

"If I can make their life a little easier, then
I'm happy"

Study on Young Carers in the Irish Population

Child and Family Research Centre
National University of Ireland, Galway

Commissioned by the Office of the Minister for
Children and Youth Affairs

Introduction

Young carers on the research agenda:

- Traditionally, the focus of care-oriented policy has been on adult informal carers
- A growing awareness of and interest in "young carers" over the last decade and a half from a policy and service perspective

Some key issues:

- definition of young carer;
- impacts, both positive and negative;
- invisibility of young carers, and mechanisms to identify young carers;
- services that are or should be provided to young carers.

Aims of the study

- (1) Examine mechanisms through which young carers (aged 5-17 years) in the Irish population can be identified,
- (2) Identify the impact of caring on their lives, and
- (3) Make recommendations for ways in which they can be assisted.

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Literature Review

Law, Policy and Practice

- No national legislation, policy or services specifically for young carers in Ireland
- UN Convention on the Rights of the Child
- Combining children's rights and "whole-family" approach

Themes and Debates

- "Invisibility" of young carers important for research
- Impacts both negative and positive
- Primary & secondary carers encountered
- Age-inappropriate care has developmental implications ("parentification")
- Close correlation with economic disadvantage

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Methodology

Sampling & Recruitment of Young Carers

- “Invisibility” of young carers
- Sampling methods: purposive, convenience, snowballing

Phase I:

- Seeking referrals via agencies & nationwide information campaign
- Resulted in 6 referrals

Phase II:

- Expand sample, engage with gatekeepers, target frontline staff
- Nationwide media campaign
- Resulted in 20 referrals

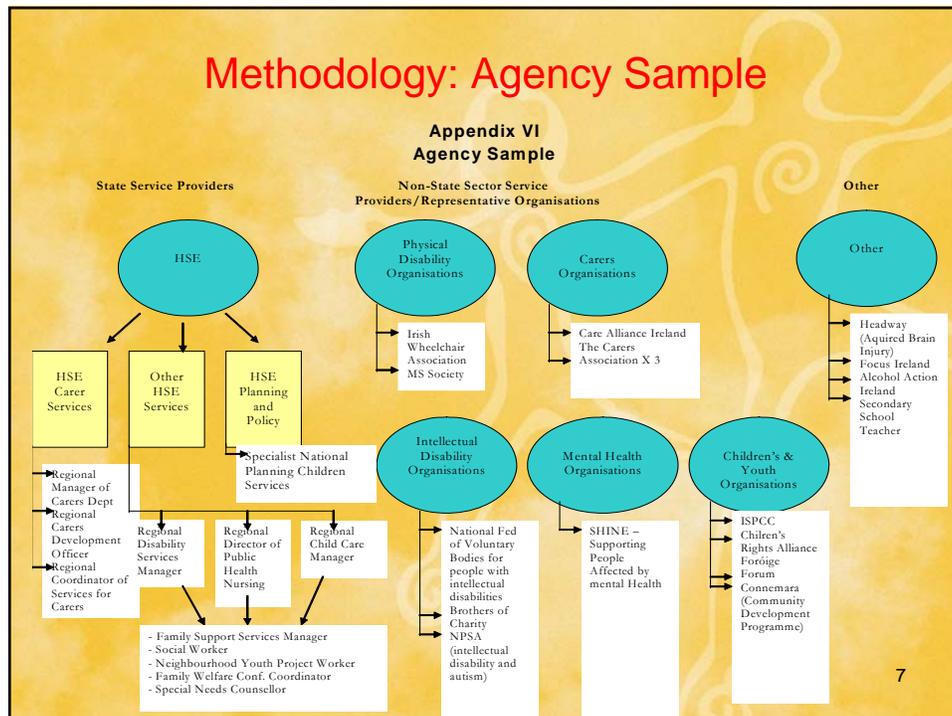
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Poster Used in Nationwide Information Campaign

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Methodology: Agency Sample



Methodology

Explanation for lack of success in Phase I:

- Most agency workers, including those from carer organisations, were not in a position to refer young carers to the research team;
- Even for those agency and frontline staff who do have direct contact with families where there is a young carer, this strategy was largely ineffectual.

Challenges to recruitment:

- “Invisibility” due to fear of intervention, lack of service, and/or perceived normality of caring
- Term “young carer” itself a challenge due to lack of awareness

Study Limitations:

- Vulnerable young carers under-represented
- Two layers of gatekeepers (service providers & parents)

Findings: Young Carers

Profile

- Seven males, 19 females
- 15 caring exclusively for siblings, seven for parents
- 10 between 5 -11 years old; 16 between 12-18 years old

Eight young carers in households without any adult in **paid work**; all were single-parent families & parent receiving care

19 **began caring** below the age of nine

Person cared for:

intellectual disability (13), intellectual & physical disability (6); physical illness (5); mental illness (3); sensory impairment (1)

Nine were **primary carers** (predominant carer)

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Findings: Young Carers

• Supports received:

Home help, income, treatment, respite, transport, renovations

Peer support, help from teachers, advice & information

• Supports wanted:

Information & advice; more home help

• Tasks performed:

domestic (n=26), general (n=19), child care (n=17), intimate (n=16), emotional (n=7), "other" (n=7)

• Intimate care:

Across gender lines, care for parents

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Findings: Young Carers

Impacts:

- Physical (back strain, sleeplessness, violence)
- Education: negative (distraction, absences) & positive
- Social: negative (time with friends & clubs) & positive
- Maturity
- Closeness
- Emotions (anxiety sometimes)

Impacts on *primary carers*:

- Positive (P2) & Negative (P15 & P16; P22; P25 & P26)

Impacts of providing *intimate and/or general care*:

- Positive (P17; P19) & Negative (P9)

Gender:

- More female carers, gendered distribution of burdens
- But male primary carers and intimate carers

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Findings: Agency Staff

Profile:

- 13 from state sector, 17 from non-state sector
- At best only ad hoc professional experience with young carers

Asked to define young carers:

- All caring by young people is inappropriate (n=14)
- Continuum of care, some caring is valuable (n=16)

Identification of young carers:

- "Under the radar", sensitive for parents, data not being recorded

Gaps in agency knowledge:

- Prevalence, intimate care, age caring begins, primary carers
- These gaps evident about those referred to the study

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Findings: Agency Staff

Supports for young carers:

- Remove need for their caring **or** lighten care responsibilities?
- HSE services now only to adult informal carers (and data base)
- “Young carers projects” suggested
- Budget needed
- Awareness raising (stigma) **and** service provision

Child protection issues:

- Alcohol addiction of parents, intimate care

Rights-based:

- Developmental needs a priority

Family support:

- Whole-family approach, early intervention, integration of services

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Discussion

This research:

- Reality of young carers uncovered/made visible

Definition:

- Cover broad spectrum of caring, but can stigma be avoided?

Identifying & accessing young carers:

- Lack of awareness, lack of services, fear of child protection intervention
- Use of gatekeepers in this study, but are other methods possible?

Impacts:

- Positive & negative impacts
 Scenario 1 (P9)
 Scenario 2 (P19)

Supporting young carers:

- Raise awareness & provide services (integrated)
- Guarantee rights & support families

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Findings: Young Carers Scenario 1

P9

Profile: 14 year old girl, cared for her mother, primary carer

Tasks: toileting, dressing and feeding

Impacts: social life affected and worried about future care needs

- “I’m trying to convince her to get the bag for going to the toilet instead of having to bring her all the time. It would be the worst part of it, like, having to lift her onto the toilet and not getting there on time and things ...”
- “Well, like, if I was invited to one of their [friends’] houses, maybe I might have to stay at home because my brothers would be gone. Someone always has to stay with Mam, and Dad’s kind of not great in health either. ... [W]e wouldn’t leave him here at night time with her because he’d need help.”
- **NB: awareness, formal services, informal supports, rights**

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Findings: Young Carers Scenario 2

P19

Profile: 16 year old boy, 3 brothers had intellectual disabilities, secondary carer, support from parents & professionals

Tasks: intimate, general and emotional care

Impacts: played on GAA teams, volunteered weekly to play the uilleann pipes in a nursing home

- “I just seen it as a duty as their older brother, you know? ... I also, see personally feel that if I can make their life a bit easier for them then I’m happy do you know. So, I think it’s not as much as a clear duty to me like, but you know, I just feel that I am their bigger brother so I should help”
- “Yes, I’ve got a different outlook on life, and how people think, and how different things can happen to people. And you know, I have a better, I have an easier, life than some people. So it’s easier to see life in a range of different feelings and thoughts and stuff like that.”
- **NB: awareness, formal services, informal supports, rights**

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Conclusion – Areas for Consideration

- **Definition:**
A young carer is a child or young person under 18 years 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. This may include a child or young person who provides direct personal care or who takes on a supportive role for the main carer. A young carer may carry out domestic tasks or may provide general, intimate or emotional care. These needs may arise on a regular or on an occasional basis. There is therefore a continuum of caring and as a result the service requirements of young carers will vary. It is important to differentiate between a level of caring that has largely positive consequences and a level of physical or emotional caring that impairs the child's health, development or welfare.
- **Tasks performed:**
Domestic, general, intimate care, emotional support, child care
- **Health problems:**
Intellectual disability, combined intellectual & physical disability, physical and mental illness, drug or alcohol addiction, sensory impairment
- **Primary and secondary carers**
- **Positive and negative impacts**

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Conclusion – Areas for Consideration

Policy issues

- **Co-ordinated, cross-sectoral, multi-departmental and multi-agency**
- **Raising awareness**
 - Raise awareness about young carers without stigmatisation
 - Awareness raising should be in conjunction with service provisionAlso needed: longitudinal research, teachers, self-referrals, Census
- **Ensuring young carers have a voice**
Rights of children
- **Recognising the continuum of care and diversity of supports required**
Formal and informal supports
- **Improved understanding of children and young people as carers**

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Conclusion – Areas for Consideration

Service issues arising

- **Needs of young carers:**

Information, support in the home, help from teachers, emotional support & advice, friends, sport and other activities

- **Create mechanisms for young carers to make contact with service providers:**

Information campaign in schools

Awareness raising among professionals

Characteristics of young carers

- **Proactively identify carers where there is a known care need**

- **Develop referral pathways to supports**

- **Ensure young carers are given a voice**

- **Develop suitable materials to inform young people**

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Becoming a primary carer

A 15 year old carer, who helps her mother with back problems, was asked how long she had been the primary carer for her mother, and responded:

P1: For as long as I can remember. When I was five or six, she broke her leg – we had to help her with her cast – she used to have to wear a cast.

I: And that wasn't related to her back?

P1: No, I don't think so. I was very young at the time

When asked whose idea it was that she care for her mother, she replied:

P1: Don't know – it's just part of life

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Awareness (Teachers)

- I: And do you get any extra help from teachers?
- P15: Well yeah, and there's an odd teacher too that knows that there's something wrong with you, they'll call you back then to the class and ask you.
- I: Ok. And would you tell them? As you go into different teachers do you explain or do you tell the principal or?
- P15: Yeah, if there's a problem, we tell the vice principal because she knows exactly who is at home and what goes on.
- I: Yeah. Ok. So if you miss days or anything it would be her that you'd talk to?
- P15: Yeah.

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Informal support (advice & discussion)

- I: And do you get any advice or support in terms of helping to look after him?
- P17: Outside the family?
- I: No, both.
- P17: In the family, well yeah, you would, yeah.
- I: So that would be from either or both of your parents would it?
- P17: The whole family really, just any observations that you might just say them: "Oh yeah, I suppose that's right." You know.
- I: Yeah.
- P17: We wouldn't do it formally, just if it cropped up.
- I: Yeah, and from outside? Have you ever spoken to a professional about it?
- P17: No.

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Home Help

I: Is there any more support that you would like?

P16: Just knowing that there is more support would be nice, not that we necessarily need it but ...

I: Yes. And more [home help] hours, or would that bother you? Yes?

P16: Yes. That would be a big help actually. I wouldn't have to do half as much.

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Respite

I: Ok, and is there any more support that you would like? Anything you think would be useful?

P23: I'm not sure, I think just maybe if we got more respite.

I: Right.

P23: Because they have cut down an awful lot.

I: Oh have they really?

P23: Yes.

I: Yes, and is that recently?

P23: Yes recently, recently because more families are kind of demanding more nights, so they have to cut down on some people.

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Agency Staff: Invisibility of young carers

PA 26:

[T]o be honest with you it's something I'd stumble across or would come in contact with through various referrals. [W]as it ever to be ... a way of actually locating and accessing them I think something formal might need to be done. If an adult is caring for another person either part time or full time there are things there that they can avail of but a child doesn't have those supports.

PA5:

[W]hat we're finding is nearly through word of mouth. If you speak to them [young carers] about young carers – there is a perception that carers are elderly and that they're female as well! It's around educating people around that. If resources were available there are ways of doing things. I know that recently here we have a photo competition around it and we had young carers who sent in applications to that.

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