

Learning Disability Special Interest Group



LDSIG - E-zine

Welcome to the Winter edition of the Learning Disability e-zine. The LDSIG was well represented at the PSI Annual Conference this year and hosted two very well attended events; a symposium of papers on broad research perspectives in disability and a workshop on the development by the national federation of its inaugural research strategy.

In this edition,

- Summary of the National Federation's inaugural research strategy;
- Review of the Inclusion Ireland website;
- Abstracts from two recently published research articles;
- Abstracts from the LDSIG sponsored symposium at the PSI Annual Conference
- Disability Allowance reversal welcomed
- An invitation to participate and engage with the LDSIG.

Planning for the Easter Workshop is still underway but members will be notified of details early in January 2009.

As always there is an open invitation from members for the submission of material for inclusion in the ezine.

Seamas Feehan, Chair of the LDSIG, and I would like to wish all members and readers a very Happy and Peaceful Christmas and a Prosperous New Year.

John Buttmer
Editor

National Intellectual Disability Research Strategy 2008-2013

Edel Tierney

The National Federation of Voluntary Bodies has finalised and launched its National Intellectual Disability Research Strategy 2008-2013.

This strategy sets out a vision for research activities across the 63 member organisations over the next few years.

It is based on the following underlying principles

- To undertake research which will lead to a better quality of life for people with intellectual disabilities who use our services;
- To promote and disseminate research among member organisations;
- To focus on a number of relevant and timely themes to maximise the quality and impact of research projects. These themes will be interdisciplinary and inter-organisational to maximise the strength of the National Federation;
- To encourage research collaboration with academic and other research centres where appropriate;
- To conduct research which will drive national policy and respond to current key issues;
- To benchmark research conducted against a list of key outcome measures.

The Research Strategy comprises 12 priorities for research as set out below:

1. Define the priority areas for research as identified through consultation with people who use services, Chief Executive Officers of organisations, management and frontline staff.
2. Identify a list of key designated experts in the Irish research community who will support the dissemination of research and assessment materials in these areas. These key experts will provide expert knowledge on these topics thus enhancing the knowledge base among members
3. Develop quality indicators for research in intellectual disability and guidelines for evidence

based practices.

4. Measure performance of research activities
5. Identify key people who may be called upon to act as associate members of the National Federation Research Sub-Committee as need and circumstances arise.
6. Develop research collaborations with national and international research centres
7. Develop a capacity to advise on how research could be funded in the future.
8. Develop a register of disability stakeholders. This will consist of organisations, governments departments, statutory and non-statutory bodies, people with disabilities and family members.
9. Continue to develop a register of intellectual disability research as per National Federation of Voluntary Bodies website.
10. Develop a National Research Ethics Committee with key national representation.
11. Continue to consult with and listen to people who use the services through research initiatives such as the Inclusive Research Network and continue to develop experience and expertise in participatory research methodologies
12. Regularly review the research strategy.

The strategy was developed with the Research Subcommittee of the National Federation of Voluntary Bodies and was derived from a series of consultations with the Research Sub-Committee, member organisations via email questionnaire, with Advocacy / Self-advocacy Groups, with the National Federation Secretariat and with the National Federation of Voluntary Bodies Board of Directors. At the heart of the strategy lies the importance of advocacy and social inclusion in research activity and the need for inclusive and participatory research methods. It also recognizes that a strong evidence base is needed to understand the health, wellness and quality of life of persons with intellectual disability

and that this evidence base should drive policy and respond to issues and be used to benchmark ourselves internationally. The National Federation has the potential and scope to promote world class research and it is hoped that the research strategy should lead to a measurable increase in the quality and quantity of research conducted in Ireland. The need for people with intellectual disability to be included in any generic population studies has also been identified.

To launch the Strategy a series of presentations were made to the Board of Directors and the General Assembly of the National Federation. In addition presentations on the research strategy and its action plans have been given to a variety of professional groups

The achievements to date since the launch of the strategy include;

- The priority topics have been identified
- Designated experts have been identified and continue to update information on the Federation website
- Collaborators have been identified and the first meeting with all parties took place in Galway in September to discuss areas of collaboration
- Work has begun on exploring developing a register of disability stakeholders group
- Database of Intellectual Disability research continues to be updated
- Work has begun on exploring the development of a National Research Ethics Committee
- Consultation with people who use services and their families underpins the strategy and there have been numerous examples of this including the ongoing work of the Inclusive Research Network

The research Strategy is available for download from www.fedvol.ie/research.

An easy-to-read version is also available.

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Disability Related Websites



INCLUSION IRELAND

National Association for People with an Intellectual Disability

www.inclusionireland.ie

Inclusion Ireland is a national voluntary organisation working to promote the rights of people with an intellectual disability in Ireland to ensure their full and equal participation in society. Inclusion Ireland was founded in 1961 (as namhi) and has now become the coordinating body for over 160 organisations providing services and supports to almost 28,000 people with an intellectual disability in Ireland.

What does Inclusion Ireland do?

Inclusion Ireland provides a central forum for its members to identify priorities and formulate nationally agreed policies to present to government, statutory bodies, other relevant groups as well as the general public. Inclusion Ireland campaigns for changes in services and legislation that will improve the quality of life and participation of people with an intellectual disability in Irish Society.

In addition to this central role, Inclusion Ireland:

- Promotes Advocacy for people with an intellectual disability, particularly self-advocacy
 - Provides an information and advice service by phone, post and through its website
 - Publishes information leaflets/booklets
 - Publishes a quarterly newsletter
 - Organises seminars and conferences on intellectual disability
 - Gives information & training talks to a range of groups
 - Represents the intellectual disability sector in Ireland at an international level by its membership of Inclusion International & Inclusion Europe
 - Promotes research into intellectual disability
- Inclusion Ireland is a member of the International Association for the Scientific Study of Intellectual Disability (IASSID)

Community learning disability teams: developments, composition and good practice A review of the literature

Journal of Intellectual Disabilities, Vol. 12, No. 1, 59-79 (2008)

Slevin, E., Truesdale-Kennedy, M., McConkey, R., Barr, O. & Taggart, L.

Abstract

This article presents the findings from a literature review related to community learning disability teams (CLDTs). Much of the existing literature on CLDTs is inspirational, theoretical or opinion based rather than evidence based. It was considered that current knowledge is insufficient to allow a systematic review; therefore a structured review of factors that impact on CLDTs was undertaken following some of the principles of a systematic review. The review covers historical and philosophical influences on the development of CLDTs; the structure and common composition of CLDTs; the main challenges facing CLDTs; and the barriers that impact on their effective working. Based on the available evidence a number of good practice suggestions are forwarded that have the potential to enhance the work undertaken by CLDTs, but it is acknowledged that there is a need for more research into the effectiveness of these teams.

Key Words: CLDTs • community learning disability teams • literature review

Levels of anxiety and sources of stress in adults with autism

Journal of Intellectual Disabilities, Vol. 11, No. 4, 359-370 (2007)

Gillott, A. & Standen, P.J.

Abstract

Clinical reports suggest that anxiety is a pertinent issue for adults with autism. We compared 34 adults with autism with 20 adults with intellectual disabilities, utilizing informant-based measures of anxiety and stress. Groups were matched by age, gender and intellectual ability. Adults with autism were almost three times more anxious than the comparison group and gained significantly higher scores on the anxiety subscales of panic and agoraphobia, separation anxiety, obsessive-compulsive disorder and generalized anxiety disorder. In terms of sources of stress, significant differences between the two groups were also found, and stress was found to correlate with high anxiety levels for the autism group, particularly the ability to cope with change, anticipation, sensory stimuli and unpleasant events. That is, the more anxious the individual with autism, the less likely they were able to cope with these demands. This has important implications for clinicians in terms of both assessment and treatment.

Disability Allowance Reversal Welcomed

The LDSIG was delighted with the effective advocacy of interest groups within the disability sector which culminated in a reversal of the proposed cut in the provision of the disability allowance to individual's aged 16-18 years in the recent Budget 2009.

There is clearly a need to have a systematic review of the payment of allowances but it needs to be done in a constructive and positive manner within a person-centred approach to inclusiveness and the creation of real and sustainable opportunities in education, employment and independent living for all.

Abstracts of Papers Presented at PSI Annual Conference 2008

Autistic Spectrum Disorders in Down Syndrome: A Review

Colin Reilly, St. Michael's House, and School of Education and Lifelong Learning, University College Dublin, Ireland.

It has been claimed that the association of ASDs and Down syndrome is rare. However, there are now a substantial number of studies to demonstrate that a subgroup of individuals with Down syndrome meet the diagnostic criteria for an Autistic Spectrum Disorder, and as a result are likely to need qualitatively different approaches in terms of supports and interventions to maximise their educational potential and quality of life. This paper discusses the prevalence, manifestation of symptoms, and correlates of ASDs in Down syndrome based on a comprehensive review of the literature. The paper concludes with a discussion on a possible diagnostic protocol for ASDs in this population and possible future research directions.

An Audit of Positive Behaviour Support Plans in Intellectual Disability Services

Gillian Martin, Niamh Marrinan & Anna Wasilewska
The Callan Institute for Positive Behaviour Support

Presented by Gillian Martin

This research investigated the status of Positive Behaviour Support (PBS) Plans that had been developed within a large service for people with Intellectual Disabilities since 1994. It aimed to establish a baseline of behavioural issues for service planning and future comparative studies.

Staff working closely with service users in receipt of PBS were asked to participate and consent sought from the Service User. A semi-structured interview was conducted to review PBS Plans in place, to

establish the current level of intervention and to look at the functionality of behaviours that challenge. The Checklist of Challenging Behaviour and Motivation Assessment Scale were also completed at time of interview.

Results discussed include the baseline rates of behavioural data, human rights concerns, personal outcomes participation and qualitative feedback provided by staff on requirement necessary for providing future PBS Services.

The Relationship between Risk Assessment and Positive Behavioural Support

John Buttimer
COPE Foundation

Review of the literature suggests a differential approach to the assessment and management of an individual's behaviour as a function of their designated status e.g. with a dedicated service for people with an intellectual disability, with a forensic service, or in the community, and theoretical model applied e.g. clinical or forensic). This paper will explore the relationship between the process of risk assessment, risk management and positive behavioural support in relation to individuals with intellectual disability who present with serious challenging behaviour. Future research strategies for combining the clinical and forensic approaches will be outlined.

Have your Say!

The PSI - Learning Disability Special Interest Group provides a forum for psychologists working with or who have an interest in people who have an intellectual disability.

It is important for the Committee that we get feedback from members about issues and topics that are current and are of interest to them.

If you have any suggestions for future workshops, discussion papers or if you feel you would like to present a workshop then please get in touch with a member of the committee.

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John Buttimer is Secretary of the LDSIG and he can be contacted by email at jbutt@cope-foundation.ie

Please mark all correspondence care of LDSIG e-zine.

We look forward to hearing from you!
