

GREATER GLASGOW HEALTH BOARD

THE NEEDS OF YOUNG CARERS

QUALITATIVE RESEARCH DEBRIEF

February 1998

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CLARE WADE RESEARCH

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## **BACKGROUND AND OBJECTIVES**

The Health Promotion Department of the Greater Glasgow Health Board is presently concerned to explore the needs of young carers, defined as those between the ages of 3 and 16 who are responsible for caring for someone close to them.

In particular, there is a need to understand how such responsibilities affect young carers' health in both physical and, importantly, mental respects and how they respond to any existing services or facilities which are there to help them.

A research programme was proposed to examine these issues, the overall aim of which was to contribute to the growing climate of awareness and thought about children in this situation.

The research focused on the activities at the North West Carers Centre in Anniesland, where the staff voluntarily run an initiative specifically for young carers. This involves organising a monthly meeting for the children and providing activities - sports, crafts etc - to entertain and stimulate them, and also occasional outings (eg to a pantomime, a boat trip, a party) when funds and facilities can be mustered.

The research set out to examine the type and level of support the young carers perceive the initiative to provide. In particular, it sought to identify the key values of the efforts made to support them by the North West Centre staff, in order to assess the role for such centres within the overall national strategy for young carers.

## **SAMPLE AND METHOD**

The research was conducted on Wednesday 17th February at the Taktent Centre in Glasgow, where the Young Carers meeting was being held for that month.

Two separate sessions were conducted, talking to 7 and 4 children respectively, with a mix of girls and boys aged between 12 and 14.

The discussions were moderated by Clare Wade and for purposes of maintaining the respondents' concentration and keeping control, the children were prompted to talk and express themselves by using a range of words and ideas in a 'collage' exercise.

The sessions were tape-recorded, following which the tapes have been transcribed and this report prepared. While the research sample was small and the consequent report is slim, **the research nevertheless has been unequivocal in revealing young carers' depth of enthusiasm for, and dependence on, the efforts made on their behalf by the North West Carers Centre at Anniesland.**

## RESEARCH FINDINGS

### Young Carers

The children interviewed had varying degrees of caring responsibilities, from 'keeping an eye' on a diabetic brother through to full-time care of a dying parent.

Some were more naturally 'talkers' than others, but generally all were prepared to discuss the issue of caring relatively freely, often in a way that was almost touching in its dedicated, unselfish acceptance of their role as carer.

"I've been brought up to this"

"Everybody learns to do it in their own time and their own place in a different way"

Certainly they were all fiercely protective of their families and unquestioning in that it is 'what we do', even though it was clear that sometimes their lives are fairly tough and lonely and distress at their parent's distress is never far away.

"See each one of us here, we've been through a lot for our age because we've had the experience all our lives of looking after people and see when I used to look after my da I used to have to wash him practically, change him, feed him and when he got to the really bad stage walk him to his chair even and make him a cup of coffee and make his dinner and everything for him and it was really hard, and I used to have to sit down at night and read all about this illness that my dad had ...

"My dad said in his last days of living he was really really grateful for us what we'd done for him, he said if we weren't here he'd have been dead years ago"

"My mum says that if it weren't for my brother and I she'd have given up years ago, she's had plenty of chances to die"



The 'downsides' of caring are already documented and easy to understand and certainly here, the admission that life could be a struggle at times was fully endorsed. The problems they encounter are complex in that one often leads to another, all of which create additional worry and tension to the already stressful duty of caring for someone who is unwell.

Perhaps the fundamental problem experienced by all young carers is **lack of time** to themselves, which creates its own series of difficulties. Particularly:

- difficulty in making friends because it's hard to develop a social life
- lateness to school, or inability to do homework, leading to (undeserved) punishment
- lateness to bed, or lack of sleep due to night caring duties

"I don't get the time to go out so everybody thinks oh we don't talk to her, she's wierd and that"

"I've hardly got any time for myself"

Beyond the lack of time factor, another striking aspect of their lives is the intense amount of **worry** they have to live with, which would often seem to make them old beyond their years.

The mental pressure of looking after someone in itself is very demanding and their responsibilities are often serious (administering medication, organising others to help with caring, medical assistance) and the children are all the more remarkable for the way in which they cope.

However, beyond the physical side there are darker fears, typically:

- fear of the social work department becoming involved and possibly splitting up the family
- fear of the illness/situation worsening and consequent results - hospitalisation, even death of a loved one
- fear that they themselves might become ill
- fear that they might not be able to cope with it all, yet they *have* to keep going
- fear that there's never going to be any sort of break or let-out from their lot.

"My mum says that when I'm in the house she feels secure, but you don't feel secure because anything could happen to your parents"

"If something happens to my mum, I don't know who to turn to other than my gran and she's disabled"

Thirdly, a frequent problem for young carers is knowing who they can **turn to to talk**. All admitted that while they had friends at school, you wouldn't really think to confide in them about any home problems or worries you might have, simply because they wouldn't - *couldn't* - understand.

One or two claimed to have a sympathetic teacher or counsellor at school but this was not the norm - more, the feeling was that it was none of the school's business (underlying which, perhaps, is the fear of interference by the authorities and possibly dreadful consequences).

"That's all about the teachers wanting to know your private life, we don't interfere in their private life"

"We don't want to get involved with social work, if they were to see the state that some of our parents were in ... then for sure I don't think we'd be allowed there any more"

Conversations about the family were thus generally limited to relations or close friends who were fellow carers - although even here there were some reservations because you never quite knew if it would be a good time to phone or not, given they might be having a difficult time as well. More notably for boys, some chose not to talk about it at all.

"You've had it for the last 7 years, so what's the point in talking about it now?"

"Sometimes you get really really depressed and you're sat in the house, practically, you're probably in tears ... sometimes I feel I have to keep it in to myself, there's just this urge that just builds up in me and I just can't get it out unless I sit and talk"

"I feel I can't talk to my ma about certain things, if you've got problems at school with your teachers you think can I talk to my ma about this and you think um, she's got problems of her own and you don't want to tell her about that incase she might do something that she might regret or something, or she might damage herself and then I feel I have to keep it in to myself"

The poignancy of these remarks clearly illustrates the very real need to have access - regular access - to people they can talk to freely and with confidence, ie those in similar situations who understand at first hand the terrific pressure they have to live with.



### The Young Carers Group at Anniesland

The prominence of these issues for young carers - lack of time, worry, who to talk to - immediately illustrate the unquestionably important role 'the Group' plays in their lives.

**Quite simply, it answers all of the above problems and difficulties and is a single focal point representing release and relaxation, which is otherwise very hard for them to come by.**

Merely the mood at the Taktent Centre indicated how much of a treat it was to be out - everyone was in extremely high spirits and you could sense the atmosphere of people looking forward to the evening, determined to make the most of it all.

Without exception, they all claimed to love their Young Carers nights out - for the freedom, the happy mood, the friendship, the activities, the people running it - and overall, for the rare and truly valuable opportunity to have *time to themselves*.

Even though the session only lasts two hours, for young carers this is time entirely to themselves when they can be 'normal' kids, free to have a good time and do the things that others of their age group take for granted and can leave all their worries behind.

"You get away, away from your family, you don't need to worry about your family for a wee while until you go home again"

"It gets you out and about for a while and you're not hanging about on your own all the time"

"You not having to see your parents all the time"

Within the time spent at the centre, they find the opportunity to make real friends, made so much easier by the fact that everyone knows your 'secret' so it is no longer something to keep quiet about or worry that people will think you are wierd in some way.

Every member understands why you are there and what you need from the session. Immediately therefore, a climate is created whereby you can feel free to talk to someone if you need to knowing that they will understand, sympathise and very possibly have worthwhile, relevant advice to offer, based on their own experience.



"It's just a chance to chat to your friends and the helpers about what it's like and stuff and how you're coping with it"

"You know Pat will understand because she knows the same things we're going through"

"There's pals for different things and they're the pals I've talked to about this kind of problem"

"You just get the message that it's no' mean people who are here, it's just normal people like you"

Perhaps because they have so little in the way of leisure and treats the children are especially appreciative, but even allowing for this it was very clear that the group and *what it does for them* is something very big in their lives.

The outings and activities had been true highlights and they spoke of Pinnocchio (pantomime), the boat trip, the visit to the Sports Centre and a birthday party with real delight. As well as the sheer pleasure of such an event they had been excellent ice-breakers and it was very clear that the efforts of the 'staff' to organise things for them had been hugely appreciated.

"If my mum didn't have arthritis I wouldn't have met as many people as I know"

"When I first came I thought it was gonna be pure wierd because I didn't know anybody, but then I went on the boat trip and that's how I met everybody"

The 'words' exercise was very illuminating as an expression of their feelings and prompted many very positive remarks. From a list of some 50 words suggesting positive and negative (see appendix), the following were selected as those the Group represented for them.

Take Action	Turning point	Inspiration
Choice	Smiles	Confidence
Happy	Welcome	Satisfying
Delight	Treat	Good
Compassion	To the Rescue	Lucky
Live and Kicking	Free	Success
Dream	Laughing	Feedback*

\* understood as you get something back for all your hard work

"I'm just delighted that I'm out of the house"

"Turning point, because you're really really depressed and Pat's the person at the Centre you can turn to"

"When you walk in everybody's always happy"

"They (helpers) have problems of their own yet they take the time out for us"

"Free, because it's free time to yourself, you're free from all the hard work and stress and all that"

These words were clearly different to those selected as representative of being a carer (and there were notably fewer chosen here). These included:

Fear	Cross	To the Rescue
Insecure	Fear	Prison
Let Down	Big Heart	Jobs
Work	Sad	Battle

The small number of words chosen is taken to be reflective of their reluctance to betray their loved ones in any way, and indeed one of the (few) negative words selected about the centre was 'awkward' in the sense that you did feel you were 'talking out of school' in some way - which, while clearly essential to your own mental health, did leave traces of guilt and uncertainty.

"It is a bit (awkward), you're saying stuff about a person you're looking after"

Apart from this, the main - and almost only - complaint about the Group was that it didn't happen often enough which was a constant source of disappointment. The word 'disappointment' was chosen from the collage exercise, together with 'dead end', 'mixed emotions' and 'complain' for the same reasons, clearly illustrating their frustration and anxiety over the limited time the facility was available to them.

Everybody wished the meetings and outings could happen fortnightly as opposed to monthly (or even less often: on this particular night the young ones' session had had to be cancelled due to lack of available premises).

It was in fact quite hard to draw them on how things could be improved (beyond a few impossible dreams - jacuzzi, running track, better looking talent!) but the one clear requirement is a venue which has a reasonable amount of space for the meetings to take place.

While they were all happy and grateful for what they had, locations are invariably cramped and the opportunity to spread out (certainly at Taktent) would have meant a lot.

Further, they would love 'somewhere we could decorate' and call their own, to listen to music, where the girls could get together and 'do makeup' and other girlie things and the boys could flex their muscles in both a physical and emotional sense.

All were fully aware and prepared to recognise, however, that the fundamental barrier to such improvements is the financial issue, given that the whole initiative is run voluntarily, but even here there were some plucky suggestions regarding fundraising initiatives they could undertake themselves.

The lack of money, however, is a constant underlying threat to the young carers of the North West Centre, since if finance is not available, their 'lifeline' is under very real threat.

"I'm just afraid for Pat because this place could close down at any time,  
we've barely got any money"



## SUMMARY

1. This short programme of research has illustrated extremely clearly the unquestionable value of the North West Centre's efforts to the Young Carers it accommodates.
2. The Young Carers Group initiative has the unique characteristic of responding to the key emotional and physical needs of young carers:
  - somewhere where your time is your own
  - a place you can go and be a free, 'normal' person
  - the opportunity to talk freely and unashamedly to people who really understand your situation, and receive genuine and realistic advice based on first-hand experience.
3. The Group offers children opportunities they would almost certainly not find elsewhere, not only in respect of outings and events but also - and arguably more importantly - in respect of moral support, caring and friendship.
4. The staff/helpers are extremely highly thought of and their unselfish contributions are well recognised and highly valued by the children, who are well placed to appreciate the efforts of others.
5. As a result, the Group at the Centre is seen as a focal point representing release and relaxation and is highly valued as a key contributor to well-being and happiness.
6. The fundamental flaw in the Young Carers' operation is that meetings and events do not happen often enough, which is a cause of great disappointment and frustration to all concerned.
7. Fortnightly meetings would be extremely welcome and there is significant evidence to believe that they would be fully and enthusiastically attended.

8. Essential to the success of any such scheme, however, will be premises that can be regarded as dedicated to the use of young carers by being:
  - reliably available
  - spacious enough for the children to form separate groups for activities, and physically run about
  - ideally, somewhere they can decorate and call their own.
9. It is clearly the absence of adequate funding which is hampering the functioning of the Young Carers Group, and this research would strongly support the justification for financial provision to develop facilities and make provision for young carers at the North West Centre.
10. Further, as a model of its kind, the North West Centre offers a highly credible and successful blueprint for the development of facilities at other Carers Centres.
11. As this research has shown, the value of such Centres to young carers cannot be overestimated.



**work** have it all success

confidence **BRAIN WAVES**

awkward smiling **lucky**

to the rescue Inspiration

*nice* satisfying wonderful

*Choice* compassion **smiles**

**Laughing** dreams

**good** a turning point

Free **Delight** let down

amazing battle jobs

**big HEART** **sad**



WELCOME

**feedback**

LIVE AND KICKING

**TAKE ACTION!** access

Half-hearted

**FEAR**

**Prison** shame prisoner

plagued by trouble terrible

lead end **under fire**

**palaver**

**CRISIS**

Disappointed

**secure**

What  
really

paradise

**concern**

matters

sour taste **Relief**

touchy

