The International Handbook of Applied Research in Intellectual Disabilities

Edited by

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Lancaster University, UK
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Preface

Research has the potential to generate knowledge that our societies can use to address the disadvantage faced by children and adults with intellectual disabilities. Of course, this potential is not always realised. Poorly conducted research may generate false knowledge or simply waste scarce resources by failing to generate any new knowledge. Researchers may address issues that are tangential or irrelevant to the social situation of people with intellectual disabilities. Our societies may choose not to implement the knowledge that has been generated.

The primary aim of the present text is to address the first of these potential failings. To do this, we have gathered together contributions from a range of active researchers of international standing in their particular field and asked them to summarise current thinking in relation to key conceptual and methodological issues.

Section I of the text addresses broader aspects of the historical and social context within which research is undertaken. An appreciation of where we have come from (Parmenter, Chapter 1) provides an important foundation for our current efforts. In this section, we also address the importance of incorporating an appreciation of culture into research (Hatton, Chapter 2), the ethics of applied research involving people with intellectual disabilities (Griffin and Balandin, Chapter 3), and contemporary movements towards more participatory or emancipatory research paradigms (Ramcharan, Grant and Flynn, Chapter 4).

In Section II, we turn to the discussion of particular approaches to measurement. These include interviews undertaken with people with intellectual disabilities (Perry, Chapter 5) and members of their families (Blacher and Mink, Chapter 6), participant observation (Angrosino, Chapter 7), and behavioural "non-participant" observation (Yoder, Short-Meyerson and Tapp, Chapter 8). While the examples given in these chapters may be specific to particular areas of investigation, the issues raised cut across the full range of research activity.

Section III addresses the application of applied research methods to understanding the nature, characteristics, and social context of intellectual disability. Research undertaken in these areas opens up the possibility of identifying areas of need (and the nature of that need) in which people with intellectual disabilities may benefit from support. Here we cover an array of more specific issues, ranging from measuring genetic contributions to behaviour (Hodapp and Dykens, Chapter 9) to contemporary understanding of the nature and measurement of quality of life (Schalock and Felce, Chapter 12). Contributors in this section address methodological issues relating to the family context within which the vast majority of children with intellectual disabilities (and the majority of adults) live (Seltzer, Floyd and Hindes, Chapter 11), social inclusion (Odom, Klingerman and Jakowski, Chapter 13), and social relationships (Kennedy, Chapter 14). The other chapters in this section address aspects of personal functioning such as adaptive behaviour (Schalock, Chapter 18),

communication and language (Warren, Brady and Fey, Chapter 19), choice making (Hatton, Chapter 16), engagement in activity (Felce and Emerson, Chapter 17), sexuality (Griffiths, Watson, Lewis and Stoner, Chapter 15), ageing (Bigby and Balandin, Chapter 10), mental health (Cooper, Chapter 20), and challenging behaviour (Carr, Innis, Blakeley-Smith and Vasdev, Chapter 21).

In Section IV, we turn to more evaluative research methods used to investigate the impact of support systems and services. In this section, contributors discuss conceptual and methodological issues relating to the evaluation of educational supports (O'Neill and Heathfield, Chapter 22), residential supports (Stancliffe, Emerson and Lakin, Chapter 23), the criminal justice system (Hayes, Chapter 24), staff performance (Hatton, Rose and Rose, Chapter 29), and a range of therapeutic approaches, including behavioural (Newton and Horner, Chapter 25), cognitive behavioural (Dagnan and Lindsay, Chapter 26), psychotherapeutic (Beail, Chapter 27), and psychopharmacological (Thompson, Zarcone and Symons, Chapter 28). We conclude with a chapter on health economics (Hallam and Knapp, Chapter 30), an often ignored aspect of evaluative research.

We hope that the experience and knowledge of our contributors will be of value to all who are contemplating or currently undertaking research involving people with intellectual disabilities, and also to people who act as the "consumers" of research. Sorting the wheat from the chaff can be a complex and difficult task. We believe that the contributions in this volume also provide some useful ideas and pointers for all who are involved in considering the potential value of the outputs of the research process.

It is, of course, impossible to focus simply on methodological and conceptual issues. Research, and particularly applied research, in such an area as intellectual disabilities takes place in a political and social context. It is inevitable, then, that along the way our contributors have also drawn attention to the social and applied relevance of research questions or topics in their particular fields. As such, they have also addressed the second potential failing of the research process we noted above (researchers addressing issues that are tangential or irrelevant to the social situation of people with intellectual disabilities). We sincerely hope that by collecting together an international cast of experienced researchers to address these two areas we will have made a modest contribution to improving the quality and relevance of research that addresses the disadvantage faced by children and adults with intellectual disabilities.

Eric Emerson
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SECTION I

The Historical and Social Context of Research

CHAPTER 1

Historical Overview of Applied Research in Intellectual Disabilities: The Foundation Years

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INTRODUCTION

In 1958, Jack Tizard, one of the pioneer giants in the field of the study of intellectual disabilities, wrote:

> What are most needed today are properly controlled experimental studies and surveys designed to answer particular questions about the social costs of various types of administrative arrangements for dealing with mentally subnormal individuals. On the psychological side, we need to discover the most efficient methods of teaching or training those who are grossly subnormal in intelligence, or handicapped in other ways. The efficacy of different forms of treatment, including the psychological effects of medical treatments, must be studied, and new methods developed. How to teach social skills to dull, badly educated people has hardly been studied at all as yet, nor has the treatment of emotional maladjustment or psychopathic instability. (Tizard, 1958, p. 448)

While we would now use more acceptable terminology when referring to people with an intellectual disability, Tizard's injunction remains relevant. Indeed, the following chapters of this book represent a timely response to contemporary challenges that are not at all dissimilar to the core issues identified by Tizard almost half a century ago. In the same year, other pioneers in our field, Ann and Alan Clarke from the UK and later Norman Ellis from the USA, highlighted the need for applied research that recognises "the intimate reciprocal and enriching relationship between theory and practice and the use of experimental method in both cases" (Clarke & Clarke, 1958, p. xiv). Ellis (1963c, p. xi) commented: "Since mental retardation is a social problem, it would seem that the main thrust . . . would have only applied significance. Such is not the case . . . research findings and the related theories

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usually have implications for training or educating the retarded." Clarke and Clarke (1958, p. xiv) further suggested that "mental deficiency is a social-administrative rather than a scientific concept, varying in different countries and within a given country at different times".

This chapter will touch upon these issues in the context of the main historical research developments in the field of intellectual disabilities in the period from the late 1950s to the late 1980s. It will trace events that saw applied behavioural research challenge the exclusivity of the medical research that had dominated the field in the first half of the twentieth century. Later chapters, however, demonstrate the present situation, where multidisciplinary research teams are characterised by their interweaving of biomedical, psychological, social, and educational theories and practices. While the emphasis will be upon applied research developments, one needs to be reminded that all research sits within social, philosophical, ideological, economic, and political contexts. This is especially the case in the field of intellectual disability, given the long history of discrimination this population has experienced (Parmenter, 1991, 2001).

Origins of the International Association for the Scientific Study of Intellectual Disability

This review will draw heavily upon a small number of resources that are representative of research activities in essentially English-speaking industrialised countries. A rich source of the trends in the field is the *Proceedings* of the regular congresses of the International Association for the Scientific Study of Intellectual Disabilities (IASSID)[1] that was formally constituted in 1964. This association was born out of three international congresses held in Europe in the period 1960–63. The first, held in London in 1960 in observation of World Mental Health Year, was sponsored by the Royal Medico-Psychological Association, the Royal Society of Medicine, and the British Psychological Society, in cooperation with the National Association on Mental Health and the American Association on Mental Deficiency. A second congress was held in Vienna in 1961 and a third in Copenhagen in 1964, at which the International Association was duly formalised with a constitution that was published in the *American Journal of Mental Deficiency* (1965, vol. 69, p. 599) and the *Journal of Mental Deficiency Research* (1965, vol. 9, p. 150). The inaugural president was Harvey A. Stevens, the then president of the American Association on Mental Deficiency and Director of the Waisman Center, Wisconsin, USA; he was followed by Alexander Shapiro of Harperbury Hospital, Hertfordshire, UK. In honour of these outstanding leaders, the IASSID awards Stevens–Shapiro Fellowships to enable young researchers to present papers at its regular congresses. These were held every three years subsequent to the Copenhagen meeting until 1988, when the cycle went to every fourth year to coordinate with the quadrennial congresses of Inclusion International.[2] The first official congress of the Association was held in Montpellier, France, in 1967. The Twelfth Congress returns to Montpellier in 2004.

[1] Formerly International Association for the Scientific Study of Mental Deficiency (IASSMD).
[2] Formerly International League of Societies for the Mentally Handicapped (ILSMH).

Major Reviews in the Field

A second important resource is the several editions of *Mental Deficiency. The Changing Outlook*, first edited by Ann and Alan Clarke in 1958, with further editions in 1965, 1974, and 1985. While the majority of contributors are from the UK, Ann and Alan Clarke's international perspective is strongly evident in each of the editions.

Across the Atlantic, Norman Ellis's editorial contributions, such as the *Handbook of Mental Deficiency, Psychological Theory and Research* (1963c, 1979) and the *International Review of Research in Mental Retardation*,[3] are relevant. Other publications have been accessed to a lesser extent. For instance, detailed analyses of significant, long-standing journals, such as the *American Journal of Mental Retardation*,[4] *Mental Retardation*, the *British Journal of Mental Subnormality*, the *Journal of Applied Behaviour Analysis*, and the *Journal of Intellectual Disability Research*,[5] have not been made. The regular Gatlinburg Conferences held in the USA, and the symposia of the American Academy on Mental Retardation that coincide with the annual conferences of the American Association on Mental Retardation, are also indicative of applied research trends in this field. Wherever possible, primary resources have been accessed.

Development of University Research Centres in Intellectual Disability

A significant feature of the last 50 years has been the increase in the sharing of research efforts across the world, stimulated in large part by the growth of scientific journals, international conferences, and the sophistication of information technology. The field has also benefited enormously from the establishment of major university-affiliated research centres dedicated to the study of intellectual disabilities in Europe, North America, and Australasia. Arguably, two of the most significant developments that have bolstered the research output in the area of intellectual disability in the English-speaking world were the establishment of the Hester Adrian Research Centre at the University of Manchester in 1967 and the establishment of the National Institute of Child Health and Human Development (NICHD) through the energies of President John Kennedy and Dr John Cooke in the USA in the early 1960s (Alexander, 1988).

A Period of Optimism

The significant initiatives of the Kennedy Administration in the field of intellectual disability resulted from the appointment of a special President's Panel on Mental Retardation on 11 October 1961. The Panel's first report, submitted in 1962, made 112 recommendations under eight headings, the first of which called for a vigorous research effort into the causes of intellectual disability and in methods of care, rehabilitation, and learning. The Panel's report also resulted in the passing of far-reaching legislation by the US Congress that authorised significant Federal funds for research, training, and services in the field of intellectual

[3] Norman Ellis was editor from 1966 to 1987, followed by Norman Bray and subsequently Loraine Masters Glidden in 1997.
[4] Formerly *American Journal of Mental Deficiency*.
[5] Formerly *Journal of Mental Deficiency Research.*

disability. These developments have had a profound impact on our field, especially in the way they focused attention not only on the research and training of researchers, but also upon the place of people with intellectual disabilities in a civil society.

In a sense, at this time, there was a recapturing of the optimism of the mid-1800s for the improvement of the functioning of people with intellectual disabilities, exemplified by figures such as Guggenbuhl, Seguin, and H.B. Wilbur, that was replaced by the darker days of institutionalisation and the eugenics movement of the late 1800s and early 1900s. Lest we are carried away by a sense of triumphalism for the advances we have seen, it is salutary to be reminded that the demise of the nineteenth-century optimism was possibly brought about because, in the words of Murray (1988, p. 101), "they attempted to do too much with too few in the face of too much need".

Despite the exponential growth of research in recent decades, the gap between research and practice remains a significant problem to be tackled. Obviously, the ecological validity of the various research outputs is a key issue. For instance, the research conducted in controlled environments has not always been translated into applied settings. As indicated above, political and economic forces have a direct bearing upon the takeup of evidence-based practices in the service sectors. A further moderating factor relates to the waxing and waning of what Ellis (1963c) termed the "public conscience" (p. ix) and its impact upon the social and political scene.

Subsequent sections of the chapter trace in greater detail the historical development of applied research that laid the foundations for the rich variety of research initiatives described in later chapters.

DEVELOPMENTS IN THE LATE 1950s AND THE 1960s

Prior to this period, the dissemination of knowledge of intellectual disability had been relatively meagre when compared to advances in knowledge of other disabilities. In the USA in particular, the 1950s saw a quickening of resolve to tackle the gaps in knowledge covering this disability (Stevens & Heber, 1964). A significant imperative that was recognised early in this period, and one that would continue throughout the rest of the century, was the importance and interrelationship of research in the biological, psychological, educational, and sociocultural aspects of intellectual disability. However, it is only in recent years that the biopsychosocial approach to disability has gained stronger focus (WHO, 2001).

This principle was highlighted by the grant made by the National Institute for Mental Health in 1955 to the American Association on Mental Deficiency for a project entitled "Technical Planning in Mental Retardation". The brief of this project was as follows:

> The basic purpose of this project was seen as the delineation of current needs, the stimulation of creative thinking, integration and organization of work which had already been done, the improvement of liaison between interested groups and individuals—professional, government, lay and parents. For functional and organizational structure the broad general problems were thought to fall into three categories: research, training of personnel, and programming. (US Department of Health, Education, and Welfare, 1955, p. 20)

One of the outcomes of this project was the publication *Mental Retardation. A Review of Research* (Stevens & Heber, 1964), which brought together, in the US context, the knowledge

Table 1.1 Distribution of papers presented to world congresses of IASSMD/IASSID (percentage of total papers)

Year	Biomedical	Epidemiological/ classification	Philosophy, policy, service models	Applied research	Early intervention	Vocational
1967	33	8	16	37	4	2
1970	41	6	13	33	1	7
1973	29	5	15	45	2	4
1976	24	6	16	46	5	3
1979	19	8	14	50	4	5
1982	12	7	27	48	2	4
1985	24	8	12	51	2	3
1988	13	5	10	66	1	5
1992	15	6	10	61	2	6
1996	18	5	14	57	2	4
2000	10	9	17	58	2	4

obtained from research in all the major scientific disciplines that had contributed to a better understanding of the complexities of intellectual disability.

In the 1950s and 1960s, a distinguishing feature between the triennial conferences of IASSMD and the editorial work of Clarke and Clarke (1958) and Ellis (1963c) was that the former covered both the broad areas of medical and behavioural research, while the latter was essentially behavioural in focus. In the case of Clarke and Clarke, later editions acknowledged the need for a more integrated approach. However, Ellis, in both the *Handbook of Mental Deficiency* and *The International Review of Research in Mental Retardation*, maintained a heavy emphasis upon behavioural/psychological research issues. As Table 1.1 indicates, over the period of the 11 world congresses of IASSMD/IASSID,[6] the relative percentage of biomedical presentations fell significantly, with a concomitant increase in the percentage of applied research presentations. The percentages of subsections such as epidemiology/classification, philosophy/policy/service models, early intervention, and vocational remained fairly stable.

Both Clarke and Clarke (1958) and Ellis (1963c) observed that until the mid-1950s intellectual disability was a relatively neglected field of study except for some outstanding work in neuropathology and genetics. There had been little change in approaches to support this population since the turn of the century. Basically, the teaching techniques, vocational training, psychological treatments, and socialisation programmes employed were the same as those used with the non-disabled population. Behavioural science was essentially employed in the area of psychometric testing and diagnosis, where the emphasis was upon documenting the nature of the defect. These processes were generally used to exclude disabled persons from a service rather than to provide a programme that might enhance their competence and lifestyle.

Clarke and Clarke (1958) contended that the legacy of the eugenics movement, and the depression and resultant high unemployment between the two world wars, produced a social climate that was not conducive to positive alternatives for these people. In the introductory

[6] At the London conference held in 1960, 37 of the 97 presentations were from non-medical disciplines, principally psychology and education (Richards, Clarke & Shapiro, 1962).

chapter of Clarke and Clarke (1958), Tizard (1958) supported this assessment of the relative neglect of intellectual disability as a field of study. He observed that

> physicians have tended to neglect it as a field because of the seeming hopelessness of effecting specific cures; educationists and psychologists have been primarily concerned with problems of normal children; society as a whole has viewed the social problem of mental defect with a mixture of alarm and embarrassment. (p. 20)

Impact of Operant Psychology

On the other hand, the extremist behaviourist views of J.B. Watson (1913, 1924) began to attract researchers to the field of intellectual disability research, possibly because they appeared to be an antidote to the equally absolutist views of those who maintained that heredity was the sole determinant of intelligence. Watson, a former student of the revered American educational philosopher John Dewey, left his footprint solidly on the operant conditioning branch of behaviourism, the legacy of which permeated much of the applied research work in the area of those with severe and profound levels of intellectual disability in the early 1970s and beyond. His influence continues to be reflected in the applied behaviour-analysis approach to ameliorating severely challenging behaviours.

Watson's first public statement on behaviourism, made in 1913, was that "psychology as the behaviorist views it is a purely objective experimental branch of natural science. Its theoretical goal is the prediction and control of behaviour" (1913, p. 158). In 1924, he asserted:

> Give me a dozen healthy infants, well-formed, and my own specified world to bring them up in and I'll guarantee to take anyone at random and train him [*sic*] to become any type of specialist I might select—doctor, lawyer, artist, merchant—chief, and, yes, even beggar-man and thief, regardless of his talents, penchants, tendencies, abilities, vocations, and race of his ancestors. (1924, p. 104)

While Watson may have been the progenitor of behaviourism of the operant school, the theoretical work of figures such as Edward L. Thorndike, Edward R. Guthrie, Edward C. Tolman, Clarke L. Hall, and O. Hobart Mowrer provided a source of inspiration for psychologists who were searching for answers to the complex problems people with intellectual disabilities were presenting. However, it was B.F. Skinner (1938), in outlining his principles of operant conditioning, who laid the foundation for many of the practices that were instituted in the 1960s and 1970s and continue to be applied in this field of research and practice (Scheerenberger, 1987).

The oft-quoted classical study by Fuller (1949), in which a person with a profound intellectual disability was taught to raise his hand via a reinforcement procedure, has been heralded as a social and educational revolution in the area of intellectual disability (Whitman & Scibak, 1979). In the 1960s, significant research was conducted in the areas of language (Schiefelbusch, 1963; Baer & Sherman, 1964; Guess, Sailor, Rutherford & Baer, 1968; Bricker & Bricker, 1970), stereotypic movements (Berkson & Mason, 1963), punishment (Birnbrauer, 1968), toilet training (Ellis, 1963b), autism (Lovaas, 1966), tantrum behaviour (Sailor, Guess, Rutherford & Baer, 1968), functional speech in echolalic children (Risley & Wolf, 1967), and behaviour shaping of people in an institutional setting (Watson, 1968). Spradlin and Girardeau (1966) and Baer, Wolf and Risley (1968) provided a comprehensive