Community Supports for Ageing
Care Pathways for Older People in Europe
Welcome to Intel’s Community Supports for Ageing

The world is facing demographic changes that will significantly impact the future of our ageing population. Intel is actively studying these changes to understand this impact and how we can affect it. The ageing of the world population is not taking place in a vacuum: other priorities and concerns, be they economic, environmental or political - all shape the responses to the challenges and changes we see taking place around us. Truly understanding the nature of the issues requires a multi-disciplinary approach.

From our European research lab, located in Ireland, we have been exploring the needs and issues which confront individuals, families, communities and states as society ages. For individual and family, organising and providing care for a loved one is a critical concern. Within communities the question is “what can we do and who can we work with?” At the national level, the concerns are likely to be about the funding, organisation and provision of care and support at a time when funding is tight and the recognition hits home that ‘business as usual’ will not succeed in meeting the challenges.

Intel is committed to deciphering this complex environment and identifying opportunities for response. This must start with a deep and empathetic understanding of health and social care communities across the continuum of care from hospital, to clinic, to ambulance to home. Helping people to continue living independently at home or transition from the hospital to the home as quickly as possible reduces costs in an already overburdened healthcare system, while improving quality of life for patients.

We know that technology has a vital role to play in enabling this transformation. But more often than not, we are not trying to fix a technology problem but rather understand the appropriate fit for technology in highly complex systems. Health and social care systems have their own traditions, peculiarities and logics. Understanding these is a precursor to developing the appropriate interventions, and the right partnerships and collaborations required to effect the change that is needed.

This booklet, written by Drs Simon Roberts and David Prendergast, outlines a short chapter in our journey of understanding. We welcome your input and comments on it as our research and innovation teams continue their work in Europe during 2009.

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Message from the Authors

The production of this document has involved a large number of people during the course of over two years of research. Our special appreciation to those who collaborated with us in our research, allowing us to explore their lives, examine their projects and learn more about ageing. We are immensely grateful for their goodwill and openness and we hope we have done them justice. Our thanks also to the interns and research contractors who worked on the projects described in this booklet: Tina Basi, Adam Drazin, Jessamine Dana, Brenda Quigley, Jonathan Lacey and Tristan Webb. Maurice ten Koppel (at Craftal) designed and laid out the booklet, with support from Stefan Nutter. John Sherry and Chris Claus have encouraged the transition of our work into this format. Our thanks go to all the Product Research and Incubation team in Ireland – special thanks to Niamh Scannell and Gráinne Miller for making much of this research possible.

Simon Roberts
David Prendergast
Introduction: Care and Support Pathways for Older People in Europe

As part of the Global Ageing Experience research project, a team of social scientists from Intel’s Digital Health Group undertook ethnographic fieldwork in seven European, and one east Asian country during 2006-07. This large scale research programme produced a broad yet deep understanding of the reality of ageing in countries undergoing marked demographic changes.

Since that pioneering study, work has continued to plug gaps in our understanding and to focus our field of enquiry. During 2007-08, the European research team has examined domestic, community and policy aspects of the ageing experience. Our research examined how care and support for older people is conceived, financed, delivered and experienced.

This work has taken us to day care centres and active retirement groups, led us to examine transportation services in rural areas and innovative initiatives exploring new ways of delivering care and support to older people and their carers. We have considered the individual experiences of people – in terms of their home environments and daily routines, and broad community responses to the challenges and opportunities of ageing societies. We have been keen to explore private, state and voluntary (or third sector) involvement in the provision and organisation of care.

By undertaking ethnographic research, survey work, and by conducting exploratory pilot projects with people and communities we have gained considerable understanding of the care and support pathways that exist in Europe. While much of the primary fieldwork has been conducted in Ireland, research in the UK and Germany, complemented by desk research on policy and funding regimes within the EU provides a more complete picture.

The booklet sets out to summarise and tie together these different projects into a single narrative. It examines care and support at three inter-linked levels: in the home, in communities and at the national or policy setting. We explore the bigger picture: the dominant and emerging trends in care provision, policy and funding and a high level view of the differences across countries. We also focus on individual experience of ageing within home and community settings. Linking the home and the state we detail research exploring community aspects of ageing.

We also profile relevant organisations central to the delivery of care and support, and the ageing experience. Gaps remain in our knowledge and understanding. Ageing presents societies with complex set of challenges and opportunities.

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A snapshot of the Life of Anna (85), Italy

Anna (85) shares a house with her unmarried adult son Dario in a village about an hour from Milan. She has lived in this area all her life and soberly recalls the poverty of her youth. “I remember a widow came to my mother and told her that her children didn’t want to sleep because they were hungry. And my mother gave her some flour…” Anna learned an abhorrence of debt after seeing her father, a seed tradesman, in difficulties and brought up her own children to work hard and be financially independent. Life wasn’t easy. To make a profit from the small café bar she and her husband ran demanded their attention eighteen hours a day. When he suddenly died from acute heart failure in 1973 she managed to close their business for eight days and then the family had to go on working. Times were hard but they were able to survive as her family had to go on working. As things stand today, young Italians entering the workforce will have to work hard and be financially independent.

In her declining years, Anna feels she has a safety net in her children and especially her oldest son who has taken on the role of family caregiver. Italian law stipulates that an elderly parent in need has the legal right to demand either accommodation or financial help from children with resources. Many would not press this right however. Anna’s daughter now lives in another part of Italy and so can only visit for holidays but they talk a great deal on the telephone. Anna’s oldest son who has taken on the role of family caregiver. Italian law stipulates that an elderly parent in need has the legal right to demand either accommodation or financial help from children with resources. Many would not press this right however. Anna’s daughter now lives in another part of Italy and so can only visit for holidays but they talk a great deal on the telephone.

Anna believes older Italians, though still reliant on the family, live better today than in the past due to the basic state pension - a welfare benefit the country guarantees the same level of benefit support received by the current older generation. As things stand today, young Italians entering the workforce will have to work hard and be financially independent. As things stand today, young Italians entering the workforce will have to work hard and be financially independent. Times were hard but they were able to survive as her children and especially her oldest son who has taken on the role of family caregiver. Italian law stipulates that an elderly parent in need has the legal right to demand either accommodation or financial help from children with resources. Many would not press this right however. Anna’s daughter now lives in another part of Italy and so can only visit for holidays but they talk a great deal on the telephone.

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Anna suggests the chronic pain in her shoulders has been troubling her recently and when she asked for more of the cream that works on her knee to fix the problem, he refused on grounds of expense. Nowadays, Anna just phones in when she needs her prescription and her son picks it up. She finds it very irritating that she has to do this every 6 to 12 days as she is only allowed one box of 12 blood pressure pills at a time and would like more pills in each box to save her the trip.

Decreasing mobility is having a significant effect on her quality of life. “I feel old because I am dependent on other people. The problems with my legs make me feel old. I don’t have any plans for the future now. I don’t want to go out dancing but I would love to visit a specialist to be able to move around better.” For the last eight weeks Anna hasn’t left her apartment. Instead she spends her days watching the world go by from her balcony and trying to do the little she can in terms of housework and her family decided to pay for a home help worker to visit four hours a week to clean. Her son has taken over the shopping duties. Anna is not able to conceive of using an electric buggy to get around as she no longer believes she is safe going out by herself. Having given up on travel, she now regrets not seeing more of the world during her life. The main variation in routine occurs when her daughter or sister comes to help look after her once a year when Dario takes a respite break from his care-giving duties and visits a health spa. “I would consider a nursing home during these times, but only for a month, for a change, never for good.”

Anna uses sticks to get around and has a stick located in every strategic position in the house. She sometimes tests and pushes herself by attempting to walk between resting points. The main obstacle for her in the house is the slippery marble steps. She schedules her visits to the clinic at home in bed being cared for by her son. Anna feels her health has seriously started to decline over the last year with recurrent problems with her knees causing her the greatest concern. In 2002, her arthritis was causing her so much pain she opted for a knee prosthesis operation against her GP’s advice. She was in hospital for three weeks and then had to spend six weeks at home in bed being cared for by her son and sister. Her treatment included an hour of physiotherapy per day and a passive exercise machine to prevent her muscles from atrophying. Her rehabilitation was paid for by the healthcare system for two months and she feels this was not long enough. She neglected her exercises and now problems have begun to emerge with her other knee due to long periods of over compensation. This is partly because she felt it demeaning to use a walker in public and preferred a single walking stick. Anna suggests the chronic pain in her legs is helped by massage and creams. Unfortunately she is unable to get massages on the public health service and private practitioners charge €40 an hour, a sum she feels guilty about spending. Anna feels alienated from her doctor so she avoids visiting her local clinic. Her shoulder has been troubling her recently and when she asked for more of the cream that works on her knee to fix the problem, he refused on grounds of expense. Nowadays, Anna just phones in when she needs her prescription and her son picks it up. She finds it very irritating that she has to do this every 6 to 12 days as she is only allowed one box of 12 blood pressure pills at a time and would like more pills in each box to save her the trip.

Anna has heard of alarm pendants but does not dare to use them. She carries a mobile phone with her in case of emergencies but never takes it into the bathroom with her, one of the most dangerous rooms in the house. Last year, Anna had a fall in her bedroom and could not get up. Her son was not able to hear her cries over the living room TV and her mobile phone battery was flat. She managed to crawl to her charger but didn’t realise that she could use the phone whilst it was plugged in. It was two hours before she was discovered.

As Anna’s mobility and social life has narrowed, her phone has become an increasingly important lifeline. Her son works long hours and she receives few visitors so she calls her sister as often as she can afford. She can still cook a little and loves to sew. She used to make clothes for her family but she has stopped as nobody wears what she makes. Reading is another hobby as is listening to the radio. The real highlight of her month is a visit from her grandchild. This occurs only rarely however, as she dislikes her second son’s wife and they do not feel she is capable of taking care of the child on her own.

“I don’t think I would want to spend another twenty years living like this, though I would love to see my grandson married. Although I am alone a lot, I am not lonely. I can always watch the street from my balcony.”

Anna’s walking sticks are strategically placed around her apartment.
What it means to grow old in Europe - the Global Ageing Experience Project

During 2006 and 2007, anthropologists from Intel visited older people and their families in countries around the world in an attempt to explore their experiences and expectations of ageing, health and daily routines and activities of living. Part of this study included extensive fieldwork in seven European countries as well as interviews with clinicians, academics, and policy experts who could illuminate core issues facing ageing populations and their healthcare systems.

During this project we collected many accounts of the positive and negative aspects of growing old, but were constantly reminded by the people we spoke to that they ‘sick’ meant being bed-ridden, and that few would identify themselves as feeling ‘old’ regardless of the years accumulated.

A recent report from the UK Audit commission (Don’t stop me now, 2008) attempted to highlight some of the complexities of the ageing process, which is summarised in the figure opposite. For all involved in providing services, care or support for older people this process of change is vital to grapple with.

A number of themes emerged from our Global Ageing Experience Project (Roberts, Plowman and Prendergast) which inspired and informed the research projects on which we report in this booklet.

People want to focus on what they CAN do, not what they CAN’T do.

Many people chose not to identify as sick or old. They seek daily lives and challenges that allow them to keep themselves sharp. However, we cannot avoid the fact that people need assistance, particularly considering the expansion in the population aged eighty or more, not to mention the sharp increase in the incidence of chronic illnesses.

We need non-threatening ways of planning for the future, and this is especially important with regard to financial aspects of their care and support as the burden of responsibility shifts away from states towards families and individuals.

The lived-in space is crucial to the experience of ageing

The home is more than just a shelter. It is a repository of memories, a place full of personal possessions and the space in which most people want, and in reality do, spend most of their later years. The physical environment of the home (and spaces beyond the home) are central to how people experience later life. The home is not just the four walls - it is the physical situation of the house in the neighbourhood, proximity to other services and opportunities for social engagement.

Healthcare networks are large and increasingly complex

People struggle to understand and navigate their health and social care systems, and find it hard to align their needs, their entitlements and responsibilities. The way that many care and support systems split out health and social care in administrative terms adds to this sense of confusion. However, people are resourceful and seem able to patch together the services they need from a range of different providers and agencies.

Health Ageing and independent living mean far more than ‘health’

There are a huge number of factors which enable a person to remain at home and independent. Health is, of course, a vital component of this. However, we need to pay attention to enabling services which make independent living possible. These include mobility and transportation services that enable people to live full lives in their communities. Also, services in and for the home - be that personal care or home maintenance - are crucial. The payment and provision of such service is a major area of change and debate across Europe. Issues of trust, safety and security also rise to the fore in the context of care services.

Healthy ageing is inextricably linked to social participation

People of all ages aspire to have a sense of belonging and a legitimate role in the life of their family and community. Humans are meaning makers and social interaction is key to that process. That desire or need does not disappear as we age and so we need to think about how we can lower the barriers to social interaction. In thinking through issues relating to care and support we need to remember that more often than not older people provide care for younger generations as well as their age cohort peers - typically their spouses. However, we need to focus on enabling people to feel useful and productive and on creating the opportunities for emotionally satisfying contact with people they care about.
Community Supports for Ageing

In Europe there is considerable diversity in the ways that welfare states are organised and how health and social care for older people is delivered. A range of factors underpin this variety: the historical development of welfare states; local, regional and national ideas about the role of the state versus the individual, family or third sector in providing care; and the fiscal and economic frameworks in which development has occurred within countries. The interplay between people, practices, policy and politics and economics has created a complex and mutable landscape, areas of which are often opaque to both users and providers.

Social Policy analysts have created a series of models that seek to describe and categorise different welfare systems in Europe. These models provide a good guide to understanding the fundamental principles or structure of how care is organised and financed. Esping-Andersen’s (1990) work identified three distinct social welfare regimes. These were the social democratic model (Nordic countries), conservative or state corporatist model (Germany or Netherlands) and the liberal welfare or Anglo-Saxon model (UK). Ferrera (1996) subsequently added a fourth category – the Southern European model (Italy, Greece, Spain, Portugal). During the 1990s classification models widened from a focus on wage earners, to exploring the balance of the relationships between state and family, gender, age, and particular ‘at risk’ groups (O’Connor, 1993; Anttonen and Sipilä, 1996).

Social Welfare and Long Term Care Systems in Europe: A Basic Overview

Projected long-term care expenditure as a proportion of GDP in Germany, Spain, Italy and the United Kingdom, under central base case assumptions.

Source: European Study of Long-Term Care Expenditure, 2003
More recently, the EU-funded WRAMSOC project, completed in 2005, refined the various models into three paradigms:

**Statist**
The state has extensive responsibility for financing and providing care and the role of the family is, in theory, secondary and voluntary. The state protects individuals from excessive costs of care although even if it funds the care it may be provided by the private sector (e.g., Sweden).

**Familialist/Individualist**
Families and individuals bear the responsibility for financing and providing their own and immediate family members’ long-term care needs and assistance is means tested. (e.g., England, Spain).

**State Pays, Others Provide**
A wide range of providers including families, NGOs, and the private and voluntary sectors provide the care which the state assumes a greater responsibility for financing with less focus on means testing. Care provided is based around dependency and need not economic means. (e.g., Germany, France).

These models represent high-level views of systems and fail to capture the local variations in delivery that often makes care provision deviate from these ideal-typical models. Over recent years and in anticipation of dramatic transitions within the demographic landscapes of Europe, there have been significant changes in policy planning and rhetoric surrounding how welfare and care systems operate. European long-term care systems for older people still show that different attitudes and expectations exist about the relative roles of family, state, and voluntary sectors. However, changes in the age structure of their populations will threaten the viability of welfare states, not least as current levels of informal care become potentially unsustainable with a shrinking dependency ratio between older and younger generations, a declining workforce and a consequent rise in dual-income households.

To answer these problems, many countries are shifting away from expensive institutional and medicalised responses towards a more community and domiciliary centred approach to care. This is being done, with varying degrees of success, through attempts to forge a mixed economy model of social and health care which seeks to utilise an optimum mix of funding and provision of care by citizens, family, state and private and voluntary sectors. This frequently entails a repositioning of the state as a financier rather than a direct provider of care to individuals through the amplified use of market mechanisms, the growth of the private and commercial care industries, and increased regulation and funding of the not-for-profit and voluntary sector.

Recent years have seen a proliferation of experiments and pilot deployments of new funding models both to third-party suppliers of care and the individuals receiving care. In the Republic of Ireland, for example, the state has been active in transforming many of the voluntary home care organisations into limited companies to coincide with the introduction and rolling out of new service level agreements. At the same time, it has been testing different modes of delivery of home care packages to enable older people to remain living in their own homes. One method provides prospective or up-front payments to the care recipient and allows them to make their own choices about how it is spent, placing the responsibility on...
the older person or their family to assume the role of employer, whereas the second approach provides a retrospective payment which is made directly to the care provider.

Since 2004 an intermediate approach has also been explored where recipients of home care packages are responsible for giving details of their care provider and also provide monthly receipts. To date, the majority of the home care packages made available have been a result of hospital admittance and discharge rather than from the community primary care teams, reflecting contemporary priorities of alleviating stress on the hospital system rather than preventative care. (Timonen, Doyle and Prendergast, 2006)

The story of long term care in Europe is one of a continued interplay between cultural and social norms and expectations, fiscal resources and the particular demographic challenges of individual countries. As resources tighten, populations’ age and expectations rise we can expect to see rapid developments and policy responses to often dramatically changing circumstances.

**Long-term care provision in OECD countries**

Some countries offer choice among providers of publicly supported formal care and some countries offer payments for informal care.

Payments for informal care play a considerable role

- Austria
- Luxembourg
- Germany

Limited choice for persons receiving public support for formal care

- United Kingdom
- Australia

Considerable reliance on informal care (paid or unpaid)

- (Korea)
- (Spain)

The extent to which countries rely on formal as against informal care has little relation to the extent to which care is publicly funded.

Considerable provision of formal care

- (Korea)
- (Spain)

Considerable reliance on informal care (paid or unpaid)

- Austria
- Luxembourg
- Germany
- Ireland
- United Kingdom
- Australia
- Japan
- Sweden
- Netherlands
- Norway
- United States

Extent of public funding for long-term care

- Germany
- Ireland
- Austria
- Netherlands
- Sweden
- Norway
- United States

Payments for informal care play a limited role

- Sweden
- Norway
- United States
- Japan

![Diagram of care and support in the EU](https://example.com/diagram)

**Key Facts about Care and Support in the EU**

- **Did you know?**
  - The EU27 population is projected to become older with the median age projected to rise from 40.4 years in 2008 to 47.9 years in 2060.
  - The share of people aged 65 years or over in the total population is projected to increase from 17.1% to 30.0% and the number is projected to rise from 84.6 million in 2008 to 151.5 million in 2060.
  - The number of people aged 80 years or over is projected to almost triple from 21.8 million in 2008 to 61.4 million in 2060.

(Source: Eurostat 72/2008)

**At a Glance: Overview of major public long-term care programmes**

- **Austria**
  - Cash allowance for care covers both home care and institutional care in the form of cash benefits, covering the whole population since 1993.

- **France**
  - Universal health coverage, financed principally by the government and through supplemental policies issued by private insurers. Co-payments are imposed for most services, but certain pensioners and persons with long-term illnesses are exempt from such payments.

- **Germany**
  - Social Long-Term Care Insurance covers home care (since 1995) and institutional care (since 1996) for over 90% of the population.

- **Ireland**
  - Public funding exists for both home care and institutional care based on general taxation.

- **Spain**
  - Public financing is complemented by out of pocket payments to the public system (e.g., co-payments for pharmaceuticals) as well as to the private sector and contributions to voluntary insurance. In 2007, the Personal Autonomy or Dependency Law came into effect, granting over a million dependent people the right to be supported by the public system.

- **Netherlands**
  - Algemene Wet Bijzondere Ziektekosten (Exceptional Medical Expenses Act) is a social insurance which covers both home and institutional long-term care.

- **Norway**
  - Local authorities have full responsibility over public long-term care according to the Municipal Service Act and the Social Services Act.

- **Sweden**
  - Municipalities are responsible and provide most of the home and institutional long-term care services based on the Social Services Act.

- **United Kingdom**
  - Social services provide both home and residential care funded by municipalities with subsidies from the central government. National Health Service provides home and institutional health care and is funded and managed by the central government.

- **United States**
  - Medicare is a federal programme for persons aged 65 and over and for certain disabled groups. It covers care in nursing homes and home health services for a short period of time after an acute event, but it does not cover continuing long-term care. Medicaid is a joint federal and state programme, which covers both home and institutional care for persons with low income.
Community Supports for Ageing

Healthy Life Years
Life expectancy is increasing across Europe, but the experience and length of a healthy retirement varies greatly across countries.

Old Age Dependency
As Europe’s population ages, the number of younger people available to provide support for elders is predicted to fall. This is also due to falling fertility rates. A shrinking workforce threatens the fiscal base of healthcare systems.

Percentage of Females and Males Living Alone
Many ageing Europeans live by themselves, especially women due to longer life expectancy than their partners. A preference for living independently is commonly expressed by older people in many northern Europe countries, often until failing health dictates relocation to a retirement home or the household of a family member.

Survey of Health, Ageing of Retirement in Europe findings (SHARE)
The Survey of Health, Ageing and Retirement in Europe (SHARE) is a multidisciplinary and cross-national panel database of micro data on health, socio-economic status and social and family networks of more than 30,000 individuals aged 50 or over. Eleven countries have contributed data to the 2004 SHARE baseline study. Funded by the EC 5th and 6th Framework Programmes.

• People in southern Europe live longer but Northern Europeans are healthier and richer.

• Around 40% of older Europeans have some degree of activity limitation due to health problems, and almost 50% report that they have some long-term health problems.

• Women suffer from most complaints significantly more frequently than men. However, men are more likely to report early onset of chronic conditions, such as diabetes or heart and lung diseases due to riskier health behaviours. Men are more likely to be obese than women.

• Across the EU, older individuals with a lower formal education are 70% more likely to be physically inactive and 50% more likely to be obese than older people with higher levels of education.

• From a preventive health and social care perspective, there is a serious lack of generic assessments and screening tests around Europe.

• Living with or close to children remains an important mechanism for restricting poverty, especially in South Europe and Germany. In Denmark only 13% of survey participants live with their offspring in comparison to 52% in Spain.

• One third of older people across Europe reported spending time every day helping others or looking after grandchildren.

• In terms of volunteering, 10% of the 65-74 age group work for free outside employment or the family. In the Netherlands this is more than 25%. This is much lower in Spain or Greece.

• There is a clear North-South division for intergenerational financial transfers in Europe. Children receive more in the North whilst in the South they give more.

• Austria, France and Southern Mediterranean countries all see a high prevalence of early retirement due to welfare state or employment incentives resulting in a large number of healthy adults outside the labour force.

• Almost all older Europeans have access to a public pension but occupational pensions or private life insurance schemes account for a much lesser percentage of income, though Sweden and the Netherlands do well in this regard.
Proportion of SHARE respondents living alone who receive non-family help with personal care

Intergenerational co-residence is less common in northern Europe and there is a greater dependency on non-family help to assist with the activities of daily living. In countries such as Italy and Spain cultural and legal expectations encourage greater family involvement.

Source: SHARE, 2005

Poverty rates among people aged 65 and over

For most of Europe poverty rates tend to be around 10% with the exception of Greece and Denmark – this contrasts with a quarter of older Americans who would be classified as poor.

Source: SHARE, 2005

Network of people who help with personal care within the household

Spouses are the primary providers of care. This is less marked in Spain, Italy and Austria where the role of the children and extended family is more pronounced.

Source: SHARE, 2005

Profile: Caritas

Caritas Germany is the Catholic Church’s welfare association organised via the Catholic dioceses. With 499,313 full-time staff members and 500,000 volunteers it is the largest welfare organisation in Germany - working with children, the handicapped and older people.

Caritas runs more than 25,400 institutions such as kindergartens, hospitals, homes for the young and older people. Caritas runs 1,780 homes for older people and almost 550 day centres. They provide a very wide range of services and activities for older people including lunch clubs, meals on wheels, services, leisure activities, internet cafes and information exchange. Information provided includes volunteering opportunities, outings and travel, as well as information about legal entitlements and social benefits. For those with higher levels of need Caritas runs nursing and retirement homes, and serviced living accommodation.
City of Bits - understanding the provision of care information in two English cities

Talking with a woman called Joan in a southern coast English city about how she found providers of the various services that she relies upon to stay independent we discover that her hairdresser was very important:

"I’ve got a list of phone numbers, such as my hairdresser’s on my mobile… If I go to my hairdresser and we’re talking about something they’ll say ‘Oh such and such, he’ll do a bit for you’.

Joan uses the hairdresser as a trusted source of information. She is lucky to have a contact with so much local knowledge - but for many this is not the case. For those without such a resource the task of discovering what services are available can be very difficult. And yet it is such services - be they someone to help with cleaning or laundry, domiciliary care providers, home maintenance or meals on wheel - that have a significant impact on the ability of someone to remain within their home as they age. Beyond core, as well as low-level preventive services, information about activities and leisure options are vital in supporting quality of life. As a member of one of the community centres we visited commented, “there’s not enough information on activities or societies going on”.

A number of factors make this issue complex to address. At one level, the mixed model of care provision in many EU countries is creating a bewildering array of private, voluntary and statutory organisations which fund and/or deliver services. It is often the case that providers of services are not aware of what other similar providers are doing for older people. As one council worker told us, candidly: “We don’t even know who does what in the council”.

The complexity is compounded when information sources are mixed. Further, people often need this information at times of crisis or emotional turmoil, after the hospitalisation or the deterioration of a loved one’s health. It is not always clear that people know where to go. At times like this the provision of accurate information is a crucial support.

The UK government is currently consulting on the future of the care and support system for England and Wales and recognises the need for change:

“Currently, accessing information on housing, finance, and care and support services can mean going to different places and talking to many different people. There are examples of good information provision – for example, the voluntary sector plays a key role in this area - but more still needs to be done to make sure that people can access information and advice more quickly and clearly”.

The case for change - why England needs a new care and support system (UK Govt Consultation document May 2008)

What we found on the ground when reviewing the current status of information provision was that apart from where pilots were being run to assess the viability of information gateways (such as the Link Age pilots in England), there was no one-stop shop. Instead, ageing organisations such as Age Concern might maintain a list of service or activity providers, and older people or carers might access this. Alternatively providers would use Age Concern staff to get a recommendation. However, despite the best of intentions no list remains current and it is hard and time consuming to maintain.

What the Age Concern list did represent to people - be they informal care providers, older people or providers themselves - was a trusted source of information. A phone number or contact at an organisation represented a ‘recommendation’. It is clear that beyond basic contact information, people require some subjective assessment of the provider too. However, a number of schemes exist to assess the appropriateness of providers of services - schemes of accreditation such as the Buy with Confidence. Given the vulnerability of many older people these schemes provide significant peace of mind.

In the future there is likely to be growing awareness of the information gaps that exist in terms of care and support services for older people. The complexity of health and social care systems cannot be reduced overnight. However, as policy moves further towards the mixed economy model, personalisation, and self directed care (in which people are empowered to develop their own portfolio of care services) takes root in many EU countries, the importance of timely, relevant, trustworthy information will only grow.
Understanding the dynamics of social care and support as they exist within communities is essential to the development of products and services that will be successful. Sometimes, in order to efficiently achieve that holistic understanding, one must conduct multi-level, multi-directional research that focuses on a specific case study. This was the thinking behind the development of ‘In Dublin’, a ‘deep dive’ project into the world of social care provision and acquisition in one neighbourhood in Europe.

‘In Dublin’ was a six month ethnographic study of social care and support for elders living in a traditionally working-class neighbourhood called Stoneybatter, located in inner-city Dublin, Ireland. The study undertook to explore the realities of the social care world for both older people and service providers. A project that drew together ‘traditional’ ethnographic practices and design-influenced mapping and workshop methods.

The model of the social care and support landscape in Stoneybatter was developed by accomplishing three core objectives:

- Document the world of gatekeepers, providers, and groups involved with social care and support in Stoneybatter
- Generate experience and information maps of social care provision and access from the perspectives of older people and stakeholders at different levels of the community
- Understand how community and individual practices and attitudes influence or impede social care and support

These objectives were met by drawing on various methods including interviews with statutory, third sector, and private organisations and individuals, tapping into the existing group of ‘Stoneybatter Senior Citizen Researchers’, educating and framing discussions about service provision, and many hours of ethnography. Through the process of realising this project, researchers from Intel became known and integrated with members of the Stoneybatter neighbourhood.

Stoneybatter is an ancient neighbourhood that is located in North-West Inner City Dublin. What began as a medieval Viking settlement has changed through the years from a rural village to become part of the heart of contemporary Dublin. Its present-day people and places have been significantly shaped by its history and imprinted by the economic fortunes of the area and Dublin as a whole.

Bounded by the River Liffey on the North Circular Road with its large, Victorian houses to the North, the old British Army barracks to the West, and what was formerly the thriving cattle market of Smithfield to the East, Stoneybatter has been affected and supported by each of the different communities at its boundaries, while maintaining its unique traditional working-class character.

The ‘In-Dublin’ Project
Walking down the main street today, Stoneybatter’s rich history and strong sense of community jostles with typical scenes of inner city life. For the 1,200 plus older people in the neighbourhood, most of whom were born and raised in the area, the poverty that began in the first half of the 20th century marks what they remember as a vibrant, connected community.

Often referred to as ‘Dublin’s Inner Urban Village’ (K.C. Kearns 1989), the Stoneybatter of their youth had its roots in the 1890s, when the Dublin Artisans’ dwellings company, working in conjunction with the Dublin Corporation, built many of its 3,000 houses for 15,000 ‘respectable’, skilled, working class people. In an open attempt at social engineering, the families allowed to buy the artisan houses were screened by the Company for the appropriate moral and social attributes, then settled close to their relatives and provided with incentives to keep property within the family line. The results of these measures, the creation of ‘respectable’ working class individual and community identities, continue to have resonance with locals, particular older inhabitants, with significant repercussions for concepts of autonomy and service acquisition. As one older woman put it when reflecting on notions of social welfare and ‘charity’,

“People don’t want to know and I don’t want to tell them. It’s a matter of pride. It was important to show that everybody had the same, even if you had more or a little less. Even if you needed the price of bread, you’d never tell. My mother would have rather died than let anyone outside of her family and close friends know that she couldn’t afford our communion dresses or whatever it was. Those chancers today know how to get anything. All they want is handouts.”

During the 20th Century, Stoneybatter experienced considerable decline as the British Army Barracks was closed, the cattle and pig markets shut down, and the Guinness, Jameson’s, iron, and glass factories largely relocated. Older Irish perceptions of Stoneybatter changed from that of a ‘respectable’ working-class area to simply being a place where the poor, unemployed, or unwell could be placed in sheltered housing or half-way houses. Previously proud of their position as non-indigent working-class, the traditional community of Stoneybatter felt themselves to be threatened by newcomers and foreigners settling or being settled there by the Dublin City Council.

This feeling of pride, privacy, and the need for autonomy from the government, encouraged greater reliance on a community of self-sufficient services that were simultaneously becoming eroded by out-migration, itinerant work requirements, and unemployment.

“All the community has either died or left. Before we had neighbours but now who do we know? Long ago, if you didn’t know your neighbour, you’d know someone belonging to them. You got to know one of the family’s relations. That’s how you build up a community. These new people only sleep in their houses and nothing else.”

“It’s the same all over Ireland – it’s the change!”

Previously, many of the men and women in Stoneybatter had derived a sense of self from helping “those more in need than ourselves”. This would take the form of holding raffles, fundraisers, and bake sales, participating in local chapters of religious charitable groups, as well as clothing, toy and money drives for the poor families in the area or on the outskirts of the artisan dwelling neighbourhoods. As unfamiliar, low or non-income foreigners or ‘blow-ins’ moved into the sheltered and council-owned housing, locals suggest they felt less comfortable performing these activities for people and less able to trust that they might be done for them when they found themselves in need.

“When a man living alone was what you would now say, ‘depressed’, his neighbours would leave a bottle of milk or some food on his doorstep just to help him get by. People wouldn’t talk about it except to call it ‘Uaigneas gan ciunas, or loneliness without peace or light’, but they knew to look out for it.”

Profile: Meals on wheels

Meals on wheels is available in all countries in Europe. However, it is organised differently in different countries and at a regional level. Meals on wheels is a good example of the way in which a voluntary service has become professionalised and commercialised, whilst retaining a volunteer component that is key to its success.

The UK is a case in point. In 2007, Meals on wheels celebrated 60 years of service, having originated in Britain during the Blitz. The Women’s Volunteer Service for Civil Defence (later WRVS) provided food for these people. After the war, the service developed into the format familiar today, with organisations such as the Women’s Royal Voluntary Service still provide the service in parts of the country.

In the UK, there are currently 40 million meals served to 200,000 clients annually. A phone survey of providers conducted by Intel found that the average cost of a meal was £2.67. Responsibility for Meals on wheels was devolved to local councils and in recent years has been outsourced by councils to providers such as Appetito.
As elsewhere in Ireland, much of the ‘good neighbour’ work done locally has been replaced by large charitable organisations with attenuated relationships to the community or the emergence of state departments that more seriously took on the responsibility for social care and support. One of the unintended effects of these changes was to disband many of the unofficial community-based support systems and ‘neighbouring’ activities that provided an informal means of circulating information about social support and activities, and an avenue to discretely obtain social services and support for the members of these groups. The other primary response to the extension of government and charitable organisations into local social care provision, was that care of older people was now included with other social services like mental illness, disability, poverty, and drug abuse. This re-categorisation of age not only occurred at the bureaucratic level, but also in the real life experiences, exchanges, and attitudes older people encountered when they sought support outside their dwindling community resources.

Key Findings
- Social, historical, and local contexts of, and associations with social care provision significantly shape contemporary perceptions.
- Social care provision and pursuit does not occur in a linear fashion in Stoneybatter, therefore the imperative for stable and reliable information networks is greater than previously recognised.
- Instability and unreliability of information networks about social services is the largest obstacle to social care in the views of both older people and service providers.
- These failures result in social isolation, dissatisfaction, and neglect of older people, as well as repetition of services and unsuccessful service provision.
- The core requirement for improving information networks is a formal system that supports linkages of information and resources between providers which enables older people to understand, trace, and feel ownership over their social care journeys.

Active Ageing and The Expansion of the Third Sector

With many populations around the world rapidly ageing, there is mounting pressure on governments and families to both ensure older peoples’ basic needs are met and to improve their quality of life. Welfare states and health systems are increasingly looking to develop partnerships with non-governmental organisations (NGOs), social entrepreneurs, communities, not-for-profit agencies and the voluntary sector to supplement or create additional resources to protect and promote the wellbeing of older people.

Case Study: Summerhill Active Retirement Group

It is in this space that a small active retirement group, born in a rural Irish village in 1988, has managed with the help of a self-taught social entrepreneur to develop into two national level organisations. Twenty years later it is poised on the edge of international expansion. Summerhill active retirement group was formed by Mary Nally, a local nurse who was appalled by the lack of social services available for older people in her area. She called together a meeting of seniors at which they decided they could ‘do it for themselves.’ Granted a scrap of land and a ramshackle portacabin by the Irish Health Service, the group began holding regular social events and a campaign of funding applications to secure the means to employ staff and begin to run direct services and roll out programmes of activities.

A long term research relationship between Intel and this group began in early 2006, when our ethnographers were invited to explore opportunities for collaborative social research, participatory design and engineering pilot studies. Key questions at this time were how the wider community - beyond the household unit - figures in understanding what it means to ‘age in place’; what are the social and economic needs and contributions of older people in Ireland; and what are the roles and challenges of the rapidly changing Irish voluntary sector.

Members of the Summerhill Active Retirement Group canoeing at the World Senior Games, Newcastle, England.

“We don’t see a lot of the people attending the active retirement group. They are generally out doing other activities and don’t have time to be thinking of ill health.”

Dr Joe Clarke, Summerhill GP
Growth in the number of ARGs in Ireland

Source: Intel survey of Active Retirement Groups in Ireland

Active Ageing Groups: Activities and Identities

The rise of the active ageing movement, and active retirement clubs neatly mirrors the changing nature of academic accounts of ageing. Disengagement theory viewed later life as a time of withdrawal from social activity and work. Later, activity theory suggested instead that the maintenance of social activities and contacts through an active engagement with life was an essential component of ageing well. Equally, ideas associated with successful or positive ageing stressed the importance of longevity and quality of life. Nowadays mainstream accounts of ageing are as likely to stress the importance of social networks as they are health status - indeed there is very strong evidence that the strong networks creates better health outcomes.

Active Retirement Groups (ARG) are firmly focused on making real the promise of an active and engaged life, which have benefits for older people and the wider community, from villages to the national level. Our ARG survey project sought to produce a detailed picture of the world of active retirement in Ireland – to understand their history, their membership and organisation and to understand what they offer members and what value and role they are seen as having.

The pre-history of ARGs in Ireland - efforts to support welfare of older people - were focused on income maintenance (Old Age Pension Act 1908) and charitable activities, largely organised by the Church. The focus
was as much on nutrition and the avoidance of deprivation. By the 1980s a shift from ‘subsistence’ towards ‘experience’ and social activity had become clear. Ireland’s first ARG was formed in Dun Laoghaire in 1978 and by 1985 a further 23 groups had been established. In the same year a Federation of Active Retirement Associations (FARA) was formed. One stated intention was to give older people a public voice to influence policies impacting the ageing population. By 1989 there were 55 groups in the FARA and as the chart on page 29 shows, the increase in numbers of ARGs has continued to this day, when there are 455 affiliated with ARI (Active Retirement Ireland [new name for FARA]). It is striking that there has been a strong increase in the number of ARGs in Ireland over the last five years. This is at a time in which Ireland has gained the reputation for being a good place to grow old - due to the relatively generous health and pension provisions - and a time when people have returned to Ireland after a life, or at least career, abroad. 44% of the groups surveyed had been established in the last 5 years. The membership, size and profile of the groups revealed by the survey is of 58% of groups being of 50 or less members. The gender profile of the groups is more striking. Whereas 44% of the Irish population over 65 is male, only 20% of the members of the groups surveyed were male. The values for females are 56% and 80% respectively, with 12% of the groups being entirely female. Our research wanted to identify what the groups offer to their members and what members value from their association with the groups. We identified the following activities as those most commonly offered by the 161 ARGs that replied to the survey:

For their members the groups have a number of benefits - they create a sense of belonging, a focus for group activities and a sense of affiliation. Being a member of a group provides practical benefits - access to cheap insurance - as well as emotional advantages. For members it is a vital demonstration of the fact that older people are as likely to provide services in their community as they are to receive them. Active Research Groups span a number of the levels at which older people operate within society. They provide basic services and amenities for very localised groups and respond to the presence or absence of formal provision by the state. They also react to the changing fabric of society - for example by welcoming into their groups people retiring from Dublin into rural areas or by teaching English to newly arrived foreign nationals as in the Failte Isteach scheme. At a regional level they provide a forum and vehicle for lobbying politicians and engage on the national stage to pursue policy reform and implementation that enhances the situation of older people. The strong visual identity of ARI - complete with slogan “Get Inspired with Active Retirement” is testament to the need to compete for funding from the state as a means of representing their members and the interests of older people more widely.

As such ARGs operate as locations for the practice of active ageing and vehicles for an identity politics in which the contribution of older people to society, as active participants not passive recipients, is articulated. ARGs, at a national and European level, are involved in the arbitration of older people’s interests in democracies in which access to resources for different groups is key.

### What it Means to be a Member

#### A Group to Belong to

“The strength of the chain is in its weakest link. Our strength lies in the regard we have for one another and our willingness to see one another’s point of view and work for the good of our ARG.”

#### A Way to be Active

“To have something to look forward to like outings and holidays, meeting club members, helping the club, using their lifetime experience to help their neighbours – physical and mental exercise suitable to their age group.”

#### A Source of Discounts

“Group rates at hotels & venues are a large incentive for ARGs to form.”

#### A Place to Socialise

“It’s something to look forward to for a lot of people...a cup of tea and a chat.”

#### A Place to Volunteer

“Many members are involved in voluntary community activities. The organisation itself provides an invaluable service to the community by helping reduce social isolation and providing activities and educational talks as required by members.”

#### A Vehicle for Meeting Others

“I would hate it if the group broke up...it’s great fun to meet different people from different places.”

#### A Source of Empowerment

“We feel we are as important as any other age group in our community. We are willing to help if asked and must not be ignored because we are getting older.”

### Participation in activities by SHARE older adults

- **Workshops**: 35%
- **Travel**: 20%
- **Day Trips**: 15%
- **Outings**: 10%
- **Sports**: 10%
- **Café / Club**: 5%
- **Holidays**: 5%

**Source**: Survey of Health, Ageing and Retirement in Europe, 2005
Successful and healthy ageing often relates to the ability of older people to maintain social networks and to sustain levels of autonomy and independence. There are a number of factors that pattern people’s ability to experience healthy ageing. Determinants include health and social services, economics, social, lifestyle, personal as well as biological factors. However, the physical environment is also crucial (Peace, Kellaher and Holland, 2005).

Healthy ageing requires people to be able to participate in the life of the communities in which they live. Participation in this context means living life to the fullest extent of their capability, for example by making contributions to the community in any number of ways - as volunteers, consumers, carers, grandparents. Being economically active is also an important aspect of ageing as older people want and need to work later into the life course.

However, there are a number of barriers to such full participation. The World Health Organisation’s Global Age-friendly Cities project sought to understand older people’s own experiences of ageing with respect to their communities and environments. In doing so it highlighted key areas that play a significant role in older people’s abilities to age successfully.

The following areas cited in the project report have particular relevance to themes developed within this booklet:

- **Outdoor Spaces and Buildings**
- **Transportation**
- **Housing**
- **Social Participation**
- **Communication and Information**

### Age-friendly Cities

- **Transportation**
  - The ability to travel through accessible and affordable transport is a major influence on successful ageing and an issue that cuts across many areas of importance for older people. The key issues are availability, affordability, reliability and frequency, age-friendly vehicles and specialised services for older people.

- **Outdoor Spaces and Buildings**
  - The outdoors environment, public spaces and buildings have a major impact on mobility and independence, and thus the quality of life of older people. Issues of importance include green space, places to rest, age-friendly pavements, and safe pedestrian crossings and adequate public toilets.

- **Community support and health services**
  - Good quality, appropriate and accessible care is a significant concern for older people. Older people want more accessible care - well located and reachable through transportation links. They want more programmes for disease prevention and health promotion, and consistently express the desire for home care support. Where people are unable to live at home residential facilities are required and these need to be designed with the highest regard for older people’s needs.

- **Civil participation and employment**
  - Many studies show the links between social support and participation and good health or well-being. Participation in leisure, social, cultural, spiritual or economic activities allows people to maintain competences and a sense of self respect and dignity. Important enablers of this are accessible opportunity (transport being key), affordability and variety, and information to increase levels of awareness about what’s available. Encouragement and support to participation are also required.

- **Social Participation**
  - Staying connected with news, events and information about the local community is vital for successful ageing. There is a strong fear of being cut off from relevant information, and social exclusion is linked with lack of access to such information. Key issues of relevance include getting the right information at the right time, age-friendly formats and design, including recognition that computers might not always be considered usable or appropriate by older people.
A consistent finding within our own research and that of others (e.g., Tinker, 1994) is that when people are asked where they want to grow old, the response is their own home. At the same time, people tend to have a more pessimistic view: that they will grow old in a residential care setting. However, as Leonie Kellaher notes, in modern western societies, “it is only a minority – around a quarter of those aged 80 or over – who move into special settings such as residential or nursing homes” (Kellaher, 2001: 222).

The chart below describes the variety of housing types that are available to older people. These are laid out in a continuum from own home through to high dependency homes. We have also noted the housing types that are emergent categories within these countries. See Guarded Flat (Spain), Retirement Villages, CCRC & Extra Care Housing (UK) below.

### Housing Options for Older People in four EU countries.

<table>
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<tr>
<th>Own Home</th>
<th>Servicehus</th>
<th>Älderdomshem</th>
<th>Gruppoende</th>
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<td>Own Home</td>
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<td>Residential Nursing Home</td>
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</table>
Germany

- Altenwohnheim – residential complex with some additional services and shared facilities. Residents dwell in private apartment-like settings and often run their own households.
- Altenheim – residential facilities with integrated service offerings. They are targeted towards people who have minor support needs but residents don’t run their own household anymore. Between 1999 and 2005 the number of beds available in care homes increased by 17%.
- Altenpflegeheim – nursing which provides full time stationary care with very significant needs.
- Betreutes Wohnen – ‘assisted living’: a new residential / housing concept that emerged in the 1990s and can be seen as an alternative to the traditional Altenpflegeheim and Altenwohnheim. It is estimated that about 150,000 people live in such settings but the market is not regulated and therefore data is hard to locate.

Spain

- Guarded Flat – a self-contained apartment with full tele-assistance support, typically on the same location as a nursing home. In 2000 there were 4,280 housing places in the country.
- Validista – community home intended for people able to cope by themselves – a nursing home with private rooms / flats and communal areas.
- Asista – Nursing home providing 24 hour nursing or medical care. In 2004, 60% of all older people in residential care were occupying ‘assisted’ places (Deleitze 2006).
- Mixta – A nursing home offering a variety of care levels, tailored to suit residents.

Sweden

- Servicehus – individual flats with social alarms, typically with communal areas and catering facilities. In 2005, it was estimated that there were 19,500 such flats in Sweden, an increase of 62% from a survey taken in 2000.
- Älderdomshejm – care home for those with high levels of need, typically small apartments with large bathroom, basic kitchen and communal areas. Care staff on hand 24/7.
- Gruppboende – homes intended for people with dementia: small numbers of grouped flats with staff on call 24/7, social alarms and communal socialising and eating areas.
- Nursing homes – residential home for residents who need round the clock nursing or medical care.
The Home as an Index of Ageing

For John, an eighty year old widower living in Cork, Ireland, home signals his independence and health. “Independence to me means that I have a key to my own door, that I can walk to my door, that I can lock the door and live in my own world like we all do, that’s my independence…” Later he adds that “health is that I am comfortable in my own home”.

For Harold and Marjorie, the mobility of their home is also important. “We’re not getting any younger” Harold says, “This is a story about change in the self and in the environment that is far from unique.” During our research we have encountered a number of such discussions in which people recounted their relationship with their homes and its suitability for them as they age. For Marjorie and Harold the stairs, the tea, the garden are features of the home which are used as a way of benchmarking their bodies – of providing a “substantial and rapidly growing element of the health care system in many post-industrialised countries”.

Wiles notes, “The drivers for this policy direction can be characterised as being both negative and positive. From a negative perspective the closure of institutional care units, waiting lists and staff shortages and significant budget constraints are driving a shift towards home based care. However, on the positive side, there is a growing recognition of the therapeutic benefits of remaining in one’s own home and the potential for individuals to evolve and grow, not decline within their own home environments. Overall, the enhanced sense of dignity gained from remaining at home is increasingly recognised.”

Harold and Marjorie moved into their bungalow four years ago. They moved into the area, on the outskirts of Macclesfield, from a two storey house with a sizeable garden. The move had been provoked by changes in the interaction between Marjorie and their home. Harold talked to me about his morning routine, or, rather how it used to be. He used to get out of bed at five past nine in the morning, after the news bulletin on BBC Radio 2. His habit had been to listen to the radio with the cup of tea that Marjorie had brought him at quarter to nine. Now that they live “on the flat” this domestic routine is restored but it had been disturbed.

Marjorie has arthritis in both her hips and has begun to find it difficult (and potentially dangerous) to walk up the stairs each morning with a hot drink for her husband. She had started to leave his tea for him at the bottom of the stairs - what Harold referred to as “take away service” had been established - such were her worries about scalding herself. The stairs were communicating to Marjorie the worsening of her hips and, as she and Harold recount it, this communication became the basis for a more wide ranging discussion about the suitability of their home as they grew older. Harold gave more thought to the lawn that needed maintaining and other features of their two-storey semi-detached house which would begin to defeat them.

Now, happily installed in a bungalow, where “It is only a matter of feet between the door and Harold’s side of the bed” the morning tea routine is re-established. Harold points to the mix of paving, cement and gravel in the garden and expresses relief that he no longer has to worry about a lawn. This is a story about change in the self and in the environment that is far from unique. During our research we have encountered a number of such discussions in which people recounted their relationship with their homes and its suitability for them as they age. For Marjorie and Harold the stairs, the tea, and the garden are features of the home and home life which are used as a way of benchmarking their bodies – of providing an index against which they can measure or track their physical abilities.
Moving beyond the Home: Mobility in Later Life

“It’s nice to have someone to talk to - put on the radio? The radio isn’t somebody who’s able to say hello to you and say ‘I’m here’ to you. I’m on my own here. My kids have all gone and I don’t see many people and in the daytime I am home by myself… I’d be lost…stuck in the house…

Picking people up on a minibus that is navigating the narrow lanes of rural Ireland it immediately becomes clear just how isolated many of these people may be. Large numbers of the passengers will have spent most of their lives in the same area. In that sense they will know, and be known, to a good deal of the people locally. However, as they age, and their social networks shrink, they risk social isolation and loneliness.

Although the general trend of urbanisation is leading to great concentrations of older people in urban areas, rural areas of Europe have an increasingly ‘ageing’ profile. Living rurally in later life presents challenges for older people. Living outside of urban centres, with little or no access to private transport, or an integrated public transport system makes independence difficult to achieve. As one woman said, “even if there was a bus running along the road nearest the house, I’d still have to walk a mile to it”.

Mobility is important. There exists a complex but important relationship between health, sociality, independence and mobility and lack of available transport has been found to be a significant barrier to utilising healthcare. Beyond health care location (clinics and hospitals), lack of transportation has negative impacts on health outcomes for older people since the maintenance of close relationships, and the possibility of engaging in meaningful activity outside of the home, can be difficult without access to transport. Mobility allows people to maintain and strengthen their social networks. Multiple studies have shown perceived social support to be the strongest predictor of physical and psychological wellbeing in later life. Lack of mobility can create the risk of social exclusion and make access to services difficult.

The research took a ‘week in the life’ approach to understand the issues up-close. Ethnographic fieldwork was conducted with five projects over five weeks, focusing on passengers, drivers, back office staff and the variety of locations to which buses travel. Our intention was to understand transportation in its wider context. Our initial impressions during research centred on the importance of journeying to older people - that being on the bus was a positive experience in itself. Much research on transportation sees it as a derived need - a means to an end - when for older people it can be an end in itself. However, we were also struck by the extent to which our own travels brought into view a very large number of services and providers on which older people depend in order to remain independent.

Key Findings

- without the transportation services, life for rural older people would be difficult and a less positive experience. Transportation is a fundamental enabler of independent living and creates a sense of autonomy. Equality, this is a big issue for urban older people who often have little access to point-to-point (to the door) transport.
- Mobile lives are sociable lives - mobility is valued for all it enables, not just the journey: journeying is fun but people often need support in the form of knowledge as to who else is travelling - the encouragement of a friend.
- Transportation is a platform that links people to places, people and resources. It is an engine of social activity and cohesion: it is important to recognise the centrality of mobility services for older people and a wide range of other stakeholders engaged with older people.

Life beyond the Home

‘All my old neighbours are gone and the younger people have all gone to work. I don’t see many people and in the daytime I am home by myself… I’d be lost…stuck in the house… I wouldn’t get out’.

Transportation is a platform that links people to places, people and resources. It is an engine of social activity and cohesion: it is important to recognise the centrality of mobility services for older people and a wide range of other stakeholders engaged with older people.
To live independently in your own home as you age you need to be able to move beyond it. For example, in County Kerry, we found an older people’s day care centre. Staff commented that the people brought to the centre - for physiotherapists, to see nurses, to get help with a shower, and see friends and have a hot meal - would not be able to live at home without the transport and the support it enables.

Finally, exploring the community transport sector in rural Ireland highlights the importance of community initiatives and bottom-up social innovation. National governments increasingly depend on such innovation and capacity for the provision of care and support for older people. Being provided by organisations close to people in their homes and communities, the services are often experienced as closely suited to the real needs of those at whom they are targeted.

Beyond the buses we experienced the operation of day care centres, shopping centres, hospitals, active retirement groups, clubs, associations, Post Offices and Meals on Wheels services. Without these providers independent living in their own home would not be possible (or pleasurable) for many older people. To this extent, mobility services are enablers of independent living.

**Service Provider Profiles**

**Profile: In Control**

In Control is a UK based social enterprise whose mission is to “create a new welfare system in which everyone is in control of their lives as full citizens”. It formed in 2003 with the specific objective of reforming the social care system in England. In Control grew out of the Independent Living movement of people with physical impairments. During the 1980s and 1990s it campaigned for the introduction of direct payments of care budgets to such people in order that they would have more control over what support and care services they can access and use. In Control works with citizens, government, charities and commercial companies to develop initiatives and extend the self-directed support agenda. The English government now wants all local authorities to change their systems towards self directed support.

**Profile: Friendly Call Service**

Based in Ireland, the Friendly Call Service was formed in 2005 to provide a lifelong to socially isolated individuals by making a brief telephone call every weekday to check their health status and provide a listening ear as well as reminders about medications. The service uses paid employees trained by the Samaritans and whilst most of its clients are older people, it does also call other members of the community referred through the social or health service provider. The Friendly Call Service attempts to act as a barometer of change about the problems of isolated or excluded sections of the population and provides monthly reports to the Irish Health Service Executive. In partnership with Intel, it has recently broadened its mandate to start training older people to use ICT (Information and Communication Technology).

**Profile: The Upstream Centre**

Funded by the UK National Lottery, the Upstream Centre in Devon uses peer mentors to attempt to reintegrate socially excluded older people into their communities. Once a candidate for the program is identified or referred to them, a peer mentor will visit the older person and spend time with them as a companion. When deemed ready, the client will be invited to attend a supportive community group of their peers run by the mentor and will be encouraged to help with a range of artistic and social activities. Transport costs to facilitate the weekly group meetings are subsidised by the Upstream Centre for several months. Over time, members are encouraged to widen their social networks and are gradually introduced to other community and activity groups.
Community Supports for Ageing

The American anthropologist Margaret Mead once suggested that to understand a culture one useful question to ask of people is ‘what does a good life in this society look like?’ In order to understand ageing in any country or culture we might pose a similar question: ‘what is it like to grow old in this village, town or city?’ Any response to that question is likely to involve consideration of the range of contexts in which people live and their experiences are shaped.

This report has used a variety of research projects, and explorations into the broader demographic and policy directions of Europe, to provide a view on the current nature of care and support for older people. We have described three contexts which shape the way such care is experienced and provided: the home, community and national/policy frameworks.

We view the relationship between older people, their carers, homes, communities and the policy setting to be dynamic and mutually constitutive. How we understand the nature of our responsibilities towards our family and others as they age is shaped by policy, economic incentives (or disincentives), by the existence (or lack) of formal care structures and by complex national, regional or local cultural understandings about what people do for themselves or others as they age.

Here we revisit these contexts to provide a summary and some indication of how the future might play out.
Community Supports for Ageing

National policy with local delivery and provision of care and support services creates complexity for professionals and care users.

Awareness and efficient use of resources is often hampered by the complexity of provision and the lack of information about what services are available, by whom they are provided and what entitlements to them exist.

People and communities are doing it for themselves as they respond to crushing needs and often inadequately tailored provision. Bottom up innovation needs to be nurtured and sustained through appropriate financial and policy instruments.

Social entrepreneurs who respond to local needs and issues are often showing policy makers and planners the way forward. Their approach blazes a trail through the complexity of the sector and demonstrates what sort of care people want and need.

Community is key. Social networks are important to people of all ages - they support, stimulate and sustain us - and have demonstrable positive health outcomes. The community environment is the frontline in people’s experiences of ageing and where those that provide care and support services to them are to be found.

Participants not just recipients. Older people are not just recipients of care - they are carers - for spouses, siblings, children, grandchildren and others - and active volunteers and members of communities and workforces. Into the future we can hope to see greater recognition of the participatory roles they take in both the private and public sphere.

Home

Home is where the heart is: people strongly desire to age in their own homes and the vast majority do. Homes provide more than shelter, such as biographical continuity and demonstrations of independence and autonomy.

Emerging models of residential care settings are to be found across Europe. Retirement communities, similar to US Continuing Care Residential Communities are springing up, extra care housing and retirement villages are taking root.

Care at home is the focus of many nations’ strategies as they attempt to enable people to live independently in their own homes.

Technology in the home is an enabler for independent living. It is a key ingredient in attempts to support people to be socially active, to assist in the management of chronic diseases, to monitor for events like falls and provide information about available services and support.

Beyond the home lies community life, friends, family, services and resources. Older people need support, encouragement, and suitable infrastructures to take an active part in the world beyond the front door.

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Fiscal constraints will impact the funding of long term care requiring countries to examine long term care insurance schemes such as those introduced by Germany in the 1990s.

Long term demographic change - the shrinking dependency ratios, as well as the population replacement rates (most acute in Germany and Italy) - will compound financial scarcity and force a fresh approach to care provision and planning.

The mixed economy of care, already the dominant form of financing and provision to some degree will continue to develop as private, public and voluntary providers respond to the needs of their populations and communities.

Rights, responsibilities and entitlements. As the systems of care and support provision continue to change, we can expect shifts in how people view what they can receive from the state in their old age. A discourse of individual responsibility, particularly with respect to the funding of long term care, is likely to become more pronounced.

Health and social care systems, have historically been distinct. In countries where this split is stark policy will attempt to create a continuum. This will allow older people and their carers to more easily navigate the care service providers around them.

Personalisation and choice are likely to continue to define the changes in care and support systems in Europe. However, attention will need to be applied to putting resources in place that make such choice manageable. Care brokers, who can help people make decisions about what care they need or can commission for themselves, are a growing cadre within the health and social care systems of Europe.

Technology is emerging as a key enabler of service provision. It allows care providers to more efficiently allocate resources, enables older people and their carers to play a more active and informed role in their care. For example, across time zones and distances it can link older people, their family and formal care providers together to better coordinate and plan necessary care.

This booklet has demonstrated that social, cultural and policy issues are vital for understanding the ageing landscape in Europe. If we are to succeed in our vision of using technology to address present and future challenges to our social and healthcare systems, then we need to base our design and innovation on a deep rooted understanding of people and practices across the continuum of care.

No one-stop shop technology solution, company or organization can succeed in meeting these challenges alone. Governments, industry, healthcare providers, NGOs, patients and their carers need to work together. A paradigm shift is required towards health and Social Care systems that offer more proactive, person centred models of care and improve quality, cost and accessibility. Intel’s goal is to help build a robust R&D ecosystem which will help pave the way for a prosperous marketplace Intel is committed to improving health and care for all. As a global technology innovator, we are in a unique position to help. We collaborate with a range of organisations and stakeholders to

- Improve acute care in institutional settings
- Advance personal health technologies
- Conduct people focused research and innovate solutions based on people’s needs, values and practices
- Support rigorous standards and policies

To create new ways of delivering health and care, we need evidence that demonstrates the efficacy and financial viability of technology, whilst ensuring that the innovations are sensitive and responsive to the cultural, policy and professional environments in which they are embedded. Intel sums up this approach as the three Es: ethnography, evidence based and ecosystem.

Field studies, open-ended interviews, observations, and other techniques that help us to understand people’s needs on a first-hand basis & in real settings.

Deploy and test prototypes in real settings—not in a lab; drive long term product roadmap, build IP portfolio, and publish.

Drive industry, academic, government and consumer groups towards collaboration and funding of healthcare solutions; promote sharing of research platforms and data.
The TRIL Centre is a research body, staffed by leading researchers from Intel, Trinity College Dublin, NUI Galway and University College Dublin. The focus of our research is discovering how technology can be used to maintain and improve the health of older people, empowering them to live as they choose.

The older person is at the heart of TRIL’s research. Currently focused on three core areas of Falls Prevention, Cognitive Function and Social Connection, TRIL technology is developed by a multi-disciplinary team of ethnographers, designers, clinicians, economists, and a range of technologists and scientists. To ensure that all the technology that TRIL designs and builds will really have the desired impact and benefit for the older person, TRIL research is guided by a mix of baseline clinical research, quantitative analysis and ethnography. Before, during and after the innovation process, researchers spend extended periods of time with older people, getting to know them and understanding their day to day lives. This helps to identify opportunities and overcome challenges of putting technologies in place which are both unobtrusive and effective in supporting health.

TRIL Clinic
Ethnography Centre

The TRIL Centre
Technology Research for Independent Living

Technology Research for Independent Living Centre
A collaboration with the Industrial Development Agency of Ireland and Irish Universities which will bring resources and attention to the field of Social Connection, Cognitive Function and Falls Prevention research.

Continua Health Alliance
Open industry alliance of healthcare and technology companies that joined together to establish an ecosystem of interoperable personal telehealth systems (devices, peripherals and services).

Dossia
Consortium of large employers united in their goal of providing employees, their dependents, retirees and others in their communities with an independent, lifelong health record.

ORCATECH
An academic-industrial collaboration with the Oregon Health & Science University that constructs a research commons—a shared pool of tools, technology & thinking—around behavioural markers & health outcomes.

Center for Aging Services Technologies (CAST)
Researching new technologies to give seniors more quality, choice, dignity, independence and personal responsibility for their care.

Everyday Technologies for Alzheimer’s Care (ETAC)
A unique consortium to address the needs of the millions of people worldwide who are living with Alzheimer’s disease.

Intel Driving Research, Policy and Standards

Continua Health Alliance

Dossia

ORCATECH

Center for Aging Services Technologies (CAST)

Everyday Technologies for Alzheimer’s Care (ETAC)
Much of the quantitative baseline data to address the physical, cognitive and social consequences of ageing is collected as part of the TRIL Clinic operating in St. James’ Hospital, Dublin. As a key component of the research programme, the TRIL Clinic performs comprehensive health assessments of people over 60 years old. The Clinic has assessed 600 elderly people in total, including 400 who have experienced falls and 200 who have not. The entire process takes three to four hours to complete, with breaks and complimentary catering provided along the way.

From this data, clinicians and scientists develop models which link particular behavioural markers to health indicators to ensure the clinical efficacy of the research prototypes. Technologists build prototypes to monitor these markers and analyse the data collected. Designers and ethnographers ensure that the technologies developed will become an accepted part of the day to day lives of older people.

A core asset of the TRIL Centre is a common technology platform of hardware and software components which are combined in different ways to support many different clinical models and research projects. The technology platform saves time and effort for clinicians and scientists, who can concentrate on their research, rather than on the machinery to support it.

The TRIL Centre has a growing network of R&D collaborations with other research teams worldwide. These include Intel Research in the US, and a number of leading universities from the US, Europe and Ireland. TRIL also has important cooperative links with hospitals, patient groups, active ageing associations, government agencies and other multinationals.

The Building Bridges concept and interface has been developed through a user-centered design process with older people. The hardware is comprised of a 12" touchscreen, a phone handset, and speakers. The interface is built on top of VoIP. Daily broadcasts are played through the speakers and may include news, documentaries, stories or music. During the broadcast the older person can see who else is listening. When the broadcast is over the user can lift the phone receiver to join a ‘group chat’ with the other listeners. The onscreen display provides visual cues to support group interaction on the phone (e.g., who is on the call, who is speaking, who wants to speak). In addition, users can initiate group calls and send messages.
About the Authors

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Digital Health Group
Product Research & Incubation

Mission - Explore & evangelise new personal health products, policies, & standards through multi-disciplinary, user-centered research and incubation.