

Consultation with parent carers about support with benefits claims and Universal Credit - for the Learning Disability Partnership Board, October 2017

The roll out of Universal Credit (UC) in Brighton and Hove began at the start of October 2017 and will include the whole city by mid January 2018. UC brings a sea change in how income related benefits and tax credits are claimed and paid. Many parent carers take the primary role in helping their young adult disabled children with benefits claims. Parent carers are not yet well-informed about Universal Credit and how it is claimed. Those that are to some extent aware of UC express fear and anxiety about it.

Amaze/PaCC contacted parent carers to ask about support with benefits claims for their teenage/young adult sons and daughters. As parent carers would not yet have experienced UC we asked questions that would give an indication how easily they will be able to claim UC and about the support they and their sons and daughters will need to do so.

How we carried out this consultation and who responded

We used an online survey but also drew on views of the parents who attend the PaCC coffee mornings in Whitehawk, Moulsecoomb and Hangleton & Knoll.

The survey was sent to parent carers of young people on The Compass disability register age 14 to 24 (eligibility ends on 25th birthday). For this consultation we did not limit those asked to the parents of people with learning disabilities as the introduction of UC will also affect those with all sorts of disabilities including ASC, speech and language needs, mental health problems, physical disabilities, sensory needs etc. All these young people have significant special educational needs or disabilities (SEND), get DLA or PIP and/or have an Education Health and Care Plan for their SEND.

47 parent carers completed the survey. The ages of the sons and daughters were spread across the whole range 14 to 24. 45 of the young people were living at home, one at a residential college and one in supported living. Existing benefits they receive:

DLA 52%

PIP 43%

ESA 27%

Other 13% (included JSA and "none" as in part time work)

Survey respondents could add comments at the end and quotations in the report are from this source.

Most Compass parents have an email address so an online survey is an effective way to consult with them. Most parents on the Compass also complete a parent carer questionnaire from which we know that 38% are single parents; 36% of families are unwaged and rely solely on benefits; 32% of families have at least one parent with a chronic illness/disability; 30% of families live in the three most deprived wards of the city; and 19% report eating less/skipping meals due to financial pressures. However we need to assume when looking at the findings for this particular survey that the parents who were able to respond to an online survey of this kind represent the more able and confident. If we were able to reach all parents the reported support needs and concerns would be higher. This is confirmed by the feedback from the coffee morning parents.

Feedback from the consultation

How do you find reading and understanding letters and forms about benefits eg from the DWP and HMRC?

How does your son or daughter find reading and understanding letters and forms like this?

Most parent carers find this manageable themselves. 32% find it easy and 45% said it was just about OK. However even in this survey group which we are presuming to be more able and confident, 24% find these letters and forms hard or very hard to read and understand.

Forms are a nightmare. Very stressfull and changing from dla to pip is ongoing and unpleasant. No one understands my young adults needs. It is very stressful for all of us.

It is quite worrying, as I don't always understand government paperwork.

When answering about their young people, only two parents said their son or daughter found it easy or just about OK. 26% said the young person finds it hard or very hard and just over 70% felt it was actually impossible for their son or daughter to read and understand this type of letter or form.

It is extremely hard for my daughter to understand any of this let alone have to complete the forms.

My son cannot fill forms in without a huge degree of help, advising him what to put, needs me to collect any info they require before it's put on the form e.g. NI number, he cannot seem to retain where to look for it or what it is, has short attention span and easily confused.

At the moment who helps you and your son or daughter with benefits claims?

Many parent carers are able to make benefits claims for or with their disabled young person. 47% currently do it themselves without any other help.

Overwhelmingly, those who use other help are currently getting this from Amaze: 23 of the 47 respondents. This is not surprising given that most of the young people are only on DLA or PIP and Amaze offers a well-known support service for claiming these two benefits for children and young people. Just over a quarter of parents look up information online to help them with claims.

Others use a friend or relative or a support worker. Just one had used a DWP or HMRC phone line for help. None mentioned other local advice services. However the parents at the coffee mornings do have experience of using other services such as Money Advice for help with family benefits claims, in addition to using Amaze for their child's DLA/PIP.

Who do you think would help your son or daughter with benefits claims if you were not around?

Parent carers could pick one or more options from a list or write in "other". There was a wide spread of answers. 21 parents thought another relative or friend would take it over, potentially with external advice.

Hopefully a friend or relative would help by accessing one or more of the services mentioned above.

19 thought the young person would use Amaze, although in reality Amaze does not help with claims for people over 25 and is not currently able to offer help with UC.

It would be good if amaze could get funding to help with universal credit applications like they do with pip and dla.

14 said a support worker and 8 a social worker.

3 thought their young person would do it by themselves. 3 said they would use a DWP or HMRC phone line. 3 thought the young person would look up information online.

He is not good at asking others for help outside the family. He would google for answers online about how to do it so I hope there is some good information out there.

One or two parents chose each of the following: Possability People, Money Advice, CAB, Carers Centre, St Lukes Advice Centre, Unemployed Centre, college, teacher of the deaf, Scope.

Several parents used the "other" box to say that they had no idea who would help their son or daughter or that they thought there was a risk that they would not be able to claim at all.

*I am not sure it would happen at all.
I really don't know.*

**Has anything ever gone wrong with their benefits?
Tell us who helped sort this out**

43% had experienced something going wrong with their son or daughter's benefits. This is a strikingly high figure and worrying given that these would have almost all been claims for disability benefits, whereas UC is a complex benefit and not designed with the needs of disabled claimants to the fore.

11 people had dealt with the problem themselves or with family help. 9 had help from Amaze. 1 was assisted by a housing association support worker. Again we should reflect here that this group of online respondents is likely to be more able and confident, but around half needed help when things went wrong.

Universal credit is claimed online and has to be paid into a bank account. To get an idea of how simple or tricky this will be please tick which of these is true.

We asked about access to the internet, banking and familiarity with doing things online to get a picture of how straightforward or not it will be for families and young adults to manage the process of claiming UC.

79% of the parent carers said they had easy access to the internet. Bearing in mind this was an online survey this might be a lower figure than expected, but illustrates that many only have access via a smart phone. Parents at the PaCC coffee mornings who don't have access to a computer, and use their mobile instead, reported being very worried about how they will be able to fill in forms on line using a small screen.

57% of the parent carers said they use the internet to do things like shopping, banking or claiming benefits. This suggests that even for this group (that we are assuming to be more confident and able) claiming UC online will be outside existing experience and skills for nearly half of them.

Looking at their sons and daughters rather than themselves, 55% say their young person has a bank account. 38% say their son or daughter has easy access to the internet, but only 27% can use a password. And only two parents said their son or daughter uses the internet for things like shopping, banking or claiming benefits. This was even though we were asking parents of young people with a wide range of additional needs and disabilities and not solely people with learning disabilities.

It is often said that young people live their lives online now and are comfortable with online activity, but this is not a safe assumption to make especially about young people with SEND. We have recently been asking young people about this in the context of the Amazing Futures peer support project. Many disabled young people who had access to the internet expressed anxiety about using it for things

that were important or personal. They are concerned about risks including privacy and bullying. Parents at the PaCC coffee mornings were also very concerned about their children needing to make UC claims online.

Overall concerns about Universal Credit from parent carers

Many parents are not yet well-informed about UC.

I feel like I have no real idea of what my daughter will be entitled to as an adult regarding benefits and the whole thing is worrying.

More information on Universal credit and SEND would be very useful, also rules on working and Universal Credit if you have a disabled child.

Where parents are aware of UC there is a high level of worry about it.

Another nightmare to negotiate.

I am terrified about universal credit as I have heard some horror story's

Parents at the PaCC coffee mornings reported particularly strong fears about UC. These parent carers are worried about the impact that such new benefit system will have on their families. Some are struggling with supporting their families and some have already accessed foodbanks because the current benefits system is very penalising if you have 'mild' mental health issues. Parents have heard that Universal Credit will have even a bigger and detrimental effect on their families. The coffee morning parents are also anxious about the six or more waiting weeks for the new benefits to start. For this group there are real concerns about how the new benefit system will create situations where families will have to decide to pay the rent and not be made homeless or buy food/pay bills and be made homeless.

Parents of young people with more learning disabilities reported that there was no way their young person could attempt a claim at all. They expected to continue to claim on their behalf. They recognise there will be a need for someone else to take over this role at some point, but some are worried about whether this support exists or will be suitable.

She doesn't have the capacity to deal with anything like this so is totally reliant on other people to sort things out for her.

My son has SLD and cannot understand anything about claiming benefits.

The only person with the in depth knowledge of the young person to complete one of these forms is a parent/carer.

But there is also a large group of parents who think their son or daughter ought to be eligible to claim as an adult but may fail because of their needs.

She thinks she knows what is being asked of her and has in the past filled things in incorrectly.

He is quite used to doing fun things online but struggles with organisation so I think he will find it hard to get all the supporting information together to do an online claim. If I am not around to help him I think he would try to do it and keep failing to

complete it. I know there is already a long gap before UC starts being paid and he could get into real trouble.

Biggest concern is regarding autistic children who have high IQ but through either anxiety, executive dysfunction, semantic/communication issues or mismatch between chronological age and emotional age, cannot manage this type of thing for themselves.

As our child rejects her diagnosis, she resents getting DLA at all as she associates it with disability and therefore would 'cut her nose to spite her face' if it was left to her.

My son is very clever but just wouldn't know where to start due to mental health issues so would just be overlooked and just wouldn't make any claims for support.

Recommendations

Young adults with learning disabilities need support to claim benefits and so do many other disabled young adults with SEND e.g. autism or mental health issues. Parent carers are used to claiming benefits on behalf of their children and most expect to continue to offer this support as they become adults, whether taking full responsibility or supporting their son or daughter to manage the process. But they are not yet well-informed about UC and they do not all have the skills and experience to make a claim without other advice and support. Some parents and most young people are not readily in a position to make a claim online. Parent carers need to know who can support their son or daughter to claim when it is no longer possible or perhaps appropriate for them to do it. The impact on disabled people and their carers if they are unable to claim successfully, get the right level of payments and avoid gaps and delays will be very substantial. There will also be a knock on effect for support services, housing providers and others. So there is a need to:

- **Make sure there is information to help families understand how UC works and be prepared for claiming UC**
- **Check if there are local advice services with expertise and capacity to help with UC claims for disabled people**
- **Let parent carers know who can help them to help their sons and daughters with claims**
- **Help family carers plan for who will take over this role when it is no longer them**
- **Look at how we can identify disabled people and families who miss out due to the new system and connect them to appropriate help**
- **Make sure the wider workforce that work with families and disabled adults are well-informed about UC and ready to help, advise or signpost according to their role**