

## Research Proposal ; Young Adult Carers

An investigation that looks at the impact Informal/ Family caring has on Young Adult Carers participation in third level education and their experiences of this.

The purpose of this document is to provide an overview of the process of undertaking this exploratory piece of research. Initial decisions regarding the specific aims and objectives of the study, possible techniques for sampling, data collection, analysis, and the timeframe will all be presented.

**Working Title:** *Together for Young Adult Carers: A Preliminary examination from the Irish Context*

### Dates and Duration of Study

|                             |     |
|-----------------------------|-----|
| <b>Proposed Start Date:</b> | TBA |
| <b>Proposed End Date:</b>   | TBA |

### Background (p29 -30 of proposal)

Extensive research has found Informal/ Family Carers to be at high risk of social isolation, low income, anxiety, depression, and poor health (Singleton et al 2008, O’Sullivan 2008, Lamura et al 2007). Specifically Young Adult Carers have been identified as being at higher risk of becoming ‘Neet’ – not in education, employment or training (Scottish Executive, 2006). In Ireland, there have been a number of studies concerning the impact on the family of a person with a disability, illness or addiction, or of bereavement and family breakup, and some of these findings are relevant to research on young carers. However, Irish research on young carers themselves is still at an early stage, thus presenting a significant challenge to developing an effective policy response. A group of researchers at National University of Ireland Galway undertook the first national qualitative study of young carers in Ireland in 2010. While it was both exploratory and preliminary, it does nevertheless provide an insight into the lives of children and young people who provide care in the home and uncovers the reality of their situation. The focus of this important piece of research was on those carers aged under 18. To our knowledge, no research has been undertaken to date from an Irish context, that specifically looks at the experiences of Young Adult Carers i.e. those aged 18 - 24.

Third level students represent a unique group of the population, mainly young adults aged between 18-24 years. This age span includes the transition from adolescence to early adulthood. Early adulthood is a crucial stage in an individual’s life. For many young people, the transition to third level education marks a time of change. However, for those young adults with caring responsibilities, it may mark a period of intense stress, as they try to balance their caring and education responsibilities. For instance, Yeandle and Buckner (2007) found that among young adults aged 16-24, caring reduces the likelihood of being a student and thus participating in further or higher education. Two reports published in the UK by young carers projects (Action for Young Carers 2005, Barnardos 2007), found that many Young Adult Carers think that their caring responsibilities will be a barrier to accessing employment.

Care Alliance Ireland is guided in this initial exploration of the impact of Informal/ Family caring on Young Adult Carers participation in third level education by a number of international studies. Two significant studies into Young Adult Carers have been conducted in the UK and Australia, namely a 2008 report published by the Princess Royal Trust for Carers entitled *Young Adult Carers in the UK: Experiences, Needs and Services for Carers aged 16-24* by Fiona Becker and Saul Becker; and *Young Carers: Social Policy Impacts of the Caring Responsibilities of Children and Young Adults* published in 2011 by the Social Policy Research Centre, University of New South Wales. Care Alliance Ireland is therefore guided in the planning of its own preliminary research by the findings of previous international projects such as the above.

### **Aim of this phase of the project**

The overall aim of this phase of the project is to undertake an investigation that looks at the impact Informal/ Family caring has on Young Adult Carers participation in third level education in Ireland, and their experiences of this. It is envisaged that this phase will take place over a 5 month period. Due to a number of factors, namely the timeframe of five months, the lack of previous research undertaken in this area from an Irish context, and the limited resources of Care Alliance Ireland, it is envisaged that this study will be largely exploratory in nature.

There are a number of proposed objectives to this phase of work, which aim to explore and investigate the following:

1. Young Adult Carers' experiences of participation in third level education
2. The barriers for Young Adult Carers participation in third level education
3. The specific needs of Young Adult Carers participating in third level education
4. Potential recommendations that may assist Young Adult Carers participation in third level education

### **Research Question**

The research question that will guide this phase of the project is as follows: *What impact does Informal/Family caring have on Young Adult Carers participation in third level education and their experiences of this?*

### **Research Design**

It is proposed to undertake a small scale exploratory study in order to investigate the impact of Informal/Family caring on Young Adult Carers participation in third level education and their experiences of this from an Irish context. This will be a mixed methods study, incorporating both quantitative and qualitative elements. It is proposed that this study will involve the completion of a series of quantitative questionnaires, ideally with a sample of

Young Adult Carers. However, difficulties in gaining access to Young Adult Carers have been noted in previous research. Therefore, should this be the case in this study, individuals working either directly or indirectly with Young Adult Carers may also be approached to complete these questionnaires. Care Alliance Ireland does, however, recognise the importance of listening to the voices of Young Adult Carers themselves when trying to gain an understanding of their own experiences. Young Adult Carers are defined for the purposes of this project as individuals aged between 18-24 with caring responsibilities (towards dependent parents, siblings, or other relatives) (see page 29 of application).

It is recognised that using one single approach may make it more difficult to validate, as a consequence, it is proposed that following the completion of a series of questionnaires, Care Alliance Ireland will undertake a series of qualitative semi-structured focus group interviews with a further or sub sample of those individuals who completed the first stage of the study (depending on the response rate), who are working either directly or indirectly with young adult carers.

At the same time as the above, Care Alliance Ireland also proposes to undertake a systematic of the available literature on Young Adult Carers in post secondary education in Ireland. For instance, information on policies, challenges, good/ promising practices and figures on Young Adult Carers in post secondary education in Ireland will be examined. Care Alliance Ireland proposes that its 85 member organisations working directly with family Carers in Ireland will assist in the fulfilment of this task. Care Alliance Ireland understands that this forms part of the wider remit of the overall project.

## Sample

In total, it is proposed to identify up to 50 individuals to participate in this research, through purposive sampling. Firstly, 25-30 Young Adult Carers will be invited to complete a questionnaire on their experiences of the impact of caring on their participation in post secondary education. Following this, a further 16-20 individuals working directly or indirectly with Young Adult Carers will be invited to participate in two separate focus group interviews. Care Alliance Ireland understands that individuals may work with Young Adult Carers in a range of educational and/ or health and social care settings in Ireland, and such individuals include; Youth Workers , Education Support Officers, Counsellors, Project Workers, Child Care Workers, Family Support Workers and Social Workers. The sample will be designed to achieve the maximum possible range of views and experiences of individuals are working with young adult carers. It is therefore intended to recruit through a purposive sample for this study. The specific steps in negotiation of access to the sample in each stage of the research are outlined below:

Stage 1 (questionnaires with young adult carers)

1. Representatives from organisations that work directly with Young Adult Carers recently attended a seminar on young carers hosted by Care Alliance Ireland, September 2012. At the event, they were informed of this study and that they may be contacted in order to participate and/or assist in the recruitment of participants.
2. In addition to the above, Care Alliance Ireland member organisations, will be forwarded letters of invitation, inviting to contact Young Adult Carers who they work with, to participate in the study. These letters will also include information sheets, reply slips and contact details, as well as consent forms for information purposes only, for the nominated participant. The representatives from organisations that work directly with Young Adult Carers who attended the seminar hosted by Care Alliance Ireland will also be sent these information packs.
3. At the same time, a public recruitment campaign may be undertaken in order to enhance the number of participants. This will entail placement of advertisements through health and social care information points (such as Activelink.ie), inviting both Young Adult Carers and individuals working with Young Adult Carers to participate in this study.
4. On receipt of reply slips, the researcher will contact individuals to discuss their potential involvement, establish any concerns and arrange to send them the details of how to complete the questionnaire (ideally through an online resource such as Survey Monkey), should they wish to proceed.
5. Care Alliance Ireland recognises the difficulties associated with accessing a sample of Young Adult Carers to participate in this research. Should insufficient numbers be recruited, individuals working directly or indirectly with Young Adult Carers will be invited to complete the questionnaires on their behalf. However, we also recognise the limitations of not including the direct experiences of Young Adult Carers themselves in this research.

#### Stage 2 (Focus groups)

1. Following from the quantitative element of the study, a sample of individuals working directly or indirectly with young adult carers, who had been approached as part of Stage 1, will be contacted at a further date in order to assist in the completion of a series of qualitative semi-structured focus group interviews. Any of these individuals who completed the questionnaire will be aware that they may be contacted at a future date and asked to assist Care Alliance Ireland in a more in-depth investigation of the topic. This will be clearly stated on all information sheets, the consent form, as well as the actual questionnaire. Participants will also be given the opportunity of

declining the option of assisting in this qualitative phase of the project, and this will not affect their participation in the quantitative element of the project.

2. It is proposed to undertake two focus group interviews with a group of individuals working with young adult carers. It is envisaged that each focus group will involve 8-10 individuals and participants will come from a range of educational and/ or health and social care settings. The purpose of this phase of the research is to allow the researcher to examine individual's different perspectives through a group discussion.

### 3. Stage 3

In parallel to stage 1 and 2, an extensive review of information on policies, challenges, good/ promising practices and figures on Young Adult Carers in post secondary education in Ireland will be carried out. Care Alliance Ireland proposes that its 85 member organisations working directly with family Carers in Ireland will assist in the fulfilment of this task. Care Alliance Ireland recognises that completion of this stage of the research fulfils the wider remit of the project.

### Inclusion Criteria

The following inclusion criteria will be put in place for all study participants in stages 1 and 2 of this of this project:

- Individual aged between 18-24 with caring responsibilities (towards dependent parents, siblings, or other relatives)  
*or*
- Currently working in an organisation that provides (or aims to provide due to lack of resources) support to Young Adult Carers aged between 18-24
- Understands the purpose and process of the research project
- Willingly volunteers to participate in the research project

The following exclusion criteria will be put in place for all study participants:

- Not an individual aged between 18-24 with caring responsibilities (towards dependent parents, siblings, or other relatives)  
*or*
- Not currently working in an organisation that provides (or aims to provide due to lack of resources) support to Young Adult Carers aged between 18-24
- Does not understand the purpose and process of the research project

- Unwilling or unable to participate in the research project

## Data Collection

### *Stage 1*

It is hoped that up to 30 quantitative questionnaires will be completed as part of the first stage of this project (See Appendix 1 for a draft example of the ideas of topics to be covered and from which potential questions could be formed). Previous international research on Young Adult Carers, as well as advice from project partners will be considered in the preparation of the questions. In this questionnaire, a defined list of questions will be present to each participant in an identical way. Participants will be asked to respond to these questions. However, there will also be a semi-structured element to these questionnaires in that they will not only be presented with a limited number of alternative answers, and this will provide participants with the opportunity to insert their own comments, where appropriate. While Care Alliance Ireland recognises the in-depth personal information that may be gathered through qualitative individual interviews, the process of recalling personal information to a stranger may be an intimidating experience for individuals. Taking this into consideration, as well the timeframe of this study, and the resources available to Care Alliance, it is felt that the information gathered through questionnaires will provide an excellent preliminary source of information on the impact of caring on Young Adult Carers participation in post secondary education in Ireland.

Care Alliance Ireland is aware that by its very nature, Family Caring is highly unpredictable. As a result, participants will be asked to complete the questionnaires during a time that best suits them. They will be provided with the information on how to complete the questionnaire through an online resource such as Survey Monkey, so as to ensure that they can complete it at a time and place that is most convenient to them. Survey Monkey is a software tool available on the Internet which can facilitate in doing online surveys. Should participants prefer, the questionnaire can also be sent as an email with the expectation that the recipients answer the questions and send the questionnaire back via email. Care Alliance Ireland believes that the completion of questionnaires on line or via email will have a number of advantages over the completion of postal questionnaires, such as the time saved, low cost, ease of use, lack of spatial restrictions and higher response rate. Demographic information on the participants will also be gathered at the start of each questionnaire. It is proposed that the questionnaires will take 15-20 minutes to complete.

### *Stage 2*

Following on from the completion of a series of quantitative questionnaires, it is also envisaged that two qualitative focus group interviews will be undertaken. Each will be semi-structured in nature, with the assistance of an interview guide (Appendix 2 for possible ideas of topics for discussion). Final topics for inclusion in the Focus group interview guide will be composed following initial analysis of the questionnaires. Individuals working directly or indirectly with young adult carers will be asked to participate as outlined above in the stages of negotiation of access.

It is proposed that the Focus Group Interviews with individuals will on average last 1 hour. 8-10 individuals will participate in each interview, with the researcher acting as a facilitator to encourage group discussion. The Focus Group interviews will be recorded and all participants will be made aware of this before in the information leaflet and consent forms.

In addition to the questionnaires and Focus Group Interviews and Individual Interviews, Care Alliance Ireland will be careful to take regular consultation throughout the project with the project partners for feedback and advice.

### **Ethical Considerations**

Care Alliance Ireland believes that quality research and ethical research go hand in hand; therefore, adhering to standards of ethical good practice at all times during the course of research project is essential. Before research commences, approval will be sought from the Board of Directors of Care Alliance Ireland. Care Alliance Ireland will also maintain regular contact with the other project partners throughout this phase of the project in order to exchange information and update them on progress. The researcher will also follow the Ethical Guidelines set out by the Social Research Association (UK) throughout the design, executive and reporting of the research project.

The principles of informed consent as well as participant wellbeing will be given priority over the research objectives at all times. Information on the contact details of relevant support services available to Young Adult Carers will be provided in each of the questionnaires. In relation to the qualitative aspect of this project, it is acknowledged that some individuals working in the Family Carer sector may find recalling their personal experiences saddening. Interviews will therefore be stopped/ suspended if individuals become distressed in anyway. Careful thought will also be given to the following ethical issues throughout the course of the research project:

- All information gathered will be kept anonymous and confidential
- Participants' right to privacy will be upheld at all times
- Each participant will be allocated a code known only to the researcher

All data stored on the computer will be password protected and all research materials will be secured in a locked filing cabinet.

### **Data Analysis**

All information provided through questionnaires will be collated and computer software such as Excel and/or SPSS may assist in the analysis of the data. Questionnaire findings will be examined through a process of content analysis. This will be undertaken in order to determine what findings may have a statistical significance (At the same time, Care Alliance

Ireland recognises the small sample size involved in this phase of the research and therefore the limitations that this may pose).

The findings from the questionnaires will then be examined with reference to those collated through the focus group interviews. In relation to the Focus groups, all recordings will be professionally transcribed. All transcripts will then be collated and themes/codes will be identified through the process of thematic analysis. It is envisaged that the researcher will take the following intensive steps in coding the data around themes:

1. Transcripts will be read through on a number of occasions, while recordings will also be listened to. Once recurrent topics are identified; they will become the codes and themes.
2. Codes will then be categorised under headings depending on their relevancy and the focus of the research project.
3. The connection between codes will then be investigated. These codes will be re-examined in light of the overall goal of the research project.

### Management Issues – Time scale and dissemination

The table below illustrates the work programme and plan of research to be undertaken for this study over a five month time scale. It is envisaged that research will take place over three interlinked stages, taking place over a 5 month period, namely phase 1: research study set up; phase 2: data collection and phase 3: final analysis and write up of research study. In total it is estimated that work on this project will take 35 days to complete.

|  | Mth. 1 | Mth. 2  | Mth. 3  | Mth. 4  | Mth. 5  |
|--|--------|---------|---------|---------|---------|
| Research study set up  |        |         |         |         |         |
| Gain board approval  | 1 day  |         |         |         |         |
| Preparation of data collection material  | 2 days |         |         |         |         |
| Identify target participants   | 2 days | 2 days  |         |         |         |
| Undertake review of relevant literature  | 2 days |         |         | 1 day   | 1 day   |
| Data collection  |        |         |         |         |         |
| Stage 1 questionnaires – prep, send out & respond  |        | 2 days  | 2 days  |         |         |
| Stage 2 focus groups – prep and facilitate   |        |         | 3 days  |         |         |
| Input data gathered from questionnaires  |        |         | 2 days  |         |         |
| Transcription of focus groups  |        |         | 2 days  |         |         |
| Final analysis and write up  |        |         |         |         |         |
| Explore/ verify issues with partners   |        | 0.5 day | 0.5 day | 0.5 day | 0.5 day |
| Data analysis of questionnaires  |        |         |         | 2 days  |         |
| Data analysis of focus groups  |        |         |         | 3 days  |         |
| Finalise data analysis   |        |         |         |         | 1 day   |
| Write up of final report   |        |         |         |         | 3 days  |
| Preparation for dissemination of findings  |        |         |         |         | 2 days  |
| <b>Estimated total number of days for completion of research over 5 month time scale = 35 days</b> |        |         |         |         |         |

## Proposed Outcomes

Care Alliance Ireland initially intends to present the findings of this research to the partner organisations at a study visit of the TOYAC project. During this study visit, Care Alliance Ireland will present the findings of each of the elements of its research to the partner organisations, namely, quantitative questionnaires, qualitative focus group interviews and the desk-based review. It will also lead the partner organisations on a visit to two examples of good practices of supporting Young Adult Carers in post secondary education as evidenced during the fieldwork stage of the research.

At the end of this exploratory piece research, important (yet preliminary) information will be available on the following:

- Young Adult Carers experiences of participation in third level education in Ireland, preferably from Young Adult Carers themselves. The perspectives of a range of educationist and health and social care professionals working with Young Adult Carers will also be provided
- An understanding of the services available/needed to assist Young Adult Carers participation in third level education in Ireland
- The current gaps that exist in assisting Young Adult Carers participate in third level education in Ireland
- Any interventions which educationist and health and social care professionals working with Young Adult Carers can identify that would contribute to their participation in third level education in Ireland

The following implications for policy and practice are also envisaged:

- The findings of this research will document the impact of informal/family caring on Young Adult Carers experiences of participation in third level education from an Irish context
- The findings of this research will allow Care Alliance Ireland to exchange information on Young Adult Carers in a structured manner with fellow project partner organisations at a European level. Following a review of the evidence, these organisations may be able to advise on good practices and tools already developed in their own countries to support Young Adult Carers
- This phase of the project may assist the one of the key overall goals, to develop innovative strategies for targeting Young Adult Carers and for the acknowledgement and enhancement of skills acquired in unpaid care-giving

In an Irish Context:

- The findings of this research can be used to inform the priorities of Care Alliance Ireland and its member organisations as advocates for Family Carers
- To build on the findings of this research with more focused quantitative work
- The findings of this research may be used to lobby Government Departments for improvements in areas relevant to Young Adult Carers
- The findings of this research will assist Care Alliance Ireland in the promotion of its vision that the role of Informal/ Family Carers is fully recognised and valued by society in Ireland
- The findings of this research can also be used to raise awareness in agencies that would not normally be associated with meeting the needs of young adult carers. For

example, Colleges and Universities may be approached by Care Alliance Ireland in encouraging the needs of this group of hidden carers

## Appendix 1 Ideas for Possible Question Topics in Questionnaire

**Project Title:** *Together for Young Adult Carers: A Preliminary examination from the Irish Context*

\*\*\* These are only suggested ideas of topics that could be considered for inclusion. They will need to be formatted to allow a number of possible answers e.g. Rate on scale 1-10, strongly agree/disagree, yes/no etc

### **Preamble to the questionnaire:**

Welcome and review the research purpose

Opening question

- How would you describe what life is like for you since you began providing care to X?

How has caring affected life:

- Could you describe a typical day for you?
- What would a good/bad day be?

Current feelings on role as carer:

- How would you describe your role as Young Adult Carer?
- How do you feel about caring for X?
- What would you say are the challenges with caring with X?

Impact on participation in education, employment and social activities:

- What are your experiences of participating in education/employment/training programmes while providing care to X?
- In what ways would you say the above has been affected by you having to provide care?
- What would you say are your needs?
- Do you have any hobbies or interests?
- How would you compare your life now with your life before you began providing care to X? Are there any things that you miss doing that you used to?

Support

- Could you tell me what is your experience of support in your role as Young Adult Carer?
- In your opinion, are there any gaps in the support you receive as Young Adult Carer?

- What do you think would help you/ what types of support would be helpful, in your role as Young Adult carer, in order to assist you in participating in education/employment/training programmes?

#### Future Aspirations

- Do you think about the future?
- Where do you see yourself in five years time?

\*\*\*Make sure to add a section at the end to allow the participant the opportunity to add anything further to end of questionnaire

Thank participant for their involvement.

Include contact details of support services available to Young Adult Carers.

## Appendix 2 Proposed Schedule for Focus Group Interviews

**Project Title:** *Together for Young Adult Carers: A Preliminary examination from the Irish Context*

### **Organisation background**

- What is the role/remit of your organisation in relation to Young Adult Carers?
- What is your experience of working in the area of Young Adult carers?

### **Identifying young carers**

- What mechanisms are being used to identify and contact Young Adult Carers and how effective are they?
- In working with Young Adult Carers, what issues are likely to arise?

### **Impact of caring**

- What tasks do Young Adult Carers perform?
- What are the impacts of caring on the young adult?

### **Engagement in Post Secondary Education**

- What are your experiences of the needs of Young Adult Carers participating in education, employment, or training?
- What are your experiences of the gaps of Young Adult Carers in education, employment, or training?

### **Best Practice and policy solution**

- Does your organisation provide support to Young Adult Carers?
- Can you describe any current initiatives in place that assist Young Adult Carers participating in education, employment, or training?
- What forms of provision and support should be provided to Young Adult Carers in education, employment, or training?