What the NICE guidelines say on Learning Disabilities & Behaviour that Challenges

Glynis Murphy
Prof of Clinical Psychology & Disability,
Tizard Centre, Univ of Kent
g.h.murphy@kent.ac.uk

National Institute for Health & Care Excellence (NICE) – www.nice.org.uk

- ‘**NICE's role** is to improve outcomes for people using the NHS and other public health and social care services by:
- **Producing** evidence based guidance and advice
- **Developing** quality standards and performance metrics
- Managed through collaborating centres: for us NCCMH
- Examples: cancer, heart failure, diabetes, smoking, obesity, depression, schizophrenia, alzheimers, etc

NICE guidelines: process

- Very organised, very fixed process, very evidence-based (systematic reviews & RCTs)
- Publish Scope of guideline; consultation on Scope
- Guideline development group (GDG) – open application process; very multi-disciplinary
- GDG meets to examine & discuss evidence in relation to all the questions in the scope
- Guidance drafted & refined; goes out for consultation & redrafted; then published (May 2015)
- Quality Standards set (drafted; consultation; redrafted)

What was in the Scope?

- Definition of learning disabilities
- Definition of challenging behavior: culturally abnormal behaviour(s) of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use, or result in the person being denied access to, ordinary community facilities (Emerson, 1995)
- Series of questions to be covered: evidence of identification and prevention of CB; family support; staff & family training; types of assessments, types of intervention (behavioural, CBT, medication, etc)

For each question in Scope

- Evidence reviewed by NICE staff; GDG help them interpret it
- Systematic literature review for each question
- PICO analysis – what population; what intervention; what comparison groups; what outcomes
- Risk of bias analysis (method of randomising; extent of blinding, attrition rates, etc)
- Meta-analysis and plot of standardised mean differences (intervention vs comparison)
- Health economics
- Terms used in Guidance: ‘Offer’ & ‘consider’

The Guidelines (371 pages)

Takes 18 mths to produce:

- Preface & Introduction (definitions, prevalence & causes)
- Methods used in producing Guidelines
- Experience of care (service users, families, carers)
- Interventions for carers
- Organisation & delivery of care (incl training staff/carers)
- Risk factors & antecedents of CB
- Assessment
- Interventions
- Environmental interventions
- Psychosocial interventions
- Pharmacological interventions
- Reactive strategies
- Summary

1. Experience of care (Service Users, families, carers)

- Service users: Griffith et al 2013 systematic review of 17 studies of service user experiences: themes: imbalance of power; atmosphere; staff as a trigger; difficulty coping; restrictive practices (purpose, ethics, dis-comfort; distress & medication); opportunities for learning & benefitting (relationships; coping strategies etc)
- Families & carers: Griffith & Hastings 2013 systematic review of 17 studies: themes love, altered identity for families; crisis management; support as a battle for inadequate services; low expectations & high hopes

Consultations & Recommendations

- Consultation with various Service User groups and family and carer groups. Broadly supported the systematic reviews
- Recommendations: Work in partnership; provide accessible information; least restrictive practices; shared understanding; early intervention; focus on quality of life, advocacy.

2. Interventions for carers

- Improving family/carer **well-being** with CBT
  - 10 RCTs & moderate evidence in 5 of these of CBT reducing depression in family carers
  - some evidence of better QOL & lower stress
  - no health economics evidence
- No good **evidence** of benefit of involving families in CB **interventions** – but expert consensus they should be

- Recommendations
  - carers assessments & right to respite care
  - **consider** family support & info groups
  - provide emotional support

3. Organisation & delivery of care

- Transition – no RCTs in LD
- Training of carers – no RCTs but a systematic review of 14 studies of PBS training for staff (AB designs, no RCTs) - MacDonald & McGill 2013 - evidence of training producing more knowledge in staff & reductions in challenging behaviour

- Recommendations: about transition care pathways & about staff training in PBS

4. Risk factors & antecedents

- Systematic review of McClintock et al 2003 up-dated. 32 studies enough data for meta-analysis (n=127,000)
- Clear risk factors: autism (most CB); severity of disability (most CB, apart from verbal aggression); epilepsy (some CB); mental health needs (physical & verbal aggression); expressive & receptive communication (all CB); physical mobility (maybe SIB); visual impairment (SIB & stereotypy)
- Not clear/none: gender; hearing impairment

Recommendations: be aware of

- personal factors, such as
  - a severe learning disability; autism; dementia; commun-ication difficulties (expressive and receptive); visual impairment (which may lead to increased self-injury and stereotypy); physical health problems; variations with age (peaking in the teens and twenties)
- environmental factors, such as:
  - abusive or restrictive social environments
  - barren environments
  - developmentally inappropriate environments
  - environments where disrespectful social relationships and poor communication are typical or where staff do not have the capacity or resources to respond to people's needs
  - changes to the person's environment (staff changes or moving to a new care setting).

6. Preventative interventions

- Prevention of CB by family/teacher interventions
  - RCTs (eg Rickards et al 2006; Tonge et al 2007)
- Prevention/intervention for health risks:
  - RCTs (health records & annual health checks)
- Recommendations:
  - **Consider** preschool interventions for children aged 3– 5 years with emerging/developing CB
  - GPs should **offer** an annual physical health check to children, young people and adults with an LD

7. Environmental interventions

- Social &/or physical environmental interventions:
- 4 RCTs & one systematic review
  - sensory interventions not effective; structured activity effective

- Recommendations:
  - **Do not offer** sensory interventions (for example, Snoezelen rooms) without a functional assessment to establish the person's sensory profile.
  - **Consider** developing and maintaining a structured plan of daytime activity

8. Psychosocial interventions

- Parent training: 15 RCTs (relating to children)
- CBT & Behaviour Therapy interventions: 8 RCTs
- Systematic review single case studies – Heyvaert 2012

- Recommendations
  - **Consider** parent training programmes for parents or carers of children with a LD under 12 yrs
  - **Consider** personalised interventions that are based on behavioural principles & a functional assessment
  - **Consider** individual psychological interventions for adults with an anger management problem.
  - **Consider** behavioural interventions for sleep problems

9. Pharmacological interventions

- Around 15 RCTs, children mostly, some adults, various meds
- Recommendations:
  - **Consider** medication for coexisting mental or physical health problems underlying CB
  - **Consider** antipsychotic medication to manage behaviour that challenges only if:
    - psychological or other interventions alone do not produce change within an agreed time or
    - treatment for any coexisting mental or physical health problem has not led to a reduction in the behaviour or
    - the risk to the person or others is very severe (for example, because of violence, aggression or self-injury).
    - **Only offer antipsychotic medication in combination with psychological or other interventions.**

10. Reactive strategies

- Such as physical holds, mechanical and manual restraint, seclusion & ‘time out’ or prn
- No RCTs; one systematic review (Heyvaert et al 2014)

Recommendations

- **Consider** using reactive strategies as an initial intervention & introduce proactive interventions asap
- Ensure ethically sound, least restrictive, best interests
- Do risk assessment (see NICE violence & aggro guide)
- **Document, review & ensure Behaviour Support Plan also in place**

Quality Standards

1. Annual health checks
2. Parent training programmes (under 12 yrs)
3. Early functional analysis
4. Behaviour Support Plan (named co-ordinator; review)
5. Personalised day activities (in support plan)
6. Antipsychotics only with psychosocial interventions
7. Regular review of anti-psychotics (12 wks; 6mthly)
8. Documented review after use of restrictive interventions (every time)

1. Annual health checks

- Rationale: poor physical health often underlies CB
- Standard: every person with an LD registered at GP should have annual health check – including review of CB & medication & care plan
- Service providers should ensure it happens
- Healthcare professionals (GPs) should do it
- Commissioners should commission GPs to do it

2. Initial assessment of behaviour that challenges

- Rationale: early identification of triggers, environmental factors & functions - should help prevent escalation
- Should include description of the behaviour (& how often, how long), how it affects the person; what events or situations make it happen; what purpose the behaviour has
- Service providers should make sure it happens
- Health & social care practitioners should do it
- Commissioners should commission services that provide this

3. Designated coordinator for behaviour support plan

- Standard: One person designated to coordinate and ensure review of behaviour support plan
- Rationale: families said this almost never happens (& in Winterbourne View there were BSPs but they didn't happen/get reviewed)
- Behaviour Support Plan to include proactive strategies to improve QOL; adaptations to environment & routine; building new skills; calming; reactive strategies
- Review every 2 weeks for first 2 mths, then every month (to include family members & carers)
- Service providers;
- Health & social care practitioners
- Commissioners

4. Personalised daily activities

- Rationale: Often people have limited opportunities to engage in meaningful occupation/activity & this is associated with CB
- Standard: meaningful activities planed for each day, recorded in daily activity schedule, developed with person themselves and family/carers (part of BSP)

5. Restrictive interventions

- Standard: documented review of restrictive intervention (eg seclusion; manual restraint; prn) every time it is used
- Rationale: restrictive interventions should be last resort and rarely used; review should involve learning about how to avoid this; family/carers involved

6. Use of medication

- Standard: People should only receive anti-psychotic medication as part of treatment that includes psychosocial interventions
- Rationale: Very high numbers of people on anti-psychotics; often no mental health problems; limited evidence of effectiveness; lots of evidence major side effects

7. Review of medication

- Standard: multi-disciplinary review (if & how beaviour has changed; side effects) of an anti-psychotic medication 12 weeks after start and then every 6 mths
- Rationale: To reduce the over-use of anti-psychotic medication

8. Family & carer support

- Parents & carers of children under 12 yrs with behaviour that challenges should be offered parent-training programmes (delivered in groups; focused on increasing communication & other skills; follow a treatment manual; accessible; typically 8-12 sessions)
- Rationale: early intervention to prevent escalation of behaviour that is already there

Thank you for listening!

Questions?