

Within the next twenty years there will be another two hundred thousand over-65's living in this country. This remarkable fact emerged during a carers' seminar held at Clonliffe College in Dublin on Saturday, 26th April last to highlight the plight of carers in Irish society.

Organised by Care Alliance Ireland (CAI), the seminar brought together a panel of politicians, representatives of caring organisations, and individual carers to discuss the needs and entitlements of this country's estimated 200,000 plus carers.

"It's been estimated that over €2 billion every year is being saved to the Irish economy and the Irish exchequer as a result of the work that is done in homes throughout this country, much of it unrecognised," Brian Hayes of Fine Gael told the seminar audience. This is part of a global phenomenon. A United Nations study has found that €1.5 trillion worth of unpaid, unrecognised work is done throughout the world every year, much of it by carers.

The issue for carers, however, is not how many euros their work is saving the state each year, but how inadequately recognised and resourced their work is. CAI's chairperson Mary Healy pointed out that this is a root difficulty facing the caring community in Ireland. "Waiting lists for hospital beds are a visible and highly emotive issue," she said, "but the unseen struggle for survival in the community and at home does not get you attention."

Many carers are middle-aged women caring in the home. Their caring work is often taken for granted as a normal part of life. This view, though, does not recognise the vast savings to Irish taxpayers their work creates. Nor does it take account of the difficulties endured by carers. Their neglect too often results in unnecessary physical, psychological, social and financial hardship.

This point was made forcibly at the seminar by Ciarán Goulding of the Independent Health Alliance (IHA). A sufferer of MS who holds a full-time job, he argued that, "The rights of our constituency have never been acknowledged. They've been totally misrepresented as in the Education Bill and the Disability Bill, which was an insult to anybody who was involved in disability issues. We've a patronising concept of the disabled or those with special needs.... Since the dawn of time our basic rights and civil liberties have been violated."

The Independents Health Alliance is a recently-formed grouping of eight election candidates aiming to redress the injustice of 'successive governments [who have] failed to provide the necessary infrastructure to support our more vulnerable citizens'.

A case in point was that of Majella Murphy, an individual carer who shared her experience of caring with the seminar. A former teacher, Ms Murphy gave up her job to care for her daughter Shiona. Three-year-old Shiona has a congenital heart defect requiring 24-hour use of oxygen which prevents her from attending school. Majella and her husband have faced many difficulties as carers – only through sustained efforts, and having moved from Dublin to Wicklow, did they qualify for a medical card to cover the €4,000 a month costs of Shiona's medications. And despite losing her teaching income, Majella has been disqualified from receiving a carer's allowance as a result of the means-test. Added to this, her constant care for her daughter has resulted in her own social isolation. Having to struggle to qualify for, or even discover, their entitlements had made their experience all that much more difficult.

Another carer shared from the audience that her allowance is €122.60 weekly. “My job is 24-hours a day,” she said. “I care for my mother, my father’s an asthmatic, I have a grown-up daughter, my husband and I are separated, my sister-in-law suffers from depression and I’m minding her two kids.” As the only woman political candidate at the seminar, addressing a predominantly female attendance, Frances McCole of Sinn Fein noted ruefully, “I can’t help but think that... perhaps if Leinster House was made up of as many women proportionately as there should be then maybe all these issues would have been addressed long ago.”

One member of the audience explained that he had to stage a protest on the steps of a particular hospital before his schizophrenic step-son was given day-care facilities. Within three months the patient was banned from hospital due to behavioural problems, and since then has been denied any further day-care services. While at home his son’s disruptive behaviour was a continual cause of hardship for the family.

These situations, representative of the lived reality of so many people, makes for grim reading, which is perhaps why their stories so rarely appear in the media. The IHA’s Mark Harrold, a psychologist working in Dublin, told the conference: “What I intend to do is go into the Dáil to change attitudes and change priorities.... And I’d have to say that there’s also work to do in the media.”

Before the foundation of Care Alliance Ireland in 1995, carers in Ireland were effectively without a voice. This year, in consultation with its members, CAI drafted an Election Manifesto and circulated it to all political parties. In the expectation that the quarter of a million voters it represents will have the power to set the parties’ health agenda, the Election Manifesto identified three core issues. Noting that, “Family carers provide the vast majority of community care to older people and those of all ages with a disability,” Ms Healy outlined carers’ needs:

- “1. A new non-means-tested cost of care payment to all carers. This would be payable to full-time carers, be independent of the carers’ allowance, and be payable on the basis of a medical certificate.
2. Expansion of respite care to all full-time carers. Full-time carers are entitled to regular breaks and part-time carers need respite also because they generally have other jobs to do as well. This respite care needs to be flexible, non-means tested, in-home where appropriate, or in acceptable settings with trained staff.
3. Emergency and out-of-hours services. Caring does not stop at 5pm or at weekends and neither should support services. Carers need back-up services 7 days a week. If a carer becomes ill, who takes over the caring role? An organised emergency service should be available to all carers on a 24-hour basis.”

CAI called on all political parties to adopt these core policies, and invited candidates at the seminar to outline their parties’ responses to their manifesto. Each of the parties represented – neither Fianna Fáil nor the Progressive Democrats were represented, though invited – agreed that these carers’ issues needed to be addressed by the next government.

Despite the inaction of successive governments on caring issues, it seems likely that the situation will have to change significantly over the coming years, in line with international trends. Gerry Broughan of the Labour Party pointed out that the British Labour Party has introduced a carers’ premium - by which carers already in receipt of a primary payment are also given an additional partial payment of the carers’ allowance -

and that the German insurance system makes provision for caring, in recognition of the fact that 40-50% of the population will at some stage be in need of care.

CAI has also called for legislation to ensure that carers have a statutory right to assessment and services. Niall Crowley, Chief Executive of the Equality Authority, who addressed the seminar on Saturday, stated that, "The Family Status ground in the Employment Equality Act and the Equal Status Act places carers at the heart of the new equality agenda. Carers need to be aware of their new rights under the legislation just as carers need to be more visible in the development of new equality strategies for the workplace and for the provision of goods, services and facilities."

The rights-based approach to caring was echoed throughout the seminar. As Kevin McLaughlin of the Socialist Party put it, "This is not about charity, it's not about generosity; this is about rights, and the state has an absolute obligation to implement and put whatever resources are behind the guaranteeing of people's rights... full stop."

It is estimated that 1/3 of carers become a financial drain on the health services as their health deteriorates due to caring. The family remains the main source of caregivers, who are predominantly women of middle-age. If the carer stops caring for health reasons, the cost to the state of replacing that care is far greater than it would cost to support the carer in their work. Without their continued work, our community care system would collapse soon, leading to the acute hospital system being completely overrun.