



# ExChange

Building Better Social Care  
in Wales

Adeiladu Gofal Cymdeithasol  
Gwell yng Nghymru

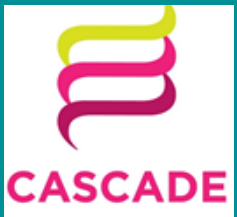
# From Identification to Support: Assessing and improving services for young carers

Faaiza Bashir  
Carers Trust Wales


Cat Hooton  
Carers Trust Crossroads Sir Gâr

Edward Janes  
School of Social Sciences, Cardiff University

Dr Jen Lyttleton-Smith  
CASCADE Children's Social Care Research and Development Centre, Cardiff University



# Workshop Structure

- Introduction to young carers and impact of caring (Faaiza and Cat)
  - Covid-19 pandemic (Faaiza and Cat)
  - What does research tell us about carers? (Ed Janes)
  - *Young Carers Speak Out* (Jen Lyttleton-Smith)
  - Assessments (Faaiza and Cat)
  - *Caring Lives* (Ed Janes)
  - Group Activity
- 

# Introduction: Who are 'Young Carers'?

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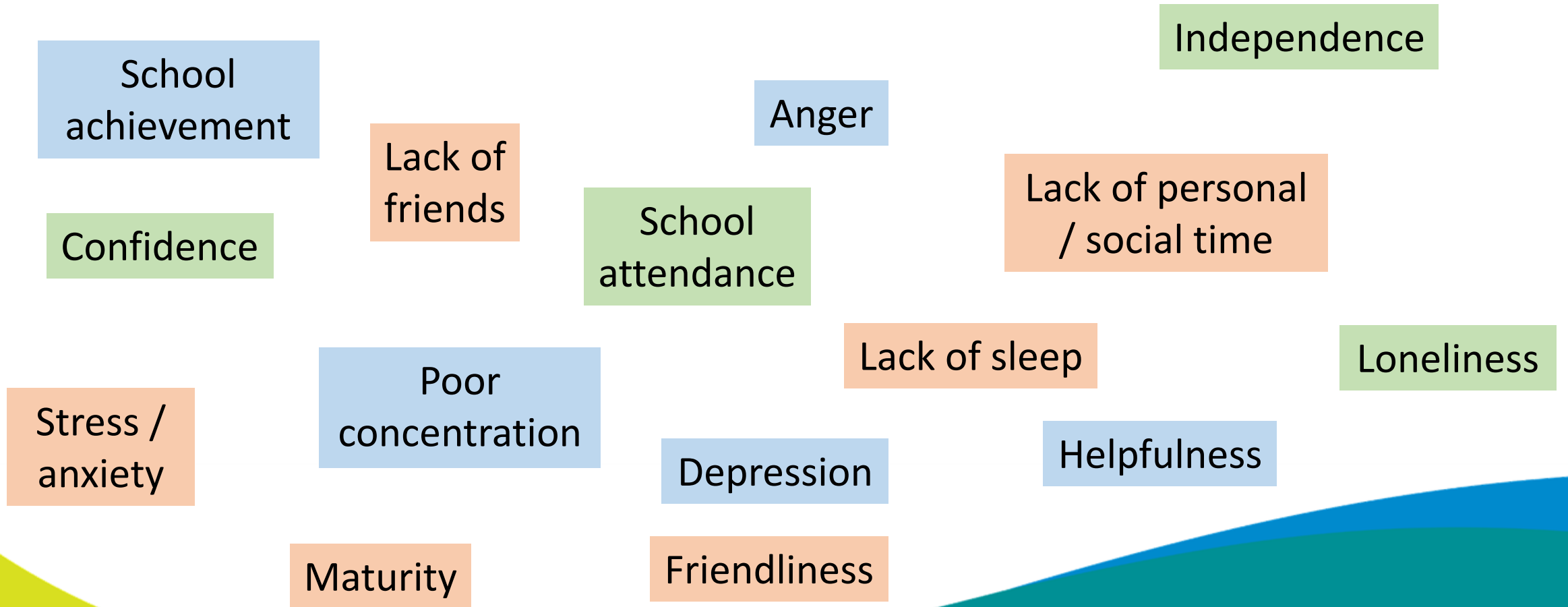


A young carer is someone under 18 who helps look after someone in their family, or a friend, who is ill, disabled, has a mental health condition or misuses drugs or alcohol.

# What is the impact of caring on young people?

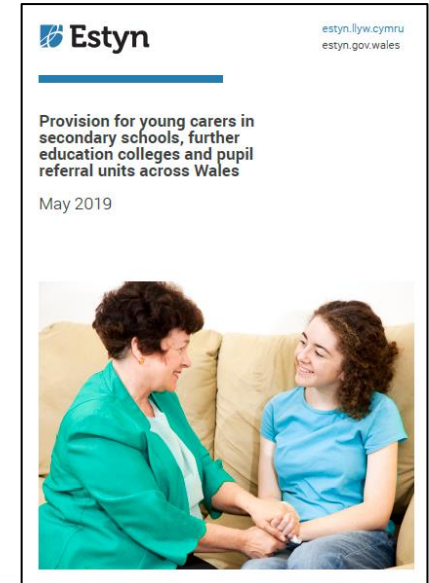
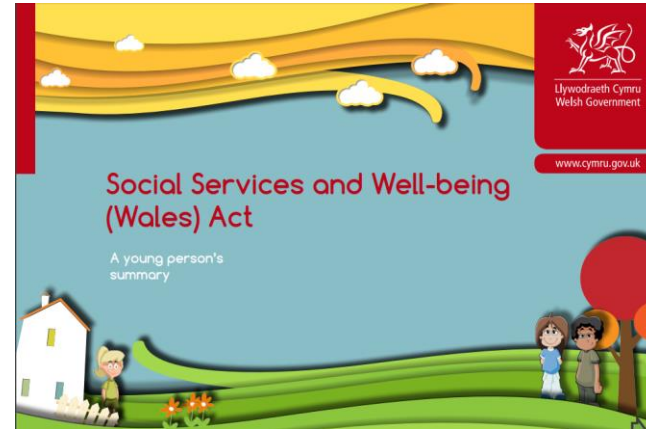


# Impacts and benefits include:

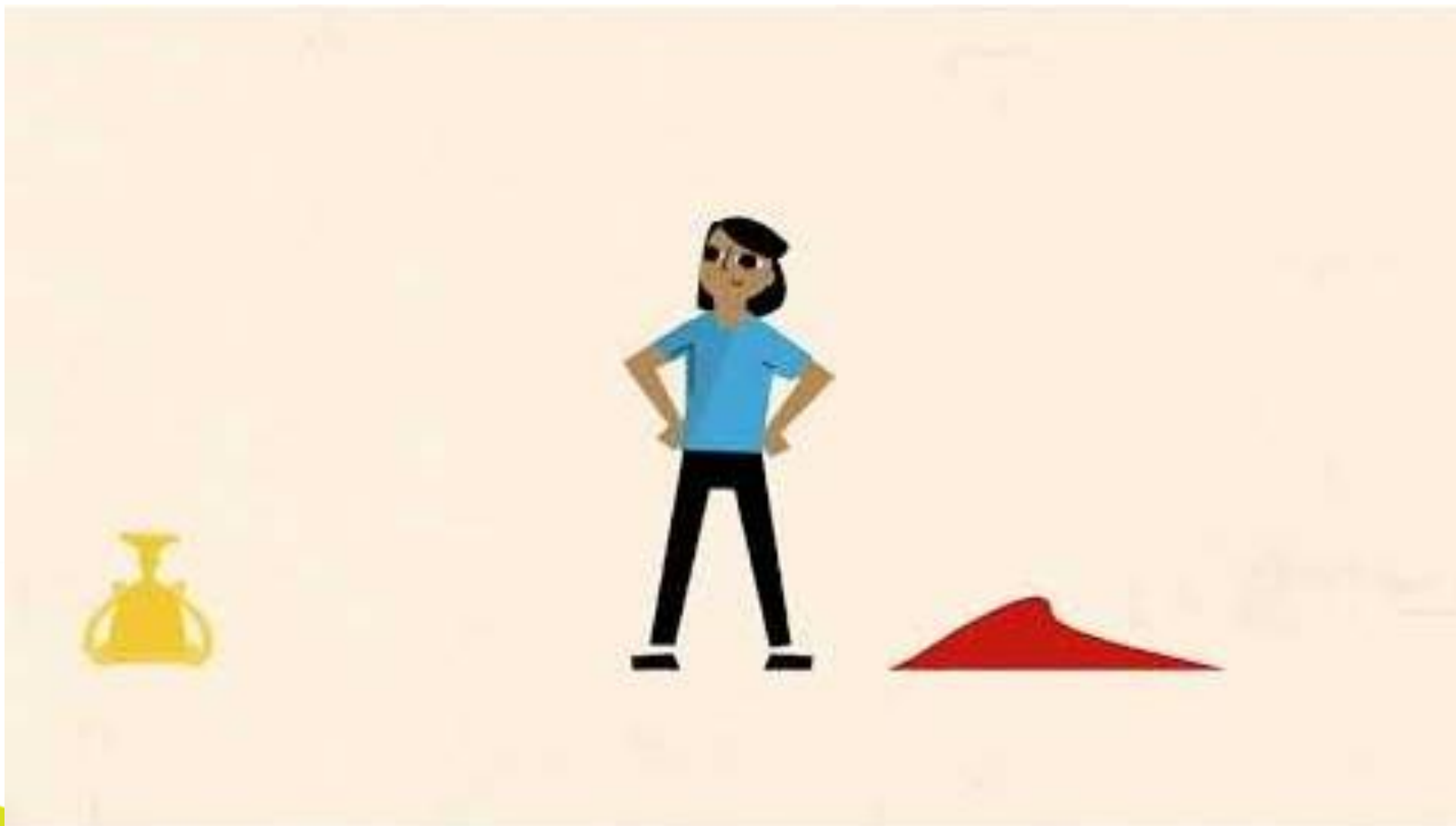


# Introduction: What are their specific support needs and what is current Welsh strategy to meet them?

- Young carers rights
- Carers Strategy consultation
- Education
- Young Carers ID Card
- Overview of organisations who support young carers



# Young Carers ID Card





# Impact of Covid-19

“It has put more stress on me and my education and has made my anxiety so high”

Young carer, 13



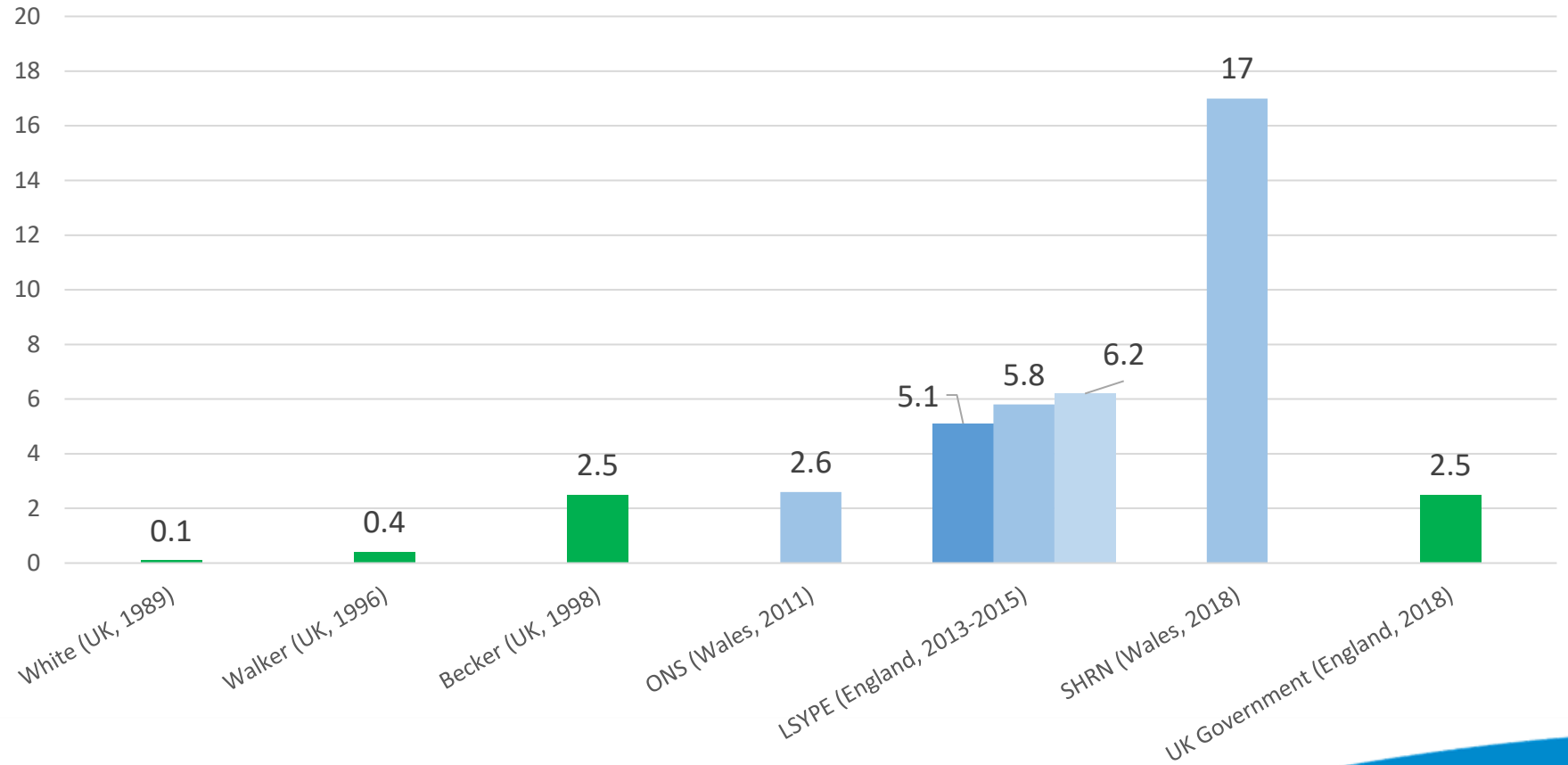
## Support not sympathy

A call to action from Wales' young and young adult carers  
July 2020

# Previous Research


Estimations of young carer prevalence varies significantly

Young carer prevalence estimations (%)



# What does previous research tell us about young carers?

Cross-national classification of awareness and policy response (Leu and Becker (2017))

- UK ranked in second of seven categories (Advanced)
  - Benefit of a large amount of research that impacted on policy and legislation
  - But lack of resources mean that many fall through gaps
- 

# What don't we know about young carers?

Identification issues present a significant challenge to research

- Difficult to reach young carers through schools, social services etc
- So majority of research recruits young carers through support projects

*Are these young carers representative of the wider group?*

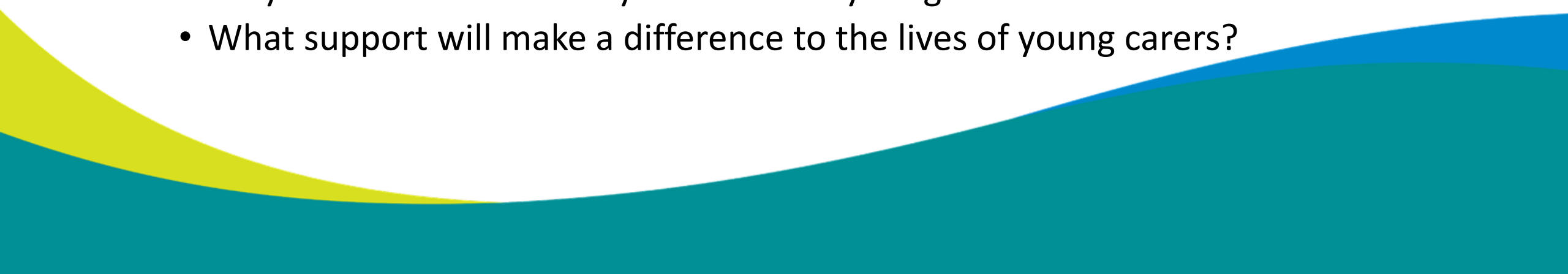


# Our Research

## ‘Young carers Speak Out’ – Jen Lyttleton-Smith

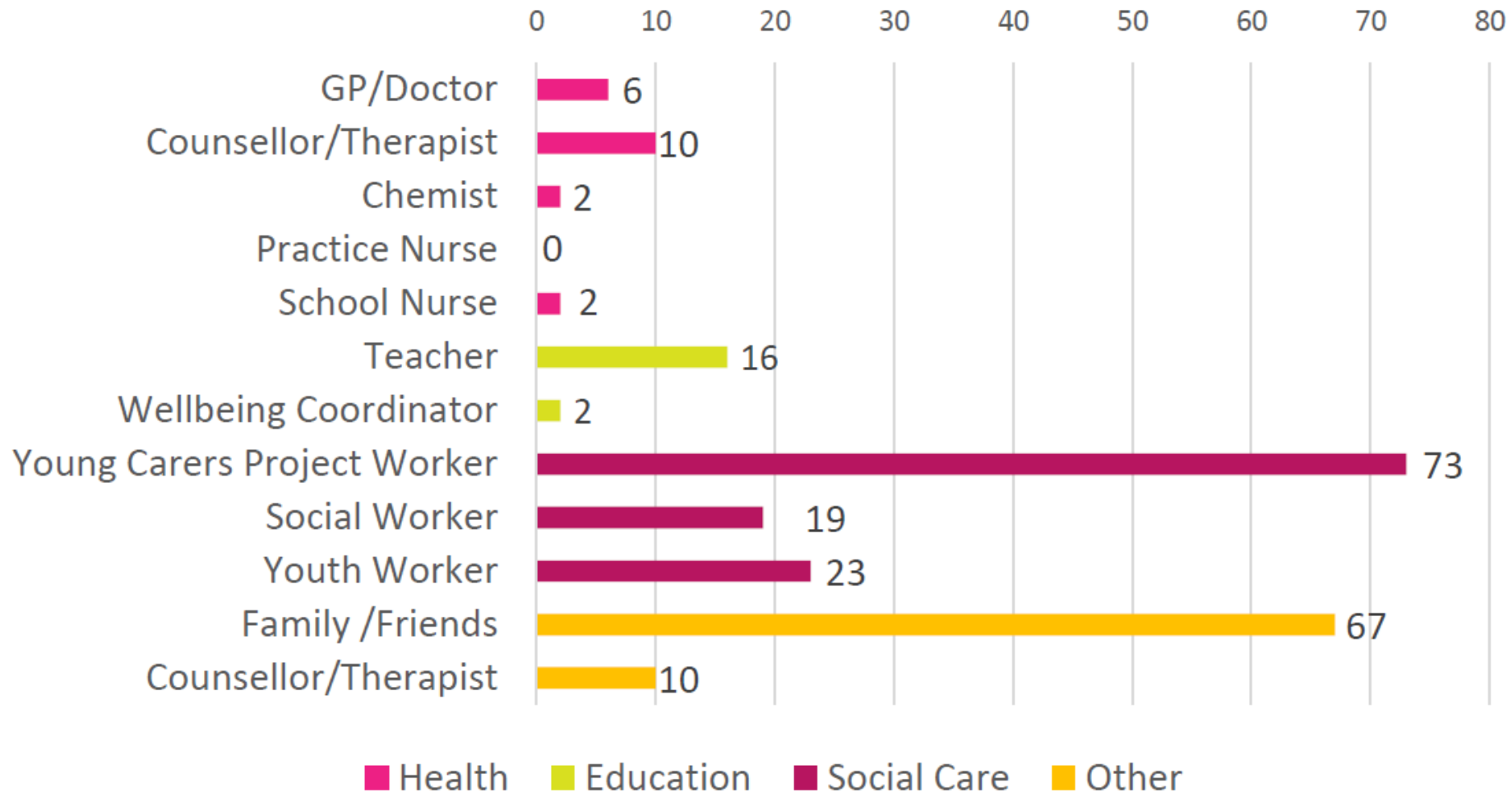
- Research focusing on children’s voices and experiences of being recognised and supported as young carers in Cardiff and Vale of Glamorgan.
- 101 survey respondents age 7-19, 50 workshop participants age 7-18

## ‘Caring Lives’ – Ed Janes

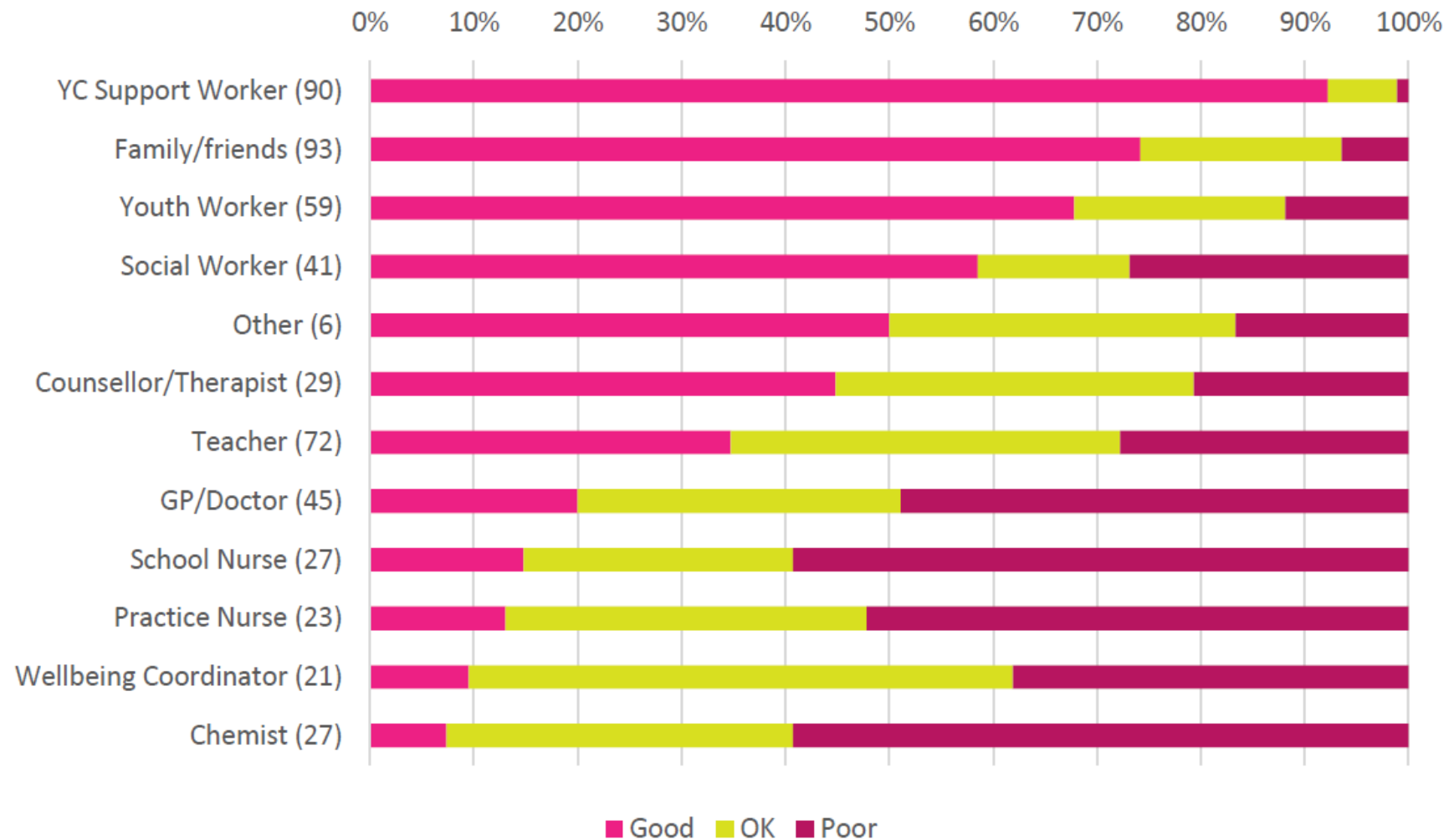
- PhD study on young carers and mental health
  - Why do the outcomes vary for different young carers?
  - What support will make a difference to the lives of young carers?
- 



# Who gives young carers support?



# Who recognises young carers in their role?





# Recognising and understanding the role that young carers have

*“My inclusion officer at school is cool but **pupil support** always too busy. My **doctor** treats me like a child and will not listen. **Chemist** is nice when I pick up medication. **Social workers** okay but just as I trust them they leave and we have to start again!!!! **Teachers** are pants they just want to shout and not listen. **Counsellor** cool, I can relax for a little while and be listened to ... **[Young carers] Project worker** listens, is there for me, makes me smile and understands and being on the project makes me feel like I belong and I don't have to explain anything as we just relax and are all the same. Some **friends** are cool but some take the mick or complain when I cannot come out. **Family** are only there when it suits them or they want to look good. **People in school** make fun of me because I am late and cannot go out with them in the evenings as I have to go home and always ask too many questions”*

# Workshop data: relationships with peers

- **Focus Groups:** many young carers referenced a lack of understanding or awareness from peers as being a significant frustration in their lives

*Most people don't understand, if all you've been doing for the weekend is literally just being there, like, my sister you have to watch her.... People think... "Don't worry, I need to watch my sister". You're like, "Yeah, but it's not the same thing", and they're like, "Yeah, yeah, but it is the same thing", and I'll be like, "No, because my sister will really hurt herself if I leave her alone".*

*"Watch out for the bullies because they seem to, like, find out what's wrong, or that something's happened they'll try take advantage of it "*

# Workshop data: relationships with peers

- **Worry Rocks activity:** Most directly referenced issues surrounding bullying and social isolation or exclusion as being young carers' biggest anxieties
- **Timelines activity:** many young carers referenced tiredness, a lack of spare time to socialise or have fun with friends, and disengagement from peers and social activities. Many turned to video games, internet, and television as recreational activities in the home, often staying up late into the night to try and capture some enjoyable time to themselves after their daily tasks were complete.

# Workshop data: relationships with peers

**My Day as a Young Carer** Age: 14

Use this timeline to show how your caring responsibilities affect your daily life. You can write, draw, or colour in – whatever you like!

06:00	07:00	08:00	09:00	School Day	Weekend Day	16:00	17:00	18:00	19:00	20:00	21:00	Night Time
sleep	wake up get brother up get them dressed	on bus	in school	work in school <u>clean the whole</u> Kitchen wash clothes mop floor wash dishes cook food make tea for brother	brush floor bins put dishes away going to the shop.	home	clean	cook	eat	meds for bro	bath	sleep internet

cat litter  
pick up dogs poo

# Education recognition and support was a particular problem...

**Only 43% said that they were always or often given the right support in school or college**

*"They make my life more difficult and stressful. Won't let me do what I need/want to do"*

*"A few of the teachers know but I don't have any help"*

*"I need someone to talk to in school"*

*"Meeting deadlines for homework assignments is the most challenging thing - schools don't really understand what a young carer does. They don't give you extra time"*

*"[One teacher] is great, pupil support is bad, some teachers are okay but even the ones who know are really rude and shout and don't let me explain stuff even though they know I have to care then I get angry and get into trouble"*

*"I'm redoing a year of school, I failed a year because I had to take a lot of time off school because my mum and dad were in and out of hospital and not many of my family members get involved. It was just left to me to look after my siblings, look after my family"*

# Workshop data: educational support

- **Letterbox activity:** When writing about their hopes for future changes and developments, 50% of the young carers' letters to the First Minister (22 of 44) identified a desire for more support in school  
*"[We need] workshops that go to schools to make teachers more aware of the difficult position and that we can't always meet deadlines"*
- **Supporting Wall activity:** Educational institutions and teachers were identified on seven bricks out of 109 in total
- **Concentric Circles activity:** 30% under 13 year olds reported moderate closeness with a teacher compared to 10% of 13+. Teachers more important for younger children, especially those with smaller overall networks

# What do young carers say they need to support them better?

More support staff  
at home

Better recognition  
for their role in  
education and in  
medical settings

Someone to talk to  
about problems

More money to  
help make things  
easier and have  
fun sometimes

Social workers  
taking action to  
help and support  
where needed

Better support and  
understanding at  
school

# Assessing young carers needs



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## Social Care Wales Resource:

Supporting young and young adult carers under the Social Services and Well-being (Wales) Act 2014

A training resource

ymddiriedolaeth  
goralwyr  
Cymru  
gwelthredu, aghortwyo, aghort

Deall y Ddeddf

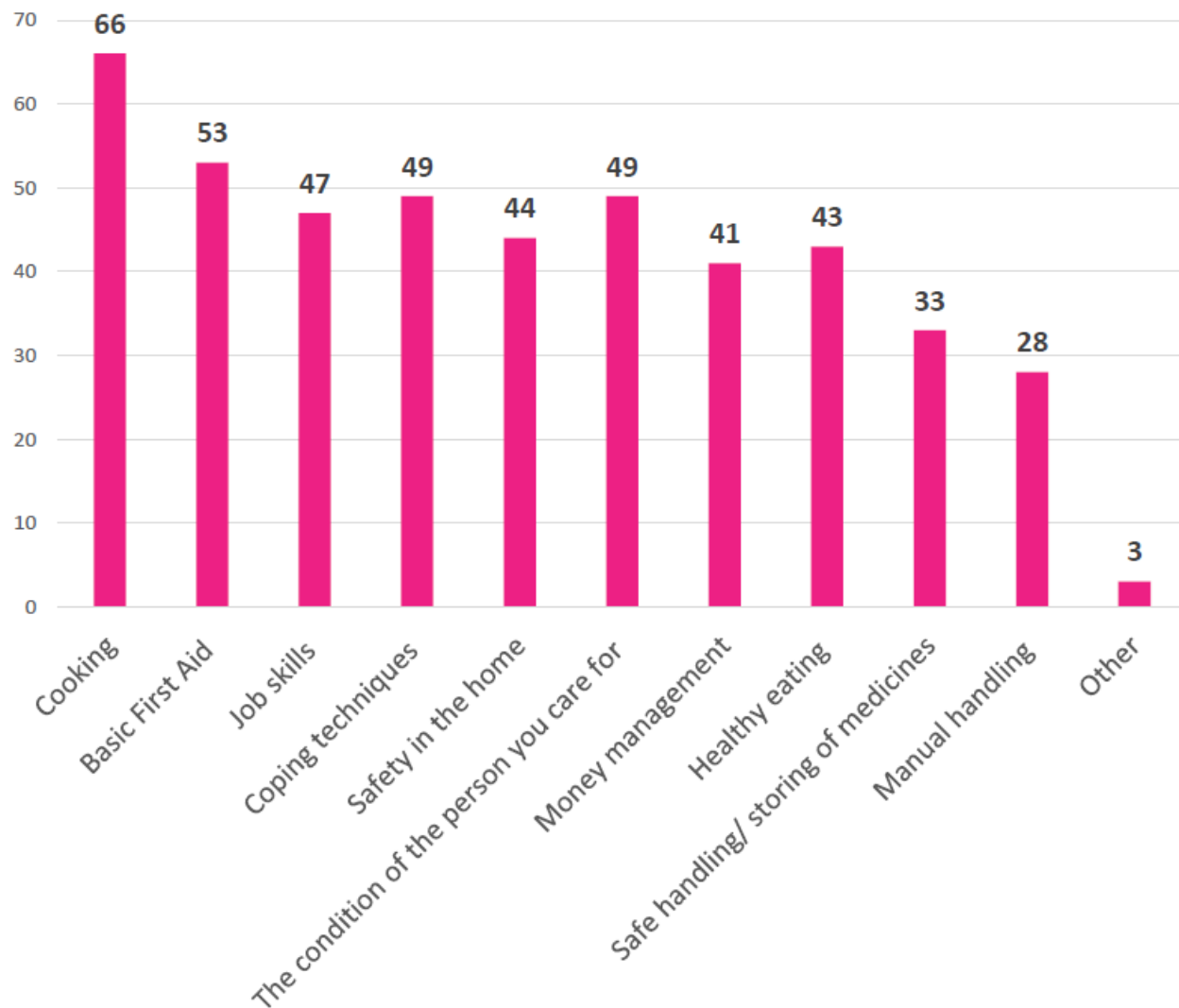
carerstrust  
Wales  
action-help-advice

Getting in on the Act

[For more detail: socialcare.wales/hub/hub-resource-sub-categories/carers-and-the-act](https://socialcare.wales/hub/hub-resource-sub-categories/carers-and-the-act)



Figure 17: What young carers want to learn more about



## What skills and support do young carers need that could be identified through assessment?

Most young carers want more practical skills such as shopping or cooking. However some also expressed anxiety or confusion about their ability to offer emotional support

**74% of young carers in the survey reported that to their knowledge no-one had assessed their care and support needs as a young carer**

# Caring Lives Research: Methodology

## Longitudinal

Conducted over a period of time rather than an individual interview

## Phenomenology

A study where the researcher aims to understand the perspective of each participant.

Method enabled consideration of the contextual changes that were happening in the life of the young carers and families, and the effect that these changes had on their mental health.

Three possible intervention strategies...

# Social care intervention strategies 1

## Health service information/training

- Sophie: Caring for mother who has diabetes

*“I think it’s called like Dawn phenomenon which links in with the hormones in Type 1 diabetes, where she’ll go to sleep and her blood sugars might be fine, and then three o’clock in the morning they’ll just shoot straight up and she’ll wake up with really high blood sugars. But sometimes in the night she goes down really low... I don’t go to bed til past midnight... I’ll like wake her up and be like ‘Check your blood sugars’ and then see what they are and then decide if I want to go to bed or not.” (I1)*



# Social care intervention strategies 1 (cont)

## Health service information/training

*“Loads of things were going wrong, and her blood sugars were like, really like, really high, and it was cos all like the needles that she was trying to use were really like dodgy, and they were going in and they were bending, so the insulin wasn’t going in properly, it was leaking out... We went to a nurse’s house quite a lot... They thought they’d found on that worked and then we went home and she woke up in the morning and it was all over the bed stuff and then that took ages to get sorted.” (I2)*

*“It’s like, because I got like a full night sleep and I didn’t have to get woken up... I wake up in the morning less tired but then I find it really hard to get out of bed!” (I3)*

# Social care intervention strategies 2

Improving relationships... what a positive relationship looks like

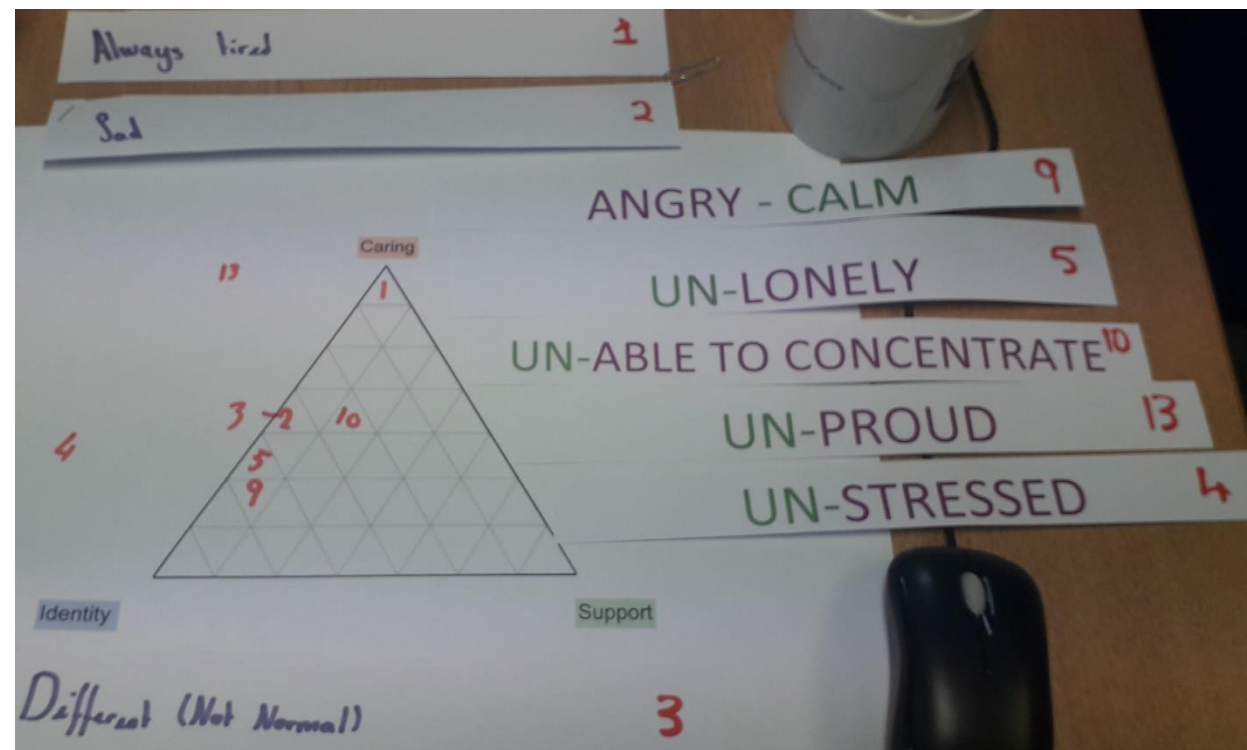
- Martin: Recent young carer due to mum developing anaemia due to a blood disorder  
*“Yeah and then I sit down... and I’m like ‘Oh here we go’ and then there’s like ‘Martin can you come and do this’ and then I’m like... I get like angry sometimes, or agitated. Like I mentioned with the stress, she like asked me to do like one thing and then it’ another, and then it’s just like I’m in the middle of doing something and she just asks me to do something else” (I2)*  
*“It’s not that bad... she does ask me to do a bunch of things now but we have had a couple of chats about it and stuff and she’s just going to ask me like one at a time... she listens to me when I like, when I come to her with an issue like, she’s very good like that... she’ll listen to me and she’ll be like I’ll try to stop doing that so yeah” (I3)*

# Social care intervention strategies 2 (cont)

Improving relationships... need for support

Patrick: Cares for sister Sara with cerebral palsy, learning difficulties and poor eyesight

*"I think somewhere she probably does but she doesn't ever show it [appreciation], she sometimes can be quite nasty to me because I didn't do something quick enough or I haven't done it like there and then so she can get quite evil at me because of it ... she can be quite loud and aggressive."* (I1)

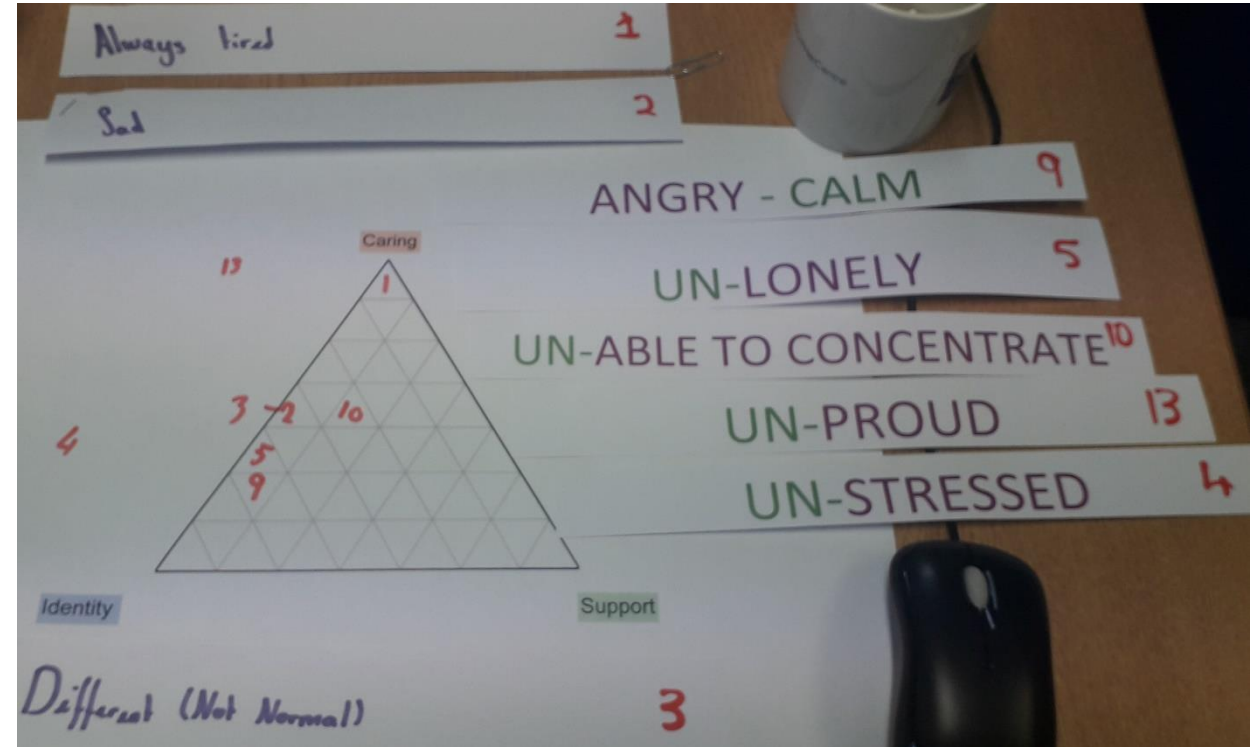


# Social care intervention strategies 2 (cont)

Improving relationships... need for support

*"She was sort of the first one to lockdown, because obviously before they sent out a warning for like asthmatics and um, people with disabilities, including cerebral palsy" (I3)*

*"She's definitely more um, you know, problematic, because she's obviously not getting the social time from her friends and stuff, because they're obviously doing course work, and so she's just sat by herself really... I think if she's bored, she finds annoying me entertaining, so it has happened a lot more... I think she thinks she can get away with more with me, because obviously I'm her brother. But that does not happen, because she can not win." (I3)*



# Social care intervention strategies 3

## Need for active support in schools

*“They don’t really ask us too much about it, they just sort of know that we’re young carers. So they don’t really know how we help out at home. They don’t really give any support to you, to people at my school” (Harry I1)*

*“We’re supposed to have a person who’s supposed to be there for us, when we have caring problems, but I haven’t seen her in about two years. She said “We’re supposed to have a meeting every term”, but she still hasn’t done one, I was in year nine when I had the last one” (Thea I2)*

*“I think it would help them out a lot, because obviously like I have time to do my homework and stuff but other young carers don’t. So if teachers just have a general understanding of what a young care is perhaps they could maybe have extra time on homework” (Harry I2)*



# Breakout session

15 minutes discussion



# Moving forward: How can we improve social care and other sector support for young carers?

## Education

- [carers.org/wales/education](https://carers.org/wales/education)
- Young Carers ID Card



## Young Carers

### Action Day

16 March 2020



# Moving forward: How can we improve social care and other sector support for young carers?



<https://youtu.be/pEBuw0hGaM8>

# Conclusions and Close



<https://twitter.com/i/status/1250091817728708609>