THE ROLE OF THE PSYCHOLOGIST WORKING WITH ADULTS WITH AN INTELLECTUAL DISABILITY

A Brothers of Charity Guidelines Document for Psychologists working with adults in the Southern Services (Seamas Feehan, Brenda Hutton (April 2003)

This policy document has been prepared to inform the Director of Services, Senior Management, Residential and Day Service Managers and other Multidisciplinary Team Professionals about the changing role of the psychology profession in Intellectual Disability services.

The terms Intellectual Disability and People with Intellectual Disability are used in this document to describe the area we work in and the client group with whom we work. It is our view that these terms are meaningful, helpful and non-stigmatising. (We recognise, however, that stigma may attach to the label via the disability, rather than the reverse). The terms are in line with current usage by the Irish Department of Health and Children.

INTRODUCTION: The Changing Perspective

The role of the Psychologist has changed fundamentally over the past 35 years. Following the Commission of Enquiry on Mental Handicap (1965) and the expansion of specialist provision the role of psychological assessment in the identification and placement of children with learning disabilities became paramount. However, it became increasingly apparent since that time that the diagnostic model of assessment did not reflect the totality of the child's and family's experience and that this was not necessarily the best way forward. Currently, the role of the psychologist has moved towards a systemic and collaborative model. This means that the psychologist engages in a collaborative process with the people in the individual's bio-psycho-social system i.e. the person with the intellectual disability, the teachers, the instructors, the support staff in the residential services and the day services, the family and community along with other professionals involved with the service user. The collaborative and team model is a more effective way of working within services for adults with intellectual disabilities. The role of the psychologist is best operated within a dedicated multi-disciplinary team. Compared to the services for children, there are fewer clinical personnel supports for adults. The multidisciplinary teams therefore have a greater reliance on the frontline staff in the residential services and day services. The preferred orientation of the psychologist within this evolving context is to work systemically and through this to harness the existing family, service and community resources.

The principles and developments which have influenced the change in psychology practice include:
- **Normalisation**: The belief that people with a disability should enjoy a quality of life and position in society which is equal to, and would be valued by non-disabled people. This means meeting special needs through ordinary means and that people with disabilities should have choice, live with dignity, participate and contribute to the community and grow in relationships (O'Brien 1987).

- **Growth in Community Based Services**: Normalisation has been the impetus for the growth of community based pre-school, school, vocational and residential services for people with intellectual disabilities. There has been a corresponding decline in the numbers of people cared for within the large institutions such as the mental hospitals. Given the range and diversity of services for children with learning disability, there is increasing pressure for the adult services to “catch-up” and thereby provide an equivalent range of essential services.

There is a recognition that adults have lived and worked in settings where overcrowding was and perhaps remains a serious problem. Adults require an individualised service that is developed systemically. Providing for adults in large groups mitigates against this approach. Consequently, there has been a growth in the numbers of community group homes and in a reduction in the numbers of service users living and working together. Because of this change and diversification, the needs of adults are now more amplified and in greater focus.

- **Social Model of Disability**: Disability is viewed as not being located within the individual but as an interaction between the person and the social and physical world designed for non-disabled people. Services have a role in reducing the restrictions the person faces and supporting them to lead their own life rather than trying to “fix” them. This means promoting equality for those citizens of this country who have a intellectual disability. This also means minimising those barriers that create the experience of disability by working with families and frontline staff to enable people with intellectual disabilities to participate more fully as valued members of society.

- **Advocacy and Empowerment**: There is an increasing awareness in society that everyone, regardless of (dis)ability, has the right to autonomy and to take control over their own life. People with a intellectual disability will need support to exercise these rights. Vigilance is necessary to ensure that people’s rights are not undermined or diminished in any way. This change has brought a growth in person-centred planning and self-advocacy initiatives.

- **Inclusion**: Promoting a commitment to people with disability remaining and “belonging” within their own natural setting. Diversity and difference are viewed as opportunity for interaction and community building. This has been pioneered in the field of education.
• **Research:** Effective work is also influenced by nationally and internationally acknowledged good practice. Evidence indicates that the move from the larger institutions to community based services has been associated with a range of positive outcomes for people with intellectual disabilities (Emerson & Hatton 1998). However, much remains to be done to reduce relative social isolation and increase enjoyment in living. Research suggests that the key to realising a good quality, individualised and integrated lifestyle is to keep Group Homes small and to invest in supported living and supported employment developments.

• **Legal Developments:** Since the 1980s, international legislation has focussed on how inclusion for people with intellectual disabilities can be supported through organisational structures, curriculum development, parental involvement and the assessment of resources. These include the Education Act (1998) which endorsed the need to promote inclusion of all children in mainstream schools and in society in general; recent court cases and legal actions such as the Sinnott (2001) and O’Donoghue (1993) judgements; and the Education (Disabilities) Bill 2002.

**Complexity of Adults with Intellectual Disability**

In addition to the developments and principles that have influenced changes in practice, it is worth noting some of the complexities of working with adults with a intellectual disability which impact on this practice.

• **Dual Diagnosis**

Research shows that people with a intellectual disability are 5 times more likely to suffer from a mental illness than the general population. This incidence increases in proportion to the degree of handicap. This has implications for the nature of supports that are made available to adults. The adults’ behaviours and difficulties may sometimes need to be understood from a Dual Diagnosis perspective. There was a historical perception that all difficulties experienced by people with intellectual disability were caused by the intellectual disability itself. It is now necessary additionally to provide a mental health focus for some adults. Also relevant to this dual diagnosis perspective is the awareness that ageing in its own right brings different needs and issues that latterly were not acknowledged.

• **Life Expectancy**

Medical research and standards of care have improved greatly over the past 30 years and people with intellectual disability are now living longer than heretofore, resulting in a growing older population with their own specific needs. In addition there is evidence that premature ageing occurs
in some individuals with intellectual disability and those with Down’s syndrome are at a greater risk of developing Alzheimer's disease, with increasing age (Zigman et al., 1987)

- Competency and the Law
  Some adults with intellectual disabilities will break the law and will therefore come in contact with the legal and judicial system. This presents us with dilemmas and issues about fitness to plead, competency to give evidence and the vulnerability of people as witnesses or interviewees. Frequently, the D.P.P. will direct that a prosecution will not happen due to the perceived lack of competence of a person with intellectual disability. This creates difficulties as some individuals who are victims of crimes will not gain justice. Other individuals who are perpetrators of crimes will not receive an appropriate penalty or therapeutic response.

- Competency and Consent
  Adult status and rights can create dilemma when service users want different outcomes and have different aspirations to those of their families. While families are still very much involved as partners in service provision, interventions may become less family focussed and more person centred. When consent needs to be obtained there is an ethical dilemma that needs to be processed as to who, if anybody else needs to be consulted, in addition to the service user. While the personal autonomy of the service user needs to be protected, the service user may be dependent on other people for support.

- Always a Child
  There is a societal prescription that tends to perpetuate the childhood of adults with intellectual disabilities. The dignity of their adulthood may be denied. There can be a reluctance to see adults with intellectual disabilities as adults and perhaps a collusion to perceive them as children.

- Sexuality
  There is a range of dilemmas around sexuality and people with intellectual disability. There is an uneasiness and lack of familiarity about responding to sexuality issues. This is connected to religious, cultural, educational and training factors. People have rights to sexual expression with other people and there are complexities around the issue of informed consent and responsibility. There can be a dilemma between the needs of families or support staff and the needs of the individuals with intellectual disabilities. People with a intellectual disability may not know how to express themselves sexually in an appropriate manner and support staff and family members may
have intense, emotional reactions to intellectual disabled service users acting in sexual ways. In supporting service users in this area of their lives, people are likely to be confronted with serious moral and ethical concerns.

- Parents who are Intellectual Disabled
Some adults with intellectual disability are fathers and mothers. There is an increasing need to provide additional supports to those individuals who become parents. This support might be delivered through the parents, the child, the foster parents (where the child is in care), professional staff and the families of the parents. Occasionally there are children in the service whose parents have intellectual disabilities.

PSYCHOLOGY: The Values and the Vision

The psychological approach focuses on personal experience, cognition, emotions and behaviour, personal strengths and support needs. This allows for the setting of positive goals, rather than concentrating on deficits or problems. Intervention is based on developing personal strengths and identifying support needs. Effective case management and service user interventions based on this approach, require careful planning, structure, monitoring and evaluating. Psychology applies existing theories and develops new models. Psychologists working in services for people with a disability are likely to come from a variety of professional backgrounds. The relevant professional training could include community psychology, educational psychology, counselling psychology and clinical psychology. Due to their diverse backgrounds, psychologists have played a significant role in the development of new approaches to working with people who have disabilities.

- Understanding and Importance of Relationships
Fulfilling relationships are essential for personal growth, and psychology has studied interpersonal relationships at many different levels and in many different settings. These studies provide a solid, research-based knowledge, which allows them to help staff and service users in every aspect of their development.

- The Knowledge Base of Psychology
Practice has been influenced by a rich philosophical base and from the results of empirical research. Training in Psychology is rigorous and empirical. Psychology is concerned with developmental, interactive functioning on many levels. Psychologists' approach to dealing with all facets of functioning, together with their understanding of organisational systems, place them in a unique position to work in a thorough and wide reaching way to combat the environmental, physical and social barriers which create the experience of disability. Psychologists' practice is characterised by responsibility, competence, integrity and impartiality.

ROLE OF THE PSYCHOLOGIST:

The role of the Psychologist can be looked at under four headings:

- Case Work - sub-divided further into
  - therapeutic work,
  - family support,
  - programmes and
  - assessment/consultation;

- Research and Evaluation;
- Organisational Support;
- Professional Responsibilities.

To be effective, the psychologist needs to work at the individual casework level, at a group level and at a systems level. While the work of each psychologist will vary from time to time and place to place, the role of a particular psychologist needs to maintain a balance between these core aspects of the role: Casework; Research and Evaluation; Organisational Support and Professional Responsibilities. Adequate protected time needs to be allocated for all aspects of the psychologist's workload and role.

In practice, while working as part of a multidisciplinary team, the role of the psychologist is created from a synergy of four factors:

1. The general climate of culture and expectation (formal and informal) under which the psychology service operates;
2. The needs of the individual service user, the staff, and families;
3. The training, skills, experience and interests of the individual Psychologist him or herself;
CASEWORK

This can involve a great variety of direct and indirect interventions with service users. This could include:

- Therapy and Therapeutic Work.
- Family Support
- Programmes to Individuals and Groups
- Assessment & Consultation
- Liaison with Statutory and other Voluntary Bodies

The psychologist devises treatment strategies for service users. This may involve therapeutic interventions that will develop their self esteem, self control, personal independence and general psychological wellbeing. Counselling and psychotherapy for individuals or groups are examples of such interventions. Psychologists work within teams and with families on multi-element, positive programming approaches. This consultative process may involve intensive and long-term work. A comprehensive, multi-element approach has many stages including careful prioritisation of goals, functional analysis,
environmental alterations, skills teaching and regular reviews of the interventions. Ethics and research make it imperative that psychologists adopt positive intervention strategies, which protect and augment the person's strengths and sense of wellbeing. A positive intervention approach is more effective than interventions, which rely on aversive consequences.

- Assessment and Consultation
The psychologist takes a holistic approach or overview of all aspects of the person's functioning rather than of one discrete aspect of functioning. Therefore the assessment concerns are with the person's emotional, social, interpersonal and intra-personal capabilities; participation and functioning in the community; personal independence and self care skills. Self determination, choice and control over her or his world and access to resources and support are important issues for exploration in assessment. Evaluation of interventions carried out with the person is an integral focus of assessment. Assessment therefore addresses the nature of supports and resources in the person's family and community as well as the person's functioning.
Comprehensive assessments are, preferably, carried out over time. The purposes of assessments vary considerably and the means by which assessments are carried out are multifaceted. Assessments are carried out in collaboration with the service user, instructors, carers, parents and other significant people in the service user's life. Assessments may include the use of psychometric tests but will not exclusively rely on the application of psychometric tests. Typically, psychological assessments will contribute to the development of Individual Care Plans and programmes delivered in Day Services. Psychologists acknowledge the value of other disciplines' contributions to assessments. Best practice indicates that collaboration between the disciplines is essential for comprehensive assessments, which identify the needs of the service user.

An integral part of the work is to act formally and informally as a consultant to service users, staff and family, interested individuals and bodies.

- Family Support
Family support involves working with parents or guardians and with siblings or other family members who have an important part in the person's life. Such support is important in helping to reduce the isolation that can sometimes occur with having a family member with special needs and a learning disability. It may involve:
- Enabling families to understand and provide for their family member's emotional and social needs and in so doing, to acknowledge the person's developmental level and personal wishes;
- Providing opportunities to support and educate siblings, to facilitate their involvement in programme planning for their brother or sister with an intellectual disability and in service development;
- Empowering families to advocate on the service user's behalf for services within and outside of the Service in order to enhance the person's quality of life;
- Helping families create their own solutions to those issues which they perceive as problematic;
- Offering emotional support to families around issues of concern for their family member;
- Creating links with others who are interested in the concerns of people with learning disabilities. This could involve helping people to access educational and support groups or indeed to create such groups.

- Programmes to Individuals and Groups
  The work can be delivered to individuals directly or within groups of individuals. Groups can be natural groups of service users that already exist or they can be deliberately created for a therapeutic, programme or assessment purpose. Examples of such programmes could include Fostering and Developing Relationships; Community and Social Skills training; Assertiveness Training, Anger Management and Personal Development

- Liaison with Statutory and other Voluntary Bodies.
  This may involve attendance at statutory case conferences, membership of core groups, advocating on behalf of service users to bodies such as the Health Board, and Support groups.

Research and Evaluation
Research is undertaken by an individual psychologist, jointly with other psychologists or as part of a clinical team. Publication of research is supported to allow for dissemination of information and good practice.

Organisational Support
Psychologists can play a key role in contributing to general service development. This includes:
  - Staff Training
    This may involve the design and delivery of courses, coordinating course provision and consulting with those individuals and agencies delivering training.
  - Team Membership
    Psychologists are important members of various teams. Protected time is required to formalise the membership and working methods of such teams. In order to contribute effectively to these teams, psychologists need to be kept informed about proposed developments.
  - Reviews
    In collaboration with other clinicians, family, teachers and carers Psychologists contribute to reviews and plans for service users.
• Service Development
Psychologists have expertise in the area of evaluation and are involved in identifying the needs of individuals with learning disabilities and their families. This means that we can play a unique and pivotal role in the development of new and innovative services. In addition Psychologists contribute to developments within the existing service structure as members of working groups on service initiatives

Professional Responsibilities
• Continuing Professional Development
It is essential for Psychologists to keep themselves up to date with relevant knowledge, research methods and techniques, through reading, peer consultation, attendance at conferences, inservice training, networking and continuing education.

• Supervision and Trainee Placement
All psychologists need to receive appropriate professional supervision in line with the responsibilities of the post. Senior Psychologists may be required to provide sufficient and appropriate supervision for recently appointed basic grade psychologists and for trainees.

• The Psychological Society of Ireland
Members of the P.S.I. have an obligation to share the responsibility for maintaining and developing the profession of psychology in Ireland. This will involve networking with other members on issues such as policy development.

• Community Awareness
There is a responsibility to continue to inform the general public about (people with) learning disability. This will help to overcome the societal barriers to inclusion. This can be achieved by challenging negative attitudes, confronting fears, educating people about rights and by promoting contact between able bodies and disabled persons.

Professional Reporting
Psychologists in the Brothers of Charity Intellectual Disability Services report professionally to the Head of the Psychology Department, who, in turn reports to the Director of Services.
Referrals

Referrals for individual casework may come from family members, residential care staff or other members of the multidisciplinary team. Occasionally, a person with an intellectual disability may also self refer. Referrals are processed in consultation with the designated manager and with the multidisciplinary team. Following referrals, a clinical decision by the psychologist is required on the priority status of each individual referral and work by the psychologist will proceed from that basis. The psychologist has autonomy to decide the most effective use of the psychology resource. In individual casework with adults with intellectual disabilities, the following criteria are used when service users are prioritised for work:

- People at risk;
- Distress in the family or care system;
- People in residential care; and
- People in transition.

Collaboration and consultation between the employing agency and the psychologist is essential for good practice. Periodically, there is a need to review the work and the working methods in order to maintain good working relationships and to deliver an effective service to the service users. Where the issue involves an ethical dilemma, there is a resolution protocol in the Code of Ethics of the Psychological Society of Ireland (PSI) that may be employed by the psychologist.

REFERENCES

1. Psychologists in the Brothers of Charity
   Working with People who have an Intellectual Disability

2. The Irish Psychologist, December 1995

3. The Irish Psychologist, June 1996


Contact: The Manager
The Psychology Department
Brothers of Charity (Southern Services)
Lota
Glanmire
Co. Cork
Phone (021) 4821012

For Further Information, go to:-

- Psychologists working in Early Intervention Services
- The Role of the Psychologist working with School Age Children with an intellectual disability
- Psychologists in the Brothers of Charity (Southern Services) Intellectual Disabilities Services