Chapter

1

Intellectual Disability

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Introduction

People with intellectual disability experience greater health inequalities and a disproportionate number of comorbid physical health disorders when compared with the general population (Emerson & Hatton 2013). They often have complex medication regimens to support them in managing their health (Eady et al. 2015). For these reasons, it is important that clinicians, people with intellectual disability, and their carers are well informed about the medication that they are likely to use throughout their lives.

The focus of this edition of the *Frith Prescribing Guideline*s is to guide clinicians in how to approach the treatment of people with an intellectual disability and ensure that they and their carers are at the centre of the decision-making process. This is to achieve the best possible clinical outcomes for the person while ensuring they are empowered as much as possible, and with due respect being paid to their autonomy and dignity.

Definitions

The Centre for Disease Control (CDC) defines developmental disorders as ‘a group of conditions which cause an impairment in physical, learning, language or behavioural development. These conditions begin during the developmental period and may impact on day-to-day functions, and usually last throughout a person’s lifetime’ (Centre for Disease Control and Prevention 2022). The important aspect of the definition of developmental disorders is their origins in childhood, as compared with cognitive disorders that may occur in adults because of disease or head injury where the adult did not have signs of a developmental disorder prior to the event causing the current impairment.

Disorders of intellectual development is a term used to describe developmental disorders that includes intellectual disability (Simpson et al. 2020; Salvador-Carulla et al. 2011). The World Health Organization describes disorders of intellectual development as ‘ a group of etiologically diverse conditions originating during the developmental period characterised by significantly below average intellectual functioning and adaptive behaviour that are approximately two or more standard deviations below the mean (approximately less than the 2.3rd percentile), based on appropriately normed, individually administered standardized tests’ (ICD-11; https://icd.who.int/browse/2024-01/mms/en#605267007).

Developmental disorders are graded according to severity, which can be helpful in clinical practice in communicating the level of functioning of a person. The categories are mild (50–70), moderate (35–49), severe (20–34), and profound (<20), graded according to scores derived from cognitive testing. Categorisations should not obscure the strengths and abilities innate to each person (American Psychiatric Association 2013).

Box 1.1 The American Psychiatric Association (APA) Diagnostic Criteria for Intellectual Disability (DSM-5 Criteria)

1. Deficits in general mental abilities.
2. Impairment in adaptive functioning for individual's age and sociocultural background which may include communication, social skills, person independence and school or work functioning.
3. All symptoms must have an onset during the developmental period.
4. The condition may be subcategorised according to severity based on adaptive functioning as mild, moderate, or severe.

(American Psychiatric Association 2013)

Causes of Intellectual Disability

The causes of intellectual disability are varied and in many cases are unknown. Genetic disorders such as Fragile X syndrome (Sitzmann et al. 2018), chromosomal disorders such as Down syndrome, disorders due to structural abnormalities such as cerebral palsy, and perinatal effects such as hypoxia at birth or prematurity have all been mentioned (Karam et al. 2015) (see Table 1.1).

The Health of People with Intellectual Disability

The health outcomes for people with intellectual disability are poor, with men and women dying more than 22 years earlier than people in the general population (Glover et al. 2017; Heslop & Hoghton 2018). People with intellectual disability experience more comorbid disorders throughout their lifetime, with estimates of a mean of 11 comorbid disorders per person (Kinnear et al. 2018). Specific examples include epilepsy that is more prevalent, especially in autistic people (Lukmanji et al. 2019). Diseases associated with lifestyle are more common: for example, obesity, which can lead to metabolic disorders such as diabetes (Hsieh et al. 2014). As a result, people with intellectual disability use more medications for physical and mental health disorders across their lifetimes, exposing them to unwanted effects of medication (McMahon et al. 2020). For these reasons, it is important to be aware of the potential impact of prescribing practice on the person and their well-being when considering drug interventions, and when assessing the overall benefit to the person of using medication.

Psychiatric Disorders and Behaviours That Challenge

The diagnosis and treatment of psychiatric disorders and behaviours that challenge in people with intellectual disability may require a different approach to that in the general population. Such conditions often present differently in people with intellectual disability compared to people in the general population. The signs and symptoms may be misattributed to the person's developmental disorder – this is described as diagnostic overshadowing (Reiss & Szyszko 1983). In addition, symptoms of an underlying physical condition, or a reaction to environmental changes, may mask an underlying psychiatric disturbance (Bertelli et al. 2015). Difficulties in diagnosis may be further compounded by a person's communication challenges.

Table 1.1 Causes of intellectual disability

Period of origin	Nature of disorder	Common examples
Prenatal period	**Genetic disorders** Chromosome aberrations Single gene mutations Microdeletions	Down syndrome (trisomy 21) Tuberous sclerosis, phenylketonuria, mucopolysaccharidoses, Fragile X syndrome, Prader–Willi syndrome, Williams syndrome, Smith–Magenis syndrome
	Congenital malformations Central nervous system malformations Multiple malformation syndromes	Neural tube defects Cornelia de Lange syndrome
	Exposure Maternal infections Teratogens Pre-eclampsia, placental insufficiency Severe malnutrition Trauma Iatrogenic	Congenital rubella, HIV Foetal alcohol spectrum disorder Prematurity Intra-uterine growth retardation Physical injury Radiation, medications
Perinatal period	Infections Delivery Other causes	TORCH infections: toxoplasmosis, hepatitis B, syphilis, herpes zoster, rubella, cytomegalovirus, herpes simplex, Anoxic brain damage Hyperbilirubinaemia
Postnatal period	Infections	Encephalitis
	Metabolic	Hypoglycaemia
	Endocrine	Hypothyroidism
	Cerebrovascular	Thrombo-embolic phenomena
	Toxins	Lead poisoning
	Trauma	Head injury
	Neoplasms	Meningioma, craniopharyngioma
	Psychosocial factors	Under-stimulation
Any	Untraceable or unknown	

Psychotropic medication is used to support people who have psychiatric disorders and behaviours that challenge. The use of antipsychotics has come under scrutiny in recent years because they have been used to manage behavioural challenges rather than to treat psychiatric disorders (O’Dwyer et al. 2019). Prescribing medication for reasons not connected to its recognised indications should not be part of good clinical care.

Evidence-Based Practice

The evidence base for the use of psychotropic medications is limited. Consequently, a wide range of psychotropic medications are used outside their licenced indications to manage behaviours that challenge, which may or may not be associated with an underlying psychiatric disorder (Bowring et al. 2017). In a Dutch study, 32% of the study group were prescribed antipsychotics for behavioural disturbances (de Kuijper et al. 2010). The reasons for this are many, including:

- Pressure from professionals/carers for immediate resolution of a problem
- Limited resources available for changing the environment
- Lack of appropriately trained staff in residential homes
- Shortfall in the number of psychiatrists
- Lack of input from clinical psychologists, specialist clinical pharmacists, and speech therapists.

Even with optimum resources and good professional input, some behavioural problems remain unchanged, causing serious risk to the person and others. In some cases, the use of psychotropic medication brings welcome relief: for example, using low doses of risperidone in those with autism may reduce stereotypies and disturbed behaviour (Jesner et al. 2007; Rajapakse & Pringsheim 2010).

In some cases, medications can reduce elevated levels of arousal, allowing the person to then participate in other therapeutic approaches (Ali et al. 2014). Nevertheless, clinicians who prescribe psychotropic medications outside their licenced indications may feel professionally vulnerable and open to criticism for 'unethical practice' (Bhaumik et al. 2015). Strong views exist about 'chemical straitjacketing' for behavioural disorders in the absence of adequate resources (Moncrieff 2013).

Prescribing Medication

The clinical activity of prescribing medication is part of the professional role of medical and non-medical prescribers. Clinicians have a professional responsibility to prescribe medication judiciously by taking in to account the benefits to the person of using medication and to be aware of their potential adverse consequences (General Medical Council 2021). It is essential to understand the purpose of prescribing medication and the desired impact that is required. Prescribing without a focused and defined purpose is irresponsible and potentially dangerous.

It is important to understand and to focus on the therapeutic benefit of medication for the person. What may work for one person may not be effective for another. When prescribing, the benefits to the person should be to arrest disease progression or alleviate suffering. Medications often have associated side effects that could have adverse consequences for the individual. Common effects such as tremor or weight gain can have important and distressing impacts on the person's health and, ultimately, their quality of life (Gründer et al. 2016). Excessive weight gain due to using medication predisposes to development of metabolic disorders such as diabetes mellitus that can have major consequences for a person's health and their lifespan (Raben et al. 2017).

Movement disorders may affect a person's ability to engage in activities and have psychological impacts affecting their participation in life (Sheehan et al. 2017). Additionally, the experience of undesirable effects may affect carers and family members supporting the person where a change in behaviour or physical health may be attributable to using medication (Hall & Deb 2008). For these reasons, prescribing is an important skill in clinical practice that clinicians must consider carefully and strive to achieve high standards in prescribing practice for the benefits of the person.

Prescribers have a duty to inform those using medication about the actions and impacts of medication on them, to enhance their understanding when gaining their consent to treatment (Adams et al. 2018). To achieve this, it is important to engage with people to support them in using drug regimens appropriately. For people who lack mental capacity or have fluctuating capacity, gaining their consent to treatment can be challenging, but appropriate processes are available that clinicians should abide by (Social Care Institute for Excellence 2009).

The Body and Medication

Considering the therapeutic indications for using medication, clinicians should be aware of the physical impacts of medication on the body and how the organs metabolise medication. When initiating medication, it is prudent for prescribers to be aware of potential adverse impacts due to drug interactions and to act accordingly to avoid untoward effects that could affect the overall efficacy of the medication (English et al. 2012).

Pharmacokinetics is the process of absorption, distribution, and elimination of medication by the body's organs, which affects the availability of the active components of drugs (Loucks et al. 2015). For a person using multiple medications, the potential for drug interactions is greater and can affect the bioavailability (pharmacokinetics) of the agent and therefore the impact (pharmacodynamics) of it on the body (Daniel et al. 2022). An understanding by the prescriber of the disease states of a person helps to inform how drugs will be metabolised: for example, lithium salts in a person with impaired renal function.

Pharmacodynamics is the study of the impact of the active component of drugs on the body, including the brain (Rowland 2010). Prescribers will be aware of the desired impacts of medication, but such impacts may not be uniform for everyone, especially people with intellectual disability and other developmental disorders. For example, standard doses of a medication may be over-sedating for one person but stimulating for another, or therapeutic for some but sub-therapeutic for others.

Pharmacogenomics

An emerging area of great interest is how a person's genes determine how they metabolise the active ingredients of medications. Knowledge about individual responses to how drugs are absorbed, metabolised, and impact on disease could unlock the prospect of clinicians designing drug regimens to optimise the therapeutic effects in a personalised approach (Carvalho Henriques et al. 2020). Such knowledge and skill could have impressive impacts and benefits for people with developmental disorders using complex drug regimens (Perera et al. 2022).

Polypharmacy

Given that people with developmental disorders experience greater rates of comorbid disorders, it is not surprising that they will use a variety of medications together to treat physical and mental health conditions (McMahon et al. 2020). Such complicated drug regimens may lead to drug interactions and compounding adverse effects that may negatively affect a person's quality of life (Valenza et al. 2017). Polypharmacy in clinical practice is not advised, but for many it is inevitable. Regardless, it is important that there is clarity for the person on the indications of using all medications and their potential consequences.

Prescribing Practice

When commencing medication, it is advisable that prescribers consider the maxim of 'start low and go slow', whereby lower doses than standard ones are suggested because of the sensitivity of people with intellectual disability to medication and the greater likelihood of developing adverse effects (Osugo & Cooper 2016). A slower approach to increasing doses is desirable to avoid adverse effects. Therefore, gaining an impression of the therapeutic effect may take longer than would be expected in the general population. For this reason, it is prudent not to abandon potentially beneficial medication where the impact is not immediately apparent but to agree a timescale for a therapeutic trial. This allows for a more informed evaluation of a drug's effectiveness.

In the absence of benefit, it is important to consider withdrawing medication and how this should be undertaken (Deb et al. 2020). With some agents – for example, antidepressants and antipsychotics – abrupt or rapid withdrawal is not advised because of withdrawal effects that can adversely affect a person's well-being and level of functioning (Davies & Read 2019; Hengartner et al. 2020). A programme of withdrawal can minimise the effects the person could experience (Shankar et al. 2019). For this reason, regular review of medication, especially psychotropic medication, is essential to avoid the unnecessary long-term use of agents that do not have discernible benefits to the person and may affect their quality of life because of adverse effects.

Overuse of Medication

An issue of great importance and concern is the overuse of medication in people with intellectual disability (Sheehan et al. 2015). Formal inquiries into incidents of poor care in in-patient services revealed that psychotropic medication was prescribed to excess and often without clinical indications, especially where it was used to control behaviour (Flynn 2012). In England, this issue has resulted in a review of the culture of prescribing psychotropic medication, in particular antipsychotics, leading to a public campaign to stop the overuse of medication in people with intellectual disability. The objective is to reduce reliance on psychotropic medication and to implement non-pharmacological approaches to support behaviours that may challenge services. The impact has been to highlight the inappropriate use of medication in people who often cannot advocate for themselves and to develop alternatives to medication. As a result, there have been changes in the attitudes of prescribers, carers, and families to a reliance on medication. Such an approach, and a change in clinical practice, could have beneficial effects on a person's quality of life and respect of their human rights.

Issues Affecting Prescribing in People with Intellectual Disability

Communication

Difficulties with communication are frequently encountered by clinicians treating people with intellectual disability; in addition, associated hearing or vision loss can often create physiological challenges (Smith et al. 2020). For the person, cognitive impairments can make attending to and processing information more difficult, while the prescriber may struggle to communicate effectively with the person (Martin et al. 2010). It is essential to involve the person at all stages of the decision-making process when prescribing new treatments, or when altering or withdrawing existing treatments. Consulting a family member or carer on their knowledge of the person is advisable when a person cannot express their personal views. Such an approach helps to inform the decision-making process and should ensure the person's best interests remain central (Bigby et al. 2019). It is important to involve the person if they plan to manage their own medication regimen. Where a person is supported by a carer to use medication, it is essential that carers understand the importance of the medication, its functions, and any side effects. They need advice on observing for adverse reactions and how to seek medical attention.

There are many methods and aids available to assist the clinician with communicating with a person with intellectual disability. Makaton signing is an effective method of communication for people with intellectual disability which utilises sign language, symbols, and speech to provide multiple avenues for communication (Grove & Walker 1990). Visual communication aids such as the Picture Exchange Communication System (PECS) and Talking Mats may be beneficial when supporting people who do not use spoken language (Murphy & Cameron 2008; Sulzer-Azaroff et al. 2009). Processing visual information may be easier than processing auditory information (Hollins 1996). Asking for the assistance of a family member or carer to advise on the best communication methods for the person is important.

Shared Decision-Making

While it is medically and ethically right to withdraw medications that people do not require, it is important to balance this with the positive medical benefits the person may receive from using them. An open dialogue with the person and, where necessary and appropriate, their family, carer, or advocate about the potential positives and negatives of continued use of medication is important to create a collaborative decision-making process (Sullivan & Heng 2018). Such an approach should ensure that the person's views and concerns are expressed and addressed while allowing the clinician to fully explain their concerns or views regarding medication regimens. This should help to achieve better clinical outcomes for the person.

Mental Capacity and Incapacity

Mental incapacity is where a person is unable, by the reason of impaired mental ability, to make a decision for themself on the matter in question, or unable to communicate that decision. No one can give consent on behalf of an incompetent adult. The assessment of an adult's capacity to make a decision about their own medical treatment is a matter of clinical judgement guided by the Mental Capacity Act (Social Care Institute for Excellence 2009). It is the personal responsibility of the professional proposing to treat a person to judge whether the patient has the capacity to give valid consent. The clinician has a duty to give the patient an account in simple terms of the nature of the treatment, the benefits versus risks of the proposed treatment, and the alternative options.

Determining mental capacity can be a complex issue when supporting people with intellectual disability. A person may have capacity to make decisions in certain areas of their lives (e.g., which clothes to wear), but lack capacity in other areas (such as personal care or finances). Capacity is not fixed but can fluctuate over time: for example, a person may lose capacity while unwell (either physically or mentally), then regain capacity on recovery. Due to these complexities, it is essential that clinicians have a solid foundation in understanding mental capacity.

To demonstrate capacity in relation to treatment, a person should be able to:

- understand in simple language what the medical treatment is, its purpose and nature, and why it is proposed;
- understand its principal benefits and risks, and any alternative options;
- understand, in broad terms, what the consequences of not receiving the proposed treatment may be;
- retain the information for long enough to make an effective decision;
- weigh that information on balance and arrive at a free choice;
- communicate their decision.

In day-to-day clinical practice, decisions regarding treatments are often taken for adults who lack capacity using ‘best interest’ principles. There is clear guidance on formulating best interest decisions within the Mental Capacity Act of England and Wales (Social Care Institute for Excellence 2009). The key principles are:

- The person remains at the centre of the decision-making process and participates as much as they are able.
- Parents, carers, and other people close to the patient need to be consulted for information about the person’s preferences, choices, and best interests.
- Consideration must be given to the least restrictive option for the person’s rights and freedom.
- For decisions regarding serious medical treatment or a change in accommodation when the person is classed as ‘un-befriended’ (i.e., has no one to speak for them aside from paid carers), then involvement of an Independent Mental Capacity Advocate (IMCA) is required.
- Intervention from the Court of Protection should be sought for treatment decisions that are more serious or contentious.

Consent to Treatment

Guidelines for medical practitioners registered with the General Medical Council in the UK state that, wherever possible, express consent should be obtained from the person, and/or where appropriate their family/guardians if they do not have mental capacity (General Medical Council 2020). Express consent is provided either verbally or in writing, but other communication methods are acceptable if it enables the person to participate in the decision-making process. Documentation of all decisions on mental capacity is essential in clinical practice.

For a person’s consent to be legally valid and professionally acceptable, they must be:

- Capable of taking the specific decision (competent)
- Acting voluntarily (free from coercion)
- Be provided with enough information (in a form they can understand) to enable them to take the decision (informed)

For adults with intellectual disability, this is often a process over time, rather than a 'one-off' effort, and particular attention should be paid to:

- The mode of communication (particularly the use of communication aids)
- The environment in which information is provided
- The person's familiarity with whoever provides the information
- The pace at which the information is provided

Person-Centred Care

Adopting a person-centred approach in care is fundamental to providing high-quality healthcare to people. The person and their family/carers should be consulted on all aspects of planning and decisions concerning their healthcare. Historically, people with intellectual disability have not been involved in decisions about their health (Sullivan & Heng 2018). Person-centred care is considered good clinical practice (van der Meer et al. 2018). Guidance on developing person-centred plans is available that should help to create holistic long-term plans for the person that recognise their needs, values, and goals in life and how to achieve them.

The six guiding principles of patient-centred care are:

- Care and support are person-centred (personalised, co-ordinated, and empowering)
- Services are created in partnership with the public and communities
- A focus on equality and the narrowing of inequalities
- Carers are identified, supported, and involved in the person's care and decision-making process
- Voluntary, community, social enterprise, and housing sectors to be involved as key partners and enablers of people
- Volunteering and social action are seen as key enablers

Conclusion

People with intellectual disability experience comorbid disorders that require complex medication regimens that can affect their quality of life. They are especially sensitive to the effects of medication. They are at risk of over-medication especially where medication is not monitored regularly, and they may not be able to advocate for themselves. Understanding mental capacity and communication styles is essential for prescribers to effectively support people with intellectual disability. Prescribing clinicians need to strive to involve people in their care with the support of families and carers.

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