College of Psychiatrists of Ireland

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CHALLENGING BEHAVIOUR AND INTELLECTUAL DISABILITY

A Paper by the Faculty of Learning Disability Psychiatry

Approved by Council
May 2016

Faculty of Learning Disability Psychiatry

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INTRODUCTION

This position paper is aimed at psychiatrists in Ireland working with people with an intellectual disability. The psychiatrists may be working within voluntary organisations, the HSE or MHID teams.

This paper will not aim to address issues such as access to services or service development as such. It is a practical paper in relation to the assessment and management of challenging behaviour generally.

Intellectual disability (ID) is defined by the following criteria: An IQ of less than 70, significant impairment of social or adaptive functioning, and onset in childhood.

Some people with ID may display challenging behaviour. This is not a diagnosis in itself but an indicator that such behaviour is a challenge to services, family members or Carers. It may serve a function for the person with ID (for example, by avoiding demands or communicating with other people).

This behaviour may include aggression, self-injury and disruptive behaviour. It may bring the person into contact with the criminal justice system.

People with ID who also have communication difficulties, autism, sensory impairments, and physical or mental health problems may be more likely to develop challenging behaviour.

Multiple factors are likely to underlie challenging behaviour. To identify these, thorough assessments of the person and their environment are needed. Interventions depend on the specific antecedents for each person and may need to be delivered through several avenues. The aim should always be to improve the person's overall quality of life whom should be at the centre of all interventions.

It is important that the process of assessment should include:

- Eliminating physical health issues (e.g. seizure activity)
- Addressing psychosocial aspects (such as life events) with a particular focus on environment.
- Assessing mental health issues

SAFEGUARDING

Those with ID are particularly vulnerable to maltreatment and exploitation. This can occur in both community and residential settings. A referral to the relevant social worker (in line with local safeguarding procedures) may be needed if there are concerns regarding abuse in any form, or if the person is in contact with the criminal justice system. Young men with severe challenging behaviour particularly can be at risk of abuse or maltreatment (Ref 1).

PRESCRIBING

The position paper will assume that prescribers will use a medication's summary of product characteristics to inform decisions made with people offered medication (or their family members or carers, as appropriate). The prescriber should follow relevant professional guidance, keeping up to date with relevant research in relation to pharmacological interventions in this area. The person offered the medication (or those with authority to give consent on their behalf) should provide informed consent, which should be documented.

PERSON-CENTRED CARE

This position paper offers best practice advice on the care of those with ID and challenging behaviour. Treatment and care should take into account individual needs and preferences. Care providers should offer service users with ID the opportunity to make informed decisions about their own care. If someone does not have capacity to make decisions, healthcare professionals should clearly document how the intervention being planned is in the person's best interests and with whom they have consulted.

WORKING WITH PEOPLE WITH ID AND CHALLENGING BEHAVIOUR, AND THEIR FAMILIES AND CARERS

a) Ensure that the professional support network has been formally identified and made known to the service user, family and other relevant individuals involved in providing care.
b) Through a person centred approach, take into account the severity of the person's disability and challenging behaviour, their developmental stage, and any communication difficulties or physical or mental health problems.
c) Aim to provide support and interventions in the least restrictive setting which can support the individual. This can include the person's home or local services.
d) Aim to take a long term approach in preventing future episodes of challenging behaviour by identifying recurrent triggers.
e) Aim to improve quality of life.
f) Make people aware of advocacy services.

DELIVERING EFFECTIVE CARE

If initial assessment and management have not been effective, or the person has more complex needs, service providers should ensure that staff providing direct care should participate in regular strategy meetings involving all stake holders. This is to coordinate a plan and ascertain if additional resources are required and also to optimise input.

The strategy meeting should inform if further advice/opinion, supervision are required from the service providers. The implementation of any care or intervention may involve a range of staff including psychologists, psychiatrists, behavioural analysts, nurses, social care staff, speech and language therapists, educational staff, occupational therapists, physiotherapists, physicians and pharmacists. Other disciplines may also be required if appropriate.

STAFF TRAINING, SUPERVISION AND SUPPORT

Service providers should ensure that all staff working with people with ID and challenging behaviour are trained to deliver proactive strategies to reduce the risk of challenges, including:

✓ developing a daytime structure taking into account personal preferences and interests.
✓ adapting a person's environment and routine.
✓ incorporating strategies to help the person develop an alternative behaviour to achieve the same purpose by developing a new skill (for example, improved communication, emotional regulation or social interaction).
✓ the importance of including people, and their family members or carers, in planning support and interventions.
✓ strategies designed to calm and divert the person if they show early signs of distress.
✓ delivering reactive strategies using the least restrictive approaches possible as a last resort.

Service providers should ensure that all staff gets personal and emotional support through a skilled facilitator to:
✓ enable them to deliver interventions effectively for people with ID and challenging behaviour.
✓ feel able to seek help for difficulties such as burnout arising from working with people with ID and challenging behaviour
✓ recognise and manage their own stress.

ORGANISING EFFECTIVE CARE

It is important for service providers to:

• minimise the need for transition between different services or providers with clear contingency plans when placements are at risk due to severe challenging behaviour.
• allow services to be built around a consistent and uniform care pathway (and not the other way around).
• establish clear links (including access and entry points) to other care pathways (including those for physical healthcare needs).

Such care pathways should be:

• understandable for people with ID and challenging behaviour, their family members or carers, and staff.
• accessible and acceptable to people using the services, and responsive to their needs.

Formal service user and family feedback should be sought in relation to this to evaluate the quality of service provision.

SUPPORT AND INTERVENTIONS FOR FAMILY MEMBERS OR CARERS

When providing support to family members or carers (including siblings):

• recognise the impact of living with or caring for a person with ID and challenging behaviour.
• consider family support and information groups.

THE ASSESSMENT PROCESS

When assessing challenging behaviour -

- the complexity and duration of the assessment process is proportionate to the severity, impact, frequency and duration of the behaviour.
- everyone involved in delivering assessments understands the criteria for moving to more complex and intensive assessment.
- all current and past personal and environmental factors (including care and educational settings) that may lead to challenging behaviour are taken into account
- assessment is a flexible and continuing (rather than a fixed) process, because factors that trigger and maintain behaviour may change over time.
- assessments are reviewed after any significant change in behaviour.
- assessments are focused on the outcomes of reducing challenging behaviour.

RISK ASSESSMENT

Assess and regularly review the following areas of risk during any assessment of challenging behaviour:

- suicidal ideation, self-harm (in particular in people with depression) and self-injury
- harm to others
- self-neglect
- breakdown of family or residential support
- exploitation, abuse or neglect by others
- rapid escalation of the challenging behaviour

Functional assessment of behaviour is usually carried out through psychology and behaviour support teams. This explores the function of behaviour in the context of its antecedents and consequences.

After initial assessment, it is important to develop a written statement (formulation) that sets out an understanding of what has led to the challenging behaviour and the function of the behaviour. This should be used to develop the behaviour support plan.

MEDICATION

Following a thorough assessment as outlined above, and eliminating physical and psychosocial factors which need to be addressed, a medication review may need to be considered.

Consider medication to manage challenging behaviour only if:

- psychological or other interventions alone do not produce change within an agreed time

or

- following treatment guidelines for any coexisting problems have 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).

Prescribing should not be used as a substitute for deficits in other areas of service delivery.

Having first optimised existing medication, consider prescribing new or additional medication if considered beneficial.

Medication is best offered in combination with psychological or other interventions. When choosing which medication to offer, take into account the person's preference (or that of their family member or carer, if appropriate), side effects, response to previous medication and interactions with other medication.

There are now several published reports describing controlled and open label clinical trials. These are used to guide clinical practice when working with ID and challenging behaviour (Ref 2).

Medication should initially be prescribed and monitored by a specialist who should:

• identify the target behaviour.
• decide on a measure to monitor effectiveness.
• start with a low dose and use the minimum effective dose needed.
• only prescribe a single drug.
• monitor side effects.
• review the effectiveness and any side effects of the medication as appropriate.
• stop the medication if there is no indication of a response.
• only prescribe p.r.n. (as-needed) medication for as short a time as possible and ensure that its use is recorded and reviewed.

Ensure that the following are documented:

• a rationale for medication (explained to the person with a learning disability and everyone involved in their care, including their family members and carers).
• how long the medication should be taken for.
• a strategy for reviewing the prescription and stopping the medication.

If there is a positive response to medication:

✓ record the extent of the response, how the behaviour has changed and any side effects or adverse events.
✓ conduct a review including other health professionals as appropriate.
✓ only continue to prescribe medication that has proven benefit.

When prescribing is transferred to primary or community care, or between services, the specialist should summarise the above and communicate it to the new prescriber.

INTERVENTIONS FOR SLEEP PROBLEMS

Consider behavioural interventions for those with ID and challenging behaviour that consist of a functional analysis of the problem sleep behaviour to inform the intervention (for example, not reinforcing non-sleep behaviours).

Do not offer medication to aid sleep unless the sleep problem persists after a behavioural intervention, and then only:

- by a psychiatrist with expertise in its use in people with ID.
- together with non-pharmacological interventions and regular reviews (to evaluate continuing need and ensure that the benefits continue to outweigh the risks).

References

1. AASRG. Building confidence, improving lives, delivering change. July 2015.

2. Taylor D, Paton C & Kapur S. The Maudsley Prescribing guidelines in Psychiatry. 2015.