Conference Rapporteur Summary

Bridging knowledge: reflections on crossing the boundaries between long-term care and support

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Abstract

In March 2009 members of the research, policy and practice communities in the fields of ageing and disability came together in Barcelona for the first international conference on bridging knowledge in long-term care and support. This paper presents a brief snapshot of some of the key themes and ideas that emerged during three days of presentation and debate on methods, policy and practice.

Keywords

ageing, disability, knowledge transfer, bridging, policy

Introduction

Historically, there has been only a modest connection in research, policy and practice in the fields of ageing and disability. In some respects this is unsurprising given that public sector budgets to support these two areas may fall under the auspices of different government departments where entitlements to care and support can be very different. Yet at the same time, many of the issues faced by those living with long-term disabilities and by older people can be remarkably similar: both groups may be subjected to discrimination and prejudice, have to rely heavily on informal family support and require a range of supports and interventions from multiple sectors including health, social care, housing, employment and transport. Both groups may rely on a mixed economy in service provision, with services provided by the public, private and not for profit voluntary sectors.

As individuals age they are more likely to have a reduction in mobility and functioning, while the life expectancy of those with physical and intellectual disabilities has increased dramatically, meaning that many more people with disabilities will enter old age. A greater rec-

ognition of these shared concerns, coupled the ageing of European populations, is now acting as a catalyst for actions to bridge the gap between the two policy areas. In fact a number of bridges need to be constructed to better link research with policy and practice between and across the two fields. Better networks involving the public, civil society and private sectors, as well as across disciplines, are essential to promoting collaboration and shared knowledge. More integrated care delivery can also help promote quality of care and the efficiency of service delivery.

Thus, it was that in March 2009 that members of the research, policy and practice communities in the fields of ageing and disability came together in Barcelona for the first international conference on bridging knowledge in long-term care and support. At the core of the conference was the increased recognition of the importance of seizing opportunities to link and bridge knowledge across the two disciplines. Numerous presentations made the point that the continued separation of ageing and disability separately, as for instance noted by Michelle Putnam (*Crossing network lines between ageing and disabilities in the US*) reinforces barriers to appropriate services for people with

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disabilities transitioning to old age, as well as for those older adults seeking to obtain help to facilitate continued independent living. This paper presents a brief snapshot of some of the key themes and ideas that emerged during three days of presentation and debate on methods, policy and practice.

Holistic health and active ageing

Taking a holistic approach to ageing and disability was highlighted in many presentations. Most notably, in his keynote address to the conference, Juan Enrique Mezzich (*Professional perspectives on bridging: the person centred approach*) highlighted the importance of taking a person centred approach to help in the bridging process. Such an approach would focus on active ageing, focusing on restoring people to full health where they can flourish, rather than simply avoiding illness or managing disability. Individuals would be empowered to take more control of decisions which impact on their health status. A similar message came from Alexandre Kalache, the former director of WHO's Programme on Ageing and Health (*Towards age-friendly societies: from research to policy, from policy to society*) when speaking of the WHO Active Ageing Policy Framework developed in 2002. He also stressed the need for bridging in respect both of contextualisation and inter-sectoral collaboration. Initiatives to develop age-friendly cities require consideration of issues including the environment, housing, transport, social inclusion and access to community information and services that impinge on many different sectors.

Key concepts in disability and ageing

Challenges remain in what we mean both by ageing and disability; one important area of discussion focused on how to move towards common definitions to allow meaningful comparisons both within and across countries and thus better inform the policy making process. How do we determine how many people there are with disabilities in society; how do we assess their level of disability; how do we assess needs and match these to available services?

The International Classification of Functioning (ICF) is one valuable tool for representing knowledge on disability and health. A generic core set of ICF categories makes it possible to compare and link data from standard health status and outcome measures; other methodologies for data comparability may extend the usefulness of ICF. Yet the implications for policy makers of the conceptualisation of disability presented in the ICF and pervasive in the literature on disability are substantial but as yet not completely appreciated, let alone assessed and measured.

José Luis Ayuso-Mateos (*The MHADIE project: a European experience on bridging in disabilities*) and Matilde Leonardi (*Defining disability—Re-defining policy*) both reflected on the outcomes of the Measuring Health and Disability in Europe (MHADIE) study. This project has demonstrated not only that it is feasible to use the ICF for comparative analysis across a range of service settings and countries, but also that better disability information can contribute to health and social policy development. This policy-oriented definition of disability was also influential in the way in which disability was characterised in the 2006 UN Convention on the rights of persons with disabilities.

Dependency, autonomy and interdependency

The issues of dependency and autonomy also need to be more adequately linked to functioning and disability to improve European health and social services for both people with disabilities and older people. Luis Salvador-Carulla *(The concept of 'functional dependency')*, argued that the dependency-autonomy distinction is as important as the functioning-disability distinction, but has not received the same level of development. He argued that failure to link these two pairs of concepts has had a significant detrimental impact on the development of health and social care services. Luk Zelderloo *(Autonomy, belonging and interdependency)* argued that the 'paradigm shift' in the understanding of disability—moving from a purely medical approach to one that acknowledges the impact of the social and physical environment—has also occurred, although with less visibility, in the ageing community. He noted the difficulty in reconciling notions of autonomy, which suggests independence and self-determination, with interdependency with its emphasis on belonging and membership in a social group.

Addressing information deficits

Regardless of definitional issues, major deficits remain in what we know about services for older people and those living with disabilities across Europe. Several Europe-wide studies related to people with intellectual disabilities, individuals living in residential care and those using mental health services all reported a lack of suitable indicators to facilitate cross-country comparisons on access, utilisation and outcomes of long-term care and support systems. The need to develop such indicators is essential given the requirements of Article 31 of the 2006 UN Convention regarding policy-relevant data for monitoring purposes.

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Helena Medeiros, for example, (*Balance of care (deinstitutionalisation in Europe). Results from the Mental Health Economics European Network (MHEEN)*) pointed out that there has yet to be adequate research on the shift, in Europe, in the balance of care away from long-stay psychiatric facilities to community-based care. Ann Netten *(Measuring social care outcomes)*, reminded us that measuring and monitoring the outcomes of community-based social care, although essential to furthering the objectives of effectiveness and efficiency of service, poses many challenges. She described a nine domain outcome measure for social care (Adult Social Care Outcome Toolkit) ASCOT that relies on interview and observational techniques to establish benchmarks and targets for care outcomes and can be linked to other routine indicators for a better measure of the value delivered by a service or intervention approach.

Of course it would be insufficient to rely solely on a crude set of indicators alone. The role of qualitative research methods and how they can be used to aid in understanding of how context and setting impact on the effective implementation of interventions was also presented. They can also help identify outcomes that are of importance to service users, which may in some instances be very different to traditional outcome indicators of interest to health and disability professionals. New quantitative techniques can also play a role. Carlos García-Alonso (*Benchmarking and DEA: how to teach to and to learn from relative technical efficiency models)* illustrated how new data analytical approaches such as data envelopment analysis can be used for evaluating the efficiency of complex social systems, as illustrated for mental health service systems in Spain and Chile.

Digitalisation of information

Another key theme was the development of automated information systems. Bedirhan Üstün and Nenad Kostanjsek (*Beyond classifications: entities of knowledge exchange*) argued that the computerisation of health and disability information systems is increasingly seen as an essential development, both to promote better health care outcomes and contain costs. An important step is to move beyond WHO's traditional standards development, with its use of the International Classification of Disease (ICD) and ICF, to formalisations that can allow for digital coding and improved knowledge representation. An essential prerequisite involves the application of ontology—a formal representation of a set of concepts relating to ageing and disability—to facilitate semantic interoperability or communication between different information systems. Only by such means can classification systems such

as the ICF play a pivotal role in the global electronic exchange of automated health information.

Alarcos Cieza (*Translational measures of functioning and disability based on the ICF*) presented the results of the genetic core set development exercise, that creates a minimum set of ICF categories to specify health and health-related domains found in widely used outcome measures and health indicators. Such a set of indicators potentially might be used to facilitate the comparison of health information among and across all health conditions and health-care settings. She also demonstrated that the ICF reference classification contains categories that can be addressed and assessed from different perspectives: disability, quality of life and satisfaction and the support and dependency perspective.

Meantime, Luis Salvador-Carulla (*Coding long-term care service—eDESDE-LTC*), described ongoing work to develop a methodology for mapping, comparing and monitoring mental health services in Europe (eDESDE-LTC). He indicated that such work was essential to overcome the semantic variability that remains a barrier to the effective management and analysis of long-term care delivery systems, undermining the prospect of Europe-wide statistics on service availability, use and quality.

Bridging knowledge in the use of technological innovation

Another theme at the conference was technological innovation. Increasingly, this may be harnessed to improve the quality of life and support, both for older people and those with disabilities and it in future it may be of even greater significance given scarcity both in the social care workforce and in access to informal care. More work is though needed on the quality of life impacts of such technologies, as well as their cost effectiveness. Again a cross-sectoral approach to the role of technology must be taken. Cristina Rodríguez-Porrero (*Accessibility and assistive products*) noted that adaptations will be required across many different sectors, housing, transport, access to the internet etc. Standards, laws and regulations should help facilitate increased accessibility of devices and services, but it is crucial that such laws are monitored and properly enforced. The importance of considering the acceptability and usability of assistive technologies and adaptations to mainstream devices for older people and those with disabilities was also noted by Claudia Oppenauer (*Usability of assistive technologies in ageing and disabilities*). Going forward, one challenge will be to see whether the economic climate is perceived as an opportunity for further innovation—making products

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accessible to reach new segments of the population—rather than being perceived as an excuse to cut back on investment.

Dissemination and knowledge transfer

Mechanisms for dissemination and knowledge transfer, as well as examples of how knowledge has been used to influence policy and practice formed a major strand in the conference. There was a broad consensus that knowledge transfer involves much more than the passive activity of writing and distributing reports and academic articles. As David McDaid (*Transferring research to policy and practice: quo vadis?*) described, knowledge transfer is not a linear one-time event; it requires ongoing active dialogue and exchanges between researchers, policy makers, practitioners and client groups. One key challenge he noted was the need not only to strengthen the capacity to conduct research but also to communicate and interpret research findings.

A number of different elements for successful knowledge transfer were outlined. These included better presentation of results in brief, clear, everyday language, presenting both the strengths and the limitations of research; the organisation of policy dialogues bringing researchers and policy makers together to determine feasible and policy relevant research questions; the development of a new cadre of professionals equally comfortable in both the research and policy making environments (so called 'knowledge brokers'); and the use of formal assessment bodies which synthesise a range of evidence to help inform key policy making questions.

Where results are communicated in academic journals it is also important that this is done in a timely fashion. To aid replication and transfer to different contexts and settings it is important that both interventions and 'care as usual' are described adequately. As Guus Schrijvers (*Incorporating bridging to scientific literature*) noted, electronic open access journals such as the International Journal of Integrated Care, which invite contributions on the implementation of innovative approaches to integrated care in everyday practice, in addition to the more routine inclusion of experimental evaluation studies, can help bridge this gap.

Much can be learnt from the experience of organisations and networks that both conduct research and seek to link this directly to the policy making process; the conference heard about the work of various organisations including SINTEF health services research in Norway and the Social Care Institute of Excellence in England, both of which place great emphasis on tailoring their messages appropriately to reach policy

audiences. There may be future opportunities to collaborate with such organisations, or to learn and adapt the approaches that they use for knowledge transfer. Demonstrating how economic benefits can be achieved through cross-sectoral collaboration might also boost support for investment in knowledge transfer mechanisms. Research funders, such as the ZonMw (The Netherlands Organisation for Health Research and Development) in the Netherlands, increasingly require applicants to provide information not only on methods for research but also on how they will implement interventions and assure local dissemination.

Continuing education and training

Education and training also present opportunities to bridge knowledge. The importance of moving towards translational research, on the assumption that being skilled in a single discipline is no longer sufficient, was also emphasised by Dieter Ferring (*Bridging education and training in ageing and disabilities: towards translational education*). It was noted that disciplines may try and resist such translational learning in order to protect their own identities, while there is also a danger of a loss of in-depth specific disciplinary knowledge.

Matthew Janicki (*Partnering the ageing and disabilities systems—the USA experience*) looked at the response to legislation in the USA which created a system of social support services for older people, as well as those with intellectual disabilities. Initiatives sought to mainstream the provision of services for this second client group within existing community based services for older people. A national training programme targeted at community service workers led to improved understanding of the needs of older people with disabilities, as well as to improved collaboration and pooling of resources for the provision of services and support. On the ground in Europe, with more cross-border movement of peoples, incentives to ensure that all the social care workforce make use of common basic minimum standards, can also help. James Churchill (*Bridging education and training in ageing and disability: the European Care Certificate (ECC)* reported on the use of an assessment process leading to a ECC recently tested within an EC supported Leonardo project.

Bridging experience and knowledge across different stakeholders

Ageing and disability relevant policies will be influenced by many factors that bring together the social

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context with the differing needs and wants of political actors, institutions and stakeholders. All stakeholders have an opportunity to provide input into needs assessment and priority setting process which help influence how budget holders allocate resources. They can also play a role in both the implementation of policies and their evaluation/adaptation. This may be of critical importance in situations, as noted by Hristo Dimitrov (*Bridging the breach in services for ageing people with disabilities in a country with challenging demographic prognoses*) in countries such as Bulgaria, where resources are limited and there is a need to focus on adaptation of services for older people to meet the needs of people with disabilities.

Stakeholders can also help to raise awareness of issues which influence the policy agenda. For instance, Elizabeth Mestheneos (*AGE—The European Older People's Platform*), President of AGE Platform, a European Network of 148 older people's not for profit organisations outlined how they interact with the European Commission, European Parliament and Committee of the Regions to influence policies and political priorities in a number of sectors including age discrimination in the workplace, poverty reduction, access to health and social care services and measures to promote active participation and social inclusion. One of their mid-term goals to further raise awareness and tackle age discrimination will be the development of a European charter.

Legislation and regulatory measures, including mainstream anti-discrimination measures, can also help facilitate change. For example, Swedish Parliamentarian, Barbro Westerholm (*Population development and the need for housing for elderly people in Sweden*), highlighted how housing adaptations should take account of the needs of older people living with disabilities. While one option may be to increase access to specialist sheltered accommodation, strengthening building code regulations to set minimum accessibility standards in new dwellings can also help increase the possibility that individuals can remain within their own homes if they so wish.

There is also scope for private and voluntary sector funding to be better co-ordinated with existing public sector resources. The mandate of voluntary sector organisations and foundations may also mean that they can play a vital role in tackling issues such as social exclusion both within their own borders, as for instance noted by Mònica Duaigües in the case of the Caixa Catalunya Foundation in Catalonia, Spain (*Transfer knowledge for younger generations*), and beyond their own national borders as Franz Karl Prüller (*Experiences from private funding sources: Austria)* in the case of the ERSTE foundation in Austria which

has been supporting social transformation projects linked to the long-term care needs of older people in central and eastern Europe.

Strengthening partnerships

Xavier Mendoza (*Relational strategies for bridging and promoting cross-sector collaboration)*, reminded us of the importance of partnership working between public agencies, civil society and the private sector. Such partnerships potentially can help overcome barriers to collaboration which include mutual distrust, fragmentation of public sector bodies, lack of effective contracting arrangements, lack of knowledge on service delivery and uncertainty over the quality of private sector service provision.

Different mechanisms are required to reach different stakeholders. Networks that develop can range from those that purely exchange information to those that develop capacity to implement solutions and those whose members actually implement policy and/or deliver services. Improved incentive structures, regulation and quality certification may be tools to help facilitate such collaborations.

Ursula Naue (*Bridging policies and practices: challenges and opportunities for the governance of disability and ageing*) further emphasised the importance of different actors from the disability and ageing communities, not just focusing on their own exclusive interests but also highlighting the needs of the other community given their commonality and the potential for mutual benefit. For instance, the need to tackle discrimination and stigmatisation, as well as the emphasis places on help and support to facilitate independent living are common to both areas.

One example of the difference that partnership working can deliver described at the conference was a collaboration involving academic organisations, service providers and service user groups to develop the Graz Declaration on Disability and Ageing in 2006. This put an emphasis on bridging across disciplines to meet the specific requirements of older people with disabilities and, according to Germain Weber (*The Graz Declaration on Disability and Ageing 2006*), has informed policy and quality framework documents prepared in countries including Austria, Germany, as well as for the Council of Europe.

Where next?

The themes discussed at the conference indicate that much work is underway to strengthen links and cross the boundaries between ageing and disability policy and practice. Mutual benefits for both communities

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from collaboration can be identified, while examples of mechanisms to help facilitate knowledge transfer are beginning to be put in place in Europe.

At the same time entitlements to health, social care and other services can vary markedly across countries and regions. It remains difficult not only to define and identify those individuals living with a disability but also to accurately map the availability and utilisation of services. Such information is critical to ensuring that ageing and disability policy prioritises the use of resources in a way that best meets needs. It will also be interesting to see how work discussed in Barcelona on the use of the ICF to inform policy and ontological tools to allow communication of information across different electronic information systems will develop.

Much was also made of the importance of service user empowerment and a person-centred approach to ageing and disability. There are opportunities for greater linkage and exchange of information on the use of mechanisms such as individual budgets, whereby in some settings service users may be able to purchase services that best meet their needs regardless of the sector in which

they are delivered. How will ageing and disability service providers adapt to this increased personalisation of service demands? Another line of research may look at the economic impacts of different approaches to the integration of ageing and disability orientated services; this may be particularly important given challenges around the sustainability of social security systems.

What further progress will be made in developing institutions and mechanisms to help facilitate knowledge transfer and implementation of evidence informed policies? One idea mooted at the conference was the creation of a common knowledge resource: a network of networks to learn and exchange info and bridge ageing and disability, social cohesion, social inclusion. Other questions to address include the role of the media and the identification of effective approaches to partnership development and their impact on implementation.

These and many issues, for instance learning from experiences within other parts of the health system, are fertile territory for future work. A follow up conference will be held in Vienna in 2011; clearly there will be much to debate.

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