

One for All

Age Friendly Health
and Social Care:
Principles and
Experience



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INTRODUCTION

A point of political transition, such as we are now experiencing in Ireland, provides an opportunity to directly address problems in Ireland's system of health and social care.

As an alliance of eight NGOs in the age sector, Older & Bolder champions the rights of older people. Our member organisations – Active Retirement Ireland, Age & Opportunity, Alzheimer Society of Ireland, Carers Association, Irish Hospice Foundation, Irish Senior Citizens Parliament, Older Women's Network and the Senior Help Line – share a vision. This is a vision of an Ireland that affirms ageing and the rights of all older people, enabling everyone to live and die with confidence and dignity, as equal, respected and involved members of Irish society.

Looking to health and social care, Older & Bolder believes that the challenge facing us is to shape a system of care and support that pools costs and risks across the generations on a basis of social solidarity. Our ambition is for an age friendly system of health and social care that meets the needs of older people, and of people of all ages.

This publication, One for All, is presented in two parts. In Part 1, Older & Bolder presents a statement on health and social care, setting out the position of the alliance on the imperative to dismantle our two tier system of health and social care. We highlight principles that must underpin any plans to repair and reshape our existing system of health and social care if it is to adequately meet the needs of older people.

In Part 2, the focus is on older people's direct experience of the health and social care system. Independent researcher, Maura Boyle, presents a summary of the health experience of participants in Older & Bolder's previous report, *Feeling the Pinch: One Year On* (2009). Maura Boyle has also researched illustrative case studies of three individual older people with health and social care issues. Their experiences, anonymised, are included in Part 2.

One for All provides a foundation for the development of Older & Bolder's position on age friendly health and social care. This is a foundation that the alliance intends to build on in the coming months. As in all other areas of our work, we will do so in direct consultation with older people around the country

This is a unique moment in our country's history; the prospect of a new government brings with it the opportunity to reshape our systems of health and social care for the better.

In this statement, Older & Bolder, sets out key considerations that must be taken into account when creating a health and social care system that meets the needs of older people and people of all ages.

Here we identify inequalities that must be redressed and we describe the changes required to meet older people's specific health and social care needs. Meeting these needs will create a better health and social care system for all citizens.

Transforming Care

The systemic problems in Irish health and social care, inadequate capacity, overcrowding and long-delays affect all Irish people, but they do not affect us equally. The unfair reality is that the ability to afford private health insurance, our age, medical card status, category of illness and even where we live can affect access-to, waiting-times-for and quality-of health and social care.

Along with this, out-of-pocket expenses (e.g the new prescription charges, GP and dental charges) are discouraging older people from making proper and prompt use of primary care services. This results in later diagnosis and treatment and adds pressure to an already strained Accident and Emergency service. Related to this, a lack of capacity in community care and shortages in step down facilities are causing delays in discharges adding to pressure on the acute hospital system.

While medical cards are highly valued, the services covered are being reduced in that those entitled to the card now have the added expense of prescription charges and routine dental expenses.

We know from talking to older people that the loss of a medical card through means testing can mean the possibility of very large medical bills, which can be particularly difficult to absorb for those living alone.

Recently, many older people have been priced out of the private health care market due to the price hikes of up to 45% by VHI and Aviva. Despite having contributed to health insurance funds for decades, many older people are frustrated to find themselves being pushed out of cover when they are most likely to need it.

These are significant challenges but with political will and the direct involvement of older people we can shape systems of care and support that pool costs and risks across the generations.

Universal Health and Social Care for All

We need to dismantle our unequal two-tier system and replace it with a universal system of health and social care.

Currently, access to health and social care is too often affected by factors such as age, ability to afford private health insurance, medical card status, category of illness or even geographic location.

We need a universal health and social care system where access to, waiting times for, and quality of health and social care is provided on the grounds of seriousness or urgency of illness.

A narrow focus on GP visits and access to hospital services is insufficient in the future evolution of a universal health and social care system.

Plans for the long-term development of a comprehensive system of universal health and social care must include provision for the long-term care of older people in the community and, where necessary, in long-stay residential care

Contribution on the Basis of Ability to Pay

We need a health and social care system we can believe in and contribute towards, through income tax or social insurance, according to our ability to pay.

No-one should be denied care because of their financial situation. Those unable to contribute should be subsidised by the State and those who can afford to pay more should pay more.

We need to end Ireland's regressive system of point-of-use payments for GP visits, prescription charges and A&E charges. An alternative model providing comprehensive cover for all citizens, making care free at point-of-use, would encourage patients to make proper and prompt use of primary care facilities, aid prevention, early diagnosis and treatment and redirect focus from costly acute care.

Any plans to finance health and social care through a 'money follows the patient' model, where funding is provided on the basis of the number of patients treated,

must ensure that hospitals and care services are not penalised for treating older people with multiple conditions (co-morbidity) and people of all ages with complex care needs.

"One in four private patients in Ireland who had a medical problem in the previous year did not attend their GP due to financial concerns and amongst paying patients it was the poorest and those with the worst health who were most affected by charges" Consultation charges in Ireland deter a large proportion of patients from seeing the GP. European Journal of General Practice, Vol: 13 (2007)

"The high levels of "pay-as-you-go" financing ignore ability to pay and give those who can afford it faster access to care" Press release, Publication of Report of Expert Group on Resource Allocation, Financing and Sustainability in the Health Sector (9 July, 2010)

"High pay-as-you-go GP charges are known to deter use of care, increasing the risk of later detection of medical problems, with the likelihood of higher costs in terms of health care in the longer term" Report of Expert Group on

Resource Allocation, Financing and Sustainability in the Health Sector, ESRI (2010)

A Joined-Up System

There is general consensus that the development of a fully integrated system of primary care, community and continuing care and acute hospital service is optimal in terms of both safety and cost.

Developing primary care as people's first and continuing point of care will ensure quality, accessible care and relieve pressure from our overcrowded and crisis-laden accident and emergency service.

In a real primary care service, citizens can avail of a range of coordinated and cross-referring services under one roof provided by a range of health and social care professionals.

However, there is concern that, so far, many of these centres are primary care teams in name only. Many primary care teams do not operate within the one centre, meet infrequently and some are entirely without GPs.

For older people it will be particularly important that primary care teams can provide age-attuned (gerontological) care to allow for

- > The safe management of prescriptions, as many older people take multiple drugs to treat multiple conditions.
- > Appropriate chronic disease management, as one in three Irish people report having a chronic illness and this number increases with age.
- > Diagnosing, advising and managing age-related conditions such as dementia, stroke, falls, incontinence, bone health and immobility.

Good health does not come from our health care system alone. We know that social, economic and environmental conditions play a major role. Accordingly, our health and social care system must 'join-up' with services and supports provided by other key Government departments. It must join up with

- > Public transport, without

which many citizens, including older people, would be unable to access local, regional and national health services

- > A range of living options and home care supports which are vital to meeting older people's needs.
- > Physical, social and cultural programmes that promote greater participation by older people. Recent Irish research has documented the importance of these programmes in sustaining older people's health and wellbeing.
- > The National Positive Ageing Strategy provides the necessary framework to enable the 'joining up' of Government departments and other stakeholders. Given the importance of the Strategy for Irish citizens' health, it is vital that the HSE engages fully with this process.

We know that countries with more comprehensive primary care systems tend to have lower healthcare costs, lower mortality

rates, longer life expectancy and greater satisfaction with their healthcare system. Primary Care: Balancing Health Needs, Services, and Technology. New York. Oxford University Press (1998).

Ensuring Dignity and Independence

Older people have consistently emphasised to Older & Bolder their strong preference for remaining in their own homes where possible and maximising their independence in all circumstances.

In addition to quality and accessible health care, a continuum of social care is vital to ensure older people's independence and dignity; in the home, in the community and in residential care right through to quality end-of-life care. Social care includes two strands; practical help with activities such as cooking, cleaning or shopping and; personal care assistance with eating, dressing and bathing.

Older people receiving Home Care Packages and their families are very positive about them and recognise how important they are in enabling them to stay in

their homes for longer and in enhancing their quality of life. The NESF evaluation of the Home Care Package Scheme (2009) has, however, revealed stark regional differences in how the Scheme is implemented which result in inconsistencies and inequalities for older people and their families.

The lessons learned from this evaluation pave the way for the future development of community care. The issues highlighted include the importance of adequate funding, consistent eligibility criteria, standardised assessment of individuals' needs, proper data collection and the implementation of agreed standards of service delivery. The recommendations from this evaluation have direct application to many other areas of care relevant to older people including home help services and Carers' supports. These recommendations must be applied to assure the effective development of our community care system.

Shedding Light on the System

Quality information to meet the needs of individuals

Older people and their families consistently report difficulties in accessing clear information about their health and social care rights and entitlements. We know that at moments of crisis and transition the availability of precise information is particularly important.

Typically, older people are told to contact their GP or Public Health Nurse if they want to find out about Home Help services, Home Care Packages and other community care services in their local area. They have no way of knowing what quantity of services is available locally, what the criteria are for accessing those services and how decisions are made about the number of hours assistance they may receive and why.

Supports and services are available at the discretion of local health offices, rather than on the basis of clear eligibility criteria, resulting in great regional differences.

We need a transparent Health and Social Care System that is answerable and accountable to citizens' queries and concerns

about service availability and quality. Planning, decision-making, funding and the implementation of services must be open and inclusive.

“Everyone should be able to understand the Health and Social Care system, know what they are entitled to receive and how they can influence decisions about the system” (Resource Allocation, Financing and Sustainability in Health Care, ESRI, (2001)

“The first hurdle faced by many people trying to access HCPs [Health Care Packages] is the lack of readily available information, and general lack of awareness of HCPs among potential beneficiaries and professionals ... Most described a process of being passed around various offices and personnel, with one submission stating that it took 18 telephone calls over a 10 day period to finally find the ‘right’ person to talk to.” Implementation of Home Care Package Scheme, NESF (2009)

Quality information for better planning

At this time of political change there are many promises to improve home and community care services and expand step-

down facilities. These changes are necessary but we do not have the information systems in place to get a good picture of what is currently available in home and community care.

We need an audit of home care, community care and primary care services to establish a baseline for planning and to improve citizen’s understanding of services in their area.

HealthStat, which provides good data about our acute services, must be expanded to provide a complete picture of home care, community care and primary care services. Without this we cannot make proper plans and intelligently allocate resources to ensure good service provision and value for money.

Specific health and social care issues require a strategic response. Older & Bolder supports its member organisations who have been to the fore in calling for strategic responses to carers’ supports, dementia supports and palliative and end-of-life care.

Part Two. Older People's Experience.

Researched and written by Maura Boyle

Health Experience from previous research

In our study, “Feeling the Pinch: One Year On” (Maura Boyle & Joe Larragy, 2010), I spoke to seven older people about how they were faring financially on their pensions.

The study could be best described as a set of true stories about the dilemmas and choices facing older people, almost all of whom were depending on the State Pension as their sole source of income. All but one had left the labour force, and so, their income was fixed. Most had dipped into their savings already and were no longer in a position to save, and indeed a number of them had lost some of their savings in the financial crisis.

All but one had Medical Cards, which covered their GP visits and Prescription charges (except the 50 cent charge introduced last year). One lady had lost her Medical Card due to the introduction of means testing and was deeply

upset, while another had just passed the means test and was greatly relieved. The Medical Card was highly prized by all the people spoken to, given that almost all had some chronic condition such as arthritis or high blood-pressure, or both, and were on regular medication. So, all needed to see their GP regularly. The Medical Card was worth in the region of €170 each month to them, in monthly GP fees and prescribed medicines. However, they had the added insurance of knowing that if they became ill, they didn't have to consider if they could afford to go back to the GP or get further prescribed medicine, such as antibiotics, for instance.

For most of those in “Feeling the Pinch”, the proximity of family for social care, transport, advocacy and a sense of security was crucially important. For instance, in the case of the one lady, Diane (81), who had lost her medical card due to the introduction of means testing, her lack of family support left her very vulnerable. When she had hip-replacement surgery, a friend dropped her off at the hospital, and she came home by taxi. However, she wasn't able to cope alone at home and she

had to book into a private nursing home, to which she was brought again by taxi. Without a Medical Card and living alone without family close-by, the expenses mounted up and the nursing home care alone cost over €1,000, over and above the VHI benefit.

All seven people spoken to in the study had continued to pay for private medical insurance. It was believed that one would be seen more quickly by a consultant, and they feared that they would encounter long waiting lists without it. That fear was well-founded in one case, where a man was initially told it would be nine months before he could be seen by a consultant, and when he said that he had VHI, he was able to be seen within a month. He was found to have cancer that was treatable if detected early.

There was also unease about local hospitals being wound down in favour of centralised “Centres of Excellence”, which in many cases would require a journey of over an hour to reach them. This was especially a worry in the event of strokes, where best practice requires a patient to be attended to as soon as possible, to prevent

irreversible brain damage. In the current Irish Heart Foundation’s awareness campaign, the T in the slogan “FAST” refers to Time.

Transport was also a key issue in accessing health services. In “Feeling the Pinch: One Year On”, all had Free Travel Passes and these were a much appreciated benefit. However, the public transport grid was frequently of little use in allowing older people to actually get to their local GP, their pharmacy, their local A&E, their local hospital, not to mention their regional hospital. Many people were holding on to their cars and trying to meet the costs involved, so as to continue to have access to these and to other essential services.

In summary, almost all the older people spoken to in “Feeling the Pinch: One Year On”, were reliant on the fixed income of the Old Age Pension. All had a chronic illness which required them to see a GP regularly and to take prescribed medication. The Medical Card was highly valued by all, but private medical insurance was maintained to avoid long waiting lists should they require seeing a consultant or having elective surgery. Losing

the Medical Card through means-testing meant the possibility of very large bills, especially if one was living alone. Some expressed concern about the centralisation of hospital services because they would take longer to reach in an emergency. All maintained private transport, despite having Free Travel Passes, because the public transport grid did not provide them with reasonable access to services, including medical services such as their GP, pharmacy, local and regional hospitals.

RIGHT CARE, RIGHT TIME, RIGHT PLACE

Declan's story

Declan is 75 years old and lives with his wife Brenda, in a small rural village in the west midlands. Declan worked as a skilled craftsman and he and Brenda have six adult children. They live in an old, two-storey house, which Declan has modernised over the years. The village that they live in is about five miles from the local town. One of Declan and Brenda's daughters, Angela, is married with a family, and lives about a mile outside the village. The two families see each other daily and provide mutual support for one another. Another of their daughters lives close-by and they see her frequently too. Both Declan and Brenda live on the Old Age Pension and have Medical Cards. They don't have private health insurance. While they have Free Travel Passes, there is just one weekly bus to the county town, so Declan has a car for their everyday needs.

Their local hospital is twelve miles away. However, the regional hospital is approximately fifty miles away and is only accessible by secondary roads. It is also on the far side of the city which can cause further delays. The regional hospital has been designated a "centre for excellence", and many of the services once offered in the local hospital have been discontinued.

The last five years have been difficult ones for Declan in terms of his health. About five years ago, he developed worrying symptoms and his GP did some tests. As Declan tells it

When I went in to Dr. B., he said "We'll send you to the local hospital. There would be a minimum wait of five months before you would be seen in the Regional, even to be assessed. So I was referred to (the local hospital) and they did the colonoscopy and a biopsy. The specialist said "There's something there, but it is too close to Christmas (10 days away). ... I'll bring you in after Christmas and I went in straight after Christmas."

Declan had cancer of the colon and that week, he had surgery

to remove the affected area. He was quite ill for some time after the surgery, but after a point, he seemed to turn a corner and has continued to improve since. He now goes back for a colonoscopy every two years and has had some polyps removed since. Declan is very happy that he was seen quickly and has recovered so well. He has nothing but praise for the doctors and nurses who took care of him.

The doctor said "Every two years I was to go back." The last time I was there, he said "I'll see you in two years" and that was that!"

However, last year, Declan suffered a stroke. He remembers the experience in detail. He had gone to the turf-shed to bring in some turf for the stove.

I caught the bucket with the back of my (left) hand and (I thought) "What's that feeling? That doesn't feel right." I went to pick up a sod of turf and I couldn't....I picked up the bucket and I came in and left it on the floor and I said "I've lost the power in my hand."

Declan thought he was dying. He was very frightened. Brenda noticed that his mouth had begun to sag on the left hand side also.

Brenda sat him in a chair and rang Angela, their daughter. Luckily, she had their doctor's mobile number and she rang him. The doctor arrived within 10 minutes. By then, Declan's speech was gone and the doctor said "Declan, you've had a stroke.... " Declan describes what happened next:

"Angela arrived and Dr B said "I could order an ambulance, but you would be best to get him up there (to the local hospital). The sooner you get there, the better they can treat him." The doctor rang ahead to the hospital and the staff were waiting. I got into the hospital between half to three-quarter's of an hour... I was well looked after straight away. They brought me down to Coronary Care. I was only three or four days in Coronary. ... Later, the doctor said that if I had to go to (the regional hospital) given the time of day it happened, at 3pm (and the traffic) I may not have made it. He said this is the secret, getting in quick, in time."

Declan soon began to have physiotherapy and occupational therapy. Just 15 days after he had been admitted, the doctor came to him and said "I am going to discharge you. You have progressed so well, I don't think they can do any more for you". By then, Declan could go to the bathroom, undress and wash, dress himself and shave.

When he was discharged, Declan had the services of the local intensive care team which included a nurse, physiotherapist, occupational therapist and speech therapist. The occupational therapist came several times a week and the physiotherapist continued to visit for about a month. He says that the attention that he got was "top class...top of the range!"

Declan and Brenda would be upset to see any further cut-backs to the services available in the local hospital. The regional hospital, as mentioned is 50 miles away via secondary roads from this rural village. In fact, what this amounts to is the centralisation of hospital facilities.

Both Declan and Brenda have Free Travel Passes, but there is no reasonable public transport service available to reach this regional “centre of excellence”, fifty miles away. The only way such a journey could be completed by public transport would be for Declan to get a taxi to the local town, take a train 30 miles in one direction and then take another train 40 miles in a different direction, at the end of which he would need to get a taxi to the hospital. This is clearly not a real option if one is trying to meet an appointment or if one is weak or ill.

Another point which Brenda makes is that even if one were going to visit someone in hospital or attending a specialist in the regional hospital and using a car, the journey would cost at least €30 in petrol, €10 for the hospital car park and given the length of time involved, you will need to get at least a cup of tea and a sandwich.

“I mean, it’s an expensive day out when you are just depending on a pension. It would cost £50. We’re not too bad at the moment, but if there was just one of us on our own, it would be a strain, it would be a big strain.”

Declan sums it up:

“The service I got? Oh, both times, the stroke and the operation, it was very good in the local hospital. The doctor that saw me, - he said that I could not have my cancer surgery there now, due to cut-backs. He said ‘They’re sending all that up to a centre of excellence.....’”

NEEDS DON'T STOP AT WEEKENDS

Mary's story

Mary is in her early 80's and lives alone in a very rural area in the East midlands. Her non-contributory Old Age Pension is her sole source of income. She has a Medical Card but no private medical insurance. Mary lives in a 20 year-old single-storey house, near the site of the farm-house in which she was born and reared. Her nearest neighbour is about 10 minutes away.

Mary was born with a developmental birth defect which has affected her mobility throughout her life. In the last

four or five years, she has been confined to a wheelchair. She describes her current state of mobility:

“Well, it’s gone fairly bad now. I can’t stand at all. I can’t walk at all. I used to be able to walk, but now, I just have to use the wheelchair all the time...The electric chair is grand, but I can only stay within my own house, my own environment. I’d be afraid to chance going too far. I’d be afraid the battery would run out.”

Mary has relatives living within a few miles and they are supportive:

“Well, as best they can. They’re good. All I would ever have to do, at any stage, is ring them. They would never leave me stuck.”

Mary’s house was built before regulations requiring that houses be wheel-chair friendly, so Mary finds that her door-ways are too narrow for comfort and the height of her kitchen sink means that she is unable to wash her dishes. While she can manage to turn on her lights, the height of the switches makes it difficult. The only modifications that have been made to her house are that it has been tarmacadamed around outside and a young relative built

a small ramp to replace the step up to the front door.

In the last few years, Mary’s eyesight has deteriorated to the point where she is no longer able to read and she has to sit near the television to see her favourite programmes. This is very difficult for her because she was an avid reader from an early age and was a highly skilled knitter. In fact, she was involved in her local Active Retirement Club, and she used to help teach knitting to the children in the local school.

The loss of her sight has had a big impact....

“because I loved reading, I loved knitting... When my sisters would be out dancing, I’d be reading and it never bothered me. I’d be happy to sit at home...I often read ‘til two o’clock in the morning...I used to knit cardigans and jumpers out of the women’s magazines. I knit baby clothes for all my nieces and nephews. I have none of that now. That’s all gone out the window. You know, I feel so idle now.”

As well as her lack of mobility and the loss of her sight, Mary is on medication for a heart problem which occurred some years ago, as well as medications for a stomach ulcer and painkillers. She has not experienced any waiting lists in relation to her other illnesses. In the case of her heart condition, she was admitted to her local hospital and then transferred to a Dublin hospital in about a fortnight, for an ECG. Luckily, she does not need to see her GP very often. That is a four-mile journey and although the GP would make a house call on occasion, Mary would normally have to use a wheelchair taxi. Her other main outings include a once a year shopping trip with the Active Retirement Group, for which she requires a carer. She also goes to the Christmas party, which sends out a bus to collect her. For all other journeys Mary needs to travel by a Wheelchair Taxi.

Mary's biggest household bill is her fuel bill. To date, this winter, she has spent €1,400 on central heating oil and €500 - €600 on briquettes. During the very cold weather, Mary went into respite care in a nursing home.

In terms of social support, Mary has 10 hours home-help service a week. That works out at two hours a day each weekday. The home help comes for an hour and a half in the morning, and a half-hour in the evening. In the morning, she does the basic household shopping, whatever has to be done for the dinner and the tea. She washes up the delph and, in the evening, she settles up the bed and puts on the light.

On weekends, however, Mary has to pay somebody to come in the mornings to do the basic jobs. This costs her €40, which she pays out of her pension. She could not afford to have somebody come in the evenings too. "If I had her twice a day, I would be paying €80 out of my pension", she says. The week-end private home-help leaves the bedroom settled "as it should be for the night". After that, Mary is alone. She manages to put on the light and pull the curtains herself. At week-ends, Mary makes do with a frozen dinner which she cooks in the microwave. Besides that, she can manage to make a cup of tea for herself. Mary, who made a vow as a child, not to be "moaning and complaining" considers being without home-

help cover at week-end a big gap in the social support services that she needs.

“As I say, I’m not able to manage during the week, (but) I can do what I like to look after that on Saturday and Sunday. That’s the way it is. It seems so silly.”

When asked about her main concerns for the future, Mary replies

“Look, I’ll leave it in God’s hands. Sometimes, I might not be feeling that great at night and I say ‘Gosh, will I be in it in the morning?’ But I want to stay at home, in my own home, as long as I can. I don’t want to go into residential care. (With a bit more support) I would say I would be able for some time yet anyway.

BORN IN A TENT

Maggie’s story

Maggie is a 67 year old woman who is a member of the Traveller Community. She lives with her husband in a 25 year old bungalow in a North Dublin suburb. The house is part of “house-group” for Travellers, in which about 40 families live. Maggie has eleven children, almost all of whom are married. Many of her children live close-by. She says that she would be lost without them, but that she helps them too. Maggie has a Medical Card. While her GP’s practice is near her, she needs a lift to get there, because of arthritis in her knees. She finds her (female) GP very nice and very easy to talk to.

Besides the arthritis, Maggie is on medication for blood-pressure and for a heart condition. She had what was described to her by a hospital doctor as a mini-stroke last year. She woke in the night with a bad headache in one side of her head, got up to get a drink of water, felt dizzy and fell against the wall. Her husband drove her in

to the nearby A&E, and although she was seen by the triage nurse quickly and was given some tablets to ease the pain, she had to wait two hours to see a doctor. She was taken for an X-ray and was admitted to the hospital, but she was waiting two days in the A&E department before being transferred to a ward. After a scan, doctors were unsure what the problem was, with one telling her it was a mini-stroke and another suggesting that it may have been a bad migraine, although she had never suffered from migraine before. Her medications were reviewed and one of her medications changed. Despite the wait in A&E, Maggie said that she was treated well in hospital and had no complaints about her own experience.

Over twenty years ago, Maggie joined a community health course for Traveller women. Before that, she says that, like many other Traveller women, "If you asked me anything about my body, I could not tell you, although I was the mother of 11 children." The main reason for this was that Maggie had not been educated to read or write. After her training, she tried to help other Traveller women and

she still works as a Primary Health Care Worker and liaises between the health and social services and the Traveller community in an area of North Dublin. She describes her work:

"We go out to the Travellers and we bring the information on the health services, and how to use the health services. We take the information back to the health service providers, trying to close the gaps between the (two).

While Maggie believes that her own education and experience has made her less afraid to ask questions and better able to defend herself against discrimination, she believes that that does not hold true for other Travellers.

"There's a lot of older people (Travellers), gets it very hard to get to the health services, they have no way of getting to the clinics to get to their appointments, (because of transport). And then, when they do go in, they're left waiting for hours and hours... I know an old woman that was eight hours waiting to be seen (in A&E). That was a long time for an old person sitting waiting to be seen to, and in the height of pain.

Some of the old people get dropped off, and they may have no-one there with them, and they're left waiting.... and God help them, they haven't it in them to get up and say 'Well, I'm hours here now.' You see, you are taught all your life, you're getting discriminated against all your life, that you're just put at the back of the book, what more do you expect?"

She believes that discrimination against Travellers runs right through Irish society, and that includes the Health Services.

For instance, she says that it is extraordinarily difficult to get home-help, meals-on-wheels or nursing home care for a Traveller person. She tells a story of an elderly friend of hers for whom she could not get a home-help:

"She had a son living near her, but when you're an old woman, you need more than your son to help you. I mean, you have a bit of dignity, of pride, in your body. You'd like if it was a woman, someone with you, to help.... (Then) she started forgetting. Probably it was her age; she was coming up to her 90's and ...she used to go back lighting an old range and (one day) her feet went on fire. Only for someone came in and quenched it, she would be burned to

death... So, he tried very hard to get that woman looked after and he could get no place to put her into, his own mother. (Then) she walked out the back door, just her back step and she was alone (and she fell) and no one knows how long she was there, but when her son walked in and got her, the ambulance was sent for. She was three weeks above in (the hospital) and then she died....I knew she was going to die fairly soon. She was old, but they could have given her a better death."

Maggie herself has a sister suffering from Alzheimer's, who is currently being cared for in the Alzheimer's unit of a hospital. She went to visit her recently and when meal-time came, a nurse handed Maggie a beaker of tea which Maggie helped her sister to drink. Her sister has become very thin and Maggie is worried by the weight loss. Maggie was waiting for the hospital staff to bring her sister's food, because they were bringing it to everyone else. However, no meal came. So Maggie walked down through the unit and saw some patient's being helped to eat and others eating by themselves. So Maggie asked a nurse:

“Is there any food going up to (my sister)?” She said ‘Who’s that?’ And I said her name again, and that she got no food. And she said “Oh, she’ll get it after.” That broke my heart, the way she answered me. So, if that was because she was old, or because she was at the very end (of the corridor) or is it that she’s a Traveller, I don’t know.”

Maggie refers to “The All Ireland Traveller Health Study (Our Geels)” published last year, which states that only 3% of Travellers are aged 65 years and over, compared with 13% of the general population. She makes the point that when health policies for the elderly are being formulated, they would need to take account of this demographic difference. By Traveller standards, one is old much earlier. Maggie’s own mother died at the age of 40, after enduring a long labour in a caravan, as Maggie says “for the want of understanding”. She was eventually brought to the hospital, where the baby was born, but her mother died. Maggie herself was born in a tent.

And that’s the saddest part, for those that do go on living up to 65 or 70, when you go back on the life they had, and they had big families in the past... If I come across an old woman today ... she’s just, I can’t describe it to you, the way she looks, the way she feels, from the hard life she put in. That’s all down to discrimination, not getting looked after, not getting treated the way they should be treated.

Maggie would like to see an end to all forms of discrimination against travellers, including those in the health services. She would like to see young Travellers being well-educated and that they would have access to jobs, such as nursing, teaching and medicine in the future.



Support equality for older people
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