roots and wings
OBJECTIVE

To provide Young Carers with the services necessary to allow them to access the same opportunities and life chances as other children and young people.
Service users, in this case Young Carers, know their own experiences best.

To understand those experiences we have strived to create a space for them to voice their genuine wants, wishes and needs.

It is also vital that current providers, associated professionals and other interested parties are consulted, as they have knowledge of existing best practice and can provide us with critical insights not available elsewhere.

Working closely with commissioners means we have an understanding of what resources can be deployed. These processes ground our findings and service design suggestions in reality.
A service design process with fresh eyes and without prior bias.

Alan Ramsay of the Roots and Wings team took the lead on developing a map of current service provisions and engaging with current service providers and professionals. So as not to bias the outcomes, this was conducted in isolation from the other members of the Roots and Wings team.

Ed Blazey and Rob Kitchen took the lead running the Young Carers Workshops, which were focused on mapping the Young Carers’ service journeys and capturing their authentic needs through multimedia and creative practice. Through these workshops we ascertained the needs of Young Carers, whether or not these needs are currently met, and what types of services the Young Carers feel would best support them.

As part of the Service Discovery stage we began our literature review. This intentionally wasn’t undertaken until after meeting the Young Carers and current service providers in order to prevent bias. This review involves researching academic papers and studies on the issues raised, as well as looking at what conclusions other organisations have arrived at to inform their own commissioning processes, including an analysis of other councils’ procurement documents, such as The Sheffield Approach.

Following our initial workshops with Young Carers (Participants present: 8 from PROPS, 12 from Barnado’s), we began to combine and analyse our findings, looking for commonalities and areas of conflict. We would then map Young Carers’ journeys over each other highlighting blockages, inefficiencies and opportunities for earlier intervention.

This process involves plotting the Young Carers’ journeys (as ascertained from the workshops) over the current service provisions map. It also involves a strong emphasis on what’s possible in terms of the commissioning process and what’s realistic to implement ‘on the ground’.
YOUNG CARERS’ IDEAL
(Young Carers)

COMMISSIONING POTENTIAL
(Commissioners)

REALISTIC IN PRACTICE
(Professionals & Literature review)

SERVICE RECOMMENDATIONS
Meetings, meetings, meetings... design.

Subsequent to these internal service design meetings, we then went on to sketch out a suggested service.

This was formed primarily by identifying the issues and ideas raised by the Young Carers themselves, combined with new solutions and solutions already apparent within the existing system, as understood through our contact with professionals and commissioners, and through our literature review.

We then returned to the Young Carers and relevant professionals to test our service design theories and explore contentious issues. This was done through further Young Carers workshops, structured interviews with parents and professionals and continued research of relevant literature. Our model was then refined and adapted accordingly. Aside from testing the service at this stage we also developed questions that required further investigation.

These questions are explored in Appendix C, Appendix D and Appendix E.
“What is the best definition [of a Young Carer] for the commissioning process?”

“How well do transition services work?”

“Could all Young Carers be supported by one service?”
We think...

THIS IS OUR THINKING

It is important that service design is an iterative process with Young Carers at its heart, and that it is periodically reviewed.

We understand how important it is that ALL of our assertions are transparently reasoned, checked and backed up through our research [See Appendices].

This document of recommendations is accompanied by a short video co-created with Young Carers to directly add their distinctive voices to the document.
Young Carers want more support at school, more care support at home and more time with their Key Workers.
What affects Young Carers’ quality of life most is the support they receive at school and the care support they receive at home. Therefore, an effective Young Carers’ service needs to proactively engage with schools and Adult Care services to ensure each Young Carer’s needs are met day-to-day.

When Young Carers come into contact with current services, the role of the Key Worker in particular is very effective in offering a high level of support and having a positive impact on all aspects of the Young Carer’s and the cared-for individual’s lives.

Two crucial issues are improving access to services and early intervention. The latter is important as too often referrals come as the result of a crisis situation. Statistics show that there are a large number of Young Carers who are not supported by current services. As it currently stands services are overcapacity leaving little resources for proactively seeking out Young Carers.

For core aspects of Young Carers’ provisions (Activities, Training, Transport, Promotion and Advocacy) there are examples of good practice across the city, but these examples need to become the expected standard, rather than the exception.

In our research we didn’t come across any Young Carers who initially self-referred, leading us to the belief that they often don’t. Therefore they need to be proactively sought out and referred.

The definition of who can access Young Carers’ services may not be appropriate considering the aspirations for the service.

All recommendations are at the discretion of the Young Carer. There’s no ‘one size fits all’ answer, so options need to be offered at every stage. Safeguarding issues must also be considered at all stages.

There’s a strong case for Health Services not only to refer, but to contribute resources.
Third party assessment procedure
- Build trust and communication
- Young carer kept informed at all times

Fear of social services splitting up the family
- Need to be identified by professionals
- Mandatory training for professionals
- YC Training, promotion and advocacy

‘Some young people accessing YC services aren’t technically ‘Young Carers’.

Fear of stigma and bullying
- Confidential services
- Young Carer is in control of who knows what about their situation
- Training, promotion and advocacy to address bullying

Don’t see themselves as carers
- Training, promotion and advocacy

Don’t want to keep having to describe their situation
- Young Carer Champions embedded in organisations
- Single contact with access to Young Carer database

Not knowing of services or the support they can offer
- Young Carer champions
- Someone who can relay information to others
- Young Carer doesn’t have to ring reception
- Someone Young Carer can trust
- Someone who can liaise with relevant organisations where necessary
- Young Carer Champions can teach others about Young Carers and raise awareness
- Young Carer can text if they’re running late, are going to miss an appointment, haven’t done their homework or need a day off

ISSUES
- Young people don’t self-identify therefore don’t self-refer
- Professionals avoid entering into conversations where they don’t know the facts or referral routes.

- Professionals assume a young person’s needs have already been met, especially in cases where social services are already involved with the family
- Professionals assume that if a young person they are dealing with has been identified as a Young Carer they would’ve been told, and for this reason, they don’t ask

- Could be used as a carrot to engage with services to alleviate guilt.
- Could manifest as resistance to involvement in services.

- Separate Key Worker’s role from other roles
  - Less time as taxi driver
  - Less time organising and form filling
  - Too much paperwork including funding bids
  - Too much time spent chasing permission forms

- Single referral point
- Training, promotion and advocacy

- Young Carers Champions embedded in organisations which the Young Carer already travels to
- More localised support
- Transport Services / Free bus passes

Unsure of Young Carer definition

Assumption that someone else has already asked questions about potential caring role.

More time with Key Worker

Distance from services (costing time and money)

Feeling guilty

Lack of clarity as to where to make referrals
The role of the Key Worker is by far the most valued part of the current Young Carers’ services. We suggest separating the Key Worker role from other activities to protect Key Worker time with Young Carers.

For example, organising Activity provision is currently a strain on resources for Key Workers and requires a significantly different skillset to casework. It is important that Key Workers attend these activities and invest in their intrinsic value, but not necessarily that they organise them. This also applies to the Training, Advocacy, Promotion and Transport elements of the Young Carers’ services. These service elements don’t need to be carried out by the Key Worker, as they are distinct roles.

The current services exhibit a potentially inefficient duplication of work. It is important that there are specialist Key Workers for cases involving drug or substance abuse [Appendix D]. The other aspects of the service [Training, Advocacy, Promotion and Transport] could be combined into a single service that supports all Young Carers. This could lead to a higher standard of provision due to greater specialisation in these tasks and greater efficiency due to economies of scale.

There are currently two referral points. There should be one single referral point to make it easier for professionals to refer, easier to collect data, as well as making savings in terms of efficiency.
Two main service providers:
One service for cases involving alcohol and substance abuse
One service for all other cases

ALL SERVICE PROVISIONS DUPLICATED

CURRENT SERVICE PROVISION

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Furthermore, the organisation of Transport and Activities provisions could be shared with other youth services.

The Training, Promotion and Advocacy services could also have some overlap with other Youth Training, Promotion and Advocacy services. For example, by putting information and contact details for all youth services into a single communications campaign, or implementing better resourced training days covering a variety of topics which could affect young people.

These measures could lead to a higher standard of provisions due to even greater specialisation in these tasks and greater efficiency due to economies of scale.
1. KEY WORKER ROLES:

- To build rapport and develop a positive, trusting relationship.

- To conduct an assessment of referred young people’s needs. Are they appropriate for this service? [See Appendix E] If they are:

  - Both Key Worker and Young Carer to agree on a framework of expectations.
  - Key Worker to co-design support plan with the Young Carer, for the Young Carer.
  - List of support options for the Young Carer to choose from culminating in tailored individualised support.
  - Key Worker and Young Carer to make an agreement regarding consent issues. For example, who does the Young Carer want to know about their situation? What level of detail would they want them to know?
  - Where appropriate (bearing in mind safeguarding issues are paramount) a whole family approach should be taken, involving visits, family meetings and regular communication with the family to keep them ‘in the loop’. This increases trust and reduces tension with the services and improves outcomes. Key Workers acknowledge that there may be cases where parents feel guilty, therefore special considerations should be built into the process.
  - Key Worker to liaise with other agencies to co-design support for the Young Carer, for example, teachers, GPs, etc...
  - Key Worker to assist in arranging care support for cared-for individual, with the Young Carer to be treated as a valued expert within this process.
  - Key Worker to assist families in accessing support and full financial entitlements or benefits for the household.
  - Key Worker to continually assess the Young Carer’s needs.
· Specialist Key Worker for cases involving drug and/or alcohol abuse.

· To provide a vital point-of-contact (‘just a phone call away’) and to be available in case of emergencies.

· To provide access to other support services and activities, and to ‘handhold’ to appointments where appropriate, rather than just signposting.

· To make sure the Young Carer is registered with GP and attends appointments.

· To make sure the Young Carer has access to mentoring and counselling, or specialised mental health services where appropriate. It is worth noting that mental health issues and substance abuse issues are more prevalent amongst Young Carers.

· To help provide access to specific careers advice, and flexible courses and jobs to suit their distinct needs – Connexions.

· To help Young Carers find and attend activities, training, afterschool clubs and outings.

· To help the young person build resilience and develop coping strategies and support networks, and therefore become less reliant on Young Carers’ services.

· To make sure the Young Carer is supported in the transition into adulthood and adult services. We recommend at least one appointment with adult services for all identified Young Carers.

· The Key Worker role is hugely rewarding, but stressful and emotionally draining. Key Workers should have readily accessible support in place, such as peer support groups and counselling.
2. ACTIVITIES PROVISION:

The most appropriate activity or activities for any particular Young Carer will vary depending on their circumstances and interests. For this reason there needs to be a range of activities on offer. These activities could either be organised in-house, or procured/provided by creative and cultural organisations. This is an excellent opportunity to forge strong links and partnerships with other third sector organisations and Arts/cultural organisations. These activities should provide opportunities for personal development, as well as opportunities for the young person to have fun and ‘be a kid’.

• Activities with other Young Carers.

These could take a variety of forms, from treats and ‘away days’ to residential breaks and outdoor activities. Through these activities the Young Carers should have the opportunity to:

- Develop peer networks and peer support groups.
- ‘Find their voice’ in a safe environment.
- Take a break from caring responsibilities.
- Learn practical skills e.g. cooking, budgeting.
- Learn to express themselves e.g. through music & art.
- Build resilience.

Activities with other Young Carers are a good opportunity to build ‘buddy’ systems between older and younger carers. It is also an opportunity to invite older carers (e.g. Northumbria University Young Carers’ group) to come back, share their stories, and act as role models.

There should be special consideration for Young Carers whose cases involve alcohol and/or substance abuse. These young people should be offered the option of a peer support group made up solely of other Young Carers in a similar situation.
• Activities with the whole family.
If properly supported these activities can provide the opportunity for the Young Carer and their family to enjoy each other’s company, building the family as a strong unit. These can be relatively simple activities, for example, going bowling.

• Support Young Carers to join existing activities, not necessarily with other Young Carers.
Some Young Carers may feel pigeonholed by only undertaking activities alongside fellow Young Carers. Instead they may want to join existing groups, but may need support in finding and accessing these groups, including ‘handholding’, organising travel, and obtaining permissions where appropriate, rather than just signposting.
3. TRAINING:

There are a number of existing barriers that may prevent a Young Carer from self-referring. These include a young person not seeing themselves as a Young Carer, a fear or distrust of social services, a fear of stigma or resultant bullying from peers, or simply not knowing where to go to find the necessary help and support. For these reasons and more, Young Carers need to be proactively identified. Training other professionals who regularly come into contact with young people is the most efficient way to do this. This training could make up part of wider training for professionals dealing with young people, for example, Young People’s Mental Health & Wellbeing, Bullying, or Domestic Abuse.

We’ve identified two main strands to this training. Firstly, the creation of specifically trained contacts within organisations (Young Carer Champions) and secondly, general awareness training for all professionals dealing with young people.

- Young Carer Champions.

Young Carer Champions are grassroots points-of-contact in organisations such as schools and GP’s surgeries. These professionals should be trained by the Young Carers’ services in how best to support young people with the responsibility of being a carer. The desired outcome of a successful training process isn’t just that Young Carer Champions make referrals to the centralised Young Carers’ Service. Where appropriate these champions could be trained to fulfil certain Key Worker roles where cases are less complicated and haven’t escalated. Resource packs and e-learning toolkits should be developed and made available to support these Young Carer Champions.

Skilled-up individuals who already come into contact with young people are well positioned to intervene earlier in a Young Carer’s journey, identifying and supporting young people at risk of becoming Young Carers and potentially preventing situations from reaching a crisis point.
Distance can be a barrier to support as it requires both time and money to overcome, which can be scarce resources for Young Carers. Having support services placed in locations that the young people already travel to, such as schools and GP’s surgeries, reduces this barrier to accessing the necessary support.

There is already good work in this field and examples of best practice, but there needs to be a city-wide, whole school and whole practice approach to this training.

The ideal is that for every school, college and GP’s surgery in Newcastle there are contact details for at least one named Young Carer Champion within that organisation. This information should be made widely available.

**Young Carers Champion Profile:**

- The Young Carer Champion should be a named member of staff already working within each organization.
- Someone who the young person feels they can trust.
- Someone who knows the young person’s situation and can communicate it effectively to other professionals, saving the Young Carer from having to explain their situation over and over again.
- Someone who will liaise with Young Carers’ organisations if necessary.
- Someone who is committed to raising awareness of Young Carer issues in general within the given organisation.
- Someone who is contactable at short notice. For example, a Young Carer can text them if they’re running late for an appointment with the GP, or warn someone at school that they haven’t done their homework.
- Someone who can offer the Young Carer special privileges, for example, can distribute time-out passes and allowances for mobile phone use.
- It is important that this role isn’t associated in any way with disciplinary procedures, for example, Young Carers bundled in with services specifically for naughty and disruptive children.
• Awareness training

Any professional who comes into regular contact with young people should be involved in Young Carer Awareness Training. This would include, for example, people who work in schools, social services, police, health workers, mental health professionals, drug support group workers, and third sector organisations.

This training should cover how and when to identify Young Carers and how to refer them to their Young Carers Champion or the centralised service. It should be made clear to them where their responsibilities begin and end. Resource packs, multimedia (e.g. videos) and e-learning toolkits should be developed and made available to support with this training.

There can be a false assumption amongst professionals that if another professional is already involved with the child or their family, that the young person’s needs will have already been identified, therefore no support is offered. Training is therefore necessary to make it clear not to assume someone else has already broached this subject.

A broadening of the definition of the term ‘Young Carer’ to include ‘young people who are at risk of becoming Young Carers may make sensitive discussions easier and referrals seem less accusatory.

Proactive training of professionals allows for earlier intervention, shifting from reactive to proactive approach. There are huge benefits to intervening earlier such as building resilience, support networks and avoiding crises. There are also significantly improved psychological and physical benefits for the Young Carer, their family and the cared-for individual, as well as significant long-term cost savings.

In retrospect, telltale signs of someone being a Young Carer are usually apparent at school. Although not always the same (and often contradictory) there are commonalities. These could include getting into trouble at school, always having their phone on, arriving early and staying late (or vice versa), irregular attendance, signs of self harm, running away, or involvement in bullying. Schools and School champions need to be trained to identify these signs.
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Healthcare workers, mental health professionals and drug support group workers are perfectly placed for early identification. They should be trained in the appropriate referral routes once they have made this identification. When they diagnose an illness that requires care they should also assess who is going to carry out that care. Likewise when an addiction is acknowledged, young people in that household fulfilling a caring role also need to be identified and assessed. Health professionals need to ask questions every time they come into contact with someone new that requires care: Are you a parent? Are your children looking after you? Are there any children in your household that will be impacted? This is a key starting point for ‘the whole family approach’ applicable across the health care profession. This should begin when the health professionals themselves are trained at college and university.

• Securing buy-in

Schools and GPs are outside the direct control of local authorities, so creating and developing partnerships is essential.

Since schools and GPs are now effectively competing with each other they could be incentivised to engage with supporting Young Carers by being rewarded for work which supports Young Carers, for example, the Young Carers in Schools Awards. Such awards serve to positively differentiate them from other schools, giving them a competitive edge. Successes in schools such as Lemington, which recently achieved a ‘Young Carers in Schools Bronze Award’, should be widely publicised and celebrated in order to encourage others to take part in these schemes.

Young Carers could be eligible for a Pupil Premium, which in turn could be a financial incentive for schools to identify and provide services for Young Carers.

There are pilot schemes in some health trusts offering financial incentives for Young Carer referrals from GPs. Aside from the dubious nature of financial incentives, they could be used for a period to instill identification behaviours and ingrain best practice.
4. PROMOTION:

There should also be a promotions campaign to complement the training suggested in the previous section, with a simple step-by-step identification and referral process at its core. This promotional campaign would be targeted towards:

- **Other professionals**
  Promotional material aimed at other professionals should raise awareness of the need to support Young Carers, facilitate appropriate referrals and encourage them to access and engage in Young Carer training. It would seem that there is a real need to convince some professionals in the value of training. Anecdotally, some services ask, “What’s the point in training? We don’t have any Young Carers?” It is estimated that there are over 2,200 0-24-year-old Young Carers in Newcastle (Census 2011, Office for National Statistics), although this is likely to be an underestimate. This equates to between 3%-6% of all young people in Newcastle.

- **Unidentified Young Carers**
  Promotions directly aimed at unidentified Young Carers in schools, colleges and GP’s practices. This could be done through assemblies, posters (providing blank space for Young Carer Champion details) and multimedia (e.g. videos) promoting services and how to access them (single referral point details). Young Carers we worked with identified the specific need to focus not just on physical care roles, but emotional and other forms of support.

- **Under represented communities.**
  A proportion of Young Carers’ services should be dedicated to exploring and overcoming barriers to further marginalised communities, particularly focusing on BME communities [see Appendix D].
5. ADVOCACY:

Young Carers need a distinctive voice to raise awareness of the issues that they face. Young Carers’ services should strive to put the needs of Young Carers on the political agenda, both regionally and nationally.

- Support services should facilitate for Young Carers themselves to become champions for other Young Carers. There are already success stories in this field.

- Young Carers employed as Apprentices in the services that provide support for Young Carers could gain employment opportunities as a result of their Apprentice experience in business administration & youth work. For example, PROPS putting Young Carers forward for National Apprenticeship Award.

- Young Carers as mentors, providing peer support, passing on their experience and acting as role models, particularly during periods of transition.

- Young Carers need a continual voice in shaping the services that they access. There needs to be an iterative loop built into the Young Carers’ service design process. Young Carers need to be periodically consulted on whether their needs are being met, and services adjusted accordingly. Young Carers’ services need to continuously evolve to better meet Young Carers’ needs, and Young Carers’ voices need to be agents for this change. There is a huge appetite amongst Young Carers to be involved in any process that helps others in their situation.
6. TRANSPORT:

Transport is an issue for Young Carers because often their parents can’t assist them in their travel for a variety of reasons. We recommend that there is a transport service provided to take Young Carers to activities and support sessions. Currently a lot of Key Worker time is spent as a ‘taxi driver’. As such, there is a need for a regular minibus or taxi service.

For example, to get Young Carers to a Performers workshop (1½ hour session), Key Workers need to begin pick-up at 3pm with a final drop off 7.30pm. This 4½ hours represents a significant proportion of their working week, especially for a part-time worker. There is some value in being able to talk to each other on route and the Key Worker facilitating at least initial access, but this time is considered by both parties to not be as valuable as one-to-one or organised group time. It is important to note that the Key Workers are not running these sessions.

- The transport service provided should be consistent and reliable. Ideally, there would be a consistent driver that can build a rapport and trust with the young people.

- Transport is a barrier not only to accessing activities and support services, but also to attending school and appointments. As well as a minibus/taxi service for organized activities, it should be considered whether free access to public transport could be an option.

- Young Carers’ services and activities should be based in central locations, easily accessible by both public and private transport.
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- Young Carers' services and activities should be based in central locations, easily accessible by both public and private transport.

A single referral point is vital for clarity when professionals refer.
The potential referral sources
- Young Carers need to be identified by professionals in order to receive support. This can be encouraged through the Young Carers service providing Training, Promotion and Advocacy activities.
- A ‘Think Family’ mindset needs to be established across all services.
- When a professional doesn’t feel they have the appropriate skills to support the young person, they need to make a referral to the single referral point.

Single referral point
- A single referral point is vital for clarity when professionals refer.
- This provides an excellent opportunity to start a Young Carers Database, with recording and information sharing protocols made simple and clear from the start. Existing Young Carer data could be inputted, for example, the information in the Connexions database.
- Young Carers should decide who has access to their information, unless there is a safeguarding issue.
- There needs to be a greater understanding of what data can and should be shared between services. The Data Protection Act 1998 is often misunderstood; its intention was to provide a framework for data sharing rather than to prevent it.
Screening

This is a pre-assessment of the young person’s needs. Is the young person appropriate for this service, or could their needs be better met by another service? It is important to define who this service is for from the outset [see Appendix E]. Special consideration allowing for early intervention should be built into this definition. If the young person meets the criteria for this Young Carers’ service then they should be assigned a Key Worker. If the young person’s needs would be better served elsewhere then they should be referred appropriately.

Key worker assigned

Key Workers should be assigned on the basis of the needs of the young person, the skills of the Key Worker and, where possible, there should be a ‘personality matching’ consideration.

Assessment

- Appropriate assessment framework used, for example, CAF/Child in need / YPSOP / CSOP / CRAFT / MACA and PANOC.
- Young Carer made aware of exactly what support services are available.
- Expectations of support agreed upon.

Tailored service provided

- Key Workers provide bespoke emotional support and practical help to Young Carers, with the Young Carer participating as a co-creator in their own service plan.
- Other agencies, services and professionals are approached and involved where appropriate.
APPENDIX A

Meetings to date

12th January- Meeting at Civic Centre- Bridget Atkins and John Leith
15th January- Young Carers Forum meeting
28th January- Meeting at Civic Centre -John Leitch
12th February- Meeting- John Leitch
25th February- Caring About Carers Conference - Civic Centre
4th March- Newcastle and the Care Act - NCVS
4th March- Sue Curry and Elizabeth meeting at Barnardo's
5th March- Meeting with Dan Carey (PhD Design Placement at Newcastle Carers) and Andy Tennant (Professor of Service Design at Northumbria University)
23rd March- Andrea meeting at PROPS
1st April- Meeting- John Leitch
16th April- Meeting with the facilitators of the ‘Performers’ group at Sage Gateshead.
16th April - 1pm–3pm Workshop with PROPS Young Carers (8 participants)
27th April- 4pm–6pm Workshop at Northern Stage with Barnardo’s Young Carers Group (12 participants)
29th April- 5pm–6.30pm Performers group at Gateshead Old Town Hall (8 participants)
1st May - Meeting- John Leitch
11th May, 12th May- Internal RaW design sessions, Refine and Combine
13th May- 5pm–6.30pm Performers group at Gateshead Old Town Hall (6 Young Carers)
15th May - Meeting- John Leitch
19th May – Halfway Point - Presentation at Civic Centre
21st May - Young Carers Steering Group meeting
27th May - Performers Workshop with Young Carers
28th May - Roots and Wings Young Carers meeting at RaW studio
28th May - Meetings with Performers’ parents (Reena’s, Sammy’s & Josh’s)
29th May - Meetings with Barnardo’s Key Workers (Jenny Low & Heidi)
1st June - Amelia Davison (Young Carers Champion) meeting at RaW studio with Jenny Low
5th June - Meeting- John Leitch
3rd June - Performers group at Gateshead Old Town Hall (8 participants)
17th June - Performers group at Gateshead Old Town Hall (6 participants)
19th June - Meeting- Paul Brownlee
23rd June - Meeting with Rachel and Laurie, Northumbria University student representatives for Young Carers.
25th June - Roots and Wings Young Carers meeting at RaW studio
26th June - Meeting- Dr Kate Reilly, Clinical Psychologist in General Practice
1st July - Performers group at Gateshead Old Town Hall (3 participants)
9th July - Roots and Wings internal design session
14th July - Meeting with Dan Carey (PhD Design Placement at Newcastle Carers)
16th July - Meeting- Katie Dodd, Newcastle Young Carers
16th July - Talked to Steve Crosthwaite (Learning and Equality Champion and Leader of Extended Services) and Miles Wallis-Clarke (Head Teacher) from Hotspur Primary School
22nd July - Meeting- John Leitch
29th July - Sage Family Day
6th August - Interviews with young Adult Carers
APPENDIX B

Literature and resource review to date


BME* Young Carers’ Pilot Project Report. Young Carers’ Version.

Caring about Young Carers (Carers Conference, Newcastle 2015)


Engage toolkit website: Supporting black and minority ethnic (BME) young carers and families carers [www.engagetoolkit.org.uk].


North of England Commissioning Support Clinical model for Primary Care Psychological Therapy Services (based on IAPT)

Provision of Adult Carer Support Services, Provider Briefing and Closure of Provider Consultation, 26th March 2015.


Young Carers’ draft regulations. Government consultation. 22nd December 2014.

Young Carers’ Identification and Recording task and finish group report (2014).
APPENDIX C

Transition to adult services

During this transition period Young Carers are deciding what they want to do with their future. This could involve further study, employment or moving out of home. Some Young Carers have to decide at this point whether or not to become an Adult Carer. Transition services for Young Carers should be particularly focused on:

• Transition into adulthood
  Provide emotional support, building resilience and teaching life skills.

• Specialist careers support
  Carers may require flexible working conditions and more bespoke careers advice to suit their specific needs.
  Adult Carers or older Young Carers could be asked to speak to Young Carers to inspire them and act as role models.
  Where appropriate Young Carers could be given work experience/apprenticeships by the very services which are there to support them.
  As some young people leave education at 16, this specialist support needs to be provided at 15-years-old or younger.

• Support with further education
  Young Carers need more support and information when considering applying for further education, as well as during the application process and once attending further/higher education.

Before application – Northumbria University has a Young Carers’ Society and at least 106 students who self-identify as a Young Carers. This can be considered an untapped resource in terms of using these older carers to inspire younger carers and raise their aspirations.

During application – There should be a Young Carer disclosure ‘tick box’ on UCAS and College Enrolment forms with associated access to support.

Once attending further or higher education – Young Carers should be provided with support and special consideration where necessary. Existing support routes are inappropriate. Currently, the two avenues are PEC (Personal Extenuating Circumstances), which takes into account extenuating circumstances when looking at attendance and performance, but this is only applicable where there is a sudden and unexpected incident and often doesn’t support Young Carers where their caring responsibilities are long-term and pre-date their enrolment at college/university. The other route is DSSR (Disabled Student Support Recommendations). Applying for DSSR is a lengthy process and therefore not accessible to Young Carers for whom spare time can be a scarce resource. On top of this, Young Carers don’t see themselves as being disabled.
• **Communication**
  When talking to Young Carers we found there was a lot of fear and misinformation regarding what support they would receive once they turned 18. To avoid this and allay fears, Young Carers need to be better informed.

• **Continuous support**
  The key to a successful transition from youth to adult services without the Young Carer feeling like they are ‘going over a cliff edge’ is to build an overlap into the age ranges the services support. Our recommendation is that Young Carers’ services should support young people up to the age of 25 years old (especially for vulnerable adults) to allow for maximum overlap with the current Newcastle Carers 18+ services (in which case the overlap would be 7 years). However, if a young carer over the age of 18 was identified they would be immediately referred to adult services. In this sense the overlap exists purely to allow for a smooth transition from Young Carer to Adult services.

• **Handover to adult services**
  We would suggest an automatic handover of all previously identified Young Carers to Adult services. This would involve the Young Carers being strongly encouraged to attend at least one assessment with the Adult Carers service, as it seems a lot of Young Carers fall through the gap at this point. Our findings would suggest that there are a number of reasons why Young Carers don’t want to attend Adult Carers support services. These reason include: by this point Young Carers may feel resilient enough to cope without support, they perceive the Adult services as being aimed at people older than themselves, or they have moved out of home so no longer fulfil a physical caring role. It is also important to note that many Young Carers maintain an informal relationship with their former Key Workers, although they don’t have a new Key Worker, meaning that if they need support in the future they don’t know where to go for help.

• **Iterative redesign**
  Transition services should be influenced by those people who have recently been through that service. This could either be through feedback, focus groups or apprenticeships, helping to reinforce the iterative loop which is vital to shaping and adapting the service.
One Service

Cases that involve Alcohol and Substance misuse

One of the key questions for this commission is whether there should be one service for Young Carers. Currently Young Carers’ services in Newcastle are split, with cases involving alcohol and substance abuse receiving support from a specialised service (currently PROPS). The question is, is this a useful distinction?

‘Young Carers’ is a far from homogenous group, but is there a useful distinction that can be drawn between types of Young Carers that would improve the effectiveness of support? It seems clear that if there is a distinction to be made then the distinguishing factor is in relation to the support needs of the cared-for individual rather than the Young Carer themselves. The support needs of individuals being cared for usually fit into one (but often more than one) of three main categories: substance abuse issues, mental health issues, and physical health issues.

Although the following issues are present across the Young Carer spectrum, they are usually more pronounced in cases involving substance abuse:

- Legal issues
- Police involvement
- Involvement of cared-for individual in associated criminal activity
- Greater social stigma for Young Carer
- Conflict
- Financial issues & poverty
- Combinations of both mental and physical health problems
- Different referral routes and points of contact with authorities.

If it is best to support different types of Young Carers separately, is it also beneficial that activities provision is separated? Would Young Carers whose cases involve alcohol or substance abuse feel comfortable in peer support situations sharing their stories with Young Carers whose cases involve just a physical health issue? Is there the same connection? Is it also worth separating out other aspects of the Young Carers’ service, such as Promotion, Training, Transport and Advocacy?
Through talking to professionals it is clear that there will be benefits resulting from providing more specialised services, but also dramatic efficiency gains from having everything ‘under one roof’. Our recommendation is that due to the differing needs of the young people and therefore the skills required, the role of Key Workers needs to be separated into those who deal with cases involving substance abuse and those who don’t. Activity provision should include opportunities for Young Carers whose cases involve substance issues only socialise with others in a similar situation. Other core services (Promotion, Training, Transport and Advocacy), although they could have different strands for different types of Young Carer, could be amalgamated to benefit from efficiency savings.

Provision will need to be made to continue to support the current services if they are not chosen for the new commission. It is very difficult to ‘hand over’ Young Carers to other services once trust and relationships have been established. The progress and development of a Young Carer may be reliant on that trust and they mustn’t feel that they are being abandoned. Existing services need to be supported for an overlap/handover period. This would allow time to signpost new referrals, complete assessments, fulfil development plans, honour support plans and handhold Young Carers and their families to the new services, allowing new relationships to form.

Young BME Carers

It was hard to access substantial primary data on Young Carers from black and minority ethnic backgrounds, however there were Young Carers from BME backgrounds in the workshops we facilitated and anecdotal stories from professionals. This coupled with our literature research has lead us to some tentative conclusions that might suggest there are increased barriers to accessing services for these communities:

- A lack of language-matched information.
- There is a need for culturally competent services, based on culturally appropriate and language-matched assessment processes.
- Language barriers and misunderstanding about, for example, medical terms.
- Differing cultural stigma surrounding particular types of ill health and disability.
- Differing views, attitudes and backgrounds between the Key Worker and the person requiring care could impact upon treatment and support given.

These factors coupled with findings from the Sheffield Approach, stating that Young Carers are 1.5 times more likely to be from a BME background, suggest that this area needs specific attention to improve the knowledge base and remove potential barriers to accessing services. A proportion of any Young Carers’ service should be dedicated to exploring and overcoming these issues.
APPENDIX E

Who is a Young Carer?

Language and definitions are important as they can affect identification (and therefore referrals), transitions and ultimately, who has access to what services.

Section 96 of the Children and Families Act 2014 (and Newcastle’s joint commissioning strategy for Young Carers) defines a Young Carer as:

‘…a person under 18 who provides or intends to provide care for another person of any age…providing practical or emotional support.’

The 2014 Care Act definition requires that there is a ‘significant impact’ on a Carer’s wellbeing in order for them to be eligible for support.

The Sheffield Young Carers (2014) definition states that a Young Carer is a young person “taking on a practical and/or emotional caring responsibility that would be normally expected of an adult”.

The above definitions both use the term ‘care’, but what do we mean by care? The following scenarios provide examples of young people who currently access Young Carers’ services, but are they Young Carers?

1. A young person’s sibling has substance misuse issues. This has a ‘significant impact’ on this young individual, but they don’t have a direct caring role. Under current provision they are supported by Young Carers’ services, but are they a Young Carer? They’re affected by someone who’s close to them not being able to care for themselves, although they personally don’t fulfil that care role.

2. A young person has limited or no support from a guardian or responsible adult due to that adult’s support needs. The young person doesn’t directly ‘care’ for their guardian physically or emotionally, but has to care for themselves much more than a young person should.
How the term ‘Young Carer’ is defined in theory has a very real practical effect in terms of which service is responsible for looking after a young person. It’s important that there aren’t any gaps in the support system’s definitions, and if a young person isn’t covered by one definition we need to make sure they’re covered by support elsewhere and referred to, for example, social services or CAMHS. The definition of Young Carer needs to be decided from the outset to make it clear who can access the Young Carers’ service.

Are services required to make black and white definitions? Are services likely to be abused if not? Is it enough to keep definitions loose and allow for professional judgement? A broadening of the definition of Young Carer to include ‘young people at risk of becoming a young carer’ may make sensitive discussions easier and referrals seem less accusatory.

For example, PROPS don’t necessarily use the term ‘Carer’ in their definition of who can access their services. PROPS’ services are accessible to any young person providing there is evidence of ‘negative emotional impact’ as a result of substance misuse in their close family.

It could be that the definition in terms of who can access Young Carers’ services includes,

‘A young person who is affected by someone in their household needing care’

or

‘A young person at risk of finding themselves in a caring role’

It is vital for early intervention that the definition encompasses young people who don’t yet have a caring role but who, due to their circumstances, are at risk of having a caring role in the future.