CHAPTER TWELVE

Working with young people with caring responsibilities (young carers)

Introduction

This chapter focuses on young people with caring responsibilities (young carers). It presents demographics relating to young carers, explains the varying needs and issues that young people with caring responsibilities may face and it offers practical advice. It concludes with a list of contacts and resources that will help you in your work with young carers.

Youth work services are ideally placed to play a vital and positive role in supporting young carers as there are few specialised supports currently

available. It is important that young people with caring responsibilities are involved in community-based youth groups and they feel welcome and supported. Your role as a youth worker may be to support a young person already attending your group who has a caring role. Your role may also involve finding ways to include and support a young carer, especially those who may have difficulty accessing mainstream services due to various constraints.

Young carers sometimes isolate themselves from mainstream youth groups as they feel other young people live very different lives from them. However, a



flexible and safe youth work environment where their experiences are understood can make a huge difference in their lives. Youth workers can help by reaching out to other young carers in the community and offering young people the opportunity to meet and mix with others who share similar experiences. Alternatively young carers may join a youth group to have time out for themselves and leave their responsibilities behind for a while. Understanding their individual needs and what you can do in response is vital.

In the Republic of Ireland under the **Equal Status Act 2000** and the **Equality Act 2004**, it is unlawful to discriminate against a person on the grounds of their family status in the provision of goods and services, education, sports, access to public facilities and accommodation. Family status includes responsibility for a family member who needs care or support on a continuing, regular or frequent basis.

In Northern Ireland under Section 75 of the

Northern Ireland Act 1998 public bodies are required to have due regard to the need to promote equality of opportunity between persons with dependants and persons without.

Terminology

This resource has been developed to be used by youth workers on the island of Ireland. At times it is necessary to make distinctions between our two jurisdictions and we had to choose a terminology to reflect this. We have chosen for the most part to use Northern Ireland (NI) and Republic of Ireland (ROI). At times we also use North and South. Additionally, for clarity, where information is significantly different we have used coloured boxes:

Republic of Ireland and Northern Ireland

Young people with caring responsibilities are unlikely to describe themselves as 'young carers' or even 'carers' so it is important to use language that is understood by the young person. A 'young person with caring responsibilities' is the best terminology to use when speaking to young people. It is also important not to define these young people by the term or role of being a 'young carer' as they are also young people with all the hopes, desires, interests and concerns of other young people but with specific added responsibilities placed on their shoulders.

The term "young carer" is commonly used in literature, research and social care practice to refer to young people with caring responsibilities. 'Young carer' in this case is referring to children and young people up to the age of 18 years. Those aged 18-25 with caring responsibilities are referred to as young adult carers. In line with good practice and in response to the recent My World Survey-National Study on Youth Mental Health it is important to support and include young carers in your youth group, where possible, up to the age of 25. In this chapter we will generally use the term 'young carer' to refer to all carers aged up to 25.



Young carers are described by The Association of Directors or Children's Services (ADCS UK) as: "children and young people under 18 who provide regular or ongoing 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."

Young adult carers are young "people aged 18-24 who provide or intend to provide care, assistance or support to another family member on an unpaid basis. The person receiving care is often a parent but can be a sibling, grandparent, partner, own child or other relative who is disabled, has some chronic illness, mental health problem or other condition (including substance misuse) connected with a need for care, support or supervision". iv

Primary and Secondary carers: A primary carer is a young person who carries out the majority or all of the caring tasks described above. Secondary carers are the other young people in the family group whose lives are affected by the caring requirement. For example, in a family where a parent has a mental ill-health or substance abuse problem, all of the young people in the family may be dealing with issues of depression, volatile, possibly violent behaviour and unpredictable mood swings from the parent.

Tasks and roles young carers may take responsibility for can vary because of:

- the nature of the illness, disability or addiction
- the level and frequency of need for care and support
- the structure of the family as a whole
- the family's level of contact with health and social services
- the ethnic or cultural background of the family

Some young carers may undertake high levels of care, whereas for others it may be frequent low levels of care. Either can impact heavily on a young person depending on their individual characteristics, coping skills and the level/type of support the family and children receive. It is important to note

that not every child who has a parent or sibling that is ill or has a disability is necessarily a young carer.

A young carer may undertake some or all of the following:

- Practical tasks, such as cooking, housework and shopping.
- Physical care, such as lifting, helping a parent on stairs or with physiotherapy.
- Personal and intimate care tasks, such as dressing, washing, helping with toileting needs.
- Managing the family budget, collecting social welfare and prescriptions.
- Administering medication and medication management
- Looking after or "parenting" younger siblings.
- Providing emotional support.
- Interpreting, due to a hearing or speech impairment or because English is not the family's first language.

IPAC (Irish Practice Advisory

Conference) on Young Carers is an open independent forum for workers, service providers, educationalists, researchers and others interested in engaging with young carers and young adult carers (see contact details at the end of this chapter).



Demographics

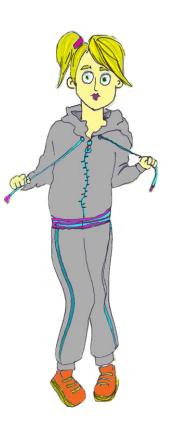
In **Republic of Ireland** (ROI) the 2011 Census produced these figures^{vi}:

- 5,761carers are aged 20-24
- 4,244 carers are aged 15-19
- 4,228 carers are aged under 15
- 1,838 carers of those aged under 15 are under 10 years of age

In **Northern Ireland** the 2011 Census produced these figures^{vii}:

- 3.4% of young people aged 5-19 (3% of males,
 3.8% of females) have a caring responsibility. This equals 11,924 young people
- 6,465 carers are aged 16-19
- 5,459 carers are aged under 16 years old
- The average age of a Young Carer is 14 (However, the experience of Crossroads Young Carers project is that most young carers are identified to them around the age of 12)
- 1,324 young people provide care in excess of 50 hours per week

The figures identified in both censuses are likely to under-represent the numbers of young people providing care as they rely on families identifying a young person as having a caring role. For example, Saul Becker's work for a BBC national survey concluded that 8% of all second level students were going home to a care-giving role. In 2010 the Young Life and Times Survey asked 786 16 year olds across Northern Ireland about their caring responsibilities. This survey identified that to the control of the control



• 1 in 10 (10%) had a caring role – most frequently for their grandmother or their mother.

Very often families view caring as an 'extension of family or personal relations' rather than as a distinct type of 'care giving'. Research has shown that in a situation where a young person may be caring for someone who has mental ill health or who misuses drugs or alcohol they are less likely to be identified as having caring responsibility within the family.

Findings from a 2009 NUIG study of young carers in Ireland and similar international studies have identified that:^{xi}

- The average age of young carers is 12 years old and getting younger
- The gender ratio is female 56% to male 44%
- 56% live with one-parent families
- Those caring exclusively for a parent tend to live in one-parent families.xii
- 82% provide emotional support
- 10-14 hours per week was the average length of time spent caring
- 10% care for more than one person
- 25% care for a sibling with a disability young people caring for a sibling are often overlooked.
- 63% are in a caring role for three years or more
- Young carers are more likely to be NEETs (not in education, training or employment) than their peers^{xiii}
- Young carers living with a parent with mental ill health are two and a half times more likely to develop a mental



health issue than their peersxiv

 17% of respondents who said that their family was not well off had caring roles compared with 5% of respondents from very well off families^{xv}.

Recognition and identification

Recognition and identification of children and young people as 'young carers' is only in a developmental stage in relation to awareness, practice, policy development, and research in **the Republic of Ireland**. However, The National Carers Strategy (ROI), 2012 has named young carers as a particular area of concern. "Young carers have similar needs to carers of any age e.g. the need for a break and support for the person for whom they are caring. However, they may have additional needs, which include support in

education to help them to achieve their full potential...both the number of children and young people with caring responsibilities, and the extent of the care provided by some, as evidenced by Census 2011, is a cause for concern".xvi

In response to their concerns The National Carers Strategy 2012 aims to:

- Raise awareness and understanding among education providers
- Encourage statutory agencies to review how they respond to young carers
- Identify support services for young carers and create mechanisms to link young carers to service providers
- Research and analyse the situation for young carers

In January 2006, the Department for Health, Social Services

and Public Safety in **Northern Ireland** (DHSSPSNI) published its strategy for carers, 'Caring for Carers: recognising, valuing and supporting the caring role'. This strategy acknowledges the importance of providing young carers with 'recognition, understanding and support' and 'to afford him or her the opportunity to contribute, where appropriate, to the caring role in a way that does not compromise his or her own developmental needs' Several recommendations are made Striii:

- Carers' assessments under Health Boards and Trusts should ensure that young carers are identified and that services are put in place to ensure their education and development do not suffer.
- The information needs of young carers should be a specific consideration when looking at ways of improving information available on the internet about services to carers.
- The Department of Education should remind schools and teachers of their role in supporting young carers. The strategy cites The Education and Libraries (NI) Order 2003 under which teachers have a responsibility to safeguard and promote the welfare of all their pupils.



Needs and issues for young carers

Various studies have clearly demonstrated the specific needs and issues affecting young carers. One of the key concerns is the 'hidden' nature of young people in caring roles.

Why are young carers hidden?

Many young carers receive little or no help. It is difficult to believe that their issues go unnoticed and unidentified but there are several reasons for this: xix

- Adult support services often fail to recognise their client as having a
 parental role and children's services often intervene too late when a
 young person's caring role has already affected their well-being, or in
 some cases, when they are at crisis point.
- Adult's and children's services have historically struggled to work together effectively and have often failed to look at the needs of the whole family.
- Families are often wary of intervention by services and they conceal illness, particularly mental illhealth and substance misuse.
- Some parents don't recognise their own child's caring role.
- Young carers may feel they will be bullied if other young people find out about their caring role and family circumstances

Young carers' support needs

A variety of studies show that young carers may present with some or all of the following needs:^{xx}



- 1. Information about services that can help them and the person they care for
- 2. Help with school work and timetabling from teachers
- 3. Help in the home
- 4. Someone to talk to
- 5. Advice from adults with useful knowledge and skills
- 6. Time to be with friends and to take part in sport and other activities or interests

Young carer's worries and problems

In one study four out of ten young carers said that they worried about the person they looked after when they were away from them^{xxi}. The Edinburgh Young Carer's project have identified the following concerns:^{xxii}

Worries expressed by young carers	Problems expressed by young carers
 The health of the person being cared for (81%) Their own health (67%) Who will look after them (if their parent is hospitalised for example) (53%) School work (68%) Money (48%) Bullying (36%) Having no friends (35%) 	 Sleeping Problems (60%) Thoughts about suicide (36%) Self Harm (34%) Eating Problems (30%) Problems with police due to parental drinking (25%)

Young carers stress the need to be listened to, to be taken seriously and included in any care planning and decisions being made both for themselves and the person they care for. Many speak about the anxiety and frustration they feel from being ignored^{xxiii}.

Effects of being a young carer

Saul Becker of The Young Carer Research Group at Nottingham University has been at the forefront of research and development in this area for over two decades. Saul has identified five areas where the caring responsibilities may have an impact and adverse effect on the lives of young people. **XiV

1. **Education**: failure to keep up with coursework and homework, persistent lateness and absenteeism, poor performance and its effect on future educational prospects. The corollary of this is that for many of these young people, school is their one refuge as they don't have to provide care there. Despite their workload, some may excel academically in school. However, many do not look forward to holidays and weekends as it may increase their workload.



- 2. **Health**: young people may provide physical care beyond their current abilities and training. Issues around poor nutrition and food poverty can also arise. Incorrect and inappropriate manual handling and bed movements may damage their backs in the long term.
- 3. **Social:** as these young people get older, many come to realise that they do not live 'ordinary' lives and some may be dealing with issues around mental illness and substance dependency. They may be singled out as 'different' by their peers with the potential for social isolation and bullying. The lack of time and opportunity for social interaction is commonly spoken of by young carers.

- 4. **Emotional:** young people may experience feelings of being trapped leading to anger, frustration, guilt and confusion. Resentment towards the person cared for may also arise.
- 5. **Financial:** many of these young people live in low income families, often as part of a one-parent family leading to lower disposable incomes and limited access to outside activities; this further increases risk of isolation from their peers.

A recent Northern Ireland study shows that young people living long term with an adult with care needs have a higher risk of poverty^{xxv}. In addition, those who live with adults that have a longstanding illness or mental distress may show poorer cognitive, educational, behavioural and general health assessments^{xxvi}. This must be seen in the context that intervention that provides recognition, understanding and support can make a difference. It is important to note that in a 2011 survey seven out of ten young carers said that they enjoyed caring^{xxvii}.

Education

Rule of thumb: When it comes to their caring role versus school, caring will almost always win out.

In school the young carer is treated as a student, appropriate to their age, so it is often a place of sanctuary. Nonetheless, young carers are particularly vulnerable in school if they go un-identified and un-supported. This can lead to school becoming a place of conflict and stress. This poses a risk both in the 'here and now' as well as their future life prospects. The full-time nature of education and training courses can be prohibitive to young carers, especially primary carers. A young carer is more likely to be Not in Education Employment or Training (NEET) than their peers.

It is also important to consider the educational needs of young carers in the context of legislation. For example, in the **Republic of Ireland**, the Education (Welfare) Act 2000 aims to promote and improve school attendance rates for

children at primary and post-primary level education. In implementing this Act authorities may come into contact with young carers who are missing school.

See Chapter 10A and 10B of the Toolkit for more information on working with early school leavers and those not in education, training or employment (NEET). Also see the useful contacts section at the end of this chapter.

Health

A young carer's personal, emotional and physical health can all be affected by their family situation and their caring role. Their caring role may have both positive and negative effects and greatly depends on the child/young person's individual coping skills. Young carers often learn practical and caring skills at an early age. However, it is important to remember that they are young people with the same emotional needs as others their age.

These additional stresses may be present: xxviii

- Stress, tiredness and mental ill-health are common for young carers.
- Young carer's physical health is often severely affected by: caring through the night; repeatedly lifting a heavy adult; poor diet; and lack of sleep.
- Many experience traumatic life changes such as bereavement, family break-up, loss of income and housing, or seeing the effects of an illness or addiction on their loved one.
- Inappropriate caring roles during childhood can impact later in life, affecting a young carer during the transition to adulthood or in adulthood itself. This can include the long-term impacts on physical or emotional health, further education and/or career opportunities.



Youth services can help the young carer by linking them with the relevant support from Health and Social Care services in both the statutory and community/voluntary sectors. Many young people know what help they need, but they may not know the mechanics of how to access and get this help for themselves and their families. Some will find it difficult to articulate the help that they need as they may feel that the person they are speaking to will not understand them or won't take them seriously due to their age. In valuing the voice of young people and encouraging them to speak up youth workers are ideally placed to support these young people in developing the confidence to ask for and access help. This is particularly important for times when they are in or approaching an emergency or crisis situation in relation to the person they are caring for.

Social needs

The Young Life and Times Survey showed that lack of free time was an issue for 85% of young people aged 16 with caring responsibilites^{xxix}.

Young carers have identified their social needs as: xxx

- Having someone to speak to (100%)
- Meeting other young carers (88%)
- Getting out and taking part in groups and activities with other young carers (86%)
- Breaks from caring (84%)

Many young carers are immensely proud and protective of their work and feel it is rewarding in many ways; but it can also be tiring, monotonous and stressful. Anyone who spends a lot of time with people who need care will realise the value of "me time" and for young carers this is especially important.

Youth services can be a valuable space for giving the young carer personal time away from the responsibility of caring. Youth services have a lot to offer young carers especially in the areas of building confidence, offering non-formal education opportunities, personal development and being a place of welcome where they are valued and supported.

Isolation can have devastating effects on young people and confidence levels can drop very quickly. This is a common problem experienced by young carers as it can be difficult to maintain or form new friendships due to a lack of opportunities to socialise. They are also likely to have reduced access to the necessary funds needed to socialize or even attend youth groups as many

young carers live on a small budget that does not allow for extras. If a youth service recognises young carer's needs, it can play a vital role in supporting them to engage with youth groups/programmes. Youth workers need to make young carers aware of what opportunities they offer and how they can support them to attend the youth group by, for example, covering transport costs or facilitating travel arrangements etc.



Emotional needs

Groups specifically set up for young carers can be very constructive for the young people involved. In addition to the positive value of youth work, it allows them to identify themselves as young carers. It also allows them to recognise that they are not alone; that there are other young people with the same needs and issues that they have. But it must be recognised that many young carers will feel anxious and apprehensive about joining a group initially.

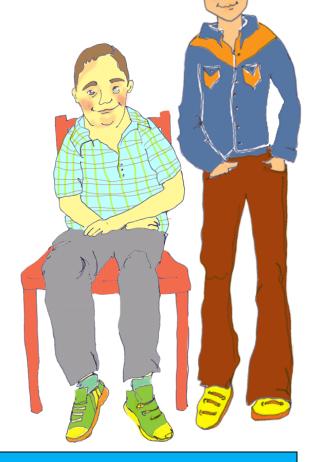
Alternatively you may already be working with a young person that you have not previously recognised as a carer. Some of the signs that someone could be a carer include: xxxi

- Anxiety or concern over an ill or disabled relative. A need to be in constant touch with home.
- Often tired, withdrawn, or stressed
- Isolated or a victim of bullying either because of a situation in the family or because they lack the social skills when they are around their peers. In contrast they may be confident with adults. They may also adopt a caring role when they are with younger children.
- Behavioural problems there is often a big difference between the young person who seems 'mature beyond their years' in their home environment, where they are very protective of a relative and the young person who takes out their pent-up frustration or stress at
- Often late or missed days or weeks off from school or youth group for no apparent reason – secretive about their home life

school or in a youth group

 Suffering from back pain due to lifting heavy loads.

For more information on supporting a young person with emotional issues see chapter 7 in this Toolkit on 'Working with young people with mental health issues'



Involving families

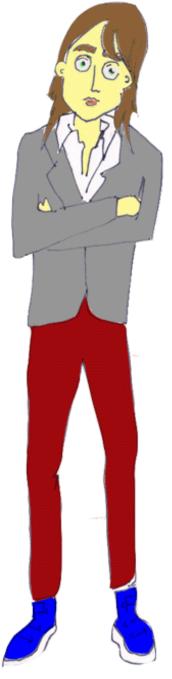
Family support can have a hugely positive influence on the lives of young carers by offering practical and emotional support. Youth workers can support young carers in communicating with their families and other adults in their lives. Home visits will help youth workers to build relationships with parents/guardians and gives a better understanding of the issues faced by the young person in their home life.

Youth workers could also support the young person to develop an emergency plan so they are fully aware what will happen to them in an emergency; where they will stay, how they will maintain on-going contact with their parent(s) etc. Download an emergency plan template here:

www.youth.ie/sites/youth.ie/files/YoungCarersEmerge ncyPlanTemplate.pdf

Financial needs

There are no financial supports paid directly to young carers in the **Republic of Ireland**. However, young adult carers can apply for and may qualify for the Carers Allowance payment and Respite Care Grants if they satisfy the criteria. Adult carers who leave work to care for someone fulltime may qualify for a Carer's Benefit^{xxxii}. The **Carer's Allowance** is a means-tested payment and the recipient must be the full-time carer and be 18 years or older. They may not be in paid employment or education for more than 15 hours per week. The **Respite Care Grant** may be given to



recipients who are full-time carers. Those aged over 16 can apply for this grant.

In **Northern Ireland**, young carers aged 16 or over can apply for and may qualify for **Carer's Allowance** if they spend 35 hours or more a week caring for someone who is ill or who has a disability. However, they cannot claim this allowance if they are in full-time education, on holiday from education or if they earn more than £100 a week once they have paid for their expenses^{xxxiii}.

Transport may be the biggest barrier to young carers attending your service. Some cannot afford the transport and for other families the logistics of dropping off and picking up children is not possible due to their circumstances. Young carers in rural areas have the added barrier of access to public transport. These issues need should be dealt with in a supportive and sensitive way. You may need to find a way to cover transport costs.

Vulnerable times for young carers

Transitional phases present increased risks to young carers in relation to their health, education, well-being and life chances. Transitions refers to the phases of life that all children progress through; childhood to adolescence and on to young adults.



Developing inclusive practice for young carers

Supporting young carers in a youth work setting

Whether you are working with one or more carers in a mainstream group or whether you decide to set up a specialised service there are resources and expertise available to support you. The Carers Association Young Carers Project has developed and adapted tools and resources to help any youth organisation identify and deliver a service to young carers. They have also established a uniform start point in language, tools and practice (see www.youngcarers.ie). In addition they have evaluation tools that allow you to measure the work with young carers that you undertake. (A list of downloadable tools and resources is available at the end of the chapter).



Crosscare and the City of Dublin Education and Training Board (CDETB) have developed a training workshop for youth workers on working with young carers. The development of the IPAC Forum (Irish Practice Advisory Conference) to share practice also provides a vehicle to support further development of projects and services around Ireland.

In **Northern Ireland** Crossroads Caring for Carers (NI) Ltd Young Carers Project can provide awareness training to youth leaders about young carers. Contact them about availability (see contact section at the end of this chapter)

Starting out

The starting point in supporting young carers is to raise awareness through staff and volunteer development days on the issues for young people with caring responsibilities.

Practical tips

Some practical ways that you will be able to support young carers include:

- Create a safe environment where a young carer can relax and take their mind off home
- Help young carers make decisions that are practical for them
- Support them to recognise and manage stress
- Encourage the young person to talk to someone about how they are feeling. Look out for signs of depression and encourage the young person to talk to their GP or a counsellor
- Offer information sessions on entitlements and back to education or employment opportunities
- Help young carers to look at what they want from life and how they can still get that if they decide to stay in a caring role
- Explore caring skills and how they will manage stressful situations, tiredness and responsibility
- Home visits are recommended where possible, especially for young carers who live in rural areas and find it difficult to access transport to your youth service.
- Create good links to other services which young carers need to access.
 Often young carers need a supportive person to go with them the first time to visit a new service

Reaching young carers

Due to the nature of their caring responsibilities young carers might not be reached by your normal advertising and promotions. You will need to go to the

places where young people are found and speak directly to them.

Undoubtedly, the place where you will have access to most young people will be in schools, and that will probably be where most of your initial work will be focused. In addition, you should promote your service/initiative to other agencies that work with young people such as other local youth organisations, faith based groups and Family Support Services within the social services.



Working within a community structure

To ensure that you are taking a community based approach you will need to make links with the various health and social care professionals, and other youth workers that come into regular contact with children and young people in your area. Many communities now have steering groups on youth mental health. Youth Diversion programmes and initiatives led by area drug task forces in your community may be useful contacts. Also make yourself aware of any relevant plans, such as those from the Local Authority, and community based health organisations that may affect young carers in the community. Once you have made these links you should have an idea of how your service can best be shaped to meet the needs of the young carers you have identified.

Other relevant organisations working with children and young people include: Educational bodies (ETB/VEC, Youthreach, Library Boards etc.), Children's

services (Barnardos, Family Support Agencies, Youthreach) and condition specific organisations often already have links with young carers. In **ROI** these include organisations such as Irish Wheelchair Association (IWA), MS Ireland, Arthritis Ireland, Irish Motor Neurone Disease Association (IMNDA). In **NI** those such as Arthritis Care, MS Society, etc. **xxxiv**

Working with schools

When working with schools, be aware that Principals and the Boards of Management in each school have autonomy over their school and youth workers can only suggest involvement in a young carers programme, not demand it.

A few tips and ideas:

- On your initial visit to a school, have copies of any information available and be clear about the message you wish to give to pupils and teachers.
- Suggest that youth workers do a short presentation within the school
 to the teaching staff. Your presentation to staff should include what
 you can offer the school. It should last no more than 15-20 minutes. If
 necessary you can look for a longer slot in regularly scheduled staff
 meetings. Ask to do a whole school presentation.
- The follow up presentation to the whole school, ideally during an assembly will give students an explanation of what the term 'young carer' means and what your service can provide for them. Highlighting the issue directly to young people will show them that 'help' is out there and encourage self-referrals.
- Seek a nominated School Leader who will work in partnership with your service.

- Have a referral system in place this questionnaire would be useful www.youth.ie/sites/youth.ie/files/ClassTalkQuestionaire.pdf
- Take advantage of lunch times and ask permission to set up lunchtime drop-ins in common areas such as libraries or parent's rooms. Think about setting up young carers' lunch clubs/homework clubs after school.
- Aim to become part of the school's curriculum, which means you will have automatic access to each succeeding year's classes. Suggest presentations with individual classes to allow for more interaction between youth workers and pupils
- Think about linking with students to organise a Youth Health Fair in the school**xxv

The Carers Association have produced a Toolkit for schools titled "Supporting young people with caring responsibilities in Ireland-School Resource Toolkit". This toolkit supplies resources, including policy templates, forms, posters, leaflets and lesson plans and is available for download as a complete manual or in sections on the www.youngcarers.ie website. Also see the tools and resources links at the end of this chapter.

Supporting young people returning to school

As part of your work you may also be supporting a young carer to return to education. The relationship you develop with schools will help you to support a young carer returning to school. Any opportunity that exists for the young carer to return to education offers a gateway to



greater autonomy and the potential for greater financial independence. Youth workers can help advocate for a reduced or flexible school programme, provision of emotional support and signposting to Third Level Access programmes. Supporting young carers can also present an opportunity for youth services to develop their working relationship with local schools.

Youth workers should encourage young carers to talk to their school principal about their school attendance. Encourage them to request information on other options they might need such as home tuition, grants and financial assistance while in school or going forward to third level, remembering that the young carer's parent may not be able to support them in the way other young people receive parental support around

Remember some carers are hidden

career guidance, grant applications etc.

Some young carers will not identify themselves for fear of being mocked, ridiculed or bullied. They may be afraid of social services splitting up the family home; afraid that the person cared for will not want anyone to know of their needs – particularly in cases of substance abuse or mental illness. Ensure young people know that your service is available to them on a private and confidential basis taking into account good child protection practice. **XXXVI* Make certain that information on how to contact your service in confidence can be accessed easily. Remember to involve a 'link person' if you feel comfortable that the young people will relate to them.

Advice from young carers

A group of young carers in Merseyside have asserted the need for those who come into contact with them and their families to: xxxvii

- "Introduce yourself. Tell us what your job is and who you are."
- "Give us as much information as you can."
- "Tell us what is wrong with our mum or dad."
- "Tell us what is going to happen next."
- "Talk to us and listen to us. Remember it is not hard to speak to us. We are not aliens."
- "Ask us what we know and what we think. We live with our mum or dad.
 We know how they have been behaving."
- "Tell us it is not our fault. We can feel really guilty if our mum or dad is ill. We need to know we are not to blame."
- "Please don't ignore us. Remember we are part of the family and we live here too!"
- "Keep on talking to us and keeping us informed. We need to know what is happening."
- "Tell us if there is anyone we can talk to. Maybe it could be you."

Working with partners

Collaborative working with one or more partners may be the most effective way to provide support to young carers in your community. You should check the following before embarking into partnership:

- 1. Are there shared vision/ values and potential for achieving objectives?
- 2. Is there clarity of roles and accountability for each partner?
- 3. Have the boundaries and limitations of all partners has been established?
- 4. Is there an effective communication system in place?
- 5. Is there open access to each other's information and resources?
- 6. Is there agreement on:

- i. how evaluations will be done;
- ii. confidentiality; and
- iii. how, and if information will be shared with outside agencies

Child protection considerations

Raising awareness about young carers in the context of your child protection training would be considered good practice.

Useful tools for your work

To help you understand a young person's caring role, and the impact – both positive and negative - on their wellbeing you can use the templates on the following pages. The first is a self identification tool and this is followed with a questionnaire to help you identify the needs of young carers. Other tools can be found online – see links at the end of the chapter in the Resources section.

Self-identification tool to identify the extent of a young person's caring role xxxviii

Self-identification/survey tool

Am I a Young Carer? - What does that mean?

A Young Carer is a young person whose life is affected in a significant way by the need to provide care for a family or household member who has an illness, disability, addiction or other care requirement. Think about the things you've had to do over the last month or so and ask yourself?.....

If you can answer "Yes" to any of the following questions then you may be a Young Carer.

Do you: Yes No Care for a grandparent, parent, brother, sister or other family member? YesNo Help someone to dress or undress because they cannot do it alone? Yes No Help someone to walk, get up the stairs, or to get in and out of bed? Yes No Help someone to use the toilet or have a bath or take a shower? Yes No Help someone to eat and drink? Yes No Give medicines to someone, give injections or change dressings? Yes No Prepare special food or diet because of the medical needs of the person? Yes No Do housework because an adult is not able to do it? Yes No Provide emotional support for someone who is unwell? Yes No Look after siblings because an adult is unwell? Yes No Take on a supportive role for the main Carer? Yes No

Needs assessment tool to identify what supports are needed

I am a young	carer, I think supports like these would help me:
	uth Services could help me by giving me access to
	One to one personal support
	Buddy system, Big brother Big sister, Peer mentoring
	Group support and opportunity do some fun stuff
	A chance to meet other young people in a similar situation
	An ID card/or other method I can use to let school staff know I need to get some time-out, to phone home, or to let someone know I need to talk
	Something else? Tell us here:
	pe of support would help me boxes as you wish)
	Feel more confident
	Make new friends
	Feel happier and less isolated
	Be less anxious or worried
	Have someone to talk to
	Become involved with the local Young Carers Service
	Something else? Tell us here:

Checklist 12 - How accessible is your organisation to young carers?

This checklist can help you to identify how you can improve your service for young carers.

Public image

How we present our service to our community

 We advertise our service and programmes in places where young carers are likely to see them e.g. doctors surgeries and health clinics, schools, community welfare offices, Family Support Agencies 	YES	PARTLY	NO
 Our service promotes a positive image of caring, through literature, posters etc. 	YES	PARTLY	NO
 Activities/events which include young carers/families are provided and promoted 	YES	PARTLY	NO
 Our service is represented on local boards/committees relevant to young carers 	YES	PARTLY	NO
 Our service links closely with carers and family members of young carers 	YES	PARTLY	NO
 Our service is listed in local publications as offering services to young carers 	YES	PARTLY	NO

Programme planning and delivery

Our programmes are designed and delivered to include the diverse needs and identities of young carers

 Our service has up to date figures on numbers of young carers in our target area 	YES	PARTLY	NO
 Young carers are involved in programme planning 	YES	PARTLY	NO
 Our programme does regular reviews and invites input from young carers with regard to changes 	YES	PARTLY	NO
Our service provides transport	YES	PARTLY	NO
 Our programmes run at times suitable for young carers 	YES	PARTLY	NO

Professional development

Our staff and volunteers are trained and supported to deliver an inclusive youth service

 Our service links with other organisations working with young carers 	YES	PARTLY	NO
 Staff and volunteers have an awareness of the issues faced by young carers 	YES	PARTLY	NO

•	Our service has good links with local schools, school completion programmes and other educational providers	YES	PARTLY	NO
•	Our service refers young carers on to more specific services depending on needs	YES	PARTLY	NO

Participation

We make sure we include the voices of young people at all levels of our youth service

 Young carers are consulted about service provision (including those who do not access our service) 	YES	PARTLY	NO
 Our service includes young carers in the decision making process e.g. inclusion on committees and boards of management 	YES	PARTLY	NO
 Meetings are timed to allow for care arrangements (e.g. ensuring substitute care) 	YES	PARTLY	NO
Our service offers an outreach service	YES	PARTLY	NO
 Our service actively encourages participation of young carers 	YES	PARTLY	NO

Policies and procedures

We have a written commitment to deliver an equal and inclusive service

 We have an equal opportunity statement referring to young carers

YES

PARTLY

NO

Resources

Useful tools you can use in a youth work setting

Policy templates, resources, tools, forms and posters are available for download from our **Republic of Ireland** young carer's website www.youngcarers.ie and on www.youngcarers.net for those in **Northern** Ireland. Resources and tools can also be downloaded here:

- Class talk questionnaire www.youth.ie/sites/youth.ie/files/ClassTalkQuestionaire.pdf
- Am I a Young Carer Survey –
 www.youth.ie/sites/youth.ie/files/AmlaYoungCarerSurvey.pdf
- Young Carers Emergency plan template –
 www.youth.ie/sites/youth.ie/files/YoungCarersEmergencyPlanTemplate

 .pdf
- Evaluation tool www.youth.ie/sites/youth.ie/files/YoungCarersSupportEvaluation.pdf
- Measuring impact tool www.youth.ie/sites/youth.ie/files/ManualforMeasuringCaringActivities
 &Outcomes.pdf
- Crossroads Survival Guide for Young Carers - www.youth.ie/sites/youth.ie/files/CrossroadsSurvivalGuideforyoungcar ers.pdf

International research and practice provide excellent pathways to establish support for young carers in Ireland. Over two decades of research from a team at the University of Nottingham led by Dr. Saul Becker has been at the forefront of these efforts. Additionally The Princes Royal Trust for Carers (Carers Trust), The Children's Society and many individual young carer projects across the UK and beyond, have produced practical guides and tools including numerous multi-media, video and initiatives. For example: www.youngcarers.net, and the Usual Suspects-Young Carers. An annual young carer festivals for England-Wales and a similar event in Scotland further add to the continuum of their support

<u>www.youtube.com/watch?v=Z66INI2ha94</u>) and <u>www.erycandtrayc.com</u>. www.youtube.com/watch?v=rlWv3NHLZuo.

Youth Advisory Panels: Many young carer groups in the UK actively encourage the development of skills and abilities of their young carers in evaluation and planning activities through Youth Advisory Panels (YAPs). See www.plan-uk.org/resources/documents/42604/

Information Pack for Youth Services <u>www.youngcarers.ie/infoforyouthservices</u>

Leaflets that explain what a young carer is and how young carers can access support are available from the Young Carers Project. A blank space at the back of the leaflet can be used to provide your own group's contact details. The Young Carers Project can help groups to obtain and use all the referral forms and support materials that you might need.

www.youngcarers.ie/researchersteachers howyoucanhelp PostersandLeaflets

Researchers Library: An array of national and international research material around young carerswww.youngcarers.ie/researchersteachers library

www.youtube.com/YoungCarersIreland This is a video wall channel that we add video to regularly. This is an opportunity for you to make videos focussing on young carers in Ireland and post them here. Although the accents on the current videos are not Irish, young people are the same the world over.

An e-learning module from New South Wales Carers on young carers that can be completed online in about 45 minutes. It is a simple user-friendly course that covers the main issues. It is a very good introduction and is easy to follow. You register and start right away. It is good for anyone who wants to get a good understanding of the issues and you can get a Certificate at the end. www.youngcarers.nsw.gov.au/pages/elearning.php

A Welsh **video called Giving Confidence** gives youth workers a very good idea of where they fit into the whole support area for young carers. It is available on http://youngcarerstoolkit.co.uk/engaging/young-carers-groups

COPMI (**Children of Parents with Mental Illness**) is also based in Australia. This website is a treasure trove of information. The link above to the eLearning course will also provide you with a good insight into the issues around supporting families where someone has a mental illness.

www.copmi.net.au/professionals/professional-tools/kfc.html

Useful contacts

Support & Referral Agencies (ROI)

The Carers Association

Phone/Careline: 1800 - 24 07 24

Web: www.youngcarers.ie

The Carer's Association offers lots of information and advice for young carers and young adult carers in the

Republic of Ireland

Care Alliance Ireland

Phone: 01-874 7776

Email: info@carealliance.ie

Web: www.carealliance.ie

Care Alliance works with organisations to provide information and support to Family Carers. They also commission relevant research that supports focussed and quality interventions in the lives of Family Carers.

IPAC (Irish Practice Advisory Conference)

Email: ipacyoungcarers@gmail.com

Phone: 01-836 0011 Rosemary Daynes

(Crosscare)

086 022 9607 Gary Rutherford

(The Carers Association)

Open independent forum for those interested in engaging with young carers and young adult carers to share and develop practice

Crosscare

Carer Support: 01 - 8360011 ext. 113

Teenline Ireland: 1800 - 833 634 (7pm-

10pm)

Crosscare is the social care agency that delivers direct services within the greater Dublin area. It uses innovative approaches to meet new and emerging needs.

St Patricks Hospital Phone/Information Line: 01 - 249 3333 Web: www.stpatrickshosp.ie/support-information-service Email: info@stpatsmail.com	The Support & Information Service is a telephone and email service staffed by experienced mental health nurses 9-5 Monday to Friday with an answering and call-back facility outside hours. You can contact the service by phone or by emailing your query.
The Samaritans Phone: 1850-60 9090 Text: 087-260 9090 Web: www.samaritans.org	Samaritans Ireland provide non- judgemental, anonymous 24 hour support for anyone in distress
Childline Phone: 1800-666666 Web: www.childline.ie	Childline is there 24 hours a day to help any young person who needs someone to talk to
Reachout Web: http://ie.reachout.com	ReachOut.com is an online service dedicated to taking the mystery out of mental health
Jigsaw Web: www.jigsaw.ie	Jigsaw offer a network of community supports for young people
Family Resource Centres Phone: 01 - 611 4100 Web: www.fsa.ie	Offer support, information and special services for those in need of extra family support. For details of your nearest Family Resource Centre and for a copy of the Support for Families Directory contact the Family Support Agency

Support & Referral Agencies (NI)

Crossroads Young Carers Project (NI) 7 Regent Street Newtownards BT23 4AB Phone: 028 - 91814363 Email: ycarer@croadscare.co.uk	Crossroads Young carers project believe that children and young people acting in a caring capacity within their families should enjoy the same life chances as all children. They provide services that include befriending, practical help, respite care to enable education
Carers Trust Northern Ireland Web: www.carers.org/northern- ireland	Carers Trust is a support service for family carers in Northern Ireland. It has two network partners – Belfast Carers Centre and Newry & Mourne Carers.
NI Direct Government Services Web: www.nidirect.gov.uk	One stop shop website for government services such as benefits and financial support, social housing, employment, education etc.
The young person's GP	The young carer's GP will be a key contact

Support sites for young carers (ROI and NI)

The Samaritans

Phone: 1850-60 9090

Text: 087-260 9090

Web: www.samaritans.org

Samaritans Ireland provide nonjudgemental, anonymous 24 hour support for anyone in distress

Childline Phone: 1800-666666 Web: www.childline.ie	Childline is there 24 hours a day to help any young person who needs someone to talk to
Reachout Web: http://ie.reachout.com	ReachOut.com is an online service dedicated to taking the mystery out of mental health
Jigsaw Web: www.jigsaw.ie	Jigsaw offer a network of community supports for young people
Family Resource Agency Phone: 01 - 611 4100 Web: www.fsa.ie	Family Resource Centres offer support, information and special services for those in need of extra family support. For details of your nearest Family Resource contact the Family Support Agency
Riprap Web: www.riprap.org.uk/	Support site for young people when their parent has Cancer
COAP Web: www.coap.org.uk/	An online community for young people living with a family member's addiction to drugs, alcohol or behaviour such as gambling
The Samaritans Phone: 0845 790 9090 Web: www.samaritans.org	Samaritans Northern Ireland provide non-judgemental, anonymous 24 hour support for anyone in distress
NSPCC (National Society for the Prevention of Cruelty to Children) Phone: 0808 800 5000	

Northern Ireland directory of

counsellors

Web: www.counselling-

directory.org.uk

Stress Management Society

Phone: 0844 357 8629

NIAMH Mental health website that gives advice

Web: www.niamh.co.uk on how to keep a healthy mind

Cruse Bereavement

Phone: 0844 477 9400

Education (ROI and NI)

The National Association of Adult **Aontas**

Education offer an internet based Web:

information referral service. www.aontas.com/inforeferrals.html

Local Employment Service (LES)

Phone: 01 - 607 050

office.

Web: www.fas.ie www.solas.ie

Youth Information Centres (YICs)

information. Check out the website to www.youthinformation.ie/

locate your nearest YIC

Contact the employment services officer in your nearest Solas/FAS

Can provide young carers with

DELNI (NI) Web:www.delni.gov.uk	DELNI offers information on what educational options are available once the GCSE's are completed. They also explain about funding options.
UCAS Web:www.ucas.ac.uk	UCAS offers a list of universities in the UK and what courses are on offer and how to apply.

Legal and advice services (ROI and NI)

AIM family services Phone: 01 - 6708363 Email: aimfamilyservices@eircom.net Web: www.aimfamilyservices.ie	AIM is a voluntary organisation which offers non-directive counselling, legal information, and a family mediation service to people experiencing marital, relationship and family problems
Citizens Information Board (ROI) Web: www.citizensinformation.ie Phone: 0761 07 4000	The website and your local Citizen's Information Centre provides information on public services and entitlements in Ireland
Citizens Advice Bureau (NI) Phone: 028 - 90261970 Web: www.adviceguide.org.uk/nireland	This is the largest advice charity in NI and helps people resolve their debt, gives information and advice about benefits, housing, legal, discrimination, employment, immigration, consumer and other

This chapter was compiled by Gary Rutherford (Young Carers Outreach & Development Coordinator), Tanya Mc Entagart, City of Dublin Education and Training Board (CDETB) and Allison Campbell (Crossroads Young Carers Project (NI)) for 'Access All Areas – a Diversity Toolkit for the Youth Work Sector' published by NYCI and Youthnet. We also acknowledge considerable input from The Carers Trust Scotland.

problems. There are offices

throughout Northern Ireland

NICCY (Northern Ireland Commissioner NICCY is set up to make sure for Children and Young People) Government keeps their professioner Solvernment keeps the Solvernment keep

Phone: 028 - 90311616

Web: www.niccy.org

Government keeps their promises to young people of Northern Ireland.
They provide legal support and advice and work towards bringing change on issues that may be of concern to young carers.

Bibliography

ASTI (2012) accessed on the Association of Secondary Teachers in Ireland website June 2012 on www.asti.ie/operation-of-schools/legislation/

Carers Association Ireland (1998) Needs of Young Carers in Ireland –Pilot Research Study

Cass et al (2011) Young Carers: Social policy impacts of the caring responsibilities of children and young adults. Social Policy Research Centre University of N.S Wales Australia

Deardan, C., Becker, S. (2002) Young Carers and Education. Carers UK London-quoted from the citation in NUIG 2009 Report – A study of young carers in the Irish population.

Donabedian A.(1988) The Quality of Care: How Can It Be Assessed? Journal of the American Medical Association. Vol 260(12): pp.1743-8. Available online from:

http://post.queensu.ca/~hh11/assets/applets/The Quality of Care How Can it Be Assessed - Donabedian.pdf

Dooley, B., Fitzgerald, A. (2012) My World Survey-National Study of Youth Mental Health Headstrong/UCD Department of Psychology Dublin

Fives, A., et al. (2009) A Study of Young Carers in the Irish Population; Child and Family Research Centre, NUI Galway. Published by the Office for the Minister for Children and Youth Affairs.

Halpenny, A. M; Gilligan, R. (2004) Caring Before their Time: Research and Policy Perspectives on Young Carers Children's Research Centre TCD-Barnardos

Law Society (2006) Rights Based Child Law: The case for reform. Law Society Dublin

O'Connell, C., Finnerty, J; Egan, O. (2008) Hidden Voices: An Exploratory Study of Young Carers in Cork Poverty Research Group Combat Poverty Agency.

Robotham, D., Beecham, E., Jackcon, C., Penketh, K. (2010) My Care: The challenges facing young carers of parents with a severe mental illness. Mental Health Foundation Scotland

Ronicle, J., Kendall, S. (2009) Improving Support for young carers-family focused approaches Department of Education Australia

Scottish Government (2010) Strategy for Young Carers in Scotland 2010-2015

UK Department of Education (2009) Guidance note 9: Improving support for Young Carers accessed on

www.education.gov.uk/publications/eOrderingDownload/Think-Family09.pdf

Young Carers Pilot Project Report: A Review of the Young Carers Pilot Project, a collaboration between Crosscare Carer Support Programme, the CDVEC and Colaiste Eoin, Finglas from May 2010 to June 2011 (2011)

References

The authors are indebted to the Carers Trust, Scotland. Much of the material in this chapter is adapted from their guide 'Supporting Young Carers - A Resource for Scottish Secondary Schools'.

¹ Carers Trust Scotland 2012 Supporting Young Carers-a resource for Scottish Secondary Schools

[&]quot;My World Report UCD/Headstrong 2012 www.headstrong.ie/content/myworld?gclid=CMrEo9Gv3rgCFcNP4QodAFgATg

ADASS, ADCS and The Children's Society (2012), Working together to support young carers and their families, www.adcs.org.uk/download/position

^{iv} Becker, F. and Becker, S. (2008) Young Adult Carers in the UK: Experiences, Needs and Services for Carers aged 16-24. London: The Princess Royal Trust for Carers

^v Carers Trust Scotland (2012) Supporting Young Carers-A Resource for Scottish Secondary Schools; Children's Society (2013) Hidden from View-The Experience of Young Carers in England

vi This is Ireland Highlights www.CSO.ie

vii http://www.nisra.gov.uk/census/2011census.html

viii www.bbc.co.uk/news/education-11757907

^{ix} Young Life and Times Survey is from Devine, P.& Lloyd, K. 'Young Carers Too' in Research Update Number 76. Economic and Social Research Council. June 2011.

^{*} Becker, S. 'Global Perspectives on Children's Unpaid Care giving in the Family: Research and Policy on 'Young Carers' in UK, Australia, the USA and Sub-Saharan Africa'. Global Social Policy 2007; 7:23. P. 27

xi C. Dearden, S. Becker (2004) Young Carers in the UK: the 2004 Report
Childrens Society (2013) Hidden from View-The Experience of Young Carers in England
NUIG (2009) Study of Young Carers in the Irish Population UCD School of Psychology/Headstrong
Cowling, V. (Ed.) (2004). Children of Parents with Mental Illness 2: Personal and Clinical
Perspectives. Melbourne: Australian Council for Educational Research.

xii NUIG (2009) Study of Young Carers in the Irish Population UCD School of Psychology/Headstrong

xiii Childrens Society (2013) Hidden from View-The Experience of Young Carers in England

xiv Cowling, V. (Ed.) (2004). Children of Parents with Mental Illness 2: Personal and Clinical Perspectives. Melbourne: Australian Council for Educational Research.

Young Life and Times Survey is from Devine, P.& Lloyd, K. 'Young Carers Too' in Research Update Number 76. Economic and Social Research Council, June 2011

- xvi National Carers Strategy, 2012
- xvii Caring for Carers, Department of Health, Social Services and Public Safety, January 2006.p.27
- xviii Caring for Carers, Department of Health, Social Services and Public Safety, January 2006.p.27 -29
- xix Carers Trust Scotland (2012) Supporting Young Carers-A Resource for Scottish Secondary Schools
- xx NUIG (2009) Study of Young Carers in the Irish Population UCD School of Psychology/Headstrong
- Young Life and Times Survey is from Devine, P.& Lloyd, K. 'Young Carers Too' in Research Update Number 76. Economic and Social Research Council. June 2011.
- Edinburgh Young Carers Project fact sheet; http://www.youngcarers.org.uk Young Carer Identification
- ^{xxiii} Blake Stevenson (March 2012) Review and analysis of existing training and education for NHS and social care staff working with carers and young carers-Final Report NHS Education for Scotland
- xxiv Young Carers-Good Practice Guide published by The Princess Royal Trust for Carers (2009)
- xxv Northern Ireland Executive: Improving Children's Life Chances: The Child Poverty Strategy. March 2011.p.24
- xxvi Sullivan, A et al. The Consequences of childhood disadvantage in Northern Ireland aged 5. Published by OFMDFM June 2010.p.2.
- Young Life and Times Survey is from Devine, P.& Lloyd, K. 'Young Carers Too' in Research Update Number 76. Economic and Social Research Council. June 2011.
- xxviii Carers Trust Scotland (2012) Supporting Young Carers-A Resource for Scottish Secondary Schools
- Young Life and Times Survey is from Devine, P.& Lloyd, K. 'Young Carers Too' in Research Update Number 76. Economic and Social Research Council. June 2011.
- xxx Edinburgh Young Carers Project fact sheet; www.youngcarers.org.uk Young Carer Identification
- xxxi Young Carers Project www.youngcarers.ie
- xxxii www.citizensinformation.ie/en/social welfare/social welfare payments/carers/
- xxxiii www.nidirect.gov.uk/carers-allowance-eligibility?source=most-popular
- xxxiv See www.disabilityaction.org for a list of their members
- xxxv Carers Trust Scotland (2012) Young Carers-Good Practice Guide
- xxxv http://static.carers.org/files/4089-vc-outcomes-manual-spreads-sb-6261.pdf
- xxxvi See Children First: National Guidance for the Protection and Welfare of Children 2011
- ********** HSE 2011 Child Protection and Welfare Practice handbook P. 69

 www.hse.ie/eng/services/Publications/services/Children/WelfarePractice.pdf
- xxxviii Young Carers Project www.youngcarers.ie