Editorial: Taking stock of the discipline

As the International Conference on Integrated Care is preparing to open its doors next month in Antwerp, it may be a good time to take stock. Reviewing how far we have come in developing integrated solutions to health and social care services may help us define more clearly where we want to go and what the future challenges may be.

I am old enough to have some personal memories of research and integrated care practice in the early 2000s, but will have to rely on public records prior to this. In addition, any reflection on the history of the field is partial and bound to be selective, containing personal emphases and omissions. Yet thinking about a reasonable narrative of how we got here may provide us with a critical assessment how far we have come on the climb to the summit of integrated care.

Surveying the last 40 years, we could distinguish between four phases. The early phase originated from a concern over fragmentation between social and health care services which triggered bespoke solutions such as multidisciplinary teams. The prime location for this work was services for people with complex healthcare needs, most prominently people with intellectual disabilities. The research of the 1990s was driven by a recognition that services urgently had to be improved for these populations in the wake of de-institutionalisation and the transfer of patients into the community. Improved collaboration across organisational and sectoral boundaries was the call of the day, and the work was mainly driven by naïve idealism, as opposed to theoretically informed evidenced based practice. Early research focused on identifying barriers and facilitators for multiprofessional work, a strand of research that has stayed with us until today.

The second phase was equally characterised by a feeling of disquiet about fragmentation of all types, as services and staff’s specialisations increased and organisations adopted targeted approaches for specific disease groups. This phase saw significant funding for research in the area of continuity of care and a series of randomised controlled trials to examine the effectiveness of interventions for various groups of patients or service users. Some initial cost effectiveness or value for money studies also emerged. It was a time of testing service models through increasingly robust and rigorous study designs. Programmes such as PRISMA, the Quebec based Programme on Research for Integrating Services for the Maintenance of Autonomy, may stand paradigmatically for this phase of practice focused research. The programme was clearly motivated by a concern for people’s quality of life and a surge of models and interpretative frameworks published in peer-reviewed journals added criticality to this applied research. The lens through which studies were seen and formulated was very much a structural one; services were perceived as enablers of higher levels of functioning or improved quality of life, a perspective that owed much to the normalisation literature.

As both Phase 1 and 2 continued to produce eminently important research, some in the practice community became increasingly uneasy about the structuralist thrust of much of the work. This presaged a shift towards emphasising agency of service users and patients, an area of concern which is still with us and something that echoed wider interests of personal responsibilities and the discourse on assets in health and social care settings. As personal agency moved into the focus of researchers in integrated care, interest in complexity and implementation science gained traction in the field. This perspective still dominates some of the work currently done in the discipline drawing on a theoretical inspiration rooted in the recognition of capabilities “activated” by contextual factors. Realist approaches in applied
science neatly correlated with the wider practical concerns and approaches of this phase and became increasingly popular with some in the research community.

So what does the fourth phase hold? Whilst all paradigms of the previous phases are still with us and produce valuable research, it seems pertinent to remind us that one of the key questions which lay at the foundation of integrated care as a field and motivates so many of us to engage in this work has been unanswered: how to design and deliver person centred care. Looking back over the last 40 years from our current vantage point, the interest in the person and his\her quality of life seems to run through like a red thread yet remains an ambition and as distant from reality as ever. To be sure, all phases had echoes of person centred perspectives, be they articulated through the concept of continuity of care (1990s to early 2000) or through organisational partnership and multi-professional collaborative models of work. Yet patients themselves or service users have rarely been in the driving seat or even at the centre of attention.

Of course, it may be argued that much of the barrier and facilitator work in the first phase as well as the work using randomised control trials was animated by person-centred care, and the myriad of papers published pay tribute to this fundamental principle. Yet, little of the early phase work or the black box research studies, such as RCTs, produced measurable improvement for patients and service users. The study reports often say so themselves. And whilst implementation and complexity science immeasurably improved our knowledge of what is going on in highly dynamic and unpredictable service contexts, arguably the net practical effect of much of this work for patients and service users is less than we hoped for. So where is the disconnect?

Perhaps we should go back to basics and ask ourselves a simple question: does our research produce actionable results? And do practitioners have the skills to implement service models which have often dozens, sometimes even a hundred different actions or steps to follow up when being implemented? I would argue that in current research our desire for sophistication has gotten the better of us. Looking at some recent studies’ findings, nurses and social workers would need a PhD to put their recommendations to work. The voluminous and convoluted nature of models and frameworks for implementing or improving integrated care is ironic given that one of the key findings of most research is that frontline staff do not have the most precious resource of all time.

To make the fourth and last phase become reality, to create genuinely person centred integrated care, we need to put the patient at the centre. It seems clichéd to mention but organisations and staff are here to provide a service to people and those people should be the ultimate judge of what we produce in theory and practice.

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