

# **The Antecedents of *An Ordinary Life***

**1946 to 1979**

**Paul Williams**

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## **Introduction**

The first large residences specifically for people with learning disabilities, called hospitals or asylums, were opened in the 19<sup>th</sup> century. At the beginning of the 20<sup>th</sup> century there were around 5000 people living in them (Tizard, 1958). At that time alarm grew that people with learning disabilities if left to their own devices were a threat to society, prone to criminality and anti-social behaviour and likely to perpetuate this social problem if they had children. In 1913 a Mental Deficiency Act was passed in parliament. It proposed the establishment of many more institutions in which people could be compulsorily detained if they exhibited unsocial behaviour or if their families requested it. The period from then until the 1950s saw a great increase in the numbers receiving institutional care, reaching a peak of 60,000. The residences were mainly run by local authorities and were often called colonies as well as hospitals. A body called the Board of Control was established by the 1913 Act to set and administer rules and regulations governing these institutions and to carry out inspections. One of the best accounts of this period, which includes a first-hand account of what life was like in one institution, is Atkinson, Jackson and Walmsley (1997); see also Walmsley (2008).

David Towell (2022) has written an account of developments that transformed this situation in the period 1980 to 2001, rightly emphasising the catalytic role of the King's Fund through its 'Ordinary Life' initiatives (King's Fund Centre, 1980; Towell, 1988). This paper outlines some of the key events in the previous four decades that laid the groundwork for the almost complete replacement of large institutional provision by small community-based facilities after 1980.

Note: Numbers in square parentheses [ ] refer to paragraphs in the text and indicate cross-reference.

## **The 1940s**

### **1946**

- 1) In 1946 two voluntary organisations were founded which would play key roles in improving both public and professional perceptions of people with learning disabilities: Mencap and Mind. Mencap was started by a parent, Judy Fryd (Mencap, 2023), and was originally called The National Association for Parents of Backward Children. It changed its name to the National Society for Mentally Handicapped Children in the 1950s and to the Royal Society for Mentally Handicapped Children and Adults in the 1980s. It has used the abbreviated form 'Mencap' since the late 60s and its official name is now the Royal Mencap Society. Mind was originally called The National Association for Mental Health and was formed from an amalgamation of three previous mental health organisations (Mind, 2023). It changed its name to Mind in 1972. Its work has included an interest in people with learning disabilities: for example, it initiated and ran training for teachers of children excluded from the education system (Mittler, 2010).

## 1948

- 2) In 1948 all the colonies and hospitals run by local authorities were transferred to the newly-created National Health Service. However, they were still governed by the 1913 Mental Deficiency Act and still operated under the Board of Control (Nuffield Trust, 2023).
- 3) Also in 1948 a Social Psychiatry Research Unit was set up by the Medical Research Council, based at the Maudsley Hospital in London and directed by Aubrey Lewis, Professor of Psychiatry at London University (Royal College of Physicians, 2023). He recruited two young psychologists, Jack Tizard and Neil O'Connor, to carry out research into the employability of people with learning disabilities that could assist their discharge from institutional care (see Williams, 2005a). Jack Tizard in particular became an important and influential figure during the following three decades (Williams, 2021).

## Summary

The 1940s saw the emergence of a more positive perception of people with learning disabilities than had prevailed previously. Voluntary organisations were founded which promoted the value and rights of those people in society, responsibility for the main long-term residential services was mainstreamed by incorporation into the new NHS, and interest grew in research on the potential of the people and the possibility of moving out of institutions.

## The 1950s

### 1951

- 4) In 1951 the National Council for Civil Liberties published a booklet called *50,000 Outside the Law*. It documented, through accounts of the experiences of people detained under the 1913 Act, that the rules and regulations set by the Board of Control were draconian and were being abused. It pointed out that the Board of Control was not accountable to anyone including parliament (National Council for Civil Liberties, 1951).

### 1952

- 5) 1952 saw the founding of The Spastics Society (called Scope since 1994) (Davies, 2002; Scope, 2023). It included people with learning disabilities in its remit and was to be a major contributor to the 'Ordinary Life' concept. In particular it provided strong support to Campaign for the Mentally Handicapped [52]. It also ran Castle Priory College in Oxfordshire which provided training for staff of services promoting new concepts of care and support from the 60s onwards.
- 6) A more general interest in psychological, educational and social – rather than just medical – research developed in the 1950s [10] and two new journals were founded to aid this. In 1952 a British Society for the Study of Mental Subnormality was founded in Birmingham

and in 1954 they began publishing a *British Journal of Mental Subnormality*. In 1957, Mencap founded a scientific journal, the *Journal of Mental Deficiency Research*.

### 1953

- 7) In 1953 the National Council for Civil Liberties campaign and similar concerns around mental illness provision led the government to set up a Royal Commission to suggest reform of mental health legislation, including of the 1913 Act. It reported in 1957 [9].

### 1956

- 8) In 1956 Tizard & O'Connor published a full account of their research into the training and employability of adults in institutions in a book *The Social Problem of Mental Deficiency* (O'Connor and Tizard, 1956). They argued that many people detained in institutions could function well in community settings.

### 1957

- 9) In 1957 the Royal Commission on the Law relating to Mental Illness and Mental Deficiency published its report (Percy Commission, 1957). It recommended that almost all patients should not be compulsorily detained but should be voluntary patients and that the Board of Control should be abolished. It argued that a completely new Mental Health Act was needed to reform previous legislation. The Commission was headed by former Education Secretary and Health Secretary Baron Percy of Newcastle, who sadly died in 1958 before seeing the fruits of his work in the 1959 Mental Health Act [12].

### 1958

- 10) 1958 saw the publication of a book with chapters by people working in the field of learning disability which took a new and far-reaching approach. Edited by Ann and Alan Clarke, psychologists at Manor Hospital, a large learning disability institution at Epsom in Surrey, it took a psychological, educational and social approach, rather than the prevailing medical and custodial approach (Hall, 2008). The contributors were six psychologists and a speech therapist. The main textbook about learning disability had previously been *A Textbook of Mental Deficiency* by the psychiatrist A F Tredgold which ran to nine editions between 1908 and 1956. The Clarks' book, called *Mental Deficiency – the Changing Outlook* (Clarke and Clarke, 1958) included chapters by Jack Tizard, the Clarks themselves and Herbert Gunzburg, a psychologist at Monyhull Hospital, Birmingham and a pioneer of social education for people with learning disabilities (Jackson, 2013).
- 11) 1958 was the date of a landmark project known as the Brooklands experiment. The Fountain Hospital in South London was a learning disability institution with many children among its residents. Since his work on employability of adults, Jack Tizard had taken a particular interest in children living in institutions. With strong support from Mencap, Tizard negotiated the transfer of 16 children from the Fountain to a large house called Brooklands in Reigate, Surrey, where there would be a developmental rather than a custodial regime of care. Progress of the children would be compared with matched children who remained at

the Fountain. The Brooklands children did show greater development, especially in verbal skills, and the project was judged a success in terms of a model of better care for learning disabled children (Lyle, 1960; Tizard, 1964).

## 1959

12) 1959 saw the publication of the new Mental Health Act which followed most of the recommendations of the Royal Commission (Mental Health Act 1959). Nearly all institution residents became voluntary patients, allowing them and their families greater say in their care. The Board of Control was abolished.

13) During the 1950s, the Director of the Danish Service for the Mentally Retarded, Neils Bank-Mikkelson, had worked with families to design a new Act to map out the shape of future services. The Act was passed in 1959 and its preamble expressed the aim of services as “to let the mentally retarded obtain an existence as close to normal as possible”. This policy was later described as ‘normalization’. In the 1960s, the Secretary General of the Swedish Parents’ Association, Bengt Nirje, and the Head of Swedish Services for the Mentally Retarded, Karl Grunewald, worked for the adoption of this policy to also underlie a similar Act in Sweden, passed in 1968 (Perrin, 1999). These developments were to have a dramatic influence on services throughout the world, though the principle of normalization itself was not formally described in print until 1969 (Nirje, 1969).

## Summary

The 1950s saw acceptance of the need to reform the law relating to people with learning disabilities, resulting in a new Mental Health Act which altered the function of services away from custody and control. This was accompanied by consolidation of research and information in social, educational and psychological areas of needs and provision, away from a primary medical concern. A key project involved the relocation of children from institutional care to a more homely and educational environment, scientific demonstration of the success of which opened up a model for future care. A new policy of normalization was initiated as a practical philosophy for development of services in Scandinavia.

## The 1960s

### 1960

- 14) In 1960 Mencap joined with the equivalent organisations in Germany and Holland to initiate what became the International League of Societies for the Mentally Handicapped (now called Inclusion International) (Inclusion International, 2023). The League quickly expanded and became a vehicle for exchange of information about developments in many different countries. One example was propagating information about the policy of normalization in Scandinavian services. The League also adopted the task of lobbying the United Nations to adopt a Declaration of Rights of people with learning disabilities, finally achieved in 1971 (Mittler, 2010) [55]. Inclusion International now has over 200 member societies.
- 15) Also in 1960 Herbert Gunzburg published an influential book *Social Rehabilitation of the Subnormal*. It further established an educational focus for institutions to prepare people for living outside in normative community settings (Gunzburg, 1960).

### 1961

- 16) In the next year, 1961, Erving Goffman in the USA published his study of the effect of institutional care on those receiving it: *Asylums* (Goffman, 1961). It was an influential indictment of the systematic harm done to people by institutional regimes. Also in that year the French philosopher Michael Foucault published *Folie et Dérison* (English translation, *Madness and Civilization: a History of Insanity in the Age of Reason*), a historical study of how people with mental illness or learning disabilities came to be treated as 'social outcasts, wild animals and misbehaving children' (Foucault, 1961).
- 17) John F Kennedy was elected US President in 1961. He had a sister, Rose, with learning disabilities and another sister, Eunice, who developed a more general interest in learning disability (she founded the Special Olympics movement in 1968) (Los Angeles Times, 2009). Eunice persuaded JFK to establish a President's Panel on Mental Retardation to inform the US government on ways to provide high quality services. This was formally made a part of the administration by President Johnson in 1966 and renamed the President's Committee on Mental Retardation (Administration for Community Living, 2020).
- 18) In the UK, Enoch Powell was Secretary of State for Health and Social Services from 1960 to 1963. His later racist 'rivers of blood' speech in 1968 makes it difficult to acknowledge his contribution to the movement towards community care. However, in 1961 he gave a speech to a conference of the National Association for Mental Health (now Mind) known as the 'water tower' speech because it characterised institutions as being in rural areas with huge water towers and chimneys reflecting their isolation from normal community life. He argued powerfully, twenty years before the 'Ordinary Life' initiative, that all large institutions should be closed (Powell, 1961).

## 1962

- 19) Following the Brooklands experiment the idea of hostels with around 20 places as an alternative to institutional care began to catch on. In 1962 Enoch Powell as Minister of Health produced *A Hospital Plan for England and Wales* (National Health Service, 1962) which recommended hostels as an alternative to hospitals for long-term residential care by health authorities. Local authorities also had the power to set up such residential care provision and hence the era of the hostel began to be established for both children and adults. Pauline Morris (1969) reports government figures that in 1965 there were places in local health authority hostels for 900 children and 1,466 adults with learning disabilities. King, Raynes and Tizard (1971) say that in 1963 there were 286 children in local health authority hostels. By 1968 there were 64 local health authority hostels for 1,200 children (an average of around 20 places in each) and similar accommodation for around 3,500 adults. Most accommodation was newly built. Further hostels for 600 children and 2,000 adults were planned to be provided by 1972.
- 20) In 1962 an American psychologist received a postgraduate scholarship to work for a year with Jack Tizard in the UK. He was impressed with the research and practical steps being taken here in education of adults with learning disabilities for work and community living by Tizard and O'Connor [8]. He was also influenced by Herbert Gunzburg [15] (Wolfensberger, 1999; Malcomson, 2023). His name was Wolf Wolfensberger and he was to build on his experience here by developing the concept of normalization into an academic discipline as well as an innovative policy. He became one of the most influential people in the world in the development of community-based non-institutional services (Lemay, Caruso and Thomas, 2023) [37, 38, 45, 56, 76]. A selection of readings from Wolfensberger's major works is given in a British book (Race, 2003).
- 21) During 1962 and 1963, Jack Tizard worked on an extremely influential and forward-looking book *Community Services for the Mentally Handicapped* (finally published in 1964). This summarised his research on employment, care of children and the needs of families. He proposed a blueprint for comprehensive services based on population areas of 100,000 people. In such an area hostels of around 20 places could replace institutional care entirely, allowing people to live in more homely environments close to their families. This would be complemented by local health, education and social work services (Tizard, 1964).

## 1963

- 22) While working on the book in 1962, Tizard negotiated funding from the Department of Health and the Medical Research Council for a project to research whether his community-based blueprint would work. In 1963 Albert Kushlick, a psychiatrist with experience of work with people with learning disabilities, was recruited to run a research team called the Health Care Evaluation Research Team, based at the Wessex Regional Health Authority covering the 2 million population of Hampshire, Dorset and the Isle of Wight. A survey of all the known people with learning disabilities in the region allowed people from particular areas of 100,000 population to be identified (Kushlick and Cox, 1968). It was proposed that 20-place hostels would be established, first for all the children in hospital care from chosen areas of that size, moving them all close to their family homes. Later there would be a



similar process for severely disabled adults. The research team would examine the feasibility of such services and compare the progress of residents and the satisfaction of their families with control groups of people remaining in hospital (Tizard and Kushlick, 1965). Albert Kushlick also began to promote strongly an educational approach in residential services.

23) In 1963, Jack Tizard had also negotiated funding (from an American organisation) for a research project, called the Child Development Project, which compared the quality of care for children with learning disabilities in hospitals, hostels and children's homes, using criteria derived from Goffman's (1961) analysis. The two researchers, Roy King and Norma Raynes, produced evidence of much better child care in hostel and children's home settings (King, Raynes and Tizard, 1971).

24) Mencap in 1963 opened a hostel and attached workshop as a demonstration project in Slough and this model achieved much publicity (Mencap, 2023).

## 1964

25) In 1964 an American, Gunnar Dybwad, published an influential book called *Challenges in Mental Retardation*. It outlined the need for dramatic improvement in services for people with learning disabilities in all areas of need, especially a move from institutional care to community care (Dybwad, 1964). Dybwad had been Director of the National Association for Retarded Children (the American equivalent of Mencap) from 1957 to 1963, was then Director of learning disability projects at the International Union for Child Welfare in Switzerland, and later became Professor of Human Development at Brandeis University in Massachusetts. He and his wife Rosemary were closely involved with the International League of Societies for the Mentally Retarded and travelled the world imparting information about promising developments in services (Bersani, 2014a, 2014b). They both visited the UK frequently in the 60s and 70s, in particular promoting deinstitutionalisation, the Scandinavian concept of normalization and the growing phenomenon of self-advocacy by people with learning disabilities themselves.

26) Jack Tizard was appointed in 1964 to a Professorship in Child Development at London University Institute of Education where he continued to promote research and teaching on learning disability (B. Tizard, 1983; Williams, 2005b).

27) Also in 1964 an International Association for the Scientific Study of Mental Deficiency was founded which ran four-yearly international conferences in subsequent years, the first being in France in 1968 (Clarke, 1991; Mittler, 2010; Parmenter, 2004).

## 1965

28) In 1965, JFK's brother Senator Robert Kennedy visited the wards for the most severely disabled people in a number of American institutions. He was severely critical of what he saw, especially at Willowbrook, an institution in New York housing 6,000 people, mostly children (Disability Justice, 2023; YouTube, 2023). He said in an interview, "I think that particularly at Willowbrook we have a situation that borders on a snake pit, and that the

children live in filth.” He was widely accused of exaggeration and false reporting, but a research professor at Boston University, Burton Blatt, undertook to provide evidence. He negotiated to make tours of the wards in question at five institutions, and he took with him a photographer with a hidden camera. The resulting photographs were printed in a book called *Christmas in Purgatory*, a thousand copies of which were distributed free to relevant politicians, policy makers and service administrators. The photos demonstrated the truth of Senator Kennedy’s observations (Blatt and Kaplan, 1966). Willowbrook was to become the subject of a highly publicised exposé in 1972 [57].

## 1967

- 29) Leslie Hilliard had been consultant in charge of the Fountain Hospital in London. On his retirement he worked with Mencap to establish an Institute for Research into Mental Retardation (Jisc, 2023b). It later received additional funding from the Spastics Society (Scope) and the Department of Health, and changed its name to the Institute for Research into Mental and Multiple Handicap. It was set up as a charity in 1967 with the aim “to endow, promote, undertake and co-ordinate research into mental retardation and to make known the results of such research for the benefit of the public.” It pursued this aim largely through organising study groups and conferences, bringing together researchers in specific topic areas. It then arranged publication of the proceedings of these events. This was an important source of up-to-date information. For example, several of the publications on the application of behavioural methods in the 1970s [59] were originated and sponsored by the Institute when it was under the direction of Peter Woodford. The Institute continued its work until around 1990.
- 30) In 1967 what is believed to be the first book by a person with learning disability was published. It was called *The World of Nigel Hunt*. It took the form of a diary recounting various adventures Nigel had had. Nigel had Down’s syndrome. His mother had taught him to type and he had typed the book on his own typewriter (Hunt, 1967).
- 31) Stanley Segal was head teacher of schools for children with learning disabilities and physical impairments. In the 1950s he had founded the Guild of Teachers of Backward Children (now the National Association for Special Educational Needs). He was incensed that Section 57 of the 1944 Education Act allowed children with severe learning disabilities to be judged ‘unsuitable for education in school’ and to be excluded from the education system. In 1967 he published a book *No Child Is Ineducable*, arguing for inclusion of all children within the school structure (Segal, 1967; Jackson, 2013). This strengthened a campaign to repeal that aspect of the 1944 Act, leading to a new Education Act in 1970. All children became eligible for education in school and the teaching of children excluded from school in places called ‘Junior Training Centres’ run by health authorities was transferred to education authorities in 1971.
- 32) Barbara Robb was a psychotherapist who, after being shocked by conditions at a psychiatric hospital when she visited an acquaintance there, founded a pressure group – Aid for the Elderly in Government Institutions (AEGIS) – to bring those conditions to greater public attention. In 1967 she published a book *Sans Everything* (a quotation from Shakespeare describing loss in old age) (Robb, 1967). It contained accounts of scandalous conditions in

seven psychiatric and geriatric hospitals, contributed by members of AEGIS and by some staff of the hospitals themselves. An inquiry by the government attempted to exonerate the hospitals (Ministry of Health, 1968), but AEGIS's allegations were widely believed to be accurate, as subsequent scandals in more hospitals were to reveal.

33) Encouraged by *Sans Everything*, a nursing assistant at Ely Hospital for people with learning disabilities in Cardiff, Michael Pantelides, wrote to the *News of the World* newspaper in 1967 with descriptions of poor conditions and treatment of patients there. The paper forwarded his letter to the government before publishing it and an inquiry was set up led by Geoffrey Howe, a lawyer who was later to become a politician and government minister [41] (Shapland, 2022).

## 1968

34) Early in 1968 a relative of a child living at Harperbury Hospital for people with learning disabilities in Hertfordshire wrote to *The Guardian* newspaper describing poor conditions in which the child was living. Ann Shearer, a young journalist who was welfare correspondent for the paper, arranged to accompany the relative to visit the ward in question. Her resulting piece in the paper was headed 'Dirty children in a locked room: A mental hospital on a bad day' (Shearer, 1968). The hospital reported the article as inaccurate and unrepresentative to the Press Council which upheld the complaint. The response of *The Guardian* was to publish the Council's findings alongside a reprinting of the original article, to allow readers to judge for themselves. This gained much publicity and substantially increased public awareness of conditions in many hospitals (Shearer, 1976), although it did not result in an official inquiry into the hospital. Ann Shearer herself was inspired to devote much energy into achieving improvement in services [52].

35) From 1968 to 1970 Richard Crossman was Secretary of State for Health and Social Services in Harold Wilson's government. He took a special interest in services for people with learning disabilities. Against pressure from civil servants in the Department he insisted on full publication of Geoffrey Howe's report on Ely Hospital [41]. He set up a Hospital Advisory Service and gave it a first task of visiting and advising on large institutions. He welcomed the Sheffield project being planned by the Department [49]. He met with Albert Kushlick to become informed about the Wessex Project [22]. And he commissioned a White Paper on future services for people with learning disabilities [50] (Crossman, 1977).

36) Mildred Stevens ran the NAMH (now Mind) course in Manchester for teachers of children with learning disabilities who were excluded from school. In 1968 she published the book *Observing Children who are Severely Subnormal: an Approach to their Education*. This emphasised that the children could benefit from mainstream educational principles, and it presaged the development of an educational approach in all services including residential care [59] (Stevens, 1968).

- 37) In 1969 the President's Committee on Mental Retardation in the USA produced what I regard as the most useful and influential publication of this whole period. It was called *Changing Patterns in Residential Services for the Mentally Retarded*, edited by Robert Kugel and Wolf Wolfensberger (Kugel and Wolfensberger, 1969). It contained chapters by Gunnar Dybwad, Burton Blatt, Bengt Nirje, Wolf Wolfensberger, Jack Tizard and nine other prominent figures involved in service improvements. Nirje's chapter was the first detailed explication of the Scandinavian principle of normalization, which he defined as 'making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society' (Nirje, 1969). Wolfensberger's chapter of over 100 pages was an analysis of the history of institutions in terms of social perceptions of the identity of the residents, for example as eternal children, as sick, as dangerous to society, as objects of pity and charity, or as objects of ridicule (Wolfensberger, 1969). He was later to combine this analysis with a development of the normalization principle to produce an evidence-based framework for improved services that he called 'Social Role Valorization (SRV)' (Wolfensberger, 1972, 1983).
- 38) Largely through contacts made by Gunnar Dybwad, *Changing Patterns* was brought to the attention of people in the UK on its publication in 1969. Nirje's chapter increased knowledge here of normalization as a philosophy and service policy. A version of it was published in the UK a year later (Nirje, 1970). An invitation was also given to Wolfensberger to write a summary of his chapter for the British magazine *New Society* (Wolfensberger, 1970).
- 39) There were two British contributors to *Changing Patterns*. Jack Tizard wrote a chapter arguing that residential services should be integrated with a continuum of services for all people with learning disabilities in a community area. He says that the primary job of residential services is to provide a home, and this could best be met in small family-type units (Tizard, 1969). David Norris, a university lecturer in teaching children and adults with learning disabilities, described the development of services in Essex. These included one hostel for 23 children and two for a total of 43 adults, but he says of moves towards hostels rather than institutions: "Life in a twenty or thirty place hostel is still a very poor substitute indeed for a normal family life" (Norris, 1969).
- 40) In the UK in 1969 a book *Put Away: a Sociological Study of Institutions for the Mentally Retarded* was published (Morris, 1969). Mencap had provided generous funding to the University of Essex and a team led by Pauline Morris carried out a study of 35 hospitals for people with learning disabilities. The book was extremely critical of hospital provision, both in terms of the overcrowded 'barrack-like' buildings and lack of comfort for residents and in terms of their lack of possessions and poor care.
- 41) Also in 1969 the full report of Geoffrey Howe's inquiry into the allegations about Ely Hospital was published (National Health Service, 1969). It confirmed that most of the complaints were accurate, and it condemned the management and care policy at the hospital. This was the first of the inquiries into hospital scandals that lasted through the 1970s (Socialist Health Association, 1981). There were inquiries about Farleigh Hospital, Bristol, in 1971; South Ockenden Hospital, Essex, in 1974; Brockhall Hospital, Lancashire,

in 1975; St. Ebba's Hospital, Surrey, in 1976; Normansfield Hospital, Teddington, in 1978; and Church Hill House Hospital, Berkshire, in 1979. Most of these inquiries confirmed poor conditions and practices, though some (for example the Church Hill House Inquiry) found the allegations to be untrue.

42) In 1969 within the Wessex project [22], the first hostel for children, Westwood House, was opened in Southampton. It brought all the children from one half of the city out of institutional care to live in a more homely environment (two large adjoining houses in a residential street made into a hostel for around 16 children) close to their families.

43) When John F Kennedy was assassinated, there was discussion in the UK about the form a memorial would take here. The National Association for Mental Health proposed the establishment of a centre for research in learning disability. When it was finally decided that the memorial would be a physical one at Runnymede, the NAMH set about raising its own funds to found the research centre. It was established at Manchester University in 1969 and named the Hester Adrian Research Centre after the vice-chairman of NAMH who had proposed the centre and had died in 1966 (Jisc, 2023a; Mittler, 2010). The first Director of the centre was the psychologist Peter Mittler.

44) Also in 1969 the Open University was founded (Open University, 2023). It would play a major role in parallel with 'Ordinary Life' initiatives, running generic courses on up-to-date research and policy relating to people with learning disabilities and developing life history work directly with those people (for example *Know Me As I Am* (Atkinson and Williams, 1990) and Mabel Cooper's contribution to Atkinson, Jackson and Walmsley, 1997).

45) After Wolf Wolfensberger's time in the UK [20] he became a researcher at the University of Nebraska in Omaha, focussing on the history of services for people with learning disabilities and ways of improving those services [37]. During his time there he worked closely with colleagues, service providers and families to develop a plan to relocate people from Beatrice State Institution, 100 miles from Omaha, back to their city of origin. In 1969 a Community Mental Retardation Services Act was passed in Nebraska (Evans, 2023; Wolfensberger and Glenn, 1969) which resulted in the establishment of the ENCOR service [48].

## Summary

In the 1960s, concern about the poor quality of institutional care and the negative effect it has on those receiving it was propagated on a number of fronts. Politicians in the UK and America expressed the need for a dramatic improvement in institutional services or their replacement altogether. Academic writers produced analyses of the damaging effect of institutional practices on residents. And multiple reports began to emerge from informed sources of scandalous treatment of people in institutional care, leading to the initiation of government inquiries. However, positive alternatives were described by a number of authors and researchers, emphasising education, normalization and a local community base for services. Dissemination of information about these was helped by the founding of international organisations and exchange of visitors between different countries. Kennedy's presidency and death were catalysts for useful developments in the

USA and the UK. A key publication by the President's Committee on Mental Retardation laid the groundwork for adoption of the normalization principle in the USA and the UK. Some major research projects began into alternatives to institutional care and ways of ensuring good quality care. Expansion began of the provision of hostels of around 20 places, by both hospital and local authorities, but the beginnings can be seen of questioning whether hostels can provide a true home for people. A campaign developed to prevent the exclusion from the school system of children with severe learning disabilities. The potential achievements of people with learning disabilities were emphasised by publication of a book authored by a man with Down's syndrome, presaging the later development of life history work with the people themselves.

## The 1970s

### 1970

- 46) In 1970 the Down's Syndrome Association was founded by a teacher, Rex Brinkworth. He led a movement for early education of children with Down's syndrome, their right to go to school, recognition of their value and achievements and their integration into community life (Down's Syndrome Association, 2023; Williams, 2017).
- 47) In that year the second Wessex hostel, Locksway House, was opened in Portsmouth, again taking all the children from one half of the city from institutions into a more homely environment closer to their families. Unfortunately the design and setting of the hostel were later used as negative examples in courses on normalization. The hostel was newly built with an industrial-type chimney making it incongruous in the neighbourhood and it was situated at the edge of a large psychiatric hospital.
- 48) The community service in Nebraska [45], based in Omaha, was launched in 1970; it was called the Eastern Nebraska Community Office of Retardation (ENCOR). Normalization would be the underlying policy and philosophy and consequently residential care would be provided in small units to facilitate community integration (Evans, 2023). It was soon realised that even group homes of six or eight people were too large and emphasis was placed on accommodating people in family placements or in groups of just two or three in ordinary housing. Word spread about ENCOR's innovative nature and throughout the 70s it attracted visitors from all over the world. Among visitors from the UK were two psychologists, Derek Thomas and Hugh Firth, and a social worker, Alan Kendall. They wrote a detailed and enthusiastic account on their return (Thomas, Firth and Kendall, 1978).
- 49) In 1970 work began on the Sheffield project. This was a plan developed by the Department of Health to create a comprehensive community-based service for the city of Sheffield, a population area of half a million people. Unfortunately, in contrast to the ENCOR service, the emphasis for residential care provision was on newly built 24-place hostels, a plan dominated by the architects' section of the Department. A network of these hostels would be set up, including a new 96-place hospital (four 24-place hostels linked together). A research team was established at Sheffield University in 1976 to evaluate the new services. Poor planning, delays in implementation, the lack of true homeliness and evidence that places of that size were not conducive to community integration, resulted in the team reporting that the project was a failure (Malin and Race, 1979; Malin, 1981). The leader of the research team, Alistair Heron, when asked for his conclusion on the outcome of an exciting opportunity for a comprehensive innovative community-based service gave a classic three-word answer: "We muffed it." The evaluation team was aware of the ENCOR service and wished that a similar service had been envisaged for Sheffield. The findings are summarised in Heron and Myers (1983).

## 1971

- 50) 1971 saw the publication of the government White Paper initiated by Richard Crossman, entitled *Better Services for the Mentally Handicapped* (Department of Health and Social Security, 1971). It envisaged that hospitals would no longer be used for long-term care of children and the number of places for adults would be reduced by about half. It expected a great expansion of local authority community-based services, particularly residential care. Interestingly it used the term 'homes' rather than explicitly mentioning hostels.
- 51) After Richard Crossman had set up the Hospital Advisory Service [35], it began visiting mental handicap hospitals. In 1971 it visited Stoke Park Hospital in Bristol and wrote a highly critical report about conditions there. The report was leaked to the media by some student nurses. Several newspapers and broadcasters contacted the hospital for a reaction and were surprised at the response. The consultant psychiatrist in charge of the hospital, Alan Heaton-Ward, said he welcomed the report and fully agreed with it. He invited journalists to come to see the 'slum conditions' for themselves. Amongst the resulting publicity was a 20-minute documentary by the BBC in their '24 hours' current affairs programme. The outcome was an injection to the hospital's budget of £1 million to build new wards and a 29% increase in the ongoing funding of the hospital. (See the piece on Bristol hospitals at Glenside Hospital Museum, 2012, and the report in Hansard, 1972.)
- 52) After Ann Shearer had written her exposé of poor treatment of children on an institution ward [34] she became a passionate advocate of community alternatives. She attended a conference about learning disability in 1971 and circulated a 'manifesto' arguing for the complete closure of institutions. She and two friends, Sandra Francklin, an architect with an interest in design of services, and Anita Hunt, a researcher working for the Spastics Society (now Scope), decided to start a pressure group to pursue the agenda put forward in the manifesto. They received support from Scope whose Director, James Loring, agreed with the aims, offering office space and printing and distribution facilities for publications. The group called itself 'Campaign for the Mentally Handicapped' (CMH, later changed to 'Values into Action' VIA) (Holman, 2012; Williams, 2013). The group quickly attracted other members from a wide range of backgrounds, including some institution staff. One of their first publications was a response to the White Paper, which they entitled *Even Better Services for the Mentally Handicapped* (Shearer, Francklin and Hunt, 1971).
- 53) Maureen Oswin was a teacher of children with learning disabilities at Queen Mary's Hospital, Carshalton in Surrey. Concerned about conditions in which such children lived in long-stay hospitals, she visited several institutions at weekends to observe the children's experiences. In 1971 she published her findings in a book *The Empty Hours: a study of the week-end life of handicapped children in institutions*. It was a powerful indictment of life for the children, constituting idleness and neglect (Oswin, 1971).
- 54) In 1971 Gerry Simon, the consultant in charge of Lea Castle Hospital, Kidderminster, founded an organisation for research and dissemination of information about learning disability, the British Institute of Mental Handicap (now the British Institute of Learning Disabilities) (British Institute of Learning Disabilities, 2023; Corbett, 1992). It founded the journal that is now known as the *British Journal of Learning Disabilities*, the first issue of which was in 1973.



- 55) Also in 1971 the United Nations formulated a Declaration on the Rights of Mentally Retarded Persons (United Nations, 1971), following lobbying by the International League of Societies for the Mentally Retarded [14]. It includes the statement: "If care... becomes necessary it should be provided in surroundings and other circumstances as close as possible to those of normal life."
- 56) Between 1971 and 1973, Wolfensberger was a visiting scholar at the National Institute on Mental Retardation in Toronto, Canada. This was a particularly productive time for him. In 1972 he published the detailed and influential account of normalization and its application and implications in the book *The Principle of Normalization in Human Services* (Wolfensberger, 1972). In 1973 he produced a refined edition of the service evaluation instrument [45] and there was a further edition in 1975. This assessed how close or far a service was from implementing normalization. It was named *PASS: Program Analysis of Service Systems* (Wolfensberger and Glenn, 1975). He also wrote a substantial text on a scheme he had worked on in Omaha to recruit ordinary citizens to link up with individual people with learning disabilities, particularly those coming out of institutions, to protect them from harm and assist their integration into community life: *Citizen Advocacy and Protective Services for the Impaired and Handicapped* (Wolfensberger and Zauha, 1973). All of these works were published by the NIMR in Toronto. The concepts involved became increasingly known in the UK throughout the 70s. Teaching on normalization and PASS became more formalised after the founding of CMHERA in 1979 [76]. A consortium of voluntary organisations including Mencap and Scope founded Advocacy Alliance in the early 1980s to establish Citizen Advocacy schemes in the UK.

## 1972

- 57) 1972 saw two further major indictments of institutional provision. In the UK a study of a large residential home for physically impaired people described their isolation. The authors characterised residents' admission as their 'social death' and the function of the home as accommodating them for the interval between their social death and their physical death (Miller and Gwynne, 1972). In the USA a television programme followed by a book described appalling conditions at the 6,000-place (mainly for children) Willowbrook State Institution in New York (Rivera, 1972; Shearer, 1976).
- 58) In 1972 the first Wessex hostel for adults, Fairmile House, was opened in Christchurch, Dorset. It brought those with the most severe disabilities from the town out of institutional care to a more homely place nearer their families. As well as evaluating the feasibility and impact of this policy, the research team also began to promote an educational approach to care both in the hostels and in the region's institutions [59].
- 59) There had been growing interest and experience in use of teaching techniques known as behaviourism or 'behaviour modification' in both the USA and the UK. 1972 saw the first of a series of publications in the UK that promoted use of this teaching in services including in residential care (Clarke and Lewis, 1972; Clarke and Clarke, 1973; Mittler, 1973; Kiernan and Woodford, 1975; Kiernan and Jones, 1977). The related concept of 'goal planning' also began to be taught and practised in services (Houts and Scott, 1975).

- 60) Also in 1972, Ann Shearer and CMH organised a weekend residential conference of people with learning disabilities themselves, held at Scope's Castle Priory College in Oxfordshire. It was called 'Our Life' and Ann wrote a full account of it, published by CMH (Shearer, 1972). A further conference was held in London with the title 'Listen!' (Shearer, 1973). These events stimulated other conferences in North America and were a catalyst to the development of a self-advocacy movement (Williams and Shoultz, 1982). Several other conferences were held at Castle Priory, one concerned with employment (Tyne, 1975) and others with the theme of equality between disabled and non-disabled people (Williams, 1974; Williams and Gauntlett, 1974). This latter theme of equal 'life-sharing' between carers and the people they care for was already practised in a few service organisations, notably L'Arche, founded in 1964 (L'Arche, 2024), and Camphill, founded in 1940 (Camphill, 2024; Jackson, 2013). Ann Shearer spent some time living in a L'Arche community in France later in the 1970s.
- 61) In July 1972 a fire broke out at night in a dormitory housing 36 young men with learning disabilities at Coldharbour Hospital, a 350-place institution in Dorset. 30 of the people died, mainly from smoke inhalation. A subsequent inquiry found that a catalogue of decisions about a recent upgrading of the dormitory to make it more homely had resulted in a fire risk (Vowden, 1972). This tragic event fuelled a widespread belief that housing people in such large numbers was unacceptable.
- 62) In 1972 a hospital administrator with a special interest in learning disability, James Elliott, was appointed to the King's Fund Centre to lead a team to research and disseminate information in that field. Later in the 70s the team became led by David Towell who began the 'Ordinary Life' initiative.
- 63) In 1972 the Briggs report on nursing questioned whether nurse training was needed for care of most people with learning disabilities. It suggested the development of a separate profession to work with people with learning disabilities in hospital or community settings (Department of Health and Social Security, 1972). In 1973, James Elliott wrote a commentary on the report, largely agreeing with that conclusion and foreseeing the deliberations of the Jay Committee which the government set up to consider the issue [75] (Elliott, 1973).

## 1973

- 64) Also in 1973, James Elliott and Stanley Segal [31] founded the Association of Professions for the Mentally Handicapped (APMH, later called 'Bridges') as a multi-disciplinary group where ideas on improving services could be exchanged. The Association ran annual conferences, the proceedings of which were published. Unusually but very helpfully the group's definition of 'professional' included family members and carers of people with learning disabilities (King's Fund Centre, 1976).
- 65) In 1973 Jack Tizard founded the Thomas Coram Research Unit at London University Institute of Education, which became a focus for research in areas of child education, care and welfare including that of children with learning disabilities (B. Tizard, 1983; Williams, 2005b). Jack died in 1979 but the Thomas Coram Unit continues to this day.

## 1974

66) A boost to the use of ordinary housing for residential care occurred as an outcome of a remarkable instance of community action in Cardiff in 1974. A student volunteer group set up in 1967 and called Cardiff University Social Services (CUSS) had been befriending and working with residents at Ely Hospital. One of the volunteers, Jim Mansell, a psychology student, hatched the idea and negotiated the funding for a project to re-house people from the hospital. A large but ordinary house was acquired to accommodate five people from Ely Hospital and three university students, living together on a basis of equality. More similar group homes were established by CUSS in the next few years (Mansell, 1976). CUSS has since developed into a service provider throughout Wales, now known as Innovate Trust (Innovate Trust, 2023).

67) In 1974 another full length book by a person with learning disability, Joey Deacon, was published (Deacon, 1974). It told the story of Joey's life. He lived at St Lawrence's Hospital in Surrey. He could not write himself and had difficulties with speech, but he was helped to write the book by three friends with whom he lived, Ernie, Michael and Tom. Ernie could understand Joey's speech and relayed his story to Michael who wrote it down. Tom had learned to type and wrote it out to be sent to Mencap who published it. Royalties from the book and subsequent personal appearances by the four friends, including on television, helped to fund a bungalow which the four moved into in 1979.

## 1975

68) By 1975 in the Wessex project attention had turned to whether more homely provision than 20-place hostels, more conducive to the care of severely disabled people and to community integration, could be envisaged. With the continuing cooperation of the Wessex health authority, accommodation in small groups based on use of ordinary housing was planned. Later, Jim Mansell joined the research team and together with David Felce and other colleagues the success of this provision even for the most severely disabled people was documented (Felce, Kushlick and Smith, 1980; Felce and Toogood, 1988; Mansell, Felce *et al.*, 1987) and was able to feed into the 'Ordinary Life' agenda and the possibility of complete closure of institutional care.

69) In 1975, Roger Blunden, a member of the Wessex research team, moved to establish a similar team at the University of Wales in Cardiff. It was called the Mental Handicap in Wales Applied Research Unit. It was set up particularly to develop an educational approach in residential care services and to evaluate new services to serve people coming out of Ely Hospital. Considerable pressure was placed on the Health Authority by the local Community Health Council, by a Cardiff branch of Campaign for the Mentally Handicapped and by Cardiff University Social Services to close Ely Hospital and establish community-based alternatives. The Mental Handicap in Wales research team suggested a pilot project to explore this and this was eventually initiated by the local health and social services departments in an area of Cardiff (Welsh Office, 1978; Mathieson and Blunden, 1980). The service, known as NIMROD (New Ideas for the Mentally Retarded in Ordinary Dwellings), started relocating local people from Ely Hospital into small group homes

utilising ordinary housing stock. Documentation of the benefits by the research team fed into an All Wales Mental Handicap Strategy adopted in 1983.

70) Also in 1975, Barbara Castle, Secretary of State for Health and Social Services, became concerned about lack of progress to meet the aims of the 1971 White Paper *Better Services*. She commissioned two new groups to advise the government on ways forward. The first was a multidisciplinary group, called the National Development Group (NDG), to advise the government on ways of achieving the goals of *Better Services*. The group would be independent but with support from civil servants and with direct access to government ministers. The psychologist Peter Mittler, Director of the Hester Adrian Research Centre [43] was appointed to lead the group. The NDG published a number of pamphlets and reports on a wide variety of issues for both hospitals and local authority services, until it was disbanded in 1980 (Mittler, 2010). Alongside the NDG would be a National Development Team (NDT) which would be available to hospital authorities and social service departments to give advice on projects for service development. It would take over the remit to advise on learning disability services from the Hospital Advisory Service established by Richard Crossman [35]. The chairman appointed to lead the NDT was the psychiatrist in charge at Lea Castle Hospital and founder of the British Institute of Mental Handicap [54], Gerry Simon. The NDT visited many service authorities to advise on planning future services. Unfortunately, for residential care it continued the obsession with the 20-place hostel, recommending 'community units' - hostels by another name (Corbett, 1992).

71) By 1975 CMH had received funding for a full-time Research Officer and Alan Tyne had been appointed. Between 1975 and 1978 he carried out a major project, funded by the Mental Health Foundation, to document the overall pattern of residential services for people with learning disabilities in the UK. He visited, for at least several hours and often for much longer, 20 hospitals and hospital units, 45 local authority hostels and 18 group homes. This included all hospitals and associated units, all local authority hostels and most group homes in the North East Thames Region. On each visit Alan took care to speak to residents as well as gaining information on the nature and functioning of the service. The results were published in an 80-page report (Tyne, 1977) and a 110-page account of what life was like for residents (Tyne, 1978). This second account was achieved through composite pictures of typical experiences in six settings: a large hospital, a smaller hospital annexe, two kinds of local authority hostel, a small group home and a private lodging house. Alan's conclusion was that the purpose of residential settings was poorly thought through. In particular, hospital and hostel residences were not conducive to participation in a local community. Many were also not homely. The aims of providing a home with access to community membership could thus not be met. Two previous publications by CMH had argued for the use of ordinary housing for residential services: Sandra Francklin *Homes for mentally Handicapped People* (1974) and Ann Shearer *No Place Like Home* (1975). Alan's findings strongly supported this message with detailed evidence from a very wide range and number of services. Alan's vision of a residential service based on ordinary housing was spelt out in a later article (Tyne and Williams, 1979).

## 1977

72) In 1977 the Spastics Society (now Scope) established a residential unit, Beech Tree House, attached to the Society's Meldreth Manor School in Hertfordshire. It used systematic behavioural methods to tackle behavioural difficulties shown by children with learning disabilities (Jones, 1983). Strict behavioural regimes have been somewhat discredited since (for example Kaur, 2023), but the unit did reinforce the view that behaviour problems in children could be managed in small residential units and did not require institutional hospital-type provision.

## 1978

73) 1978 saw publication of another book by Maureen Oswin, *Children Living in Long-stay Hospitals* (Oswin, 1978). She had joined the Thomas Coram Research Unit and had spent 18 months observing the care of children in eight learning disability hospitals. She described great neglect suffered by the children and argued powerfully for a complete transformation in the structure and content of residential care.

## 1979

74) In 1979 Bronach Crawley, a researcher at the Hester Adrian Research Centre, carried out a study of committees of attenders at day services for adults with learning disabilities, usually called Adult Training Centres (Mittler, 2010). This was reported as a PhD thesis (Crawley, 1982) and in two publications (Crawley, 1983, 1988). This democratic process, supported by staff at the centres, was quite prevalent and constituted an early form of self-advocacy by people with learning disabilities which eventually became the 'People First' movement (Williams and Shoultz, 1982).

75) The Committee of Inquiry into Mental Handicap Nursing and Care, chaired by the Labour politician Dame Peggy Jay, reported in 1979. It agreed with the suggestion for a new profession made by the Briggs Committee and James Elliott [63] and made concrete proposals how it could come about. (Unfortunately it never did come about, largely due to opposition from the existing learning disability nursing profession.) The report powerfully argued that the principle of normalization should underlie services, and that institutional care was outdated. Arguments respectively in favour and against the report's conclusions were given by Alan Tyne of CMH and David Wild, a representative of the mental handicap nursing profession (Tyne and Wild, 1979).

76) From 1973 Wolf Wolfensberger had been Director of the Training Institute for Human Service Planning, Leadership and Change Agency at Syracuse University in New York State. There he developed training courses and materials on normalization (which he renamed 'social role valorization' in 1983), service evaluation, service identity, citizen advocacy and personal commitment to the needs of disadvantaged people (Wolfensberger, 1983; Lemay, Caruso and Thomas, 2023). His work became well known to Ann Shearer and other members of CMH. In 1979, Alan Tyne, the Research Officer of CMH, decided to set up a sister group to bring to the UK Wolfensberger's training, particularly on normalization and service evaluation. This was facilitated by contact with people in the

USA who had experience of presenting and further developing this training, including Wolfensberger himself and his colleague Susan Thomas, and John and Connie O'Brien. The new organisation was called the Community and Mental Handicap Education and Research Association (CMHERA) (Charity Commission for England and Wales, 1985). Alan Tyne became its Director while CMH continued with its research, publications and lobbying, led by Alison Wertheimer. Between 1979 and the mid-90s CMHERA and its associates supported the 'Ordinary Life' initiative through providing training in the form of intensive week-long workshops, based on the work of Wolfensberger (for example, Wolfensberger, 1972, 1975 and 1983) and John O'Brien (for example, O'Brien and Tyne, 1981; O'Brien and Lyle O'Brien, 1987) to around 3000 people. (See also Brown and Smith, 1992; Race, 1999; Williams and Tyne, 1988; and Wainwright, 1999.)

77) Alan Tyne is also credited by David Towell for proposing in 1979 that the King's Fund team produce guidance on moving towards a comprehensive residential service based on ordinary housing, a suggestion that led to the 'Ordinary Life' initiative (Towell, 2022).

## Summary

The 1970s saw continued documentation of the harm done to people in large institutions. Particularly graphic were Maureen Oswin's accounts of children in long-stay hospitals in the UK and the television exposé of the Willowbrook institution in the USA. Although the alternative of 20-place hostels was still promoted, particularly in the Sheffield project and by the National Development Team, research evaluations showed that these could not achieve the aims of homely environments that allow community participation. Projects in Wessex and Cardiff in the UK and in the ENCOR service in the USA showed the feasibility of use of ordinary housing to provide homes for small groups. A philosophical and practical underpinning of this was developed by refining the principle of normalization and documenting its implications. Allied to this were the beginnings of citizen advocacy to assist community integration and self-advocacy to give people with learning disabilities a voice. An educational focus in residential care was strengthened by interest in behavioural psychology. Two important political developments were the publication of a government White Paper *Better Services for the Mentally Handicapped* in the UK and the adoption of a Declaration of Rights of Mentally Retarded Persons by the United Nations. A number of organisations providing campaigning, research and information dissemination were founded, including Campaign for the Mentally Handicapped, the British Institute of Mental Handicap, the Association of Professions for the Mentally Handicapped, the Mental Handicap team at the King's Fund Centre and the National Development Group. Interest grew in the work of Wolfensberger and his colleagues, resulting in the establishment of an organisation to further this work in the UK. An inquiry into the training of staff in residential services was commissioned by the UK government and it strongly commended normalization as a foundation for services. A unifying theme in all these developments was a concerted move away from justifying large institutions, leading to an increasing awareness that hostel provision was not an effective alternative and that services could and should be based on ordinary housing. Fertile ground was thus provided for the 'Ordinary Life' initiative.

## **Footnote: institution staff**

I have sometimes heard it said that the problem with the old institutions was that staff had poor values, and that training courses such as those run by CMHERA [76] instilled new and better values. I don't see it quite like that. It is true that some institution staff were sadistic, unpleasant, abusive and uncaring towards people they cared for, as witnessed by the Inquiries of the late 60s and 70s (with the jailing of some staff after criminal charges) [41]. However, it is also true that many tried to treat people as well as they could with the poor environments, scant resources and isolation of many of the institutions. The basically high values of many of the staff who had come into this work with altruistic motives were very difficult to apply in those conditions. Training courses on normalization, social role valorization, service evaluation and related concepts served to remind many of those who attended of these values and provided practical ideas for implementing them, even if they were still trapped in unhelpful service structures. The 'Ordinary Life' initiatives described by David Towell did the same.

It is true that there was considerable opposition from institution staff to their complete closure. Some consultant psychiatrists in charge of institutions argued for injection of greater resources to enable them to function more like the independent 'village communities' such as Camphill at Botton in Yorkshire (Camphill Village Trust, 2024) or Ravenswood in Berkshire (Norwood, 2024). In 1984 an organisation, the National Society for Mentally Handicapped People in Residential Care, widely known as 'Rescare', was founded to argue also for hospitals to become special village communities, offering families a different choice from integration within an ordinary community. Rescare had much support from people inside and outside institutions, in one case submitting a petition of 70,000 signatures to retain a hospital proposed for closure (Rescare, 2021).

On the other hand, there are many examples of strong support by institution staff for community-based homely care. Within the auspices of CMH [52], Maureen Oswin used to run occasional meetings for institution staff, mainly nurses, to discuss their problems and wishes for better care in the future and to support their own personal efforts towards that future. Similarly, I ran courses for learning disability nurses at Scope's Castle Priory College at which those attending were largely positive and welcoming of ideas for improvement of services, if a bit sceptical of their realisation. Many of those who attended CMHERA's courses gave positive feedback and expressed determination to go back to their places of work with renewed enthusiasm for change. Also of course the 'Ordinary Life' initiatives involved many institution staff and managers, and the success of those initiatives owes much to them.

It should be remembered that many community services that replaced the institutions were staffed by ex-staff of the institutions. Some issues of transfer of institutional practice could be observed, but by and large those staff did a good job which greatly benefitted the people they supported. Psychiatrists from the institutions became community psychiatrists providing advice and support in community settings. Qualified nurses became community nurses, also offering advice and support, or managers of community-based services. Other staff became supporters of people in smaller social care settings. Some senior staff of institutions became pioneers of the new pattern of services, working hard for the closure of their former institutions and initiating and managing innovative community alternatives. Here are some examples known personally to me:

Hindole Sen, a psychiatrist and neurologist at Starcross Hospital in Devon, one of the first hospitals to close, became a highly respected community psychiatrist travelling all over the South-West advising community care settings on the care of severely disabled people. Tom McLean, principal nursing officer, and Chris Gathercole, psychologist, worked for the closure of Calderstones Hospital in Lancashire. Ken Day, consultant psychiatrist, Vince Gorman, principal nursing officer, and Derek Thomas, psychologist, pioneered alternative services to Northgate Hospital, Northumberland. David Towell (2022) describes the enthusiastic work of Audrey Emerton, the health authority's chief nursing officer, to bring about the closure of Darenth Park Hospital in Kent.

John McLynn trained as a learning disability nurse at the 2000-place St Lawrence's Hospital in Surrey in the 1950s. During the 1960s he was a charge nurse at Coldharbour Hospital, Dorset, where residents, including many children, were housed in huge barrack-like 'villas'. Despite working with very low staffing resources he was known for his kindness and professionalism. He met Albert Kushlick [22] and was inspired with the vision of community-based alternatives to institutions and the possibility of an educational rather than control function of services. He became the manager of the first Wessex hostel for severely disabled adults, Fairmile House at Christchurch in Dorset [58]. He was then appointed as overall manager back at Coldharbour Hospital with a mission to work towards closure of the hospital. This he achieved in 1990 and he then went on to found and manage a community learning disability nursing service in Dorset, supporting families and service staff with specialist advice.

The success of replacement of institutions with community-based services is due in no small part to the idealism, enthusiasm and effort of many of those with a background as institution staff, such as Hindole Sen, Tom McLean, Chris Gathercole, Ken Day, Vince Gorman, Derek Thomas, Audrey Emerton and John McLynn.



## Paul Williams – biographical note

In the 1980s I worked with Alan Tyne carrying out CMHERA's training and service evaluation work [76]. After Alan left in 1988 I continued this work part-time until 1996. From 1991 I was a lecturer in social work at Reading University teaching on work with people with learning disabilities, research methods and anti-oppressive practice. I retired in 2007. This biographical note covers my previous work up to 1979.

In 1962-3, during my 'gap year' before university, I spent nine months working as a nursing assistant in a hospital for people with learning disabilities, which inspired an interest in that field as well as giving me first-hand experience of the poor conditions in such places. I then studied psychology and philosophy at Oxford University. During that time I and a friend, Peter Moss, regularly visited a newly-established local authority hostel for children with learning disabilities, St. Nicholas House, giving voluntary support to the children and staff. I also became a committee member of the local Mencap society. In the third year of my psychology course, 1965-6, I was required to carry out research for a dissertation. I wanted to do it on some aspect of learning disability but no-one in the Psychology Department felt able to supervise that. My tutor, the social psychologist Michael Argyle, was editing a journal with Jack Tizard, Professor at London University and a world authority on learning disability [3, 8, 21], and he referred me to Jack for supervision. I carried out a study of the children at St. Nicholas House which was well received and earned me my degree. Alongside the dissertation I wrote a paper about a very severely disabled young man who had been given a trial at a sheltered workshop which had been very successful. It won the Fred Esher Award for innovative research given by the British Society for the Study of Mental Subnormality and was published in their journal under the title 'Industrial Training and Remunerative Employment of the Profoundly Retarded' (Williams, 1967).

My referral to Jack Tizard for supervision was of great fortune to my future career. On graduating, my contact with him led to me being offered a job as a member of Albert Kushlick's Health Care Evaluation Research Team in Wessex, which Jack had set up [22]. I began work there in 1966. Peter Moss had also had contact with Jack for career advice and later he was to work with Jack, becoming Professor of Early Childhood Education at the Thomas Coram Research Unit at London University [65].

At the Research Team I was involved in assessments of children, the establishment of the first children's hostels, and induction training of staff. While I was at Oxford, the local branch of Mencap organised a speaking event by Gunnar Dybwad [25] (Dybwad, 1966) which I attended and I kept in touch with him afterwards. In 1969 he sent me a copy of the President's Committee publication *Changing Patterns* [37] which inspired me also to contact Wolf Wolfensberger [20]. I had also come across Ann Shearer, Anita Hunt and Sandra Francklin and when they founded the Campaign for the Mentally Handicapped [52], I and Peter Moss, who I was still in touch with, were amongst the very first people to join as members. I was in some trouble at work because such campaigning was felt to be at odds with the role of an impartial researcher, and in 1973 I moved to a post as a tutor and course organiser at Castle Priory College, the staff training centre run by The Spastics Society (now Scope). Also In 1973 I attended the inaugural meeting that founded the Association of Professions for the Mentally Handicapped [64] and throughout the 1970s I was a committee member representing Scope.

Whenever courses at Castle Priory were about people with learning disabilities I included teaching on normalization, some of it taught by Peter Moss. I had attended the first CMH conference for people with learning disabilities themselves, 'Our Life', held at Castle Priory in 1972 (Shearer, 1972) and I later helped to organise several further such conferences there together with my friends Alan Tyne and Tim Gauntlett. (Williams, 1974; Williams and Gauntlett, 1974; Tyne, 1975) [60]. In 1979 I worked with Alan Tyne to establish CMHERA (although I did not join as an employee till 1983) and I helped to organise, host and participate in the first American-style workshops at Castle Priory in the late 70s on normalization and the PASS evaluation instrument [76].

In 1979 I gave a paper at an international conference on cerebral palsy held in Oxford, attempting to present what might be the views of people with learning disabilities themselves about their experiences. It had the theme that so-called 'non-disabled' people had just as much difficulty relating well to 'disabled' people as the other way round. The paper was titled *Our Mutual Handicap*; it was later published by CMH (Williams, 1979). A number of Americans at the conference told me about a growing phenomenon of people with learning disabilities getting together in 'self-advocacy' groups to have a voice. They suggested I apply for a grant to visit the US to study these groups. I applied for and received a Rosemary Dybwad Award from the (American) Association for Retarded Citizens to carry out this study and I spent five weeks, accompanied by a friend with learning disabilities who I knew well from CMH, travelling to visit many American self-advocacy groups. The trip resulted in a full account of the trip, entitled *Make Us Citizens and See Us Grow* published by CMH in 1980 (Williams, 1980). I also began to research the origins and extent of self-advocacy in the UK and together with Bonnie Shoultz, a major supporter and developer of self-advocacy groups in America, we produced the first full-length book on the self-advocacy movement in the US and the UK, *We Can Speak For Ourselves* (Williams and Shoultz, 1982).

I was therefore personally involved with many of the key developments that are the subject of this historical account.

## References

Administration for Community Living (2020) Fact Sheet: President's Committee for People with Intellectual Disabilities. [acli.org/sites/default/files/news%202017-03/PCPIDfactsheet.pdf](https://acli.org/sites/default/files/news%202017-03/PCPIDfactsheet.pdf)

Atkinson D., Jackson, M. and Walmsley, J. (eds.) (1997) *Forgotten Lives: Exploring the History of Learning Disability*. Kidderminster: British Institute of Learning Disabilities.

Atkinson, D. and Williams, F. (eds.) (1990) *Know Me As I Am: an anthology of prose, poetry and art by people with learning difficulties*. London: Hodder Education.

Bersani, H. (2014a) Gunnar Dybwad: American author, administrator and activist. [www.britannica.com/biography/Gunnar-Dybwad](https://www.britannica.com/biography/Gunnar-Dybwad)

Bersani, H. (2014b) Rosemary F. Dybwad: American author and activist. [www.britannica.com/biography/Rosemary-F-Dybwad](https://www.britannica.com/biography/Rosemary-F-Dybwad)

Blatt, B. and Kaplan, F. (1966) *Christmas in Purgatory: a Photographic Essay on Mental Retardation*. Boston, Massachusetts: Allyn and Bacon.

British Institute of Learning Disabilities (2023) [www.bild.org.uk/about-bild](https://www.bild.org.uk/about-bild) (Accessed December 2023)

Brown, H. and Smith, H. (eds.) (1992) *Normalisation: a Reader for the Nineties*. London: Routledge.

Camphill (2024) [www.camphill.org.uk/about/adult-communities](https://www.camphill.org.uk/about/adult-communities) (Accessed January 2024)

Camphill Village Trust (2024) [www.camphillvillagetrust.org.uk/locations/botton-village](https://www.camphillvillagetrust.org.uk/locations/botton-village) (Accessed January 2024)

Charity Commission for England and Wales (1985) Community and Mental Handicap Education and Research Association: charitable objects. [register-of-charities.charitycommission.gov.uk/charity-search/-/charity-details/292424/governing-document](https://register-of-charities.charitycommission.gov.uk/charity-search/-/charity-details/292424/governing-document)

Clarke, A.D.B. (1991) A brief history of the International Association for the Scientific Study of Mental Deficiency (IASSMD). *Journal of Intellectual Deficiency Research*, Vol.35, 1-12.

Clarke, A.D.B. and Clarke, A.M. (eds.) (1973) *Mental Retardation and Behavioural Research*. Edinburgh: Churchill Livingstone.

Clarke, A.D.B. and Lewis, M. (eds.) (1972) *Learning, Speech and Thought in the Mentally Retarded*. London: Butterworths.

Clarke, A.M. and Clarke, A.D.B. (eds.) (1958) *Mental Deficiency – the Changing Outlook*. London: Methuen.

- Corbett, J. (1992) Obituary: Gerald Bernard Simon. *Psychiatric Bulletin*, Vol.16, 122-123.
- Crawley, B. (1982) *The Feasibility of Trainee Committees as a Means of Self-Advocacy in Adult Training Centres in England and Wales* (PhD thesis). Manchester: University of Manchester.
- Crawley, B. (1983) *Self-Advocacy Manual: an overview of the development of self-advocacy by mentally handicapped people and recommendations for the development of trainee committees*. Manchester: Hester Adrian Research Centre.
- Crawley, B. (1988) *The Growing Voice: a Survey of Self-Advocacy Groups in Adult Training Centres and Hospitals in Great Britain*. London: Campaign for the Mentally Handicapped.
- Crossman, R. (1977) *The Diaries of a Cabinet Minister, Volume3: Secretary of State for Social Services 1968-1970*. London: Hamish Hamilton.
- Davies, C. (2002) *Changing Society: A Personal History of SCOPE (Formerly The Spastics Society) 1952-2002*. London: Scope.
- Deacon, J. (1974) *Tongue Tied: fifty years of friendship in a subnormality hospital*. London: Mencap.
- Department of Health and Social Security (1971) *Better Services for the Mentally Handicapped*. London: HMSO.
- Department of Health and Social Security (1972) *Report of the Committee on Nursing (Briggs Report)*. London: HMSO.
- Disability Justice (2023) The closing of Willowbrook. [disabilityjustice.org/the-closing-of-willowbrook](https://disabilityjustice.org/the-closing-of-willowbrook) (Accessed December 2023)
- Down's Syndrome Association (2023) [www.downs-syndrome.org.uk/about-dsa/our-history](http://www.downs-syndrome.org.uk/about-dsa/our-history) (Accessed December 2023)
- Dybwad, G. (1964) *Challenges in Mental Retardation*. New York: Columbia University Press.
- Dybwad, G. (1966) The mentally handicapped child under five: talk given at Oxford Town Hall, September 1966. <https://mn.gov/mnddc/parallels2/pdf/60s/66/66-MHC-GUD.pdf>
- Elliott, J. (1973) Perspectives of the Briggs report: a discussion paper on the future role and training of subnormality nurses, and their relationship with residential care staff. London: King's Fund.
- Evans, E. (2023) There was no place like Nebraska: Wolf Wolfensberger and the beginning of community-based services. In: R. Lemay, G. Caruso and S. Thomas (eds.) *Wolf Wolfensberger: the Influence of the Person and his Ideas Today – a Festschrift*. Plantagenet, Ontario: Valor Press.

- Felce, D., Kushlick, A. and Smith, J. (1980) An overview of the research on alternative residential facilities for the severely mentally handicapped in Wessex. *Advances in Behaviour Research and Therapy*, Vol.3, 1-4.
- Felce, D. and Toogood, S. (1988) *Close To Home: a local housing service and its impact on the lives of nine adults with severe and profound mental handicaps*. Kidderminster: BILD.
- Foucault, M. (1961) *Folie et Dérison: Histoire de la Folie à L'âge Classique*. Paris: Plon.
- Francklin, S. (1974) *Homes for Mentally Handicapped People*. London: CMH
- Glenside Hospital Museum (2012) Learning disability in the NHS, page4.  
[www.glensidemuseum.pwp.blueyonder.co.uk/learning\\_disability\\_4.htm](http://www.glensidemuseum.pwp.blueyonder.co.uk/learning_disability_4.htm)
- Goffman, E. (1961) *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*. New York: Doubleday.
- Gunzburg, H. (1960) *Social Rehabilitation of the Subnormal*. London: Baillière Tindall and Cox.
- Hall, J. (2008) Looking back: Mental Deficiency – changing the outlook.  
[www.bps.org.uk/psychologist/looking-back-mental-deficiency-changing-outlook](http://www.bps.org.uk/psychologist/looking-back-mental-deficiency-changing-outlook)
- Hansard (1972) Stoke Park Hospital  
[api.parliament.uk/historic-hansard/commons/1972/may/09/stoke-park-hospital](http://api.parliament.uk/historic-hansard/commons/1972/may/09/stoke-park-hospital)
- Heron, A. and Myers, M. (1983) *Intellectual Impairment: the Battle Against Handicap*. London: Academic Press.
- Holman, A. (2012) The end of VIA – and the end of an era? *Community Living*, Vol.26, No.2, 22-23.
- Houts, P. and Scott, R. (1975) *Goal Planning with Developmentally Disabled Persons*. Hershey, Pennsylvania: Pennsylvania State University College of Medicine.
- Hunt, N. (1967) *The World of Nigel Hunt*. Beaconsfield: Darwen Finlayson.
- Inclusion International (2023) [inclusion-international.org/about-us/our-story](http://inclusion-international.org/about-us/our-story) (Accessed December 2023)
- Innovate Trust (2023) [innovate-trust.org.uk/innovate-trust-history](http://innovate-trust.org.uk/innovate-trust-history) (Accessed December 2023)
- Jackson, R. (2013) Karl Koenig, Stanley Segal and Herbert Gunzburg: pioneers in the field of intellectual disability in Britain. *International Journal of Intellectual Disabilities*, Vol.59, 47-60.
- Jay, P. (1979) *Report of the Committee of Enquiry into Mental Handicap Nursing and Care*. London: HMSO.
- Jisc (2023a) Hester Adrian Research Centre.

archiveshub.jisc.ac.uk/search/archives/e283882d-cca8-336d-a5ea-08d5c54a57e2 (Accessed December 2023)

Jisc (2023b) Institute for Research into Mental Retardation.  
archiveshub.jisc.ac.uk/data/gb133-hil/hil/4 (Accessed December 2023)

Jones, M. (1983) *Behaviour Problems in Handicapped Children: the Beech Tree House Approach*. London: Souvenir Press.

Kaur, D. (2023) The Harmful Effects of Behaviour Modification. [projecthaans.com/the-harmful-effects-of-behaviour-modification](http://projecthaans.com/the-harmful-effects-of-behaviour-modification) (Accessed December 2023).

Kiernan, C. and Jones, M. (1977) *Behaviour Assessment Battery*. Slough: National Foundation for Educational Research.

Kiernan, C. and Woodford, P. (eds.) (1975) *Behaviour Modification with the Severely Retarded*. Amsterdam: Associated Scientific Publishers.

King, R., Raynes, N. and Tizard, J. (1971) *Patterns of Residential Care: Sociological Studies in Institutions for Handicapped Children*. London: Routledge and Kegan Paul.

King's Fund Centre (1976) Collaboration between parents and professionals: a statement by a group of parents and professionals meeting under the auspices of the King's Fund Centre, London and the Association of Professions for the Mentally Handicapped. London: King's Fund.

King's Fund Centre (1980) *An Ordinary Life: Comprehensive Locally-based Residential Services for Mentally Handicapped People*. London: King's Fund.

Kugel, R. and Wolfensberger, W. (eds.) (1969) *Changing Patterns in Residential Services for the Mentally Retarded*. Washington, DC: President's Committee on Mental Retardation.

Kushlick, A. and Cox, G. (1968) The ascertained prevalence of mental subnormality in the Wessex region on 1<sup>st</sup> July 1963. In: B. Richards (ed.) *Proceedings of the First Conference of the International Association for the Scientific Study of Mental Deficiency*. Reigate, Surrey: Michael Jackson Publishers.

L'Arche (2024) [www.larche.org.uk/who-we-are](http://www.larche.org.uk/who-we-are) (Accessed January 2024)

LeMay, R., Caruso, G. and Thomas, S. (eds.) (2023) *Wolf Wolfensberger: the Influence of the Person and his Ideas Today – a Festschrift*. Plantagenet, Ontario: Valor Press.

Los Angeles Times (2009) Eunice Kennedy Shriver dies at 88; Special Olympics founder and sister of JFK. 12 August.

Lyle, J. G. (1960) The effect of an institution environment upon the verbal development of institutional children: III – the Brooklands Family Unit. *Journal of Mental Deficiency Research*, Vol.4, 14-23.

- Malcomson, T. (2023) Wolf Wolfensberger's use of history. In: R. Lemay, G. Caruso and S. Thomas (eds.) *Wolf Wolfensberger: the Influence of the Person and his Ideas Today – a Festschrift*. Plantagenet, Ontario: Valor Press.
- Malin, N. (1981) *Evaluation Research Group Report 12: Residential Services for Mentally Handicapped Adults: Stage Two*. Sheffield: University of Sheffield Department of Psychology.
- Malin, N. and Race, D. (1979) *Evaluation Research Group Report 4: Residential Services for Mentally Handicapped Adults: interim report on Stage One*. Sheffield: University of Sheffield Department of Psychology.
- Mansell, J. (1976) Students show the way. *New Psychiatry*, 19<sup>th</sup> February, 12-13.
- Mansell, J., Felce, D., Jenkins, J., de Kock, U. and Toogood, S. (1987) *Developing Staffed Housing for People with Mental Handicaps*. Tunbridge Wells: Costello.
- Mathieson, S. and Blunden, R. (1980) NIMROD is piloting a course towards community life. *Health and Social Services Journal*, 25<sup>th</sup> January, 122-124.
- Mencap (2023) [www.mencap.org.uk/about-us/mencaps-history](http://www.mencap.org.uk/about-us/mencaps-history) (Accessed December 2023)
- Mental Health Act 1959. [www.legislation.gov.uk/ukpga/Eliz2/7-8/72](http://www.legislation.gov.uk/ukpga/Eliz2/7-8/72).
- Miller, E. and Gwynne, G. (1972) *A Life Apart: A Pilot Study of Residential Institutions for the Physically Handicapped and the Young Chronic Sick*. London: Tavistock Publications.
- Mind (2023) [www.mind.org.uk/about-us/our-achievements](http://www.mind.org.uk/about-us/our-achievements) (Accessed December 2023)
- Ministry of Health (1968) *Findings and Recommendations Following Enquiries into Allegations Concerning the Care of Elderly Patients in Certain Hospitals*. London: HMSO.
- Mittler, P. (ed.) (1973) *Assessment for Learning in the Mentally Handicapped*. Edinburgh: Churchill Livingstone.
- Mittler, P. (2010) *Thinking Globally, Acting Locally – a Personal Journey*. Milton Keynes: AuthorHouse.
- Morris, P. (1969) *Put Away: a Sociological Study of Institutions for the Mentally Retarded*. London: Routledge and Kegan Paul.
- National Council for Civil Liberties (1951) *50,000 Outside the Law*. London: NCCL.
- National Health Service (1962) *A Hospital Plan for England and Wales*. London: HMSO.
- National Health Service (1969) *Report of the Committee of Inquiry into Allegations of Ill-treatment of Patients and Other Irregularities at the Ely Hospital, Cardiff (Howe Report)*. London: HMSO.

Nirje, B. (1969) The Normalization Principle and its Human Management Implications. In: R. Kugel and W. Wolfensberger (eds.) *Changing Patterns in Residential Services for the Mentally Retarded*. Washington, DC: President's Committee on Mental Retardation.

Nirje, B. (1970) The Normalization Principle – Implications and Comments. *British Journal of Mental Subnormality*, Vol.16, Issue 31, 62-70.

Norris, D. (1969) An urban-rural area in Britain: Essex county. In: R.Kugel and W. Wolfensberger (eds.) *Changing Patterns in Residential Services for the Mentally Retarded*. Washington, DC: President's Committee on Mental Retardation.

Norwood (2024) [norwood.org.uk/our-services/adult-services](http://norwood.org.uk/our-services/adult-services) (Accessed January 2024)

Nuffield Trust (2023) [www.nuffieldtrust.org.uk/health-and-social-care-explained/the-history-of-the-nhs](http://www.nuffieldtrust.org.uk/health-and-social-care-explained/the-history-of-the-nhs) (Accessed December 2023)

O'Brien, J. and Lyle O'Brien, C. (1987) *Framework for Accomplishment: the five essential service accomplishments – community presence, community participation, respect and dignity, choice, competence*. Lithonia, Georgia: Responsive Systems Associates.

O'Brien, J. and Tyne, A. (1981) *The Principle of Normalisation: A Foundation for Effective Services*. London: Campaign for Mentally Handicapped People.

O'Connor, N. and Tizard, J. (1956) *The Social Problem of Mental Deficiency*. London: Pergamon Press.

Open University (2023) The history of the OU. [about.open.ac.uk/strategy-and-policies/history-ou](http://about.open.ac.uk/strategy-and-policies/history-ou) (Accessed December 2023)

Oswin, M. (1971) *The Empty Hours: a study of the week-end life of handicapped children in institutions*. London: Viking Books.

Oswin, M. (1978) *Children Living in Long-stay Hospitals*. London: Heinemann.

Parmenter, T. (2004) Contributions of IASSID to the scientific study of intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities*, Vol.1, 71-78.

Percy Commission (1957) *Report of the Royal Commission on the Law relating to Mental Illness and Mental Deficiency*. London: HMSO.

Perrin, B. (1999) The original Scandinavian normalization principle and its continuing relevance. In: R. Flynn and R. Lemay (eds.) *A Quarter-Century of Normalization and Social Role Valorization: Evolution and Impact*. Ottawa: University of Ottawa Press.

Powell, E. (1961) Enoch Powell's Water Tower Speech. [studymore.org.uk/xpowell.htm](http://studymore.org.uk/xpowell.htm)

Race, D. (1999) *Social Role Valorization and the English Experience*. London: Whiting and Birch.



- Race, D. (2003) *Leadership and Change in Human Services: Selected Readings from Wolf Wolfensberger*. London: Routledge.
- Rescare (2021) Our History. [www.rescare.org.uk/our-history](http://www.rescare.org.uk/our-history) (Accessed December 2023)
- Rivera, G. (1972) *Willowbrook: a report on how it is and why it doesn't have to be that way*. New York: Random House.
- Robb, B. (1967) *Sans Everything – A Case to Answer*. London: Nelson.
- Royal College of Physicians (2023) <https://history.rcplondon.ac.uk/inspiring-physicians/sir-aubrey-julian-lewis> (Accessed December 2023)
- Scope (2023) <https://www.scope.org.uk/about-us/history> (Accessed December 2023)
- Segal, S. (1967) *No Child Is Ineducable*. Oxford: Pergamon Press.
- Shapland, S. (2022) Scandal that led to hospital closures. *Community Living*. Vol.35, No.2, p30.
- Shearer, A. (1968) Dirty children in a locked room: A mental hospital on a bad day. *The Guardian*, 28<sup>th</sup> March.
- Shearer, A. (1972) *Our Life: a Conference Report*. London: Campaign for the Mentally Handicapped.
- Shearer, A. (1973) *Listen!* London: CMH
- Shearer, A. (1975) *No Place Like Home*. London: CMH
- Shearer, A. (1976) The news media. In: R. Kugel and A. Shearer (eds.) *Changing Patterns in Residential Services for the Mentally Retarded*, 2<sup>nd</sup> edn. Washington, DC: President's Committee on Mental Retardation.
- Shearer, A., Francklin, S. and Hunt, A. (1971) *Even Better Services for the Mentally Handicapped*. London: CMH.
- Socialist Health Association (1981) *Official Inquiry Reports into National Health Service Mental Hospitals*. <https://www.sohealth.co.uk/national-health-service/democracy-involvement-and-accountability-in-health/complaints-regulation-and-enquiries/the-production-and-reproduction-of-scandals-in-chronic-sector-hospitals-1981/official-inquiry-reports-into-national-health-service-mental-hospitals>
- Stevens, M. (1968) *Observing Children who are Severely Subnormal: an Approach to their Education*. London: Edward Arnold.
- Thomas, D., Firth, H. and Kendall, A. (1978) *ENCOR: A Way Ahead*. London: Campaign for the Mentally Handicapped.

Tizard, B. (1983) Jack Tizard: A Brief Memoir. In: A. D. B. Clarke and B. Tizard (eds.) *Child Development and Social Policy – The Life and Work of Jack Tizard*. Leicester: The British Psychological Society.

Tizard, J. (1958) Introduction. In: A.M. Clarke and A.D.B. Clarke (eds.) *Mental Deficiency: the Changing Outlook*. London: Methuen.

Tizard, J. (1964) *Community Services for the Mentally Handicapped*. London: Oxford University Press.

Tizard, J. (1969) Residential services within the service continuum. In: R. Kugel and W. Wolfensberger (eds.) *Changing Patterns in Residential Services for the Mentally Retarded*. Washington, DC: President's Committee on Mental Retardation.

Tizard, J. and Kushlick, A. (1965) Community services for the mentally subnormal: an epidemiological approach and a plan for experimental evaluation. *Proceedings of the Royal Society of Medicine*, Vol.58, 373-380.

Towell, D. (2022) Towards *An Ordinary Life*: Insights from a British story of social transformation, 1980–2001. *British Journal of Learning Disabilities*, Vol.50, 199-207.

Towell, D. (ed.) (1988) *An Ordinary Life in Practice*. London: King's Fund.

Tyne, A. (1975) *Working Out: Conference Report*. London: CMH

Tyne, A. (1977) *Residential Provision for Adults who are Mentally Handicapped*. London: CMH

Tyne, A. (1978) *Looking At Life in a Hospital, Hostel, Home or Unit*. London: CMH

Tyne, A. and Wild, D. (1979) The Jay Committee Report. *Community Medicine*, Vol.1, 324-327.

Tyne, A. and Williams, P. (1979) A 'home service' for all mentally handicapped people. *APEX: Journal of the Institute of Mental Subnormality*, Vol.6, No.4, 23-24.

United Nations (1971) Declaration on the Rights of Mentally Retarded Persons. New York: UN.

Vowden, D. (1972) *Report of the Committee of Inquiry into the Fire at Coldharbour Hospital, Sherborne, on 5 July 1972*. London: HMSO

Wainwright, T. (1999) The impact of normalization and social role valorization in the United Kingdom. In: R. Flynn and R. Lemay (eds.) *A Quarter-Century of Normalization and Social Role Valorization: Evolution and Impact*. Ottawa: University of Ottawa Press.

Walmsley, J. (2008) Institutionalisation: an historical perspective. In: K. Johnson and R. Traustadottir (eds.) *Deinstitutionalization and People with Intellectual Disabilities: In and Out of Institutions*. London: Jessica Kingsley.

- Welsh Office (1978) *NIMROD: Report of a joint working party on the provision of a community-based mental handicap service in South Glamorgan*. Cardiff: The Welsh Office.
- Williams, P. (1967) Industrial training and remunerative employment of the profoundly retarded. *Journal of Mental Subnormality*, Vol.13, No.24, 14-23.
- Williams, P. (1974) *A Workshop on Participation*. London: CMH
- Williams, P. (1979) *Our Mutual Handicap*. London: CMH
- Williams, P. (1980) *Make Us Citizens and See Us Grow*. London: CMH
- Williams, P. (2005a) The work of Jack Tizard – 1: 1950 to 1964. *Learning Disability Review*, Vol.10, 7-11.
- Williams, P. (2005b) The work of Jack Tizard – 2: 1965 to 1979. *Learning Disability Review*, Vol.10, 18-21.
- Williams, P. (2013) The roots of a true campaigning movement. *Community Living*, Vol.26, No.3, p17.
- Williams, P. (2017) A passionate advocate. *Community Living*, Vol.31, No.2, p28.
- Williams, P. (2021) A More Humane Approach: the life and work of Jack Tizard. [www.bps.org.uk/psychologist/more-humane-approach](http://www.bps.org.uk/psychologist/more-humane-approach)
- Williams, P. and Gauntlett, T. (1974) *Participation with Mentally Handicapped People*. London: CMH
- Williams, P. and Shoultz, B. (1982) *We Can Speak For Ourselves: Self-Advocacy by Mentally Handicapped People*. London: Souvenir Press.
- Williams, P. and Tyne, A. (1988) Exploring values as the basis for service development. In: D. Towell (ed.) *An Ordinary Life in Practice: developing comprehensive community-based services for people with learning disabilities*. London: King's Fund.
- Wolfensberger, W. (1969) The origin and nature of our institutional models. In: R. Kugel and W. Wolfensberger (eds.) *Changing Patterns in Residential Services for the Mentally Retarded*. Washington, DC: President's Committee on Mental Retardation.
- Wolfensberger, W. (1970) Models of mental retardation. *New Society*, Vol. 15, No.380, 51-53.
- Wolfensberger, W. (ed.) (1972) *The Principle of Normalization in Human Services*. Toronto: National Institute on Mental Retardation.
- Wolfensberger, W. (1983) Social Role Valorization: a proposed new term for the principle of normalization. *Mental Retardation*, Vol.21, No.6, 234-239.

Wolfensberger, W. (1999) A contribution to the history of normalization. In: R. Flynn and R. Lemay (eds.) *A Quarter-Century of Normalization and Social Role Valorization: Evolution and Impact*. Ottawa: University of Ottawa Press.

Wolfensberger, W. and Glenn, L. (1969) *Program Analysis of Service Systems (PASS): a Proposed Review Mechanism for Funding of Service Project Proposals under Nebraska's Community Mental Retardation Services Act of 1969*. Omaha: Nebraska Psychiatric Institute.

Wolfensberger, W. and Glenn, L. (1975) *Program Analysis of Service Systems (PASS): a Method for the Quantitative Evaluation of Human Services – Handbook and Field Manual*, 3<sup>rd</sup> edn. Toronto: National Institute on Mental Retardation.

Wolfensberger, W. and Thomas, S. (1983) *Program Analysis of Service Systems' Implementation of Normalization Goals (PASSING) – Normalization Criteria and Ratings Manual*. Toronto: National Institute on Mental Retardation.

Wolfensberger, W and Zauha, H. (eds.) (1973) *Citizen Advocacy and Protective Services for the Impaired and Handicapped*. Toronto: National Institute on Mental Retardation.

YouTube (2023) Sen. Robert F. Kennedy Visiting Willowbrook. (Accessed December 2023)

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