

HIDDEN YOUNG CARERS IN CORK– AN EXPLORATORY STUDY

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HIDDEN YOUNG CARERS

- Overview of Presentation:
 - Rationale for Research
 - Definition of Young Carers
 - Research Management and Methods
 - Profile of Young Carers Interviewed
 - Hidden Young Carers: Experiences and Attitudes and Impacts of Caring
 - Findings from Service Providers' Seminar
 - Further research steps

Research Rationale

- Extensive International Literature and Service Provision contrast with Ireland
- Relatively little research, low policy awareness and provision in Irish context.
- Research aimed to give initial, exploratory, qualitative, insights into experiences of hidden young carers, and assess extent of awareness of service providers.
- Longitudinal dimension to explore longer term impacts on former young carers

Defining Young Carers

- Age Range: this is perhaps the most straightforward definitional issue to resolve, as a common ceiling would be 18.
- Unpaid, usually a close relative and perhaps typically in the same household.
- Extent of caring responsibilities (hours per week) and the nature of caring responsibilities is key:
- Focus in the literature is levels of 'inappropriate care', involving duration of caring and 'high intimacy care'.
- This would typically be linked with the nature and extent of the impact on the young carer in the areas of socialising, education, health, and life chances.

Management of Research

- Establishment of Research Steering Group for professional, ethical and practical guidance:
 - SHB (HSE) PHN Regional Carers Co-ordinator,
 - DoSFA,
 - SHB (North Lee) Community Worker
 - Cork City Partnership Community Worker
 - Cork City Council Social Inclusion Unit
 - M.S. Representative Carer

Data Selection: accessing hidden young carers

- Extensive efforts made to identify and contact young carers.
- Wide range of organisations and individuals who work with families and young people contacted to try to identify young carers in Wider Cork area.

Contacts

- Youth Organisations
- Educational Establishments
- School Completion Programmes
- Community Development Programmes
- Family Centres
- RAPID Co-ordinators
- Sporting Clubs
- Carers' Organisations
- Disability Groups
- Southern Health Board (Principally PHN's)

Difficulties identifying Young Carers

- Key potential source - Public Health Nurses - felt unable to co-operate on professional / ethical grounds despite representation on Research Steering Group.
- Few contacts identified young carers.
- Does not mean that young carers do not exist.
- Reflects invisibility of young carers and hidden nature of issues being researched.
- Lack of awareness of young carers.
- Possible fear of labelling and adverse professional interventions

Fruitful Contacts

- Youthreach
- Carers' Support Group
- Multiple Sclerosis Society
- Personal Contact by researchers

Data collection: interviewing young carers

- Qualitative interviews with young carers and former young carers

Participant Profile

- Five young carers
- Four former young carers
- One person being cared for by a young carer

Age and Gender

AGE	FEMALE	MALE	TOTAL
12-13	1	1	2
14-15	0	2	2
16-17	0	0	0
18-19	1	0	1
20's	0	1	1
30's	1	0	1
40's	1	0	1
50's	1	0	1
TOTAL	5	4	9

Person Cared For

- 8 of 9 caring for mother
- 9th caring for younger sister because mother had nervous breakdown
- 4 of 9 (44%) caring for more than one person
- 7 of those cared for had physical disability
- 4 of those cared for had mental health problem
- 3 needed care because of their age (younger siblings)

Person Cared For and Why

Person Cared For	Reason Care Needed
Mother	Stroke causing mobility difficulties and partial paralysis
Sister	Sister has Downs Syndrome. Mother unable to care for her because of nervous breakdown
Mother, Aunt & Grandfather	Mother had mental illness. Aunt had Schizophrenia. Grandfather elderly.
Mother	Multiple Sclerosis
Sister / Mother	Mother had Manic Depression, unable to care for youngest daughter
Mother	Multiple Sclerosis
Mother	Multiple Sclerosis
Mother and Brother	Mother physically disabled. Father alcoholic. Caring for younger brother.
Mother and Brother	Mother had Recurrent Depressive Disorder. Caring for younger brother

Age when Caring began

- 4 began caring under age of 6 (44%)
- 5 began caring under age of 10 (56%)
- 4 began caring in their teens (44%)
- Current young carers
 - 3 began caring under age of 6 (60%)
 - 2 began caring at age of 11 or 12 (40%)
 - **100% of current young carers began caring at age 12 or younger**

Length of Time Caring

- All young carers and former young carers interviewed had been caring on a daily basis.
- All had been caring for long period of time, from minimum of four years to over forty years of caring.

Family Circumstances

- 4 lived in households where parents had separated and the father was absent. (44%) 3 of these lived with mother and siblings.
- Father present in home of 5 young carers or former young carers. (66%) In 4 of these cases, father out at work, leaving primary caring responsibilities to child. In other case, father had given up work to assume prime caring responsibilities.

Experiences and Attitudes and Impacts of Caring

- Interviewees expressed a range of emotions in relation to their caring role:
 - Acceptance
 - Resentment
 - Anger
 - Annoyance
 - Stress
 - Trauma
 - Upset

"Its not all that bad like....The odd time there you'd get fed up of it like. But what can I do, its my Mam. You have to look after her."

"It was difficult but you knew nothing different at that time."

"Very stressful: you just want to run away sometimes. Everyone just wants to run away from it coz its horrible like. You just want to get away from it."

"Looking back it was absolutely atrocious; I don't know how we survived it. It was completely traumatic."

"What hurt me most is the fact that all that went on and there was no one took any notice."

"You were in a cage and you couldn't get out."

Impact of Caring on Young Carers

- Being a young carer has a significant, and usually negative, impact on the lives of the young people involved.
- The impacts are multidimensional, affecting:
 - Physical and Mental Health
 - Social Life
 - Education
 - Work / Career
 - Poverty
 - Life chances and choices

Physical and Mental Health

- Being a young carer can have a detrimental impact on the health (mental and physical) of the young people involved.

Physical Health

- Some physical health problems directly linked to caring work, for example physical exhaustion and back problems.
- Some physical health problems linked to stress associated with being a young carer, for example headaches and allergies.

"It hurts my back sometimes. And I pull my muscles a lot as well."

"I'm exhausted from it."

Mental Health

- Often the greatest impact of being a young carer is on the young person's emotional and mental health.
 - Most experienced stress because of being a young carer
 - Not understanding what is going on
 - No one explaining situation to them
 - Confusing and frightening
 - Depression and anxiety
 - Need for counselling

"Emotionally you get very depressed when it gets like this, coz you don't know what to do or you feel like nobody's there for you to help or anything."

"Looking back I would say most certainly my older brother and myself, I would say certainly our mental health suffered. And I would say that we became depressed for quite some time."

Social Life / Relationships

- Less time to spend with friends, to 'hang out' and have fun
- Embarrassed to have friends come to their home
- Less time for social activities and hobbies
- Impacting on ability to form and maintain relationships
- Constant interruptions – called away to help out in middle of social activities
- Feeling that they were the only ones in that situation

"I never had time to get into a relationship because you couldn't go out, you didn't have babysitters and things like that. There was never kind of a relationship. You couldn't. Being a carer is a very lonely experience."

"I have to arrange weeks beforehand if I want to go out for a night or anything like."

Education

- Missing out on education, partially or entirely
- Less time for homework and studying
- Stress and tiredness affecting ability to concentrate and study and performance in exams
- Longer-term impact on life chances and choices

Education

- Little or no support from schools
- No intervention to ensure that education was not affected by caring responsibilities
- 2 young carers having more positive experience of education when they began to attend Youthreach centre.

"I went through the net, stopping at home from school and caring at home. And nobody ever came to say, this can't go on, this child has got to go to school."

"I mean there wasn't time for schoolwork as such."

"I simply could not study at all."

"Its hard trying to balance it all."

Poverty

- Financial hardship and impoverishment
- Dependence on social welfare if parent unable to work
- Having to leave school to work to support family
- Having no money for food

■ *"We were completely pauperised through all this as well."*

■ *"Money was very, very tight"*

Work / Career

- Impact on education having consequences for life choices and employment opportunities
- Ending up in factories or doing 'menial work'
- Most former young carers ended up working in caring field, caring at home, working as home help or as social worker
- Some current young carers expressing interest in working in caring field, in childcare, counseling or medicine (valuing prior learning)

"I would have probably taken different roads. There would have been different paths open to me."

Life Chances

- Impact on educational opportunities
- Reduced life choices
- Impact on employment options and earning potential
- Impact on social lives, relationships and interaction with peers

Young Carers' Views of Professional Supports

- Even where professionals aware of situation, such as doctors, teachers, social workers, nobody intervening to assist the young carer

Young Carers' Views of Supports Needed

- Need for adequate and age appropriate information
- Need for professional engagement with young carers and provision of supports
- Need for adequate Home Help and Respite Care to relieve pressure on young carers
- Benefits of contact with other young carers to combat isolation – e.g. MS Society event
- Current young carers interested in meeting other young carers and participating in Young Carers' Support Group if established

"I actually didn't realise that there were others. It was good to talk to them. You'd think you were the only one."

"Someone to talk with that they know what you're dealing with and we know what they're dealing with."

"We could share problems and you wouldn't feel so isolated."

"Doing this you feel very alone. You feel that there's nobody else around. So it would be nice to find out how other people deal with it and stuff. I think that (a young carers' group) would be a very good idea alright."

Dissemination of Findings

SEMINAR WITH SERVICE PROVIDERS IN THE GREATER CORK AREA

Service Providers' Seminar – Objectives

- To disseminate and validate the findings of the interviews with young carers (via presentation)
- To assess the levels of awareness of the existence of young carers among statutory, voluntary and community organisations in Cork
- To explore the extent to which agencies are willing to engage in response to the needs of young carers.

Attendees at Service Providers' Seminar (12 organisations, 36 attendees)

Southern Health Board (HSE)
Southern Health Board Support for Carers Office
Multiple Sclerosis Ireland
National Education Welfare Board
Department of Education Home School Community Liaison Officer
Cork City Partnership
Gurraneabraher Youth D.C
Cork Rapid Programme
Irish Society for the Prevention of Cruelty to Children
Department of Social and Family Affairs
Local Employment Service
Carers Association

Seminar Findings (1) Young Carers are Hidden

- General consensus that the existence of young carers is largely unacknowledged by service providers and their needs go unrecognised within policy and support services for carers in general.
- Of the 12 organisations / service providers represented at the seminar none made specific provision for young carers in their policy brief or service provision.
- All acknowledged the validity of the research findings

Seminar Findings (2) Services Providers' Willingness to Engage

- Service providers expressed a willingness at a principled level to take account of the existence and needs of hidden young carers, once the experiences revealed by the research were highlighted.

Seminar Finding (3) Context of Potential Engagements

- Participants agreed that whatever concrete service responses emerge should ensure that young carers' needs be responded to in an appropriate way.
- Observations made included:
 - Young carers have a variety of reasons for remaining hidden. Accordingly, service providers must balance engagement with young carers against the risk of stigmatising them through exclusively targeted provision.
 - A further reason young carers may remain hidden is the anxiety over child protection interventions among service providers eg PHN's.
- Responses by service providers will vary according to factors such as their voluntary / statutory status and nature of service being provided.

Next Steps

- The current research with hidden young carers and service providers has been exploratory:
 - small-scale,
 - localised,
 - qualitative
- Replicate this research on a national scale with young carers and service providers, to examine prevalence, role and impacts