School Nurse Programme: Supporting implementation of the new service offer:

Supporting the health and wellbeing of young carers

Context and rationale

Supporting the health and wellbeing of young carers

Seamless support through local solutions

What works locally: case studies
Context and rationale

This pathway sets out the key messages for services and professionals to meet the needs of young carers. It is of interest to all professionals providing on-going care where a child or young person may be involved in caring duties. It is particularly aimed at school nursing services and will be of interest to professionals and provider organisations and commissioners. School Nurses play an important role in identifying young carers in the school aged population, both in and out of education. Public Health Nurses can play an important role in identifying and supporting families where there may be a child or young person caring or who could become a carer. As the number of adults with long term conditions and mental health issues are increasing, children, young people and families are taking on more caring responsibilities.

The pathway is designed to support integrated working between the school nursing service, other public health nurses and partners in supporting young carers and their families. It sets out the rationale for effective partnership working recognising the need to offer support within a school and community context. It pulls together core principles to assist local areas to develop their own framework to ensure effective working and enhanced support. It provides more focus and clarity for school nursing services, partners, and young carers and family services in understanding roles. School nurses need to work with partners to provide holistic support which will require systematic approaches to promote communication and collaboration. Additionally, school nurses can play a crucial role in encouraging schools to develop a whole school approach to identify and support pupils who have caring responsibilities.

The pathway provides a model for a coordinated approach between school nursing, education, local authorities and young carers’ services to ensure early identification of health and wellbeing needs and the provision of primary healthcare services to young carers and their families. It focuses on promoting the health and welfare of all children and young people including due regard to safeguarding and the UN Convention on the Rights of the Child (1989), ensuring every child and young person should enjoy the best possible health and health service. School nurses and partners need to work together to improve outcomes and measure the impact of their interventions. Supporting young carers’ health needs requires a whole family approach; young carers may be supporting a parent, family member or sibling.

The pathway will:

- Adopt a life course approach and provide a clear focus on identified outcomes for children, young people and their families.
- Build on evidenced-based practice and provide clarity relating to identified complex needs and service structure.
- Provide an understanding and clarity around roles, functions and engagement with key partners.

The current NHS and Public Health Outcomes Framework contain indicators for child health, each having an impact on the health and wellbeing of the population along the life course. Families with particular illnesses or disabilities such as HIV, mental ill-health and substance misuse may still feel stigmatised and fear seeking external support. Practitioners supporting young carers should be aware of the prejudices that may exist around cultures, and disability or about adults who misuse drugs/alcohol or have mental health needs in terms of their parenting capacity and competence. (Working together to support young carers and their families August 2012)

Definition of a young carer

There is no single definition of a young carer; however the following may be used:

The term Young Carer should be taken to include children and young people under 18 who provide regular and on-going care and emotional support to a family member who is physically or mentally ill, disabled or misuses substances.

A young carer becomes vulnerable when the level of care giving and responsibility to the person in need of care becomes excessive or inappropriate for that child, risking impacting on his or her emotional or physical well being or educational achievement and life chances (MOU 2012).

Although this definition relates to under 18s, this support should include young adult carers aged 16 – 24 years of age. Young carers may be providing support for a parent, sibling or other family member.

A young carer may undertake some or all of the following:
- Providing emotional support
- Physical & personal care such as lifting, washing, dressing, giving medication
- Practical tasks and responsibilities such as cooking, housework and shopping.
- Managing the family budget, paying bills; and
- Responsibilities such as looking after younger siblings, interpreting etc.

There may be some positive outcomes of caring for young carers such as feeling valued within the family and developing personal and life skills. However caring can have an adverse effect on a child or young person’s health and wellbeing, development and opportunities.

For some this can lead to children and young people at risk of, or experiencing significant harm through abuse and/or neglect and for some it can lead to safeguarding issues.

Why do we need a specific pathway for young carers?

Data, compiled from the 2011 census, shows nearly a quarter of a million people aged 19 and under in England and Wales were caring for parents, siblings and others – http://www.guardian.co.uk/society/2013/mar/16/thousands-children-caregivers-family-data

These young carers may remain hidden due to the fear of being identified, not realizing they are a young carer or through professionals not acknowledging their role and therefore failing to identify and support them.

Key statistics:

- 9% of the 663,963 young carers in England care for 50 hours a week or more (census 2011)
- 80% care for 1-19 hours per week; and 11% for 20 – 49 hours per week
- 22% of young people under 16 in the UK (2.6 million) live with a hazardous drinker (BMC Public Health 2009).
- In the UK, 335,000 children live with a drug dependent parent (BMC Public Health 2009)
- Young carers have significantly lower educational attainment at GCSE level, the equivalent of nine grades lower overall when their peers e.g. the difference between nine Bs and nine Cs (The Children’s Society, Hidden from View, 2012).

Data collection: Use and interpretation of the data from the Joint Strategic Needs Assessment (JSNA) will form the basis to assess health needs and how they can be met using evidence based interventions. Collection of data pertaining to the Healthy Child Programme outcome measurements should be available locally; the pathway aims to build on local evidence to validate the success and quality assurance of the pathway.

Messages from young people to professionals supporting them ‘Time for me to be me’

During the development of this pathway, young carers shared their views and key messages for professionals. Young carers need:

- To know who the school nurse is, what support they can provide and how to contact them
- Recognition that their caring responsibilities can affect their health and wellbeing – including emotional, physical and social health and educational attainment
- Access to services that are non-judgemental, who listen to them, understand and support their needs
- Reassurance that school nurses have the skill, knowledge, training and confidence to support them
- To know that school nurses work in partnership with schools, teachers and other health services to support young carers
- To only have to tell their story once and not to feel pressured into sharing information
- To be able to contact their parent and for time out when things are difficult
- Access to support and respite when they need it most to avoid crisis
- Confidence that they have ‘time to be me’ but know that their caring responsibilities are being met
- To be recognised as an ‘expert’ in care and their contribution valued
- For support to be non-intrusive support and tailored to their needs
- To be treated like other children and young people but remember they have additional needs and need support

Responding to young carers’ messages: school nurses and their teams

In response to young carers messages, school nursing teams need to:

- Become champions for young carers
- Provide a visible, accessible and confidential service and ensure young carers are aware of the service
- Promote partnership working with schools, young carers services and other partners (e.g. Linking in to schools support framework for young carers / making referrals to young carers services)
- Promote the need for schools to implement a School Lead and a policy for young carers and families and use resources, for example Supporting Young Carers: A Resource for Schools and the Healthy Schools e-learning
- Understand young carers’ issues and how best to support them ensuring a range of support is available and easily accessible through both adult and children’s services
- Promote positive physical and emotional wellbeing of young carer
- Ensure young carers are registered with and engaging with GPs / Dentists / opticians
- Understand the hidden emotional impact on young carers and promote the safety of young carers within their caring role
- Support with a crisis and emergency plan to ensure the young carer is well supported if the needs of the person being cared for increase or the young carer is not coping
Supporting the health and wellbeing of young carers

Understanding the role and challenges for young carers is essential. School nursing teams are well placed within schools and wider community settings to support young carers. The school nursing model provides a useful framework on which to plan and structure service delivery and tailored support. The model, as outlined in Getting it Right for Children, Young People and Families below outlines the contribution the school nursing team can provide to ensure young carers are supported through partnership and effective approaches.

All young carers have equal opportunities for their health and wellbeing needs to be identified, assessed and met in a timely manner

**Community**
- Improved health outcomes and a reduction in health inequalities
- Reaching and influencing the wider community, promoting healthy lifestyles and social cohesion
- Improved planning of local services to reduce health inequalities

**Universal Services**
- Provision of high quality healthcare services, delivering the Healthy Child Programme
- Awareness of specific risk factors for young carers eg bullying, stress, isolation, self-harm, depression, physical injury
- Awareness of the risk factors for young people eg alcohol, poor diet, low levels of physical activity, tobacco, early sexual activity
- Alerting other professionals to the needs of specific young carers at all stages of change – key transition within education eg from year to year or school to school, development change
- Identify and support young carers, signposting to a range of services
- Ensure pathways are in place for access to all universal services through a coordinated healthcare response
- Early identification of health and wellbeing needs
- Young people empowered to take responsibility for own health and support to achieve optimum health
- Preventing identified needs escalating
- Assessment of need and acknowledgement of family and community support

**Universal Plus**
- Joint planning and delivery to meet young person’s needs
- Working with partners to provide support and respite

**Universal Partnership Plus**
- Early seamless support and multi-agency team provision to support young people.

Compassion in practice:
Nursing, Midwifery and Care Staff: Our Vision and Strategy, provides a platform to examine the core values of school nurses and their contribution to supporting young carers. The purpose of public health nursing is to maximise the contribution to high quality, compassionate care and to achieve excellent health outcomes. Values and behaviours are at the heart of all we do. Foundation to the implementation of this pathway is underpinned by six fundamental values listed below. Young Carers and professionals vision of these values are as follows:

**Compassion**
- Ensuring whole family approach
- Providing holistic support which reflects need and individual circumstances
- Showing respect and dignity
- Demonstrating strong desire to support identified health and wellbeing issues.
- Building trusting relationships which reflect empathy

**Commitment**
- Achieving optimum health and wellbeing for young carer
- Including young people in service developments and decisions where appropriate
- Engaging with young carers and other health services (dentists, GPs)
- Improving delivery through sharing what works
- Ensuring services meet quality standards
- Ensuring mechanisms are in place to review and evaluate care plans
- Ensuring services meet You’re Welcome Quality Criteria and that young people are involved in service improvement

**Care**
- Delivering the Healthy Child Programme 5-19, identifying and assessing young carers’ needs
- Contributing to the development of a crisis plan for children, young people and family
- Providing timely, tailored support (non-judgemental)
- Promoting positive health and wellbeing

**Competence**
- Acting as an expert in children and young people’s health
- Identifying issues early, providing timely intervention
- Assessing young carers role and its impact
- Raising awareness of local services and referral to appropriate services
- Understanding and sharing best practice
- Empowering young carers, building on their strengths, resilience and competence

**Communication**
- Developing key partnerships and collaborating with:
  - Young carer
  - Peers and friends
  - Parents/family
  - Wider health services including community nursing and GPs
  - School/education
  - Voluntary services
  - Youth Offending Services
  - Adult services
  - Mental Health Services
  - Substance Misuse Services
- Ensuring clear lines of communication
- Ensuring offers of support are actualised and timely
- Ensuring services working in partnership using local assessment tools

**Courage**
- Knowing when to question/challenge
- Embracing innovation and new ways of working
- Acting as advocate and confidant
- Being tenacious, seeking solutions, and maintaining the commitment to improve support
- Working transparently with young carers and their families

**SAFEGUARDING**
Seamless support through local solutions

Providing comprehensive and seamless support requires partnership and collaboration across health, social care and education. This will lead to smooth transitions particularly as young people become carers for the first time or when young carers become young adult carers. Support should not simply end at age 18, achieving this may require joint commissioning that encompasses targeted support, from several agencies. Commissioning Services for Young Carers and Their Families: Careers Trust 2012 School nursing teams have a crucial role in co-ordinating; liaising and signposting to support. This will draw upon their specialist public health influence to provide access to the universal Healthy Child Programme. There are public health challenges that cannot be addressed solely by this partnership pathway, including local variation in service configuration and delivery. Such issues require local collaboration between school nursing and young carers service leads, schools, commissioners and practitioners. This will enable them to adopt partnership pathway principles and adapt them to meet the needs of local children, young people and families taking account of local health priorities, identified health needs and resource deployment. The 6 priority actions from the compassion in practice provides a comprehensive framework to address the identified challenges and offers suggested options for local delivery.

The interface between the school nursing service model and 6Cs:

Maximising health and wellbeing

School nurses and Public Health Nurses supporting young carer’s public health

Proposed Options for delivery:
1. Deliver evidence based care
2. Make every contact count to promote health and wellbeing across all settings and community levels across all care pathways
3. Enhance professionals, carers and agencies awareness and identification of young carers
4. Adequate explanation to service user regarding each professional’s individual roles and responsibilities
5. Support collaborative approaches to support young carers and families (GP and practice teams etc)
6. Ensure children and young people have access to health services to support their needs, e.g. GP and dentist
7. Ensure robust Health Needs Assessments for all young carers
8. Develop systems to assess health needs, for example, annual assessment
9. Ensure family members are receiving the care they need – work with public health nurses and partners to support this
10. Provide targeted support at any school transition for young carers and family

Supporting positive staff experience

School nurses and their teams are motivated and embrace supporting young carers

Proposed Options for delivery:
1. Support for each support service
2. Ensure Professional accountability
3. Be supportive of, and use, new technology
4. Ensure joint multi-agency clinical supervision
5. Ensure productive and efficient healthcare services
6. Ensure transition handovers
7. Explore possibility of a named link nurse
8. Celebrate good practice and achievements and ensuring timely feedback of outcomes and impact of the their engagement
9. Measure contribution to quality
10. Be transparent and share achieved outcomes

Building and strengthening leadership

School nurses leading and coordinating supportive partnerships with other agencies

Proposed Options for delivery:
1. Embrace leadership role, be advocate for young carers
2. Ensure clear undersigning of roles, responsibilities and leadership and articulation of the school nurse offer to young carers
3. Ensure awareness of, and informing, local young carers strategy
4. Develop partnerships with schools and local young carers services
5. Support schools to implement a holistic school approach for young carers and their families
6. Provide a point of contact for young carer to access supportive services
7. Support partnership networking including presentations re each others roles within the community
8. Work in collaboration with named school lead for young carers
9. Develop young carers champions
10. Develop a local Lead Member for Children’s Services champion and identifying a school nursing champion

Ensuring the right staff with right skills, in the right place

School nurses and their teams are equipped to support the needs of young carers

Proposed Options for delivery:
1. Know about and understand young carers issues and how best to support them
2. Work in partnership with schools, young carers services and other partners, understand responsive role and contribution
3. Assess extent of caring as well as impact of caring
4. Access to training and development to ensure school nurses support young carers and families effectively
5. Act as point of contact between existing young carer services and other service providers
6. Ensure networking with local services within localities
7. Ensure regular audits and reviews. Findings shared with staff members
8. Share good practice and new ways of working

Working with young people to provide a positive experience

School nurses and their teams ensure their services are young people friendly

Proposed Options for delivery:
1. Engage young carers and families in service design and delivery and reviews
2. Promote young carers awareness of their own situation and of available services.
3. Monitor and action complaints
4. Involve young carers in service review, ensuring timely feedback of outcomes and the impact of their engagement
5. Promote how school nurses can support young carers in age appropriate ways
6. Provide confidential services to young carers – working on the You’re Welcome (DH, 2011) example
7. Provide a safe environment where young carers can safely self identify
8. Promote innovative and safe ways of engaging and communicating with young carers, e.g.: - Makewaves is a safe social learning environment that makes it easy for schools to deliver fun learning activities through blogs, video and podcasting. Makewaves are working with The Children’s Society on a safe networking page for schools to use with young carers.
         - YCA, is a dedicated website and online support service for children and young people aged 11 and under who help to look after someone in their family with an illness, disability, drug/alcohol addiction or mental health problem
9. Be transparent and share achieved outcomes

Delivering care and measuring impact

Ensuring services are needs led and evaluated

Proposed Options for delivery:
1. Deliver evidence based practice for high quality outcomes to those accessing healthcare services
2. Measure impact of services provided to support quality healthcare delivery
3. Use robust measures to identify caring activities, e.g. The Manual for Measures of Caring Activities and Outcomes for Children and Young People (Joseph, S, Becker, S, Beckler, S, 2012)
4. Provide a named school nurse within each school nursing service to act as liaison with existing young carers groups and other service providers to meet unmet health needs
5. Develop local multi-agency networks for support of young carers within a whole-family working model
6. Use School Monitoring Systems to identify unmet needs, track attendance and then monitor progress of young carers receiving support

Supporting School Nurses role to
1. Identify where caring by children risks becoming excessive and/or inappropriate and putting in place the support that prevents this happening. Even when not excessive needs poignant support
2. Timely assessment and early intervention can reduce the impact on the child and ultimately the need for long term support for them during their life.
What works locally: case studies

The following case studies are drawn from local areas and illustrate how school nurses are supporting young carers.

Emerging good practice – early intervention

Working with secondary schools to support young carers

Since 2004 Winchester and District Young Carers have employed an education worker. This resource ensures Winchester and District Young Carers work in partnership with schools and as a result the majority of schools have engaged with and implemented a young carer’s policy which requires identification for a designated lead within school to be responsible for young carers. The leads receive training from Winchester and District Carers. The designated lead delivers an annual assembly highlighting young carers, this is supported by the service. This approach has generated a huge increase in referrals from education with early intervention and support being delivered to young carers at an earlier stage, avoiding crisis situations. The Schools and Support Coordinator runs staff training, school assemblies, ‘exploration’ groups, drop-in groups and other activities to identify and support young carers in secondary schools across Winchester.

Emerging good practice – Joint commissioning

Health Needs Assessment

Wakefield District Young Carers informs the school nursing service when a child or young person is referred to their service. School Nurses offer an annual health needs assessment to all young carers within schools. The assessments continue on an annual basis so young carers remain supported and assessed following discharge from young carer service. Wakefield District Young Carers work in partnership with School Nurses when specific health needs are identified for example personal hygiene, sexual health. This partnership approach has successfully supported over 250 young carers to date.

Sustainability

The Children’s Society initiated a joint approach in Basingstoke. This initiative involved all stakeholders in the area in the ‘setting up phase’ (both voluntary and statutory) in scoping a young carers’ project and finding funding. Partners included Local council, education representatives from school, youth services, school health, Basingstoke Voluntary Services (BVS) and The Hours Out. This successful project has acquired sustainability, funded through charities via BVS with a growing number of young people accessing clubs out of hours and projects in schools. The project is supported by the young carer manager in schools. This initiative also supports young people to attend the annual Young Carers Festival.

Virtual support for professionals

The Children’s Society, commissioned by Hampshire County Council. Online Virtual Staff Room where school staff, including school nurses, can access resources to support young carers including:
- Information on tracking progress/monitoring pupil’s attendance through SIMS (school monitoring system)
- Hampshire multi-agency guidance in supporting young carers within a whole family-working model

Measuring outcomes:

Oxfordshire

The initiative collected data on the attendance and school attendance of young carers. This analysis formed part of a wider mapping of young carers by the local authority, carried out in order to better understand the needs of young carers in the county of Oxfordshire. This example of practice is part of a suite of practice collated and showcased by Carers Trust at http://professionals.carers.org/young-carers/articles/supporting-young-carers-and-their-families-examples-of-practice,7139,PR.html

The Manual for Measures of Caring Activities and Outcomes for Children and Young People (Joseph, S, Becker, F, Becker, S, 2012) contains a range of tools relevant for assessment and evaluation work with young carers. These tools should not be used in isolation rather they can complement what is already known about a young person and their family including existing information gathered in the course of formal assessment processes, for example, a Common Assessment Framework or a core assessment. http://professionals.carers.org/young-carers/assessments,3063,PP.html


Why do young carers fall to use services?


DH (2009) Healthy Child Programme -from 5-19 years


Whole Family Pathway 2012, Children’s Society Include Programme

http://www.youngcarers.net/resources/whole-family-pathway

School Nurses and Community Nursers Supporting Young Carers, Royal College of Nursing

http://learning.rcnp.org.uk/ims/young-carers

References and Resources:

Dardan & Backer (2004) Young carers in the UK. Carers UK and The Children’s Society

DH (2012) Getting it right for children, young people and families

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Publications about our future Kent Children and Young People’s Plan 2008-2011


Supporting Young Carers and their Families: Examples of Practice (Carers Trust)

A collection of case studies, showcasing the diverse range innovative practice that is taking place across the UK.


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