Research in mental health learning disabilities: present challenges and future drivers

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Abstract

Research in mental health learning disabilities has advanced significantly in recent years. Many important papers have helped to change practice and to pursue innovative ideas that cut across the nature/nurture divide. Several new journals have been launched that cover an array of subjects from basic sciences to policy and practice. The advent of evidence-based practice has been slow to develop in mental health learning disabilities but rigorous epidemiological studies and related developments such as the more precise calibration of diagnostic tools have been some of the notable outcomes. The scope of this article, written from the perspective of a clinical academic in the psychiatry of learning disability, is not to report on the whole of the research field in learning disabilities and so, inevitably, there will be important omissions. The aim is to discuss scientific enquiry as it pertains to mental health issues in this population and to consider some of the future drivers that show promise in helping to deliver high-quality care to our service users.

Keywords epidemiology; evidence-based practice; genetics; health services research; interventions; learning disabilities; mental health; research

Introduction

Learning disability has often been called a 'Cinderella' subject, lagging behind in several areas of research compared with other specialities. A combination of guarding against past unethical practices and a 'therapeutic nihilism' brought about by the advances in the treatment of mental disorders has created a stalemate.

Despite the well documented problems in accessing participants and the vigorous gatekeeping by professionals or carers, certain types of research have flourished, in particular, epidemiological studies, neurocognitive investigations and instrument development and evaluation. However, areas where problems continued to exist in conducting research include large-scale clinical trials of interventions and evaluation of models of service provision. Despite the pivotal role of evidence-based practice, ongoing tensions between a social and medical perspective where drug interventions are concerned has not served the field well.

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In recent times, 'social capital' has been used to explain differences in health between various settings or between groups of people.[1] Social capital may be a significant contributor to the incidence and prevalence of mental illness. This idea is gaining currency as an explanatory factor in understanding the health inequalities in people with learning disabilities as well as the excess of mental illness beyond the biological imperative.

What follows illustrates innovative research that has led to changes in practice and further development of our understanding of the etiology and implications of mental disorders in our population. Finally, I delineate the challenges faced by researchers both in terms of academic endeavour and the promotion of learning disabilities as a valid theme in the international research community.

Mental health

Over a period of six years, a quarter of all papers published in the *American Journal on Mental Retardation* dealt with research on problem behaviours and mental health. This may reflect the greater awareness of mental disorders in people with learning disabilities, based on several robust epidemiological studies and secondary analyses of large datasets. Regarding models of service delivery, the arguments for and against the use of generic mental health services are not resolved, although there is a suggestion that, without support from specialist learning disabilities services, the needs of those admitted to generic mental health facilities are not met.[2] Furthermore, a new group of individuals with borderline intelligence who were declassified as a result of the changes in the definition of learning disability and therefore were not eligible to receive specialized services is emerging. They may have significant psychopathology and difficulty in accessing mental health services, falling between stools as neither service is willing to claim responsibility for their care.[3]

In epidemiological research, a main problem in comparisons of prevalence between studies is the ascertainment of mental disorders brought about by the heterogeneity of people with learning disabilities and the complexity of existing classification systems that are in the majority inappropriate for application to people with learning disabilities. Recent attempts to address these problems are the publication of adapted diagnostic criteria based on ICD 10 (DC-LD)[4] and DSM IV (DM-ID).[5]

Problem behaviours and their treatment have been the mainstay of scientific publications for many years, which in the majority were case reports or case series of behavioural interventions for several types of problem behaviours.[6]

Whilst only 5% of the papers published in the *American Journal in Mental Retardation* were intervention studies,[7] recently, there has been an increase in randomized controlled trials of a variety of, e.g. anger management, medication for problem behaviours, psychological interventions, anticholinergic agents in Down syndrome, to name but a few.

This is encouraging because it means that the longstanding unwillingness to engage in trials in which people with learning disabilities were participating is waning, and this is true for both participants and researchers.

Basic sciences

Advances in genetics and neuroscience, including neurocognition, have led to significant insights into the neural basis of

behaviour and the origins of some mental disorders. However, most of the work has been undertaken in people with learning difficulties rather than learning disabilities. Many aspects of cognition have not been examined in children and adults with the latter disorders despite the fact that certain deficits in executive function and inability to transfer knowledge between different situations are clearly dysfunctional in those with learning disabilities.[8] Examples that link essential neural mechanisms to problems in development such as language development include: impairments in visual processing in autism spectrum disorders; visuospatial processing in Turner syndrome; visual saccadic planning in Williams syndrome.

Early detection of problems may lead to early intervention that is likely to allow the developmental trajectories to normalize as far as is possible.

An important strand of research that has grown over many years is the study of behavioural phenotypes. This work has enabled, to an extent, the mapping of the route from genetic defect to brain effect to cognition to behaviour and the environment. It is a multidisciplinary effort based on collaborations between different research approaches. The *Journal of Intellectual Disability Research* has published 82 original papers on syndromes in a ten-year period. Approximately 40% of those focused on Down syndrome followed by Prader Willi syndrome, Fragile X and Williams syndrome whilst a few papers examined other more rare genetic conditions, e.g. Rett syndrome, Cri du Chat. The main methodology is that of matched case control design. However, the link between the genetic etiology and its phenotypic expression is multistage, including neurodevelopmental and neurocognitive levels.[9]

The study of the behavioural phenotypes, although without its flaws illuminates the need for broad collaborations across a diverse field of disciplines in order to encompass the richness and complexity of the underlying mechanisms. Indeed, the range of heterogeneity at least in IQ across a range of syndromes has prompted the change of name of the former *American Journal on Mental Retardation* to include developmental in addition to the intellectual disabilities (*American Journal of Intellectual and Developmental Disabilities*).

Other populations

People with autism spectrum disorders have been relatively well researched but new groups of individuals are emerging who merit specific research focus. In particular, older people with learning disabilities without Down syndrome are becoming a significant service user group as mortality is decreasing due to better lifestyles and improved health. Overall, the life expectancy of people with learning disabilities is now approaching that of the rest of the population. Dementia and other psychiatric disorders and associated mental health needs are ripe for further investigation.

Furthermore, attention deficit disorders (ADD) are now considered to continue into adulthood. There is an established association with learning difficulties as well as disabilities in addition to other psychiatric comorbidities. Epidemiological and health services research is paramount in order to understand the size and course of the disorder as well as how to treat sufferers effectively. Many adults with learning disabilities and ADD may be undiagnosed due to accepted wisdom that ADD is a disorder of childhood and tends to wane in late adolescence.[10]

Costs

Learning disabilities services require substantial financial resources. Published data suggest that learning disabilities not only pose a burden on the National Health Service (an example is the ever increasing budget for continuing care), but also on social services.[11] It will be of interest to examine how rolling out personalization plans will affect those budgets. In the meantime, tentative attempts to cost interventions have had variable outcomes, most notably in those with autism spectrum disorders but less so in investigating cost effectiveness in mental health care. The health economic evaluation of interventions for mental disorders lags behind when compared with studies in other fields of medicine and in psychiatric specialities. Recent studies have begun to address this problem[12,13] but economic evaluations will need to be included as an integral part of future projects in the field.

Lastly, an area of increasing interest is that of inequalities in service provision for difficult to treat service users, e.g. those with problem behaviours which are a lifelong difficulty. Costly out-of-area places are habitually used for people with long-standing physical and/or mental health problems including forensic problems. There does not appear to be any fact-based decision on spending on learning disabilities services to reflect the current patterns of population distribution despite significant demographic changes following closures of long-stay hospitals and the proliferation of community care.[14]

Adversity

Recent analysis of a UK-wide survey dataset shows that learning disability per se may not be the core influence on the perpetuation of mental disorders. Social adversity, exclusion and displacement may be more powerful contributors to the development of mental disorders in children and young people with learning disabilities.[15] The authors argue that lower socioeconomic position and social capital have a significant impact on the health outcomes of children with learning disabilities, and that the known associations between poverty and adversity that operate in the general population are likely to also affect children with learning disabilities and their families, having a long-term effect on their wellbeing. The relationship is complex due to interplays of social and biopsychological process that involve pre-existing mental capital as well as support from services and social networks. Further examination of potential explanatory models is necessary in order to advance our understanding of the determinants of this association.

Ethics

Research in people with learning disabilities is fraught with difficulties owing to the perceived problems of obtaining informed consent of incapacitated adults and the fear of perpetrating abusive and harmful practices as a result of including a marginalized and vulnerable group in research. Anecdotal information as well as published papers have documented the perils of applying for research ethics approval, which, in the past, appears to have been 'hit and miss' and at times too restrictive.[16] The upshot of such an approach is that people with learning disabilities may be subjected to treatments of no therapeutic

