Supporting young carers from under-represented backgrounds

The event will start at 2pm

@YCAlliance  @CarersTrust
Welcome and housekeeping

➢ Ensure microphones are on mute
➢ We will be recording the session after the first item
➢ Introduce yourself and make use of the chat
➢ Unanswered questions will be followed up after the event
➢ Join in the conversation on Twitter - @YCAAlliance @CarersTrust
Being Sunshine – A film by Mari Yamamoto

@YCAAlliance  @CarersTrust
When you live within a community that is under-resourced, racially diverse or economically set back, it becomes very hard to believe that there are opportunities to thrive and dream because their starting point already affects their ideas of worthiness, even within the young carer community.

It is important for us as community leaders who work with young carers, to better recognise that they come from all backgrounds, religions and cultures. They have continuously been failed and ignored and we must work together to end this. No more tokenised discussions, we must actively work together to support these children.
Young carers from under-represented backgrounds – A literature review

Daniel Phelps

@YCAlliance   @CarersTrust
Supporting young carers from hidden and seldom heard groups - A literature review

Daniel Phelps
Twitter: @youngcarersinfo
www.youngcarers.info
Introduction & Background

The Children’s Society’s project –
- funded by DHSC

Project aim:
- To evidence whether and how increased identification of young carers from disadvantaged and seldom heard groups can be achieved in order to support the authority in meeting the objectives in the field of young carers.
The Literature Review

- Literature review to inform this project: [https://tinyurl.com/54caw9fw](https://tinyurl.com/54caw9fw)

Project aim:

- Informed by steering group, overarching research question developed:

  ‘Whether and how increased identification of young carers from cohorts perceived to be ‘hidden’, ‘hard to reach’, ‘seldom heard’, or ‘specifically disadvantaged’ can be achieved?’
Three Sub-questions

- What are the ‘hidden’, ‘hard to reach’, ‘seldom heard’, or ‘specifically disadvantaged’ groups?

- What are the barriers to identification and engagement for ‘hidden’, ‘hard to reach’, ‘seldom-heard’, or ‘specifically disadvantaged’ groups?

- How can we increase recognition and identification of young carers from the ‘hidden’, ‘hard to reach’, ‘seldom heard’, or ‘specifically disadvantaged’ groups? (solutions)
Search Terms

- hidden
- ‘seldom heard’
- ‘hard* to reach’; ‘harder to reach’
- unrecognised
- not recognised
- stigma, stigmatisation
- disadvantage, disadvantages,
- disadvantaged
- barrier, barriers
- excluded
- fear
- secrecy, secret
- identify, identification, identified
- unknown
- not known
- invisible
- Unidentified

Search terms used in combination with the term ‘young carer’

[Image] Carers.info
Databases

- ERIC
- Education Source
- Child Development and Adolescent Studies
- APA PsycArticles
- APA PsycINFO
- Academic Search Complete
- PubMed
- Carer Research and Knowledge Exchange Network (CAREN)
- Google Scholar

Plus:

- Carers Trust, Barnardo’s, and The Children’s Society websites
- Leu & Becker (2019)

Mendeley software used to collate literature
General Findings

Despite improved recognition & awareness since 2014 legislation - young carers generally remain a hidden population…

Not all young carers are identified through the statutory young carers needs assessment - many not receiving these

Further work required to achieve:
- Consistent, effective, early identification of young carers across all sectors
- In particular through health services & adult social care
Identification Not in a Vacuum

One unexpected finding - just how broad the issue of identification of hidden young carers is, and how interconnected and interdependent it is with and on other areas of practice.

- Has implications for development of local services
- Identification of young carers = first step
- However, support itself = a factor in improving subsequent identification
Identification Not in a Vacuum

Identification is linked to and underpinned by:

- societal awareness and awareness of professionals, young people, families
- the referral and assessment processes
- the participation of young carers (in developing policy & practice)
- the promotion and awareness of support
- how services engage with communities and families
Barriers to Identification

Young carers can face multiple and common barriers to identification and support which are both interconnected & interdependent.

Can be viewed as falling under **three categories**:

1. lack of self-identification
2. lack of professional awareness and recognition
3. systems that are lacking
Especially Hidden Groups

A: Young carers whose caring is related to stigmatised conditions/disabilities:

- Parental alcohol misuse; parental substance misuse; and parental mental health
- HIV/AIDS;
- Caring for parents with dementia;
- Caring when a family member is in prison
Especially Hidden Groups

B: Young carers from communities with cultural barriers to identification and support:

- Black, Asian, and minority ethnic communities (BAME communities)
- Young carer refugees or are seeking asylum
- Armed forces families
Especially Hidden Groups

C: Young carers with particular hidden caring roles:

- Factors = the illness, condition, or disability itself:
  - sibling carers
  - emotional care
  - supporting alcohol-dependent parents
    (Professionals not recognising caring roles or focus on person who is ill / needs care)

Likely to be numerous other hidden groups & communities - (not picked up in this review)
Other Factors that Impact Identification

Number of other factors that may impact identification & engagement of young carers & families

- Parental barriers
- A fluctuating caring role
- Language barriers
- Poverty
- Social class
Some young carers experience a more complex mix of factors that may further inhibit identification & support.

Intersectionality = unique and individual

Perhaps common combinations of factors:

- e.g., a YC from some a BAME community caring for a family member with a mental health condition.
- or a YC from a middle-class family with harmful parental drinking.
Conclusion

Q: ‘Whether and how increased identification of young carers from cohorts perceived to be ‘hidden’, ‘hard to reach’, ‘seldom heard’, or ‘specifically disadvantaged’ can be achieved?’

A: Yes - an increase in identification can indeed be achieved
How (General Approaches)

- Understanding different barriers
- Broad, proactive, strategic approach

- Improve identification of all young carers

- Plus targeted approaches for particularly hidden groups
  - Engagement and communication with communities
What Can Be Done?

Focus on ‘**big hits**’ – through **national & sustainable** approaches:

- **campaigns to counter stigma & increase awareness about who young carers are, impacts of caring & support available**
- **workforce development** for all relevant sectors to include training on identifying young carers
- **developing and improving mechanisms for triggering early identification** in schools, primary care and social care
- **developing and showcasing case studies** of good practice in identification of young carers targeting specific groups
Consideration

Helpful to consider delineating identification

- i.e., Identification *before* a young carers needs assessment and the *identification through* a young carers needs assessment
Thank you
Any Questions?

Daniel Phelps
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Young carers and young adult carers from under-represented groups: What do we know? Ethnic minority and LGB+ young carers and young adult carers

Beth Neale
Research and Engagement Officer
According to the 2021 Census, in England and Wales:

- 0–5-year-olds: 606 unpaid carers from ethnic minorities
- 6–10-year-olds: 5930 unpaid carers from ethnic minorities
- 11–15-year-olds: 14,950 unpaid carers from ethnic minorities
- 16–18-year-olds: 18,424 unpaid carers from ethnic minorities
- 19–25-year-olds: 70,033 unpaid carers from ethnic minorities
### Ethnicity of young carers aged 0-18

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>White: English, Welsh, Scottish, Northern Irish or British</td>
<td>74.1%</td>
</tr>
<tr>
<td>Asian, Asian British or Asian Welsh: Pakistani</td>
<td>3.7%</td>
</tr>
<tr>
<td>White: Other White</td>
<td>2.6%</td>
</tr>
<tr>
<td>Mixed or Multiple ethnic groups: White and Black Caribbean</td>
<td>2.5%</td>
</tr>
<tr>
<td>Black, Black British, Black Welsh, Caribbean or African: African</td>
<td>2.3%</td>
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<tr>
<td>Asian, Asian British or Asian Welsh: Indian</td>
<td>2.2%</td>
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<tr>
<td>Mixed or Multiple ethnic groups: Other Mixed or Multiple ethnic groups</td>
<td>1.8%</td>
</tr>
<tr>
<td>Mixed or Multiple ethnic groups: White and Asian</td>
<td>1.7%</td>
</tr>
<tr>
<td>Other ethnic group: Any other ethnic group</td>
<td>1.5%</td>
</tr>
<tr>
<td>Black, Black British, Black Welsh, Caribbean or African: Caribbean</td>
<td>1.4%</td>
</tr>
<tr>
<td>Asian, Asian British or Asian Welsh: Other Asian</td>
<td>1.2%</td>
</tr>
<tr>
<td>Asian, Asian British or Asian Welsh: Bangladeshi</td>
<td>1.2%</td>
</tr>
<tr>
<td>Black, Black British, Black Welsh, Caribbean or African: Other Black</td>
<td>1.1%</td>
</tr>
<tr>
<td>Mixed or Multiple ethnic groups: White and Black African</td>
<td>1.0%</td>
</tr>
<tr>
<td>Other ethnic group: Arab</td>
<td>0.7%</td>
</tr>
<tr>
<td>White: Gypsy or Irish Traveller</td>
<td>0.4%</td>
</tr>
<tr>
<td>Asian, Asian British or Asian Welsh: Chinese</td>
<td>0.4%</td>
</tr>
<tr>
<td>White: Irish</td>
<td>0.4%</td>
</tr>
<tr>
<td>White: Roma</td>
<td>0.1%</td>
</tr>
</tbody>
</table>
Ethnicity of young adult carers aged 19-25

- White: English, Welsh, Scottish, Northern Irish or British: 71.0%
- Asian, Asian British or Asian Welsh: Pakistani: 4.5%
- White: Other White: 3.6%
- Asian, Asian British or Asian Welsh: Indian: 3.0%
- Black, Black British, Black Welsh, Caribbean or African: African: 2.6%
- Mixed or Multiple ethnic groups: White and Black Caribbean: 1.9%
- Other ethnic group: Any other ethnic group: 1.9%
- Asian, Asian British or Asian Welsh: Bangladeshi: 1.8%
- Asian, Asian British or Asian Welsh: Other Asian: 1.6%
- Black, Black British, Black Welsh, Caribbean or African: Caribbean: 1.5%
- Mixed or Multiple ethnic groups: Other Mixed or Multiple ethnic groups: 1.3%
- Mixed or Multiple ethnic groups: White and Asian: 1.2%
- Other ethnic group: Arab: 0.9%
- Black, Black British, Black Welsh, Caribbean or African: Other Black: 0.7%
- Mixed or Multiple ethnic groups: White and Black African: 0.6%
- Asian, Asian British or Asian Welsh: Chinese: 0.5%
- White: Irish: 0.5%
- White: Gypsy or Irish Traveller: 0.3%
- White: Roma: 0.2%
What did ethnic minority young and young adult carers tell us in our annual survey? Support they want:

**Ethnic minority young carers and young adult carers**

- Help with money or finances: 31%
- Support to stay healthy: 32%
- Ideas for things to do while at home: 32%
- Mental health support: 39%
- Support with my education: 40%

**White young carers and young adult carers**

- Help to access practical support: 32%
- Support to have a break from caring: 35%
- Help with money or finances: 40%
- Support with my education: 41%
- Mental health support: 48%
What did ethnic minority young and young adult carers tell us in our annual survey?

Education
• 63% of young carers and young adult carers from an ethnic minority said they ‘always’ or ‘usually’ struggle to balance caring with school, college or university work, compared to 52% of White young carers and young adult carers. This is a statistically significant difference.

Finances
• 41% of young carers and young adult carers from an ethnic minority said they ‘always’ or ‘usually’ face additional costs because they are a carer, compared to 27% of White young carers and young adult carers. This is a statistically significant difference.

Time away from caring
• 44% of young carers and young adult carers from an ethnic minority said they ‘always’ or ‘usually’ find it hard to stay in touch with friends, compared to 34% of White young carers and young adult carers. This is a statistically significant difference.
What did ethnic minority young and young adult carers tell us in our annual survey?

**Wellbeing**

- 62% of young carers and young adult carers from ethnic minorities said they ‘always’ or ‘usually’ felt safe, compared to 72% of White young carers and young adult carers. This is a statistically significant difference.

**Feeling understood**

- 20% of young carers and young adult carers from ethnic minorities said they felt their family did not understand their needs as a carer ‘very well’ or ‘at all’ compared to 13% of White young carers and young adult carers. This is a statistically significant difference.
LGB+ Census data

Young carers and young adult carers identifying as LGB+

- The Census 2021 contains information for 16- to 24-year-old unpaid carers.

- 448,380 straight or heterosexual identifying unpaid carers
- 51,040 LGB+ identifying unpaid carers
What did LGB+ young and young adult carers tell us in our annual survey? Support they want:

**LGB+ young carers and young adult carers**

- Support to stay healthy: 34%
- Support with my education: 40%
- Support to have a break from caring: 42%
- Help with money or finances: 45%
- Mental health support: 61%

**Heterosexual identifying young carers and young adult carers**

- Support to have a break from caring: 31%
- Help to access practical support: 31%
- Help with money or finances: 38%
- Support with my education: 39%
- Mental health support: 42%
What did LGB+ young and young adult carers tell us in our annual survey?

Education

• 38% of young carers and young adult carers who identified as LGB+ said their school/college/university did not understand their needs as a carer ‘very well’ or ‘at all’, compared to 28% of young carers and young adult carers who identified as heterosexual. This is a statistically significant difference.

• 20% of young carers and young adult carers who identified as LGB+ said they ‘never’ or ‘not often’ have enough time to send on their school/college/ or university work compared to 12% of young carers who identified as heterosexual. This is a statistically significant difference.

• 45% of young carers and young adult carers who identified as LGB+ said they ‘always’ or ‘usually’ struggle to balance caring with school, college or university work, compared to 31% of young carers and young adult carers who identified as heterosexual. This is a statistically significant difference.

• 45% of young carers and young adult carers who identified as LGB+ said they ‘never’ or ‘not often’ get help in school/ college/ university to balance caring and their school, college or university work, compared to 35% of young carers and young adult carers who identified as heterosexual. This is a statistically significant difference.
What did LGBTQ+ young and young adult carers tell us in our annual survey?

Paid work

• 39% of young carers and young adult carers who identified as LGB+ said their workplace did not understand their needs as a carer ‘very well’ or ‘at all’, compared to 22% of young carers and young adult carers who identified as heterosexual. This is a statistically significant difference.
• 40% of young carers and young adult carers who identified as LGB+ said they ‘never’ or ‘not often’ had someone at work to talk to about being a young adult carer, compared to 22% of young carers and young adult carers who identified as heterosexual. This is a statistically significant difference.
• 34% of young carers and young adult carers who identified as LGB+ said they ‘never’ or ‘not often’ got help from work to balance caring and their work commitments, compared to 21% of young carers and young adult carers who identified as heterosexual. This is a statistically significant difference.
• 52% of young carers and young adult carers who identified as LGB+ said they ‘always’ or ‘usually’ struggle to balance caring with paid work, compared to 42% of young carers and young adult carers who identified as heterosexual. This is a statistically significant difference.
What did LGBTQ+ young and young adult carers tell us in our annual survey?

Finances

- 63% of young carers and young adult carers who identified as LGB+ said that they ‘always’ or ‘usually’ worried about the cost of living and things being more expensive, compared to 54% of young carers and young adult carers who identified as heterosexual. This is a statistically significant difference.

Wellbeing

- 46% of young carers and young adult carers who identified as LGB+ said that they ‘always’ or ‘usually’ have someone to talk to about their feelings, compared to 55% of young carers and young adult carers who identified as heterosexual. This is a statistically significant difference.
- 51% of young carers and young adult carers who identified as LGB+ said that they ‘always’ or ‘usually’ feel worried about their future, compared to 40% of young carers and young adult carers who identified as heterosexual. This is a statistically significant difference.
- 43% of young carers and young adult carers who identified as LGB+ said that they ‘always’ or ‘usually’ feel lonely, compared to 31% of young carers and young adult carers who identified as heterosexual. This is a statistically significant difference.
What did LGBTQ+ young and young adult carers tell us in our annual survey?

Physical health

• 32% of young carers and young adult carers who identified as LGB+ said they either ‘never’ or ‘not often’ felt like they get enough rest, compared to 18% of young carers and young adult carers who identified as heterosexual. This is a statistically significant difference.
• 39% of young carers and young adult carers who identified as LGB+ said they either ‘never’ or ‘not often’ felt like they got enough sleep, compared to 23% of young carers and young adult carers who identified as heterosexual. This is a statistically significant difference.

Feeling understood

• 26% of young carers and young adult carers identifying as LGBTQ+ said they felt their family did not understand their needs as a carer ‘very well’ or ‘at all’ compared to 12% of young carers and young adult carers who identified as heterosexual. This is a statistically significant difference.
What did LGBTQ+ young and young adult carers tell us in our annual survey?

Time away from caring

- 43% of young carers and young adult carers who identified as LGB+ said they felt it was ‘always’ or ‘usually’ hard to stay in touch with their friends, compared to 35% of young carers and young adult carers who identified as heterosexual. This is a statistically significant difference.
- 50% of young carers and young adult carers who identified as LGB+ said caring ‘always’ or ‘usually’ affects how much time they can spend with their friends compared to 38% of young carers and young adult carers who identified as heterosexual. This is a statistically significant difference.
- 32% of young carers and young adult carers who identified as LGB+ said they ‘never’ or ‘not often’ feel included with all the things their friends do, compared to 22% of young carers and young adult carers who identified as heterosexual. This is a statistically significant difference.
Experiences of Unpaid Carers from Black and Minority Ethnic Communities

Dr Tim Banks
Research and Engagement Manager
How does caring affect your life?

Caring can have an impact on many aspects of your life:

Money and benefits

Health and wellbeing

Getting out and about

© Carers Trust. All library photos posed by models
Research into unpaid carers in Wales who are from an ethnic minority: Initial objectives

- To understand the experiences of carers of all ages from Black, Asian and minority ethnic communities in Wales

- Recommend actions and activities for local authorities, Welsh Government, NHS Wales and the health and social care sector more widely to improve provision for carers from ethnic minorities

- Recommend actions and activities for Carers Trust Wales and other local organisations to support the provision for carers from ethnic minorities
Methods

- Focus Groups
- Small Survey
- In-depth interviews
Challenges faced by unpaid carers

- Practical barriers
- Awareness/perception of certain conditions and disabilities
- Cultural expectations within the community
- Perception of being a carer
- Felt assumptions from services
Practical barriers

• Language barriers

• Lack of awareness of services available
  • ‘I don’t think many even understand social services. They’re only understanding is children are taken away by social services.’

• Services being inappropriate
  • Respite not meeting diet or religious requirements
    • ‘He wants to be speaking in Somali and doing what he knew as a child....there is nowhere they can go and talk about what is important to them...those services are not available which is really sad and in this day and age, do you think that is acceptable? Personally I don’t.’
Practical barriers cont.

- Practices in the home not being met by care workers
  - Approach to skin care for example
    - Not enough time for this.
- Lack of cultural sensitivity
  - A one size fits all approach
  - ‘The reality is we have to treat people how they want to be treated. It’s not us bringing what we want and changing the way they have lived all their lives….why should they have to change the way they have been all their lives?’
‘We don’t even had words for mental health. My head hurts or I’ve hurt my head.’
‘It is not something we do’

‘People do not want to have these conversations for fear they are being judged by others. It is not something that we do.’

‘He had to be in a care home whilst (his room) was being prepared for him but the amount of people who said why did you put him in a home? We don’t do this.’

‘That may be ok and seem sensible in white, western culture but bring it in a Pakistani setup, and even though it is not religious but putting Muslim religion in it as people perceive it, if you are making those decisions, you are not trusting the creator. Your faith is weaker on the creator that is why you are taking the matter into your own hands.’
Perception of being a carer

‘I see people struggling in the community and then there is no respite. They just have to get on with it’

‘You are the carer. You are this foundation for these people. If you go down, who is going to be there for them? It is not easy. It is a huge burden. I am the eldest in my family. You have got to pretend you are strong but I have had my cries. I have gone in the bathroom and cried my eyes out, washed my face with cold water and come out so it is not easy.’

‘Sometimes people put themselves in situations which are unbearable, they know they are going to get sick, just so they are not seen (in a certain way). Sometimes they make it worse for themselves.’
'Because the health services have already made assumptions about your family, about what you’re able to do and who you are as a person, what can I do if they’ve made those decisions?'
Opportunities/Solutions

• Policy changes
  • ‘The only way we are going to see change is from the top.’

• Community hubs
  • Places where someone can walk in and get everything they need

• Awareness raising sessions
  • Go into community. Put on an event with stalls and information

• Those already influential in the community can help educate
  • Faith leaders for example

• Culturally specific groups
  • People more likely to go to something if they know someone already there.
  • Others say the opposite.
    • They will not go where they will be judged.

• There needs to be variety
Recommendations

Carers Trust

- Support Carers Trust Network Partners to collect ethnicity data as standard and monitor reach in comparison with local population prevalence
- Ensure lessons from successful services reaching carers from minority ethnic communities, funded under Making Carers Count, are captured and shared with the wider Network to encourage roll out

Carers Trust Wales

- Facilitate connections between carers organisations, organisations representing people from ethnic minority communities and local statutory partners to encourage the development of services tailored to the needs of unpaid carers from minority ethnic groups.
- Raise awareness of findings
Network Partner Organisations

- Consistently capture service users’ demographic data, including ethnicity, and report on reach in comparison with the local population prevalence annually

- Consider alternative avenues and methods of advertising services and support. This includes identifying a variety of different locations and mediums used by different communities

- Proactively engage with organisations representing ethnic minority communities locally to partner in services tailored for minority ethnic carers

- Specific drive to recruit support staff from minority ethnic communities. This will not only encourage a change in attitude and understanding of available support, but also promote services and make them more attractive for others within the community who recognise it as appropriate to their needs
Local authorities, health boards and RPBs

Awareness raising

- Undertake a targeted and appropriate awareness raising campaign to change perceptions of the role of statutory social services. This includes increasing communication from service providers in terms of support available, entitlements, what can and cannot be expected from providers and clear communication as to how decisions are reached.

- When services are culturally appropriate, ensure this is widely promoted, using appropriate language and terminology, to encourage awareness and take up.

- Work with influential people within communities, such as faith leaders, to raise awareness and promote understanding and acceptance of different disabilities, conditions, the role of the carer and the positive aspects of seeking support.
Local authorities, health boards and RPBs

Communication

- Offer information in a variety of different languages during routine communications. In advance of meetings and appointments, make sure necessary translation services are available and allow sufficient time and space for information to be understood.

Planning

- Ensure a person-centred approach to the organisation of service provision and support. Where possible, be flexible and innovative to different patterns of care that best suit the needs of both the individual in need of care and the person who cares for them.
- In commissioning services, ensure they include meeting the needs of minority groups.
- Consider a central point, accessible at the heart of the community, to provide all information regarding unpaid care.
Welsh Government

- Ensure findings are considered by working groups delivering the Welsh Government Anti-racist Wales action plan and strategy for unpaid carers
Next Steps

- Publishing Report
- Identify and organise dissemination opportunities to present the findings of this work to a variety of audience and through different mediums.
- Organise a round table with key stakeholders to discuss findings and to identify tangible solutions organisations feel able to undertake
- Ensure participants and relevant organisations receive a copy of the report with a request for feedback and further comment
- Organise a conversation with Welsh Government to identify how findings align with the Race Equality Action Plan and Strategy for Unpaid Carers
- Organise an internal Lunch and Learn for Carers Trust Staff
- Feeding into Carers Trust Race Equality Working Group
- Ensure appropriate related activity receives media exposure to maximise reach and impact
- Identifying further research opportunities to evaluate progress and impact
Thank you for listening

Tim Banks
tbanks@carers.org
The impact of culture in relation to parental mental illness

Helena Kulikowska, Development Director – Our Time – **In conversation with Antoinette Njoku and Jess Streeting**
Q&A/Discussion

@YCAlliance  @CarersTrust
Comfort break

We will resume at 3:45pm

@YCAliance  @CarersTrust
Young Carers from the Gypsy, Roma and Traveller Community

Jill Nooij,
Carer Awareness and Voice Coordinator
Caring Together is a charity that provides information, runs services in our local communities and campaigns, so that carers have choices.

It is our mission that people know where to go for help before, during and after their caring role and get the practical support that matters.

Over the last 2 year we have been involved in projects working with people from the Gypsy, Roma and Traveller Community. We have covered Cambridgeshire, Peterborough and Norfolk. During these projects we discovered many hidden carers within this community.
What did we learn?

- The word “carer” isn’t always recognised within the GRT communities. Families can be described as “close knit” and will care for each other without identifying as a carer.

- In 2011, 14.1% of Gypsy and Irish Traveller people in England and Wales rated their health as bad or very bad, compared with 5.6% on average for all ethnic groups, as a result there will be a greater demand for carers.

- Young people from the GRT community can have lower attendance rates in education settings and less likely to access their GP, therefore are less likely to be identified and referred to services of support.
What did we learn?

• Practical tips which we picked up from the project included:
  - The use of WhatsApp voice notes as a way of cascading important information
  - In relation to emergency planning – for those on traveller sites if there is an issue (e.g. carer unwell), they will seek support within the site
  - Trust is key
    - Need time to build relationships
    - Being able to provide support through trusted contacts was a real enabler.
  - Wary of “Swoop in, swoop out”
Where to access support?

Friends, Families and Travellers is a leading national charity that works to end racism and discrimination against Gypsy, Roma and Traveller people and to protect the right to pursue a nomadic way of life. They support individuals and families with the issues that matter most to them, at the same time as working to transform systems and institutions to address the root causes of inequalities faced by Gypsy, Roma and Traveller people.

**What Support is Available for Young Carers?** - Friends, Families and Travellers (gypsy-traveller.org)

They provide advocacy casework, advice and information to Gypsies and Travellers via their national helpline.

They have a FAQs page - [Frequently Asked Questions - Friends, Families and Travellers](gypsy-traveller.org) and offer training (there is a cost)
Understanding the emotional response of being a young carer of a combat veteran with PTSD: A Narrative Inquiry

Dr Paul Watson PhD
Assistant Professor Child and Young Peoples Nursing & SCPHN School Nursing.
Manager of the Northern Hub for military and Families Research
PhD: Young Carers of Veterans with PTSD

Paul5.Watson@Northumbria.ac.uk

Twitter: Dr_PaulWatson
Research Aims

The study had two main aims:

• To explore the impact that parental Post Traumatic Stress Disorder, which is associated with combat, has on children within the home environment.

• To explore the impact on parental and child relationships when a child assumes the role of ‘young carer’ for the parent with combat attributable Post Traumatic Stress Disorder.
Why Inquiring into Narratives are important in truly understanding the lived experience.

Narrative Inquiry “storytelling is used as a means of analysing data and presenting findings”, while narrative analysis is research in which “stories are used as data” ” (Barkhuizen, Benson & Chik, 2014, p. 3)
Being a young carer of a veteran with PTSD:

A Cultural Insiders Narrative – my story.

Narrative Analysis: Temporality, systematic & thematic

Narrative Inquiry: individual meaning to text, applying to theory
What happens when we don’t engage with children and young people from the military community in research?

- Perceptions of the impact a military career has on children
- Parental reports of serious illness and disability among children aged 3–16 years from UK military families
- Perceived effect of deployment on families of UK military personnel
Why is the voice of a young carer important?

• A child's Rights to express his or her views is enshrined in the United Nations Convention of the Rights of a Child (UNCRC) (Article 12 & 13).
• We need to pay attention to what the young carer is AND is not saying, and how the young carer behaves.
• Listening to a young carer helps develop relationships and validates who they are.
“he was would take me out for food, just he would do the father type stuff. Mum obviously told him about how I don’t see my dad and he’s not a part of my life”.

“He got a lot angrier. His eyes, I always remember his eyes, like something just clicked and he was an entirely different person.”

“I would take the boys up to my room. I had a desk in my room, and we would put a chair under the door.”

“I make sure he took his tablets. I would make sure he would go to his AA meeting and his meetings at ?? I would help him with his paperwork, stuff like that”

“supporting D had a huge effect on my own mental health...I needed support!”

“...it’s been a rollercoaster. But I wouldn’t change it for the world.”
“Me and dad went on a lot of cycle rides, we went to the park and stuff like that. I used to go to work with him for a week, which I enjoyed. We went to the shooting range”.

Yeah. You can just see the difference (in him)...

“He can get angry at times and just snap, it can be scary...I just stay out of the way in my room when he gets angry”

“but it doesn’t bother me too much now”

“...we go for walks and we talk, I think it really helps him...”
Young Carer 3

“...sad we didn’t know if we would be able to see him again.”

“He wouldn’t be himself, he wouldn’t be taking the mick out of one of us or something, or making jokes...so I would go and give him cuddles...it calmed him down”.
“we used to spend quality time together, until he broke down. Now he is emotionally distant, which is hard!”

“My mum does so much (for him), I am also worried about her…”

“…I can’t just slack off I need to help…especially when mum is working.”
## 3D Analytical Framework

<table>
<thead>
<tr>
<th>INTERACTIONS</th>
<th>SOCIAL</th>
<th>PAST</th>
<th>CONTINUITY</th>
<th>FUTURE</th>
<th>SITUATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>PERSONAL</td>
<td></td>
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<tr>
<td>Inner state of affairs; For example: Feelings, emotions</td>
<td>Interactions with others within the context of their environment.</td>
<td>Backward: remembering previous experiences, feelings and relationships</td>
<td>Now: Current experiences, feelings and relationships</td>
<td>Forward: Hopes for their future relationships</td>
<td>Context, time and place: Placing the lived experience within the concept of locality, its intention and purpose.</td>
</tr>
</tbody>
</table>
Storying Stories

Scenario: Living with PTSD

Title: You can just see the difference.

Abstract

It wasn’t scary it was more like, you still had to be good you just had to be cautious I would say.

Orientation:

I was a bit older then, so I Knew what it was. He came back so it was fine. I was worried [PTSD presentation] but I got used to it after a while.

Evaluation:

Things like he started to get angry more and more often, to other people and us. He snapped more quickly. If something frustrated him, he would get really angry.

Then what…

So, you had to be a bit careful and stuff, not to annoy him too much, because we were still quite young then. It was really scary when he would shout at you because he got upset quite easy then. We had to be good. We could be naughty every now and then, but not too naughty otherwise we set him off.

Coda:

It’s PTSD
<table>
<thead>
<tr>
<th>Findings Within Families</th>
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</thead>
<tbody>
<tr>
<td>Lens of Language</td>
</tr>
<tr>
<td>Lens of context</td>
</tr>
<tr>
<td>Lens of moments</td>
</tr>
<tr>
<td>Lens of symbolic interaction</td>
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</tbody>
</table>
Why is inquiring into the voice of a young carers important?

• “I miss him a lot. Something is missing at home, we have a big house, and when someone is missing it’s like empty.”

• “It’s difficult I would say because people don’t really get how it is when your dad is going out [Conflict], they think oh he is coming back, but you never know, that’s scary not to know if he is going to come back or not.”

• “I try to help my dad, but he keeps pushing help away. So, I feel I am doing wrong.”

• “Sometimes it’s hard because we get angry at each other and sometimes we start to fight...you can’t say it’s easy because it’s not easy being in a family where people have a symptom [PTSD].”
Findings across families

Presentation of PTSD within the home

Relationships

Young carer identity

The effects of caring for a parent with PTSD
Inquiring into the Narratives: Adverse Childhood Experience
Pause for Reflection

What are children and young peoples narratives telling you?
Thank you for listening and doing what you do...
Making Carers Count

Tanya Coles, Carers Trust
Jessie Haig, Bridgend Carers Centre
Phil Hollis, Harrow Carers

@YCAliance    @CarersTrust
MAKING CARERS COUNT

May 2023

Tanya Coles, Programme Lead (Young and Young Adult Carers), Carers Trust
Jessie Haig, Young Carers and Young Adult Carers Service Manager, Bridgend Carers Centre
Phillip Hollis, Young Carers Manager, Harrow Carers

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VISION: Unpaid carers from under-represented groups across the UK can access the support they need to live their lives

Programme partners have increased understanding and ability to engage and support unpaid carers from under-represented groups.

Unpaid carers from under-represented groups have improved access to carer support, information, advice and services.

Wider stakeholders have increased recognition, understanding and ability to support unpaid carers from under-represented groups.

CARERS TRUST Programme management & capacity building

LOCAL CARER ORGANISATIONS: Local placemakers and convenors for unpaid carers, working with local actors to coordinate engagement of carers from under-represented groups

INVOlVEMENT & VOICE
Carer involvement takes place programmatically and locally to identify and remove barriers, shape services, and raise awareness.

ACTIVITIES
• Carer forums
• Peer mentoring
• Action research
• Exploring innovative ways to provide info, support & guidance

• Skills/knowledge development to inform service delivery
• Developing new or adapting existing services for carers from under-represented groups
• Community engagement and awareness raising across key stakeholders
• Building partnerships to improve referral pathways

OUTCOMES
• Unpaid carers from under-represented groups have improved access to carer support, information, advice and services
• Wider stakeholders have increased recognition, understanding and ability to support unpaid carers from under-represented groups

INPUTS
CARERS UK Project delivery

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Programme Timeline

- **Inception** (Jul - Dec 2020)
  - Consultation
  - Evidence of need
  - **Carers UK**
  - Covid-19 Support Fund **£5.8m**

- **Mobilisation** (Jan - Aug 2021)
  - Defining 'under-represented'
  - Theory of change
  - Programme criteria
  - Application and assessment
  - Grants awarded

- **Partnerships** (Sep - Oct 2021)
  - Two national carer organisations
  - **27** local carer services
  - England, Scotland and Wales
  - **36,500** carers who are currently under-represented

- **Delivery** (Oct 2021 - Mar 2024)
  - Raising awareness
  - Local partnerships
  - Engaging new carers
  - Identifying and removing barriers
  - Testing what works
  - Sharing learning

- **Legacy** (Apr 2024)
  - Increased understanding
  - Improved services
  - Increased engagement with carers from under-represented groups
  - Sustained services
Supporting young carers from under-represented backgrounds

Rural Communities

LGBTQ+

Sibling Carers
Rural Communities

- Working with schools - newsletter to English and Welsh schools.
- Providing staff training.
- Visibility in the community.
- Networking with those working with young people.
LBGTQ+

- Share information with local LBGTQ+ groups.
- Led to more networking opportunities with local theatre groups and sports teams.
Sibling Carers

- Attend school events – especially schools for children with additional needs.
- Staff training.
- Referall process – awareness of who is classed as a young carer.
MAKING CARERS COUNT
Phillip Hollis, Young Carers Manager, Harrow Carers
Any questions or comments?

@YCAliance  @CarersTrust
Thank you for attending
Upcoming Young Carers Alliance webinars

**Young Carers Alliance (hosted by Carers Trust) Events | Eventbrite**

**Monday 22 May, 10am-12pm** – Roundtable on identifying young carers in a health setting

**Thursday 8 June (5-7pm) and Friday 9 June (9-11am)** – Young Carers’ Voices – International perspectives

**Thursday 22 June, 1-4pm** – Transitions – Opening up opportunities for Young Adult Carers

**Wednesday 12 July, 10am-1pm** – A whole-family approach to identifying and supporting young carers

**Thursday 5 October, 1-4pm** – Where next for identification and support for young carers in schools?

**Thursday 2 November, 10am-1pm** – Young carers – a health perspective
Thank you

To find out more about the Young Carers Alliance or become a member/subscribe to updates

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