Employment and Volunteering within the Learning Disability Community

Report by the Carers Centre and PaCC/Amaze, April 2018





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Introduction

This consultation has been requested by the Learning Disability Partnership Board with the aim of looking at the support and advice given to people with *Learning Disabilities* (LD), both at school and in the adult world re gaining employment or volunteering roles. The focus of The Carers Centre and PaCC/Amaze was the carers of people with Learning Disabilities, rather than the people themselves.

Possible questions to explore included:

- Are people with learning disabilities scared to work because they will lose benefits?
- Are they scared the job might not last?
- Have people been offered any support?
- Do people know where they can go for advice?
- What information has been provided by schools and colleges?
- What information are young people given?
- Are Education Health and Care plans contributing to preparing young people for employment?

Methodology

The Carers Centre and PaCC/Amaze arranged a joint focus group, some phone interviews and considered the possibility of running an online survey for any carers unable to attend. The online survey was not carried out as response to the focus group and phone interviews was good and the messages were consistent. Amaze also contacted some young people with Learning Disabilities and this contributed to the Speak Out report.

The Carers Centre identified 27 adult carers and invitation letters or emails (depending on whether a communication preference had been set on our database) were sent out, followed by a phone call where a response had not been received after one week. In total, The Carers Centre had 3 positive responses to the invite and 3 more that were willing to complete a phone interview. At the focus group, 2 of The Carers Centre invitees attended.

Amaze identified parents caring for young people with LDs in the transition age range 14 to 25 via the Compass database and sent invitations. Ten parent carers were able to attend the focus group. Two others contributed by email giving a response total of 17 carers; 12 face to face, 3 phone interviewees and 2 by email.

3 attendees at the focus group were willing to provide a comprehensive view of the experience they, and their cared for person had had to provide a structure to the session and offer participants a chance to learn from each other's experience as well as contribute to the consultation.

The focus group discussion centred on the experiences detailed by these carers with questions and others responses interspersed to give a rich range of experience.

The focus group age ranges of the **Person Cared For** (PCF) were 14 to 49:

7 in their teens: 14, 15, 16x2, 17, 19x2,

5 x 20-30 yrs 1 x 40-50 yrs

Two of the carers at the group cared for two people with LDs.

The PCF all have learning disabilities including severe and PMLD, five also ASC, two with speech and language needs and three with additional health issues.

Executive Summary

Carers responding to this consultation were keen that the people they care for with learning disabilities have the opportunity to work. Many of the people cared for (PCF) have had some experience of paid or voluntary work. Carers saw strong benefits to be gained from work and few disadvantages. Finding suitable work or volunteering was not easy and was usually only possible through sustained effort and use of personal contacts by carers or in some cases from the Supported Employment Team. Online application processes are a new and significant barrier.

Work and volunteering roles were rarely long lasting in the experience of this group although sometimes this was about changing circumstances. Volunteering was used both as an end in itself and as a route towards paid work. There was low awareness of the interaction between work and claiming benefits. Advice and support about finding work was not seen as readily available. Carers reported some disappointment that schools and colleges were not able to offer effective support to young people around employment and volunteering. They would value information about welcoming employers or places that offer supportive volunteering.

Carers were realistic about the ability of those they care for to be reliable and flexible about work. They recognised the lack of incentives for employers to take on staff who would need extra support. But they also felt there was a lack of awareness about the potential for people with LDs to be valuable volunteers and employees, and the adjustments that could help them do so.

Carers thought schools and colleges could do more to prepare young people for work. Carers of young people with EHCPs did not find these focused on future employment. Carers felt the Council could do more to promote work opportunities for people with LDs, increase funding into supported employment and educate local employers on the use of volunteer roles etc.

The report concludes with 5 recommendations for action.

Responses to questions

An overview of responses to each question posed is below.

Experience

1. Has your Person Cared For ever had paid work or a volunteer role?

(What? How did it make them/you feel? What advantages are there to your PCF (person cared for) having a job or volunteer role – for them and you? What are the disadvantages?)

Had a role?

Most respondents PCF had had either paid work or volunteered. Two respondents stated that their person would never be able to find employment. This is due to the severity of their disability which prevents them from even performing very basic tasks independently. They still felt that experience in a work environment would be of value to them.

Where employment or volunteer roles had been obtained, these varied from full time employment as a bike mechanic for Halfords, packing in a factory, part time work at the council, to volunteer roles with charities or other organisations.

Benefits

There were a number of benefits identified to working:

Independence

Confidence and feeling valued

Valuing money

Budgeting (and being able to spend own money)

Learning social skills "fitting in with society by doing everyday activities such as going to the pub with friends" and learning how to use public transport on their own.

Parent carers of younger people with LDs were keen for them to have voluntary and unpaid or part time work experience as a stepping stone that would make "real" work more achievable in the future.

In some cases there was also a physical benefit to the work undertaken such as keeping fit by landscape work.

Where the person was attending college, it was also seen as beneficial as a constructive use to their time and additional learning experience given that "full-time" courses post 16 are in practice part time.

A couple of parent carers have sons or daughter who are never likely to be able volunteer or work without direct support at all times from a carer, but still felt this could offer dignity and purpose.

Disadvantages

Carers worry about safeguarding.

Disappointment if role not offered.

2. How did they get this job?

(Did they get support? Were they approached about a role or did they apply? Was it easy or hard?)

Easy to get?

The general view was that it is difficult to obtain jobs or volunteer roles due to:

Perception that a person with LD will be an extra insurance risk

Perception and sometimes reality that they are incapable of doing the job

Require extra supervision

May be unreliable as far as attendance/behaviour

How did they get roles?

It was clear that in every case where a PCF had achieved a paid or volunteer role this had relied on active research and the pursuing of contacts and networks by the carer, although one person had invaluable assistance from Supported Employment, one from YAC (YMCA youth advice centre). One had followed a supported internship course and others followed college courses which were intended to offer progress towards employment, although this was not always reality.

Having a CV of skills and education and making shortlists of potential employers or volunteer organisations were seen as valuable. It was also useful to visit the organisation to see if it was a suitable place to work i.e. welcoming but also appropriate for the individual's particular needs and interests. This also helped to allay carers' concerns over vulnerability, risk and safeguarding (to a degree). It was regarded as important to not be negative about the person's needs but also this was seen as quite difficult to do and was balanced by a need to be realistic and clear with potential supervisors.

Most applied for roles with encouragement from parents, friends or other carers. Or the carer applied on their behalf. One role was obtained by the carer driving past the YMCA Youth Advice Centre and "popping in on the off chance" to see if they could give advice and support. Using personal contacts, asking friends and neighbours and searching the internet were all methods employed. Charities were often targeted since it was felt they would have inclusive policies but work in charity shops is the most common option and this did not appeal to all. Where personal contact was made or already existed, it was seen to be much easier to convince the organisation to consider taking on someone with LDs and a number of roles were obtained due to personal contacts within the organisation, charity etc.

It was seen as important to understand that while some organisations will employ people with LD, some will require a Disclosure Barring Service check. A DBS check for voluntary work is free, and can be made portable. Preparation and timing were seen as important to try to get roles early and not to wait until term time starts. Christmas jobs were seen as very hard to get due to university students applying.

One respondent had not been accurately diagnosed with LD and ASC until they had a "meltdown" in the Job Centre. This prompted seeking assessment for autism. It was felt that the Job Centre were very good at spotting that the person may have an undiagnosed condition but the treatment previously and the expectation to find work and the hours that must be worked was what led to the "meltdown".

Some sectors/organisations that were felt to be open to employment, work experience or offering suitable volunteering for people with LD are:

The Council

Some charities, especially charity shops

Duke of Edinburgh Award Scheme

National Citizenship Scheme

Guides and Scouts

Nurseries and Playgroups

Animal shelters

Cafes, especially community cafes and social enterprises

Food-banks

Some larger retailers especially supermarkets though some require an exam to start (Waitrose) and one provided a very negative experience (see "Online" below).

Marks and Spencer's

Screwfix had been flexible for one individual (although this had started through a personal contact)

Carers had turned to registers of volunteer opportunities such as "Do-It.org" and Community Base's list. The specific volunteer roles advertised were often not a match for the PCF but they did provide an indication of organisations worth approaching on a more personal basis. It was also seen as valuable to participate in the Duke of Edinburgh Award Scheme and also to look for institutions that take D of E volunteers as they may be more open to younger volunteers or volunteers with more support needs.

One respondent had been part of the Youth Council at school and done a variety of volunteering. Links with an after school club led to part time work experience in their office with mail outs and shredding. It was noted that under 16's that apply for a role at a nursery or youth group may be unsuccessful since they will be counted as one of the children or young people for the purposes of adult to child ratios.

Online

Applying for roles online has created a huge barrier since many people with LD cannot even get past the initial questions even though they and their carers are certain they could fulfil the role. This is particularly true of large retail organisations.

One respondent described trying to complete the online application for ASDA followed by a group interview at which they were asked to "Pitch for a coffee sale". The job applied for was stock replenishment and the experience was described as "hideous" and disproportionate to the nature of the job on offer. Carers had also found that these employers sometimes had a quota of jobs per store that they would offer to disabled people and if these were full no others would be employed.

3. Do they still do this work?

Most of the voluntary, work experience and paid work roles obtained had been part time and/or temporary. Some are still in roles but all had changed over time. For some this was due to changes in education (e.g. school to college) or leaving education. Some moved from choice but for oters things had not worked out long-term.

The respondent who had broken down in the Job Centre had a volunteer role at the British Heart Foundation shop but has had to leave this and is now "at home" and his carer is concerned at his weight gain and lack of motivation.

4. If not why did this work end?

(How did it make them/you feel?)

One person had been sacked from his employment due to playing practical jokes at work with "encouragement" from his colleagues. He has tried (with enormous help from his carer) many different avenues to find work but has either been placed in unsuitable environments (he is asthmatic and was given a role in a carpentry workshop) or has been turned down. This individual was even denied additional support by a charity, when his carer was offering to set up and fund a cycle workshop for him as part of his role within a charity.

Some respondents were unable to continue with volunteer positions due to their changing circumstances meaning that on most days they could perform the role but on others they were unable to even leave their home.

Some respondents had simply moved onto other roles. One had expectations that they wished to work full time and have a career in Digital Media. The carer felt this was unrealistic as the person does not understand the nature of the job marketplace and expectations of employers and also "the limit of their skills". This means their work always needs checking.

Support and information

1. Do they/you understand how much money can be earned with benefits?

Several respondents stated that they did not have any idea how much could be earned before benefits were affected. The carer of the person who worked for Halfords previously, had never heard of any mention of benefits and how they might be affected.

The majority said they had some understanding or were going to look into the details more closely since they had not considered benefits vs wages up to now as their PCF were too young.

2. Who would they/you ask if you had a question about work and benefits?

(Would they/you trust it was the right answer?)

Carers said "Not sure" several times.

"Google it" was also mentioned.

Both Amaze and the Carers Centre can offer advice on this.

3. Have they asked you for help getting a job?

(Who did you ask? Was the help you got good?)

Yes, most PCF had talked about some form of employment with their carer/parent, though in some cases the drive comes from the carer. Amaze also discussed the topic of employment with young people involved in the Amazing Futures peer support project. All these young people clearly aspired to have a job. Where the cared for person had asked for help, it was always initially via their carer.

The Princes Trust had been a valuable support to a couple of young people since they offer courses that build skills including public speaking/confidence etc. The YMCA Youth Advice Centre can help with CV creation, lists of jobs, dressing and behaviour in interviews. They have a drop in session every day.

Carers reported some disappointment that schools and colleges were not able to offer effective support to young people around employment and volunteering. Where courses were supposed to include work experience this was not necessarily forthcoming. Some tutors gave good advice but time for this seemed to have been cut.

4. If work worries them is there someone they/you could talk to about it?

(Who? Have they helped in the past? Was it useful?)

Generally, this was not directly answered by most respondents, though from other commentary, actually working did not appear to be a worry. Problems were indicated to arise from a lack of motivation to find a role and a lack of understanding that it was not "optional" to attend work.

Most respondents spoke with their parent(s) or other carer about any issues they had. One respondent was very nervous about being in contact with the general public but was happy to do work in a back area where they could have limited contact with people they did not know. Some young people had sensory issues which made the workplace challenging and controlling for or ameliorating this was not easy.

5. Have you heard of the Supported Employment team?

A mixture of responses. Some had never heard of this team, while others knew about it and some had received a lot of help from it leading to volunteer and paid roles.

The SET had looked at "Job Carve" where a role was split into the sections that a person was capable of doing and other parts of the job were done by someone with a different skill set. They also helped one person gain a role at Brighton and Hove Council where they were able to use their computer skills (which were seen as good) while not being in contact with the public since this worried the individual.

6. Have they (on own or with you) ever been to the Job Centre?

(What was it like? What would make it better for people with learning disabilities?)

A number of respondents were carers of under 18s, so had not been to the JC yet. Several respondents stated that they had accompanied their PCF for to the JC.

"They provided a sheet of jobs but no other help".

One respondent had been highly stressed by attending the JC and the expectations they felt were put onto them. This led to them having a "meltdown" in the centre which then led to their diagnosis. The JC were felt to be very good at recognising that the person may have an undiagnosed disability or condition. The undiagnosed person stated afterwards that it was a relief being diagnosed as they had felt excluded and unwelcome before this.

Another respondent stated that their cared for person attended the JC every six months and they felt that a particular person there was very patient and calm.

7. What sort of information would help them/you most?

"Sitting down with the JC staff and them explaining how to find a job."

Routes into work for people with LD. It was felt by some, that there was support until school/college finishes and then it ends when the person may be looking for life outside of school or college. This appears to be prevalent where the LD is not severe, whilst for the more disabled there was no focus on work at all.

8. Where do you usually go for advice and information about other things?

The Carers Centre coffee mornings or call them.

Amaze

Princes trust

Find out for myself

Internet

Other parents

The NHS have a talk about employment for disabled people.

What is it like having a job?

1. Would it be easy for them to turn up to work when expected?

(Would they need support to plan so that they knew when they had to be there?)

Reliability appears to be impacted by three factors:

Motivation – respondents may have ideas about the type of role they wanted and be demotivated if unable to obtain this. Many struggle to leave the house or even their bedroom due their particular needs and this this hard to overcome if work or volunteering is challenging, anxiety provoking or unrewarding.

Health – this plays a major role. One respondent was described as being ok most of the time but on a bad day, like a six year old. Another suffers badly from Asthma which was heavily impacted by the work role they were given first in a carpentry shop and then as a cleaner. Their living accommodation also played a significant role since it had 70+ steps. In another instance this person was placed in accommodation with some other young people who intimidated him so found it hard to get out to work. One respondent has to take medication which would affect their ability to reliably work. And some had multiple health related appointments.

Full time work was not seen as practical for many of the PCFs by their carers. One young man who had attempted full time work one summer had become exhausted and distressed. The effort involved in performing at work can be considerable. He is currently in a part time role.

Transport – some respondents stated their cared for person would not be able to travel on their own to work. Some had valuable help with independent travel training. One had this via Grace Eyre. In another example the carer had put huge effort in to changing this, using a visual travel book, repeated practice journeys, recording journeys and showing progress.

2. Would they and you be able to be flexible and work when needed?

(This might mean moving appointments and arranging travel and support?)

Yes to a degree in some cases but not all.

Some responses stressed the need for routine and being calmly eased into a role. Being flexible was challenging for people with autism. One carer of a person with autism felt that there was no general understanding of the condition. An individual manager might be very tolerant and understanding while colleagues or other managers may have very little idea how to interact or what to expect.

For young people also attending college courses there was an issue of timetable changes and late information about timetables which impeded getting paid or voluntary work set up.

People with LDs and their carers end up relying on a mix of activities to fill their week and keep them engaged in the community. Some would not want to risk losing a valued activity to be flexible about work that might not work out and last.

3. Has anyone ever explained what employers expect?

(Reliability, phoning in when sick etc.?)

Carers of young people felt that schools and colleges could do more of this but it was not part of the curriculum.

Where people got a role this had generally been discussed when the person took on a role. A mini contract was created for one respondent.

Parents and carers had spent time explaining to their PCF that work was not optional and how they must behave.

4. Would you be happy to commit to a permanent contract?

(People may feel their health/mental health is too unpredictable to commit long term)

Some would and had permanent contracts, though one respondent was described as being frightened of letters.

"No he couldn't do it." was emphatically stated by one carer.

5. Do they enjoy the work/role they have and what type of role is it?

One respondent liked the routine of work (changes to condition have meant this is no longer possible) but not the actual work itself. This was a volunteer role at British Heart foundation and it led to anxiety which results in displays of temper or the person "goes to pieces".

One respondent now works in a volunteer role at a nature reserve and enjoys the physical aspect of the work they are able to do even though they are not physically robust. One sociable young woman enjoys her unpaid role at a café. The young man working part time at Screwfix is delighted to feel part of the team and appreciated being offered training.

Another respondent works for the council on reception one day per week and volunteers at a charity on another day but has stated they don't want to be working this little when they are 30.

Even though some respondents said their PCF enjoyed their work, they still had difficulty motivating them to attend.

Education

What did you learn about employment at school/college? (Was it useful?)

The view in the focus group was varied and appeared to depend on the school or college attended. Generally carers felt there was not a strong focus on preparing their young people for work whilst they were in education. They would like schools and colleges to help young people start a CV, have interview practice, discuss realistic work aspirations and how to behave in the workplace. They also felt more travel training would be useful. It is possible that some activity of this kind does happen at school/college but the carers are unaware. However the young people asked about this by Amaze also reported not being prepared for work at school/college.

None of the parent carers of young people who had Education Health and Care Plans felt that these were used to prepare for adulthood in terms of work. Some plans recorded young people's aspirations and had outcomes related to personal and life skills but were not actively focussed towards future employment.

Plumpton was seen as good in promoting future employment. Brighton Met was not viewed so positively as the young people were not able to access the vocational courses that really lead to jobs. South Downs at Lewes was seen a good environment but help with work experience was not as great as hoped. Parent carers' responses often focussed on the support with the transition from school to college rather than support towards employment.

"Little – it was mostly my own research."

One person who provided a detailed response at the focus group stated that "At school (Downs Park) they started with a work mind-set." The parent also started to prepare their PCF early by ensuring that they were used to using the bus instead of taxis and the school was supportive with this.

2. Did you do work experience?

(Did you like it? did you learn anything new? Was there a chance of a job at the end of it?)

"No and no."

"Some."

Downs Park arranged work experience at Marks & Spencer and this was viewed as very positive. This led to the application for work with ASDA described earlier ("Hideous").

A supported employment course at Plumpton (2 terms of college and one term at BH Council) was arranged and seen as highly beneficial.

"School did some work placements but these varied." This respondent also stated that "money was cut" affecting time for careers advice and support and that the college sent a "form asking for ideas" from parents about potential work placements rather than the college being able to find these.

3. Did they help you understand about benefits?

The general consensus was that if the schools had mentioned benefits it had not been clear enough for the PCF to communicate back to their carer. No carers responded that the school had spoken with them directly about benefits.

"No there was no help about benefits."

"No."

"Not that I am aware of."

4. Did they help you understand about what it is like having a job?

Again, there appeared to be very little information passed on by schools or this was easily forgotten and therefore had little or no impact.

"No." was a typical response.

Carers speaking amongst themselves appeared to be a more usual route for carers or parent carers to obtain information about the realities of work life for their PCF. A phrase used was, "No but some other carers did."

5. Did they tell you where you can get help and advice?

"No."

"No."

"Told about being able to get a free bus pass if work starts after 9.30."

6. What sort of information would help you make decisions and plan for the future?

Responses were all focused on practical measures such as advice on routes into employment and open minded employers.

"Information or a list of open minded employers."

What do you think?

1. Do you think it is easy for people with learning disabilities to get jobs?

The view was that it is extremely difficult for people with LD to obtain jobs or volunteer roles though there is an understanding that this varies depending on the severity of the conditions.

Some typical comments were:

Not at all.

No, especially if they have lost a previous job.

No you normally need to have some sort of personal contact.

Online applications can prevent getting roles even when the person is capable and likely to be reliable.

2. What sort of jobs do you think people with learning disabilities get?

Mechanical / Computer— if they are skilled in this, since they may accompany this skill with a high degree of precision.

Reception.

Supermarket (tends to be stock replenishment).

Charity shops or offices.

Nurseries/Playgroups.

Animal shelters or similar.

3. What is the biggest thing that stops people with learning disabilities getting jobs?

There was no single biggest factor identified though online applications and lack of knowledge and understanding by employers were highlighted as possibly the two key factors.

"Lack of knowledge by employers. Everything is fast paced. My son works at a steady pace but is very precise."

No incentive for employers to take on people with LD especially with the commitment they often need to enable them to flourish and become effective workers. "It takes her a very long time to learn something new. Once she has done that she could be useful and reliable but who's going to allow her that amount of time?"

Online applications.

Distance from workplace.

Some employers will not even enter into discussion (The LEGO shop was given as an example).

4. Is there something the council could do that they don't do?

There was a realisation that the council have funding issues, however, it was also felt that there was not enough promotion of the capabilities of people with LD to counter the negative image many employers still appear to have.

Closure of facilities was seen as especially unhelpful as it reduced the opportunities for people with LD to socialise, practice skills in a safe environment and also provide some respite for carers.

Some comments were:

"Provide more activities for people with LD."

"They closed 'Belgrave' where people could try to get work!"

One respondent was extremely angry with the actions of the council and how they had placed his PCF with a charity who were "awful". The carer felt that this charity used their person as unpaid workforce in unsuitable jobs with no correct certification (food hygiene) or in work which impacted his health

(carpentry). This was described as "Training for work" and had the constant threat of eviction if the role was lost. This led to the carer having absolutely no confidence in the council and even going to the local newspapers.

Encourage people into work where they have a particular skill.

Increase funding into supported employment.

Educate local employers on the use of volunteer roles etc.

Improve the transition from school to college.

5. Where would you like to work?

(Why? Do you think it could ever happen?)

This was not asked directly since we were talking with parents and carers, however, one carer did state that their son wished to work in digital media and was looking to do a course (3 weeks) which they would pay for with a slight possibility of work at the end. The carer felt this was probably not realistic due to the competition in Brighton and Hove for these types of jobs but did not want to completely discourage their PCF.

Another carer outlined in detail the measures he had personally gone to try to fund a bicycle workshop for his PCF. He had spoken with the charity that was providing housing and "training" but they were not interested at all even though he was stating he would fund the project.

Conclusions

- 1. Many people with LD wish to find employment or a volunteer role.
- 2. Often the initial driver in finding employment is the parent or carer and this continues where the person has obtained a role. The parent or carer's desire to research, advise and make contact with potential employers, appears to be the major factor as to whether the person obtains a role or not.
- 3. There are opportunities available though these are perceived as difficult to obtain and frequently are more about "who you know" rather than any other factor. Supported Employment was the other effective support in finding opportunities and making them work in practice.
- 4. As recruitment has moved into the digital age and is now increasingly online, obtaining roles has become increasingly problematic for people with LD as they are confronted by inflexible technology at the first step. Many are simply unable to overcome this first hurdle.
- 5. Understanding of the capabilities of people with LD varies hugely in the employment sector. Some employers are open minded or may have a quota they wish to fill while others are unwilling to employ someone they perceive as requiring extra cost, responsibility and commitment to employ.

- 6. School and college education and information re seeking employment or volunteering appears limited and to vary considerably dependent on the institution. The EHCP system is not as focused on preparation for adulthood as the original legislation and statutory guidance intended.
- 7. Many people with LD are capable of fulfilling job or volunteer roles, with some flexibility from employers and an understanding of their true potential and capabilities.
- 8. Carers of young people with disabilities who will not be able to work or volunteer independently would like opportunities for them to volunteer alongside a carer/PA.

Recommendations

- 1. The Carers Centre and Amaze to produce a factsheet for carers about how they can help the person they care for to obtain employment or volunteer roles. Tips and advice to be included for carers regarding what works and what does not work. As well as useful contacts including the Supported Employment Team.
- 2. The LDPB to consider how we can ask the Learning, Skills and Employment Partnership to give additional thought to how work opportunities for adults LDs can be developed in the city, in line with *Priority 1 No one left behind* as set out in the city's Employment and Skills Plan.
- 3. This report and the Speak Out report to be passed on to the chair of the SEND Post 16/Post 19 Working Group for discussion about how to encourage schools and colleges to do more to prepare young people with LDs for employment, including use of EHCPs.
- 4. Digital Brighton to be asked if they can help people overcome the barriers created by on-line application forms.
- 5. LDPB to share the reports with volunteer centre at Community Works to initiate discussion about how they promote volunteer opportunities for people with LDs.