

The Hidden Reality of Young Carers

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Young Carers Initiative of Niagara (YCIN)

- First identified in 2002 as an issue by the Alzheimer Society of the Niagara Region
- YCIN formed in 2003 to promote awareness of the young carer issue across Canada
- 14 community agencies within the Niagara Region are represented
- 3 Phase Project: literature review, research, program development

Context

- ❑ No prevalence rates established in Canada
- ❑ Unknown if young carers' needs are currently being addressed in Niagara Region
- ❑ Local research needed to support program changes and additional funding for new programs to meet needs
- ❑ Previous research in UK and Australia have shown that caregiving can have negative impacts on the young person's development, social relationships, and family relationships.

Method & Participants

□ Study 1: Young Carer Interviews

- 14 participants (4 male, 10 female, aged 14-26) were recruited by YCIN community agency members
- Taped 40-90 minute semi-structured interviews took place in a mutually convenient location
- The initiation of caregiving was in early childhood
- Reasons for care were due to Multiple Sclerosis, Alzheimer's, brain injuries, spinal cord ailments, mental health and addiction issues.



Method Continued

- Study 2: Community Program Scan
 - A blanket fax was sent to all agencies listed in Information Niagara's database
 - Executive Directors of the agencies completed either a Children's Program Scan survey or an Adult Program Scan survey
 - One reminder fax was sent two weeks after the initial recruitment
 - 54 adult programs and 20 children's programs responded



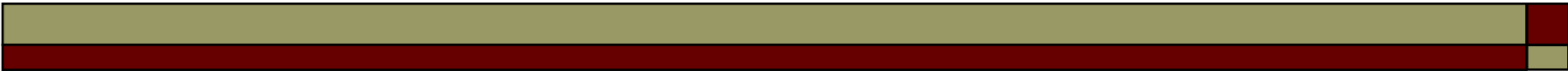
Results Study 1: Interviews

- Impacts:
 - Friends
 - Family Roles and Responsibilities
 - Intrapersonal
 - Education
- Advice for Others

Friendships

- Few friends were aware of situation
 - Limited emotional support was offered by those who knew of situation
 - Long-time friends most likely to know of the situation
 - Screened friends before bringing into home to minimize impacts on the ill person and judgments made about the situation
 - Often the first time friends learned of the situation was when they were invited into the home

- Loss of friendships due to lack of time to be with them



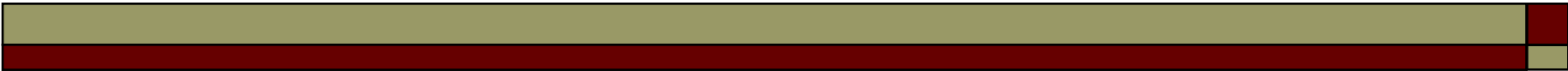
“I saw my other friends out doing normal things, playing having a good time, just generally being kids and I was forced to give that up and stay at home”

“They [my friends] used to phone every day or ask me at school to come and hang out and every time I said no, so less and less offers came after that and at one point I didn’t talk to friends for probably a year and a half”

Mike, 23 years

Family Roles and Relationships

- Multiple tasks were undertaken: medication management, companion, financial management, housekeeper, yard maintenance, grocery shopping, emotional supporter/confident, parent to siblings
- Saw role as part of being a family member
- Not always first born or female who took on caregiving role
- In some cases, parents tried to ensure there was “time to be a kid”
- Extended and immediate family not always a source of support
- Sibling relationships negatively impacted
 - Boundaries and roles blurred



“When my mom’s in bed and we come home from school, I make sure that everyone’s doing what they are supposed to be doing”

Amy, 18 years

“I’ve never had a conversation with my dad about *any* of this, even remotely, like about her being sick or you know about how it played out, and only now like does he start like saying thank you for doing that or that was great or, thanks for picking up Jessica or whatever like that’s a new thing”

Jane, 26 years

Intrapersonal Impacts

- Caregiver appeared to be the most intrinsically empathetic within the family
- Worry about parent evident perhaps as a result of lack of knowledge about the illness and outcomes
- Reports of young person experiencing depression, eating disorders, self-injurious behaviour, drug abuse, and bullying
- Feelings of isolation and lack of support evident
- Positive aspects reported were that they liked the “preparation for adulthood” and the maturity caregiving offered



“Sometimes I feel like I always have to do stuff, sometimes it feels that way, I just get overwhelmed”

Jane, 16 years

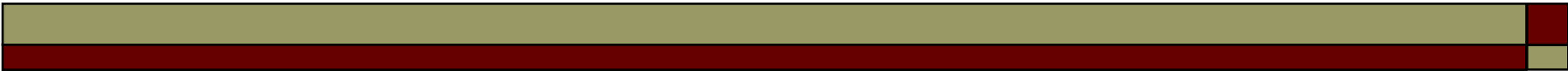
“I was different in the sense that I was always the most mature out of all of my friends and I never really acted like them I always acted just myself... the fact that I always seemed as if I knew myself I always seemed calm and I never really said like really stupid things, I never I never talked back to adults...”

John, 15 years



Educational Impacts

- Teachers unaware
- Mixed experience of supportiveness within the educational setting
- Distrust telling people for fear of being labelled
- Academic plans delayed



“The fact that I haven’t gone to school stresses me out but yet it’s scary, the fact that I am going to [go to] school so that’s over on this side.... so slowly every part of me feels like it’s consumed with I don’t have enough time to do what I naturally or normally need to do”

Barb, 20 years



Advice for Others

- While participants did not ask for help themselves, all participants recommended that other young carers tell people about their situation and seek help
- Recommended that others try to keep as “normal” a life as possible



Results Study 2: Program Scan

- Most programs were unsure if their client-base had children living in the home
- No programs screened for young carer needs
- Programs and services focused on the needs of the primary client, the person fitting their mandate
 - Reasons given for not screening for family needs were mandate and/or resource focused

Conclusions

- ❑ Young carers do not view themselves as “caregivers” but as being a good member of the family
- ❑ Impacts in all areas of their lives and continue into adulthood
- ❑ Role is secretive but want support from family and service providers
- ❑ Education about the illness/disability important to alleviate anxiety/uncertainties
- ❑ Service providers recognize there is a need for support but are reluctant to ask questions for fear of the added responsibility for care and the limited resources available
- ❑ Mandates need to support a family-centred approach to service provision
- ❑ While young carers like the maturity this role has offered, it is a challenge to balance caretaking tasks and normal developmental tasks



Recommendations

- The key is for professionals to ASK QUESTIONS!
- Medical professionals, educators, and service providers should be alert to young people in caregiving situations
- Important to educate the family about the illness and its implications
- Agencies and programs should take a family-centred approach
- Funders and policy makers must support young carers