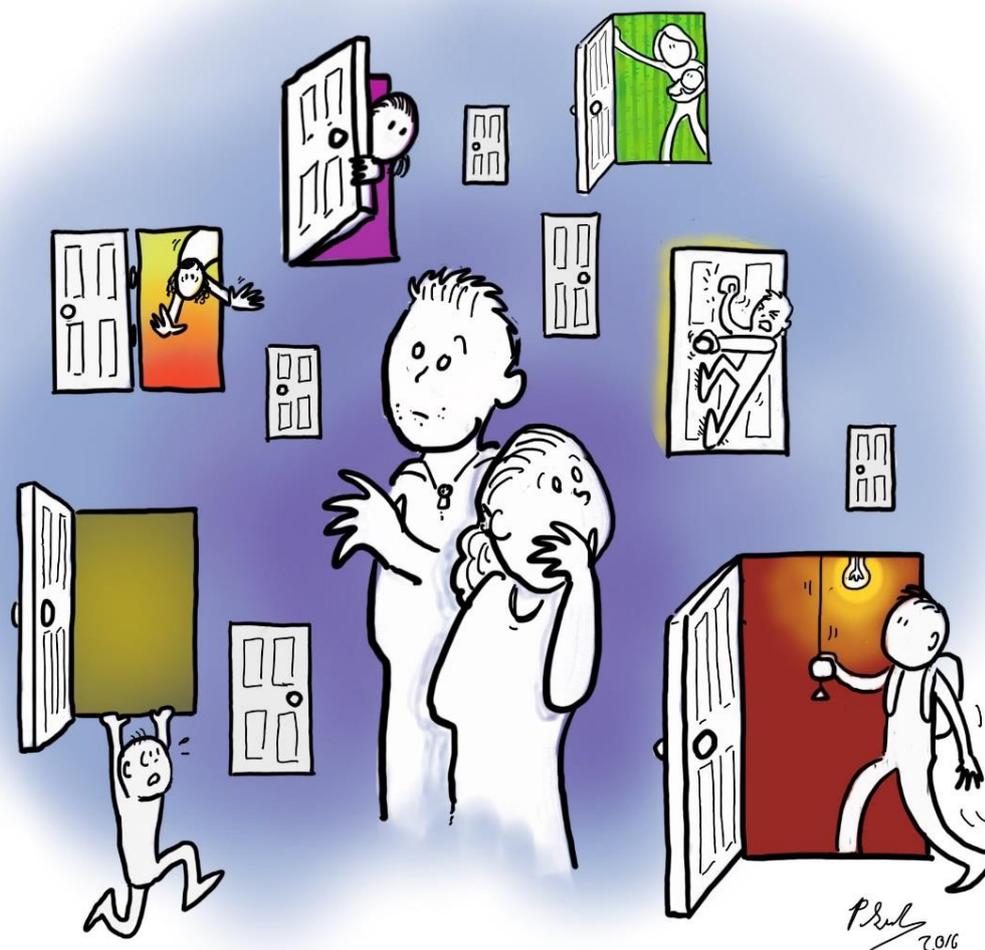


## *“I found out the hard way”*

Young People with Mental Health and/or Learning Disabilities

Leaving Care:

A summary for young people



Berni Kelly, Seana Friel, Eithne Gilligan & Theresa McShane

## OUR THANKS

The study was funded by the Public Health Agency's HSC R&D Division and this summary was developed in partnership with VOYPIC.



We couldn't have done this research without the young people who took part. We thank them for letting us read their case files, for doing interviews and for sharing their personal stories. We learnt so much from listening to each young person and really appreciate the time and effort they spent with our team. Thanks also to the:

- Care leavers on the Care Leaver Advisory Group and to VOYPIC.
- Carers and parents who also met the research team.
- The Professional Advisory Group and staff in Trusts.
- Other research team members: John Pinkerton, Gavin Davidson, Paul Webb, Teresa Hazzard.

Finally, special thanks to the peer researchers who worked so hard. They taught us about real participation and how best to interview young people:

- Ally Campbell
- Ciaran Carville
- Seana Friel
- Darren Smith



## WHY AND HOW DID WE DO THIS RESEARCH?

We wanted to find about young people who were leaving care who had mental health needs and/or learning disabilities. We really wanted to know how well services are supporting them.

So, the first thing we did was read **policies and research** to find out more about what should be provided for care leavers in Northern Ireland.

**We found out** that care leavers with mental health and/or learning disabilities are often a forgotten group.

**We believe** that these young people should be more clearly included to ensure they have good support as they move on from care.

Then we asked social workers working with care leavers across NI to complete a **survey** that told us more about this group of care leavers.

**We found out** there were 314 care leavers with mental health and/or learning disabilities - almost a quarter of the whole population of care leavers in Northern Ireland

Some Trusts found it easy to identify these care leavers but others found it difficult to give us this information.

**We believe** that there should be better ways of collecting and keeping records about these young people.

Then we **interviewed 31 care leavers** with mental health needs and/or learning disabilities. We talked to them three times over 18 months as they moved into their young adult lives. We also talked to social workers or personal advisers, some birth parents and carers.

We recruited and trained five care experienced **young people as peer researchers** to help with these interviews.

## YOUNG PEOPLE'S EXPERIENCES

Here's what we heard from young people and their carers about their experience. We've organised their stories into ten key themes.

### 1. Our mental health and learning disability

Over half of the young people in our survey had a mental health need and another fifth had an learning disability. Just over one in ten had autism.

*I've had quite a lot of low mood... It affects your daily life... you just can't be bothered talking to people... Just kind of feeling stuck as well. It just kind of consumes you (Norah)*

*I do have a learning disability... I just need extra help with my work and sometimes I get stuck on words... and I forget things very quickly (Simon)*

Almost one fifth of the young people had a mix of mental health needs, learning disabilities and/or autism. In the year before we talked to them, more than a fifth of young people had attempted suicide – some of them more than once.

Some young people were not getting any help from specialist services even when they were at risk of harm or suicide.

Some young people felt there was a stigma attached to having a mental health need or disability and people treated them differently or had low expectations for their futures. So some young people preferred not to have a diagnosis or refused to use mental health or disability services.

*I don't want to have bipolar cos you can't get rid of it... I more than likely do have it. But I just don't really want to tell myself I do (Sara)*

*I have... autism... I was trying to keep it a bit of a secret... Everybody knew then that became the brand new reason to bully me (Danny)*

## 2. Staying in touch with our family and parenting

Most young people were in touch with their siblings and parents as well as grandparents, aunts or uncles. Contact with family could be difficult for some young people and several had stopped all contact with them.

*All my brothers and sisters have been in foster care... Our relationship is kind of awkward because we don't really know each other (Jamie)*

*It can be trying at times... we get on sometimes and sometimes we don't. It usually depends on what sort of state their mind is in... It's never going to be perfect (Lorna)*

Some young people had children of their own but not all of them are living with their children. Young parents need time to look after their children and want 16+ support to be extended to after age 21 to help them get back to college, training or employment.

*When you are 21 they close it unless you are in full-time education. I think that is wrong... Even when I go back to Tech... I wouldn't get no finance... I can't say I want my social worker back because it is not an option... which I don't think was very fair. Whereas if you are in full-time education you get to keep them until you are 25 (Jack)*

### 3. Preparation for leaving care

Most of the young people said they were involved in plans for leaving care but some felt they weren't always listened to and pathway plans could be better.

*They need to listen to the young person... I wasn't asked once in that meeting... They were all making decisions about me and me sitting there listening (David)*

*Pathway plans are still very childish... They seem to forget it's adults they are dealing with. I have had social workers that will speak down to me like I am a child just because I have got a mental disability... I said to them 'I am coming 20. I'm not five' (Danny)*

Young people sometimes felt they had become dependent on carers or staff and didn't have the skills to cope on their own when they left care.

Some young people felt they had rushed leaving care because they had moved on too early or because they had to leave residential care when they were 18. Young people in foster or kinship care had more options to leave care more slowly.

*Being in care made me very mentally lazy in the sense of people doing things for me.... If things hadn't been done for me I would have had to do them myself so I'd have had more time to prepare myself (Tony)*

*I wanted to be independent quite quickly and I found out the hard way that I couldn't be... If I had of been more prepped for it, it would have been easier. But I kind of just turned 18 and went 'Right you are 18 now there you go (Tina)*

#### 4. Support where we live

Some care leavers stayed with carers under the GEM (Going the Extra Mile) scheme, returned to their own families or moved to residential care placements. Others moved into supported accommodation or independent housing. Decisions about placements in residential or supported living were often delayed because of funding.

Many young people struggled to cope on their own and needed support. Young people had problems getting house repairs organised, managing money and looking after their homes and themselves. Supported accommodation worked best to help young people learn the skills they need to cope on their own.

*It's really good. It's definitely one of my best placements... I have a flat here... There is staff here all the time (Dawn)*

But supported accommodation wasn't always available. Also, some young people with learning disabilities in supported accommodation felt that staff were too heavily involved in their lives.

*Sometimes they like to know where I'm going... You go through... 3 to 4 people... I'm getting sick of it... I don't want to be depending on people all the time (Simon)*

Some young people felt lonely which didn't help their mental health. Several young people had been abused or bullied in their area and had to wait a long time to be moved to a safer place.

*This big rock came through the window and it landed right on the bed... It scared me because I was only there by myself... The housing executive was useless... They didn't really class it as a threat (Jamie)*

## 5. Support when we leave

Most young people had a social worker or a PA. Some young people didn't see them often or find them helpful but most had good relationships with their social worker or PA.

Young people liked social workers or PAs who treated them as adults, were more informal and provided support when they most needed it. Foster carers also provided important support for young people.

*The social worker... done it out of the kindness of her own heart because we got very close and she wanted to see the best for me herself. So the support I had from her was really helpful (Diane)*

*He's always there when I want to talk... He's there no matter what... He would be my point of call... in the long term (Danny)*

Young people who couldn't get access to adult disability or mental health services relied on 16+ teams. When 16+ services reduced at 18 or stopped at 21, they often had no services to support them.

## 6. Getting disability support

Very few young people had disability services, especially adult disability services. Some had support from their school or voluntary organisations.

*If young people don't meet the criteria for adult learning disability... they will not be accepted... We haven't actually got a service within the Trust to refer them onto (Simon's social worker)*

Young people over 18 with autism or mild learning disabilities found it really hard to get disability services support. These young people were most risk of not coping, becoming homeless or being exploited by others.

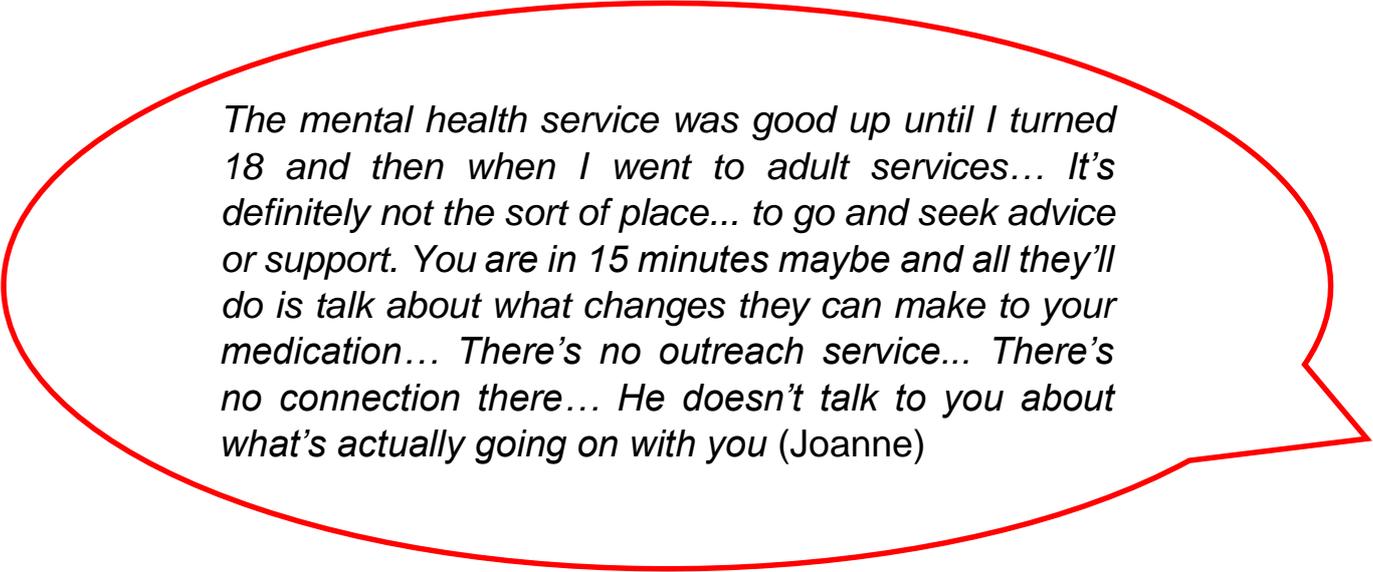
## 7. Getting mental health support

Young people found it hard to get access to adult mental health services and had to wait a long time before they got the help they needed. Very often, young people with both a learning disability and a mental health need could not get any support from mental health services.

Without a diagnosis or support, some young people find it hard to understand their mental illness and keep taking medication.

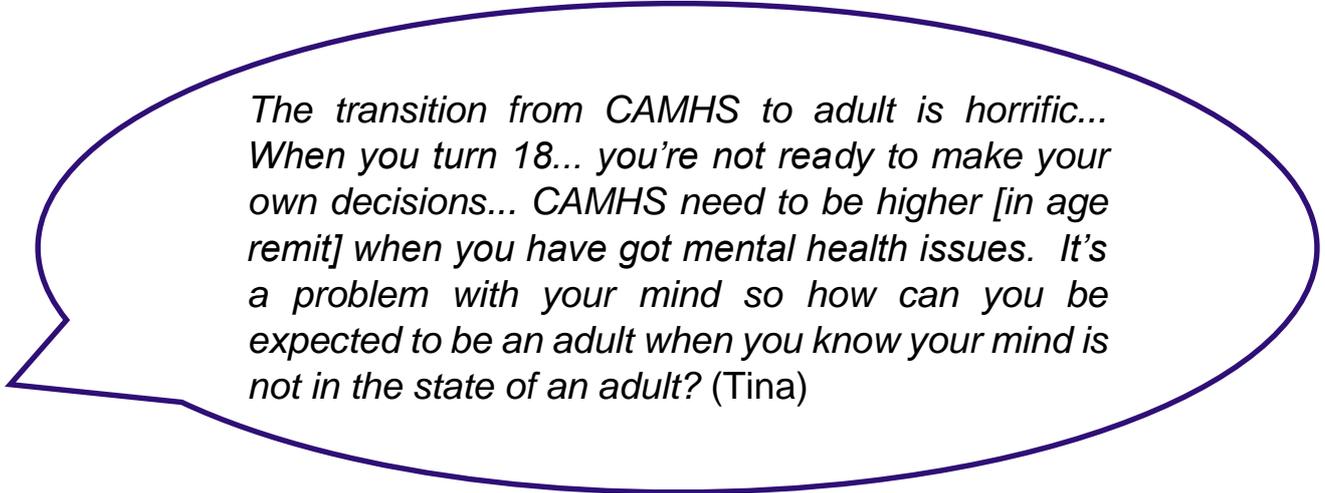
Only GPs could refer young people to adult services but GPs often knew very little about the young person's care history or mental health needs.

Young people had positive things to say about children's mental health services but adult mental health services were more focused on medication and less helpful.



*The mental health service was good up until I turned 18 and then when I went to adult services... It's definitely not the sort of place... to go and seek advice or support. You are in 15 minutes maybe and all they'll do is talk about what changes they can make to your medication... There's no outreach service... There's no connection there... He doesn't talk to you about what's actually going on with you (Joanne)*

Young people wanted more time with children's mental health services.



*The transition from CAMHS to adult is horrific... When you turn 18... you're not ready to make your own decisions... CAMHS need to be higher [in age remit] when you have got mental health issues. It's a problem with your mind so how can you be expected to be an adult when you know your mind is not in the state of an adult? (Tina)*

## 8. Going out and keeping safe

Young people had lots of interests but found it hard to take part in social activities if they had social anxieties, worried about keeping safe or practical problems with travel or money to cover costs.

*Nobody ever really sort of taught me how to socialise... I had a fear of socialising with people because every time I got to know somebody it seemed to be that I got hurt... I have to catch myself on (Lorna)*

Care leavers who had been bullied because of being a care leaver or having a mental illness or disability didn't have much confidence and worried about socialising with others.

*Basically I have been bullied my whole life... It makes me feel scared to go out on my own (Danny)*

## 9. Managing our money

Most care leavers were living on a very limited income. Some were managing their money well but others struggled to cope and faced confusion about benefits, debt and poverty.

*Finances is really hard... You don't get much money on the dole. I tried to save up every week for oil for the end of the month. I can't save... once you get your shopping... you're skint (Sara)*

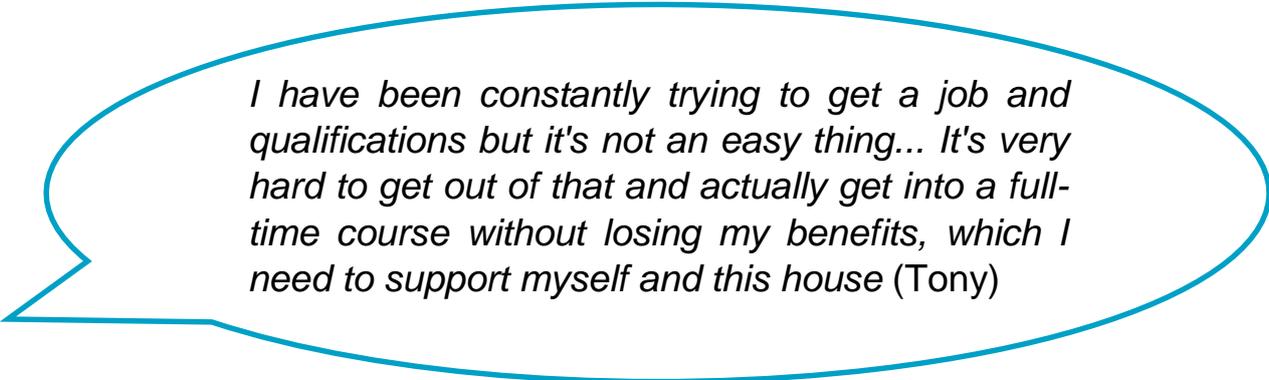
*I had to add debt repayments... on top of what I owed... I am living on £63 per two weeks... below what the government advises people should have to live on... It is really, really tight (Tony)*

## 10. Going to college, training and work

Young people who had a hard time at school or had been excluded from school found it hard to move on to further education or training. Without qualifications it was hard to get into college or university or get a job.

Young people who were parents, were mentally unwell or didn't have good support also struggled to get into work, education or training.

Some young people were afraid of losing their benefits if they went back to education or work. Others had career ambitions but needed help to cope with anxieties and become more confident first.



*I have been constantly trying to get a job and qualifications but it's not an easy thing... It's very hard to get out of that and actually get into a full-time course without losing my benefits, which I need to support myself and this house (Tony)*

## WE BELIEVE SOME THINGS NEED TO IMPROVE

We believe this study has found out a lot about care leavers with mental health and/or learning disabilities in Northern Ireland.

We found out about best practice in relationships, flexible and creative ways of working. There are some things that are working well:

- ✓ When some professionals build good relationships with young people
- ✓ The flexibility of the 16+ service - working at the pace of young people and providing support when most needed
- ✓ Children's disability and mental health services (when available)
- ✓ Ongoing support from foster or kinship carers for some
- ✓ Participation of most young people in pathway plans

In our long report you can read that we have set out 20 recommendations. Here are the five things we think are most important.

## 1. PAY ATTENTION TO US

**Young people with mental health needs or a learning disability have unique leaving care experiences**

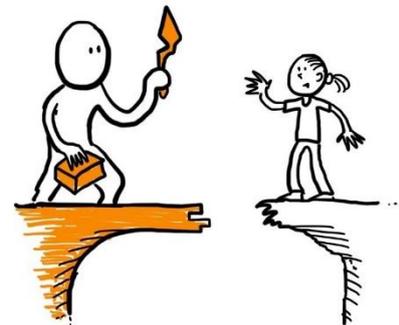
- ✓ Do assessments of health and disability needs on entry to care and when preparing to leave care
- ✓ Review access to 16+ services for care leavers with learning disabilities and/or ASD
- ✓ Review uptake of welfare benefits and direct payments to work out how best to financially support care leavers



## 2. BUILD BETTER BRIDGES

**Young people go through more than one change when they leave care and it's complicated**

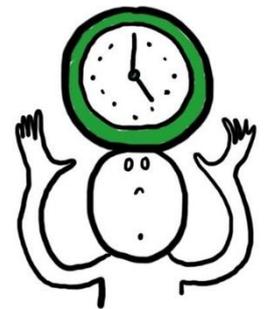
- ✓ Make clear pathways between services to meet needs and entitlements
- ✓ Develop services to meet the needs of young people with ASD, borderline levels of learning disability and those engaged in substance misuse
- ✓ Review aftercare services across NI, especially for care leavers living in rural communities



## 3. WE NEED MORE TIME

**Young people aren't fully ready to manage on their own when they leave care**

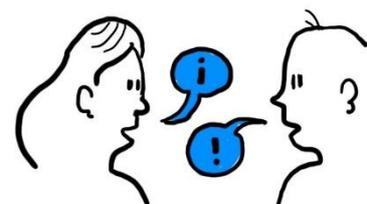
- ✓ Support a more gradual approach to move from residential care to independent living
- ✓ Extend 16+ services to 25 for care leavers with mental health and/or learning disabilities
- ✓ Extend CAMHS to 21 or 25 for care leavers who require ongoing therapeutic support



## 4. TALK TO EACH OTHER

**Everyone needs to take responsibility and act for care leavers**

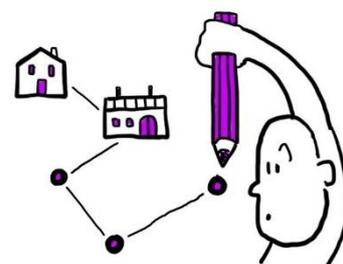
- ✓ Set out responsibilities for those supporting care leavers so everyone knows what they're doing
- ✓ Do joint training to share knowledge and work together
- ✓ Invite care leavers with mental health and/or learning disabilities to be part of training



## 5. JOIN THE DOTS

Young people need access to more than one service

- ✓ Try a joined up approach to support care leavers
- ✓ Include professionals who know about disability, mental health and aftercare
- ✓ Involve care leavers in designing this approach



## CONCLUSION

This study has helped us to understand more about the needs and experiences of care leavers with mental health and/or learning disabilities in Northern Ireland.

We will be working with policy makers, funders and professionals to tell them about the views of young people in this report and ask them to make the changes we recommend to improve support services.

**If you would like to hear more about the study or tell the researchers what you think about this report, contact:**

**Theresa** - Email: [t.mcshane@qub.ac.uk](mailto:t.mcshane@qub.ac.uk) Tel: 0775 345 1059 OR  
**Berni** - Email: [b.r.kelly@qub.ac.uk](mailto:b.r.kelly@qub.ac.uk) Tel: 02890 971486

**If you have been affected by any of the issues included in this report and would like further support or information, please contact VOYPIC:**

**DO YOU CARE? WE DO!**

**FIND OUT ABOUT**

**ADVICE & SUPPORT | A LISTENING EAR  
FUN ACTIVITIES FOR CHILDREN IN CARE  
& CARE LEAVERS**

**VOYPIC**  
Voice of Young People in Care  
Supporting Children & Young People Across NI

9-11 Botanic Avenue, Belfast BT7 1JG  
T: 028 9024 4888 E: [info@voypic.org](mailto:info@voypic.org) W: [www.voypic.org](http://www.voypic.org)  
Registered with the Charity Commission Northern Ireland NIC105019

f  
t