

## REVIEW

## The challenges of providing eye care for adults with intellectual disabilities

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This review is intended to raise awareness of the importance of providing high-quality eye care for people with intellectual disabilities and the increasing need for this eye care to be community-based. We describe the challenges to the provision of high-quality community-based eye care for people with intellectual disabilities and ideas, evidence and methods for overcoming them.

The prevalence of visual impairment in people with intellectual disabilities has been reported to be at least 40 per cent, rising to as high as 100 per cent in those with profound and severe disabilities. A progressive move toward deinstitutionalisation has shifted the provision of care for people with intellectual disabilities. Individuals can have the freedom to access health-care services of their choice. This has posed challenges to the health-care system, including how to deliver high-quality community-based eye care, creating a current significant unmet need for eye-care services. Undiagnosed refractive error and under-prescription of spectacles are major reasons for avoidable visual impairment among people with disabilities. There is an apparent reluctance of optometrists to engage in this work due to the perceived difficulties of working with people with intellectual and multiple disabilities.

There are challenges associated with diagnosis and management of ocular conditions in people with intellectual disabilities and the demand is clear. Small shifts in training, knowledge and awareness would place optometry well to meet the challenges of this specialised area of eye care.

**Key words:** autism spectrum disorder, cerebral palsy, deinstitutionalisation, Down syndrome, intellectual disability, ocular manifestations, refractive error correction

In the 1880s, people classified as 'mentally retarded' were housed and cared for in large residential institutions or 'hospitals for the insane'. The terminology of 'mental retardation' has now been replaced with 'intellectual disability' or 'intellectual developmental disorders'.<sup>1</sup> Over the last 200 years, various terms have been used to describe the condition, such as 'mental defective', 'idiocy' and 'mental handicap'. According to the American Association on Intellectual and Developmental Disabilities (AAIDD), intellectual disability (ID) is a disability characterised by significant limitations in both intellectual functions and adaptive behaviour. Intellectual disability begins during the developmental period (before the age of 18). The fifth edition of Diagnostic and Statistical Manual of Mental Disorders (DSM-V) published by the American Psychiatric Association, uses 'intellectual disability' interchangeably with 'intellectual developmental disorders'.<sup>2</sup>

People born with intellectual disability were often admitted into institutions at a

young age due to lack of support within the community to facilitate family care. Some residents could spend 50 or 60 years of their lives under institutional care. Typical institutions were large, with 100 to 200 residents cared for in regimented systematic order. Regimens adopted within these institutions impacted on patients' lifestyles and limited personal choices and freedom. Institutional life was often segregated, resulting in a lack of involvement in the community. Health care, including eye care, was provided within the institutions by visiting medical and allied health practitioners. Over time, this contributed to a general misconception that people with disabilities were too difficult to be cared for in community settings.

With the introduction of new antipsychotic drugs, such as chlorpromazine, improved service utilisation and political reforms based around patient choice, deinstitutionalisation of people with intellectual disabilities started in the 1950s.<sup>3</sup> In developed countries, deinstitutionalisation shifts the health and

social care provision to local service providers and closes the large institutions. Over time, the majority of people with intellectual disabilities have been transferred to smaller community-based homes across local communities.<sup>4</sup> Only those with the most profound disabilities have remained within institutions. Overall, this resulted in improved living conditions and freedom, leading to improvement in quality of life and social interactions.<sup>5,6</sup>

According to DSM-V, the classification of severity of intellectual disability is defined by adaptive functions which determine the level of assistance required for the person.<sup>2</sup> The 'intelligence quotient' (IQ) scores do not factor into this classification but are useful in determining the individual's intellectual function. Given the nature of this article being optometry-related and not for diagnosing disorders, a summarised version of the classification of intellectual disability with the approximate IQ levels is shown in Appendix 1.<sup>2,7</sup>

There are approximately 200 million people with some form of disability worldwide. In the most recent Census data, four million Australians were identified as having a disability,<sup>8</sup> of whom 33 per cent have intellectual disability. Other types of disabilities include physical and psychiatric. In addition, the number of individuals requiring disability support in Australia has risen by 29 per cent over a four-year period (to 2012).<sup>8,9</sup> There is also growing evidence suggesting that those with severe or profound intellectual disabilities receive fewer health care services than those in the general population.<sup>10</sup> This is particularly relevant as research shows a strong correlation between the presence of physical, sensory and intellectual disabilities.<sup>11,12</sup> Over the last few decades, the life expectancy of people with intellectual disabilities has increased significantly due to improved health-care provision. Increased longevity means they are more likely to experience age-related conditions such as neurodegenerative diseases, along with eye conditions such as cataracts and presbyopia that may further complicate existing cognitive, behavioural and physical disabilities. Down syndrome (DS), cerebral palsy (CP) and autism spectrum disorder (ASD) are common conditions affecting people with intellectual disabilities. The prevalence of people with Down syndrome within the developed world is one in 1,000,<sup>13</sup> ASD is six in 1,000<sup>14</sup> and the incidence of cerebral palsy is two to four per 1,000 births.<sup>15,16</sup> The co-existence of ASD in patients with DS is between three and seven per cent.<sup>17,18</sup> These conditions can involve damage to vision and cognition.<sup>19-21</sup> Diagnoses of ocular diseases can be compounded by complex medical conditions, behavioural issues that restrict investigation and the possible loss of medical records due to involvement of multiple support services.

Complex syndromes such as Moebius syndrome or 'fragile X syndrome' often present with other disabilities, to the extent that visual impairment often goes unrecognised.

The Australian Government initiated the National Disability Insurance Agency (an independent statutory agency), with the task of fully implementing the National Disability Insurance Scheme (NDIS) by 2016. The priority is to raise social awareness of disability, provide support and create opportunities for individuals with permanent and significant disabilities, including families and carers.<sup>22</sup> NDIS provides funds to support participants to reach their goals, gain independence and develop their confidence to be involved in the community. The changes which have occurred over the last 60 years present opportunities, challenges and responsibilities for local health-care practitioners, including optometrists; however, there are both real and perceived difficulties in providing health-care services to people with intellectual disabilities that will be discussed.

#### THE COMPLEXITY OF OCULAR MANIFESTATIONS

Van Splunder and colleagues' population-based epidemiological study<sup>23</sup> (n = 1,539) showed that the prevalence of visual impairment varied from 2.2 per cent in young adults (under 50 years) with mild intellectual disability and no DS to 66.7 per cent in older adults (50 years and older) with profound intellectual disability and DS. The study also showed an increase in the prevalence of blindness as severity of intellectual disability worsened (from 0.7 to 38.9 per cent). Ocular abnormalities were reported in 56 per cent of patients with CP, with strabismus being the most common finding.<sup>24</sup> A more recent but smaller cross-

sectional survey by Fong and colleagues<sup>25</sup> showed that 43 per cent of their sample population (n = 91) with DS had moderate visual impairment. Van den Broek and colleagues<sup>26</sup> and Evenhuis<sup>27</sup> also provided similar evidence that visual impairment was more significant in patients with profound intellectual disabilities, when compared with those with severe intellectual disabilities. This highlights the association between visual impairment, ageing, the severity of intellectual disability and the presence of DS. Table 1 lists some of the common ocular and visual pathway manifestations found in these patients.

Refractive error in patients with intellectual disabilities is often significant. McCulloch and colleagues<sup>28</sup> demonstrated a wide range of refractive errors in patients with intellectual disabilities varying between -16.50 and +8.00 D (spherical equivalent). The study did not find a correlation between the magnitude of refractive error and the severity of intellectual disability. Similarly, Fong and colleagues<sup>25</sup> found a range of spherical equivalent refractive errors from -23.25 to +3.00 D in patients with DS, with 59 per cent of DS participants being myopic with an average spherical refractive error of -5.75 ± 4.6 D. Significant astigmatism (defined as 1.00 D or more) was found in 72 per cent of patients, with the average value being 2.06 ± 1.1 DC; however, Fong and colleagues' study<sup>25</sup> was carried out on Chinese patients with DS, which does not represent the global prevalence. The prevalence of myopia in patients with intellectual disabilities varied between 18 and 33 per cent among other populations.<sup>29,30</sup> Significant refractive error has also been associated with other ocular manifestations, such as keratoconus (common in patients with DS and ASD) and strabismus.<sup>31,32</sup> A correlation of increasing incidence of strabismus has

<b>Down syndrome</b> <sup>25,31,34,35</sup>	<b>Cerebral palsy</b> <sup>36,37</sup>	<b>Autism spectrum disorder</b> <sup>38,39</sup>
High refractive errors	High refractive errors	High refractive errors
Strabismus	Strabismus	Keratoconus
Amblyopia	Amblyopia	Visual attention deficits
Accommodative dysfunction	Cortical blindness	Eye movement dysfunction
Keratoconus	Optic atrophy	Behavioural visual symptoms
Recurrent keratitis	Nystagmus	
Cataracts	Fundus abnormality	
Chronic eye infections	Accommodative dysfunction	

**Table 1. Ocular manifestations in patients with Down syndrome, cerebral palsy and autism spectrum disorder**

also been noted with increasing severity of intellectual disability.<sup>28</sup> In patients with CP, the prevalence of hypermetropia and astigmatism was 10 times more than those without CP. The range of hypermetropia found in patients with CP was between +1.00 and +6.50 D, while astigmatism ranged between -1.00 and -4.50 DC.<sup>33</sup>

Although glaucoma is the second leading cause of blindness globally,<sup>40,41</sup> there is very little in the literature discussing the diagnosis and management of glaucoma among people with intellectual disabilities. The prevalence of glaucoma may vary widely among different groups, for example, studies have found 1.19 per cent in people with various severities of intellectual disability;<sup>42</sup> 11.5 per cent in those with DS;<sup>43</sup> and 11.8 per cent as glaucoma suspect among high school students with intellectual disabilities in Taiwan.<sup>44</sup> It is likely that glaucoma often goes undiagnosed in people with intellectual disabilities due to difficulties in measuring intraocular pressures, assessing visual fields or obtaining a good view of the optic nerve heads. Unless a patient presents with signs and symptoms of acute angle closure glaucoma, other variations of this condition could be easily missed or be diagnosed only in its advanced stages.

Evidence of poorer engagement of spatial attention was demonstrated in patients with ASD.<sup>45,46</sup> Extensive research studies have been performed to understand the nature of visual processing in these patients. Studies have included measures of contrast sensitivity,<sup>47</sup> face recognition,<sup>48</sup> visual search,<sup>49-51</sup> motion perception<sup>52</sup> and depth perception.<sup>39,53</sup> Interestingly, performance during psychophysical testing suggested enhanced perception, when particular stimulus features were shown. This may explain some commonly observable behaviours such as reduced attention span,<sup>45,46,54</sup> over-reaction to lights and patterns, limited eye contact and self-stimulating behaviour, such as hand flicking or self-inflicted injury.<sup>39,55</sup>

Behavioural disorders can be associated with self-inflicted trauma, which can lead to secondary ocular problems. Damage to various ocular structures has been reported in patients with intellectual disabilities.<sup>56-59</sup> Anterior eye infections may be noted during eye examinations in patients with DS due to predisposing factors such as ectropion and blepharitis.<sup>60,61</sup> This could also be related to eye rubbing, often seen in patients with keratoconus<sup>62</sup> or result from ocular surface exposure due to ocular malformation and abnormal cranial nerve innervations. Given the

high prevalence of ocular diseases found in patients with intellectual disabilities, Van Splunder and colleagues<sup>23</sup> suggest that people with severe to profound intellectual disabilities should be considered as being visually impaired until proven otherwise.

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## THE COMMON CHALLENGES

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People with intellectual disabilities often have multiple and complex conditions that make their health examination more demanding and time consuming. General medical practitioners (GPs) play a major role in providing health care to people with intellectual disabilities; however, they have expressed concerns over the difficulties they face when they see these patients.<sup>63</sup> The common concerns raised by physicians include limited specialised training, difficulty in communicating with patients, inadequacy of medical information provided by carers, which in turn led to physicians being dissatisfied with the quality of medical services that they provided. These factors apply to dentists,<sup>64</sup> optometrists and other health-care providers.

The Australian College of Optometry (ACO) co-ordinates the Visiting Disability Services (VDS), providing optometric services to Victorians with intellectual disabilities in community settings. The VDS was established 25 years ago as the ACO's first outreach optometric service and is now part of a broader Outreach Service, which receives funding support from the Victorian state government's Department of Health. In addition, the ACO also runs a Disability Service at its Carlton headquarters, for people who are able to travel. The ACO currently provides approximately 110 disability consultations at Carlton and 150 VDS consultations per annum. The demands for optometric services for people with intellectual disabilities have increased over the years and this led us to explore the challenges that VDS posed for our optometry colleagues. The common challenges identified (through an unpublished internal staff questionnaire) were difficulty in patient communication, dealing with challenging behaviour, a lack of staff support when visiting residential units and general concerns regarding own safety. These challenges are similar to those identified by GPs.<sup>63</sup> Given that the ACO provides eye-care services to people from various ethnicities, language barriers and cultural differences further complicate the challenges faced, when examining patients with intellectual disabilities. Other challenges faced by

individuals with intellectual disabilities seeking to attend conventional clinics include difficulty in transportation and its associated cost.

In Australia, the government-funded Medicare system aims to ensure all Australians can access low-cost health-care services. This enables optometrists to provide eye-care services using a bulk-billing system or to set their own fee (which can result in an out-of-pocket expense for the patient). Financial, accommodation and transportation support (funded by the Department of Human Services) are available for people with disabilities. This provides flexibility and freedom for people to access various types of health care and community services. In addition, the support from NDIS for people with intellectual disabilities may include transport to daily life activities, work and education; assistance with housework, mobility equipment and home/vehicle modifications.<sup>22</sup>

To further support people experiencing disadvantage, the Victorian Eyecare Service (VES) provides subsidised eye care and low-cost visual aids for permanent residents of Victoria who hold a Pension Concession or a Health Care Card. Melbourne metropolitan residents can access VES at ACO (based in Carlton), its metropolitan clinics (located within community health facilities) and outreach services. People who live in regional and rural areas can access VES through a network of participating independent optometrists and ophthalmologists.

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## PATIENT COMMUNICATION AND DEALING WITH CHALLENGING BEHAVIOUR

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Freedman and Chassler<sup>65</sup> reported that people who were institutionalised exhibited more disruptive behaviour than those who lived at home. Lowe and colleagues<sup>66</sup> found the prevalence of serious challenging behaviour to vary between 5.5 and 16.8 per cent of the intellectually disabled population. The behaviour is affected by the level of intellectual disability, the degree of sensory impairment, mobility issues, the level of communication ability and associated conditions such as ASD and mental illness.<sup>58,59</sup> Interestingly, visual impairment also contributes to behavioural issues, typically self-injurious behaviour rather than aggression.<sup>67</sup> Patients with severe visual impairment and intellectual disabilities show self-stimulatory behaviour, such as light gazing, eye pressing or poking.<sup>68</sup> Such behaviour can in turn

damage ocular structures. Hearing impairment has a prevalence as high as 50 per cent among institutionalised populations with intellectual disabilities.<sup>69-71</sup> This indicates the need for alternative methods of communication during a consultation.

Encountering what is perceived to be challenging behaviour in a patient can be disturbing to less experienced eye-care providers; however, non-cooperation and disruptions can be misinterpreted as challenging behaviour to clinicians, who are unfamiliar with seeing patients with intellectual disabilities. This behaviour may appear to be more pronounced at times of distress, for example when they do not understand what is happening during test procedures. Clinicians should modify their approach and clinical tests to better engage patients, allow them to be more comfortable and subsequently establish a better consulting atmosphere.

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## MODIFICATIONS IN THE CLINICIAN'S APPROACH AND VISUAL FUNCTION ASSESSMENT

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### The setting

As a general rule, the testing area should be quiet and spacious with good ergonomics (for example, appropriate lighting). It should also have minimal clusters of objects. Assessing a patient with multiple disabilities may require extra space for accessibility and to make observations of the patient's visual-motor or visual-vestibular skills. Clinicians and administrative staff should also allocate appropriate consultation time to allow extra time for assessment and enabling breaks for the patient when necessary.

To minimise distress, it is important for the patient to understand how the eye test will be performed and its purpose. Prior to the day of the eye examination, written information and consent forms should be provided, so that the patient and the primary carers are aware of the nature of the eye examination. This includes information about any procedures and diagnostic eye drops which may be used during the assessment. To obtain more accurate measurement of subjective tests, it may be useful to provide appropriate portable visual acuity charts for the patient in advance, so that they can practice naming or matching symbols with the support of their carers (if needed). In some cases, it may be helpful to provide a picture of the testing room, equipment or even the clinician's

photograph to familiarise the patient with the concept of the eye examination.

Questionnaires can be valuable tools in assessing health-related quality of life and supplement clinical measures and outcomes.<sup>72</sup> By using modified questionnaires, Cui and colleagues<sup>72,73</sup> studied the impact of visual performance on the quality of life in children with mild to moderate intellectual disabilities in China, with the emphasis on self-perception of functional status and life quality. The results of the study showed some of these questionnaires were useful in providing information on health-related quality of life in children with intellectual disabilities.<sup>72</sup> It may provide valuable information to complement clinical measures and aid decision making and remains an interesting area to explore.

The 'Functional Vision Assessment for People with Learning Disabilities' (FVA) is a set of questionnaires which was developed by SeeAbility,<sup>74</sup> a charity based in the United Kingdom. It can be used to evaluate different aspects of the individual's visually related symptoms and behaviour. The FVA has a checklist with seven domains:

1. appearance of the eyes
2. behaviour
3. central vision
4. peripheral vision
5. sensitivity to light
6. colour vision and contrast sensitivity
7. poor vision in one eye.

Each section contains comprehensive questions that are written in plain language. Carers can answer these questions while observing the individual at home or at a day placement centre. One benefit of the FVA is that it raises carers' awareness of the visual, ocular health and visual-motor related issues of the patient. In most cases, the FVA can form the basis of history-taking for a patient's examination.

### Patient's consent

The aspect of informed and written consent is crucial when clinicians provide medical examinations, in particular at an outreach setting (for example, respite care facilities) or at locations where guardians are absent. Clinicians should aim to obtain informed consent from patients (over the age of 18) to the procedures and the management plans that take place throughout the eye test, including the use of diagnostic eye drops, prescription of visual aids and referral to specialist services. The purpose, potential benefits, risks, prognosis

and cost should be explained in plain language. While recognising there will be cases in which patients do not have the capacity to consent, the informed consent is usually obtained from the patient's legal guardian or next-of-kin.<sup>75,76</sup>

Although written consent may be obtained from the legal guardian, clinicians should be aware that patients maintain the right to refuse procedures being performed during the consultation. This indicates a consent withdrawal, which should be documented in clinical records for future references.

### Clinician's approach

Clinicians should get a general understanding of the preferred method of communication and the mental capacity of the patient. This enables the use of appropriate language and suitable examination techniques to obtain information from the patient. Simplified, short or even forced-choice questions are often useful. Talking to the patient directly (rather than to the carer) and allowing time for a response, encouraging the patient to maintain interest and participation in the consultation, can all aid communication. If the response is difficult for the clinician to understand, it is important to ask the patient to repeat what has been said rather than simply ignoring the response. Recognising the presence of a hearing impairment and/or speech difficulty means the clinician may need to adapt by using other methods to communicate, such as sign language, pictures or symbol.

Staff support can vary in different settings. It is important for the clinician to be able to work independently and carry out an eye examination without assistance; however, when examining patients with more severe intellectual disabilities, the presence of the patient's carers may be more important. Carers such as close family members or a primary support worker can provide useful information regarding the patient's habits and routines, as well as reporting their observations of visually related problems. They can also provide positive reinforcement (for example, approval or praise) to help maintain the patient's attention and help avoid known behaviour triggers.

### Assessment modifications

Assessment of visual function (for example, visual acuity, visual field, contrast sensitivity and colour discrimination) assists practitioners' understanding of patient visual

perception; however, these assessments rely on varying degrees of subjective responses and may be difficult to elicit in those with severe or profound intellectual disabilities.

### VISUAL ACUITY

Equipment and methods are important. In cases of mild to moderate intellectual disability, optometrists may be able to quantify visual acuity using high-contrast logMAR letter or symbol acuity charts (for example, Lea symbols or Kay pictures). Simpler tests including preferential viewing tests (for example, Teller acuity cards, Lea paddles or the Cardiff Acuity Test) can sometimes be used to measure spatial resolution in those with moderate to severe intellectual disabilities. The Pacific Acuity Test may provide a new option for measuring recognition rather than resolution in those with moderate to severe intellectual disabilities.<sup>77</sup> In cases with profound intellectual disability, it may not be practical or possible to use these methods for measuring visual acuity.

Patients with limited comprehension of letters and shapes or those who perform poorly on preferential testing may be more attentive when presented with objects that are relevant in their daily activities (for example, sweets or small toys). If edible objects are used, the clinician should ensure there are no known food allergies or swallowing difficulties. When assessing vision with everyday items, it is important to use objects of various sizes, colour and contrast (Figure 1). Using targets of different sizes at various test distances enables the clinician to estimate the potential vision at near and intermediate distances, at which common daily tasks are undertaken. Wesson and Maino<sup>78</sup> illustrated the estimated visual acuity based on targets of various sizes (from 0.5 to 5.0 mm in size) in the Candy Bead Test. Table 2 shows a modified version of the test, which includes typical objects placed at

common testing distances and the relative estimated visual acuity. It is worth noting that if the patient is attentive to a single presentation of an edible object, the task is a detection rather than resolution or recognition test.<sup>79</sup> It is possible that the patient may have limited attention to task, therefore limiting the number of trial presentations, making the visual task relevant and interesting can often maintain the patient's interest.

### VISUAL FIELDS

An assessment of the 'useful field of view' (UFOV) may provide an explanation as to why a patient avoids certain activities or has restricted mobility. Behaviour such as being overly cautious with stairs should be considered as a possible sign of visual field loss. Automated static visual field examinations are rarely tolerated by patients with intellectual disabilities and kinetic perimetry can be difficult to perform. Information obtained by using conventional confrontation testing can be useful but must be interpreted with caution as patients may have limited understanding of instructions. Modified confrontation testing to assess the UFOV should be considered (for instance, using a colourful small object as a fixation target, while presenting a visual stimulus in the peripheral visual field).<sup>80</sup> Eye movements and head turns toward peripheral targets may be indicative of the extent of the UFOV. Interpretation of the UFOV in patients with more severe intellectual disabilities should be done with caution and should be considered in conjunction with other information from the ocular health assessment.

### REFRACTION

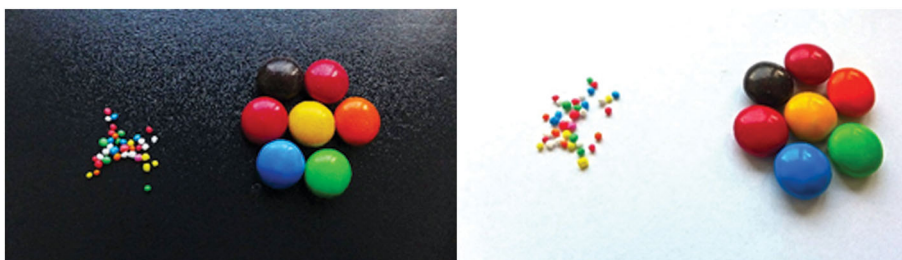
There is a general misconception that patients with intellectual disabilities have limited sensory demand, in particular visual

demand. A natural extension of this misconception is that glasses will be of limited value and as such performing refraction will be a relatively fruitless activity. The more complex and profound the disability, the greater the temptation to believe this misconception. Comments like 'Mr X doesn't do much around the house', 'she can't read' and 'she doesn't show any interest in near tasks' are commonly heard; however, is it because the patient has no interest in the task or are they unable to engage in it because of limited vision?

Appropriately selected testing methods also provide an opportunity for the patient to understand the procedure more easily and create a more pleasant experience. Patients with mild intellectual disabilities may handle the attention and intellectual requirements of subjective refraction to a certain level; however, to determine the magnitude of refractive error in patients with more severe intellectual disabilities, clinicians should rely on retinoscopy. It requires clinical proficiency and an ability to rapidly evaluate a fleeting retinoscopic reflex. Using a trial frame or even holding lenses close to the patient's face can be difficult as this process invades personal space. Variations such as Mohindra retinoscopy<sup>81</sup> and cycloplegic retinoscopy may further refine refractive error measurement; however, the use of cycloplegic drops should be weighed against the higher risks of systemic toxicity in patients with CP, particularly in children.<sup>82-87</sup> On the other hand, adults lose their accommodation as they age<sup>88</sup> and the use of cycloplegic drops may not add extra information other than dilating the pupils and allowing a better view for retinoscopy and ophthalmoscopy. Common daily tasks are often performed at near to intermediate distances, therefore, the 'monocular estimation method' (MEM) retinoscopy or equivalent should be considered as an essential component of refraction. It is particularly important for young adults with DS and CP because they often have poor accommodation.<sup>34,37</sup>

### OCULAR HEALTH ASSESSMENT

Assessing the ocular health of the patient with an intellectual disability can be a challenging part of the consultation, particularly if the patient exhibits unpredictable head and hand movements. Nevertheless, clinicians must always attempt to examine the eye health of the patients. Certain aspects of overall ocular and neurological health can



**Figure 1.** Targets of different sizes presented on dark (L side) and white (R side) backgrounds demonstrate the relationships between size, contrast and visibility. Small targets (100s & 1000s) and large targets (M & Ms) are shown.

	Approximate target size (mm)	Task	Snellen fraction equivalent (6/?) and logMAR equivalent for test distance:					
			0.25 m	0.30 m	0.40 m	0.50 m	1.00 m	2.00 m
N5 letter	1.77	Recognition	15 (0.40)	13 (0.34)	9.4 (0.19)	7.5 (0.10)	3.8 (-0.20)	1.9 (-0.50)
100 s & 1,000s	1.50	Detection	124 (1.32)	103 (1.23)	77 (1.11)	62 (1.01)	31 (0.71)	15 (0.40)
M & Ms	7.00	Detection	577 (1.98)	481 (1.90)	361 (1.78)	289 (1.68)	144 (1.38)	72 (1.08)
Starburst	15.00	Detection	1236 (2.31)	1030 (2.23)	773 (2.11)	619 (2.01)	309 (1.71)	155 (1.41)

**Table 2. Estimated visual acuities calculated for several commonly used targets and testing distances. Both Snellen denominator (in regular font) and logMAR (in italic) equivalent are included**

be performed before assessing visual functions, for example:

1. ocular alignment, eyelid position, pupil asymmetry, involuntary eye movements and head posture as indicators of strabismus, nystagmus, cranial nerve palsies, gaze palsies or other neurological issues to investigate in more details
2. visual attention as an indicator of visual capacity and/or cognitive/attentional ability
3. obvious red eye, eyelid conditions and
4. corneal scars, proptosis and red reflexes as indicators of ocular health issues.

Clinicians should understand that patients may be unable to sit near fixed equipment for ocular health examination. Therefore, the use of robust portable equipment, including a portable slitlamp and a binocular indirect ophthalmoscope is essential. The posterior aspect of the eye is best examined with mydriasis or after cycloplegic refraction.

**MANAGEMENT AND THE CONTINUITY OF CARE**

**Spectacle prescribing**

The prevalence of significant refractive error found in patients with intellectual disabilities and the rate of spectacle prescribing is not in a linear relationship. Studies have shown lower spectacle prescription rates for people who were institutionalised (24 per cent) compared to those who lived at home (45 per cent)<sup>25</sup> and yet more significant refractive errors were found in those living in institutions.<sup>30</sup> McCulloch and colleagues<sup>28</sup> demonstrated that more spectacles were prescribed for patients with mild intellectual disabilities and prescribing rates dropped in groups with more severe intellectual disabilities. As the independence of performing daily tasks reduces in patients with complex medical issues and more severe intellectual disabilities, their visual requirement to complete a task may also be compromised. This may be a contributing factor for lower rates of spectacle

prescribing and uptake by patients with severe intellectual disabilities.

Warburg's study<sup>42</sup> involving patients with moderate, severe and profound intellectual disabilities found that less than 50 per cent of their participants had used glasses prior to the study, despite identifying patients with high refractive errors (up to -6.00 D). It is possible that these significant refractive errors had been undiagnosed previously but probable that they had not been managed appropriately by eye-care practitioners due to reasons mentioned above. Warburg<sup>42</sup> also commented that hypermetropic corrections were more commonly seen than myopic corrections because patients with uncorrected myopia are more likely to be able to cope with near tasks unaided, compared to those with hypermetropia. This reflects the importance of using relevant testing distances and prescribing accordingly.

Typically, clinicians determine the necessity of prescribing spectacles based on the severity of the refractive error, functional use and related tasks. Predicting how a patient with an intellectual disability will respond to wearing a correction and whether there would be any functional improvement can be difficult. Therefore, clinicians should not make assumptions about the appropriateness and practicality of spectacle correction based on the presenting behaviour. When possible, clinicians should consider trialling the prescription during the examination and observe for evidence of alteration in visual perception or behaviour. This may not occur immediately and patients should be given the opportunity to adapt to the spectacle correction under supervised conditions, if possible. In all cases, the decision to prescribe spectacles should involve discussions with the patient and his/her carer. Best compliance is achieved when the optometrist provides clear task-specific instructions on the use of spectacles (for example, watching television) and arranges appropriate review to allow for the impact of spectacle wear to be evaluated over time.

Accommodative dysfunction is common, particularly among people with DS and those taking neuro-active medications. Stewart, Woodhouse and Trojanowska<sup>89</sup> found over 75 per cent of a DS population sample (n = 114 children) had reduced accommodation. Bifocals are well tolerated and effective at correcting accommodative problems in people with DS. The improved near visual acuity and focusing are believed to help improve learning potential.<sup>89</sup> Furthermore, participants in another study demonstrated improvement in the speed of completing word identification tests after bifocals were used.<sup>90</sup> This indicates that prescribing bifocals for patients with DS could provide opportunities to improve reading skills and gain educational benefits.<sup>90</sup> Although the above studies involved children as subjects, it is important to be aware that reduced accommodation could affect young adults and perhaps more significant accommodative dysfunction could be found in adults with DS compared with an age-matched population.

**Alternative refractive error corrections**

Contact lenses are rarely the correction of choice when spectacle wear is adequate in the intellectually disabled population; however, they can be very successful in carefully selected patients with keratoconus. If all options of visual aids have been trialled, clear lens extraction (refractive lens exchange) may be considered. Tychsen<sup>91,92</sup> and Waring<sup>93</sup> reviewed the potential use of refractive surgery in children with visual impairment and had generated interest in using the same technique in patients with intellectual disabilities. For instance, clear lens extraction may be useful in cases with bilateral hyperopia with accommodative esotropia.<sup>92</sup> Appropriate patients must be selected carefully. Extensive examination and discussion are essential to ensure the patients and their guardians understand the

benefits, risks and potential side-effects of clear lens extraction compared to its alternatives.

### Visual ergonomics

So far, management of refractive error corrections is discussed. It is worth noting that there are also several other reasons to not prescribe spectacles, including concerns regarding safety from self-inflicted injuries or falls. Reasons for resistance to wearing glasses or repeated damage to glasses should be addressed. In these circumstances, where unsuccessful wear occurs (after multiple trials), optometrists should have a discussion with the patient and the carer regarding visual ergonomics. These factors are also useful to keep in mind for all patients who have visual impairment. Considerations may involve:

1. systematising the position of household objects to promote mobility in people with restricted visual fields (for example, rearranging furniture to provide clear walkways, and maintaining object positions in a familiar environment)
2. introducing shorter viewing distances for people with myopia (for example, when watching television)
3. advising on lighting and contrast enhancement for people with cataracts or keratoconus (for example, lighting improvement, using cutlery with high contrast) and
4. using materials with larger prints, different textures, colours and contrasts.

### Referral to other services

When the need for specialist referral is identified (for example, ophthalmology, low vision), clinicians should consider whether such referral will lead to an improvement or prevent significant further loss of quality of life. Cooke, Frazer and Jackson<sup>94</sup> retrospectively studied the outcome of intraocular surgery in patients with moderate to severe intellectual disabilities. They found that post-operatively, most patients had improved mobility and social interaction. To support this view, McCulloch and colleagues<sup>28</sup> also found no significant relationship between the rate of referral to ophthalmological services and the level of intellectual disability. Referral to specialist services should still be considered regardless of the severity of intellectual disability.

Any referral should be discussed thoroughly with the patient, guardians, primary carers and the GP. Careful documentation should be recorded in the patient's health-care plan. The Comprehensive Health

Assessment Program (CHAP) is a documentation which was developed by Lennox and colleagues<sup>95,96</sup> and is now widely used in different states of Australia and other countries. Its aim is to implement different aspects of health care provided to people with intellectual disabilities. It allows documentation and communication between carers, support workers and allied health-service providers. The use of the CHAP also enables house supervisors and carers to keep different aspects of health checks up-to-date and provide some consistency in the structure of the health-care plan.

It is recommended that regular eye examinations for adults with intellectual disabilities should be performed every two to five years.<sup>28,42</sup> The frequency of eye examinations should be adjusted according to the individual's needs, the status of ocular health and the complexity of the individual's medical conditions.

### CONCLUSIONS

Individuals with an intellectual disability have a higher prevalence of visual impairment, sight-threatening disease and ocular pathology than those from the otherwise normal population. There is also considerable evidence to suggest that both the overall prevalence and magnitude of these conditions increases with the degree of intellectual disability. Conducting eye examinations for patients with intellectual disabilities can be challenging. Improvisation and adaptation of standard techniques allow patients to feel more at ease and clinicians to obtain useful information. This may improve the identification of deficits of visual function, the determination of refractive error and aid to diagnose ocular pathology. Treatable visual impairment is common in people with intellectual disabilities and detection and management of these ocular conditions are part of the responsibility of community-based primary eye-care practitioners. Successful management benefits from taking a multi-disciplinary approach and involves active communication between the patient, carers and health-care professionals. Optometrists should recognise the eye-care needs and rights of people with intellectual disabilities and provide the best possible eye-care services.

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**APPENDIX 1**

Classification of the severity of intellectual disability, with corresponding descriptions of its adaptive domains and level of IQ.<sup>2,7</sup> The three criteria for the definition of intellectual disability include: (a) intellectual functioning, that is, reasoning, problem solving; (b) adaptive functioning which subdivides into (i) conceptual (for example, skills in language, writing, mathematics and memory), (ii) social (for example, the awareness of other individuals, thoughts, feelings, relationships and interpersonal communication skills) and (iii) practical (for example, ability in self-care, responsibility and work); and (c) onset of the disorder occurs during the developmental period (before 18 years old). For full description, please refer to DSM-V.<sup>2</sup>

Severity of intellectual disability	Conceptual domain	Social domain	Practical domain	Level of IQ	Mental age (years)
Mild	<p>The individual may have difficulties in learning academic skills. Support is needed to meet age-related expectations.</p> <p>Abstract thinking, executive function, short-term memory and the functional use of academic skills are impaired.</p>	<p>The individual's communication, conversation and language used are immature in social interactions when compared with others of similar age.</p> <p>Difficulties regulating emotion and behaviour, limited understanding of risk in social situations; social judgment is immature for age. The person is at risk of being manipulated by others.</p>	<p>Function age-appropriately in personal care. The individual may need some support with complex daily tasks.</p> <p>The individual generally needs support to make health-care decisions and legal decisions and to learn to perform a skilled vocation competently. Support is typically needed to raise a family.</p>	55 - 70	9 – under 12
Moderate	<p>Conceptual skills, language and pre-academic skills lag markedly compared to peers. In adulthood, academic skill development is typically at an elementary level.</p> <p>Support is required for all use of academic skills in work and personal life. Ongoing assistance on a daily basis is required and carers may take over these responsibilities fully for the individual.</p>	<p>The individual shows marked differences from peers in social and communicative behaviour across development. Spoken language is much less complex compared with others.</p> <p>Capacity for relationships is evident in ties to family and friends. Social judgment and decision-making abilities are limited. Carers must assist the person with life decisions.</p> <p>Significant social and communicative support is needed in work settings.</p>	<p>An extended period of training is required for the individual to care for personal needs, household tasks and recreational skills.</p> <p>Ongoing supports will be required; independent employment in jobs that require limited conceptual and communication skills can be achieved but considerable support from others is needed to manage social expectations, job complexities and other responsibilities.</p> <p>Maladaptive behaviour is present in a significant minority and causes social problems.</p>	35 - 54	6 – under 9

(Continues)

Severity of intellectual disability	Conceptual domain	Social domain	Practical domain	Level of IQ	Mental age (years)
Severe	<p>Conceptual skills and written language are limited. Caretakers provide extensive supports for problem solving throughout life.</p>	<p>Spoken language and speech are quite limited in terms of vocabulary and grammar. The individual can understand simple speech and gestural communication.</p> <p>Relationships with family members and familiar others are a source of pleasure and help.</p>	<p>The individual requires assistance to make responsible decisions and supervision for all activities of daily living. Participation in tasks at home, recreation and work requires ongoing support and assistance.</p> <p>Maladaptive behaviour, including self-injury, is present in a significant minority.</p>	20 - 34	3 – under 6
Profound	<p>Conceptual skills generally involve the physical world and objects rather than symbolic processes.</p> <p>Activities are more goal-directed. Certain visuospatial skills, such as matching and sorting based on physical characteristics, may be acquired.</p> <p>Co-existing motor and sensory impairments may prevent functional use of objects.</p>	<p>The individual has very limited understanding of symbolic communication in speech or gesture; however, simple instructions/gesture can be understood.</p> <p>The expression of own thoughts would be done via non-verbal and non-symbolic communication.</p> <p>The individual enjoys relationships with familiar family members and caretakers. He or she can initiate and respond to social interactions through gestural and emotional cues. Co-occurring sensory and physical impairments may prevent many activities.</p>	<p>The individual relies on others for all aspects of daily activities, while he or she may be able to participate in some of the activities. Individuals without severe physical impairments may assist with some daily work tasks at home.</p> <p>Recreational activities would require the support of others.</p> <p>Co-occurring physical and sensory impairments are frequent barriers to participation in various activities.</p> <p>Maladaptive behaviour is present in a significant minority.</p>	<20	Below 3

**APPENDIX 1. (Continued)**