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# PSYCHOLOGICAL INTERVENTIONS AND PEOPLE WHO HAVE AN INTELLECTUAL DISABILITY

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CDS

Creating & disseminating knowledge about disability

The University of Sydney

*"Health is a state of complete physical, mental and social well-being,*

*and not merely*

*the absence of disease or infirmity."*

~World Health Organization, 1948~

# GENERAL POPULATION

- Depression and anxiety affect more than 2 million Australian adults each year
- Less than 40% seek treatment in a 12 month period
- Only 15% see a Psychologist and/or Psychiatrist
- Psychological therapies are effective, but not enough therapists + significant barriers to treatment seeking

# Intellectual Disability

- Prevalence of ID – 1.8% of population (AIHW, 1998)
- Increasing life span - 55-65 years
- Higher risk of physical and mental health problems
- Majority live in the community
  - with families / supported accommodation
- Access generic health services

# Dual Diagnosis

- 20% to 35% of all non-institutionalised persons with intellectual disability are diagnosed as having both an intellectual disability and mental illness
- Compared to 15 to 19% of the general population who meet the criteria of mental illness as defined by the American Psychiatric Association.

(American Psychiatric Association, 1995; Einfeld & Tonge, 1991; 1992; Iverson & Fox, 1989; Menolascino & Stark, 1984)

# Prevalence: mental health problems

- 41% have a mental health problem

  Einfeld & Tonge (1996)
- Schizophrenia/delusional disorder
  - 3 times higher than in general population
- Depression
  - 3 times higher in people with Down Syndrome
- Dementia
  - 4 times more common than in general population

# Types of mental health disorders

- Same range as in general community
- Some specific associations
  - Down Syndrome - depression, Alzheimer's disease
  - Fragile X syndrome - anxiety, autistic behaviours
  - Prader Willi Syndrome - psychosis, OCD
- Other problem behaviours/challenging behaviours
- Epilepsy common co-morbid condition

# Differential diagnoses

- Organic causes
  - physical illness, pain, effects of medication
    - e.g. GORD, middle ear infection, sleep apnoea, psychotropics
- Psychiatric disorders
- Behavioural phenotypes
  - e.g. Prader Willi Syndrome
- Environmental
  - lack of choice, change in routine, frustration
- Life events - grief, loss, abuse

# Clinical Presentation

- May be different to that of general population (especially if severe/profound disability) due to:
  - reduced cognitive abilities
  - communication difficulties
  - high prevalence of co-morbidities
- Some atypical clinical presentations
  - aggression
  - self injurious behaviour
  - non compliance
  - loss of skills

# Issues that can adversely influence assessment & treatment

- Diagnostic overshadowing
- Overemphasis on the intellectual disability at the expense of the psychiatric condition
- Attention to symptomatology rather than signs (observed behaviour)
- Additional stigmatisation
  - (Luckasson et al, 1992; Reiss, Levitan, & Szysko, 1982).
- Emphasis on behaviour
- Limited access to psycho-social interventions

# NSW DD Health Unit

- Statewide consultative health service
- Located at RRCS RYDE
- Part of CDS
- Operates 2 days per week
- Medical & psychological services for adolescents and adults with ID
- Specialized clinics
- Training & research in collaboration with CDS

# Unit staff

- Consultant Medical Officer and Lecturer
- Two Visiting General Practitioners with expertise in developmental disability medicine
- Three Psychologists
- Visiting Rehabilitation Physician
- Visiting Professor in Rehabilitation Medicine to conduct Ageing and Dementia Clinic
- Emeritus Consultant Physician
- Clinic coordinator / Typist

# PERFORMANCE INDICATORS

- The DDHU operated for 48 weeks over the 12 month period July 2008- June 2009
- Total 632 consultations provided
  - 145 new patients
  - 487 review consultations

# Clinics 2008-2009

- 190 general medical clinics
  - 4 Clinics for people with Down syndrome (NB people with Down syndrome also seen in general medical clinics)
  - 4 Clinics - Fragile X syndrome
  - 1 Clinic - Cornelia de Lange syndrome
  - 8 Specialist rehabilitation clinics
  - 9 Ageing and dementia clinics
- 93 Psychology clinics
- 6 Outreach clinics (including home visits)

# Number of consultations by clinic type

- Medical clinics - 478 consultations
- Psychology clinics – 124 consultations
- Rehabilitation clinics – 16 consultations
- Ageing and Dementia clinics – 14 consultations
- Outreach clinics – included in these figures, 30 outreach consultations were held, either at an accommodation service provider's site, work site or at the person's home.

# *Age distribution of new DDHU patients, July 2008-June 2009*

| Age group (years) | Number | % Total |
|---|---|---|
| 15-19 | 18 | 12.4 |
| 20-29 | 40 | 27.6 |
| 30-39 | 32 | 22.1 |
| 40-49 | 30 | 20.7 |
| 50-59 | 15 | 10.3 |
| 60-69 | 10 | 6.9 |
| ***Total*** | ***145*** | ***100*** |

# Distribution of new DDHU patients by Area Health Service

| Area Health Service | N | % Total |
|---|---|---|
| Northern Sydney Central Coast | 55 | 37.9 |
| South Eastern Sydney/Illawarra | 17 | 11.7 |
| Sydney South West | 19 | 13.1 |
| Sydney West | 44 | 30.3 |
| Hunter New England | 4 | 2.8 |
| North Coast | 1 | 0.7 |
| Greater Western | 3 | 2.1 |
| Greater Southern | 1 | 0.7 |
| Queensland | 1 | 0.7 |
| ***Total*** | ***145*** | ***100*** |

# *Main Diagnosis 110 New DDHU Patients July 2008 -June 2009*

| Main diagnosis | N | % |
|---|---|---|
| Down syndrome | 27 | 24.6 |
| Cerebral palsy | 10 | 9.1 |
| Fragile X syndrome/ X-linked conditions | 8 | 7.3 |
| Autism spectrum disorder | 24 | 21.8 |
| Cornelia de Lange syndrome | 1 | 0.9 |
| Other syndromes/chromosomal abnormalities | 10 | 9.1 |
| Traumatic brain injury | 3 | 2.7 |
| Congenital infection | 2 | 1.8 |
| Other | 5 | 4.6 |
| Unknown / not specified | 20 | 18.2 |
| ***Total*** | ***110*** | ***100*** |

# Formal referrals from DDHU

- 44 referrals to psychiatrists (30%)
- 26 referrals to psychologists (18%)
- 36 referrals made to DADHC for behaviour/case management (25%)
- 0 referrals to Community Mental Health Services (0%)
- 0 referrals to Drug & Alcohol Services (0%)

# 2008-2009 data x 2 Psychs
# N=46 new psychology clients

| | | N | % |
|---|---|---|---|
| Gender | Male | 24 | 52 |
| | Female | 22 | 48 |
| Age range | < 20 yrs | 5 | 11 |
| | 20-29 yrs | 19 | 41 |
| | 30-39 yrs | 10 | 22 |
| | 40-49 yrs | 39 | 20 |
| | 50+ years | 3 | 6 |

# Referral Source (N=46)

| Referral Source | N | % |
|---|---|---|
| DDHU GP | 14 | 30% |
| Employment/TTW program | 10 | 22% |
| NGO group Home | 10 | 22% |
| DADHC Group Home | 2 | 4% |
| Parent/family | 7 | 15% |
| Case management service | 2 | 4% |
| External GP | 1 | 2% |

| Presenting Problem/s* | N | % |
|---|---|---|
| Abuse (sexual, physical) | 4 | 7% |
| Anger | 6 | 11% |
| Anxiety & OCD | 13 | 24% |
| Behaviour of concern | 7 | 13% |
| Depression | 8 | 15% |
| Disability Assessment | 2 | 4% |
| Grief | 4 | 7% |
| Moral Development | 4 | 7% |
| Psychosis - schizophrenia | 2 | 4% |
| Social/ relationships | 4 | 7% |
| Obsessive slowness | 1 | 2% |
| Total (* multiple reasons accepted) | 55 | 100% |

# Psychological Interventions

- Cognitive Behaviour Therapy (CBT)
- Relaxation techniques - scripts, tapes, exercises for physical and mental relaxation
- Anger control, anger bank work ....
- Recording - Mood diary, & activity level, self monitoring, behaviour charts, token economy
- Grief & loss – use of memory books & pictures, grief resources, story books
- Moral development training
- Positive programming
- Risk assessment and trauma counselling

# Common interventions . . .

- Social Stories (individually developed)
- Questions books
- Visuals: weekly schedule boards
- Person centred plans/tools
- Drawing (basic art therapy)
- Mental Health booklet – what makes me angry, happy, sad, worried + what helps me to feel better

- Guidelines/wall posters e.g. how to get a good night's sleep
- Attending staff meetings (at NGOs) to promote consistency
- Training & support to parents / carers
- Mediation meetings with family and/or staff
- Referral for sensory assessment
- Development of work profile

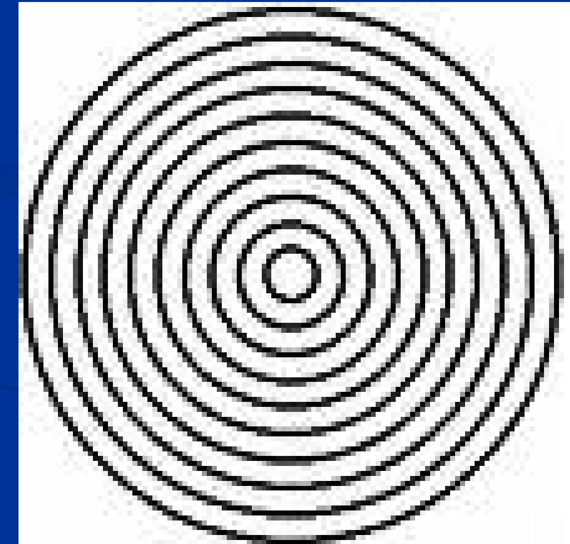
# Case study: Angry Andy

- Male
- 48 years
- Moderate intellectual disability
- Polite, mild mannered
- Excellent memory
- Pt/time open employment
- Anger bank – Number of rude customers, teased at school, angry father figure

# Working with Anger

The ruler (or thermometer)

- Anger thermometer
- Anger bank work - specific incidents
- Changing channel
- Shielding self (Starwars force field)



# Case study: Susie Stealgood

- Female, 23 years
- Down Syndrome, moderate support level
- Lives with family
- Active social life
- Supported open employment pt/time
- Ongoing issues with stealing and lying

- Steals food, money, personal items
- Denies stealing
- Friend/acquaintance steals
- High Shame level

- Black/white thinking

# Moral Development

- Motivational interviewing to address benefits and losses of stealing/lying
- Moral development training
- Explore erroneous thinking
- Consequences for behaviour
- Address self esteem and shame issues
- Preparing for and controlling urges and cycles of behaviour

# Case Study: Danny Blue

- Male
- Late 20s
- Pt/time supported employment
- Living family home
- Rural environment
- Death of neighbour and family friend
- Loss of siblings through marriage and leaving home for employment

# Depression

- Comprehensive assessment
- Problem identification
- Medication
- Increased Activity - in home and in community
- Pleasant events and activities
- Greater family involvement
- Problem solving
- Person-centred planning - holidays and sibling visits

# Case study: Terry Tearful

- Male
- Mid 30s
- High support needs and non verbal
- Death of father and grandfather
- Move from family home to Group home
- Withdrawal and SIB

# Grief and Loss

- Visual aids eg photos and resources to work through concept of loss, death, funerals, changes in life….
- Memory Book for key persons lost …
- Rituals and events to celebrate relationships
- Increased family involvement
- Pleasant events and person centred planning
- Relaxation training and social stories

# Recommendations

- Effective partnerships between all service providers and families to enable effective assessment and diagnosis, psychotherapy and support pathways.
- Strategies and methods to facilitate empowered decision making by clients.
- Person Centred Planning (PCP), Mental Health Care Planning and Positive Behaviour Support strategies.

- Comprehensive analysis of behaviour utilising industry recognised tools within a multi-disciplinary framework to ensure accurate and timely diagnosis and treatment of mental health needs.
- Co-ordinated cooperative integrated care approach between GPs and other healthcare professionals to develop and implement goals and strategies and achieve continuity of care.
- Interventions tailored to the communication and support needs of the individual.
- On-going evaluation of effectiveness of interventions with clients as partners

# Contact

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