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COMMENTARY

# Ethical Prescribing of Psychotropic Medications for People with Neurodevelopmental Disorders

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## Abstract

**Objectives** People with neurodevelopmental disorders (NDDs) such as intellectual and developmental disabilities (IDD) and autism are subjected to restrictive practices like physical restraint and the overuse of psychotropic medications for challenging behaviour in the absence of a psychiatric disorder. This practice may lead to human rights violations. Rational and evidence-based shared decision-making for person-centred planning will help reduce this practice.

**Methods** We have discussed in this paper the issue of the overmedication of people with NDD, explaining how this practice may violate the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD).

**Results** We have discussed how the following UN CRPD Articles may be affected by overmedication, including Article 15 (degrading treatment or punishment), 16 (abuse), 17 (the integrity of the person), and 25 (health). The other Articles that may be indirectly affected by this practice are 5 (equality and non-discrimination), 9 (accessibility), 19 (independent living and community inclusion), 21 (access to information), 24 (education), 26 (rehabilitation), 27 (work and employment), 28 (adequate living standard), and 30 (participation in recreation and leisure).

**Conclusions** Overmedication of people with NDD, particularly the off-licence use of psychotropics for challenging behaviour, the side effects of these medications impacting the person's quality of life are likely to violet several UN Articles on Rights of Persons with Disabilities. Following the right guidelines may help reduce these human rights violations.

**Keywords** Neurodevelopmental disorders (NDDs) · Intellectual and developmental disorders · Autism · Overmedication · Off-licence psychotropic prescription · Human rights violations · UN CRPD

People with neurodevelopmental disorder (NDD) are vulnerable to being affected by the violations of the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006). This is evident because people with NDD are often subjected to restrictive practices such as physical restraint and inappropriate overprescribing of psychotropic medications (National Disability Insurance Scheme, 2020). Approximately half of the adults with intellectual disabilities (ID) (see review by Deb et al., 2023a; Song et al., 2023) and a similar proportion with ASD (see review by Bertelli et al., 2022; Rotta et al., 2022; Shurtz et al., 2022) are prescribed psychotropic medications such as antipsychotics, antidepressants, mood stabilisers, and anti-anxiety medications. These medications are indicated for the treatment of various psychiatric disorders. However, in people with NDD, these medications are often used outside their licenced indication to treat challenging behaviour in the absence of a psychiatric disorder (de Kuijper et al., 2010; Sheehan et al., 2015). It is estimated that every day in England, around 35,000 adults with ID receive antipsychotic and antidepressant medications for conditions for which they are not indicated (Glover et al., 2015). This off-licence use of psychotropics in people with NDD in the absence of a psychiatric disorder is a cause for major public health concerns and may constitute unethical practice, particularly in the absence of good quality evidence for their efficacy.

This practice may impact several Articles in the UN CRPD (2006). For example, Article 15 prevents people from receiving degrading treatment and punishment, whereas inappropriate psychotropic prescription may be perceived by many as a restrictive practice leading to punishment

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and abuse (Article 16), affecting the integrity of the person (Article 17). Article 5 gives people the right to equality and non-discrimination, whereas, in the absence of explicit consent, the use of medication which may cause harm and where there may be a less harmful alternative available may be seen as discriminatory. Article 9 emphasises the right to accessibility, and Article 19 independent living and community inclusion. Side effects associated with many psychotropic medications may prevent people from exercising these rights. In a similar way, these side effects that affect a person's quality of life (QoL) may affect their health (Article 25), right to education (Article 24), appropriate rehabilitation (Article 26), access to appropriate work and employment (Article 27), and participation in appropriate recreation and leisure (Article 30). Similarly, because of these side effects, the person may be unable to exercise their rights to access adequate living standards (Article 28). Their access to information (Article 21) may be affected if the medication-related information is not provided to them in an appropriate format (such as an accessible or easy-read format).

## Overmedication

The use of pharmacological treatment for people with ASD has increased significantly over the years, from 57% in 1998 to 64% in 2014 ($p < 0.05$) (Murray et al., 2014), and is also used in children as young as 2 years of age (Mandell et al., 2008). The rate increases with age (11% among children aged 3–5 years, 46% among 6–11 years old, and 66% among 12–17 years old) (Coury et al., 2012).

Antipsychotics are prescribed for 24–32% of adults with ID compared with 1% in the general population who do not have ID (Deb et al., 2023a). However, only 2–4% of adults with ID are diagnosed with schizophrenia (Deb et al., 2022a), for which antipsychotics are indicated. Therefore, antipsychotics are used for psychosis among only 22% of adults with ID, and in 72% of cases, no severe psychiatric illness is present. On the other hand, antipsychotics are used 58% of the time for challenging behaviour (de Kuijper et al., 2010; Sheehan et al., 2015). Similarly, 45% of people with ID with challenging behaviour receive antipsychotics. Furthermore, the long-term use of antipsychotics carries an increased risk of medication-related adverse events, which can impair a person's QoL (Ramerman et al., 2018).

In Australia, the National Disability Insurance Scheme (NDIS), Quality and Safeguarding Commission (2020) described this practice as 'chemical restraint' which is defined as 'The use of medication or chemical substance for the primary purpose of influencing a person's behaviour, control or sedate them. It does not include the use of medication prescribed for the treatment of, or to enable treatment of, a diagnosed mental disorder, a physical illness or a physical condition (Page 9)'. This practice is likely to affect Articles 15 (degrading treatment or punishment) and 16 (abuse) if the medications are used solely to sedate a person or control their behaviour in the absence of a psychiatric disorder and evidence of efficacy.

## Off-Licence Prescribing

The off-licence use of psychotropics for challenging behaviours may not be inappropriate if the right safeguards are in place and the relevant guidelines are followed (see Table 1). However, the off-licence use of medications may be considered unethical even in the absence of harm if there is no evidence for their efficacy (Cervantes et al., 2017). However,

**Table 1** Guideline for off-licence use of medication.

| | |
|---|---|
| Ensure that the medication's efficacy is established in other populations or people with disabilities for other indications | Please adhere to any published guidelines, if any |
| Ensure that the medication's risk profile is acceptable in other populations | Involve as much as possible the person with disabilities, their family, and other carer givers and professionals involved in the care and try to come to a consensus |
| Ensure that the medication has been shown to be safe for use in people with disabilities | Keep a record of all discussions |
| Consider whether a body of experts in the field would consider the same medication for the same indication for the same population | Make it explicit to relevant people that the medication is used outside its licenced indication and explain the rationale for its use |
| Always carefully weigh the possible benefit of using the medication against potential risks and discuss this openly with all relevant stakeholders | If applicable, please be explicit about the evidence or lack of it for using the medication in people with disabilities |
| Ensure that the procedure for appropriate monitoring and follow-up is in place and adhered to | Ensure other accepted interventions with less risk have been considered, and the medication is still needed |
| Use the lowest possible dose for the shortest possible time, and increase the dose slowly, if necessary | Review its efficacy and adverse effects regularly with the plan to discontinue at the earliest possible opportunity if appropriate. Set the next review date at each review |

the evidence to support these medications for challenging behaviour is weak (see review by Deb et al., 2023a).

The US Federal Drug Administration (FDA) approves the short-term use of risperidone and aripiprazole for irritability and agitation among children and adolescents with ASD. Similar indications are proposed in the UK British National Formulary (BNF). However, psychotropics are not licenced for long-term use in children and adults with NDDs for challenging behaviour in the absence of a psychiatric disorder. Therefore, clinicians are advised to follow recommendations in published guidelines for off-licence prescribing of these medications in people with NDD. Several organisations in the UK provide guidelines on the off-licence use of licenced medication, including UK Government Medicine Safety (www.gov.uk), the General Medical Council (www.gmc-uk.org), the National Institute for Health and Care Research (www.nice.org.uk), and the UK Royal College of Psychiatrists (2017). We have summarised these recommendations in Table 1. Similar recommendations are available in other countries.

## Polypharmacy and High-Dose Medication Use

Despite the widespread condemnation of and lack of evidence for the efficacy of antipsychotic polypharmacy (simultaneous use of more than one antipsychotic), this practice remains widespread (Taylor, 2010). The merits and demerits of combining an antipsychotic with another group of psychotropic medications specifically for challenging behaviour in adults with ID are currently unknown (Olson et al., 2002). In a recent Dutch study, 13% of the 103 participants with ID who did not receive psychotropic medications (23% of all participants) and 61% of those treated with more than two psychotropic drugs had more than three adverse events (Scheifes et al., 2016). Psychotropic polypharmacy rates vary between 5.4 and 54% in people with ASD (Jobski et al., 2017; Spencer et al., 2013). Polypharmacy increases the chance of drug-drug interactions leading to side effects affecting the person's QoL. Therefore, this practice, in the absence of their efficacy, could be considered unethical.

Similarly, the off-licence use of higher than recommended doses of antipsychotics for people with ID for addressing challenging behaviour is not uncommon (23–28%) (Branford, 1996; Deb et al., 2015) and raises ethical concerns as this may lead to side effects. This rate did not seem to have changed over the last two decades. The UK Royal College of Psychiatrists (2023) produced guidelines on the use of high-dose antipsychotics, which should help reduce this unethical practice. Their executive summary states, 'While there is little convincing evidence that off-label prescription of doses of antipsychotic medication above the licenced dosage range has any therapeutic advantage in any clinical setting, there is clear evidence for a greater side-effect burden and the need for appropriate safety monitoring (Page 6)'. They recommend that 'this should be seen as an explicit, time-limited individual trial with a distinct treatment target. There should be a clear plan for regular clinical review, including safety monitoring. The high-dose regimen should only be continued if the trial shows evidence of benefit that is not outweighed by tolerability or safety problems (Page 6)'. They also recommend shared decision-making for this involving the patients and their caregivers.

## PRN Medication

As required (PRN), psychotropic medications such as antipsychotics and benzodiazepines are often used to manage acute episodes of challenging behaviour in people with NDD. However, in the absence of a proper guideline, this practice is vulnerable to misuse, and inappropriate and overuse of PRN medication may lead to human rights violations affecting UN CRPD Articles 15 (degrading treatment or punishment), 16 (abuse), 17 (the integrity of the person), and possibly 25 (health) if this causes side effects. The recommendations from the national (Deb et al., 2006) and international good practice guidelines (Deb et al., 2009) are presented in Table 2.

## Adverse Effects

While the efficacy of psychotropic medications in people with NDD is either unknown or supported by poor evidence, there is definite evidence of the risk of adverse events associated with these medications. Therefore, clinicians must carefully weigh the benefits against the risks before considering these medications. A recent meta-analysis of antipsychotic RCTs for people with ASD has shown that people receiving medications are at 2.25 higher risk of developing any adverse events, 4.15 higher risk for developing increased appetite, 3.9 for weight gain, and 6.66 odds for developing sedation when compared with those who received placebo (all statistically significant) (Deb et al., 2023b).

These medications are often prescribed for a long time without an appropriate review. This happens although monitoring adverse effects may not always be possible in people with NDD, particularly those who have severe and profound ID. The risks for drug-drug interaction and side effects increase as psychotropic medications are used over and above many medications that the person is already taking for physical conditions. Physical problems such as acid reflux, pain, constipation, and epilepsy are more prevalent

**Table 2** Guideline for as-required (PRN) medication (www.ld-medication.bham.ac.uk).

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|---|---|
| The prescription of 'as-required' medications should be part of an overall 'person-centred treatment/care plan' and, when possible, should be prescribed after discussion with the person with disabilities, their caregivers, and other professionals involved in the care of the person | The 'as-required' medications that may be administered by multiple routes (e.g. via oral or intramuscular route) must be prescribed separately, with clear instructions as to why one should be preferred over another |
| The choice for the route of administration of PRN medication (oral vs parenteral) by the person with disabilities and their caregivers should be recorded clearly and respected | Discontinuation of any 'as-required' medication that has not been used for 6 months or longer (the exception is rescue medication for status epilepticus, prolonged seizures, or prolonged cluster of seizures) should be considered |
| The reasons/indications for administering 'as-required' medications must be recorded clearly, with objectives set at the outset for measuring the outcome over a set period | Two medications of the same class for the same condition (exceptions are the antiepileptic medications) should not be used |
| The 'as required' prescription must be monitored at regular intervals, the date for which should be set at the time of prescribing | Prescriptions must be reviewed and, where appropriate, re-written as regular prescriptions if needed regularly, even though they were originally prescribed as 'as-required' medications |
| The minimum interval between doses and the maximum dose allowed within 24 hours should all be clearly recorded | Medications from the same therapeutic categories used simultaneously as regular, and 'as-required' prescriptions should be monitored frequently to avoid overdosing |

among people with ID than the general population (Cooper et al., 2015). This may affect Article 25 (health) if not properly diagnosed and treated promptly.

The adverse effects of psychotropic medications may be compounded by some characteristics associated with ASD. These include communication difficulties, complex autonomic, dysmetabolic, and general psychosocial vulnerability. People with ID may be more vulnerable to developing adverse effects because of the underlying brain damage. There is evidence that extrapyramidal symptoms are more prevalent among people with ID treated with antipsychotics than people without ID (Sheehan et al., 2017) and may lead to hospitalisation (Zhou et al., 2019). Therapeutic drug monitoring is essential for minimising the risk of adverse events and maximising the effect of the medication. This should reduce unethical prescribing and improve the person's QoL.

One Dutch study found that 84.4% of 103 adults with ID who displayed challenging behaviour had at least one psychotropic-related adverse event and 45.6% had over three adverse events. The presence of adverse events had a significantly negative influence on the person's QoL (Scheifes et al., 2016). Another recent Dutch study of 99 individuals with ID treated with antipsychotics found extrapyramidal symptoms in 53%, overweight or obesity in 46%, and metabolic syndrome in 11% of participants. In addition, hyperprolactinaemia was present in 17% and the evidence of abnormal bone metabolism in 25% of participants (de Kuijper et al., 2013). We have summarised the main adverse effects of psychotropic medications in Table 3 (Deb et al., 2022b).

The short- and long-term adverse effects will likely affect the person's QoL and impact several UN Articles such as 25 (health). They are also likely to affect Articles 19 (independent living and community inclusion), 24 (education), 26 (rehabilitation), 27 (work and employment), 28 (adequate living standard), and 30 (participation in recreation and leisure).

## Lack of Evidence

Randomised controlled trials (RCTs) are considered the gold standard of evidence, as case studies may produce bias. There are many practical difficulties in involving people with NDDs in RCTs. These include obtaining informed consent to participate in RCTs and caregivers' anxiety about the unknown effect of the placebo (Oliver Africano et al. 2010). Therefore, good-quality RCTs are rare in people with NDD. As a result, the evidence in support of psychotropic medication is weak. We have summarised the RCT-based evidence of the efficacy of different classes of psychotropics in NDD in Table 4 (Deb et al., 2023a, b). The off-licence use of medication such as psychotropics, even in the absence of harm (which is not the case with psychotropics), may still be considered unethical if their efficacy is not established (Cervantes et al., 2017).

## Deprescribing Psychotropics

One way to address the overmedication of people with NDD is to rationalise the use of psychotropics by reducing the dose or discontinuing the medication where appropriate. Published papers show that the proportion of participants among whom antipsychotics were discontinued totally has increased in recent years from 25–33% in 1996 and 2000 to 44–61% in 2014 and 2018 (see Table 5). However, reinstatement of medication remains a problem.

Deprescribing where appropriate will safeguard the UN CRPD Articles 15 (degrading treatment or punishment) by removing degrading treatment and punishment through unethical use of medication, 16 (abuse) by eliminating abuse caused by unethical prescribing, and 17 (the integrity of the person) by empowering the person with NDD.

**Table 3** Main adverse effects of psychotropic medications.

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|---|---|
| Hyperactivity, restlessness, irritability, and aggression are most often seen in treatments with SSRIs and benzodiazepines | Sedation, drowsiness, and lethargy are associated with several psychotropic medications |
| Obesity, metabolic syndrome, and diabetes, particularly related to antipsychotic medications, pose a significant risk of premature death if not promptly treated | Another rare but potentially fatal adverse effect of carbamazepine is Stevens-Johnson syndrome, which starts with a skin rash |
| Extrapyramidal symptoms such as akathisia (often confused with agitation and improperly treated as such), oculogyric crisis, opisthotonos, and Parkinsonism are particularly associated with antipsychotic medications, particularly the old generation ones, although the new generation antipsychotics like risperidone could still cause them. They are often misinterpreted as an expression of the ASD itself, especially when comorbid with ID. These adverse effects seem more common in people with NDD than the general population (Sheehan et al., 2017) | NMS (neuroleptic malignant syndrome), a rare but life-threatening adverse effect, is associated with antipsychotic treatment. Symptoms include raised body temperature, fluctuating blood pressure, muscle stiffness (cogwheel rigidity), sweating, and other evidence of autonomic dysregulation. Muscle CPK is raised. Treatment is symptomatic and immediate withdrawal of antipsychotics |
| Constipation, if neglected, can cause severe suffering (e.g. headache, depression, abdominal pain), which, in people with disabilities, can express itself with sleep disturbances, decreased appetite, agitation, and aggression. It occurs mainly following treatments with tricyclic antidepressants, benzodiazepines, and some antipsychotics | Cardiac side effects, particularly the prolongation of the QTc interval, sometimes leading to unexpected deaths, are associated with tricyclic antidepressants and some antipsychotics |
| The anticholinergic syndrome is associated with the use of tricyclic antidepressants and some antipsychotics. The main neuropsychological symptoms of this syndrome are agitation, motor restlessness, dysarthria, disorientation, hallucinations, and convulsions, and the most frequent peripheral symptoms are severe constipation, urinary retention, dry mouth, fever, blurred vision, and tachycardia | Serotonin syndrome is a rare but serious adverse effect usually associated with using SSRI (particularly with SSRI polypharmacy). Symptoms include tachycardia, sweating, raised blood pressure and body temperature, dilated pupils, and myoclonus (hyperreflexia) leading to shock. Treatment is symptomatic and immediate withdrawal of SSRI and, if necessary, use of serotonin antagonists such as cyproheptadine |

**Table 4** Summary of RCT-based evidence for the efficacy of psychotropics in NDD.

| | |
|---|---|
| There is moderate quality evidence to show that short-term low-dose risperidone is probably effective in improving irritability, agitation, and aggression in children with NDD | Based on pharmaceutical company-conducted studies, there is some preliminary evidence that aripiprazole may improve irritability and agitation in children with ASD |
| However, the evidence shows a pronounced placebo effect, and also, after initial improvement within a week or two, the effect tends to plateau, sometimes leading to further dose increase | More independent research is needed without the involvement of pharmaceutical companies to reach a definitive conclusion |
| The evidence of the efficacy of risperidone in adults with NDD is equivocal | Based on the current evidence, the US Drug and Food Administration Agency (FDA) has licenced the short-term use of low-dose risperidone and aripiprazole to treat irritability and agitation in children with ASD |
| Weight gain and sedation remain the two main worrying adverse effects. Sedation improves over time, but weight gain remains a long-lasting problem | Psychostimulant such as methylphenidate improves ADHD symptoms in children with ID and ASD with a smaller effect size than the typically developing children. However, no evidence is available for adults |
| Other important adverse effects of antipsychotics are raised serum prolactin levels, drooling, metabolic syndrome, and extrapyramidal symptoms | There is not enough evidence to draw any definitive conclusion about the efficacy of any other medication for treating psychopathology in people with NDD |

**Table 5** The UK and the Dutch antipsychotic discontinuation studies.

| Studies | Total discontinuation | > 50% dose reduction | Reinstatement |
|---|---|---|---|
| Branford (1996) | 25% (31/123) | | 42% |
| Ahmed et al. (2000) | 33% (12/36) | 19% (7/36) | |
| de Kuijper et al. (2014) | 44% (43/98) | | 16% (12 weeks) |
| de Kuijper & Hoekstra (2018) | 61% (79/129) | | 20% (40 weeks) |
| Shankar et al. (2019) | 46.5% (33/71) | 11.3% (8/71) | 0% (12 weeks) |

The following principles should guide deprescribing (Gupta et al., 2018). Deprescribing should be (a) person-centred and highly individualised depending on the person's need and, as such, should be part of a wider person-centred care planning (see review by Ratti et al., 2016), (b) provide hope for the person so they know that deprescribing is possible even after many years of inappropriate medication use, and (c) based on shared decision-making in which the person with ID, their families, and independent advocates are treated as equal partners from the outset, if necessary by providing them with the appropriate support (Deb & Limbu, 2022). The shared decision-making should empower the person with ID and their family caregivers by putting them in the driving seat as the decision concerns their own (and their loved ones') medication.

In most cases, discontinuing antipsychotics or dose reduction will improve the person's QoL by reducing medication-related adverse effects (Deb et al., 2023a). Improved QoL will impact UN CRPD Articles 25 (health) by improving the person's physical and mental health. Examples of these are massive weight loss upon withdrawal from antipsychotics and less sedation, leading to a more animated person who will participate in activities within the home and community. Similarly, this may improve their chance of independent living and community inclusion (Article 19). This will also increase their chances to access better education (Article 24) and allow for better rehabilitation (Article 26), increase the chance of better work and employment opportunities (Article 27), improve their living standard (Article 28), and increase the opportunities for taking part in better recreational and leisure activities (Article 30).

However, withdrawal from psychotropics, particularly antipsychotics, is not without risks. Sometimes, it may precipitate challenging behaviour. There are many reasons for this potential deterioration in behaviour upon withdrawal from antipsychotics. For example, the behaviour deterioration may not be related to the withdrawal process and may be part of the usual pattern of cyclical behavioural changes. In that case, a thorough multidisciplinary assessment of the causes and the effects of the challenging behaviour, taking a bio-psychosocial approach, is needed (Deb et al., 2022c). In some cases, an underlying psychiatric disorder may be unmasked, which was unknown before. Often, withdrawal side effects like agitation, sleep problems, and extrapyramidal symptoms will lead to a deterioration in behaviour. These possibilities must be assessed properly rather than re-instating psychotropic medication inappropriately, further affecting UN CRPD Articles.

In many cases, caregivers' anxiety about anticipated possible deterioration in behaviour upon antipsychotic withdrawal may exacerbate their perception of the deterioration in behaviour, leading to an exaggerated perception of the severity of the challenging behaviour and over-reporting due to the so-called nocebo effect (Planès et al., 2016). Clinicians must keep this important possibility in mind while considering antipsychotic withdrawal. Educating caregivers and involving them and people with NDD from the outset will help with shared decision-making and alleviate caregivers' anxiety (Deb & Limbu, 2022).

## Alternatives to Medication

One way to decrease the overmedication of people with NDD is to use non-pharmacological psychosocial and behavioural interventions for challenging behaviour (Tapp et al., 2023). A variety of non-pharmacological interventions have been used to manage challenging behaviours in people with NDD, including behaviour analytic treatments (see Luiselli, 2021; Virues-Ortega et al., 2022), positive behaviour support (PBS) interventions (see Gore et al., 2022), and more recently mindfulness-based programmes (see Singh et al., 2021, 2022).

## Informed Consent

Many people with NDD lack the capacity to give informed consent to treatment. In relation to off-licence medication use, this may have implications for ethical prescribing. For example, once lithium is prescribed, it becomes very difficult to withdraw it, so it becomes almost a lifelong treatment. However, lithium treatment carries significant risks, and regular blood tests are necessary to mitigate them. It may not be possible to conduct the necessary investigations on many people with severe and profound ID. Therefore, treatment with lithium without informed consent raises a serious ethical issue, particularly if other less harmful alternatives are available. The same applies to clozapine, which carries major risks and requires regular blood tests.

The UK *Mental Capacity Act* (Department of Constitutional Affairs, 2005) stipulated the following five fundamental guides regarding capacity. Similar recommendations are made by other organisations and in other countries in the world.

1. A person must be assumed to have capacity unless it is established that they lack capacity in relation to a particular matter if, at the material time, they are unable to make a decision for themselves because of an impairment of, or a disturbance of, the mind or brain.
2. A person should not be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
3. A person is not treated as unable to make a decision merely because he makes an unwise decision.

4. An act done or decision made under the Act for or on behalf of a person who lacks capacity must be done or made, in his best interests.
5. What is proposed can be as effectively achieved in a way less restrictive to the person's rights and freedom of action.

These principles apply to psychotropic prescribing in NDD. All reasonable measures should be taken to assess the person's capacity to consent, including, where appropriate, using accessible information, picture boards, and any other communication aids. If a communication partner is available to support the person with the decision-making, they should be involved in the process.

The following should be assessed to determine the capacity to give consent: (a) whether the person understands the nature and purpose of the intervention, (b) the risks of having and not having the intervention, (c) the alternative interventions, (d) the ability to weigh up the pros and cons of the intervention and come to a meaningful judgement, (e) the ability to contain the information for a sufficient length of time to come to a conclusion, and (f) the ability to convey their decision to the assessor of their capacity.

If all attempts to communicate with the person with NDD fail, a decision must be taken by a multidisciplinary team involved in the person's care. Where appropriate and available, families should be involved in the decision-making about the care of their loved ones. If available, an independent legal advocate should be involved to support the decision-making. In the meeting, a thorough discussion should take place about the advantages and harms of the proposed intervention, what alternatives are available, and the least restrictive/harmful intervention should be chosen in the person's best interests to enhance their QoL. The discussion details should be recorded and circulated among the stakeholders on a need-to-know basis.

In many people with severe and profound disabilities, it may be difficult to determine their compliance with the treatment in the absence of informed consent. This may lead to deception or coercion in administering the medication, potentially violating human rights. Sometimes, in the absence of informed consent, compliance is assumed, and medication may be administered by mixing them in the food. This covert medication administration raises a major ethical issue and is likely to violate UN CRPD Articles 15 (degrading treatment or punishment), 16 (abuse), and 17 (the integrity of the person). This action may also violate Article 25 (health) if it produces side effects. If this action is really necessary, the same principle of multidisciplinary consensus decision in the best interests of the person as discussed in the previous section should apply, and the least harmful method should be chosen.

## Shared Decision-Making

People with NDD are often not involved in the decision on psychotropic prescribing for them, which is an unethical practice and a violation of human rights. Prescribers will often speak with a caregiver rather than the person with NDD themselves. This violates Article 5 (degradation, discrimination). One study showed that some adults with ID were dissatisfied with medication, mainly due to lack of involvement in the treatment decision, adverse effects, lack of efficacy, and a 'desire to lead a normal life' (Hall & Deb, 2008). Authors found that most adults with mild to moderate ID are capable of making an informed decision about their medication if the right information is shared with them in the right way. However, often, information is not shared properly with them, which violates Article 21 (access to information). We have developed accessible leaflets on 32 commonly used psychotropics for people with ID (see https://spectrom.wixsite.com/project). These information leaflets could be printed and handed over to the person with ID and their caregivers in the clinic. The caregiver can take the person with ID through the information in the leaflets, which should help to improve shared decision-making. A recent study (de Kuijper et al., 2022) found that involving people with ID and preparing them thoroughly for any eventualities helped with the successful discontinuation of antipsychotics even after many years of prescribing.

Family caregivers are often not involved in the decision about psychotropic prescribing for their loved ones (Hassiotis et al., 2016; Knox, 2000; Redmond & Richardson, 2003). In a recent study (Deb & Limbu, 2022), the consensus among family caregivers was that they did not have much influence over the decision-making process regarding care planning for their relatives with ID. Family caregivers felt that they did not have enough knowledge about medications and their indications to decide on prescribing for their loved ones. In general, they were keen on non-pharmacological interventions for challenging behaviour. This lack of communication and shared decision-making has led to family caregivers' frustration, who expressed their negative feelings by making statements such as 'battle' and 'banging your head against a brick wall' (Elford et al., 2010). Therefore, there is an urgent need to make prescribers aware of these views and train them on how to involve a person with ID and their family caregivers in the decision-making process. Not involving families in the decision-making for their loved ones where people with NDD want their families to be involved constitutes unethical practice. This practice may violate UN CRPD Article 21 (access to information) and possibly Article 5 (equality and non-discrimination). An online resource, SPECTROM, for training caregivers to address these issues and encourage shared decision-making

has been developed recently (see https://spectrom.wixsite.com/project) (Barratt et al., 2023; Deb et al., 2021; Wilson et al., 2023).

## Guidelines

To address many ethical issues mentioned in this paper regarding the overmedication of people with disabilities, the National Institute for Health and Care Excellence (NICE, 2015) in the UK and the World Psychiatric Association developed international guidelines for rational prescribing of psychotropic medications for challenging behaviours in people with NDDs (Deb et al., 2009). The aim of the guideline is to encourage ethical and rational clinical practice to avoid human rights violations. These guidelines are obvious examples of how a change of practice can help eliminate unethical prescribing and eventually help to reduce overmedication and safeguard the rights of the person with NDD. The guideline emphasises that a thorough person-centred multidisciplinary assessment of the causes and functions of the challenging behaviour, their effects, and the person displaying the behaviour taking a bio-psychosocial approach is an essential prerequisite for prescribing psychotropics. This will help to assess and address the underlying issues rather than using psychotropics as a symptomatic treatment.

However, despite these guidelines, the poor and unethical practice still continues. Therefore, there may be a need to train the prescribers on this crucial issue or even make regulatory bodies mandating a peer review of unethical practices, even legalising this if necessary. In this context, the need for an amendment to the current education and training on ethical issues in medical schools and pharmacists' organisations could be reviewed to address the potential violation of the rights of people with disabilities. Similar legislation may be required to prevent unethical practices like using online prescription-only medicine or prescribing by professionals who do not have expertise in the area. Professionals are responsible for monitoring and reporting their peers' unethical practices, including bias and prejudice toward minority populations.

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**Data Availability** Data are available on request from the corresponding author.

## Declarations

**Ethics Approval** This is a review article, and as no new data are analysed and presented here, it does not require ethics approval.

**Conflict of Interest** The authors declare no competing interests.



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