



“Time To Care, Time To Live”

The Situation and Experiences of
Family Carers / Support Persons
In West Cork

Executive Summary
2012

Foreword

This report, “Time to Care, Time to Live - The Situation and Experiences of Family Carer/Support Persons in West Cork”, marks the culmination of a five year project. In 2007, the Interagency group tasked with undertaking research focused on the Carer experience, met for the first time. The inclusion of Mental Health and Disability service providers broadened the terminology to Carer/Support Person.

On behalf of the Interagency group I would like to sincerely thank the Carer/Support Persons who participated in the research, without whose energy and commitment this work would not have been possible. A sincere word of thanks also to Dr. Jane Pillinger, Research Coordinator, and the peer research team who undertook the fieldwork in 2010, their work and commitment brought this project to fruition.

A special word of appreciation to the members of the Interagency group who have consistently committed their time and energy to this project, including: Joanna McCarthy (Public Health & Community Nursing HSE), Fiona Murray (National Learning Network), Alison Steeds (RehabCare), Tracy Griffiths (Mental Health Services HSE), Martin McCarthy (CoAction West Cork), Rose O'Sullivan, Richard Day and Sally Ann Back (West Cork Carers Support Group), Gina Kelly (Community Work HSE).

The “Time to Care, Time to Live - The Situation and Experiences of Family Carer/Support Persons in West Cork” report (with particular emphasis on recommendations) will be considered by the West Cork Carers Issues Forum.

Margaret O'Donovan

Chairperson Interagency Group

18th October 2012

1. Introduction

An inter-agency partnership, made up of statutory and community/voluntary organisations in West Cork, was established in 2007 to undertake research aimed at improving the coordination of service provision and information for Carers/Support Persons. The partners, who formed the Steering Group for the research, included the HSE Community Work Department, HSE Public Health Nursing, HSE Mental Health Services, CoAction West Cork, the National Learning Network, Rehab Care and the West Cork Carers Support Group (WCCSG).

The research was carried out using participatory research methodology, which resulted in eight former Carers/Support Persons being trained to carry out the research, overseen by a Research Coordinator. A total of 70 interviews were carried out with Carers/Support Persons in four District Electoral Divisions in West Cork. The participants were identified via the organisations represented on the inter-agency partnership, which also put in place a system for service users to provide consent for their Carer/Support Persons to be interviewed.

2. Key Findings

An overwhelming number of the 70 Carers/Support Persons interviewed in the study highlighted isolation, lack of recognition of their roles, low levels of support, poor health and well-being, and low quality of life. Stress, anxiety, depression, exhaustion, lack of time and low levels of confidence were common experiences. The vast majority of the Carers/Support Persons interviewed gave their time and love to care willingly, with many stating that they would do the same again.

The research documents a wide range of support needs that would enhance and sustain care/support roles.

a) Profile of Carers/Support Persons

- 19% of Carers/Support Persons were over the age of 65 years and this group faced unique challenges and stresses related to providing care/support. Some were in their eighties and nineties and received very little support.
- 50% of Carers/Support Persons had dependent children, which often put strains on their parenting roles and devoting time to their families.

- 93% of the sample were women, 7% were men.
- All of the Carers/Support Persons interviewed were the sole Carers/Support Person for the family members they were caring for.
- 30% of Carers/Support Persons, compared to 56% of Carers/Support Person nationally, had some form of paid work, the majority working under 15 hours a week.
- Financial stress and difficulty was one of the main factors affecting Carers/Support Persons who were unable to take up paid work. Six Carers/Support Persons had had to give up their jobs or take early retirement in order to provide care/support to family members.

b) Care and support provided by Carers/Support Persons

- 85% of Carers/Support Persons lived with the people that they cared for, while some had to travel some distances to provide regular care to family members. Two Carers/Support Persons, with dependent children, had had to move out of their family homes to care for a parent.
- 62% of Carers/Support Persons had been providing care/support for a family member for more than 10 years, 9 for more than 20 years, and one Carer/Support Person had provided care/support for 57 years.
- The majority of those interviewed provided care and support 24/7, with 68.5% of those interviewed providing more than 59 hours of care a week.
- Nearly one-third of Carers/Support Persons had cared for more than one person over a period of time. Just over one-quarter of those interviewed were currently caring for more than one family member.
- Of the adults being cared for, over half were over the age of 65 years. The largest group being cared for were frail, elderly family members, followed by adults with a long-term illness or disability. For children being cared for, the main group were children with an intellectual disability, followed by children with a mental health disability and/or a physical disability.

c) Needs of Carers/Support Persons

- Nearly half of all Carers/Support Persons interviewed were not receiving a Carer's related benefit. For those receiving a benefit the most commonly received benefit was the Respite Care Grant, followed by Free Travel, Carers Allowance and Household Benefit.

- In around one-third of cases, Carers/Support Persons did not receive any Home Help or respite support. For those receiving services the most commonly received service was a Home Help, followed by Public Health Nurse, Residential Respite Service, and services from a community organisation.
- The majority of Carers/Support Persons found the services they received to be inadequate, with more than half stating that the services they received did not meet their needs.
- Very few Carers/Support Persons complained about services and most were not aware of the HSE's complaints service 'Your Service, Your Say'.
- Carers/Support Persons for children with intellectual disabilities noted the improvements in services in recent years, and particularly the provision of Special Needs Assistants in mainstream schools. Many were very concerned that the withdrawal of this service would impact on their children's participation in education and long-term development.
- Many Carers/Support Persons had to 'fight' for services and several stated that this added stress and difficulty to their caring roles. Some issues were raised about poor communications with health professionals, difficulties in accessing services and rationing of services, and an awareness of significant workloads of health care staff, particularly Public Health Nurses.
- A wide range of needs were identified by Carers/Support Persons including having access to Home Help and home-based respite services, to befriending and advocacy services, and to a wider network of support services, including home-based respite and emergency support. Significant concerns were raised about difficulties in accessing specialist services, as well as access to adequate levels of Physiotherapy, Speech and Language Therapy, and Occupational Therapy.
- Other needs identified included having access to training in caring skills and techniques, and training in confidence building and personal development.
- Many Carers/Support Persons received low levels of support from family and friends, which contributed to their isolation; the level of support tended to diminish over time, with those caring the longest receiving the lowest level of support from family and friends.

d) The role and value of family care

- Significant numbers of Carers/Support Persons were concerned and anxious about who will care for their family members if they become ill or are no longer

able to provide care. Few saw any alternatives for their family members but residential care. Many were concerned about cuts in services, and how they would cope if services were reduced or removed.

- Carers/Support Persons highlighted the importance of family care and support to providing a loving, caring environment. Key elements of quality of care were highlighted to be love, respect, dignity, compassion and independence. Many believed that care in the family environment was the best place for care to take place.

e) Health, well-being and quality of life of Carers/Support Persons

- Isolation was a major factor impacting on the health and well-being of around two-thirds of Carers/Support Persons. Only 17% of Carers/Support Persons felt that their needs were fully met, while the rest felt their needs were either not met or were only partially met.
- Time was identified as one of the key factors in the lives of Carers/Support Persons, with the majority stating that they had little time for themselves. This was particularly the case because the majority of those interviewed were caring 24/7.
- Forty per cent stated that they did not have time to participate in their local community or in local community groups; 36% had no time to socialise with family and friends; 60% did not have time to take up paid work; and over 50% had no time to take up education and training.
- Key elements of caring that were identified as being most difficult were being constantly on call, sadness for the person they care for, followed by stress, frustration, emotional strain, isolation and lack of sleep.
- Poor health was a regular factor impacting on the lives of Carers/Support Persons, with a higher number reporting “not so good”, “fair or good health”, than “good or excellent health”. 46% stated that their health was directly related to their care roles. Some Carers/Support Persons also had existing health problems or disabilities that impacted on their care roles.
- The majority of Carers/Support Persons stated that their quality of life was directly affected by their care roles, with only 4% stating that they had an 'excellent' quality of life. Factors impacting on quality of life were related to isolation, stress, ill-health, low levels of confidence, poverty and financial strain, lack of time to socialise or to participate in sports and leisure activities, difficulties in accessing transport, and difficulties in accessing information. Around half of

the Carers/Support Persons interviewed had had some contact with and support from a community group or organisation.

- Some Carers/Support Persons had access to a counselling service to help them cope with the stresses of caring. However, 64% had had no access to a counselling service, and of these, 71% stated that they would like to avail of, or would consider availing of, a low cost counselling service if it was available.

3. Findings Related to Specific Services

Public Health Nursing / Primary Care Team

One third, 32.8%, of the Carers/Support Persons interviewed received a regular service from a Public Health Nurse. Despite positive comments about the role of the Public Health Nurse in supporting Carers/Support Persons and an awareness of their workloads, several people interviewed felt that more could be done to support Carers/Support Persons, for example, in providing more help, support and home visits. As a front-line service provider the Public Health Nurse is often the link to other services and they have an invaluable role to play in providing information about statutory and non-statutory services.

Carers/Support Persons also highlighted the need for more services in the area of Physiotherapy, Occupational Therapy and Speech and Language Therapy. Again this has implications for how people can access an enhanced level of services, particularly if they are living in remote areas and are required to travel long distances to take up a service.

Home Help Support and Respite Care

More than half of the sample stated that the services they received were not sufficient or adequate to meet their needs. The most frequently reported service needs were for Home Help support, home-based respite and residential respite. 36.5% of Carers/Support Persons received a Home Help service and 31.4% received residential respite services, based on an assessment of their need for these services.

A large proportion of the Carers/Support Persons interviewed highlighted significant pressures on time, social isolation and a lack of an opportunity for short periods of time off during the day. This has implications for how more home-based respite services can be provided, as this would have a major impact on the quality of life for Carers/Support Persons. Another important issue raised by a large number of

Carers/Support Persons was the need for support with care/support at short notice in the event of a crisis or an emergency, while flexibility in the planning of Respite Care was also highlighted as an issue that would benefit Carers/Support Persons, particularly in planning holidays with other family members.

Mental Health Services

Although fourteen adults and four children with a mental health disability were being cared for/supported, only four Carers/Support Persons stated that the person they cared for/supported received support from the Community Mental Health Team. A key issue raised by Carers/Support Persons was the need for support and training in dealing with depression and mental health difficulties for the person they cared for/supported. Another issue was the need for more support, advice and help in supporting a person with challenging behaviour. In one case, a young person with schizophrenia was unable to access an age-appropriate respite service.

In addition to these service needs, a large number of Carers/Support Persons experience isolation, depression and mental health difficulty themselves as a result of their care/support roles. This has implications for how the Community Mental Health Team and community-based support services can reach out to and support some of the most socially isolated Carers/Support Persons who may be at risk of mental ill-health. One-third of Carers/Support Persons stated that they would like to avail of low-cost counselling if this was available. There are also emotional relationship and personal adjustments that take place for Carers/Support Persons when they take on a care/support role. This is particularly important for people caring for their partners.

NGOs and Community Organisations

Social isolation and lack of time for a break were the two most important social issues affecting Carers/Support Persons in the sample. There are implications for NGOs and community organisations in how they can reach-out to isolated Carers/Support Persons. While WCCSG provides a rich range of services there is a key role to be played by WCCSG, with other organisations, to find new ways to reach out to the most socially isolated Carers/Support Persons.

There are resource implications if WCCSG are to extend their excellent services in the future. However, this should be a priority if some of the psycho-social effects of care/support roles are to be mitigated and in the long-run to ensure that people remain within their own homes for as long as possible.

Providing support services is particularly important in the current economic climate where many families are struggling financially, and in the light of the fact that there will be rising numbers of people providing care/support roles as the population ages.

In some cases Carers/Support Persons stated that they require training in caring skills, particularly when they first start caring or when there is the onset of a disability or health condition affecting the person they care for/support. This can be supported by all of the organisations involved in the inter-agency partnership, and can further complement the existing training provided by WCCSG. Some Carers/Support Persons highlighted the need for 'someone to talk to' to break isolation. This has implications for the development of befriending, visiting and advocacy services in the future.

Education Providers

Three Carers/Support Persons had school-age children with an intellectual disability who were accessing education in a mainstream school. The main concerns expressed by this group of Carers/Support Persons was that the current provision of Special Needs Assistance would be reduced or withdrawn, thereby making it difficult for a child with an intellectual disability to participate fully in education and society, and in the long-term, to live an independent life.

Other Services

The survey has also identified the need for Carers/Support Persons to have access to subsidised transport, to sports and leisure facilities, and to low-cost counselling services.

Access to information about statutory and non-statutory services, rights and entitlements is a key area highlighted by Carers/Support Persons. This requires a coordinated and inter-agency approach.

Overall the research has shown the extent of isolation, stresses and strains experienced by many Carers/Support Persons, and the overwhelming need for more support and time off from caring. The care/support role is particularly difficult for those Carers/Support Persons caring and supporting family members with challenging behaviour and high support needs, and is particularly acute for older Carers/Support Persons.

The findings also point to the need for better coordination of services and information

to reach those Carers/Support Persons that do not currently receive the benefits and services to which they may be entitled.

Summary of Needs Identified in the Research

Many of the needs identified by participants in the interviews were related to the need for practical and day-to-day support in providing care, in accessing services and in helping to alleviate social isolation.

The following is a summary of the key needs that were identified by Carers/Support Persons in the interviews:

- Access to information about rights and entitlements, local services and support groups.
- Improved levels of support for Home Help and Respite Care, as well as improved access to Physiotherapy, Occupational Therapy, Speech and Language Therapy services and Mental Health support services; and access to a full assessment of need twice a year.
- 24 hour emergency cover and support, for example, through a 24-hour helpline.
- More home-based respite and support to enable Carers/Support Persons to take short breaks, for example, for an occasional day or night off, or a few hours during the day.
- Weekend and Bank Holiday cover and support from service providers.
- More help and advice from the Public Health Nurse (PHN) about services and benefits, including support services from community organisations.
- Advocacy and support for the Carers/Support Persons, particularly in accessing information about benefits and services; an advocate to turn to, to help with accessing benefits and services, filling in forms etc.
- Access to subsidised transport to enable a Carer/Support Person to attend meetings and accompany the person they care for/support to social events, appointments or other activities.

- Access to sports and leisure facilities, including subsidised transport to access these facilities.
- Access to low cost counselling to help Carers/Support Persons deal with stress.
- From the beginning of a care/support role, a starter pack with information on entitlements and advice on services.
- Training and personal development for Carers/Support Persons, including practical training in caring roles, such as lifting and bathing, as well in preparing Carers/Support Persons for caring roles.
- Support to Carers/Support Persons through a buddy/befriending system.

4. Recommendations

As a result of the needs identified in the research the following recommendations are made.

i) Continue the innovative inter-agency structure that has been established in West Cork

- a) The needs of Carers/Support Persons should be prioritised through training for Primary Care Teams in West Cork.
- b) Raise awareness of the needs of Carers/Support Persons across the different Care Groups – older people, mental health, intellectual disability and physical/sensory disabilities – and the coordination of services between care groups.
- c) Consideration should be given to how the representation of Carers/Support Persons can be facilitated through local Primary Care Teams and Community Mental Health Teams, for example, through regular meetings with NGO service providers (CoAction, National Learning Network, RehabCare) and the West Cork Carers Support Group.
- d) A local plan should be drawn up by the inter-agency partnership for a systematic and coordinated approach to the assessment of need across all care groups.
- e) Improved practical coordination between local service providers could be established through a log book held by each Carer/Support Person. In the log

book visits for different service providers or support organisations can be listed and information provided is logged. This will enable Carers/Support Persons and local service providers to have all information about services provided, follow up and outcomes noted.

- f) One effective way to raise awareness, improve recognition of Carers/Support Persons locally, and to make the case for the ring-fencing of resources for Carers/Support Persons, is for the inter-agency partnership to disseminate the findings of this research report widely.
- g) It will be important that the findings from this research feed into national policy and in particular in making the case for the future development and implementation of the *National Carers' Strategy*, and in the implementation of the Positive Ageing Strategy. In this regard it is suggested that the report be submitted to national policy makers in the Department of Health and Children and the HSE.

ii) Enhance the provision of information about rights and entitlements

- a) The inter-agency partnership should develop an information pack for service providers and Carers/Support Persons, with a checklist of information for service providers and support groups and contact information on services provided for Carers/Support Persons by the HSE, NGO and community and voluntary organisations.
- b) In relation to hospitals, the information pack could be disseminated as part of the discharge planning service. In the community, the pack could be disseminated via Public Health Nurses, Community Mental Health Teams, NGOs, community organisations and local support organisations.
- c) The inter-agency partnership should work collaboratively with the local Citizen's Information Service, local hospitals, health care centres, GP surgeries, NGOs, community and voluntary organisations and public libraries to enhance the provision of information. This could be further publicised through local newspapers and local radio.
- d) The WCCSG newsletter could be used to disseminate information to Carers/Support Persons about local services, the West Cork Rural Transport Service, the West Cork Counselling and Support Services, the Citizens Information Service and other information services in local areas.
- e) Agencies providing services to Carers/Support Persons should put in place an 'information month' and consciously promote relevant information and support services in every home that they visit for that month.

iii) Enhance the levels of service provision to meet unmet needs

Home Help Services

- a) The HSE should provide clear information about the purpose, assessment criteria and appeals systems in place for assessing Home Help support.
- b) Home Help support should be reviewed regularly to ensure that Carers/Support Persons over the age of 70 years receive the level of support that they need.

Respite Care

- a) Aim to meet the preferences of Carers/Support Persons who require a whole week of respite, which has been identified as being relevant for service users in intellectual disability, physical and sensory disability and Mental Health Services.
- b) Provide more flexibility in Respite Care provided by Community Hospitals to allow for varying lengths of respite care for older people.
- c) Respite Care should be coordinated so that a person caring/supporting more than one person, for example, an older person and a young person with an intellectual disability, can have a break from their caring/support role.

Home Based Respite

- a) Provide information and raise awareness about the purpose of the Respite Care Grant.
- b) The HSE should consider creating a panel of suitably qualified, Garda vetted personnel who would be available to provide home based respite.

Age-appropriate services

- a) More attention needs to be given to the provision of age-appropriate services. A model of age appropriate services should be drawn up by West Cork Mental Health Services, Physical and Sensory Disability Services and NGOs for young adults with an acquired brain injury, physical and sensory disabilities and mental health difficulties.

Physiotherapy, Occupational Therapy and Speech and Language Therapy Services

- a) Provide information about and support from Occupational Therapy Services in lifting a person with a disability and in how a home assessment can be requested.
- b) Provide information about Physiotherapy Services for older people, people with physical and sensory disabilities and people with an intellectual disability.
- c) Ensure that people with recently acquired disabilities have information about how to access Physiotherapy Services and Speech and Language Therapy Services, for example, to enable people who have recently had a stroke, an acquired brain injury or a brain haemorrhage to reach their full potential.
- d) In the Dunmanway area, provide a local Physiotherapy Service for older people, people with physical and sensory disabilities and people with an intellectual disability.

Independent Living

- a) Appropriate independent living, with support services, should be made available for people who are no longer able to be cared for/supported by a family member. This is particularly identified for young people with an intellectual disability and young people with an acquired brain injury.

Day Care Centres

- a) The inter-agency partnership should discuss and put in place a plan for establishing local Day Centre services to meet the needs of people with dementia and Alzheimer's, and people with an acquired brain injury.

iv) Provision of support to Carers/Support Persons in an emergency

- a) The inter-agency partnership should discuss how they handle emergencies and provide information on what services are available to Carers/Support Persons in an emergency and how they can deal with different emergency scenarios.
- b) This could include, for example, a local list of family members or neighbours that can be contacted in an emergency and a system for emergency referrals to the local Primary Care Team or Community Mental Health Team. This should also include information about the '24 hour listening service', which is a help-line

provided by West Cork Mental Health Service at the Centre for Mental Health Care and Recovery, for people concerned about their own mental health or the mental health of others. The issue of client confidentiality is paramount and advice and support is to be offered as appropriate and with the client's consent.

- c) Raise awareness about residential services that can be available in the longer-term when a Carer/Support person dies or is no longer able to provide care/support.

v) Establish local community support, befriending and advocacy services

- a) The WCCSG should seek the support from the inter-agency partnership to establish a local befriending and visiting service, for example, by linking with Transition Year students in local schools and in building contacts with local volunteers. It is recommended that funding be sourced from the HSE for this and that links be made with existing visiting or phone support services, such as the Caring Peninsulas project.
- b) The inter-agency partnership should examine the feasibility of establishing a volunteer advocacy programme, with the provision of a training programme to train former Carers/Support Persons, to become advocates for Carers/Support Persons who are isolated or unable to access the services or information that they require. This could be linked to the National Advocacy Programme for Older People and the Cork Advocacy Service. It is recommended that a pilot programme be managed and organised by WCCSG.

vi) Training and awareness raising for staff

- a) WCCSG and the inter-agency partnership should provide training and awareness raising for staff who provide front-line services, including the provision of compassionate, respectful and dignified care, and in enhancing communications with Carers/Support Persons.
- b) Public Health Nurses, as key front-line service providers, should also have raised awareness of the important role that they can play in providing reassurance and support to isolated Carers/Support Persons.

vii) Training and personal development for Carers/Support Persons

- a) The WCCSG should examine the possibility for Carers/Support Persons to participate in local training provided for HSE personnel, for example, in manual

handling or mental health awareness.

- b) In providing options for 'life after caring', WCCSG should consider making links with local training providers and voluntary and community organisations to provide Carers/Support Persons with work experience and opportunities for paid employment. It is particularly important for the skills gained in care roles be valued for potential employment in caring professions.
- c) All statutory and voluntary service providers should disseminate information to Carers/Support Persons about the current training courses provided by WCCSG (in personal development and self-esteem, patient handling and back care, caring in the home and first aid).
- d) WCCSG should consider providing one-off training courses in each of the four local areas covered in the research, to enable Carers/Support Persons that experience difficulties in travelling to Bantry an opportunity to avail of the courses. For example, these could be carried out in liaison with Family Resource Centres in Adrigole and Dunmanway or other community-based venues in each area.
- e) WCCSG could also consider, in consultation with service providers, how the training could be extended to include the emotional skills associated with caring, dealing with stress, pain management, dealing with challenging behaviour, and, in coping with the changing relationship with the person cared for.
- f) Local service providers should also consider how they can customise their training courses to take account of skills development of Carers/Support Persons. There is also a key role for Occupational Therapists to provide support and advice to Carers/Support Persons in their family homes on lifting and manual handling.
- g) Specific training could also be provided in helping to care for and support a person with depression and mental health difficulties. The innovative West Cork Mental Health Service recovery model, developed in line with 'Vision for Change' (HSE 2006), provides an excellent basis for this. Training and support in this way of thinking is very important in giving hope and well-being for Carers/Support Persons who care for and support people with mental health difficulties, and for those Carers/Support Persons who experience stress and other mental health difficulties as a result of their caring/support roles. Training should be provided for local service providers, NGOs and support organisations in how a 'recovery' philosophy can help Carers/Support Persons.
- h) There is also a key role that Local Development Companies can play under the Local Community and Development Programme in providing training for Carers/Support Persons to access the labour market and in promoting

awareness, knowledge and uptake of statutory, voluntary and community services.

viii) Access to transport, recreational and sports services

- a) WCCSG should provide a link to the West Cork Rural Transport scheme to support access to recreational and sports services for Carers/Support Persons. This could be developed using the model of the innovative West Cork Rural Transport service, Cancer Connect, which has supported people in accessing cancer treatment in Cork city.
- b) The WCCSG, with the inter-agency partnership, should examine how there can be improved access for Carers/Support Persons to sports and recreational facilities. There should be a long-term plan drawn up by the County Council to provide a leisure centre/swimming pool in the Castletownbere area.

ix) Specific recommendations for agencies involved in the inter-agency partnership

Mental Health Services

- a) Specific supports are needed from the Community Mental Health Team for Carers/Support Persons who care for people with challenging behaviour and for those who have been recently diagnosed with a mental health difficulty.
- b) The provision of independent living services for people with mental health difficulties needs to be discussed and planned for by the Community Mental Health Team and relevant service providers.
- c) WCCSG and West Cork Community Mental Health Team should consider establishing (1) new Support Groups for Carers/Support Persons caring for and supporting people with mental health difficulties in each of the four areas covered in the research, and (2) Support Groups for Carers/Support Persons experiencing depression and mental ill health arising from their caring roles and social isolation. This should be carried out in cooperation with RehabCare and the National Learning Network.
- d) There is a role to be played by the West Cork Community Mental Health Team, using 'recovery' principles, in providing support for Carers/Support Persons of people in mental distress and to help maintain well-being for Carers/Support Persons that experience stress and depression.
- e) This research study produced limited evidence of the experience of Carers/Support Persons who provide care and support for people with mental

health difficulties. It is recommended that a research study, using similar methodology of the peer-led research model, be considered in the future.

Public Health Nursing Service

- a) The Public Health Nursing service, along with other members of the Primary Care Team, should ensure that Carers/Support Persons receive information about services and benefits, and referrals for support services such as the WCCSG support groups and the WCCSG helpline.
- b) The needs of Carers/Support Persons should be included as a topic for discussion in Primary Care Team meetings in West Cork, with a view to examining how Carers/Support Persons can be provided with support, information and access to services.

NGO service providers (CoAction, National Learning Network and RehabCare)

- a) NGO service providers should continue to work in partnership with other service providers. Through the inter-agency partnership they can work alongside statutory service providers and support organisations to promote information sharing between agencies and in disseminating information about rights and entitlements to benefits and services.
- b) They should also play an active role identifying any Carers/Support Persons who have specific support needs and in ensuring that there are seamless referrals to relevant support services where needs are identified. They have an important role in working closely with WCCSG and in providing information about their services.

West Cork Carers Support Group

In addition to the recommendations made above in relation to WCCSG's role in information, training, support, befriending and advocacy it is recommended that:

- a) A Carers Support Group should be established in the Ballydehob area.
- b) WCCSG should consider how it could extend its confidential support helpline, which currently operates on two mornings a week. A long-term objective should be to establish a 24-hour support line that is run by current and former Carers/Support Persons who are trained to operate the line.
- c) Provide a buddy system/telephone tree for Carers/Support Persons.

5. Conclusions

The research, which was developed through a peer-led methodology, has identified a wide range of needs of Carers/Support Persons in West Cork. In particular this has highlighted the isolation and the significant burden of care faced by many Carers/Support Persons. The research was developed by the innovative inter-agency partnership of service providers and community/voluntary organisations in West Cork in order to provide a coordinated response to progressing the needs of Carers/Support Persons.

The research findings have implications for national policy in ensuring that there is a coordinated and strategic approach to meeting the support needs of Carers/Support Persons, in implementing existing policy commitments, and in ensuring that Carers/Support Persons receive the services and benefits to which they are entitled. While noting these national policy implications, the recommendations of this report have been specifically targeted to local service providers so that there can be innovative responses to the issues raised in the research at a local level.

These findings not only point to the need for a more systematic support structure for Carers/Support Persons to assist them in their care/support roles, to provide time off from the rigors and stresses of caring, but also for Carers/Support Persons to receive training and personal development, advocacy and better access to information about their rights and entitlements. Finally, giving Carers/Support Persons recognition for their roles and contribution will go a long way to giving Carers/Support Persons self-worth and improving the status of caring.

While the current economic climate makes some of these recommendations more difficult to achieve, it is essential that policy makers are made aware of the longer-term savings that arise from supporting Carers/Support Persons more effectively. However, there are a large number of improvements to services that can be put in place within existing resources, for example, through improved coordination of information and service provision.

RehabCare



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive



CoAction
EMPOWER • SUPPORT • CARE

National Learning Network

Investing in People, Changing Perspectives