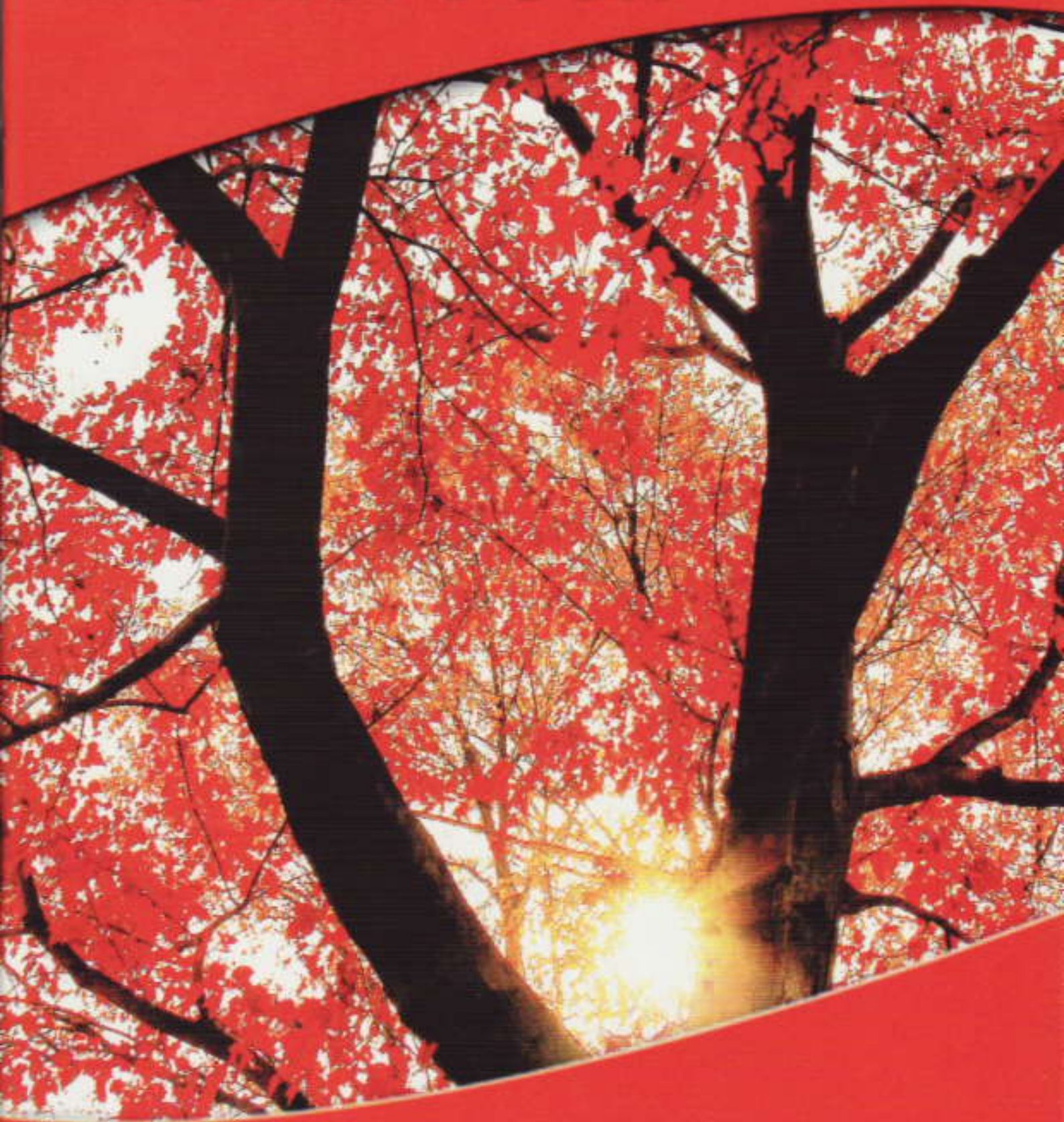


Every Mother's Son



Summary Report

Waterford Parents and Carers Research and Advocacy Project

Every Mother's Son

Summary Report

on

The needs and responses of families working to
remove barriers in caring for adult children and
family members with mental health difficulties

by

Waterford Parents and Carers Research and
Advocacy Project

Every Mother's Son

Born to me with pain and love
Such a joy to see you son
A childhood of happiness and laughter
Lovely grandparents helped make that matter
Like your loving Granddad you took
On his passion for nature and outdoors
The fields, the sea and the birds in the sky
What a shame they had to die
Then your life began to change
Confusion in your lovely face
Feeling lost and out of place
Help me Mam, I feel so bad
I don't mean to do things that make you sad
Every time you lash out
I see the fear, frustration
Hurt and desperation
But through it all I always see
The beautiful boy
Who was given to me
The loving and gentle soul
Whose life is more precious than gold.

The title of this research project is taken from the above poem. This poem was written by Alice Sullivan, a member of the research team. It provided a focus and impetus for the project and a copy was included with each questionnaire.

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Waterford research team members

We would like to acknowledge the dedication and commitment shown by members of the Waterford Carers Support Group who volunteered for this project.

Introduction

Waterford Carers Support Group was established as a support to parents and families of people suffering from mental ill health. Over time carers felt the need for greater involvement and empowerment in relation to their role as carers. An invitation to participate in advocacy training provided a welcome opportunity to explore the issues and challenges of the caring role. This research project is an outcome of the advocacy training.

Background

This summary report is the result of eighteen months collaboration between members of the Waterford Carers Group, Irish Advocacy Network and those families who agreed to participate in the research project.

Process

1. The needs and challenges facing families with adult children and family members experiencing mental health difficulties has seldom been prioritised in mental health policy and practice.
2. The new National Mental Health Policy "A Vision for Change" (2006) stresses the importance of a partnership approach between all stakeholders in a model which embraces care in the community.
3. The Mental Health Commission's "Quality Framework for Mental Health Services in Ireland" (2007) and "Quality in Mental Health – Your Views" (2005) articulate the need for evidence based standards set in partnership with consumers, highlighting the importance of service users,

their families, parents, carers and chosen advocates engaged in a collaborative working process.

4. The burden of caring in the community largely depends on the efforts and sacrifices of families and carers. A key recommendation in "A Vision for Change" (2006) is that parents, families and carers be empowered and that their role is acknowledged and valued. "Vision for Change" (2006) Executive Summary.

5. The issues and challenges facing carers influenced the chosen methodology for this project i.e., *participative action research*. This research methodology builds parity of esteem, equal relationships, shared learning and empathy amongst all participants.

6. The research results, it can be suggested, are authentic because they capture the genuine subjective experiences of respondents. They are reported honestly because the peer relationship in the one-to-one interview fosters trust. Shared learning in the research group was experienced by participants as both empowering and energizing. It increased their capacity to identify issues and concerns while gaining valuable skills and increasing their self esteem to effect change. With participative research the process is also the product.

7. As the advocacy training programme developed the knowledge gained shaped the design of the research project.

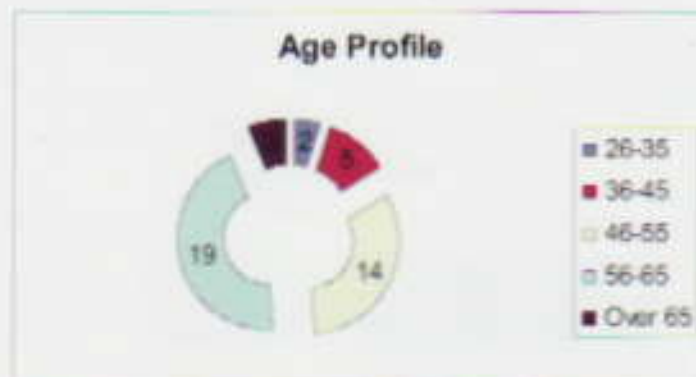
8. The intention from the outset was that all the project members would be involved at every stage of the process. The involvement of parents and carers was seen as vital if authentic data was to be collected.

9. As part of the research project a questionnaire was designed to identify common challenges and areas of concern for carers. Participants conducted the face-to-face interviews on a safe and confidential basis.
10. The results were analysed and key issues for parents and carers were identified. Appropriate conclusions and recommendations resulted from this process.

Profile of the Respondents

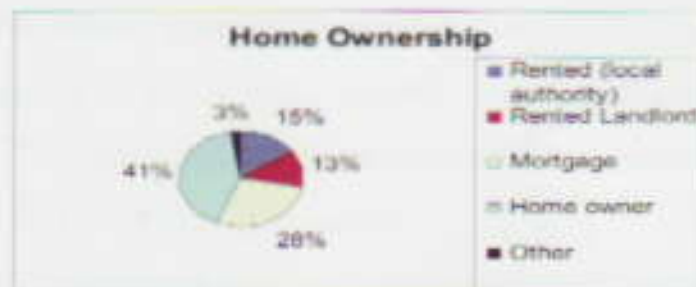
1. The group sought to identify other parents and carers in a similar situation in the South-East. They made contact with individual members from other support groups in South Tipperary, Carlow, Kilkenny, Wexford and explained the project. Other contacts were made through personal friendships and by word-of-mouth.
2. It was envisaged that fifty completed questionnaires would provide a valid sample. Forty-three are included in this report. Further questionnaires received too late for inclusion will be added to the database for further analysis.
3. The scale of this achievement should not be undervalued. The process was time consuming in the lives of people who already devoted much of their time to caring for family members. The commitment and demands were significant. The completed project is a tribute to their dedication and determination.

Figure 1: Age Profile of Respondents



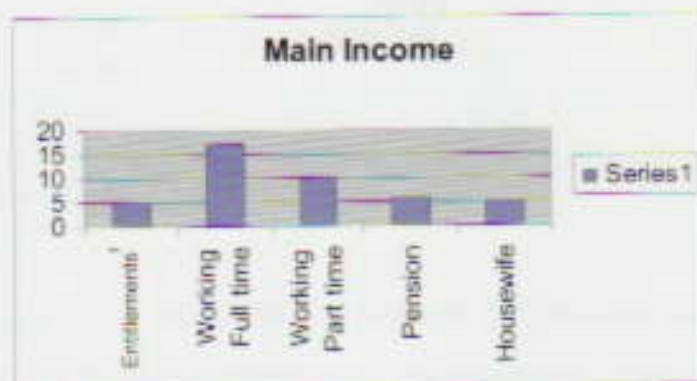
As indicated, the majority of respondents are in the 46-65 age range. The numbers in the lower age range are siblings.

Figure 2: Home Ownership.



The group wished to make the distinction between those who owned their houses outright and those with the extra burden of mortgage repayments. The statistics are in line with home ownership rates nationally.

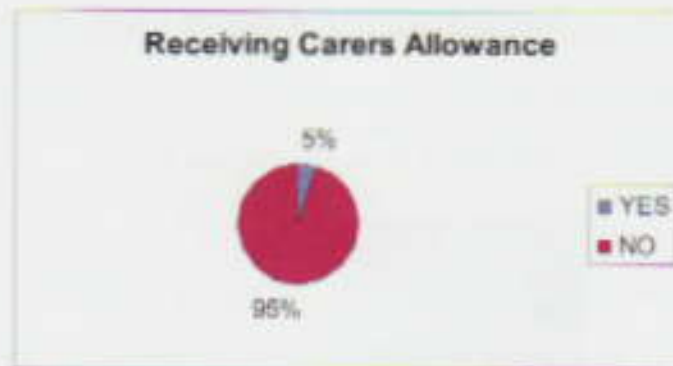
Figure 3: Main Source of Income.



Less than half the respondents are in full-time employment (39%). A significant number are living on a pension or other entitlements (approximately 12.5% in each category). Average income levels are therefore unlikely to be high. This has implications for the extra pressure that inevitably arises for those who are caring for others.

The average family size of those surveyed is 3.1 children. This increases the levels of responsibility for parents and carers in their every day lives where the needs of all family members and the needs of the person who is ill have to be met and balanced.

Figure 4: Carers Allowance.



Analyses of Figures 3 and 4 above indicate a stark reality. The significant financial burden of caring for a family member with poor mental health is borne mostly by the carers themselves. Government help is limited and the rules for securing a Carers Allowance as an entitlement are so rigid that the people caring for those suffering episodic conditions and/or relapses in their mental health are excluded from this benefit. Other burdens increase as a result.

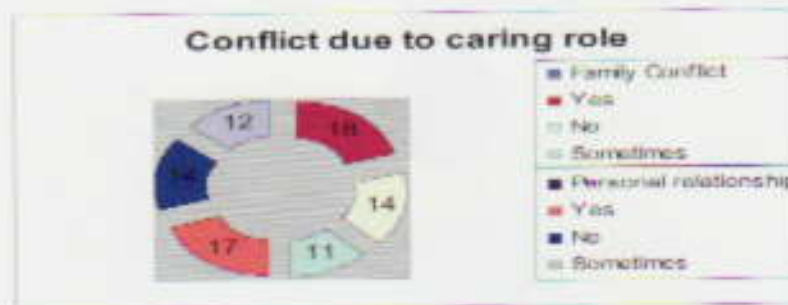
Emotional Well-being of Carers

Respondents felt that their own lives were sometimes "put on hold" due to the demands of their caring role.

This section of the questionnaire demonstrates the scale of the problem and illustrates the sacrifices made as a matter of course in the daily existence of parents and carers. It also highlights the crucial need for targeted supports to be put in place for carers as part of the development of a comprehensive community model of care.

Figure 5: Conflict within the family.

“Have you had any problems because the person for whom you are caring lives with you?”



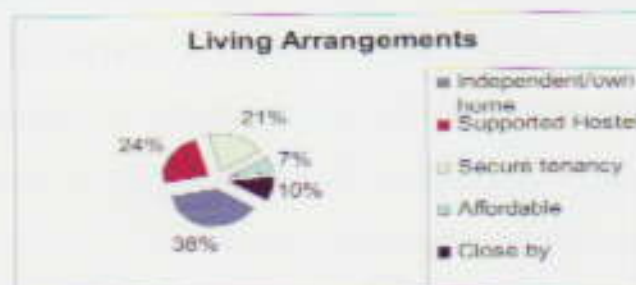
Inter-family conflict replicates the interpersonal conflict. This pictogram demonstrates that carers are operating in a highly stressful environment.

Within the family sibling rivalry and jealousy were described as major factors in terms of conflict.

Personal differences arose mainly over accusations of favouritism, “he gets all the attention”, or one parent not backing the other partner’s stance.

Figure 6: Living arrangements.

“What type of accommodation for the person you are caring for would best suit your needs?”

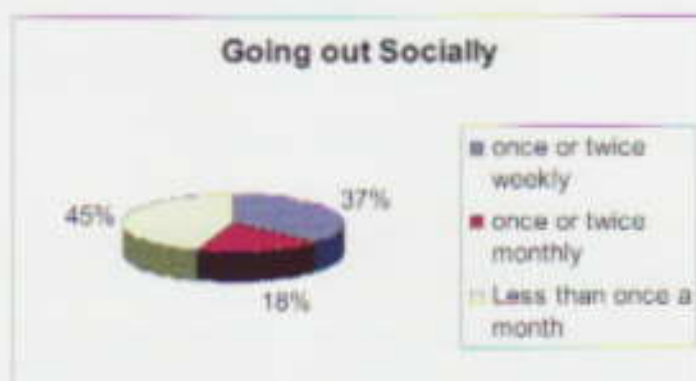


Housing is a high priority for service users but the most important factor has always been a secure tenancy. Carers priorities are a little different as they are expressing their own needs and concerns in relation to their adult children.

There is clear agreement on the need for provision of suitable accommodation although this should not be necessarily seen as a function of the HSE. The provision of suitable supports however is clearly part of their remit. Such support is crucial to the individual's ability to live an independent life.

The recovery ethos that underpins current strategy will need to address the issue of independent living. The recovery ethos is the belief that it is possible for all people with mental health difficulties to achieve control over their own lives. "Vision for Change" (2006) - chapter 12.

Figure 7: How often do you go out to purely social/entertainment occasions?



As indicated above 45% of respondents went out to social occasions less than once a month.

Some of the reasons offered for this reclusive pattern were: *"I am constantly drained of energy"*, *"We're not always at our best in social situations"*, *"I feel shy and too embarrassed to talk about my life and illness in the family"*, *"home problems affect my personal life"* and *"often too depressed"*

Figure 8: Do you feel your caring role affects your own emotional well-being?



93% of respondents felt that their own emotional health was negatively affected as a result of their caring role. In addition 31% said they suffered from depression while 16% cited stress as a major factor in their lives.

Responses included: *"I nearly cracked up myself"*, *"I get angry and depressed myself, I too have ended up using services"*, while another respondent said *"My own life has little meaning."*

These responses would indicate an urgent need for support services for carers. These needs are further explored in the final section.

Dealing with Service Providers

One of the recurring phrases in responses from participants was that they felt they were "getting the run-around" from service providers and staff.

Other responses given in this section clarify this all-embracing phrase and will give little comfort to those managing the mental health services.

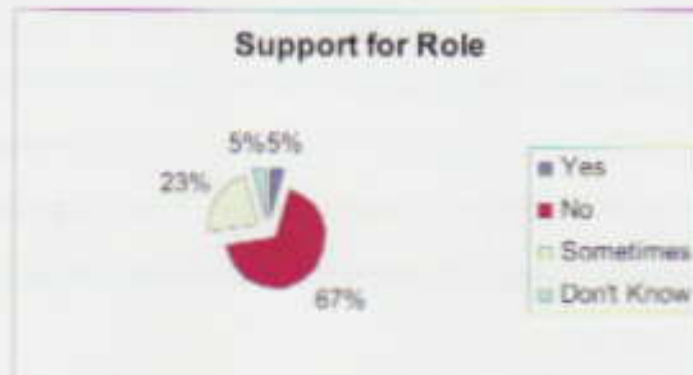
It should be emphasised however that respondents have reported improvements in this area since they began assuming a more assertive stance in their relationships with the services. These responses it can be suggested merely highlight the immediate need for a more respectful and collaborative approach.

Figure 9: Demand for an advocacy service.



Figure 9 indicates the responses to the question asked about advocacy. 90% agreed that they would like an advocacy service. This finding supports the original belief of the group that advocacy skills would be a support to them. One respondent who disagreed said, *"I am able to advocate for myself, thank you very much"*.

Figure 10: Support for carer role in the context of section 3-of questionnaire - Hospital procedures and contact with professionals.

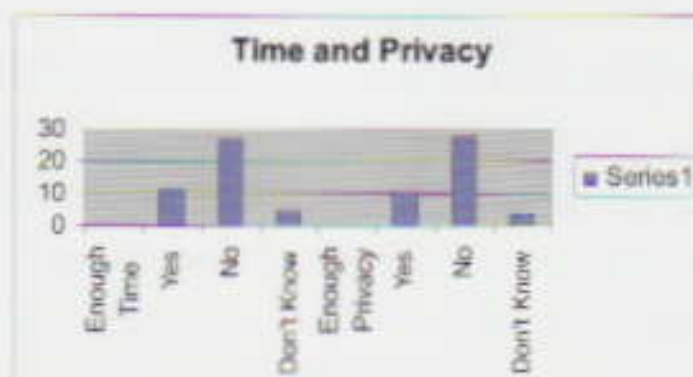


The answers highlight a clear need for a shift in staff attitudes. Overall, respondents reported being more comfortable with nurses and ancillary staff than with doctors or consultants.

26% of those surveyed said that they felt treated at all times with dignity and respect. There is constant debate about the need for greater investment in mental health services. Change in the area of customer relations is largely cost neutral but clearly of vital importance.

Figure 11: Time and Privacy.

Respondents were asked if they felt they had enough time and adequate privacy when discussing issues with members of staff. The figure below illustrates the answers given.



While it is acknowledged that time management for front line staff in an under funded mental health sector is always problematic efforts should be made to respond to the clear need shown.

The privacy issue is difficult as space tends to be at a premium, however effort and resources must be put into this area of concern.

Figure 12: Recent Experiences.

Respondents were asked about their recent experiences of mental health services and how they felt overall.



Some of the responses were: *"I feel excluded from any decision-making"*, *"I don't know the system"*, *"The nurses are pleasant and kind"*, while one person described meeting the treating consultant as *"an exercise in futility"* because the type of alternative treatment he was seeking to get information about was unavailable.

Information Deficits

The need for information and how best to use it was a recurring theme in respondents' replies. Several questions highlight lack of knowledge, a necessity for suitable involvement with the mental health services and with other services in the community.

Respondents generally had limited knowledge of diagnoses or medication that might typically be prescribed.

Respondents indicated that they required assistance in understanding what the information meant and how it would help them in their caring role.

"Knowledge is power" is only true if people know how to interpret and make best use of that knowledge.

Figure 13: Information on Diagnosis.

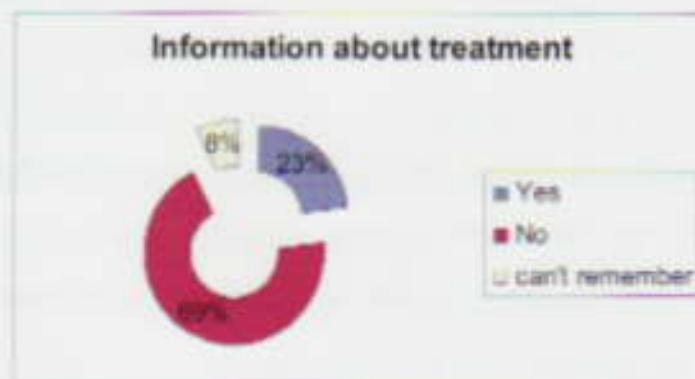
"When the person you are caring for was first diagnosed with a mental health problem was this explained to you in terms you could understand?"



Because of patient confidentiality there is always debate on how much information can properly be given about an individual with mental health difficulties. It is however important for a parent or carer to receive an explanation of exactly what the diagnosis means and what the treatment implications are. This information may need to be repeated.

Figure 14: Treatment Information.

“Did you receive any treatment information?”

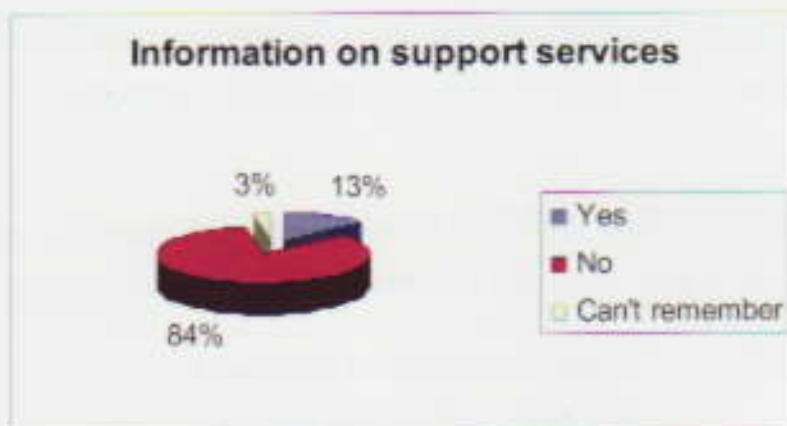


Personal information relating to a service user may only be passed on with their consent. This is often a source of interpersonal conflict.

A standard information pack could be made available in situations where conflict arises containing information that is freely available to the general public.

Figure 15: Information on support services.

“Did you receive information on support services available to you at the time of diagnosis?”



This response indicates a huge deficit. The respondents perception is that the HSE does not provide direct support services for carers. Such services are available in the voluntary sector and this information should be provided to all service users and their carers.

The provision of information is a support in itself.

Complaints Systems

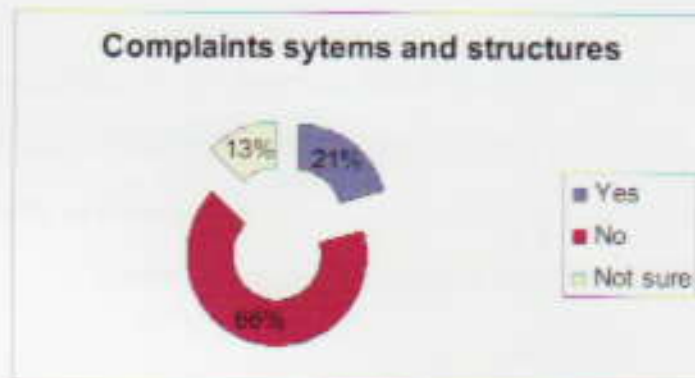
Openness and accountability are two of the “buzz-words” often cited by organisations as underpinning their service to consumers.

A clear and responsive structure for dealing with complaints is a necessary component of a service that aspires to “openness and accountability”.

Respondents were asked if they were aware of any formal complaints system or structures available to them. The answers are shown in figure 16.

Figure 16: Complaints systems/structures.

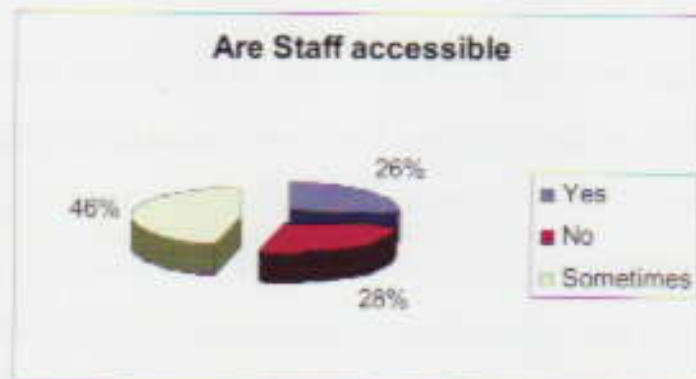
"Are you aware of any formal complaints system/structure for carers?"



The need for improvement in this area could not be clearer.

It should be noted that people might be reluctant to ask direct questions about a complaints system as such questions might be perceived as implied criticism of the service providers.

Figure 17: Are Staff accessible and approachable?



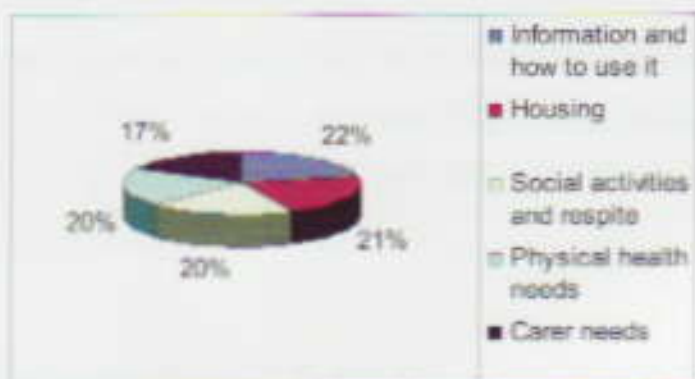
Access to information is identified by respondents as a key issue.

Accessibility of staff is crucial in order to address this need.

Preferred Changes

In this section people were asked to nominate the changes and improvements in Mental Health Services that would, in their opinion, bring about the greatest benefit. They were also asked to prioritise actions that the project team might pursue in the future.

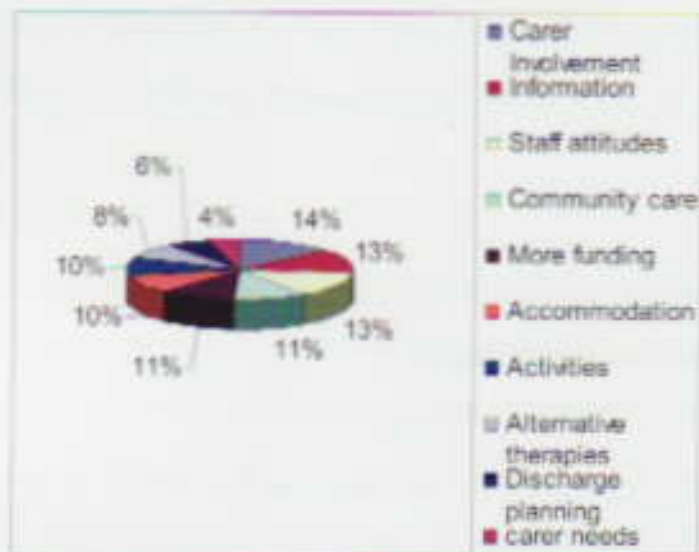
Figure 18: Group Priorities.



This illustrates the priority respondents put on their most important and urgent needs. It is notable they put their own needs at the bottom of the list.

Figure 19: Necessary Improvements.

191 individual responses were given covering 28 different topics. The top ten necessary improvements identified are shown below.



Among the suggestions were: *"Flatten the hospital – provide clean, modern facilities"*, *"A complaints system that really works"*, *"Listening skills for staff"* and *"No discharge into homelessness"*.

Conclusions

The majority of these conclusions flow directly from the issues clearly identified by the research. The challenges perhaps are more about the ways in which the conclusions may be addressed. The recommendations are an attempt to put a structured approach forward. The research has demonstrated that:

1. Information is a key issue. It should be of good quality and freely available. It should be repeated if required.

2. Housing and accommodation for service users is an urgent priority. It must be affordable. Secure and appropriate supports must be in place.
3. Advocacy is central to the empowerment of parents, carers, families and service users.
4. A holistic approach to meeting health needs of respondents and those they care for is essential.
5. The emotional health and well being of carers should be supported. They should not be excluded from necessary financial or other supports.
6. The process has strengthened the individual and group skills of the research team and enhanced their capacity to engage with mental health services.

Recommendations

Meeting the challenges identified by the research will require sustained and active participation of a range of organisations/agencies. This collective effort should focus on:

1. Clear provision of information on diagnoses, medication, current treatment options, care, recovery and discharge plans.

2. Service users and their carers should be involved at every stage of the recovery process.
3. Suitable housing is central to the recovery process. Local Authority and Voluntary Housing Associations should participate in delivering appropriate secure accommodation. The HSE should negotiate the provision of adequate supports with all stakeholders.
4. Advocacy initiatives should be promoted in order to enhance the capacity of parents and carers to advocate for better services for those they care for.
5. The physical and psychological health needs of individuals are inextricably linked. A holistic approach involving individuals, their families, carers and chosen advocates is fundamental to recovery.
6. Significant support systems for carers need to be designed and delivered. Carers should be encouraged to maintain their own health and well-being.
7. Rest and respite care should be available when needed.
8. The expertise and knowledge of carers should be utilised and integrated in all care, recovery and discharge plans.

Waterford Parents and Carers Research & Advocacy Group would like to acknowledge the support and assistance of the following:

- John Redican, Chief Executive, Irish Advocacy Network, for his time, patience, commitment, drive, knowledge and dedication in bringing this project to fruition.
- Una Tobin of Citizens' Information Centre, Waterford for her practical support in securing financial assistance and for the use of the premises in Gladstone Street, Waterford.
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- All respondents who willingly participated in the project and completed questionnaires. Without your active participation this project would not have succeeded. Your co-operation is deeply appreciated.

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For this we are sincerely grateful.

Waterford Parents and Carers Research & Advocacy Group

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For further information or to contact
Waterford Parents and Carers Research and Advocacy Group
Call 087 2515476