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Melatonin and sleep disorders associated with intellectual disability: a clinical review

Background  Melatonin is used to treat sleep disorders in both children and adults with intellectual disability (ID), although it has no product license for such use. The evidence for its efficacy, potential adverse effects and drug interactions are reviewed in the context of prescribing to people with ID.

Methods  A literature search was performed using multiple electronic databases. More literature was obtained from the reference lists of papers gathered through the searches.

Results  Most of the studies were uncontrolled and the few controlled trials available were of small size. Melatonin appears effective in reducing sleep onset latency and is probably effective in improving total sleep time in children and adolescents with ID. It appears to be ineffective in improving night-time awakenings. Melatonin is relatively safe for short-term use. Its safety for long-term use is not established. Potential drug interactions, possible effects on puberty and concerns regarding the use of melatonin in epilepsy, asthma and depressive disorders are discussed.

Conclusions  Melatonin appears to be an effective sleep-initiator for children and adolescents with ID and probably has a similar effect for adults. There may be heterogeneity of response depending on the nature of the sleep problem and cause of the ID or associated disabilities. Further studies are necessary before firm conclusions can be drawn and guidelines for the use of melatonin for people with ID formulated.

What symptoms predict the diagnosis of mania in persons with severe/profound intellectual disability in clinical practice?

Background  While researchers have attempted to address the difficulties of diagnosing affective disorders in the intellectually disabled population, diagnosing bipolar disorder in an individual with severe intellectual disability (ID) remains a challenge. The aim of this study was to identify what symptoms can predict a diagnosis of mania in the intellectually disabled population.

Methods  Three groups of persons with ID participated in this study: (1) individuals with a bipolar diagnosis who were currently manic; (2) individuals with an Axis I diagnosis other than bipolar disorder; and (3) individuals without an Axis I diagnosis. Two recognized measures of mania (i.e. Diagnostic Assessment for the Severely Handicapped-Revised and Parent Version of Young Mania Rating Scale) were used to evaluate symptoms of mania. A logistical regression procedure was conducted on mania items to identify which items correctly identify persons with ID who were currently manic.

Results  Psychomotor agitation, decreased sleep, changes in mood and aggression were significantly related to the diagnosis of mania. Further, psychomotor agitation and disturbed sleep were significant predictors of a diagnosis of mania.

Conclusions  Problems of sleep and psychomotor agitation should alert clinicians that further assessment of bipolar symptomatology is warranted. Focusing on observable behaviours based on Diagnostic and Statistical Manual of Mental Disorder-IV criteria can be useful in formulating a diagnosis of bipolar disorder in persons with ID.
Participation of Students with Moderate to Severe Disabilities in the General Curriculum: The Effects of the Self-Determined Learning Model of Instruction
Research and Practice for Persons with Severe Disabilities Volume 31 Number 3 Fall 2006 pp.230-241

This study investigated the effects of the Self-Determined Learning Model of Instruction (S.D.I.M.I) on the academic skill performance of three junior high school students with moderate to severe intellectual disabilities. The academic skills taught were aligned to the district general curriculum, and extended benchmarks were individually determined. The students were instructed to engage in a self-regulated problem-solving strategy, as well as to use one or more additional student-directed learning strategies. The results suggested that all students were able to acquire and maintain target academic skills to mastery levels. Also, all stakeholders had positive perceptions about the value of such instruction. The implications of these findings relative to the general curriculum initiative are discussed.

A National Survey of the Educational Planning and Language Instruction Practices for Students With Moderate to Severe Disabilities Who Are English Language Learners
Research and Practice for Persons with Severe Disabilities Volume 31 Number 3 Fall 2006 pp. 242-254

This article examines findings from a national survey of a sample of special educators who serve students with moderate to severe disabilities who are English language learners (ELLs). The survey requested information related to respondent assessment and instructional practices, second language resource availability, satisfaction, and language decision procedures for ELL students. Results indicated many of the respondents assessed and instructed their students in English, lacked ELL training, experienced resource shortages, and did not include parents in the language of instruction decision. Additional findings revealed that teacher satisfaction was predicted by the availability of second language resources, and the administration appeared to have a significant influence on the inclusion/exclusion of parents in the language decision process. The implications of these findings are presented.

Juggling and Struggling: A Preliminary Work-Life Study of Mothers With Adolescents Who Have Developmental Disabilities
Mental Retardation Volume 44 Number 6: 393-404 December 2006

A focus group study was conducted to develop an understanding of the experiences of mothers who are trying to balance employment with caring for an adolescent with developmental disabilities. Mothers reported facing considerable difficulties balancing work and caregiving responsibilities because support service rapidly declined when their child reached adolescence. Service cuts were related to the fact that adolescents are expected to be able to care for themselves, despite the fact that for many adolescents with disabilities, this is not possible. The mothers also reported that the preponderance of the responsibility for arranging care for their children was theirs and was not shouldered by their partners. Policy implications are discussed.

Longitudinal Frequency and Stability of Family Contact in Institutional and Community Living
Mental Retardation Volume 44 Number 6: 418-429

We examined the frequency and stability of family contact with long-term institutional residents during a major deinstitutionalization project. Movers relocated to community accommodation between Assessments 1 (baseline) and 2. Stayers remained institutionalized. We investigated family contact longitudinally over four annual assessments. There was no significant between-group difference in frequency of family contact than did stayers. There was a significant decline over time in the proportion of stayers with family contact and a significant increase in movers with family contact, with a marked resumption of contact by movers during the first year of community living. Carefully supporting family (re)involvement during the relocation process may be associated with stable, long-term family contact.
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All pregnant women, regardless of their age, should be offered screening for Down syndrome in their first trimester, according to new practice guidelines issued today by the American College of Obstetricians and Gynecologists.

Noninvasive screening tests developed over the last decade have made it possible to predict the risk of Down syndrome and certain other chromosomal abnormalities with high accuracy.

Those identified as being at risk can then be offered further screening with invasive, and more dangerous, tests such as amniocentesis or chorionic villus sampling, according to the guidelines published in the January issue of the journal Obstetrics & Gynecology.

Invasive tests have previously been offered routinely to women older than 35, who are at the highest risk of bearing affected children. But the risks in older women have been managed so successfully that the largest number of Down syndrome children are now being born to younger women, according to Dr. Edward McCabe of the Mattel Children's Hospital at UCLA.

The committee that wrote the guidelines recognized "that counseling has been much more effective in the older group, and now it is important to begin looking at younger women," he said.

The guidelines are already followed in most academic centers, but not in many private practices, especially in those that are small and in rural areas, said Dr. Gautam Chaudhuri, executive chair of the obstetrics department at UCLA's Geffen School of Medicine.

Down syndrome is caused by the presence of an extra copy of chromosome 21 and is characterized by congenital heart defects and mental retardation.

The risk is low — about one case for every 1,300 births — in young women, then increases sharply to one in 350 births beyond age 35 and one in 25 beyond age 45.

The original rationale for screening only older women was that the invasive tests could be dangerous for the fetus, leading to one death in about every 200 examinations. That risk has declined over the last decade, but many women still prefer to avoid it unless there is reason to believe the Down risk is higher, said Dr. Nancy Green, medical director of the March of Dimes, which is focused on preventing birth defects.

Beginning in the 1990s, obstetricians began using assays for three chemicals —
alpha-fetoprotein, unconjugated estriol and human chorionic gonadotropin — in the mother's blood stream during the first trimester. This so-called triple test identifies about 70% of Down cases.

A major breakthrough occurred at the end of the decade with the recognition that an accumulation of fluid in the fetus' neck is associated with a broad range of chromosomal abnormalities, including Down syndrome. This nuchal translucency can be readily measured by ultrasound.

Major trials in both the United States and the United Kingdom have recently shown that adding ultrasound for nuchal translucency to the triple test raises the detection rate above 90%.

The new guidelines thus call for all women to be offered a combination of blood and nuchal translucency tests during the first trimester. Those who test positive should then be offered either amniocentesis or chorionic villus sampling during the second trimester.

Appropriate counseling should be offered in all cases, according to the guidelines.

The primary limitation to the guidelines is that many technicians who carry out ultrasound exams have not yet been trained to perform nuchal translucency studies.

To overcome that, the Society for Maternal-Fetal Medicine is organizing training programs to teach the procedure to technicians.

thomas.maugh@latimes.com
Insurance coverage for work experience placement welcomed

Human Rights Commissioner and Commissioner responsible for Disability Discrimination, Graeme Innes AM, today congratulated the Australian Government for paying the costs of personal accident and general liability insurance for disadvantaged job seekers, including those with disabilities, participating in the Work Experience Placement program.

“There is a large and talented pool of jobseekers with disabilities that are continuously overlooked by employers,” Commissioner Innes said.

“I hope this new work experience program will help jobseekers with disabilities to enter the workplace more easily and enable them to demonstrate their capabilities to employers.”

The Human Rights and Equal Opportunity Commission held a National Inquiry into Employment and Disability last year and found that one of the main barriers to the employment of people with disabilities was employer concerns about perceived increased exposure to legal and financial risks related to occupational health and safety.

“There is a perception that employees with disabilities are a higher safety risk than other employees, but there is no evidence that this is true: in fact the evidence suggests the contrary - that people with disabilities have fewer injuries and days off than other workers,” Commissioner Innes said.

“The perception however appears to be strong enough to have a significant impact on hiring decisions by employers.

“People with disabilities have a valuable contribution to make to workplaces in Australia and are keen and eager to work.

“I hope this program will help employers overcome their concerns and hire more people with disabilities.”
Father tells: why I froze my little girl in time
Chris Ayres, Los Angeles
January 05, 2007

HER name is Ashley X, and she is a little girl who will never grow up. Until New Year's Day, not even her first name was known. Ashley was a faceless case study, cited in a paper by two doctors at Seattle Children's Hospital as they outlined a treatment so radical it brought allegations of eugenics, of creating a 21st-century Frankenstein's monster, of maiming a child for the sake of convenience. The reason for the controversy is this: three years ago, when Ashley began to display early signs of puberty, her parents told doctors to remove her uterus, appendix and still-forming breasts, then treat her with high doses of oestrogen to stunt her growth. In other words, Ashley was sterilised and frozen in time, for ever to remain a child. She was 6.

Ashley, daughter of two professionals in the Seattle area, never had much hope of a normal life. Afflicted with a severe brain impairment known as static encephalopathy, she cannot walk, talk, keep her head up in bed or even swallow food. Her parents argued that keeping her small was the best way to improve the quality of her life, not to make life more convenient for them.

Because of her small size, the parents say, Ashley will receive more care from people who will be able to carry her: "Ashley will be moved and taken on trips more frequently and will have more exposure to activities and social gatherings ... instead of lying down in her bed staring at TV all day long."

By remaining a child, they say, Ashley will have a better chance of avoiding everything from bed sores to pneumonia - and the removal of her uterus means she will never have a menstrual cycle or risk developing uterine cancer.

Because Ashley was expected to have a large chest size, her parents say removing her breast buds, including the milk glands (while keeping the nipples intact), will save her further discomfort while avoiding fibrocystic growth and breast cancer. They also feared that large breasts could put Ashley at risk of sexual assault.

The case was approved by the hospital's ethics committee in 2004, which agreed that because Ashley could never reproduce voluntarily she was not being subjected to forced sterilisation, a form of racial cleansing promoted in the 1920s and known as eugenics. However, the case of Ashley X was not made public, and as a result no legal challenges were made.

Ashley's doctors, Daniel Gunther and Douglas Diekema, wrote in their paper for the October issue of the Archives of Pediatrics and Adolescent Medicine that the treatment would "remove one of the major obstacles to family care and might extend
the time that parents with the ability, resources and inclination to care for their child at home might be able to do so".

The paper inspired hundreds of internet postings: many supportive, some furious. "I find this offensive if not perverse," read one. "Truly a milestone in our convenience-minded society."

It was the critical comments that finally provoked Ashley's father to respond. While remaining anonymous, he posted a remarkable 9000-word blog entry at 11pm on New Year's Day, justifying his decision.

The posting includes links to photographs of Ashley, in which the faces of other family members, including her younger sister and brother, have been blanked out.

"Some question how God might view this treatment," he wrote. "The God we know wants Ashley to have a good quality of life and wants her parents to be diligent about using every resource at their disposal ... to maximise her quality of life."

Ashley's father went on to describe how her height is now expected to remain at about 1.3m and her weight at 34kg.

The medical profession is divided. "I think most people, when they hear of this, would say this is just plain wrong," wrote Jeffrey Brosco, of the University of Miami.

"It is a complicated story ... (But) high-dose oestrogen therapy to prevent out-of-home placement simply creates a new Sophie's Choice for parents to confront.

"If we as a society want to revise the nature of the harrowing predicament that these parents face, then more funds for home-based services, not more medication, is what is called for."

*The Times*
Inclusion International Denounces “the Ashley Treatment”

January 8, 2007 (London) FOR IMMEDIATE RELEASE

Inclusion International and its more than 500,000 individual members around the world expressed its condemnation of the “Ashley Treatment.” The “Ashley Treatment” is the name being given to a collection of medical interventions including hysterectomy, breast bud removal and the use of hormone treatment to stunt growth and stop development into adulthood. It is being used at the request of parents of a nine-year old US girl who has a severe disability to prevent her from growing as she ages.

Diane Richler, President of inclusion International decried the treatment as threefold discrimination against Ashley as a person with a disability, a girl and a child. “Just last month we celebrated the adoption of the new United Nations Convention on the Rights of Persons with a Disability,” said Richler. “Ashley’s situation teaches us that our celebrations were premature. Until the Convention is fully ratified and implemented, discrimination against Ashley and millions in similar situations will continue.” The Convention specifically recognizes the need for special caution in protecting the rights of women and children, for awareness-raising “including at the family level…and foster(ing) respect for the rights of persons with a disability”, for combating stereotypes, for equal treatment under the law, including supports for decision-making, freedom from degrading treatment and the right to ‘full physical development’.

Inclusion International is a federation of national family-based organizations in more than 115 countries, so its members identify strongly with Ashley’s parents. Parents should not be forced into making such hideous choices. Especially in a country with the wealth and resources of the United States, supports should be available so that Ashley could be supported to remain with her family and to grow and develop to her maximum. “It is when our countries and communities let families down, and leave them the full responsibility of care that families are sometimes pushed to make choices that would be unthinkable if their personal and financial resources were not being stretched to the breaking point,” concluded Richler.

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For further information contact:

Diane Richler,
President
+1 (416) 661-7754
dianer@inclusion-international.org
Prime Minister John Howard's welfare revolution has generated dramatic early results in curbing the soaring growth in disability pensions.

Since the overhaul of welfare rules in July, more than 3500 disabled Australians have been put on the dole and forced to look for part-time jobs.

Under the old rules, many would have qualified for the higher-paying disability support pension, which did not compel them to seek work.

Figures requested by *The Age* reveal that in the six months to December, the number of new disability pensioners fell by 1500, or 5.5 per cent, compared to the same period in 2005, to about 26,000.

But with more than 3500 people deemed to have a "partial capacity" to work, the figures suggest the changes may have prevented a further 2000 people going onto the pension.

Workforce Participation Minister Sharman Stone said the early figures showed the welfare-to-work reforms were effective. But how successful they had been in placing disabled people in lasting jobs would take a few more months to emerge.

"International research strongly supports the fact that the best way to overcome an injury or to enjoy a full community life is by regaining employment," she said.

Disabled people judged able to work 15 to 29 hours a week are put on the dole. They are paid $420.90 a fortnight, compared with the $512.10 disability pension, plus $18.20 in
Australian Federation of Disability Organisations chief Maryanne Diamond said some people who should be entitled to the disability pension were being put on the dole because they did not have all the required paperwork when assessed.

"We are hearing that the assessments are happening so quickly that people are not getting the material together in time," she said.
A Melbourne mother who claims her disabled child was unfairly discriminated against at school has lost her legal battle with the education department.

Jenny Harrison claimed her 11-year-old daughter Lindsay Sutherland, who has severe cerebral palsy, was denied the same learning opportunities as her classmates because of her disability.

Ms Harrison filed a discrimination complaint with the Victorian Civil and Administrative Tribunal (VCAT) seeking compensation and the appointment of a full-time qualified teachers' aide to help Lindsay, who is wheelchair bound and cannot speak.

The claim was dismissed on Friday following a 23 day hearing.

"It's a very disappointing result, everything has been dismissed," said Ms Harrison, who refuses to send her daughter to a specialist school.

"It's a real indictment and parents of children with disabilities should be really concerned about their kids' education and this government's commitment to it," she said.

The complaint was first lodged with the Equal Opportunity Commission in 2004 when Lindsay was a pupil at Hobson's Bay Primary School in suburban Newport.

Her mother alleged Lindsay's education was compromised because the school did not enable her to equally participate in the classroom and socialise with other pupils, including being excluded from school camps.

In 2005, Lindsay - who communicates with a knee-activated
electronic device - moved to Spotswood Primary School because the fallout from the complaint made her school "unbearable".

In her 73 page finding, VCAT deputy president Anne Coghlan dismissed the claims.

She said she was not satisfied that the school was responsible for Lindsay's diminished learning outcomes, "rather than her cognitive and physical impairments".

A spokeswoman for Victoria's education department declined to comment before reviewing the findings.

Ms Harrison is considering an appeal.

Julie Phillips, representing Ms Harrison, said the decision was unacceptable and had implications for all parents raising disabled children.

"It's basically reinforcing that even though the policy of the department is inclusion, that doesn't necessarily mean that you'll be educated and socialised in the same way everybody else is," she said.

Ms Harrison said research proved the learning outcomes for disabled children were better in mainstream schools.

"What has been said to me for years is that she shouldn't be in a mainstream school, she should be in a specialist school. I disagree with that, I have read the research and I believe that (research) to be true."

© 2007 AAP
JENNIFER KELLAWAY is a double amputee - it says so on her driver's licence.

The gold licence, which she has had for 30 years, states clearly on the back that she is unable to drive without her prosthetic legs.

But every three years she is forced to undergo the humiliating procedure of furnishing the Roads and Traffic Authority with a medical certificate to prove she is "still disabled", and therefore still entitled to park in disabled spots.

In September, a Herald investigation found that 25 per cent of drivers using disabled parking permits in Sydney were doing so illegally. But despite being genuinely and permanently disabled, Mrs Kellaway has at times been without a parking permit, owing to what she sees as the discriminatory and ridiculous requirements of the authority.

The battle, which she likens to a "Monty Python sketch" began in September 2003, when Mrs Kellaway went to her local RTA office in Dubbo to renew her Mobility Parking Scheme card.

The 60-year-old, who has been disabled since birth, was told the rules had changed. She would now have to provide a medical certificate to prove she was still incapacitated and pay a $30 fee, which she was told had been introduced to deter "frivolous and fraudulent applications".

"I said, 'I know it's on your system that I'm a double amputee - because it's written on my driver's licence,'" Mrs Kellaway said. "I told them they could stab my legs with a letter opener if they
wanted to prove it."

In protest Mrs Kellaway refused to pay the fee to renew her MPS card.

All was well until about October 2004, when she was fined $392 for parking in a disabled spot at a shopping centre, because she was displaying her out-of-date permit.

After much letter writing and many dealings with the Infringement Processing Bureau, the RTA told her that if she simply gave it a letter consenting for her medical information to be passed between its departments it would process the permit.

"Not only did I consent to them looking at the medical records, but I had been asking them all along just to look at the records, and bypass the need for a medical certificate."

Eventually in 2005 the RTA finally agreed to issue a new permit to Mrs Kellaway. Which only left the matter of the $30 fee - supposedly to deter frivolous applicants.

"In the end I paid my $30 but I did it in protest," Mrs Kellaway said. "I said there should be a one-off application for the permanently disabled."

The RTA told the Herald that it would change the process so permanently disabled people would have to provide medical certification only once, and not for subsequent renewals of their MPS cards. These changes would come into effect "later this year".

But Mrs Kellaway still believes it is unjust that bona fide applicants should have to pay a $30 penalty just because some people abuse the system.

"Anyway, the thing about the abusers is they are quick enough to get away from the parking police, unlike us."