



HEALTHWATCH LEICESTER YOUNG CARERS' FORUM IN PARTNERSHIP WITH BARNARDO'S - SUMMARY REPORT

1. AIM

The aim of the Young Carers' Forum was to enable young carers and young adult carers in Leicester city to have their voice heard in relation to local health and social care services.

2. BACKGROUND

- We invited representatives from each of the city's seven young carers' groups (aged 12-18) and from the city's Young Adult Carers' group (aged 16-20) to meet three times during February to May 2017 with a final session being held to film young carers sharing their key issues and messages from the work undertaken.
- Healthwatch Leicester and Barnardo's had identified the priorities for the Forum, rather than this being self-directed by the young people themselves.
- The young carers were advised that the outcomes of their work will be used as a training and awareness tool for practitioners and managers in the local area and uploaded onto member websites and social media.
- Membership was fluid in order to reflect individual group member interests, ensure diversity and maximise engagement.
- A central venue, transport support (where required) and refreshments were provided. The Forum meetings were staffed by Barnardo's and one session was also attended by the Healthwatch Leicester staff member leading on the project.
- Informal training and support was provided for members who wished to access the Forum to enable them to engage fully.
- Members will be encouraged to engage in media and promotional work to disseminate messages from the Forum but this is not a requirement.

- A budget of £1500 was utilised to facilitate the Forum meetings and filming.

3. PRIORITIES

The Forum was asked to work on the following priorities with a view to influencing service development and delivery:

- Their experiences of Whole Family Working and associated key messages.
- Their experiences of engaging with Primary Care and associated key messages.

4. DEMOGRAPHICS OF THE YOUNG CARERS

- 10 young carers engaged in total.
- All the young carers live in the city of Leicester.
- Their ages were 15-19.
- There was an ethnicity mix broadly representative of the city demography, including young carers from Asian, mixed heritage, Black Caribbean and White British backgrounds.
- Both male and female young carers engaged in the process.

5. WHOLE FAMILY APPROACHES

5.1 Key messages for practitioners:

- Involve young carers in care planning.
- Provide child / young person friendly care plans.
- Ensure young carers are aware of care planning arrangements for their parent and have key contact details.
- Care plans need to encourage family to ask for help earlier.
- Care plans and crisis plans are not shared with young carers and are often not sufficiently detailed.
- Care plans do not represent a young carer's understanding and insight into their parent's ill health.
- Care plans should include a map of family support which is updated regularly.
- Extended family and community groups should be considered in plans to stay well.

- Ensure better communication regarding parent's hospital discharge.
- Parents are reluctant to or refuse to engage with the Crisis Team due to inconsistent staffing which impedes developing relationships.
- Support comes too late when a parent's health deteriorates- services are perceived as reactive rather than proactive.
- Adult health and social care services staff should work in partnership with other agencies to support the care for person and the whole family.
- In particular those staff should, with consent, liaise with school or college to triangulate the parent's account of the home situation.
- Young carers feel that if their parent says they are ok, professionals take this at face value without checking with family members, especially young carers themselves.
- Adult Health and Social Care staff should talk to children and young people to get a picture of their world and family life from their perspective.
- Those staff should also advise young carers when they are going to close their parent's case.
- Adult Health and Social Care staff should talk to children - children and young people do not get to see or meet Adult workers so they feel can't trust they are there when needed.
- Respecting young carers as partners in care will help parents to stay well and avoid relapse.
- Some young carers understand that their parent's health puts them, as children and young people, at risk. They would prefer an open and honest discussion about this rather than avoidance - emergency planning will help prepare for this scenario and make it less frightening and/or anxiety provoking.

5.2 What young carers want to see in the future:

Young Carers want:

- To be involved, spoken to in a language they understand and given time to ask questions.
- To be a priority in care planning.
- Care plans to include a relapse pathway or 'family friendly crisis plan' that acknowledges and respects the role young carers play and caters for their needs.
- To know that help won't just stop without professionals first checking with the young carer.
- To know about the health of the person they care for to ease their fear, anxiety and sense of isolation.

- Professionals supporting their parent to take time out to ask them about their experiences and what could help them, and the person they care for, to stay well.
- A break from caring and the confidence to know their loved one will be well looked after.
- Rapid and easy access back into support for their loved one if they have a relapse.
- More home visits from Adult Health Care professionals - young carers recognise time pressures for staff but parents may tell professionals they are coping but a visit to the home may indicate otherwise.
- Family friendly emergency planning (eg 'Message in a Bottle').
- Better consideration of sibling carers - when a parent shares the care role for a sibling with other children in the family.
- Professionals to work together to support the whole family.
- A visual indication that people and places are 'young carer friendly' eg a kitemark.

6. PRIMARY CARE, GP'S (AND SCHOOL NURSES):

6.1 Key messages for practitioners:

- Appointments that can be booked in advance are crucial in facilitating attendance and planning to manage health better both for care recipients and young carers
- When attending medical appointments with parents young carers often do not understand the language that is being used.
- Discussing personal information at reception feels very uncomfortable and intrusive and often leads to understating issues and concerns.
- To have priority for clinic appointments and be seen quickly to minimise the impact on the person they care for - especially if this is a disabled child
- Young carers find it really difficult to talk about their own health and that of their parents. This is exacerbated by restricted appointment times. This was particularly an issue with CAMHS appointments and assessments.
- When young carers are seeking help for their own emotional health and wellbeing they need time to get to know the professional who is supporting them and this is not available.

- GP appointments often involve a great deal of emotional and practical planning for young carers and/or their parents (including missing school). As a result, often several issues have accrued before a young carer and their parent make an appointment. Appointment times only allow for one issue to be discussed.
- Young carers are not aware of the full remit of School Nurses eg that they can support with emotional wellbeing and lower level mental health issues. They also feel that School Nurses are not visible.
- More broadly, young carers do not know how to access emotional support and/or counselling if they are not able to access CAMHS.
- Young carers benefit from the emergency planning tool - the Lions 'Message in a Bottle' which CareFree promotes with families.
- Young carers do not know which professionals are aware of the existence of young carers - who is 'Young Carer Friendly'?

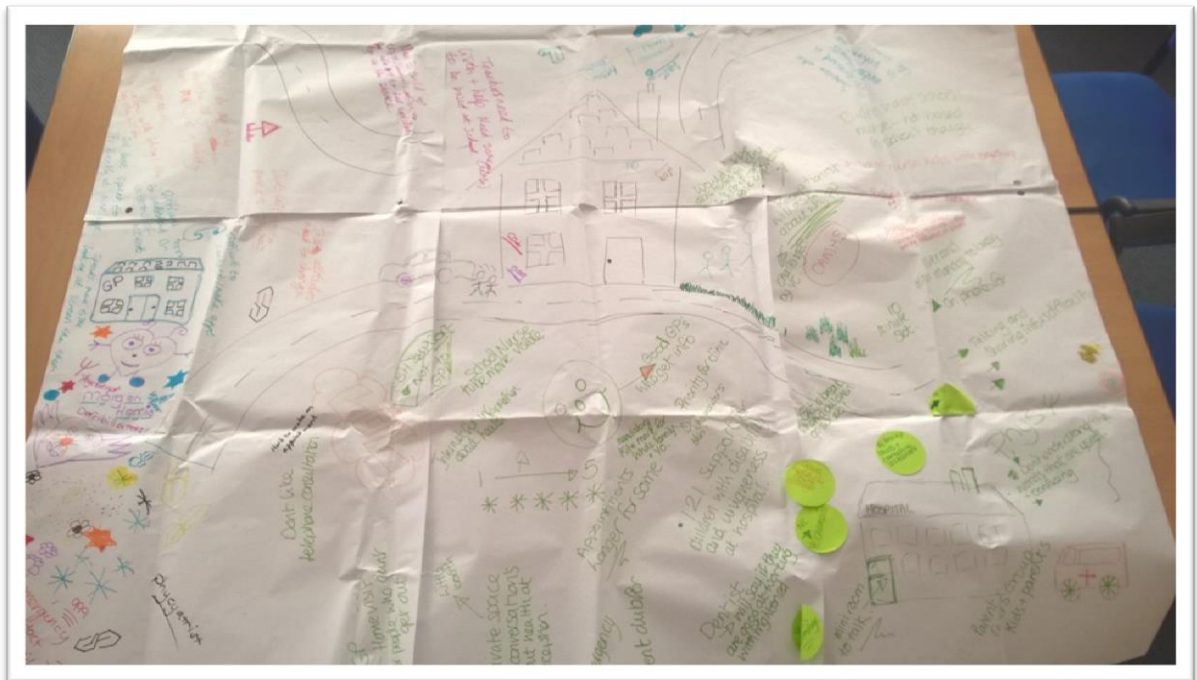
6.2 What young carers want to see in the future:

Young Carers want:

- Primary care staff to know they are young carers and make reasonable adjustments to meet their needs and the needs of those they care for - to minimise stress and planning and maximise health outcomes.
- Pre-bookable appointments.
- Reception staff to advise patients why they ask questions about their health needs when they arrive at the surgery.
- To have information shared with them that is accessible and not full of medical terminology they do not understand.
- School Nurses to help young carers to understand the information their parent has been given (eg information the GP prints off the computer in appointments about health conditions).
- To be actively encouraged to talk about their perception of their parent's health issues, solutions to challenges and ideas for how they think their parent can be helped.
- To be able to ask questions and have them answered.
- Time to explore their thoughts about what has been said in appointments.
- A private space to talk at reception.

- Priority and timely appointments that minimise waiting, particularly when disabled children are involved.
- A prompt to book an appointment to address more than one medical issue.
- Prompts for medication reviews and repeat prescriptions.
- A clear understanding of how School Nurses can support them and how to access that support.
- School nurses to be more visible in school and to offer home visits to those who are not in school.
- ‘Message in a Bottle’ emergency care planning tool to be promoted as standard practice for all health care practitioners.
- Accessible information about how and where to access counselling and emotional wellbeing support services.
- Information on line regarding ‘Young Carer friendly services’ (This lead to a discussion re ‘kite marks’ and rating services which are ‘young carer aware’).

Young Carers Forum Mind Map, March 2017



7. NEXT STEPS - CREATING A LEGACY

- Young carers have relished having their voice heard and have developed plans for future work they would like to undertake now that the Healthwatch Leicester funding has ended.
- Some thoughts they have had include:
- Development of a Whole Family Approaches kite mark. This is in draft form and is being developed by a designer, funded by Leicestershire Partnership Trust.
- Development of series of 'What good looks like' summaries for key practitioners in Health and Social Care, to complement the kite mark work.
- Further consideration of how to measure outcomes for services which would also complement the kite mark work e.g. secret shopping.
- Occasional merged Forum meetings, to include cared for parents.
- The development of tools to assist with preparation for medical appointments (care recipients and young carers).
- This report and the more detailed records of each Forum session will be used to influence the Leicester, Leicestershire and Rutland Carers' Strategy Refresh which is presently underway.
- Filming is presently underway to capture the key messages above in the young carers' own words. This will be edited and made into film clips that will be uploaded onto partner websites, shared with the city council Local Safeguarding Board Participation and Engagement Group, used for Barnardo's training and included in a training resource currently being developed by Barnardo's for Leicestershire Partnership Trust to promote Whole Family Approaches amongst its adults and children and families work force.
- Further consideration will be given to how to enable messages to be shared via social media.

8. OUTCOMES

- Young carers and young adult carers in Leicester were given the opportunity to have a voice and to influence local policy makers, commissioners and providers.
- Young carers reported feeling skilled and empowered to speak up about issues which affect their lives and those of their family.
- Young carers have been inspired to work together beyond the life of the Health Watch funded project to drive forward other work they wish to pursue in order to enable more young carers to be identified and supported in Leicester.
- Young carers will leave a legacy that will be used to influence decision makers after the life of the project.

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