

Lost and Found

Voices from the Forgotten Generation

April 2004

rethink
severe mental illness

Stella's story

“In the early 1970s, I was a young woman with a toddler and a baby on the way when my brother, who is six years my junior, started to become ill.

Now, both my parents have passed away and my children are adults. David has been “stable on medication” for 20 years. He has no statutory input at all. Six months after our parents’ deaths, David suffered a heart attack.

David has been targeted by cynical individuals, who live locally, with requests for money and goods. He does not seem able to handle this. He often contacts me, or his other siblings, either when his money runs out or he has no food for the week or when items such as his TV, CD player and vacuum cleaner are removed from his flat.

David has no conception of the amount of work put in by his siblings – all of which has been undertaken in addition to our jobs and maintaining our own family relationships.

It is very difficult to receive an email from one’s brother in which he says that he has no money, no food and is hungry. This is our little brother, we all played together as children.

Now he is middle-aged but looks older, and presents as indecisive. We are the only people who seem to care but, because we are not indecisive, we present as pushy.

In fact, we are merely burnt out and it feels like we are the only people who haven’t forgotten David.”

Introduction

Mental health has for decades been treated as the “Cinderella service,” though for the past six years, it has sat alongside cardiac care and cancer as one of the government’s three health priorities.

Its priority status has led to a period of dramatic reform and, in certain areas, dramatic investment. However, this period of reform has bypassed many people. The reform process has focused predominately on crisis support but not on those who have been within the mental health system for some years.

We are launching this campaign to highlight the needs of a group of people we call the ‘forgotten generation’. These are people with severe mental illness living in the community who have been largely forgotten by mainstream mental health services.

For the most part, these are the people who have lived with a severe mental illness for many years, passing through and surviving a series of early crises, feeling rejected by society and who now live their lives without the all-round help and support that would allow them to raise their quality of life.

The forgotten generation can be found amongst the four in five people with schizophrenia who are without paid employment; they are to be found amongst the people living cut-off lives in tower blocks and on run-down estates or isolated in rural communities. They may have few contacts with family members and many have

experienced homelessness at some point in their lives.

Some of this group have older relatives who provide substantial support with everyday domestic jobs such as shopping, cooking and cleaning. Elderly carers worry about what will become of their relative when they are gone or are no longer able to care.

The forgotten generation place few demands on the state. Their contact with health and social services is mainly restricted to collecting their “meds.” They rarely complain or cause a fuss.

In terms of mental health service reforms, this group of people have been forgotten.

Rethink believes that advances in the understanding of severe mental illness, its treatment and the potential for recovery and personal empowerment should not be confined to the few. We believe that everyone has the potential to take greater control over their lives and should be offered real choice and effective involvement in planning their mental health care.

Rethink does not accept that anyone should be left behind and simply forgotten.

In the following pages you will read what it means for service users and carers to be part of the forgotten generation. You will read some powerful stories of missed opportunities and hopelessness.

We hope that you will also be inspired by what is possible and join us in our campaign to find routes out of isolation, to discover the forgotten generation and to work with us to make sure that everyone has the chance to share in a better quality of life.



Robert Banner
Chair, Rethink



Cliff Prior
Chief Executive, Rethink

Forgotten and often hidden

Rethink and partner organisations have carried out two major surveys of service user and carer views in recent years.¹ The surveys were carried out amongst Rethink members, the people who use our 390 community services or who attend one of our more than 130 local groups, plus the networks of our partner organisations.

Inevitably, these are the views of people “in contact” with a support organisation, people who by the very fact that they took part in the surveys can be seen and heard. In carrying out the surveys, we became aware that we were not reaching large numbers of people who were by their nature “hidden.”

Often carers, usually elderly parents, would add insistent pleas to their survey forms to focus not just on people well enough and motivated enough to fill in a questionnaire but on their son, daughter, brother or sister who was struggling to engage in everyday life. Staff would refer to people who might use a Rethink service once or twice and then disappear from the scene.

Traditional research methods find it difficult to capture the silent voice or the hidden view. Lost and Found captures this silent voice and identifies a real problem for the future development of mental health services – how to engage the most easily forgotten people and how to offer this group the chance to raise their quality of life beyond simple survival.

Lost and Found is constructed from people’s experiences. It marks the beginning of a major Rethink programme that will challenge the outlook of statutory services and the priorities of government. In this report the names and identifying features may have been changed at individuals’ requests.

Who are the forgotten?

Rethink carers and service users have told us that the ‘forgotten generation’ are a group of people with mental health problems who are in the main ‘invisible’ to both society and the mental health world. Below we outline four people’s stories.

“I was diagnosed with schizo-affective disorder nearly 20 years ago when I was a teenager. I see a community psychiatric nurse once a month and used to attend a Rethink day centre. I don’t anymore. I can’t socialise because the medication I take makes me stand out. I want to work and used to do voluntary work but I don’t anymore. The only people I talk to now are my Mum and Dad.”

Kumar

“Lack of confidence is my biggest problem. I live in a supported home with other men like me, but I feel lonely and don’t have any friends. Sometimes I go walking by myself, but mostly I stay in bed.”

Richard

Forgotten generation?

“Ten years ago university finished me. I got really ill. It has taken 10 years of medication, yoga classes and sitting in smoking rooms for me now to be left to my own devices. There are endless questions and worries that have been left unanswered and now there is no one around to help me get answers.”

Dawn

“I was diagnosed with schizophrenia in the early 1970s. I lived at home with my parents, both of whom are now in their late seventies. I left home when I was 23. I have been on medication since my breakdown. Despite ups and downs with my parents over the years, I now depend on them. I ring them three or four times a week and visit every six weeks. My Mum has a life-threatening illness. Fortunately my Dad is in good health. I see my GP every month or two. He is a good listener and keeps an eye on me. I see a consultant psychiatrist every three months – but it is a different one every time; a problem with recruitment. I will be devastated without my Mum and Dad. I overdosed when my Nan died, but I am more stable at the moment. Things are not in my case as bad as perhaps in others. I’m just grateful that I have lived this long.”

Graham

In our latest service user survey, we asked people to name just one change that would improve the quality of their life. Sixty two per cent named a non-medical change, such as more money, improved social relationships and an end to stigma and discrimination.

Responses also described changes that would support recovering good mental health, benefiting from improved medication and receiving a better deal from psychiatry.

The quotes below illustrate the types of changes that people who have been in touch with mental health services for over 10 years would like to see to improve the quality of their lives.

“Would like to make friends with people who are not mentally ill and not be shunned by most of the population – even relatives.” (Martha)

“To talk with a mental health care specialist, I feel totally alone and frankly forgotten.” (Bill)

“Knowing that there are professionals who understand me. Know clearly who to turn to and feel safe with. Interests that I can be involved with meaningfully.” (Ida)

“Securing my future so I need not worry what will happen to me when my parents die and I am left alone.” (Sarah)

“An improved social life - I have lost friends due to my illness and now find myself isolated.” (Karen)

“Full-time work - at the moment I work part time on therapeutic earnings. I would like to be ordinary.” (Donna)

The concerns of carers

Caring for someone with a severe mental illness can be a roller-coaster ride of emotions.

It is made doubly frustrating when, after long periods of acute illness, the person cared for becomes “stable.” It is often at this point, that help and support from health and social services begins to fade away.

Our survey showed that 52 per cent of carers feel that they never have a choice about whether to continue providing substantial support and 51 per cent are extremely concerned over what will happen to their relative or friend in the future. For those who provide support 24 hours, seven days a week, 64 per cent are extremely worried about the future².

Particular concerns in this group were raised about the lack of appropriate supported accommodation and the pressure on siblings to take on the caring role when parents are unable to carry on. Only 20 per cent of carers felt that health and social services would be able to provide the necessary support if they were unable to do so. Only 15 per cent knew where to go for information and advice to plan future care.

Even where practical help can be provided, carers are still concerned that the amount of emotional support they provide will be far harder to replace.

When statutory services concentrate their resources on the newly diagnosed and the acutely ill, carers are left to fall back on their own resources.

“My own GP has no idea of the considerable emotional and practical input I have had into my son’s everyday life for all these years. We fear what will happen when we are gone.” (Margaret)

“No confidence in care son will receive when we are gone, no nearby relatives. Must try to get sheltered accommodation and independent living before we are no longer able to care. Easier said than done.” (Peter)

“My son is socially isolated due to his illness and I feel he will become even more isolated when I am no longer able to provide care.” (Sophia)

“Proper supported accommodation is not available, as a vulnerable adult this is what she needs. I have great fears that without my support she would not survive.” (Jackie)

Caring for someone with a severe mental illness can be a roller-coaster ride of emotions.

In the spring of 2003, carer Pauline Arksey wrote an article in the Rethink member magazine *Your Voice* about the frustrations felt in her family as support for her 46-year-old son Paul was withdrawn leaving him “stable mentally but doing nothing on most days”.

The article sparked a huge response. Here Pauline Arksey summarises the responses and why they have led to a new campaign for the forgotten generation.

“For many, frequent changes in staff and in service provision mean that the family remains the only stable human factor that understands the whole person and appreciates their expressed and unexpressed needs. I have had letters from service users and carers expressing their loneliness and boredom, and a feeling of hopelessness that their circumstances are not appreciated by service providers. They welcome changes such as safe houses, crisis provision, home treatment and early intervention, and the newer medications. But they are concerned about the services that have been withdrawn or down-sized.

Many of the letters spoke of tiredness and falling asleep during the day, people remaining in their rooms listening to music and seeing no one but the community psychiatric nurse - if they have one.

Most asked for simple things - a friend, a letter and work. However, while wanting to work, many people were frightened of taking the step. Coping with people after living an isolated life is a horrendous thought. Having expectations of you that you might not be able to sustain is fearful.

Other letters spoke of the need for better, affordable housing in friendlier communities - and regular physical health checks from primary care.

For many isolated service users, the family remains the constant human contact. Families provide the practical skills to do jobs around the house. Financially, many meet the costs of big items such as holidays and transport. This forgotten generation has been let down. By their absence of need for hospital admission or acute care they are forgotten and their holistic needs ignored.

Appropriate support must be available. Services, not always professional, but befriending and support services that provide more than a visit to the doctor and dentist, services that can offer friendship, hope and motivation are required. By reducing the stigma of severe mental illness could perhaps the community be more involved and create a friendly environment in which to live?³”

Rethink solutions

A staggering 85 per cent of carers stated that advice was not available, or they weren't sure if it was, to help plan for when they are no longer able to provide care². Provision of services and support for carers is one way of addressing this issue.

Rethink has over 50 relevant services and 130 support groups working locally. The services they provide include some or all of the following:

- One-to-one support
- Networks
- Supporting groups
- Respite
- Accessing respite funds for carers from the carers grant
- Offering information and training for carers, family members and other people supporting those with mental health difficulties

For more information contact:

Rethink Carers Forum
Tel: 0845 456 0455
Email: info@rethink.org
Web: www.rethinkcarers.org

Often carers do not want to think about what will happen after their death. However, forward planning can make a difference.

Writing a will that makes provision for a person with a severe mental illness may take special knowledge. One of the best ways to make such provision is to form a Trust - an arrangement where a person gives control of money or property to someone, a 'trustee', to manage on behalf of other persons, the 'beneficiaries'. It does not mean that the trustee acts as a carer. Not all solicitors have experience of trusts. Rethink may be able to help in finding a solicitor with the relevant knowledge.

Rethink also provides a service through its subsidiary, NSF Trustees Ltd. This is a company staffed by

people with long experience of dealing with trusts, who are able to give advice on the subject. It is also able to act as a trustee.

For more information on wills and trusts, contact:

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Supporter Care
Rethink
28 Castle Street
Kingston-upon-Thames
Surrey
KT1 1SS
Tel: 0845 456 0455
Email: grant.usmar@rethink.org

Physical health problems

The physical health needs of people with severe mental illness – particularly the forgotten generation – often go unrecognised. People with mental health problems are more likely to experience coronary heart disease. In a recent study, psychiatric out-patients were found to be nearly twice as likely to die as the general population³.

According to an international review of published studies in 1997⁴, schizophrenia is associated with a large increase in mortality from suicide and a moderate increased mortality from natural causes.

The most common causes of mortality for people with schizophrenia are respiratory disease, digestive diseases, genito-urinary diseases and cardiovascular disease. The reviewed studies estimated that people with schizophrenia are:

- 2.2 times more likely than the general population to die from respiratory diseases
- 1.8 times more likely to die from digestive problems
- 1.6 times more likely to die from genito-urinary problems
- 1.1 times more likely to die from cardiovascular disease.

Other research shows that 74 per cent of people in institutions who have schizophrenia smoke, compared with 27 per cent of the general population⁵. Smoking is just one of the things that can add to physical ill health that can then go unchecked and subsequently cause increased health risks.

The National Service Framework for Mental Health says that people with a severe mental illness should have their physical health needs regularly assessed. The National Institute for Clinical Excellence (NICE) guidelines on the treatment of schizophrenia make the same point.

Poor physical health may arise for a variety of reasons, including:

- Poverty
- Side-effects of medication
- Social isolation and exclusion
- Poor motivation and tiredness, which are long-term effects of chronic illness
- A poor life-style, which can include homelessness, a poor diet, lack of exercise, smoking and poor personal hygiene

One in three service users taking part in Rethink's recent surveys said that regular physical check ups were a top priority.

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Jenny's story, below, illustrates the difference that can occur where mental and physical health issues are addressed together and treated successfully:

“When I was 35 and had been treated with depot medication for schizophrenia for 15 years, I was working long hours as a care assistant in a home for the elderly. I had no care programme and little time for a social life. The injections were given every three weeks by my GP. I developed problems with my eyesight and an ophthalmologist told me that the cause was my antipsychotic medication. The Rethink National Advice Service helped me to obtain an expert second opinion on my treatment, which was changed to one of the new atypical antipsychotics. I soon felt more energetic, and asked my employer to reduce my hours of work so that I could attend adult education classes and learn to use a computer. Within a year, I became an administrator in a residential care home and am engaged to be married!”

Carers are also reporting improvements in GP practices. A Rethink carer project in Fareham and Gosport, Hampshire has set up a Local Implementation Team sub group focusing on carers issues.

The group has membership from local GP practices and this is making a real difference in terms of care on the ground.

Physical health checks have been highlighted as a priority and they say that GPs are listening to their concerns. As a result they and the service users they support are experiencing improvements in care.

Find out more about physical health

For people in the forgotten generation, physical decline can be as serious a risk as mental illness. Some help may at last be available. GPs are being financially encouraged to improve the physical health of people with severe mental illness. We are keen to explore how a renewed contact with primary care can act as a “gateway” to other forms of support.

The National Institute for Clinical Excellence (NICE) guidelines on the treatment of schizophrenia state that people should have regular physical health checks that pay particular attention to things such as weight gain, blood pressure and heart problems and blood sugar levels.

From April 2004, GPs and others in primary care are being offered cash incentives through the new General Medical Services (nGMS) Contract to provide these physical health checks annually. Rethink believes that, as a minimum, annual physical health checks should cover:

- Measurement of blood pressure and weight
- Regular dental and optical appointments
- Early detection of diabetes and cancer
- Monitoring chest and heart, which may be adversely affected by tobacco smoking
- Detecting and monitoring the side-effects of medication

Rethink is working with the National Institute for Mental Health in England, the Manic Depression Fellowship and Mentality to produce a joint leaflet for service users explaining the mental health aspect of the nGMS Contract. For copies, which will be available in spring 2004, please call 0845 456 0455.

For more information on physical health issues contact:

Rethink National Advice Service
Tel: 0845 456 0455
Email: advice@rethink.org
Web: www.rethink.org

National Institute for Mental Health in England (NIMHE)
Blenheim House
West One
Duncombe Street
Leeds
LS1 4PL
Tel: 0113 254 3811
Email: Ask@nimhe.org.uk
Web: www.nimhe.org.uk

To view the nGMS Contract and read about how it is to be implemented visit:

Web: www.doh.gov.uk/gmscontract

For best practice guidance on the treatment of schizophrenia, contact:

National Institute for Clinical Excellence (NICE)
MidCity Place
71 High Holborn
London
WC1V 6NA
Tel: 020 7067 5800
Fax: 020 7067 5801
Email: nice@nice.nhs.uk
Web: www.nice.org.uk

Social isolation

A strong support network is important for promoting good mental health. People with severe mental illness tell us that they feel isolated and lonely. They only have a small network of connections that they can draw upon for company, help or support. Having a severe mental illness can change relationships with family and friends – childhood friends disappear, family members struggle to understand, new friendships are difficult to forge and loss of self-esteem and self-confidence prove barriers to everyday activities.

Life experiences, including friendships and new skills, are gained during people's recovery journey but loss is also an important component of living with mental health problems:

If I were to describe my mental distress I would say it was ...

“Loneliness, loss of purpose, direction and achievement and exhaustion from over-working with no positive results.” (Diane)

“A complete loss of confidence and hope about my life and the future.” (Sharon)

“Life destroying - confidence total loss - frightening – and enlightening.” (Delia)

“Frightening, lonely and isolating.” (David)

“A confusing, painful, isolating experience leaving me vulnerable, lacking in self esteem and any sense of purpose to my life.” (Christine)

In 1998, Mind ran an inquiry into the social exclusion experienced by people with mental health problems⁶ that highlighted the non-citizen status that many people feel. It pointed to difficulties getting involved with ordinary everyday activities through work, education, faith communities, arts, music, sports and recreation.

Strategies to promote social inclusion place friendships at the heart of activities⁷. The government's Social Exclusion Unit report, due for release in spring 2004, into mental health should guide best practice for addressing the inequalities and injustices that people with mental health problems experience.

What helps?

Rethink's most recent research survey of over 3,000 service users looked at patterns of social participation⁸. People engaged with mental health services, self-help groups and a range of activities from community involvement to physical exercise are more likely to find supportive relationships.

Four in five people diagnosed with a severe mental illness are unemployed. However, 80 per cent of those occupied in employment, volunteering or education, report benefits from supportive friendships compared to only 55 per cent of service users from the unoccupied group.

Eighty five per cent of people with psychosis who take regular physical exercise report supportive friendships compared to 52 per cent in the group that does not exercise regularly.

For those people with mental health problems who are not engaged in mental health, community and family networks, opportunities for building supportive relationships are few.

“Supportive friends and family have made all the difference to me on my journey towards recovering my mental health.” (Carmella)

“I want to develop friendships through working as a volunteer in a charity shop.” (Karen)

“ My problems go way back a long way and prevent me from developing supportive relationships which would help me recover / improve my life.” (Ann)

Rethink solutions

Rethink is exploring a range of new and innovative support for people who experience severe mental illness.

People experiencing severe mental illness are often deemed to have specialist health and social care needs.

While that is true, it is also the case that people want to be seen first and foremost as people, not just an illness.

In some newer mental health services, such as early intervention teams, home treatment services and assertive outreach models, person-centred holistic approaches are making a real difference.

How should services be adapting to meet the needs of those who have been in the mental health system for a long time?

Our Recovery Learning Sites initiative is rolling out new approaches in a variety of our community service settings.

To find out more about Recovery visit:
www.rethink.org/recovery

Or contact:
Dick Frak
Director of Quality and Standards
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Email: dick.frak@rethink.org

The Rethink Self Management Project supports people taking active steps toward their own recovery.

One service user involved in the project said: "The struggle for self-management has been life affirming. I have become a stronger and even better person. The efforts and achievements of other service users have been inspirational and have given me hope and strength⁹."

For more information visit:
www.rethink.org/recovery/self-management

Or contact:
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Rethink's Anti-Discrimination Network is a programme of initiatives working in partnership with other mental health organisations to address stigma and discrimination associated with mental health problems.

Karan Billimoria, chief executive of Cobra Beer, Rethink Patron and Network supporter said: "Mental illness is an invisible illness that the majority of the public do not understand. I am saddened by the lack of support in the form of public awareness, or help for those suffering at the hands of mental illness."

For more information visit:
www.rethink.org/research

Or contact:
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we need your help

Lost and Found set out to highlight the problems affecting the forgotten generation and their friends and carers. We hope that this will stimulate debate to find solutions.

We need your help and suggestions to find the most appropriate solutions.

We have touched on how the new General Medical Services Contract covering physical health checks in GP surgeries may help. We have also listed some of the other services offered by Rethink that are making a real difference. But we need your views too.

What else could have an impact?

Perhaps:

- Befriending schemes
- Pen pals
- Trusteeships
- Education links
- Employment schemes
- Modern-age day centres

Please let us know your solutions to help the forgotten generation.

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Recommendations

- Government reform and local service planning and delivery must include people who are medically “stable” but experiencing a low quality of life.
- Rethink believes that annual primary care physical health checks must be available to everyone with a severe mental illness.
- As a minimum, annual primary care physical health checks should cover:
 - Measurement of blood pressure and weight
 - Regular dental and optical appointments
 - Detection of diabetes and cancer
 - Monitoring chest and heart, which may be adversely affected by tobacco smoking
 - Detecting and monitoring the side-effects of medication
- People with severe mental illness should be able to access holistic support, whatever their stage of recovery. This should include:
 - Psychological or talking therapies
 - Access to the best medications
 - Choice of professional
 - Choice of treatments
 - Decent accommodation
 - Regular and sufficient income
 - Meaningful occupation
 - Opportunities to build social networks
- Long-term carers should be offered information, advice and support to get the best from health and social services.
- Long-term carers should be offered choice in continuing their caring role.
- Long-term carers should be able to put in place alternative care provision for when they are no longer able to care.
- Significant investment into research; to quantify the scale of the Forgotten Generation; the problems they and their carers face; the resourced solutions to address their needs.
- Primary care and secondary care services need to find more effective ways to talk to each other and work together.

For more information on Rethink, and the service it offers contact:

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Notes and references

- 1 A Rethink survey carried out in 2000 with Manic Depression Fellowship (MDF) and Mind resulted in 3 reports (A Question of Choice, That's Just Typical, Doesn't it Make You Sick) and Our Point of View survey carried out in 2002 with Carers UK, MDF, Depression Alliance and the Institute of Psychiatry has generated four publications (Right from the Start, Just one per cent, Under Pressure and Who Cares?).
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The Forgotten Generation programme is supported by Rethink members and supporters, the Pfizer Foundation and Calouste Gulbenkian. If you would like to become a Forgotten Generation Programme supporter, call our fundraising department on 0845 456 0455 or email: supportercare@rethink.org.



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Rethink publishes an extensive range of publications for service users and carers including *Only the Best* - a guide to getting best fit medication, *Caring and Coping* and *What is Severe Mental Illness?* To order copies or to find out more about Rethink's publications call 0845 456 0455 or log on to www.rethink.org.

If you feel it is important that Rethink continues to speak out about the issues dealt with in this report why not become a Rethink member and help us speak out for everyone affected by severe mental illness. Call 0845 456 0455 or join online at www.rethink.org/membership.

To find out more about the experiences of service users and carers, visit: www.rethink.org/research

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