

Psychotherapy and learning disability

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Changing needs

In Ireland today it is considered that approximately 6.7% of the population have learning disabilities.¹ According to the *National Intellectual Disability Database Report*,² 26,760 people are registered as being in receipt of, or in need of, a learning disability service (prevalence rate of 7.38/1000 total population). Many of these people have coexisting physical disabilities and psychiatric disorder, both of which increase in prevalence in proportion to the severity of the learning disability. Actual estimates of co-morbidity of learning disability and psychiatric illness have ranged across studies from 10% to 39%,³ but all are significantly higher than the general population and the prevalence of behaviour disorders (which often reflect psychiatric disorder in this group) has been found to be even higher at 60.4%.⁴

The World Health Organisation,⁵ in its definition of learning disability, points to the importance of holistic approaches to understanding individual needs; however there is still a tendency to attribute much emotional distress experienced by an individual to the disability rather than to particular emotional needs or psychiatric disorder.

Over the last 20 years many changes have taken place in the development of care and services for people with learning disabilities. The philosophies of normalisation⁶ and inclusion have brought about a change in focus for these services, with more emphasis on individual characteristics and needs than disabilities, so that even people with severe problems are seen as having a right to be supported in community settings.

Increasingly, people with mild and moderate learning disabilities now find themselves working and living within the community, where they benefit from the advantages of choice in many aspects of life but also have to endure the many stresses and disadvantages, including difficulties with access to *mainstream services*. It is within this changing context that the whole issue of psychotherapy provision for people with learning disabilities is beginning to be addressed.

Psychological difficulties

The development of a child with learning disabilities will be

affected to varying degrees and in various ways. The child-environment interaction may be impaired due to organic damage.⁷ Weaknesses in personality structure may result from this distorted interaction process.⁸ Ego weakness, the persistence of primitive object relations and problems with the development of the superego,⁹ as well as difficult separation-individuation from the caregiver⁸ have all been described. An adult with learning disabilities may well have to experience lifelong dependency on others, and is more likely to suffer the painful consequences of vulnerability and stigma, ie. neglect, abuse, exploitation and isolation.¹⁰

In addition parents and families of people with learning disabilities often experience ongoing emotional responses, akin to a bereavement, in trying to accept the loss of the 'perfect child' who has not arrived or has been taken away through illness or accident.¹¹ These bereavement-type symptoms can be re-kindled at times when previously held expectations for the disabled person are not realised. Therefore, it is not just the individual who may need treatment and support, but family members and care staff also.

It is not surprising then to find that people with learning disabilities are particularly vulnerable to psychiatric illness. As referred to above, actual estimates of psychiatric illness in people with learning disabilities have varied widely. It is clear that methodological problems concerning diagnosis and classification are responsible for this large variability. A new diagnostic classification (the DC-LD) has recently been published,¹² which is designed for use with adults with learning disabilities, which is expected to help diagnosis and research.

Therapeutic difficulties

Traditionally, people with learning disabilities were excluded from the 'talking therapies'.¹³ In the first instance, many emotional and mental health problems were not recognised as such, and when they were, low IQ was commonly used as an exclusion criterion for suitability for therapy. In practice, there are significant problems in adapting psychotherapeutic approaches to working with this patient group. These include a high frequency of sensory disabilities, communication problems, dependence on others to access therapy, and related to this, consent to engage. However, regarding the dynamic based treatments, an acknowledgement of the importance of the therapeutic relationship between therapist and patient has allowed a rethink of the capacity of people with learning disabilities to participate and benefit.^{14,15} Similarly the cognitive based therapies require some adaptation to suit the level of understanding, and different communication methods often need to be employed.¹⁶

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Evidence based psychotherapy

While research in this area of treatment is in its infancy, there is a developing literature on using different models of psychotherapy with this population, mainly concentrating on the process of therapy rather than outcome.

Many studies since the meta-analysis of Smith and Glass¹⁷ have shown the effectiveness of psychotherapy for the general population. To date, there have been few studies of effectiveness of psychotherapy with people with learning disabilities. There have been promising findings with some outcome studies using psychodynamic treatment, in which significant reductions in psychological symptoms were shown.^{18,19}

Psychotherapy using behavioural approaches, especially those involving social-learning and cognitive-behavioural based strategies, are clearly the forerunners in providing studies of documented efficacy. Several investigations have included randomised group methods with well-defined populations, reliable measures, social validity measures and adequate follow-up assessments.^{20,21}

There have been many anecdotal reports concerning the benefits of a group therapy approach. Nezu *et al* have reviewed this literature and report overall positive effects, and suggest that group treatments can serve as a viable alternative or adjunct to individual psychotherapy; however the research currently lacks systematic or comparative studies.²²

Prout *et al*²³ recently conducted a large systematic review of a wide range of studies in which they identified approximately 90 studies that were published from 1968 to 1998. Due to the nature of the vast majority of the studies examined, it was not possible to carry out a formal meta-analysis. The authors found that the area of study was dominated by case studies and single subject designs, contributing much to our knowledge of the therapeutic process. Overall the authors concluded some degree of effectiveness and they were positive about using psychotherapeutic interventions with people with learning disabilities.

Prout *et al*²⁴ have made recommendations or guidelines for improving psychotherapy outcome studies with people with learning disabilities, and proposals have been made to carry out an international multi-centre case-control study in the British Isles examining the outcome of using specific psychotherapies with people with learning disabilities. It remains difficult to secure funding for such research which crosses conceptual as well as service boundaries.

Clearly research is at an early stage in development and could be improved and made more meaningful by adapting better clinical research standards and by making efforts to improve on the deficiencies of the existing research base. We must, however, be realistic about our research ambitions: people with learning disabilities represent a very complex and disparate group, with different levels of ability, and associated communication methods and different aetiological diagnoses for the learning disabilities. This presents us with huge challenges with regard to carrying out psychotherapy research, challenges over and above what would be found in the general population. The aim of setting up a randomised control trial to prove effectiveness seems both unattainable and unrealistic for such a heterogeneous group.

New directions

In response to the growing interest in extending psychotherapeutic methods to people with learning disabilities, the Faculties of Psychiatry of Learning Disability and Psychotherapy of the Royal College of Psychiatrists formed a Joint Working Group in May 2000, with a brief to examine the present position, and to make recommendations concerning training and service provision for the future.²⁵

It became evident that developments in services and training have been led by a small number of interested professionals, applying their training in psychotherapeutic modalities with the general population to their work with people with learning disabilities.

As one of the tasks of the Working Group, a survey was carried out of psychiatrists and psychologists in Britain and Ireland, who work with people with learning disabilities. Findings confirm that access to psychotherapy is very patchy, and there are significant barriers including the negative attitudes of others and lack of appropriate training and supervision. Supervision when available is eclectic and varies according to local service characteristics. However, a range of psychotherapeutic models is being employed by a variety of disciplines and there is perceived to be a significant demand. Most encouragingly, there are a number of high quality innovative services that are multi-disciplinary, and in some areas, developments in practice are well ahead of strategy.

These more experienced services highlight the very particular issues that need to be addressed with this client group, particularly around disability, its impact on development and the traumas commonly associated. There is a growing confidence in modifying established models of psychotherapy to working with this client group, but this requires specific training and supervision, yet to be formally structured and regulated. A significant development in this regard is the establishment of the Institute of Psychotherapy and Disability, in May 2000, which in due course will set standards in training for psychodynamic approaches.

Future

A century ago Freud was considered controversial in recognising the emotional life of children. It has taken us all this time to put a value on both the ordinary and special emotional needs of people with learning disabilities. This knowledge needs to become part of the culture in specialist services and widely shared by all professionals who may come into contact with people with learning disabilities. Recent work is showing how different therapeutic approaches can be adapted to work with people with different levels of ability, and that this is of benefit. There is a growing demand by professionals for training and a growing demand for services for clients.

If people with learning disabilities are to have equality of access to psychotherapy services, a number of significant changes are needed in policy and strategy to enable psychotherapy services to open up to this group (in the first instance through education and training of staff), and to enable learning disability services to develop the expertise to meet the psychotherapeutic needs of those most disabled.

Now that we recognise the emotional life and needs of

people with learning disabilities, we cannot ignore their rights to have access to services that respect and meet these needs.

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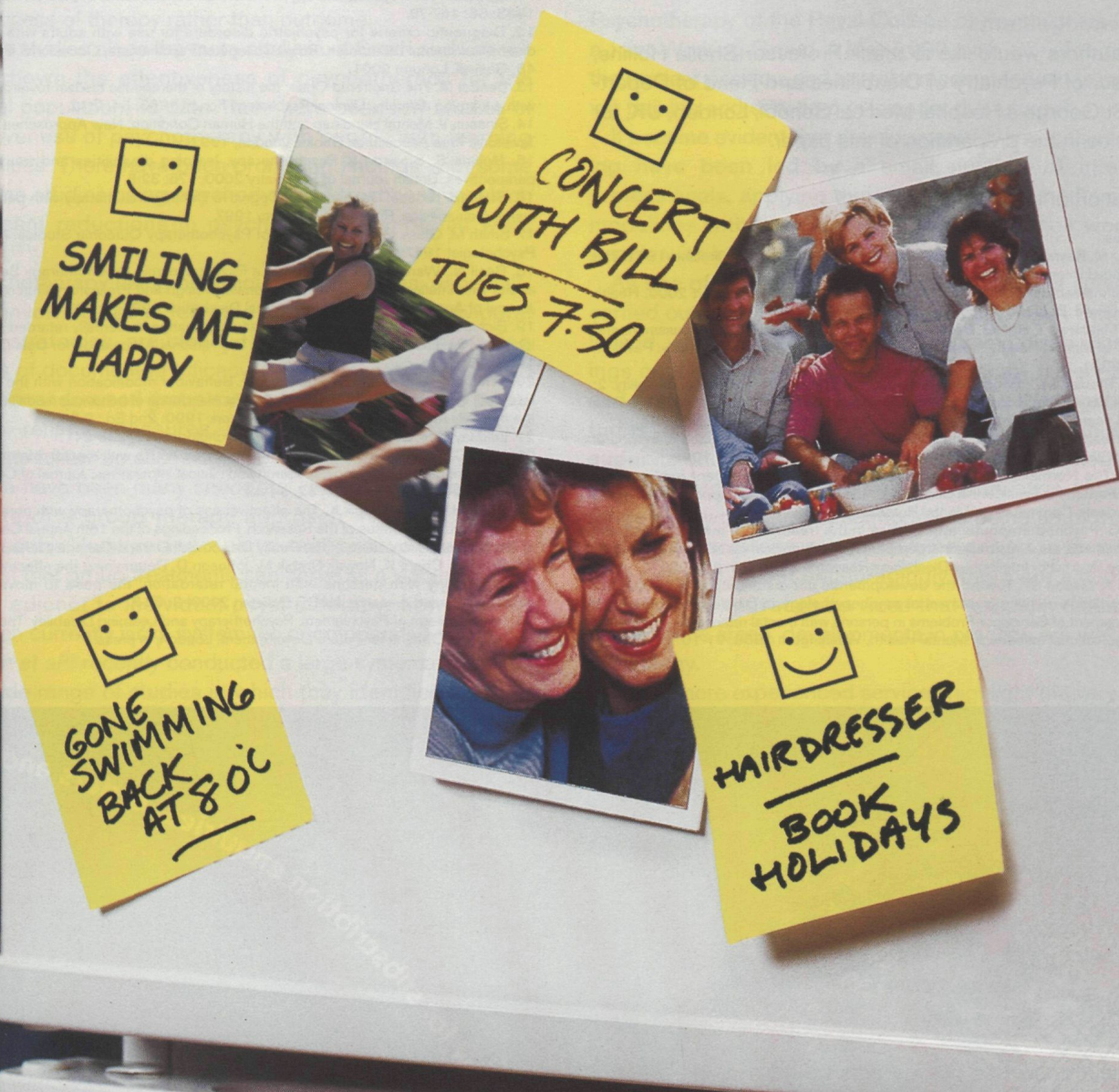
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