of making mistakes.

**Lack of understanding amongst some health and social care professionals** regarding the adaptations they may need to make to their language and practice when they are working with someone who has a learning disability.

**Lack of knowledge about learning disability amongst non-specialist VCFS organisations.** Providers who may be keen to support people with learning disabilities (e.g. social prescribing; arts or sports activities) do not always feel they have the knowledge to support these participants (or know where to find the necessary support).

### Not recognising that people with learning disabilities are a heterogeneous group

**Different people will feel comfortable in different types of space and need different types of support** – especially if they have additional needs. This is true of leisure services (e.g. activity groups; hubs), employment opportunities (e.g. internships; volunteering), and housing (where providers reported a lack of single person supported accommodation suitable for people with learning disabilities and autism).

**Not taking composition into account when assessing the capacity of services** – some groups (e.g. some youth groups) function best with a smaller number of participants due to the nature of the activity or the mix of personalities and behaviours of beneficiaries. To expand capacity it may be more appropriate to increase the number of groups (or replicate the service elsewhere) than to seek to enlarge an already successful group.

### Excluding people who are socially isolated or in rural areas

**Lack of suitable venues outside the main towns** (e.g. for youth groups or activities), and the **clustering of services in main towns** (Crewe; Macclesfield) risks excluding those in more rural parts of the region.

**Inability of some people with learning disabilities to access or use public transport** to attend groups.

**Limited outreach** to potential beneficiaries who may be socially isolated and/or anxious about attending services.

#### Ensure funding opportunities encourage the full range of services

**There is a need for all three types of VCFS provider** (specialist; generalist; all inclusive) as they offer different types of support to different users. Ensure support is not limited only to providers who may reach the widest audience or greatest number of people.

**Continue to encourage services that are not specifically designed for people with learning disabilities to make their activities available to this group**, supporting them to adapt their activities where necessary – including how they might reconfigure their physical spaces to make them more welcoming or accessible.

#### Utilise the unique nature of the support offered by the VCFS sector

**Is there scope to develop closer working relationships between statutory and VCFS services?** Consider how the additional support offered by VCFS services (e.g. emotional and social support; time and attention; practical assistance) and the informal nature of the provider-beneficiary relationship might complement the more formal medical and financial support provided by statutory healthcare and social services.

**Consider how best to utilise VCFS support to mitigate some of the stress and uncertainty associated with the transition from children's to adult's services** (e.g. funding youth groups to age 21 rather than 18).

#### Support people to access services

**Support VCFS services to help people with learning disabilities to become more independent** by offering travel training as widely and early as possible.

**Investigate whether more mobile services** would better serve to people with learning disabilities in rural areas.

#### Expand the number and variety of short-break opportunities

Consider working in partnership with VCFS providers (and their beneficiaries) to **think more creatively about short-break provision** in order to offer a wider range of opportunities to people with learning disabilities and their families.

*"We've done quite a lot of travel training. We'll look at Google Maps. We're looking at how to get to Manchester. We've gone across as a group to the train station to look at how you physically buy a ticket. We've mapped out routes for people and looked at alternatives, so if the train doesn't come, what do I do?"*

*The more we do with them and the more they try it themselves, the more confidence they have. I think they all feel a bit more confident now because the PCSO gave them his mobile number so they feel honoured they've got that!"*

(Provider D)

### Opportunities for improvement

#### Make it easier for VCFS services to apply for funding

VCFS organisations are often lacking the time and resources to apply for funding, and many opportunities to apply for commissioned funding are project-based rather than service-based. The language used by commissioners can also be difficult for those outside local authorities/CCGs to understand.

Consider ways of articulating more clearly what external applicants need to do to secure funding and avoid relying on terminology that is only commonly used amongst commissioners.

#### Facilitate greater collaboration between VCFS colleagues

**The most productive VCFS partnerships are between providers whose services complement one another**, whether within the field of learning disability (e.g. when seeking work placements) or across the third sector (e.g. when building relationships with specialists in other fields).

Consider how statutory bodies might **help to facilitate the establishment of partnerships** that would be of benefit to providers by creating focused opportunities for providers to meet organisations that would add value to their service (e.g. an event focused on supported employment), or opportunities for providers to meet colleagues who specialise in a topic their beneficiaries might benefit from (e.g. money advice).

**Opportunities to build partnerships with VCFS colleagues working in mental health** may be particularly valuable, particularly when signposting beneficiaries to appropriate support, as this is an area in which providers feel people with learning disabilities struggle to find appropriate support.

Facilitating VCFS partnerships across different specialisms could also **provide opportunities for staff and volunteers to access training** in other fields (e.g. some providers have delivered training to, and received training from, staff in VCFS services who work in other fields e.g. counselling).

Facilitating partnership working may also **help providers in the delivery of more person-centred support**, as it may enable them to offer their beneficiaries a greater choice (and the opportunity to encounter a greater variety) of activities and experiences.

*“We’ve always felt it’s really important to be pushing people to accept some rigour in their lives because nothing has ever been expected of the people we support, nothing has ever been asked of them. And that, in a way, is a form of negligence. You’re keeping people at a distance from their own lives.”*

(Provider O)

Haigh et al (2013) asked people with learning disabilities about their lives and what makes them happy. They found that the **staff who ran the activities and services they attended were an important source of advice, guidance and comfort** to them – from helping them resolve arguments with friends, to making a GP appointment.

#### Facilitate greater collaboration between VCFS and statutory colleagues

**Improve understanding of learning disability amongst health and social care professionals** Providers reported that health and social care services can lack understanding of learning disability, and Mencap (2017) found that 66% of healthcare professionals would like more training on learning disability. The government has stated that mandatory disability awareness training should be provided to all NHS staff, and “strongly recommend employers involve people with lived experience in the development and deployment of training” (DoHSC and NHS England, 2018). A few VCFS providers already deliver limited training to statutory partners in education and health, but many lack the capacity to offer this service on a large scale. Consider inviting VCFS staff and beneficiaries to contribute to the design (and delivery) of training to staff in statutory services.

**Support staff in other statutory services (e.g. education; housing) who regularly work with people with learning disabilities to improve their knowledge** Providers who work with teachers and teaching assistants to improve their practice reported that there was significant demand for this type of collaboration, but that schools were reluctant or unable to pay for this service and VCFS organisations have struggled to fund the delivery of these sessions themselves. Explore ways of supporting this type of collaboration where possible.

**Consider engaging with VCFS organisations at an earlier stage in the commissioning process** to better understand beneficiaries’ needs, the way services are responding to these (e.g. developing new types of support; ad-hoc activities), and their ideas for improving provision. Draw on VCFS knowledge of what makes the most difference to beneficiaries’ lives to inform the development of commissioning objectives before outcomes are agreed and collaborate with providers to give beneficiaries a voice in these discussions. The King’s Fund observed that involving voluntary organisations at an early stage (before tenders have been drawn up) enables VCFS providers to use their local knowledge to inform commissioning priorities. In the words of one commissioner, “we should have a conversation about what we’re jointly trying to achieve before we start talking about money – the conversation is the wrong way round” (Weeks and McKenna, 2015).

**Encourage commissioners and health and social care professionals who refer in to VCFS services to visit providers in person** to gain a better understanding of their work, and engage more directly with those accessing these services.

*“We raise awareness of disability in schools and colleges, so we’ll go out and talk about disability and appropriate language, the challenges people can face. We’ve never been able to get funding for it, because I think the view is that the school should pay for it. When we didn’t charge we were asked a lot, [but] now we offer it as a paid-for service schools are more reluctant.”*

(Provider G)

Interviews by Newberry et al (2015) with people with learning disabilities aged 60-81 found that the quality of their relationships is central to their enjoyment of life and identified **the need for services to support older people in maintaining friendships** as a key finding of their research.

### Opportunities for improvement

#### Facilitate greater collaboration between VCFS and statutory colleagues

##### **Support commissioners to continue to develop and maintain productive relationships with VCFS providers.**

A number of providers observed that their relationships with commissioners had improved thanks to the efforts of individuals at Cheshire East Council, but others felt that they had little to no relationship with, or access to, commissioners in their local authority or CCG.

**Raising awareness of commissioning constraints** Commissioners have their own financial and administrative challenges to contend with, and while VCFS groups are aware of these it may be useful for commissioners to enter into a dialogue with VCFS providers to discuss what limits and enables the commissioning of services and where VCFS providers and commissioners might work together to improve service delivery within these constraints.

#### Facilitate access to all types of work and employment

**Broaden the range of work opportunities**, rather than focusing only on increasing the numbers of people with learning disabilities who are in permanent, paid employment. Consider improving access to other types of work (e.g. funding community projects and social enterprises; supporting people with learning disabilities to volunteer; encouraging employers to offer fixed-term supported work placements). These types of work can offer beneficiaries who are not well suited to full-time employment (e.g. those who will be unable to reach the level of skill necessary to perform tasks without support) some of the benefits of work, without the pressures of employment.

**Support people with learning disabilities to secure employed roles.** A significant number of people with learning disabilities are able (and would like) to secure paid employment, and, given the right initial training and support, will be successful in their roles. Consider how best to support programmes of supported employment that offer significant work-based preparation for tasks and working conditions in advance of placements.

**Increase the numbers of employed roles** available to people with learning disabilities. Explore ways of drawing on the VCFS expertise to improve employers' understanding of the capabilities of people with learning disabilities and the adaptations they can make to support them in employment. Consider ways of bringing VCFS organisations and businesses together to facilitate the development of supported employment relationships.

*"Community enterprises are a good way for people to gain experience of work. A café that is a training opportunity. We've done some good gardening projects. It's just having the time and space to develop it."*

(Provider M)

*"We're always looking for partnerships. We've hosted business-to-business breakfasts, so people look around, see our activities, meet our beneficiaries. Joining the Chamber of Commerce is a valuable way of making contacts. We invite small and large companies to visit us [and volunteer], maybe doing some painting and repairs, or working on a project with our members. We've found that's a really valuable way to break down barriers."*

(Provider O)

#### Improve access to independent advocacy services

The review of services provided to people with learning disabilities that was launched in response to the Winterbourne View scandal recommended that “people with learning disabilities and/or autism and their families should be given a ‘right to challenge’ decisions” and that “they should receive independent expert support to exercise that right, including high-quality independent advocacy” (Bubb, 2014).

Providers observed that, in Cheshire East, advocacy services for people with learning disabilities are limited, which means beneficiaries and their families rely on peer support (e.g. parents or carers who are also experts in a particular field e.g. law) for informal advice, and on VCFS staff to help them negotiate systems, deal with problems, attend meetings, and complete paperwork. While VCFS providers are willing to help beneficiaries wherever they can, many are not equipped (or lack the resources) to offer this kind of support and guidance.

Providers also felt it was important that some advocates were independent both of statutory bodies and of VCFS services, to avoid any conflict of interest and reassure all parties that the advocate is representing the best interests and views of the beneficiaries themselves.

Consider ways of improving beneficiaries’ access to independent advice and advocacy services, and of supporting VCFS providers to develop expertise and capacity in this field where appropriate.

*“The level of bureaucracy is a massive issue. Lack of support through that bureaucracy is a massive issue... The thing we’re asked for most is to help families on an individual basis. Families wanting someone to come into a meeting with them, go to a doctor’s appointment, come to school and tell them what they need to do... they want someone who a) knows them and b) knows about autism specifically. These services should be out there, but they’re not. Or they’re not expert enough.*

*Our Facebook page is very useful because we have well-informed parents. We have two very good solicitors who are parents who will say, no, the law requires x, y, z.”*

(Provider J)

*“We can support people to challenge [decisions], but it has to come from them or their parents, which can be quite difficult for them because it can be intimidating to challenge an assessment, or a decision, or a service.”*

(Provider H)

*“I want to train people to be advocates and also do benefit advice. We’re doing a lot of form-filling for people, the DLA. We spend two hours doing a draft and then another two filling it in properly. Because we spend half the time crying! Because you have to write about your worst day... tell me the worst night, tell me the worst day... it’s not a good place to be. So it takes time, and you can’t just have an hour appointment. It takes as long as it takes.”*

(Provider A)

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#### My Life My Choice

##### [My Life My Choice website](#)

A self-advocacy organisation, which supports people with learning disabilities in Oxfordshire to have their say and claim their rights.

#### British Association for Supported Employment

##### [British Association for Supported Employment website](#)

Supports, promotes and develops supported employment for people with disabilities.

#### Remploy

##### [Remploy website](#)

Runs free workshops and webinars for employers to improve confidence around disability in the workplace. Courses include: *employment for people with learning disabilities*, and *supporting colleagues with sensory impairment*.

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See appendix for details

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## Appendix 1

### Cheshire East Council Supported Employment

August 2019 (41)

Cheshire East Council Supported Employment Services help people with disabilities to secure employment.

For more details, visit [Cheshire East Council Supported Employment webpages](#)

#### Supported Internship Coordinator

Cheshire East Council's Supported Internship Coordinator is working with providers to significantly increase the number of supported internship places available in Cheshire East.

##### **Supported Internship Coordinator**

Cheshire East Council - Zoe Macey

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#### Working with employers

**Cheshire East Welfare to Work Partnership** (hosted by Cheshire East Council) is a partnership of services that help to support people who are at a disadvantage in the labour market (including people with learning disabilities) into employment.

They have organised a number of employer engagement events, including breakfast seminars and 'speed-networking' sessions.

They are also developing a series of short-courses to provide training for employers.

#### Supported employment projects

In May 2019 Cheshire East Council (CEC) were successful in securing funding to deliver Systematic Instruction Training to staff (local authority, education and VCFS) supporting people with complex learning disabilities and/or autism.

By October 2019 CEC will have delivered this 5-day training to 36 staff. The idea is to develop a cohort of personal assistants who have been trained to provide in-work support to people with learning disabilities as they participate in employed roles.