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Borderline Personality Disorder and Intellectual Disability

Presented by the
Victorian Dual Disability Service

Victorian Dual Disability Service (VDDS)

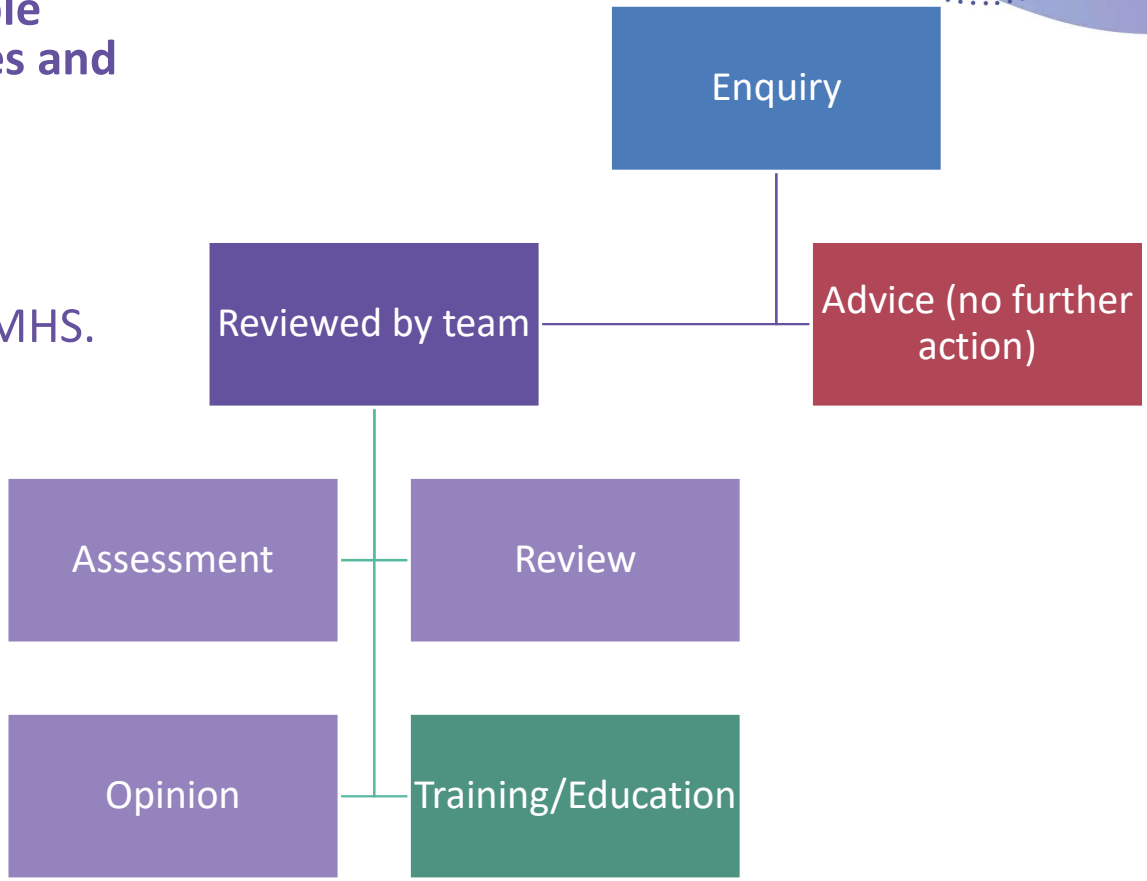
State-wide mental health service for people with co-occurring mental health challenges and a developmental disability.

What does VDDS do?

- Telephone consultation to anyone.
- Assessment & consultation for public AMHS.
- Assessment & consultation for NDIS participants
- Education & Training
- Service Development

How to make a referral or request training:

- *Telephone Referral: (03) 9231 1988*
- *Email: vdds@svha.org.au*



Outline

Aim: Increase awareness of the presentation, assessment & management of Borderline Personality Disorder in people with ID.

1. BPD & ID co-occurrences
2. Issues in assessment
3. Approaches to treatment & management

Intellectual Disability

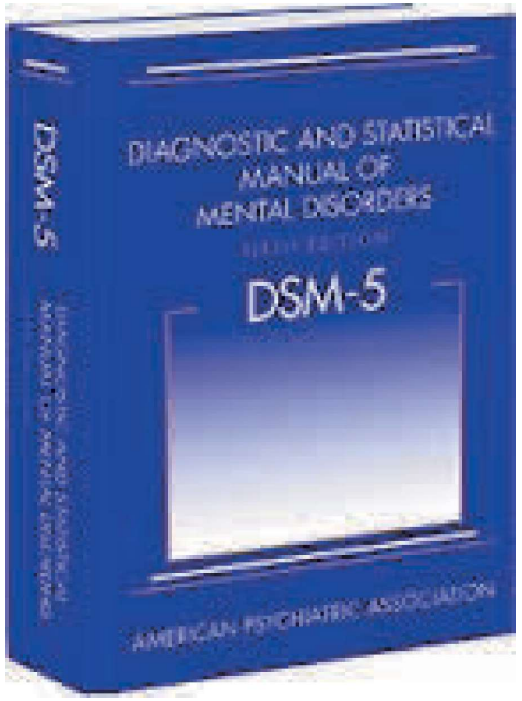
DSM 5 - Neurodevelopmental Disorders

- Intellectual developmental disorder (ID)

A. Deficits in intellectual functions:
- Confirmed by clinical assessment AND standardised intelligence testing (IQ<70)

B. Deficits in adaptive functioning:
- At least one of academic, social or practical domains
- Needs ongoing support

C. Onset during the developmental period (before age 18 years)



Implications of Intellectual Disability

People with intellectual disability:

- Learn and process information more slowly
- Have difficulty with abstract concepts such as money, time and the subtleties of interpersonal interactions

The kind of support & assistance they require depends on:

- Their cognitive / communication ability
- Expectations on them within particular environments
- Whether they have other associated developmental disabilities such as cerebral palsy, autism or sensory impairments
- Co-occurring conditions (medical or psychiatric)

1-3% of general population

Personality Disorder

- Enduring pattern of inner experiences & behaviour deviates markedly from expectations of the individual's culture.
- Affecting cognition, emotions, interpersonal functioning & impulse control.
- Persistent & pervasive.
- Causes significant distress & impairment.
- Not better explained by another mental disorder (including ID), substance use or medical condition.
- Prevalence data is rubbery
  - **4% - 15%:** General population
  - **26% - 65%:** Clinical or forensic population

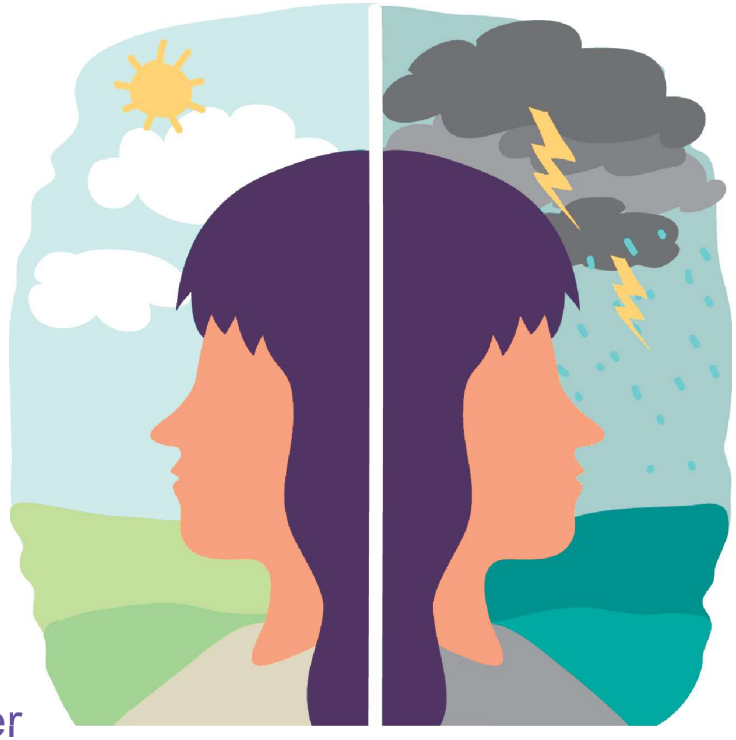
DSM 5 Diagnostic Criteria for Borderline Personality Disorder

At least 5 of:

- Frantic efforts to avoid real or imagined abandonment
- Pattern of unstable intense relationships characterized by alternating between extremes of idealization & devaluation
- Identity disturbance: markedly and persistently unstable self-image or sense of self
- Impulsivity in at least two areas potentially self-damaging (e.g., spending, sex, substance abuse, reckless driving, binge eating)
- Recurrent suicidal behaviour, gestures, or threats, or self-mutilating behaviour
- Affective instability due to marked reactivity of mood (e.g., intense episodic dysphoria, irritability, or anxiety usually lasting a few hours & only rarely more than a few days).
- Chronic feelings of emptiness
- Inappropriate, intense anger or difficulty controlling anger (e.g. frequent displays of temper, constant anger, recurrent physical fights)
- Transient, stress-related paranoid ideation or severe dissociative symptoms

BPD; *Disorder of Instability*

- Unstable affect *(intense anger, mood swings)*
- Unstable relationships *(abandonment, love vs hate)*
- Unstable sense of self *(emptiness, self view, self esteem)*
- Unstable cognition *(impulsivity, reality, paranoia, hallucinations)*
- Unstable behaviour *(self-harm, suicidal, aggression)*
- Both ID and BPD can be associated with behavioral dysregulation
- Symptoms of BPD often attributed to the individual's ID rather than to a diagnosable disorder = **diagnostic overshadowing**



Prevalence and Aetiology of BPD

- Population prevalence **1-4%**
- MH settings **>23%**
- Female **3:1** Male
- Gene & environment interaction
- Abuse and adversity in development increases risk of BPD
- **ID increases risk of:**

➢Neurobiological dysfunction

➢Psychosocial adversity

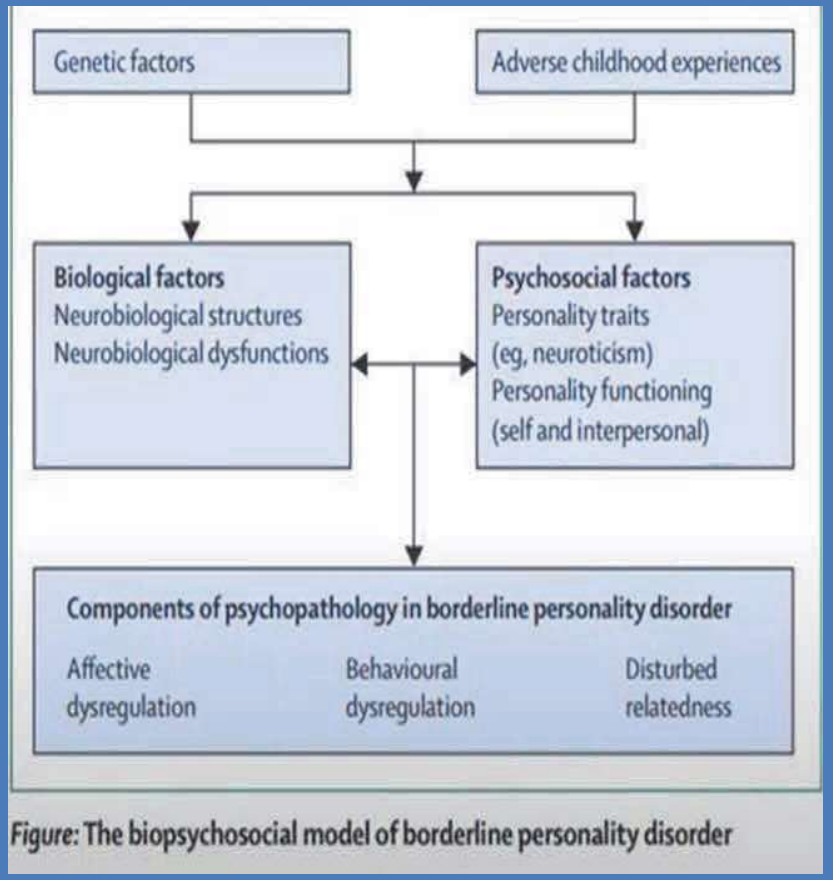
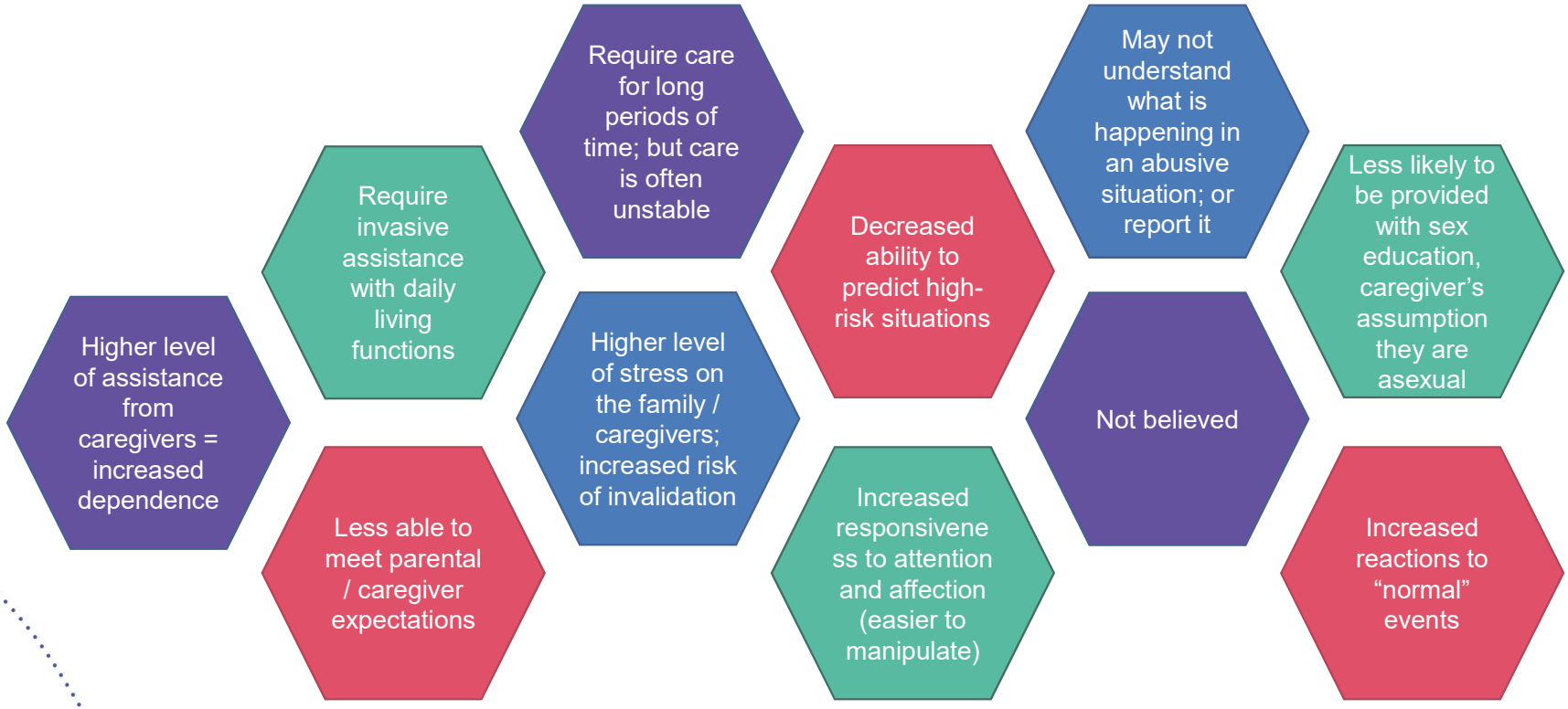


Figure: The biopsychosocial model of borderline personality disorder

Increased Vulnerability to Adversity; Risk of BPD in ID



Prevalence of BPD in ID

- Literature is limited to specialist clinics or populations
- No accurate prevalence / incidence, data is more rubbery (Torr 2003)

➢ Community settings: **1%-91%**

➢ Institutions: **22%-92%**

Review of 14 papers by Alexander & Cooray (2003)

➢ Forensic population: **39%**

(Lindsay 2006)

➢ VDDS: **22%**

(Tomasoni & Pridding 2005)

General consensus: **20-30%**

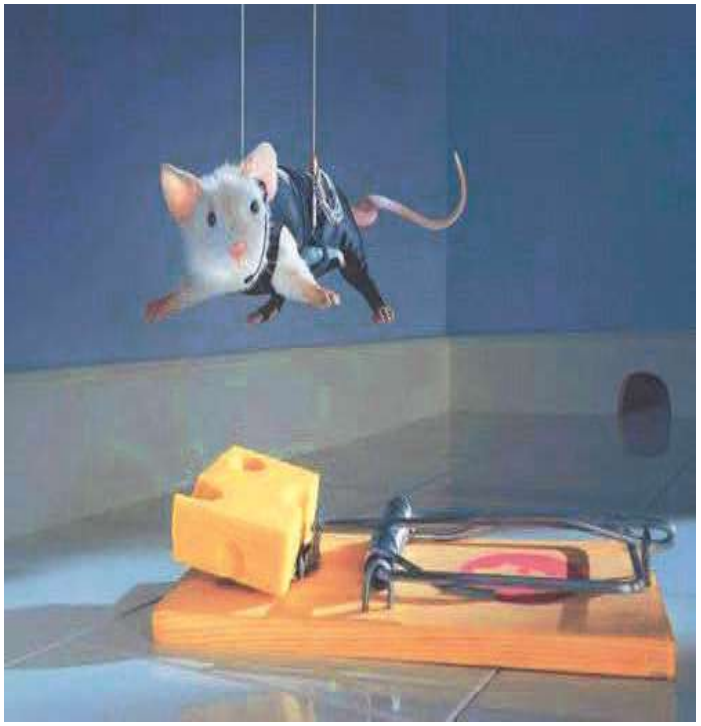
➢ There has not been convincing research into the true prevalence of the co-occurrence of these two disorders

Assessment

Diagnosis of Personality Disorder in Intellectual Disability

Individuals with intellectual disability (ID) are not immune from PD, although the diagnosis is controversial due to:

- Philosophical objections about adding an additional pejorative label
- Practical difficulties with assessment & treatment due to cognitive and communicative impairments
- A diagnosis of exclusion?



Difficulties with Assessment

Diagnostic overshadowing (attribute problem to the ID or *"It's behavioural!")*	? Validity of personality assessment if IQ<50 (or non-verbal)
Diagnostic criteria requires sophisticated cognitive & communication ability (psychosocial masking)	Unstable living situations (limits cross sectional assessment)
Difficulty in obtaining history from individual	"Institutionalized behaviours" (superficial relationships, aggression maybe culturally appropriate)
Difficulty in obtaining reliable longitudinal collateral information or history (can't establish baseline)	Delayed development of personality (RCPsych recommends against dx until age 21 ?)
Lack of professional training (failure to consider)	Lack of treatment options (why diagnose if no treatment is available?)
Lack of family / carer knowledge	

Behavioural Considerations

Behavioural assessment needs to account for personality.

Behaviour is NOT due to ID

Behaviours of concern occur in people with:

- Intellectual and developmental disabilities
- Organic disorders (dementia, delirium)
- Psychiatric illnesses (psychosis, affective disorders)
- Personality Disorders
- General populations

Challenging Behaviours and PD

“Functions” of challenging behaviour may be driven by ‘relationships’

- Fear of abandonment
- ? Enjoy the impact on others
- May fluctuate with idealisation / devaluing

Personality may contribute to frequency of behaviour

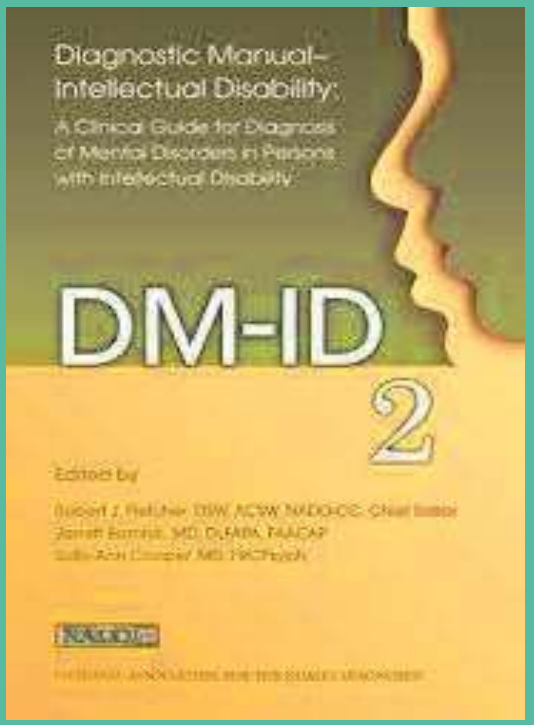
- Impulsivity
- Mood (lability)
- Anger outburst

Personality may determine nature of behaviour

- Aggression/violence
- ‘Payback’
- Targets weaker individuals

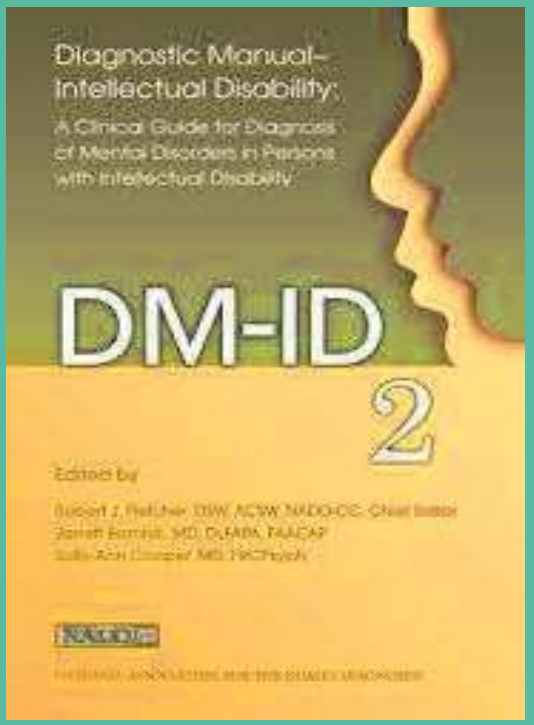
Consideration of Diagnostic Criteria

Abandonment	• Dependent on others for practical & emotional needs. • Many have been repeatedly abandoned. • Little choice of carers. • Is it culturally appropriate?
Unstable Relationships	• Difficulty understanding relationships, learned functional behaviour to meet needs.
Splitting	• Frustration / powerlessness • Dependent on others for relationships. ? Friends / family. • High rates of ASD (black & white thinking). • Splits in staff group or between professionals / services.
Identity	• Requires sophisticated cognitive & verbal skills. Understanding of abstract concepts.



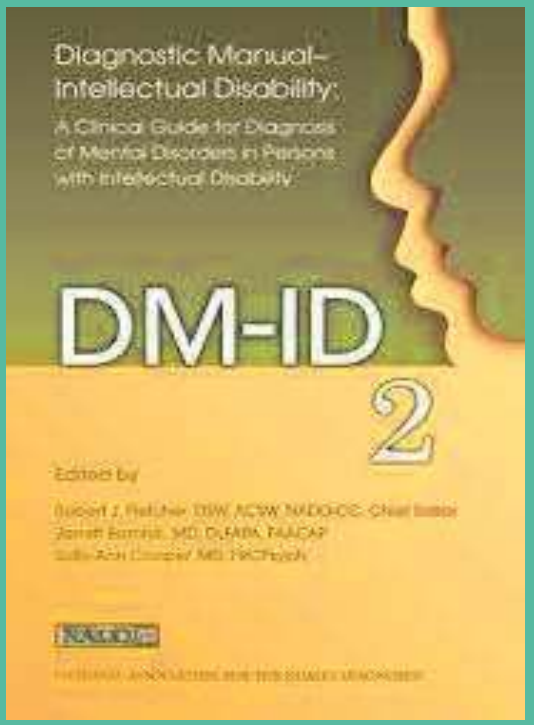
Consideration of Diagnostic Criteria

Impulsivity	• People with ID often lack impulse control & distress tolerance and may have little understanding of consequences. • Limited opportunities / choices. • May be a feature of genetic disorders, FASD, ADHD or ASD.
Suicide and NSSI	• Self injury is common and other reasons should be excluded (e.g. genetic, medical, sensory, communication) before BPD is considered. • Self injury vs self harm.
Emptiness	• Requires overt verbal skills & good cognitive ability. • May be reflected in persistent complaints of boredom. • Are sufficient activities & supports available?



Consideration of Diagnostic Criteria

Affective Instability	• Challenges with dysregulation, distress tolerance. • Is it health, drugs/ medication, environment, expectations, routine. • Anxiety or mood disorder? • ASD meltdown – overwhelmed by social demands, sensory stimuli.
Anger	• Intense anger & aggression can be frequently exhibited, exclude other causes. Loss of routine or scaffolding. • Avoidance of unwanted tasks or stimuli.
Transient Psychotic Symptoms	• Cognitive disintegration. • Schizophrenia? Auditorisation of thoughts? Excuse?
Developmentally Appropriate	• Tendency to focus on IQ not level of emotional development or 'mental age'



Highly Suggestive Features of BPD in ID

- Extreme change in affect out of proportion to environmental factors & difficult to support.
- Tend to test program structure & search for "loop-holes."
- Create environment of turmoil and chaos around them.
- Splitting (favourites amongst staff, frequent complaints)
- Manipulative behaviour
- Subjective perception of victimization
- Stress related paranoia or hallucinations
- Impulsive patterns of self-destructive behaviors

Suicide

- Recurrent suicidal threats, gestures, & attempts are common, 8-10% complete suicide
- Difficult to predict even when monitored carefully
  - ➢ Chronic – not aimed at dying, need and urgency of rescue from unmanageable distress
  - ➢ Acute – clear plan & intent to die
  - ➢ Acute on Chronic
- What can change the risk from chronic to acute?

Self Harm (Self-Injurious Behaviour)

- Non-suicidal deliberate self-injury such as cutting (usually limbs or abdomen, burning, bruising)
- Emotional regulation strategy, relives painful emotions & inner tension, followed by shame
- Occurs in 50-80% of people with BPD
- Usually triggered by an event (separation, loss)
- Associated with impulsivity & childhood abuse
- Endorphin release – increased pain threshold

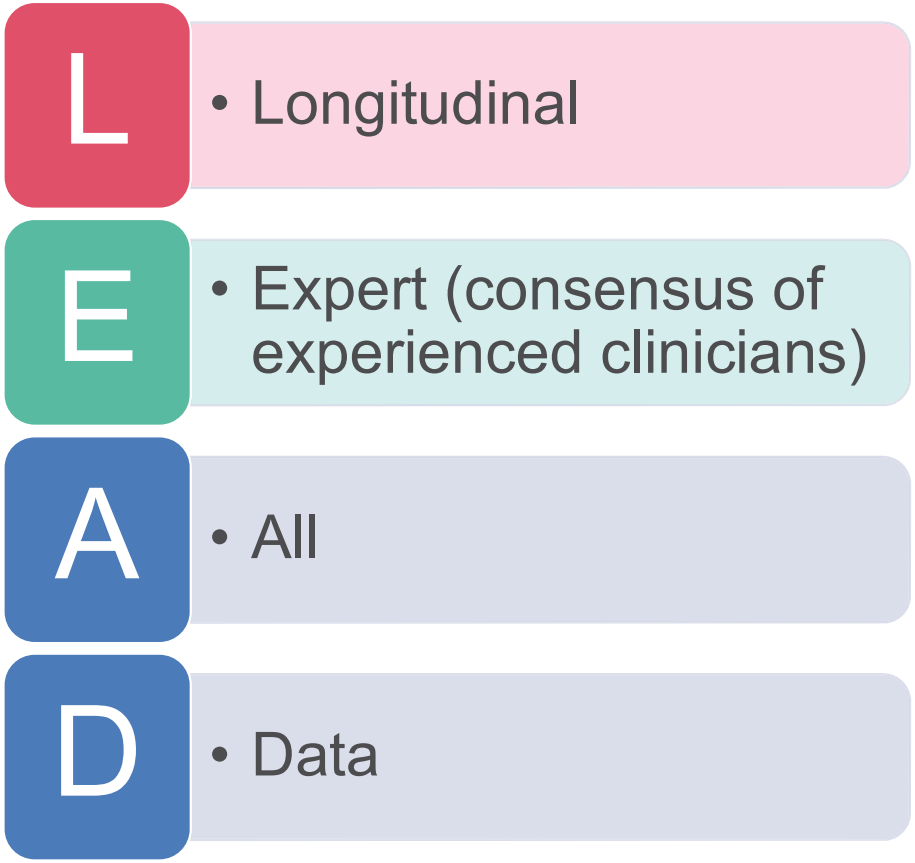
Assessment Considerations

- People with intellectual disabilities are amongst the most marginalised groups in society.
- Beware of double stigma (ID & PD) & service exclusion.
- Caution in assessing younger people with intellectual disabilities as personality development may be delayed.
- PD diagnosis for moderate or severe intellectual disability should be rare & only made after robust assessment by ID specialist (NICE 2009).
- Recognition of BPD can result in more appropriate supports.

Assessment Method

LEAD (Spitzer 1993)

- Designed to overcome assessor or self report biases and single interview “state” distortions
- A comprehensive mental health assessment incorporating information from a variety of sources including direct interview and/or observation, informant interviews with key stakeholders, review of records, detailed developmental history and where appropriate use of assessment instruments.
- Then manage and evaluate, review diagnosis



Assessment Instruments

- No validated screening tools (? SAPAS).
- The Standardized Assessment of Personality (SAP) or SCID-5 can be useful in some circumstances as part of a comprehensive assessment.
- Poor correlation between instruments and also between instruments and clinical opinion.
- Very little evidence of validity of assessment instruments.
- Gold standard is expert clinical assessment against DSM or ICD diagnostic criteria.

Management

Overview of Treatment and Management

- People with ID & BPD can be highly complex
- Usually supported by carers with least expertise
- Like walking through thick fog
- **Any guidance is welcome!**
- Limited evidence on management
- Unclear about what would constitute an effective intervention

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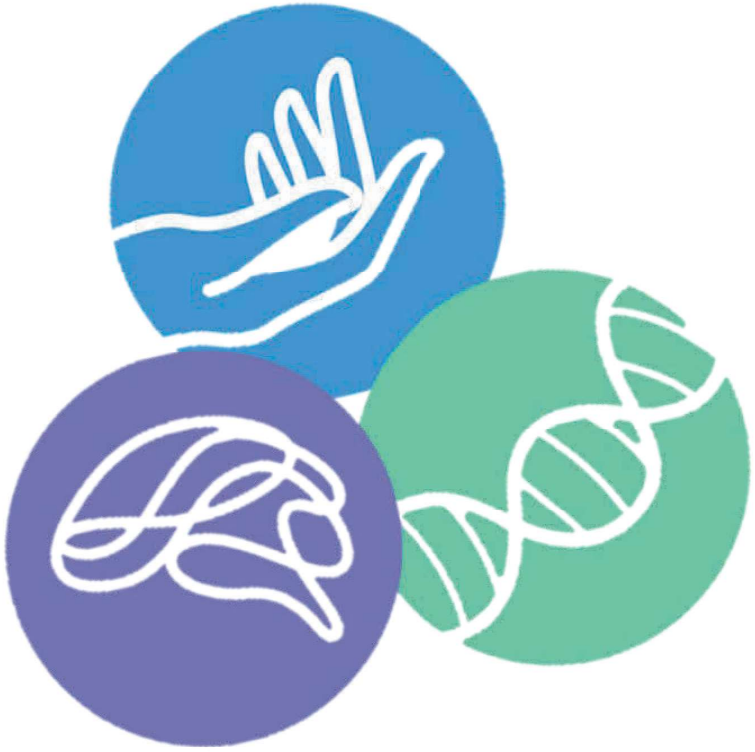
Evidence



- Treatment & Management strategies are largely extrapolated from evidence in the general population
- Psychosocial interventions are recommended as the primary treatment for personality disorders with pharmacotherapy as an adjunctive treatment
- Pridding and Procter (2008) identified only three papers on nonpharmacological interventions
- Williams and Rose (2018) identified a further 8 studies

  "All studies provided weak research evidence littered with methodological flaws, and so findings should be treated with caution."

Guidelines

- Clinical Practice Guideline for the Management of Borderline Personality Disorder, NHMRC 2012
- Borderline Personality Disorder: Treatment and Management: National NICE Clinical Practice Guideline No 78 (2018)
  - Access to the same services as other people with borderline personality disorder
  - Structured approach
  - Seek specialist consultation
- Intellectual Disabilities and Personality Disorder: an integrated approach (Webb 2014)

Treatment & Management Challenges

Finding appropriately skilled experienced therapists

May not fit standard treatment programs

Practical complications (cost, no accessible services, transport, need for carers to attend)

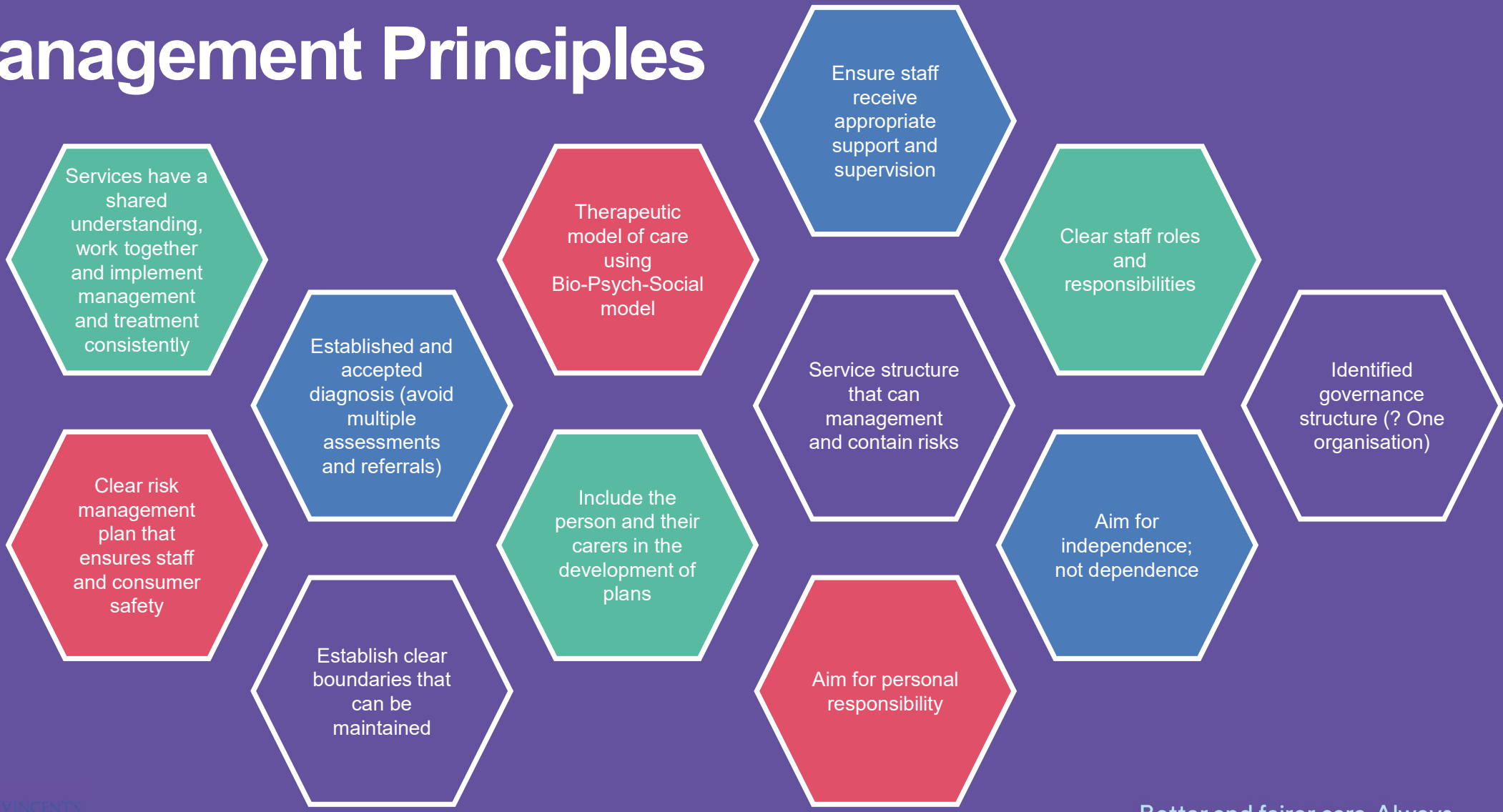
Lack of clinical policies, pathways or guidelines

Diagnostic overshadowing (everything is due to ID)

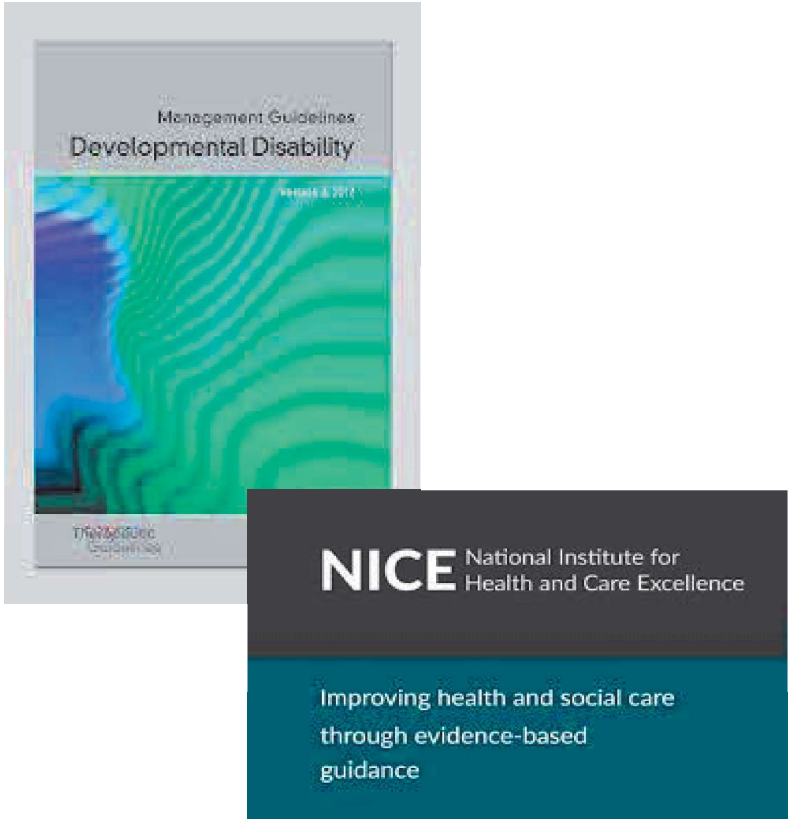
Therapeutic nihilism

Stigma, exclusion & over enthusiastic gatekeeping

Management Principles



Management Planning



- Bio-psycho-social approach informed by assessment
- In collaboration with the person & their support network
- Provides information about the plan in an accessible format
- Addresses risk, crisis support / response
- Agreed goals & evaluation strategy
- Refers to generic or ID specific existing guidelines
  - NICE guideline [NG54] Mental health problems in people with learning disabilities
  - Therapeutic Guidelines: Developmental Disability

Biological (Pharmacological) Interventions

- Identify & where possible address medical issues (incl. dental)
- High rates of psychotropic prescribing esp. antipsychotics
- No clear treatment target, limited monitoring or evaluation
- Treatment as usual for clear concurrent mental health problems
- Adopt the same principles as for the general population with BPD
- No TGA labeled medication for BPD = NDIS restrictive practice

Prescribing Considerations

- May help manage specific symptoms or improve concordance with non pharmacological management e.g. mood stabilizer (lamotrigine, valproate) for emotional instability, antipsychotic (risperidone) for irritability
- Define clear target for treatment & evaluation plan/timeframe
- Exercise caution due to unpredictable responses and inability to communicate effects, also risk of overdose
- Start low, go slow, monitor & evaluate, add or change one agent at a time, withdraw if ineffective
- Psychoeduction for the person & their supports

Non-pharmacological Interventions

- Dialectical Behaviour Therapy (DBT) is the most commonly described intervention
- Positive outcomes reported include decreased self harm, anxiety, depression, distress, impulse control, thought disorder and scores of total pathology BUT evidence is weak (Williams & Rose 2018)
- Systematic review by McNair et al (2016) identified 7 studies all methodologically weak.
- Poor adherence to model, inadequate description of adaptations or outcomes

Dialectical Behaviour Therapy (DBT)

May need longer or shorter, more frequent sessions

Group skills training preferred but individual work is also effective

Simplify concepts & language

Use visual communication

Greater use of demonstration, role play, rehearsal

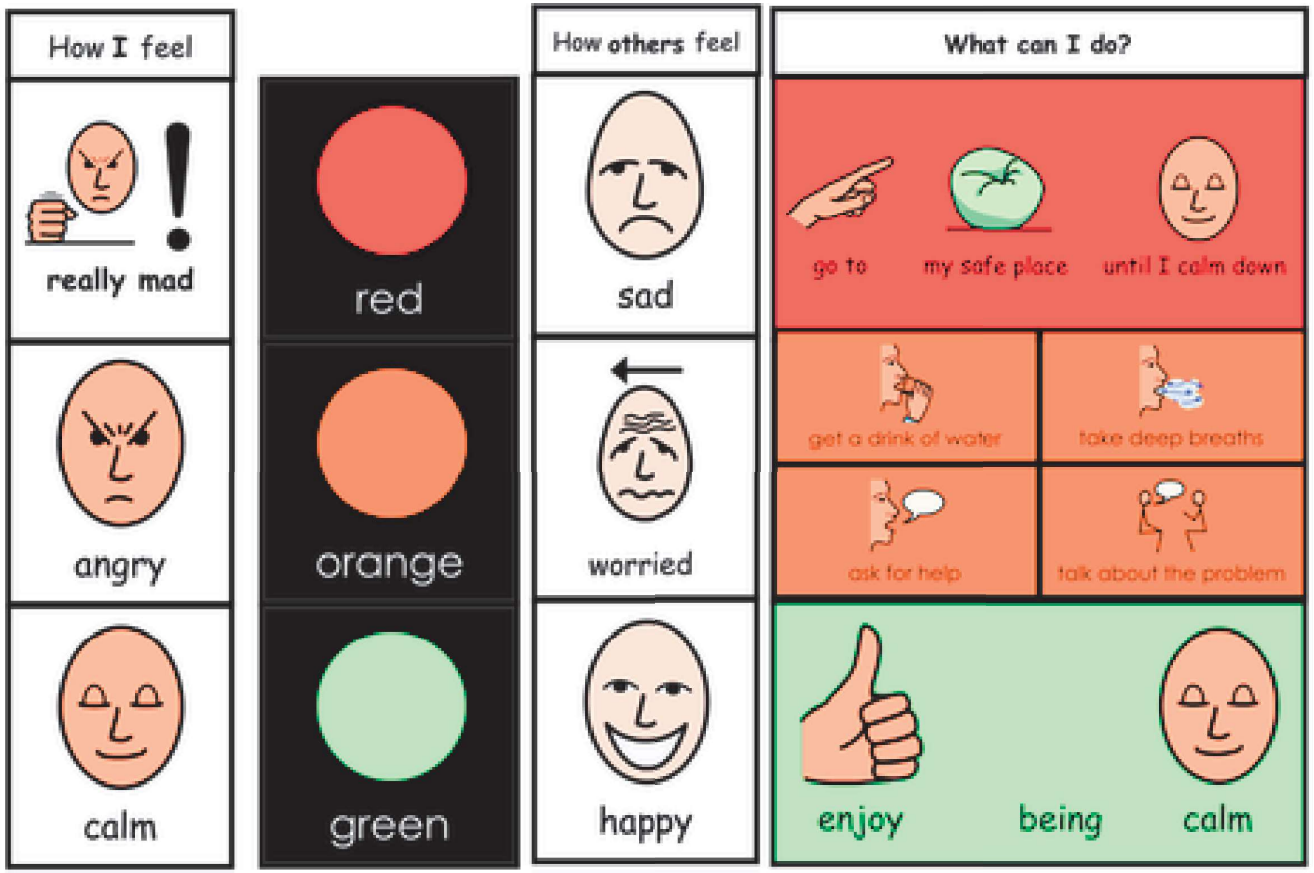
Enlist carers to help with homework, prompt & reinforce learned coping behaviours in real life situations

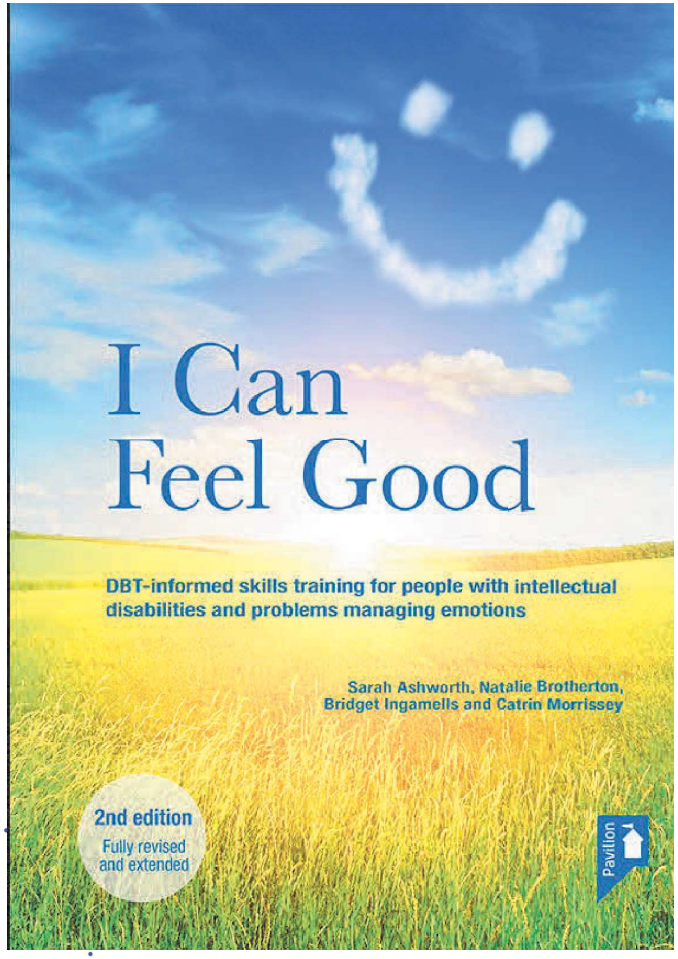
Telephone support - need visual cues

Lew et al 2006 recommends that DBT should be taken up only if there is strong long term service system support.

May requires multiple repetitions

Use simple visuals





The program is designed for delivery in a group setting, but can be adapted for individual intervention.

The training manual features twelve modules with learner handouts (worksheets, forms and printable resources). It also contains guidance regarding staff training, program evaluation, additional resources regarding mindfulness exercises, guided imagery, role plays and composite characters to increase the ease of group facilitation.

Other Therapies

- Some evidence that mindfulness can improve psychological wellbeing and reduce emotional dysregulation (Chapman et al 2013)
- Mentalization Based Therapy (MBT) or Transference Focused Psychotherapy (TFP) may be possible for those with very mild ID but little information
- Case studies of Positive Behaviour Support report improved quality of life and reduced rates of challenging behaviour (Togood 2019)
- Selection of therapy depends on individual abilities and preferences, and available services or supports

Social Interventions

- **Positive social relationships play a crucial role in mental health & thriving whereas the lack of such contributes to poor mental health.**

- **Environment has a major impact on mental health**
  - Accommodation, work, day program (stability, familiarity, facilities, décor, location)
  - Structure & stability
  - Co-residents, carers/family, loneliness
  - Sensory concerns (noise, lights, smell, movements, how busy is it?)
  - Meaningful activities vs boredom

- **Supports**
  - Level of support required & compatibility of supports with the person
  - Stability of supports
  - Training & education of support providers
  - Amount of supervision/containment

Lifestyle/Social Interventions

Benefits	Barriers
• Build resilience through improved coping skills • Reduced stress – reduce relapse • Enhance recovery • Improve confidence & self-esteem • Improve physical health & social well-being • Improve relationships • Improve quality of life • Reduce symptoms & impact of mental disorders	• Needs support & collaboration • Dependence on others • Cost • Cognitive & communication challenges • Lack of suitable resources & opportunities • Stigma & exclusion • Practical issues e.g. transport

Managing Expectations

Do they know what to expect?

- Structure, predictability, consistency
- Clear communication of rules
- A schedule that the person understands

Do they know what is expected of them?

- Structure, visual supports
- Clear specific communication of when activities start, finish & what they need to do
- Clear communication of rules

Is there a mismatch in expectations & / or abilities?

General Psychiatric Management

- **Treatments for BPD varied significantly but had similar outcomes**

- **Common features of DBT, MBT & TFP:**
  - Primary clinician + PRN specific clinical support
  - Case management with dyadic relationship & agreed goals
  - Supportive psychotherapy
  - Active responsiveness & safety planning

- **3 manualised general therapies adopting these characteristics were better than treatment as usual & comparable to specialised treatment:**
  - Supportive psychotherapy (Appelbaum 2005)
  - Good Psychiatric Management (Gunderson 2014)
  - Structured Clinical Support (Bateman & Fonagy 2009)
  - + Nidotherapy (Tyrer 2019)

Generalised Psychiatric Management in ID

- No specific evidence in ID/BPD
- Regular structured supportive, directive, pragmatic case management
- Emphasis on psychoeducation & collaboration
- Goal of having a productive and satisfactory life
- Flexible support
- Acknowledges the role of pharmacotherapy as an adjunct
- Training is required but can be undertaken by most experienced clinicians
- **Clinical experience is that this approach works!**

Management Model for BPD in ID

Table 1. General Overview of the Four-Stage Format

Stage 1	Stage 2	Stage 3	Stage 4
Optimal Function	**Antecedents/ Precursors**	**Crisis**	**Resolution**
Behavior: Individual is engaged in typical daily activities	**Behavior:** Individual engages in behavior signaling impending instability	**Behavior:** Individual is acting out	**Behavior:** Individual is calm/ exhausted
Goal: Maintain function at this stage	**Goal:** Return to Stage 1	**Goal:** Maintain physical safety of all involved, and move to Stage 4	**Goal:** Gradual return to Stage 1
Interventions: Teach and reinforce appropriate behavior Maintain structure Teach and practice skills for coping, soothing, and distracting	**Interventions:** Initiate procedures for coping, soothing, and distracting Maintain structure	**Interventions:** Initiate safety procedures Observe for signs of resolution	**Interventions:** Reinstate structure Validate feelings Initiate procedures for coping, distracting, and soothing

- Wilson (2001) developed a four stage model SPECIFIC to managing crises in borderline PD in ID:
  - Stage 1: Optimal function.
  - Stage 2: Antecedents / Precursors.
  - Stage 3: Crisis.
  - Stage 4: Resolution.
- Primary focus is to enable direct care staff to adopt effective and consistent approach.
- 4 stages allows staff to adjust interventions in a coordinated fashion.

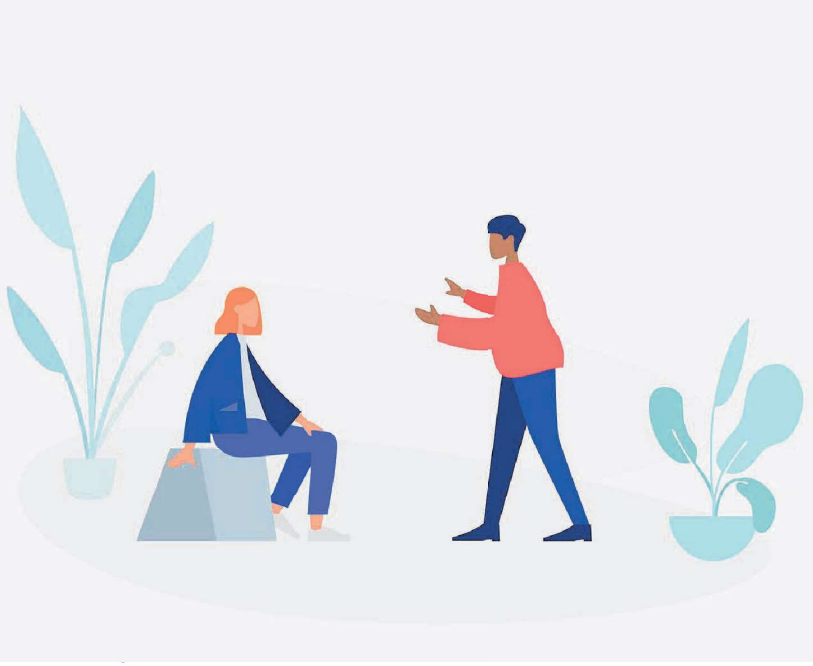
Wilson, R.(2010) "A Four-Stage Model for Management of Borderline Personality Disorder in People With Mental Retardation.

Stage 3: Crisis Management

Reactive Strategies

- Only one component of intervention plan
  - ➢ De-escalate potential incidents
  - ➢ Manage incidents that occur
  - ➢ Aim to establish rapid, safe and ethical control
- Not treatment
- Not punishment
- Least restrictive
- All key carers should be able to perform
- Identify precursors
- Individual plan

Stage 3: Crisis Management



- Follow the plan
- Listen & validate
- Accept that what they say is true for them at that time – do not challenge them
- Keep interactions short & matter of fact
- Use short simple sentences & minimize choices
- Do they need space or company?
- Encourage soothing techniques if appropriate
- Consistency, consistency, consistency, consistency

Stage 4: Resolution

- Behaviour: *Signs of calming down and exhaustion*
- Goal to continue with de-escalation and return to stage 1 (client may re-enter crisis)
- Interventions:
  - *Reinstate structure*
  - *Validate feelings initiate coping, distractions and soothing*
  - *PRN may be considered*

Management Overview

Need stable long term accommodation with consistent staff who can:

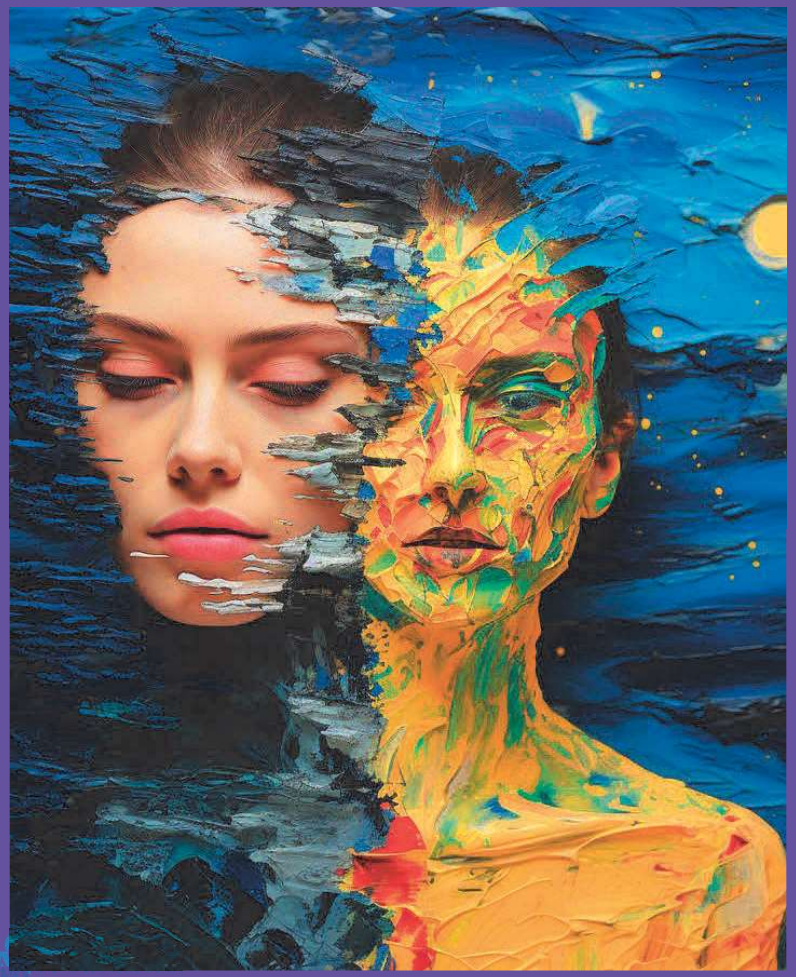
Deliver therapeutic interventions

Manage and contain risks

Provide predictability and stability

Some can benefit from the usual interventions with reasonable adjustments

Conclusion



- PWID + BPD are a vulnerable and disadvantaged group with high rates of distress and disturbed behaviours
- Complex needs & major management challenge
- Practical and philosophical difficulties with assessment & diagnosis
- Require comprehensive longitudinal assessment
- Management focused biopsychosocial framework, collaboration & structure
- Some with mild ID may respond to usual interventions with adaptation
- Stable long term accommodation & supports are a major factor in good outcomes

Thank you

For a copy of these slides, please email vdds@svha.org.au with subject header *“Please send BPD webinar slides”*

Resources

- Clinical Practice Guideline for the Management of Borderline Personality Disorder (NHMRC 2012)
- https://www.nhmrc.gov.au/guidelines-publications/mh25

- Borderline personality disorder: recognition and management
- https://www.nice.org.uk/guidance/cg78

- Spectrum Personality Disorder Service for Victoria
- https://www.spectrumbpd.com.au/

- Project Air Strategy for Personality Disorders
- https://www.projectairstrategy.org/index.html

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