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DOES THE NHS ABIDE BY ARTICLE 25 OF THE UNCRPD? USING THE STOMP-STAMP GUIDELINES TO CHECK, A UK STUDY

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ABSTRACT

INTRODUCTION: Article 25 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD), states that persons with disabilities have the right to the enjoyment of the highest attainable standard of health. Psychotropic medications are sometimes used when a person with intellectual disabilities (ID) presents with a challenging behaviour. Such behaviour could lead to the child being expelled from school or being sent away from family to reside in a residential setting. The first line of interventions should be psychological and a behavioural support plan should be commenced; in addition, a parent-training programme should be considered to try to tackle the behaviour according to National Institute for Health and Care Excellence (NICE) Guidelines.

STOMP-STAMP Guidelines were launched in December 2018 by NHS England and The Royal College of Paediatrics and Child Health. The British Association of Childhood Disability and the Council for Disabled Children pledged to ensure that children and young people with intellectual disability, autism or both, have access to appropriate medication [in line with NICE guidance] and are not prescribed inappropriate medication.

PURPOSE: The aim of this study is to identify the compliance of the Child and Adolescent Intellectual Disability Psychiatric Service (CAID) in South Wales with the STOMP-STAMP guidelines in the monitoring of children and adolescents with Intellectual Disability who are prescribed psychotropic medications.

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METHODOLOGY: A retrospective study of clinical notes of children and adolescents with moderate to severe intellectual disability (that is an IQ of less than 50), who are currently under CAID's tertiary mental health service.

RESULTS: The notes of 59 children and adolescents were studied (78% males and 22% females, age range 8–17 years with mean age of 13.49 years and STD 2.254). Autism Spectrum disorder was the most common comorbid diagnosis, followed by anxiety disorders. A total of 3.3% of the children had an additional diagnosis of Down's Syndrome. Epilepsy was increasingly associated with polypharmacy, poor response to medications and severe challenging behaviour. Consents to medications were well documented and obtained from those with parental responsibilities. More than half of the participants were on monotherapy. The antipsychotics were the most common medication prescribed, followed by antidepressants. Diagnoses of the comorbid conditions were well documented in each file. Insomnia was the most common symptom with the majority being on sleeping medicines. Obesity was the commonest physical health problem in the sample followed by constipation; both are known side effects of antipsychotic medication. Most of the children could not have the appropriate investigations recommended by NICE guidelines before initiating the medicine, such as blood work and an ECG.

STUDY LIMITATIONS: This study has some limitations. The sample size is relatively small. The catchment area of the service is relatively a deprived one so the findings could not be generalised. The study excluded children and adolescents with mild intellectual disability.

CONCLUSIONS AND RECOMMENDATIONS: Medication, including polypharmacy, is still the main method of controlling severe challenging behaviour in the absence of evidence-based psychological therapy such as Applied Behaviour Analysis (ABA). Judicious use of antipsychotics is required in the ID population given the increased risk of the side effects to the child and young person's short-term and long-term physical health. The importance of multi-agencies working to minimise use of antipsychotics should be stressed.

ORIGINALITY VALUE AND PRACTICAL IMPLICATIONS: Although this study was conducted at a national level, linking this work to UNCRPD provides for a macro level accountability framework. The practical implications are that by engaging in a systematic time serious analysis of practice, this will ensure continual service improvement, ultimately safeguarding the rights of such vulnerable children and adolescents.

KEYWORDS: *Intellectual Disability; Children and Adolescents; UNCRPD; Mental Health Service*

INTRODUCTION

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and its Optional Protocol (A/RES/61/106) was adopted on 13 December 2006 at the United Nations Headquarters in New York, and was opened for signature on 30 March 2007.

The UNCRPD (UN, 2006) views persons with disabilities as "subjects" with rights, who can claim those rights and make decisions for their lives based on their free and informed consent, as well as being active members of society instead of "objects" of charity, medical treatment and social protection. It states that persons with disabilities have the right to the enjoyment of the highest attainable standard of health under Article 25. Those rights should also be protected by professionals who treat people with disabilities as not every person with a disability can make an informed choice or consent, mainly when the disability is an intellectual or cognitive one.

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Article 25 has six important elements that explain what is required to ensure optimum health provision for persons with disabilities. The six elements include:

1. “Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes.
2. Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimise and prevent further disabilities, including among children and older persons.
3. Provide these health services as close as possible to people’s own communities, including in rural areas.
4. Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care.
5. Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner.
6. Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.”

Intellectual Disabilities (ID), Autistic Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD), Tourette Syndrome (TS) are collectively referred to as neurodevelopmental disorders. They are a group of conditions with onset in the developmental period and are characterised by a range of cognitive deficits, with or without physical impairments. This may vary from limited to global impairment affecting various components of a person’s ability. This includes social, personal skills, learning abilities, intelligence and academic achievements (DSM-5) (APA, 2013).

Patients who present with some of the above neurodevelopmental disorders are frequently prescribed a suite of psychotropic medications, including antidepressants, sedatives and mood stabilising agents such as antipsychotics. These agents are used to manage clinical symptoms of ill health or challenging behaviour reported by carers of the patient in question. That said, it was found that decisions on the initiation and/or continuation of these medications may not have always been guided by established clinical practice and recommended guidance. As such, this cohort of patients is more likely to receive inappropriate pharmaceutical management, with increased risk of overprescribing and polypharmacy where these medications are not appropriately reviewed as part of an holistic, person-centred review on a regular basis. Inappropriate use of these medications can lead to serious side-effects, poor health and in some cases, premature death.

Public Health England produced a report in 2015 that highlighted that those psychotropic medicines, including antipsychotics and antidepressants, were given to almost 35,000 adults with ID, without having the designated mental health conditions for which the medications were recommended. A campaign called ‘Stopping over medication of people with a learning disability, autism or both (STOMP)’ was launched in 2016 by six organisations including NHS England, the Royal College of Psychiatrists (CR 200), the Royal College of Nursing, the Royal College of GPs, the Royal Pharmaceutical Society and the British Psychological Society.

The STOMP advises that professionals prescribing psychotropic medications to patients with intellectual disability should clearly document capacity and consent to treatment, regularly monitor treatment response and side effects according to the clinical guidelines associated which each medicine. They should also regularly review the need for continuation, discontinuation or titration of the medication.

Subsequently, the STOMP-STAMP Guidelines were launched in December 2018 by NHS England, The Royal College of Paediatrics and Child Health, the British Association of Childhood Disability and the Council for Disabled Children (NHS England, 2018). The organisations collectively pledged to ensure that children and young people with intellectual disability, autism or both, have access to appropriate medication, in line with National Institute for Health and Care Excellence (NICE) guidance. This initiative is aimed at tackling disparities in the care provided to persons with disabilities; this is central to the tenets of Article 25 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

The main aims of the STOMP-STAMP guidelines are:

> “Reduce inappropriate prescribing of psychotropic medications, which can have significant side effects and may be used inappropriately to manage challenging behaviour.”

1. Promote non-pharmacological interventions and positive behaviour support as the first line of treatment for challenging behaviour.

2. Ensure that psychotropic medications are only prescribed when clinically appropriate and at the lowest effective dose for the shortest possible time.

3. Enhance the monitoring and regular review of psychotropic medication use, including plans for safe withdrawal if appropriate.

4. Improve communication and involvement of individuals, their families and caregivers in treatment decisions.

5. Provide training and resources for healthcare professionals, social care staff and families to better understand the appropriate use of psychotropic medications.

Shortly following the launch of the STOMP-STAMP in 2018, my team and I embarked on a series of studies to ensure that we imbed these guidelines in our daily practice as part of a wider multidisciplinary team involved in the provision of care for persons with disabilities. This aligned with our collective desire to ensure we are constantly providing evidence-based, quality and equitable healthcare services in keeping with the mantra of the UNCRPD. This is the fourth study in a series of consecutive cross-sectional studies conducted over the years as an accountability tool to ensure adherence to the guidelines and a means to ensure continued service improvement for vulnerable patients with neurodevelopmental disorders.

AIMS OF THE STUDY

The aim of the study is to identify the compliance of the Child and Adolescent Intellectual Disability Psychiatric Service (CAID) in South Wales with the STOMP-STAMP guidelines in the monitoring of child and adolescents with Intellectual Disability who are prescribed psychotropic medications. The compliance with Stomp-Stamp guidelines was used to check the compliance with Article 25 of UNCRPD.

THE CHILD AND ADOLESCENT INTELLECTUAL DISABILITY SERVICE

The Child and Adolescent Intellectual Disability Service (CAID) service, provides consultation and treatment to children and adolescents with intellectual disabilities who reside in the catchment area of Cwm Taf Morgannwg University Health board in Wales as part of the National Health Services (NHS) in the United Kingdom. The clinics are held jointly with community paediatricians and wider multidisciplinary team (MDT). The service was launched in April 2012 in Wales and consists of a consultant child psychiatrist and a mental health nurse.

METHODOLOGY

This was a retrospective study of clinical notes of children and adolescents, who are currently under CAID tertiary mental health service. The study was registered with Cwmtaff Morgannwg University Health Board, and was subsequently granted ethical approval. A *pro forma* was designed to capture demographic and clinical data.

The Welsh Clinical Portal was used to identify patient details, diagnoses, medications and how closely they have been monitored in order to complete the audit. Patient details were anonymised and then added into a spreadsheet for analysis.

INCLUSION AND EXCLUSION CRITERIA

All children and adolescents under the age of 18 years with moderate to severe intellectual disability, that is with an IQ of less than 50, were included if they were on psychotropic medications. Exclusion criteria were children with mild intellectual disabilities (IQ above 50) and those who are not on any psychotropic medications.

SETTINGS

The study started by auditing the child and adolescence mental health service (CAMHS) intellectual disability (ID) tertiary service. All patients were diagnosed with moderate to severe ID and co morbid psychiatric disorders and/or severe challenging behaviour.

Data Analysis

Data Abstract and Coding

Data were extracted from the patients by the first author and each patient was given a code number. Demographic details (date of birth, age, sex) and clinical details, such as psychiatric diagnoses, investigations done such as ECG and bloods, other comorbidities medications used, were extracted by the first author to a *pro forma* in an Excel sheet. The second author transferred the data to SPSS and ran the statistical analysis and ensured data cleaning.

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RESULTS

The notes of 59 children and adolescents with moderate to severe and profound intellectual disability (78% males and 22% females, age range 9–17 years with mean age of 13.49 years, STD 2.254) were studied (see Figure 1).

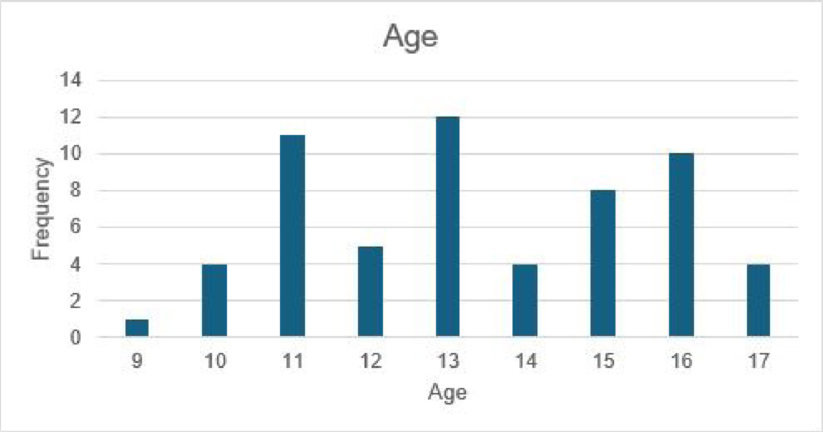

Figure 1 The figure shows the age distribution of all children involved

Source: Developed by the authors

Autism spectrum disorder was the most common comorbid diagnosis (80%) followed by anxiety disorders (41%). Sleep problems, such as insomnia, were very common with 64% of the children being on one or two sleeping medicines. Epilepsy was found in 12% of the sample. Attention Deficit Hyperactivity disorder was found in 12% of the sample, followed by Tourette syndrome in 8%. Down’s syndrome was the diagnosis for 5% of the children sampled.

There was a clear statement of medication indication in the 59 files audited (100%). Consent to medications was well documented and obtained from those with parental responsibilities, whether parents or social services, for all children and adolescents. There was no evidence of any capacity assessment for adolescents who were 16 and 17 years old. Discussion about the risk and benefits of each medication and its mode of action was well documented, even with a contingency plan should the child develop any side effects. More than half of the participants (59%) were on one psychotropic medication, almost a third (36%) were on two medications, and a small number (5%, all males) of patients were on three medications (Figure 2). The antipsychotics were the most common medication prescribed, followed by antidepressants.

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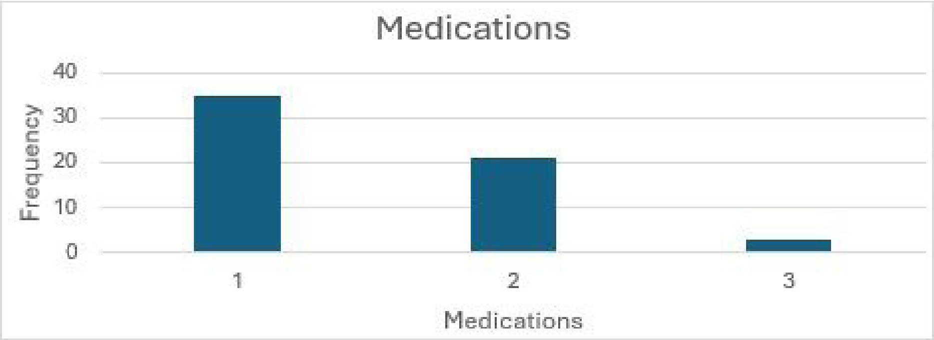

Figure 2 The figure shows the number of children prescribed for medications

Source: Developed by the authors

Diagnoses of the comorbid conditions were well documented in each file. Obesity was the most common physical health problem in the sample followed by constipation; both are known side effects of antipsychotic medication. Most of the children could not have the appropriate investigations recommended by NICE guidelines before initiating the medicine such as blood and ECG.

DISCUSSION

Research and People with Intellectual Disabilities

Carlson (2013) debated the double danger of including people with intellectual disabilities in research and the risk of them being exploited, let alone exposing them to high risk. On the other hand, some argue that excluding them from research is unfair and risks undermining the provision of quality evidence-based medicine.

In the study, there were almost four times more males than females in the sample: research showed that males are affected more with neurodevelopmental disorders (Nowak and Jacquemont, 2020). This is also illustrated by data from Public Health England that found that 65% of children with severe learning disabilities in England were male (PHE, 2015).

Children and adolescents with intellectual disability (ID) and psychiatric illnesses can present with challenging behaviour. Over 15% of children and adolescents with ID requiring specialist education, health or social care services have behaviour that challenges. This behaviour can cause them, or those around them, considerable harm and often requires support from a specialist paediatric or mental health service. It is imperative to unravel the cause of the challenging behaviour and develop a management plan that reduces this antecedent.

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The Use of Psychotropic Medications and Health Monitoring

Some children continue to present with harmful challenging behaviour despite this psychosocial support. In these cases, antipsychotics can be prescribed as short-term intervention and only as part of a wider management plan. The National Institute for Health and Care Excellence has produced guidelines on this, which are discussed below (NICE, 2015, 2016, 2018).

Antipsychotics can cause a range of metabolic and cardiovascular adverse effects. Atypical antipsychotics prescribed in children and adolescents have been linked with weight gain and an increased risk of developing diabetes, hyperlipidaemia and hyperprolactinemia; this could easily and subsequently lead to metabolic syndrome (Frighi *et al*., 2011). Children and adolescents have also been found to be more vulnerable to adverse effects because of their size and developing physiology. It is therefore even more important that these medications be titrated slowly, and patients are monitored closely for potential side effects.

Recently there has been concern that antipsychotics are being excessively prescribed for people with ID. While both the Public Health England report and the STOMP campaign have focused on adults, children and young people may be affected by similar practices.

The ability to monitor these children through blood investigations is a challenge in itself; however, growth parameters are accurately recorded and readily available through health or educational settings. Serial standardised measurements should be reviewed during an individualised risk benefit analysis of the use of antipsychotics. Consideration of short-term use of antipsychotics must an adjunct to pre-emptive multiagency support, which is likely to prevent a crisis point for these children and their families.

The audit revealed that Risperidone is most common prescribed anti-psychotic in children. A study looking into the anti-psychotic medication prescribing trends in children and adolescents found that Risperidone was the most prescribed anti-psychotic. The audit found that 78% of patients that were on anti-psychotic medication were prescribed Risperidone. According to the same paper, Risperidone has been shown to be the most effective to reduce aggression, irritability, tantrums, agitation and mood swings in patients with autism (Harrison *et al.,* 2012).

ADHD is known to be underdiagnosed and misdiagnosed in people with intellectual disability, and that might result into irrational polypharmacy and worse health and social outcomes (Sawhney *et al.,* 2021).

Physical Comorbidities and Problems

Obesity

Research showed children and adolescents with intellectual disabilities that are obese compared to those without intellectual disabilities.

A study by Webster *et al.* (2019) showed that over 60% of male cases became obese or morbidly obese after the initiation of antipsychotics.

Sleep Problems

Sleep disturbances, in particular insomnia, were found in almost two thirds (64%) of the sample, which was evident by the use of sleeping medicine. Previous research reported a slightly higher percentage of 75% (Ogundele and Yemula, 2022). The problem of insomnia might be higher than the findings from the study as many children and adolescents are on sedative antipsychotics such as Risperidone, which could mask insomnia. Research reported that sleep problems are usually chronic in children and adolescents with intellectual disability and are common with Autism Spectrum Conditions (Richdale and Baker, 2014). Melatonin was used as first line followed by antihistamines. Research reported useful effects with melatonin treatment with minimal side effects (Schwichtenberg and Malow, 2015).

Epilepsy

Epilepsy was associated with polypharmacy, poor response to medications and severe challenging behaviour.

The rate of epilepsy found in the study was almost half the rate found in previous research (25–30%) of children with intellectual disabilities, with higher rates in those with more severe intellectual disabilities, that is, an IQ below 35 (Dunn, 2019). Also, children and adolescents with epilepsy have higher rate (7.1% to 32%) of neurodevelopmental disorders compared to their peers without epilepsy (Oguni, 2013).

Antiepileptics were used to treat severe challenging behaviour in children and adolescents without epilepsy in 8% of the study, with Sodium Valproate used only in males and Lamotrigine in females. Research is controversial with regards to the effectiveness of antiepileptics in treating severe challenging behaviour, some found no difference between placebo and Sodium Valproate (Hellings *et al.,* 2005).

CONCLUSIONS

The findings from this study show that the service of CAID in South Wales abide or comply with many of the recommendations of article 25 of the UNCRPD. One of the important and serious breaches of the right of this vulnerable group found in the study was the lack of capacity assessment for those aged between 16 and 18 years (24% of the sample).

Medication (polypharmacy) is still the main method of controlling severe challenging behaviour in the absence of evidence-based psychological therapy such as Applied Behaviour Analysis (ABA) and Positive Behaviour Support (PBS). Judicious use of

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antipsychotics is required in the LD population given the increased risk of the side effects to the child and young person's short-term and long-term physical health. This stresses the importance of a multi-agency approach working to minimise use of antipsychotics.

Although promoting non-pharmacological interventions such as PBS as the first line for managing challenging behaviour, unfortunately it is not used in many parts as first line, despite evidence of the moderate effect for short- and long-term use (Bruinsma *et al*. 2020). There are several reasons why non-pharmacological interventions and PBS may not be consistently used to address challenging behaviour in children with intellectual disabilities in the UK. One of the main reasons for not adopting such an approach is lack of training and resources: Many professionals working with children with intellectual disabilities, such as teachers, caregivers and support staff, may not have received adequate training in implementing non-pharmacological interventions and PBS strategies.

Time and funding limits are another obstacle to not applying comprehensive behavioural interventions as the approach could be time and resource consuming (Sheehan, 2020). It requires ongoing assessment, individualised planning, consistent implementation and regular monitoring and adjustment. While efficacy and ease of medication has been observed in some cases, there may be a perception that medication is a quicker and more effective solution for managing challenging behaviours, particularly in acute situations.

Shortage of staff and lack of access to specialist services: in some areas of the UK, there may be limited access to specialised services that could offer comprehensive behavioural interventions and positive behaviour support (Griffith and Hastings, 2014). This can lead to an over-reliance on medications secondary to a lack of alternative treatment.

The costs of employing specialised professionals, such as behaviour analysts, psychologists and trained therapists, can be substantial. Interventions delivered in specialised settings, such as residential schools and colleges, may have higher associated costs compared to community-based interventions (Iemmi *et al.,* 2016).

Research has shown that these interventions can lead to savings in the long run by reducing the need for more expensive and intensive services, improving quality of life, and promoting greater independence and community integration for children and adolescents with intellectual disabilities and challenging behaviour.

Despite all that, medication may still be a vital addition, especially when the risk of harm, mainly to others and self is high. Additionally, the level of risk sometimes needs to be reduced to enable or facilitate behavioural intervention.

Although mental health services for children and adolescents with intellectual disabilities in the UK have developed and continue to develop, there are still areas with no dedicated services. The shortage of in-patient psychiatric beds for intellectual disability is another challenge. The UK Government, Department of Health, Royal College of Paediatric and Child Health, and Royal College of Psychiatrists need to unite efforts to improve access, co-ordination and specialised care for this vulnerable population.

Study Strengths

This is the fourth study in a series of consecutive cross-sectional studies conducted. The first study was done in 2018 after the STOMP-STAMP guidelines were launched, followed by studies in 2022, 2023 and the current study in 2024. There was no study done during the COVID-19 years (2019 to 2021); this reflects the commitment of the service to protect the rights of this vulnerable population. Each study followed the same methodology, examined the same population and monitored the practice of the child and adolescent intellectual disability psychiatric tertiary service in South Wales. Each study had recommendations that were implemented and followed through to improve the practice of the service. The findings with regards to adherence to STOMP-STAMP guidelines remainedconsistent with audits of the same service made earlier. There was a clear reduction in the percentage of people being on two medications from 40% in 2018 study to 36% in the 2024 study.

The studies will hopefully help inform policy-makers and decision takers at the Welsh Government with regard to the importance of not only addressing the needs of this vulnerable population but also stressing the unmet needs.

Study Limitations:

This study has some limitations. The sample size is relatively small. The catchment area of the service is a relatively deprived one so the findings could not be generalised. The study excluded children and adolescents with mild intellectual disability.

Recommendations:

1. Continuous education and training of the wider multidisciplinary team (MDT) to stress the centrality of psychological and behavioural interventions and first line. These interventions should be routinely reviewed, both in the home and school setting.
2. Repeated prescriber training and education is needed to ensure the appropriate investigations (e.g., routine bloodwork, ECG) recommended by NICE guidelines are

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undertaken prior to the initiation of any medication. This can be facilitated by the introduction of prescribing aids that prompt practitioners.

3. Factoring the physical risk of obesity associated with some psychotropic medications such as antipsychotics, it is critical to ensure safeguards are in place to manage this side-effect with appropriate non-pharmacological interventions as well as regular monitoring.
4. Acknowledging the additional high prevalence of sleep disturbances in this cohort of patients, the first-line treatment for sleep should include good sleep hygiene and other behavioural interventions. These should be taught to parents via parenting classes and hopefully this intervention will help in reducing polypharmacy mainly for sleep deprivation.
5. There should be a capacity to take medication assessments for all 16 and 17 year olds. Health services should look to capitalise on the wider MDT, including the use of pharmacists to rationalise prescribing, and undertaking regular medication use reviews.
6. Finally, given the difficulty in recruitment into research and the scarcity of research into children with ID in general (Lindblad *et al.*, 2011), researchers may need to find better methods or sophisticated techniques for involving and encouraging this vulnerable population to participate in research. As most of the diagnoses being made for these children are based on criteria applied to children without intellectual disabilities, this will ultimately lead to improved evidence-based medical practice, thereby ensuring parity of care for this vulnerable population.

Standards

NICE published ‘Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges’ (NG11) guidelines in 2015. These guidelines contain specific recommendations for children and adolescents, as well as general recommendations for people with intellectual disability. For children and adolescents requiring antipsychotic medication as part of their treatment plan, it references ‘Psychosis and schizophrenia in children and young people: recognition and management’ (CG155). These guidelines were produced by NICE and last updated in 2016.

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BIOGRAPHY

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Dr Sarah Karrar is currently a Senior House Officer at Sandwell and West Birmingham Hospitals NHS Trust (SWBH). She has a Bachelor of Medicine and Surgery (MBChB) and a Bachelor of Medical Sciences (BMedSci) from the University of Nottingham. Dr Karrar's academic pursuits culminated in a dissertation exploring the comparative effectiveness of global versus focused parental ratings of Attention-Deficit/Hyperactivity Disorder (ADHD) using the SNAP-IV criteria. This research provided valuable insights into the nuanced perceptions and diagnostic

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