

# Down Syndrome International



**International Guidelines for  
the Education of Learners  
with Down Syndrome**



# International Guidelines for the Education of Learners with Down Syndrome

## **Publisher: Down Syndrome International**

Publication date: 2020

ISBN: 978-1-78972-083-9

Authors:

Rhonda Faragher  <https://orcid.org/0000-0003-0245-9934>

Penny Robertson, OAM

Gillian Bird

## **Registered Office**

Down Syndrome International

Langdon Down Centre

2A Langdon Park

Teddington

Middlesex

TW11 9PS

United Kingdom

+44 (0)1395 493108

[contact@ds-int.org](mailto:contact@ds-int.org)

## **Cite as:**

Faragher, R., Robertson, P., & Bird, G. (2020). *International guidelines for the education of learners with Down syndrome*. Teddington, UK: DSI

Copyright ©2020



This work is licensed under a Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License.

## ■ CONTENTS

<b>Acknowledgements</b>		<b>i</b>
<b>1. Introduction</b>		<b>1</b>
1.1	Aim	1
1.2	Background	1
1.3	Structure and overview of these Guidelines	2
<b>2. Key considerations in the education of learners with Down syndrome</b>		<b>4</b>
2.1	Human rights concepts from the UNCRPD	4
2.1.1	Inclusive education for learners with Down syndrome	4
2.1.2	Lifelong learning	5
2.1.3	Equal Opportunity	5
2.2	Characteristics of a learner with Down syndrome	6
2.2.1	Vision	6
2.2.2	Hearing	6
2.2.3	Speech, language and communication	7
2.2.4	Memory and cognition	8
2.2.5	Fine and gross motor skills	8
2.2.6	Health issues and Pain	9
2.3	Recommendations arising from key considerations	10
<b>3. Guidelines for Leading</b>		<b>11</b>
3.1	Building an inclusive culture in an education setting	12
3.1.1	How to establish a shared common purpose around inclusion	13
3.1.2	Aligning with system policies and procedures	14
3.2	Leading, managing and organising staff	15
3.2.1	Process of inducting new staff into the culture	15
3.2.2	Leading a team including learning support assistants (LSA)	16
3.3	Recommendations for leading	18
<b>4. Guidelines for Teaching</b>		<b>19</b>
4.1	Teacher Education	19
4.1.1	Initial teacher education	19
4.1.2	Professional learning on Down syndrome	21
4.1.3	Specialist teachers	21
4.2	Planning for teaching	22
4.2.1	Planning for inclusive practice	22
4.2.2	Strategies for learning support needs	23
4.2.3	Individualised planning	24
4.3	Teaching in an inclusive classroom	26
4.3.1	Establishing a classroom for learning	26
4.3.2	Encouraging behaviour for learning	26
4.4	Recommendations for teaching	28

<b>5. Guidelines for Learning</b>	<b>29</b>
5.1 Prior to School	29
5.1.1. Early intervention	29
5.1.2. Transitioning to school	30
5.2 School	31
5.2.1. Primary School	32
5.2.2. Secondary School	32
5.2.3. Transitioning from school	34
5.3 Post school	35
5.3.1. Tertiary and vocational education	35
5.3.2. Learning on the job	37
5.3.3. Lifelong learning	38
5.4 Recommendations for learning	40
<b>6. References</b>	<b>41</b>
<b>Appendix</b>	
Full List of Recommendations	<b>50</b>
Key considerations	50
Leading	50
Teaching	51
Learning	51

## ACKNOWLEDGEMENTS

These Guidelines were developed for Down Syndrome International by Rhonda Faragher, Penny Robertson and Gillian Bird with input and oversight from Helen Powell and Andrew Boys. Iffat Jahan assisted with literature searching.

Name	Declared interest
<b>Dr Rhonda Faragher, PhD</b>	<ul style="list-style-type: none"><li>• Director, Down Syndrome Research Program at The University of Queensland</li><li>• Associate Professor in Inclusive Education, School of Education, The University of Queensland</li><li>• Trustee, Down Syndrome International</li><li>• Independent Director, Down Syndrome Australia</li><li>• Chair, Down Syndrome Special Interest Research Group of the International Association for the Scientific Study of Intellectual and Developmental Disabilities</li><li>• Mother of an adult daughter with Down syndrome</li></ul>
<b>Penny Robertson, OAM</b>	<ul style="list-style-type: none"><li>• Mother of an adult daughter with Down syndrome</li><li>• Past President: South Australian Down Syndrome Association, Australian Down Syndrome Association and Asia Pacific Down Syndrome Federation</li><li>• Founding Board Member and current trustee: Down Syndrome International</li><li>• Founder: Australian International Schools, Indonesia</li></ul>
<b>Gillian Bird</b>	<ul style="list-style-type: none"><li>• Gillian Bird, Services Director, Down's Syndrome Association (England, Wales and Northern Ireland)</li></ul>
<b>Helen Powell</b>	<ul style="list-style-type: none"><li>• Programme Manager, Down Syndrome International</li></ul>
<b>Andrew Boys</b>	<ul style="list-style-type: none"><li>• Executive Director, Down Syndrome International</li><li>• Brother with Down syndrome</li><li>• Mother is Chief Executive of the Down's Syndrome Association (England, Wales and Northern Ireland)</li></ul>

# ■ 1. INTRODUCTION

## 1.1 AIM

With the publication of these Guidelines, Down Syndrome International (DSi) aims to improve the education of learners with Down syndrome internationally and to contribute to the realisation of their right to inclusive and equitable quality education and the promotion of lifelong learning opportunities, in line with Article 24 (Education) of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, United Nations, 2006) and Sustainable Development Goal 4 (SDG 4 - Education) of the United Nations 2030 Agenda for Sustainable Development (United Nations, 2015).

Through these Guidelines, DSi aims to:

- distil recommendations from research, policy and practice;
- assist DSi member countries to meet their obligations under the UNCRPD in terms of education;
- assist education stakeholders, including, but not limited to, DSi's national and world regional member organisations, to advocate for positive change and hold education authorities to account;
- provide specific guidance to all education stakeholders (including people with Down syndrome, their families, carers and advocates, education professionals, managers, commissioners of services and authorities, national, world, regional and international disability and education organisations and bodies) on how to adopt best practice education for learners with Down syndrome; and
- encourage the development of national (or other regional) guidelines for the provision of evidence-informed, best-practice education for learners with Down syndrome, taking into consideration resource differences in education settings around the world.

## 1.2 BACKGROUND

Research, practice and policy operate around the education provision for learners (OECD, 2007) including those with Down syndrome. These Guidelines sit outside those three, with the potential to inform and be informed by each. In Figure 1, we give a diagrammatic representation of the position of these Guidelines. Research, Policy and Practice influence each other in any country or context. These Guidelines may guide policy and practice and influence research undertaken. The double-headed arrows indicate that these Guidelines have been developed from evidence from those three aspects.

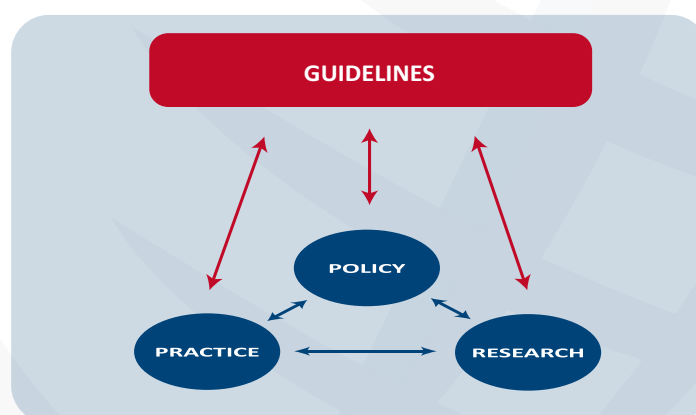


Figure 1- Relationship of these Guidelines to Research, Policy and Practice

There are many factors that impinge on the education of learners with Down syndrome, such as health, socio-economic status (SES) and context. In Figure 2, we have listed some of the factors that may have an impact on learning. While the importance of these is recognised, they are not our central focus.

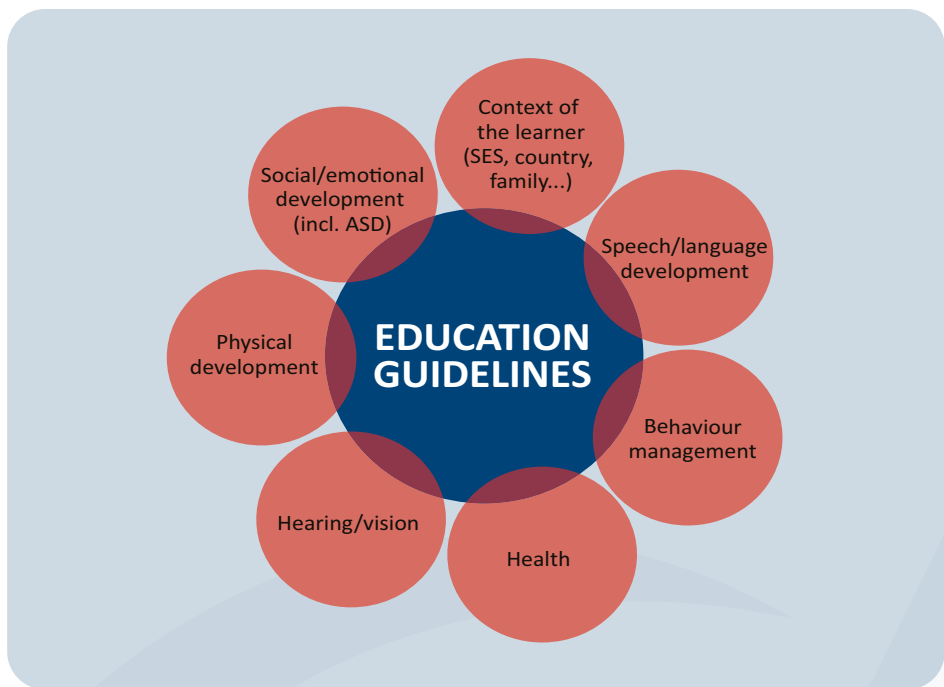


Figure 2 - Factors affecting learning and the place of the Education Guidelines

It should be noted that the overlapping regions in Figure 2 are often the place where issues educating learners with Down syndrome arise. The Guidelines acknowledge this and research, policy and practice evidence provides guidance. Key points are distilled in the Recommendations.

### 1.3 STRUCTURE AND OVERVIEW OF THESE GUIDELINES

Factors that influence the learning of people with Down syndrome across the lifespan have been organised into three sections: Leading (Section 3), Teaching (Section 4) and Learning (Section 5). In each section, we identify main findings from research, policy and practice and we distil recommendations. In Figure 3, we give a graphic overview of the Guidelines to follow.

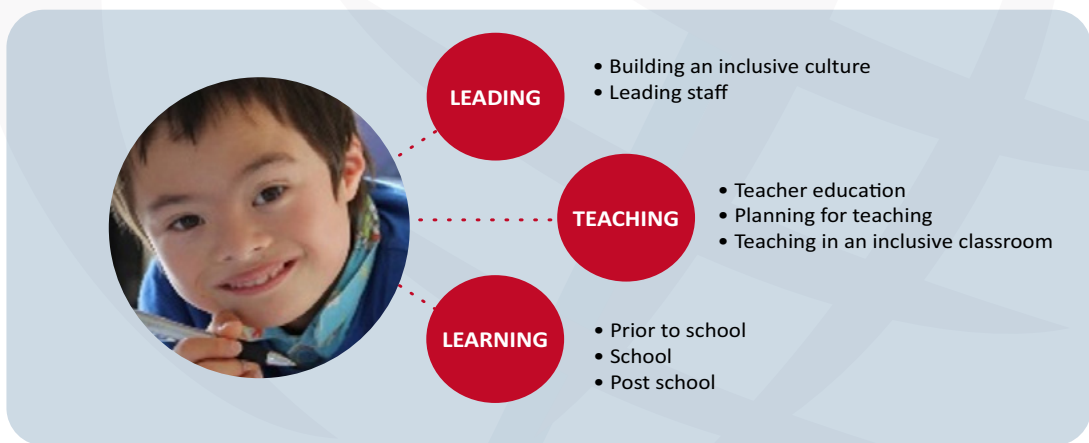


Figure 3 - Graphic overview of the DSi Education Guidelines

Prior to this, Section 2 of these Guidelines outlines some key considerations in the education of learners with Down syndrome, with recommendations to assist in the interpretation of the Guidelines into local contexts. Three key human rights concepts identified in Article 24 of the UNCRPD of relevance to the education of learners with Down syndrome are considered in Section 2.1: namely, Inclusive Education, Lifelong Learning and Equal Opportunity. We discuss those concepts in these guiding notes to the Guidelines. That is followed by a brief overview of the learning characteristics of people with Down syndrome in Section 2.2.





## ■ 2. KEY CONSIDERATIONS IN THE EDUCATION OF LEARNERS WITH DOWN SYNDROME

### 2.1 HUMAN RIGHTS CONCEPTS FROM THE UNCRPD

Underpinning these Guidelines in support of the implementation of the UNCRPD, are three key concepts related to education.

#### 2.1.1 Inclusive education for learners with Down syndrome

A recent UNESCO International Forum on Inclusion and Equity in Education (UNESCO, 2019) defined Inclusion as:

*a transformative process that ensures full participation and access to quality learning opportunities for all children, young people and adults, respecting and valuing diversity, and eliminating all forms of discrimination in and through education. The term inclusion represents a commitment to making preschools, schools, and other education settings, places in which everyone is valued and belongs, and diversity is seen as enriching.*

**Inclusive education** means that all students attend and are welcomed in their local educational setting and are supported to learn, contribute and participate in all aspects of that context. **Inclusive schooling** means all are welcomed by their neighbourhood schools and taught in age-appropriate, regular classes engaging in all aspects of the student life of the school, and all receive support appropriate to their needs.

By these definitions, special schools, and special classes are not inclusive, but we recognise that they may be the only option available in some contexts, and with discernment, some aspects of these Guidelines may apply in those settings. In those contexts, the Guidelines could be considered aspirational, in view of the commitment to Inclusive Education.

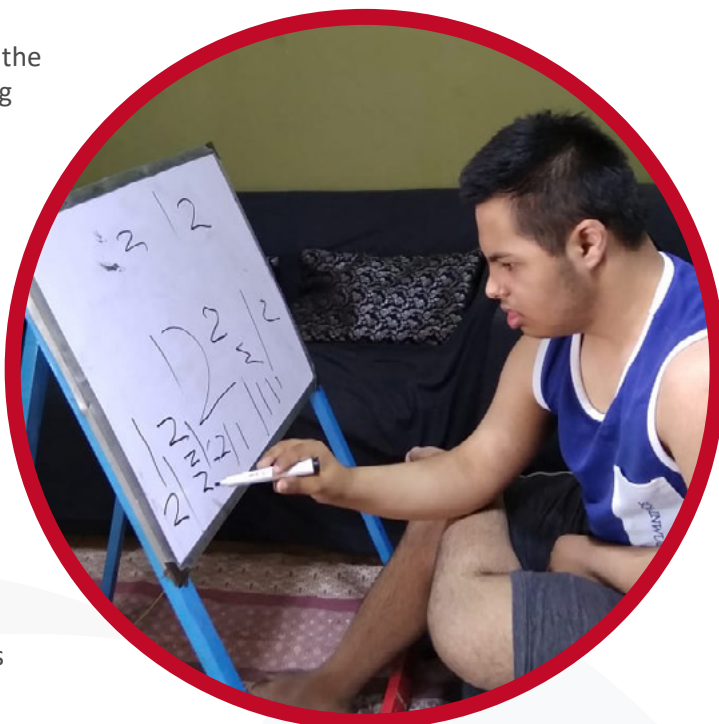
Similarly, Inclusive Education differs from Exclusion, Segregation and Integration, as defined by the CRPD Committee:

**Exclusion** occurs when students are directly or indirectly prevented from or denied access to education in any form. **Segregation** occurs when the education of students with disabilities is provided in separate environments designed or used to respond to a particular or various impairments, in isolation from students without disabilities. **Integration** is a process of placing persons with disabilities in existing mainstream educational institutions, as long as the former can adjust to the standardized requirements of such institutions. (United Nations Committee on the Rights of Persons with Disabilities, 2016, p. 4)

Students with disabilities educated in general education classrooms outperform students who have been educated in segregated settings (for a review of the research literature, see Hehir et al., 2016). Research specifically in the context of Down syndrome also supports this finding (de Graaf, van Hove, & Haveman, 2013). Social / emotional development is greater in inclusive settings (Buckley, Bird, Sacks, & Archer, 2006). The link between inclusive schooling and social inclusion has also been established (European Agency for Special Needs and Inclusive Education, 2018).

### 2.1.2 Lifelong learning

The second important concept of the UNCRPD is the recognition that learning is a lifelong activity. Lifelong learning means that education occurs throughout life, including prior to and after the formal years of schooling. For people with Down syndrome, there are important implications for education. Currently, life expectancy is into the fifties with one in ten living into their seventies (Torr, Strydom, Patti, & Jokinen, 2010). A long adulthood can be anticipated. Whereas it was once thought that learning plateaued in late adolescence, various studies have refuted those claims and also indicate the critical importance of continuing opportunities for learning beyond secondary school (de Graaf & de Graaf, 2016; Moni & Jobling, 2001). Adults with Down syndrome are entitled to continue formal and informal learning after secondary school has finished.



### 2.1.3 Equal opportunity

Decisions about what is taught to students with Down syndrome are often framed around predictions of what will be needed for adulthood. In practice, this has the potential to limit learning opportunities e.g. the primary school child who is withdrawn from the foreign language awareness class or the secondary student who is not offered science studies. The right to a broad and balanced curriculum and extra curricula opportunities on an equal basis with others is a right affirmed in the UNCRPD. In these Guidelines, further explanation is provided about ways this might be achieved in various learning contexts.

Notwithstanding the above, it is important to note that all human rights are interlinked. It is not possible to realise the right to education unless other rights are realised. And if the right to education is realised, this can lead to the realisation of other rights.

## 2.2 CHARACTERISTICS OF A LEARNER WITH DOWN SYNDROME

Learners with Down syndrome are individuals with a variety of strengths and challenges. All have the capacity to learn and continue to do so throughout their lives. The myth that learning plateaus in adolescence has long been countered by research and practice. Around the world, individuals with Down syndrome are providing examples of accomplishments in many fields of education where they have received good teaching with the right support from educators who expected them to be able to succeed. There are some features of Down syndrome that are known to affect learning to a greater or lesser extent in individual learners. In this section, we provide a brief overview of the important characteristics that need to be taken into account when planning for learning. For further detail, refer to Couzens and Cuskelly (2014). It is important to be clear that every learner who has Down syndrome is unique and the following characteristics represent probabilistic attributes and are not necessarily found in all learners. Where learning issues exist, provision of learning support and adjustments must be provided. Lack of success with learning can be due to lack of appropriate provision of adjustments and not due to a student's inability to learn.

### 2.2.1 Vision

Vision impairments are common in individuals with Down syndrome. Many will need corrective lenses. Cataracts are also common. Even if the person does not need glasses or is wearing the correct glasses, visual acuity may be diminished. Charleton and Woodhouse exhort:

*It is vitally important that parents, educators and health professionals are aware that people with Down syndrome do not see the world as clearly as the typical population. Learning materials in schools that are easily seen by typical children may prove an obstacle for children with Down syndrome. Modification of materials, such as writing in black pen, and boldening faint lines, can make the difference between success and failure in a school task. (Charleton & Woodhouse, 2015, p. 84)*

### 2.2.2 Hearing

The majority of individuals with Down syndrome experience hearing loss. This is mostly conductive loss resulting from otitis media (glue ear) which affects up to 93% of toddlers and 68% of school-aged children (McNeill, Sheehan, & Marder, 2015). This is the time when language development is at its peak, so aggressive treatment of the condition is helpful where available. Sensorineural hearing loss (due to disease of the inner ear or nerve damage) is also prevalent, being the most common type of hearing loss in adulthood.

Conductive hearing loss in the early years may have a more significant effect on later speech and language development on learners with Down syndrome than on other children (Laws & Hall, 2014). Where available, speech and language therapy in combination with medical treatments and educational activities is recommended. Children with conductive hearing loss may not exhibit other symptoms, such as fever. Also, this condition fluctuates, making it particularly difficult for parents and teachers to be able to discern when hearing is compromised. It may be appropriate to assume a student's hearing is diminished.

### 2.2.3 Speech, language and communication

Learners with Down syndrome frequently have speech and language impairments, although the nature of their language learning difficulties varies between individuals. In addition, as noted in the previous section, the extent of hearing impairment and the availability of treatment and provided supports affects the level of speech, language and communication impairment.

Learners show specific relative strengths in receptive vocabulary (what they understand), and they may have more advanced vocabulary than their grammatical knowledge would suggest. The learning profile includes verbal processing difficulties (understanding what they hear) associated with verbal short term memory limitations. They also may experience phonological difficulties – their awareness of the sound structure of words (Couzens & Cuskelly, 2014). Reading is a relative strength for learners with Down syndrome (Cologon, 2013). Sign and gesture supports the learning of new vocabulary.



Learners may experience a range of difficulties that affect the clarity and fluency of their speech. This can be due to physical difficulties, such as low muscle tone, as well as cognitive difficulties of speech production. Keyword sign is an effective approach that supports initial communication during the development of speech. Speech and language therapy can be helpful, where available, as can activities such as participating in choirs and public speaking clubs. It is important to stress that communication takes many forms, and individuals without speech, or where speech is difficult to understand, should be supported to communicate in other ways, such as, for example, sign language, keyword sign, and electronic text to voice software. Support for communication development should continue throughout all stages of an individual's life.

Some individuals with Down syndrome have more extensive social communication difficulties and approximately 10-18% meet criteria for dual diagnosis of autism spectrum disorder (Rachubinski, Hepburn, Elias, Gardiner, & Shaikh, 2017).

## 2.2.4 Memory and cognition

Aspects of memory for individuals with Down syndrome have been studied over a number of years, mostly using Baddeley and Hitch's model of working memory (Baddeley, 2000). Couzens and Cuskelly (2014) have summarised the research findings on memory and Down syndrome, concluding:

- Visual-spatial working memory is a relative strength. This is the memory system involved with retention of visual or spatial information, such as images or objects and their locations.
- Verbal working memory appears to be a significant weakness, even for those with relatively advanced spoken language. This is memory for holding speech-based and acoustic information and is called the phonological loop in the Baddeley Hitch model.
- Long-term memory appears to be intact and may be a relative strength. Long-term memory refers to the storage of information beyond the few seconds of storage in working memory systems. Also, once material has been learned, the rate of forgetting mirrors that of those without Down syndrome.

Recent work by Zimpel (2016) suggests heightened memory records of people with Down syndrome may be due to strong emotional responses caused by increased activity of the brain's limbic system.

Limitations of verbal working memory for storing and processing verbal information, and capacity for manipulating information in working memory, should be considered in education planning.

The ability to learn by imitation (I. Wright, Lewis, & Collis, 2006) is well-known and indeed was documented by John Langdon Down in the nineteenth century. This attribute is a powerful strength in an inclusive classroom where learners with Down syndrome are surrounded by students on whom they can model learning behaviour.

The learning profile of students with Down syndrome includes evidence for specific visual-spatial learning strengths (Couzens & Cuskelly, 2014). Visual support for learning is an effective strategy for all learners and the cognitive profile strengths in Down syndrome make it particularly valuable. Visual supports, unlike auditory input, remain in the learning setting allowing students to refer to them as often as they need.

## 2.2.5 Fine and gross motor skills

The pattern of gross motor development is the same though delayed when compared with normative development. Further, the delay is greater for more complex physical movements (Capiro, Mak, Tse, & Masters, 2018). Clumsiness of movement is a pervasive feature of Down syndrome producing slow, less efficient gross motor movements in addition to high velocity, inaccurate fine motor movements (Vimercati et al., 2015).

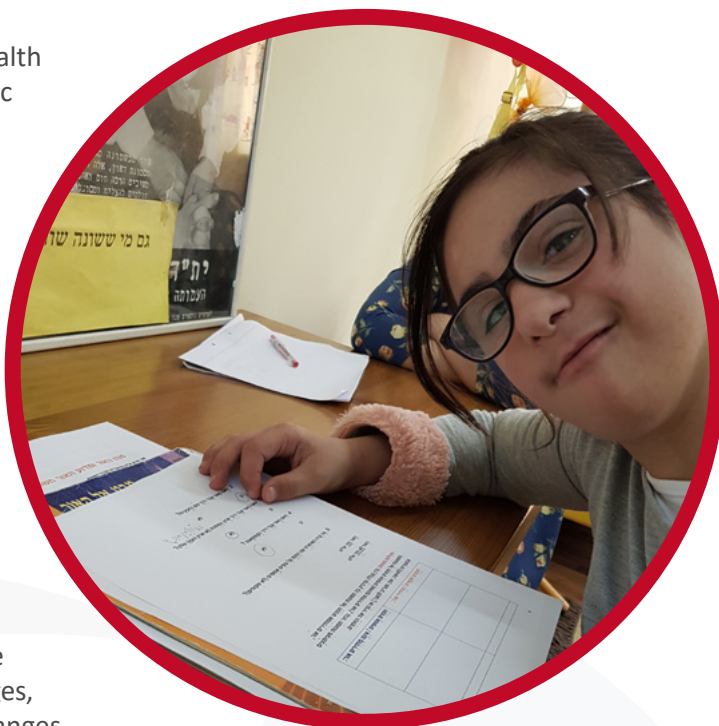
Encouraging active movement and participation in physical education, recreation, sports and dance is important and will also promote good health (Jobling, Virji-Babul, & Nichols, 2006). Although learners will continue to develop handwriting and drawing skills throughout their lives, encouraging the use of computers will enhance the ability to communicate effectively. Occupational therapists, where available, can support the development of fine motor skills and advise on devices and aids to compensate for limitations.

## 2.2.6 Health issues and pain

Ill-health has an impact on learning, so regular health checks are recommended, as for any child. Specific guidelines from DSi on health issues and Down syndrome are in development. Pain is experienced differently by people with Down syndrome. Following a review of research, McGuire and Defrin tentatively concluded “that individuals with Down syndrome are more sensitive to pain than normal. The evidence suggests that although pain expression appears to be delayed, once pain is registered, there appears to be a magnified pain response” (McGuire & Defrin, 2015, p. 5). They also noted that pain responses lasted longer.

Even articulate people with Down syndrome are known to have difficulty expressing the extent of their pain and locating it on their body. Those who are close to the individual might notice behavioural changes, e.g. becoming angry or aggressive, or physical changes, such as pallid skin colour. In an education context, if students exhibit challenging behaviour, it could be that they are in pain and unable to communicate their extreme discomfort.

In noting the impact of pain on behaviour, it is important to recognise that there may be many contributing factors that manifest in behavioural changes. Critically, challenging behaviour is not in itself a characteristic of Down syndrome, and the underlying cause or motivation needs to be addressed. This is especially the case where an individual has limited speech. See Section 4.3.2 for more discussion about managing behaviour.



## 2.3 RECOMMENDATIONS ARISING FROM KEY CONSIDERATIONS

1. In all school settings, learners with Down syndrome should be placed in the mainstream classes appropriate to their age. Students should be withdrawn from those settings as infrequently as possible.
2. Education settings for all learners, including those with Down syndrome, should be safe, welcoming and free of all forms of violence, bullying and abuse.
3. Opportunities to learn should continue beyond the school years and throughout adulthood.
4. Decisions about what is taught to learners with Down syndrome should be framed around the right to a broad and balanced curriculum and extra-curricula opportunities, on an equal basis with others, and not based on predictions about what will be needed for adulthood.
5. Academic achievement should be expected for all learners with Down syndrome with provision of appropriate learning supports.
6. Teaching staff should be aware of the high probability of vision and hearing impairments in learners with Down syndrome and that appropriate adjustments may be required to ensure effective learning and communication.
7. Speech and language therapy and other activities which promote good speech clarity and fluency should be available to learners with Down syndrome.
8. Teaching staff should make appropriate adjustments as required, given that learners with Down syndrome may have extensive social communication difficulties.
9. Teaching should take account of limitations of verbal working memory and information manipulation in working memory.
10. Visual supports for learning (including written words) should be used.
11. Active movement and participation should be used where possible.
12. Occupational therapy can support the continued development of fine motor skills throughout life.
13. If a student displays unusual behaviour, teachers first should rule out pain as a cause.

### ■ 3. GUIDELINES FOR LEADING

Leadership in an education context involves more than just those in designated leadership positions (Gaffney, Bezzina, & Branson, 2014). Leadership can be exercised by any person working with a team and all can be instrumental in developing inclusive education practices. As noted by Riehl (2000, p. 58) “leadership can be dispersed across many persons and roles in educational contexts, and indeed is usually more effective as a distributed practice”. The school principal becomes the “leader of leaders” (Ainscow & Sandill, 2010, p. 408).

The school principal has a critical role in the provision of education for learners with Down syndrome. Through developing a school culture, leading, managing and organising staff (including learning support and specialist staff), school principals can be the key factor in the success of a child’s education. They can be particularly influential on the attitudes of staff (Jordan, Schwartz, & McGhie-Richmond, 2009). The alignment with system policies is also critical (Gaffney, Clarke, & Faragher, 2014).

The key tasks involved have been summarised by Riehl thus, “school administrators who seek to respond to diversity in their schools attend to issues of meaning construction, promote inclusive school cultures and instructional practices, and work to position schools within community, organizational, and service-related networks” (Riehl, 2000, p. 68).

Challenges of establishing inclusive education in low- and middle-income countries is frequently discussed, and problems such as extremely large class sizes, lack of qualified teaching staff, and limited educational resources are frequently cited. However, research (Ahmmed & Mullick, 2014; Ainscow & Sandill, 2010) indicates there can also be learnings from these contexts that can contribute to improvements in high-income countries, including the development of effective practice when resources are limited. Countries in the process of establishing an education system should avoid copying the outdated and expensive segregated special school model introduced in western countries where originally no education was on offer for students with intellectual disabilities. It was a start, but inclusive education has since been proven to offer the best education outcomes.

These *Guidelines for Leading* deal with three major areas that are fundamental to the education of learners with Down syndrome, namely: building an inclusive school culture, aligning with system policies and procedures, and leading staff. The literature underpinning this section arises almost exclusively from research in broader contexts than Down syndrome, however, it is supported by practice evidence that would suggest the findings are applicable to leading the education of learners with Down syndrome.





### 3.1 BUILDING AN INCLUSIVE CULTURE IN AN EDUCATION SETTING

An inclusive culture comes from policy direction and strong community commitment to that policy, sharing a common moral purpose. Four key groups - education staff, students, carers and the community – must cooperate in decisions and implementation of inclusive policies (Ahmmed & Mullick, 2014). The leaders of the education system and each education setting need to be in complete agreement with the UNCRPD Article 24 on Education and both must be held to account by the community.

Changing a school culture so that the school becomes a place where all learners thrive will rely on understanding the features of social learning processes (Ainscow & Sandill, 2010). Simple technical solutions such as checklists and standardised processes are unlikely to lead to lasting change. Rather, building an inclusive school culture is an adaptive challenge embracing ‘the practice of mobilizing people to tackle tough challenges and thrive’ (Heifetz, Grashow, & Linsky, 2009, p. 14). A leader can support this process by providing opportunities for teaching teams to build communities of practice (Wenger, 1998) where teaching can be discussed, reflection on practice encouraged, and strategies for change proposed. Research indicates that whole school reform towards inclusive practice can be stimulated by the enrolment of diverse learners:

*The presence of children who are not suited to the existing menu of the school can provide some encouragement to explore a more collaborative culture within which teachers support one another in experimenting with new teaching responses. In this way, problem-solving activities gradually become the reality-defining, taken-for-granted functions that are the culture of a school that is more geared to fostering inclusive ways of working. (Ainscow & Sandill, 2010, p. 407)*

Allocation of necessary resources to support inclusion signals an intention to enact policies (Ahmmed & Mullick, 2014). In most situations, resourcing inclusive education for learners with Down syndrome is not expensive as most adjustments can be undertaken within a regular classroom by the teaching team. School leaders who support staff by enabling access to timely professional development and planning time for teaching teams, encouraging the use of technical support, demonstrate their commitment to effective inclusive education (Faragher & Clarke, 2016).

Principals, themselves, need support. Changing a school culture is challenging and leaders are likely to face resistance to innovation, particularly where staff or the community are not committed to, or do not value, inclusive practice (Osiname, 2018; Riehl, 2000). Building their own community of practice where they can discuss and share concerns while gaining strategies and support is essential. Virtual online communities can support leaders working in contexts where local support is not available.

### 3.1.1 How to establish a shared common purpose around inclusion

In order to have a shared common purpose around inclusion, all educators from the staff at the classroom level to government policy advisors need to be aware that students with disabilities thrive when, to the greatest extent possible, they are able to participate in educational and social opportunities available to other students.

Inclusive education is still an emerging practice in many school systems around the world and misconceptions are prevalent. Inclusive schools welcome all students into the school. A school is not inclusive when it does not accept all students, even if it labels itself as inclusive (see section 2.1). Cultural and attitudinal change based on greater awareness of the value of inclusive education is required. Parents and support organisations are best placed to advocate for this change (Riehl, 2000).



Advice from the Right to Inclusive Education (General Comment No.4) on the United Nations Convention on the Rights of Persons with Disabilities (2016) is an appropriate starting point for establishing a shared understanding of the importance of inclusion. As at 2020, 181 countries have ratified the UNCRPD . The following paragraphs from the General Comment are relevant to these Guidelines.

*Historically viewed as welfare recipients, persons with disabilities are now recognized under international law as rights holders with a claim to the right to education without discrimination and on the basis of equal opportunities. (I.1.)*

*Only inclusive education can provide both quality education and social development for persons with disabilities, and a guarantee of universality and non-discrimination in the right to education. (I.2.)*

The law alone will not change community values, though it does provide protection and direction for those who seek to implement change. Opportunities for dialogue between all members of the school community is a practice supportive of cultural change (Osiname, 2018). Principals should acknowledge difficulties that teachers face in teaching diverse learners and support their staff. However, this support should be through the provision of assistance to ensure that all students are taught well, rather than to affirm that some students are problems.

Key staff in the school (not necessarily those in designated leadership positions) who will be required for implementation of new inclusive education policies and practices need to be identified and involved in early planning (Poon-McBrayer, 2017). Similarly, distributing leadership to staff who do not have the skills and experience to lead change may be counter-productive (Miskolci, Armstrong, & Spandagou,

2016). A great deal of effort is likely to be required to build a shared vision if change is imposed on those who will be tasked with enactment. Poon-McBrayer's research (2017) offers three strategies for establishing a shared vision: 1. Forming partnerships with the learning support team leaders, 2. Serving as role models and 3. Motivating teachers through support.

The following strategies have been found effective in practice in establishing a shared culture of inclusive education.

- Begin with the designated leadership team showing alignment to system policies. It is important that advocates are able to articulate their goal of full inclusion in school to others, and to convince the school community.
- Widen the team to key staff in the school and eventually to all staff by providing professional development for all.
- Demonstrate that inclusion is central to the core business and not simply an add-on to school business. Act as a role model, interacting with students in and outside class to build rapport, teach or offer positive behaviour supports.
- Always address issues which concern staff openly and frequently refer back to the school's shared vision.
- Don't expect new staff to have all the skills. These skills take time to develop and require an open minded attitude to acquire them.
- Recognise that peers without disability in the regular classroom are an important resource, as are the students with disability.

### **3.1.2 Aligning with system policies and procedures**

Almost all countries in the world have signed and ratified the UNCRPD. This process requires individual countries to enact legislation and formulate policies. System policies and procedures then support compliance within local contexts. Alignment of the policy and practice in individual education contexts with system policies supports the enactment of inclusive education. Advocacy and modelling is necessary as legislation and policies alone will not change practice. Advocacy is essential to ensure that system policies match the spirit and intent of inclusive education.

All in the education community (including self-advocates, parents, and teachers) are required to ensure alignment between these system policies and the application in context. In order for changes to inclusive structures and the resulting practices to be sustained, changes to beliefs, attitudes and values must also occur (Riehl, 2000).

## 3.2 LEADING, MANAGING AND ORGANISING STAFF

The ethos of the school comes from the school leadership and sets the tone of the school. This has the effect of perpetuating the culture (Ainscow & Sandill, 2010) as teachers and families who feel the ethos of the school matches their philosophy will stay while others, where they can, move on.

Teachers will choose to come to the school as will parents as they learn the benefits of good inclusive education practice. Selection of staff is an important factor in building an inclusive school culture (Riehl, 2000), however many schools still report their systems limit principals' opportunity to select appropriate staff (Ahmmed & Mullick, 2014). In all cases, careful induction of staff into the culture of a school is critical for inclusive practice. This would be particularly important where principals have not been involved in staff selection.



### 3.2.1 Process of inducting new staff into the culture

It is important that all staff are made aware of the policy of inclusion and that under the UNCRPD it is a right of every child to receive an inclusive education. This message must come from the leadership team and staff faculty and it must be instilled throughout the whole school. This is an important mechanism by which acceptance is demonstrated to all students (Ainscow & Sandill, 2010). Furthermore, ongoing support for all new staff is important as the education of a person with Down syndrome is the responsibility of ALL academic staff, not just the specialists in the field.

Research shows that the skills, techniques and attributes required of teachers in educating students with disabilities are those that can be applied effectively across the general classroom to the benefit of all students (see, for example, Riehl, 2000). Research also shows that there is “clear and consistent evidence that inclusive educational settings can confer substantial short-term and long-term benefits for students with and without disabilities” (Hehir et al., 2016, p. 1).

Orientation training that provides specific professional development in inclusion (Baker-Ericzen, Garnand Mueggenborg, & Shea, 2009), the vision of the school (Gaffney & Faragher, 2010) and strategies for working in inclusive education settings (Baker-Ericzen et al., 2009) help induct staff and support them in settling in to the new educational environment. Support for new staff through initial professional development will have most benefit if continuing professional learning is promoted (Webster-Wright, 2009), including continuing opportunities to engage with the inclusive education vision of the school and to reflect on aligning teaching practices.

### 3.2.2 Leading a team including learning support assistants (LSA)

In many countries, teachers work in teams which may include learning support assistants, specialist teachers, therapists and administration staff. Learning support assistants (also termed teacher aides, inclusion aides, para-professionals, teaching assistants, shadow teachers etc.) are found in many schools around the world and provide additional adult presence in a learning environment. General Comment No. 4 (Committee on the Rights of Persons with Disabilities, 2016, para 32) notes, “support can ... consist of a qualified learning support assistant, either shared or on a one-to-one basis, depending on the requirements of the student.”

The classroom teacher has a responsibility to manage the work of these teams and coordinate the planning, working collaboratively with LSA. Attention to school structures needs to be addressed at policy level. Adequate numbers of staff are needed to be able to support learning adjustments. Individual, full-time support is rarely required, but sufficient staffing to allow adjusted activities to be used in every lesson is important e.g. assistance with resource preparation.

School leaders need to ensure teaching staff are aware of their responsibilities for the education of all students within their care. Teachers need to have the appropriate leadership skills to manage the collaborative work of the teaching team including LSA, other professionals (e.g. therapists, learning support teachers) and para-professionals.

While we could find no study that explicitly investigated the role of LSA with students with Down syndrome, LSA work is likely to have considerable impact on the educational experience of those students. The role of LSA appears to be changing with a number of studies researching the role and discussing the evolution from general classroom support to undertaking increasingly sophisticated teaching and learning support roles for students with specific educational support requirements (see, for example, Cockroft & Atkinson, 2015).

Various studies have highlighted the importance of defined duty statements (Attwood & Bland, 2012; Keating & O'Connor, 2012; Roffey-Barentsen, 2014) with clear, shared understanding of their roles by teachers, principals and LSA. The importance of involvement in planning was identified by Keating and O'Connor and acknowledged by Roffey-Barentsen whose study participants indicated the need for a thorough briefing for anyone not involved in the lesson planning. Both studies also identified concerns about the practice of assigning the lowest attaining students or those with challenging behaviours to the LSA so those students who required highly skilled teaching were less likely to be taught by the qualified teacher. Butt (2016) in a detailed study of models of LSA support considers this practice to be inequitable; students without special education needs receive their instruction only from a qualified teacher in contrast to those with learning support needs who often have less time with the qualified teacher.

Cockroft and Atkinson’s findings raised the common practice of external therapists giving instructions to LSA, indicating concern that this was specialised work that the LSA did not feel qualified to deliver.

A common theme in the research studies was the training of LSA (see, for example, Butt, 2018) either as professional development within their job or through vocational studies. Both were considered important with opportunities for LSA to build their skills overall and for specific contexts, such as gaining skills in a particular communication system to support a student under their care. One study (Maher & Macbeth, 2013) addressed the prioritisation of some subject areas such as English and Mathematics and identified the issue that professional development opportunities to support development of skills of LSA in non-priority areas can be limited.



Other research has identified risks in the use of LSA and the finding that increased support time does not equate to improved learning outcomes (see, for example, Blatchford, Bassett, Brown, & Webster, 2013). It would seem necessary to take account of the research that indicates LSA can indeed add value so long as the practices adopted are supported by research evidence.

To obtain the most effective use of LSA, the assistants should be given:

- opportunities for induction and ongoing professional development and, where possible, formal vocational qualifications;
- clearly defined lines of supervision;
- explicit duty statements, taking advantage of the skills they bring without expecting LSA to undertake teaching roles for which they are unqualified;
- clear guidance by the teacher who remains responsible for the learning of all students in the class. In particular, the purpose of the lesson (learning intentions) must be made clear to the LSA.

Further, teachers should be given:

- professional development in leadership and staff management in order to be able to guide the work of assigned LSA;
- support from the school leadership team to implement school-wide inclusive policy around learning support teams; and
- opportunities to plan in collaboration with LSA or time to provide explicit guidance on the learning intentions and the role of the LSA in the lesson. The most challenging teaching should remain the work of the teacher.

### 3.3 RECOMMENDATIONS FOR LEADING

14. Leaders need to be in complete agreement with Article 24 of the UN CRPD on education and aware of their role in driving the cultural change required.
15. Countries in the process of establishing an education system should avoid introducing a segregated special school system.
16. Leaders should provide opportunities for all staff, including learning support assistants, to undertake professional development on aspects of inclusive practice.
17. Leaders should ensure adequate planning time for teaching teams.
18. Leadership teams should be supported through the establishment of networks and communities of practice.
19. Leaders should establish a shared vision of inclusion across all levels of the educational system, working in partnerships with families and the broader community.
20. Principals should have responsibility for the selection of staff.
21. Teachers should be responsible for the learning of all students in their classes and must guide the work of assigned teaching assistants.
22. Support must be provided by the school leadership team to implement school-wide inclusive policy around learning support teams.

## ■ 4. GUIDELINES FOR TEACHING

Teaching learners with Down syndrome has similarities across various educational contexts (including work and home), however, in this section, the Guidelines for Teaching specifically refer to teachers working in school settings. Three main areas are covered: the first refers to teacher education – initial and further professional learning; the second deals with planning for teaching; and the third with teaching in an inclusive classroom.

### 4.1 TEACHER EDUCATION

Inclusive education, being the practice of welcoming, valuing and supporting the learning of all students in the shared general classroom, requires teachers who are able to successfully manage the learning in these settings. Initial teacher education must prepare teachers for inclusive practice. Graduates must enter the profession with knowledge, skills and approaches that will allow them to teach all their students. This is the role of initial teacher education (ITE).

Evidence-informed teaching practice relies on strong connections between the university and school sectors. Effective teachers engage in career-long professional learning. In the event of being assigned a class with a learner with a specific learning support need, such as Down syndrome, targeted professional development is required. In some jurisdictions, it is possible to access support from a specialist teacher who can provide guidance and advice.

#### 4.1.1 Initial teacher education

With inclusive education being an international goal for over a decade, ITE in many countries has undergone reform to ensure teachers entering the profession are competent to lead learning in inclusive classrooms with diverse students. For example, Australia has substantially revised accreditation requirements for ITE degree programs and the Australian Professional Standards for Teachers (Australian Institute for Teaching and School Leadership (AITSL), 2011) contains four standards explicitly directed towards inclusive practice. Even so, challenges continue in ITE. Teachers tend to replicate practices from their own educational background, particularly in situations where the issue to be resolved is not clearly defined or straightforward. However, changing work situations imposes changes to the “signature pedagogy” of a profession (Shulman, 2005). Pre-service teachers who were taught in inclusive classrooms during their own school years may demonstrate more acceptance and understanding of inclusive practice and as inclusive education rolls out around the world, students will enter ITE with lived experience of inclusive classrooms and be ready to learn how to build their own.





Effective inclusive education is skilled work for teachers and requires a reflective attitude to professional practice, based on a research orientation. Adequate support in ITE is necessary for developing an ethical commitment to, and personal values around, inclusive education (Symeonidou, 2017). A thorough understanding of the legislative and policy requirements for inclusive education is also critical (Forlin, Sharma, & Loreman, 2007).

Robinson (2017, p. 172) identifies the following components of an effective ITE program:

- the importance of collaboration;
- the value of adopting a research orientation;
- the importance of carefully structured field experiences;
- the relevance of critical-theorising and reflexive work;
- the centrality of deconstructing unhelpful discourses;
- the centrality of belief-systems; and
- the promise of a theory into practice model.

Professional experience opportunities within ITE programs are common practice and the opportunity to gain experience and to experience success working in inclusive classrooms is recognised as important. Forlin and colleagues note that “teacher education programs need to consider practicum placements in schools and classrooms where inclusion has been embraced as a philosophy and practice, and where appropriate supports exist to help ensure a successful experience for pre-service teachers” (Forlin et al., 2007, online). Unfortunately, in most countries at present, examples of effective inclusive practice on which pre-service teachers may model their practice are inconsistently available (Robinson, 2017; Symeonidou, 2017). This may explain why research findings on the value of practicum placements infused within initial teacher education programs are mixed (Symeonidou, 2017).

On completion of ITE, students must graduate with

- a well-formed, research-based personal philosophy for inclusive education;
- the skills to manage the learning in a classroom of diverse learners; and
- an understanding of the legal and policy framework that underpins their practice.

### 4.1.2 Professional learning on Down syndrome

Attainment of initial teacher qualifications prepares teachers for inclusive classrooms. Research suggests a link between teacher training and positive attitudes towards inclusion (Forlin, Sharma, & Loreman, 2014; Hoskin, Boyle, & Anderson, 2015). At some stage in their careers, teachers may have a student with Down syndrome in their class. At this stage, targeted professional learning is required (Faragher & Clarke, 2016). The following components of professional learning, which ideally should be available throughout the school year, were found to be valued by teachers:



#### 1. Provision of syndrome-specific information

- phenotypical characteristics of Down syndrome;
- impact of Down syndrome on learning, focusing on strengths and strategies to work around challenges; and
- establishing productive behaviour for learning, as for all students in the class, including how the teaching team can foster positive interactions with peers.

#### 2. A focus on academic learning and curriculum adjustment

- engaging in professional learning targeted at curriculum issues, rather than syndrome-specific information; and
- opportunity to engage in a community of practice (Wenger, 1998) with other colleagues and mentors or learning support advisors.

#### 3. Sharing success

- opportunity to reflect on development of teachers' inclusive practice; and
- opportunity to share their knowledge with other teachers, particularly if the student with Down syndrome would be taught by a different teacher in the subsequent year.

### 4.1.3 Specialist teachers

Some teachers may undertake post-graduate study to become qualified specialist teachers in learning support (Florian, 2012) and the education of students with Down syndrome. Learning support teachers can assist regular classroom teachers with particular issues, becoming a vital part of a community of practice. In some countries, these specialists are employed by a central education authority or by Down syndrome associations and are available to support teachers across a district, as needs arise. General classroom teachers indicate a need for syndrome-specific information, support for designing curriculum adjustments, behaviour support strategies and general classroom management approaches (Faragher & Clarke, 2016).

Specialist studies should equip learning support teachers to be able to assist their colleagues with these aspects. Specialist teachers need training in coaching strategies, approaches to building communities of practice and how to guide teachers to work with teams and families (Robinson, 2017; Staples & Diliberto, 2010). Extensive opportunities to work with, and to learn from, individuals with Down syndrome of various ages should be provided to ensure learning support practice is based on lived experience (Forlin et al., 2007).

In summary, postgraduate specialist studies in Down syndrome should comprise:

- syndrome-specific information;
- behaviour support strategies;
- inclusive classroom management strategies;
- coaching strategies;
- supporting teachers to lead teams and work with families; and
- extensive professional/field experience with people with Down syndrome

## 4.2 PLANNING FOR TEACHING

Effective inclusive teaching practice is underpinned by teachers' attitudes to inclusive education. Attitudes matter a great deal, and negative attitudes among educators can affect the response of students to those with disability in their classes (Jordan et al., 2009). Teachers and school leaders need opportunities both to confront these attitudes and to demonstrate that successful inclusion does work (Jordan et al., 2009).

Inclusive education practice is not a technical process or procedure. Instead, collaborative problem-solving is required. Through the development of a culture of collaborative problem solving, research indicates that working to include all learners leads to improved outcomes for all students (Florian, 2012; Jordan et al., 2009). This problem solving approach underpins professional learning and is a major factor in whole school improvement, as noted by Ainscow and Sandill, "students are likely to be more successful at school if their teachers are actively engaged in learning how to teach within the local context of the school" (2010, p. 409).

This section of the Guidelines provides guidance for planning for inclusive education of learners with Down syndrome from the premise that "educational programming and planning must start with the assumption of competence" (Toson, Burrello, & Knollman, 2012, p. 503).

### 4.2.1 Planning for inclusive practice

Inclusive education as a philosophy and practice avoids a focus on some students who are different to others in the class and in need of remediation. Rather, there is attention to provision of learning adjustments and curriculum differentiation that support the learning of everyone in the class. As Florian explains,

*[Effective inclusive education teachers] have changed the way they think about the concept of inclusive education. Rather than only accommodating learner differences, they focus on extending what is available to everybody. This focus on learning as a shared activity is a subtle but important shift in thinking about individual differences between learners that avoids the potentially negative effects of treating some students as different. (Florian, 2012, p. 277)*

Classroom planning techniques such as the Universal Design for Learning (UDL) framework (Rose, Gravel, & Gordon, 2014) underpin inclusive practice. By designing into the lesson learning adjustments available to any student who finds them helpful, teachers develop curricula that accommodate the diverse strengths and challenges of all learners, minimising the need for additional adjustments.

An important concept in inclusive practice is the teaching of year level curriculum with adjustments (Spooner & Browder, 2006), also known as ‘age-appropriate’ curriculum. In this approach, a classroom teacher begins planning with the curriculum materials established for the year level of the class. Appropriate adjustments are then planned, taking account of the anticipated needs of the diverse learners in the class, and paying careful attention to adjustments specified in Individual Education Plans. Enabling prompts are designed to assist a learner to be able to engage with the task but are only offered after the learner indicates the need for this support. Extending prompts are designed to provide challenge and greater depth for learners to go beyond the set task. This is preferable to assigning work from later year levels which would lead to boredom in subsequent classes. Examples of this approach in the context of mathematics have been developed by Sullivan and colleagues (Sullivan, Mousley, & Zevenbergen, 2006). Mitchell and colleagues in a review of research identified the following approaches for curriculum adjustment and modification:

*To make the curriculum accessible, consideration should be given to the following alternatives in relation to content, teaching materials, and the responses expected from the learners:*

- (a) modifications (e.g., computer responses instead of oral responses, enlarging the print),*
- (b) substitutions (e.g., Braille for written materials);*
- (c) omissions (e.g., omitting very complex work); and*
- (d) compensations (e.g., self care skills).*

*Other modifications can include*

- (a) expecting the same, but only less,*
  - (b) streamlining the curriculum by reducing its size or breadth,*
  - (c) employing the same activity but infusing IEP objectives, and*
  - (d) curriculum overlapping to help students grasp the connections between different subjects, for example.*
- (Mitchell, Morton, & Hornby, 2010, p. 51)*

Following the approach of adjusting the curriculum for the year level has led to remarkable results in the area of mathematics. Examples of learners with Down syndrome who had not demonstrated accomplishment of simple arithmetic achieving learning goals in areas such as algebra and trigonometry have been reported (Faragher, 2014; Monari Martinez, 1998; Monari Martinez & Pellegrini, 2010). It is important to note that these students were supported by the use of calculators as needed.

#### **4.2.2 Strategies for learning support needs**

The learning of students with Down syndrome in the general class will be enhanced with good teaching and the right support. Fundamentally, the most significant factor in inclusive education is the implementation of established effective education pedagogy, as noted by Jordan and colleagues, “effective teaching is effective intervention for all students” (Jordan et al., 2009, p. 536), and it underpins the clear research findings that high quality inclusive education benefits all learners (Hehir et al., 2016).

Students with Down syndrome will benefit from effective support targeted to their individual requirements. In keeping with inclusive practice, additional supports and adjustments should be made available to all students in the class, should they wish to make use of them (Florian, 2012). The following supports have been found from extensive practice evidence to be effective for many students with Down syndrome. It is important to reiterate that learners with Down syndrome are individuals, and teachers should determine whether or not these or other supports are required.

In the classroom, limitations of verbal short-term memory may need practical supports in classroom contexts requiring extended attention and listening, such as whole class discussions, listening to a story, participating in school assemblies and responding to long sentences or complicated requests. Effective strategies include the use of:

- visual supports to focus attention;
- visual scaffolds such as photos and pictures to support language teaching;
- common classroom aids such as number lines, calculators, letter charts, grids and diagrams (ready availability of these supports reduces the load on a student's working memory and visual supports, such as letter and number charts, can be affixed to a child's desk or kept in the back of an older student's workbook);
- commonly available tools, such as using the calendar on smart phones for the classroom schedule (this supports attention as well as providing opportunities to become adept with devices in common usage);
- models, where relevant, of completed work as a guide.

### 4.2.3 Individualised planning

The practice of developing Individual Education Plans (IEP) for students with disability originated in the United States in the 1970s (Mitchell et al., 2010) and it is now common practice in many countries around the world (King, Ni Bhroin, & Prunty, 2018). IEP have been criticised in recent times for entrenching a theoretical perspective which is at odds with inclusive practice with the focus on individual difference requiring remediation (Shaddock, MacDonald, Hook, Giorcelli, & Arthur-Kelly, 2009). In a literature review undertaken by Mitchell and colleagues (2010), three main criticisms of IEP were identified: (i) an undue influence on behavioural psychology where learning is reduced to achievement of component parts; (ii) over-emphasis on the individual, in contradiction to the aims of inclusive practice; and (iii) unproven efficacy, where aside from behaviour intervention plans which have some evidence base, the evidence for the effectiveness of IEP does not exist.



Individual planning is a common approach so it is important to ensure the planning process and the resulting plan follow best practice principles. The following recommendations arise from research, policy and practice evidence.

- Plans must be developed collaboratively, including the family, and with the learner as a key member. Planning meetings should be arranged at a convenient time for the family, not at a time that suits school or system personnel. Planning should also include input from other agencies if they are involved in supporting the learning of the child, such as therapists and learning support experts.
- Involvement of students in planning meetings must be supported and can serve as the development of expertise in self-advocacy. Students can be supported to understand planning meetings and to improve their involvement. Gibbons et al (2016, p. 89) note, “using clear and simple language understandable to the student, speaking directly to the student, and preparing the student prior to the meeting can help enhance student performance and increase self-determination”.
- Students can be encouraged to set their own learning goals that might be generic learning skills such as giving oral presentations or identifying keywords in a sentence. Teachers can then fold those goals into curriculum planning.
- Plans should be reviewed regularly and goals should not be carried over from one plan to the next. This ensures that the plan is a ‘living’ document that genuinely underpins learning. Goals that were not achieved are studied to understand the reason for their non-achievement.
- All staff involved in the planning process (including all classroom teachers in secondary schools) should undertake professional development (Stephenson & Carter, 2015) focused on the development of IEP and ways of collaborating with families.
- Plans should be comprehensive of all school learning, including social (social inclusion and friendships) and academic learning and suggested adjustments. Transition planning for learners at an appropriate age should be included in the plan. (For planning strategies, see Browder & Spooner, 2014).

## 4.3 TEACHING IN AN INCLUSIVE CLASSROOM

Including a student with Down syndrome in a regular classroom requires similar considerations as managing any other class. Effective classroom management involves prior planning and designing activities that will support the attainment of the learning goals for the lesson. Consideration of the individuals that make up the class leads to decisions about grouping, furniture arrangement and timings, over and above the planning of the learning activities. In this section, the Guidelines address two issues that concern teachers when they first move into this role, namely establishing a classroom for learning and managing behaviour.

### 4.3.1 Establishing a classroom for learning

An essential feature of establishing an inclusive classroom is to begin with the assumption that all learners can learn (Toson et al., 2012), that all are welcome and belong (Swinton, 2012) and that teachers have a powerful influence on the inclusive culture of the classroom, because “students without disabilities are more likely to feel positively toward classmates with disabilities if their teachers do, as teacher attitude partially mediates peer acceptance” (Silverman, 2007, p. 42). The research evidence is strong that all learners benefit from being taught in effective inclusive classrooms (Hehir et al., 2016).

The practices of effective teachers of inclusive classes with students with Down syndrome have been studied recently (Clarke & Faragher, 2015). In key aspects of their practice, teachers:

- explicitly plan the lesson, including the tasks to be undertaken by learning support assistants (LSA);
- explain the learning intention of the lesson to the LSA prior to the lesson, including contingency plans such as alternative activities should they be needed;
- include the student with Down syndrome in all phases of the lesson, including whole class instruction and they support these activities through planned adjustments;
- monitor the learning of all students in their class, including the student with Down syndrome by moving around the class during group and individual activities;
- make learning adjustments available to all learners;
- assess learning throughout the lesson through questioning, observing and gathering work samples;
- provide adjustments to tasks such as recording learning, to ensure the learner with Down syndrome is able to take part;
- model respect and hold high expectations for all learners in the class; and
- display enjoyment in their teaching and speak with affection about the learner with Down syndrome.

### 4.3.2 Encouraging behaviour for learning

Behaviour is communication and it has an underlying purpose. This is particularly true when a person has limited language skills to draw on. Behaviour that achieves its purpose is rewarded and therefore reinforced, meaning that it is likely to be repeated. Behaviour that does not achieve its purpose will disappear. Humans are very good at learning from their experiences, including learning which behaviours produce desired results.

Behaviour patterns in individuals with Down syndrome have additional drivers. It has been known for some time that even very young children engage in behaviour to avoid learning tasks, even when the tasks are within their capability (Wishart, 1993). A second important influence on behaviour patterns results from a difference in the limbic system (Zimpel, 2016) with the result that emotional responses last longer and lead to strong long-term memory associations. A third factor to consider is that expressive language levels are most often below normative age expectations. This has the effect of reducing the ability of individuals to negotiate, so that they may appear stubborn or defiant.



Each of these factors should be taken into account when aiming to build behaviour patterns that support learning. Positive Behaviour Supports is an evidence-based approach with training available in many countries. The important point is to focus on learning. If a behaviour does not impede learning it can be ignored (for example, if a child wants to write in green pen and not blue). For behaviour that is impeding learning, the first step is to consider the purpose. Do not react to the behaviour itself because that will reinforce the behaviour (even punishment can be a reinforcement) (Stein, 2016). Carefully observe and consider the context in which the behaviour is occurring.

1. Rule out pain. Any behaviour change (such as a usually gentle child hitting a teacher or student) should be investigated by a doctor to rule out underlying causes such as wax in ear drums, menstrual pain, pre-menstrual tension (even prior to menarche), and constipation.
2. Is it avoidant behaviour? Many children with Down syndrome (and some adults) use their social skills to avoid engaging in potentially challenging tasks. It is not always appropriate to make the task easier, as the work of Wishart (1993) found that avoidant behaviour was evident even when the task was within the ability of child. Supporting the learner, of whatever age, to persist and then to acknowledge achievement builds habits of learning.
3. Is the person unable to negotiate? A myth of Down syndrome is that learners are stubborn. Stubbornness is a trait that might be described as 'tenacious' in an adult without disability and is usually an indication that the person will not do what another adult wants. Providing choices is one solution to this situation. Another is to give a more explicit explanation of the reason for the request. A third approach is to give careful attention to the steps required to undertake the task. It could be that the person does not understand or is unable to do what they have been asked to do.

For students with significant challenging behaviour that is having serious impacts on learning and social inclusion, special support from psychologists trained in Functional Behaviour Assessment may be required.



#### 4.4 RECOMMENDATIONS FOR TEACHING

23. Initial teacher education should prepare graduates to manage the learning of all students in inclusive classrooms.
24. At the point when a teacher is assigned a class including a student with Down syndrome, targeted professional development should be provided. It is recognised that in some countries, availability of support may be limited, however, online professional learning resources are increasingly accessible.
25. Students with Down syndrome should be given the opportunity to learn the curriculum specified for their school year level, adjusted as necessary to enable their engagement with the learning outcomes.
26. Additional supports and adjustments should be made available to all students in the class, should they wish to make use of them.
27. Where individual education plans are used all members of the teaching team, including a member of the school leadership team, should be involved in the planning and progress of the individual education plan and its evaluation. At least one family member or advocate should be included in this process. The student should be included and supported to contribute.
28. Teaching in an inclusive classroom requires the learning needs of all students to be accommodated.
29. Behaviour is communication. It is necessary to determine the purpose behind the behaviour and act on the cause.
30. Avoidant behaviour is common and teachers need to guard against students using these strategies so that they develop persistence in learning.

## ■ 5. GUIDELINES FOR LEARNING

Most children with Down syndrome need additional support for optimal learning in all types of schools. These Guidelines for Learning are to be read in conjunction with the Guidelines for Leading and Teaching because all three aspects are interlinked. In this section, the focus is on what students will be learning and how that might best be supported. The sections have been divided by schooling level as this represents the context in which the learning takes place.



### 5.1 PRIOR TO SCHOOL

#### 5.1.1 Early intervention

Good early intervention programs provide an important basis for future educational outcomes (Kendall, 2018). Programs offering information and support to the family may encourage warm and caring relationships to develop as well as helping families adapt to disability in their own domestic and social contexts. There are potential difficulties with some approaches to early intervention where the emphasis is on remediating perceived deficits in the child (Bridle & Mann, 2000). Care must be taken to avoid placing too much stress on families or reinforcing the view that parents are solely responsible for their child's development (Paige-Smith & Rix, 2006).

The purpose of early intervention programs is to promote optimal growth throughout childhood in the main development domains: Physical (including gross motor and fine motor), Cognitive, Language, and Social and Emotional. Research, policy and practice over at least the last century have explored approaches to child development (Slee, Campbell, & Spears, 2014). Early intervention in inclusive settings has been shown (Baker-Ericzen et al., 2009) to lead to greater learning and better social outcomes than programs undertaken in segregated settings. Research also indicates advantages for children without disabilities in those settings as well (Baker-Ericzen et al., 2009). Activities such as play, language-rich environments, music, art and sport are known to enhance development. Furthermore, children enjoy these activities. A valuable approach to early intervention is to support children to engage in typical experiences known to promote development.

In a review of early intervention, Guralnick (2017, p. 222) noted the following practice principles:

- the importance of ensuring high levels of coordination and accountability;
- individualising interventions;
- focusing on families;
- using evidence-based strategies;
- establishing surveillance procedures;
- ensuring participation in inclusive settings;
- developing programs and intervention strategies that are culturally appropriate; and
- ensuring that the professional workforce is well trained.

The model developed by Guralnick (2013) emphasises the interactions between three important aspects: the child's social and cognitive competence, the family's resources and the family's patterns of interaction. From this model, the central importance of the family is clear. Therapists working with a child in isolation from the family is not the most appropriate model of intervention. An effective approach is where parents are taught the strategies for development in a guided tutorial fashion where the techniques can be practiced in the family setting on a daily basis. Home visits by a therapist, where possible, can assist in engaging the family and increasing the correct implementation of the intervention. The value of organisations of and for families, such as Down syndrome associations, has been acknowledged in the report *Early childhood development and disability: A discussion paper* by the World Health Organisation and UNICEF (2012).

Features of effective inclusive education for young children with Down syndrome are:

- information about a child's disability and development progress, what steps can and should be taken, and the resources available for support and treatment (World Health Organization & UNICEF, 2012, p. 28);
- support groups including opportunities for discussion and listening, providing opportunities for peer support (World Health Organization & UNICEF, 2012, p. 29); and
- activities targeted to account for developmental differences due to Down syndrome, including recognition of developmental strengths (Guralnick, 2017).

An example of an activity that specifically responds to developmental strengths of children with Down syndrome, is the use of gestures to support communication (C. A. Wright, Kaiser, Reikowsky, & Roberts, 2013). While gestures are naturally used by most people in communication, explicit use of key word signing and how to teach an infant may need to be explicitly taught to parents.

Parent interactions have an effect on language acquisition (Chapman & Bird, 2012; Cologon, Wicks, & Salvador, 2017) and executive function (Schworer, Fidler, Lunkenheimer, & Daunhauer, 2018), showing the importance of supporting family interactions as well as providing therapy for the child.

### 5.1.2. Transitioning to school

One of the outcomes of successful early intervention is to ease the way into inclusive education settings (World Health Organization & UNICEF, 2012), which should be ready to welcome and support all learners.

Parents in many contexts have the opportunity to make the choice of which school their child with disability will attend, however, they are not always in a position to make informed decisions and rely on professional advice (Wilder & Lillvist, 2017). Therefore, it is critical that professionals, such as school principals and system leaders, support families to access inclusive placements. This support may include encouraging families to attend initial school visits with an advocate who knows the processes and rights of a person with a disability. Wilder and Lillvist report that parents are also influenced by the perspectives of doctors communicated at the time of diagnosis. Decisions on school placement, therefore, can be made over long time scales and medical professionals should refrain from giving advice about education unless they have the background knowledge and accurate information to do so.

An issue with transitions at many life stages is that resources, where they are available, also transition between providers (e.g. disability services to education departments). This can cause challenges and discontinuities in services and may result in children commencing school without the needed supports being in place (Dockett, Perry, & Kearney, 2011). In addition, available information such as assessments

and diagnostic information may not be adequately shared leading to duplication of assessments or delays in the provision of necessary supports (Janus, Kopechanski, Cameron, & Hughes, 2008).

Transitions involve the child, families and education contexts (leaving and receiving). Each of these needs to be considered. Families need to be supported in their concerns for their child, and valued for the expertise they bring (Dockett et al., 2011). Families also may have worries about the impacts on the family as they establish relationships and routines with the new school (Wilder & Lillvist, 2017). Attention to building partnerships with all involved is an important consideration for smooth transitions into formal education. Research by Villeneuve and colleagues (Villeneuve et al., 2013) highlights the value of a facilitator, a designated school officer, to support families in at least the first year of school transition.



Schools should not impose arbitrary transition requirements for students with disabilities such as half day attendance, only permitting attendance when a teacher aide is funded, or attendance on only some days of the week. These practices are a form of exclusion.

## 5.2 SCHOOL

The second most important context in the life of a child after the family is the school. As noted previously, the evidence for the benefits of education in inclusive settings is clear. However, the practice of education in a local school is not always done well and can lead to great strain on families, some of whom may make the decision to move their child to a segregated setting (Mann, Cuskelly, & Moni, 2018). Poor practices of inclusion should not force families to opt for segregated settings; the imperative is to improve the quality of inclusive education. Similarly, students should not be required to repeat grades due to lack of achievement. Instead, adjustments to the year level curriculum (see 4.2.1) should be made to allow the learner to continue to make progress. This section of these Guidelines offers evidence from research, policy and practice to support all involved to provide the best inclusive education.

In a general classroom, vicarious learning, beyond what might be included in Individual Education Plans (IEP) can occur in areas such as social customs and in curriculum subjects such as science and curriculum extension, including foreign language studies. Creative approaches to teaching may be required, which is likely to benefit other students in the class. The following strategies are supportive for learners with Down syndrome:

- setting up and scaffolding situations for learning by imitation;
- daily practice of targeted skills built into engaging class activities;
- planned activities that become part of the child's routine;
- support for positive behaviour and for friendships; and
- adaptations which use learning strengths and support areas of difficulty.

### 5.2.1. Primary school

Students with Down syndrome in the primary years are initially focused on learning how to ‘do school’ or in other words, learning how to be a primary school student. School routines vary school to school, system to system and country to country, and all children have to learn the expectations. Explicit, patient teaching is required. Here, the marked ability to learn by imitation is of benefit for learners with Down syndrome. Buddies (peers or older children) can assist them to understand what is expected. The opportunity for the learner with Down syndrome to be a leader is also a powerful strategy. For example, to encourage the child to finish playtime and return to the classroom, they could be asked to call the other children or to form the start of the line into classroom.

Many parents of older children with Down syndrome recall considerable behaviour problems being exhibited by their child in the early years of primary school. For some parents, those times led to earnest conversations with school staff to consider special school placements. Teachers sometimes feared that when more challenging academic work was required in the middle school years, the child would not cope and problem behaviours would be exacerbated. The experience gleaned from evidence of countless children is that as they mature and settle into the primary years, they become much more able to behave appropriately in class and they desire to be seen as responsible learners like the other students.

Friendships are an important part of primary school (as in any other learning context). Providing opportunities for children to get to know others is important. Close adult supervision at playtime can harm the formation of friendships. Isolating the child in areas such as the library at lunchtime should also be avoided. Opportunities outside school and in school-related activities (such as scout groups and drama groups) can support the development of friendships. In many cases, intentional activities may be needed to facilitate social involvement.

A major learning activity for children with Down syndrome in the primary years is the development of literacy skills, particularly learning to read. This often starts before the school years and continues throughout life (Cologon, 2013; Moni & Jobling, 2001). For many children, reading is a relative strength and serves an important foundation when learning to read is replaced by reading to learn.

### 5.2.2. Secondary school

Students who have had a successful and supported experience in primary school can be expected to transition well into inclusive secondary school. Research indicates that students with special educational needs transition just as well as other students in general (Lightfoot & Bond, 2013; Vaz et al., 2015).

Lightfoot and Bond (2013) report statistics for the UK indicating that while up to 80% of students complete inclusive primary schooling, only 20-25% complete inclusive secondary schooling. Similar statistics are likely in other countries. Possible reasons could be the perception that secondary curriculum subjects are more difficult to adjust for learners with intellectual disabilities. With reduced numbers of students with significant learning support needs being educated in inclusive secondary settings, teacher expertise and practice tradition are lacking, although research findings are emerging (Buckley et al., 2006; Faragher, 2014; Monari Martinez & Benedetti, 2011).

Research indicates the importance of inclusive secondary education (Buckley et al., 2006) with statistically significant gains in communication, expressive language and literacy skills when compared to the education received by students in special schools. Further, students attending mainstream classrooms

show fewer behaviour problems and enjoy benefits such as social and emotional development, improved peer relationships and enhanced cognitive and psychological development. On completion of secondary school, opportunities for open employment or further study are greater for students from inclusive settings (European Agency for Special Needs and Inclusive Education, 2018). Therefore, it is important to encourage students to attend inclusive secondary classes and to be supported to remain there until the end of secondary school.

Literacy development continues in the secondary years. Popular texts have been found to be effective (Moni & Jobling, 2008). There is also value in adjusting texts being studied by other students in a regular class environment. In many countries, Shakespearean plays are studied, even though the texts are many centuries old. These plays continue to be performed, released as films, television series and modern adaptations because the themes are timeless and have continuing relevance. People with Down syndrome have a right to engage in this cultural practice as well. Many adjustments are possible such as viewing film adaptations, listening to audio books and engaging in performances. This is an example of a general principle – if the learning is of value to students in a general classroom, with appropriate adjustments, it should be available for all.

One issue that can cause concerns in the secondary school years is the management of sexual development. Girls who are independent with toileting are likely to manage their menstrual hygiene (Mills et al., 2015), however they may not be able to indicate that they are experiencing menstrual pain or to understand mood changes. Analgesia along with medical support can assist young women to manage their cycle and minimise disruption to their schooling. Both males and females with Down syndrome experience the same sexual feelings as others in the general population. They may need guidance to manage these feelings in culturally appropriate ways. Concerns about inappropriate sexual behaviour in young males can sometimes lead to recommendations for special school placements, however, they are no more likely to learn appropriate expression of their sexuality in segregated schooling than they would be in mainstream schools. Mills and colleagues note that people with Down syndrome have a right to “receive sex education, including counselling on personal relationships, and the social rules of sexuality, sex and sexuality, contraceptive advice and sexual health support services” (Mills et al., 2015, p. 53). This education, as for any other topic, should be taught in a manner that enables understanding.



### 5.2.3. Transitioning from school

Inclusion in mainstream primary and secondary schools affords academic benefits, increased likelihood of entering post-secondary education, employment and independence (European Agency for Special Needs and Inclusive Education, 2018). Transition programs increase the likelihood of post-secondary employment: “High quality transition programmes provided in secondary school may increase the likelihood of people with disabilities being employed” (ibid, p.15). ‘High quality’ is an important qualification and we provide indicators for high quality programs at the end of this section. Also, the qualifier ‘may increase ... being employed’ is a reminder that other factors also influence employment. In a discussion of transition, it is critical to consider the position into which the student is being transitioned. Workplaces need to be ready. Workplaces also need to be flexible and ready to change.

In a study investigating the efficacy of employment preparation programs, Joshi, Bouck and Maeda (2012) noted the value of work experience occurring outside school operations, (in contrast to school-sponsored work) .

*Given the positive relationship between participation in some form of work experience while in school and postschool employment, providing students with mild intellectual disability work experience in school is a critical first step to helping these individuals secure more positive outcomes. p.105*

The importance of work experience in community settings was also identified in a study by Siperstein, Heyman and Stokes (2014), where opportunities exist to develop non-academic attributes essential for employment such as emotional and behavioural skills. It should be noted that work experience in sheltered workshops or other segregated settings during the school years does not provide the necessary opportunities for learning about open employment, in the same way that work in segregated settings does not lead to open employment.

A study by Baer et al (2011), suggests caution in devoting extensive time in secondary school to transition programs, noting that “Inclusion was the only evidence-based program predictor for postschool engagement of students with ID [intellectual disabilities]” (Baer, Daviso III, Flexer, McMahan Queen, & Meindl, 2011, p. 139). Further, the study by Cimera (2010) notes that transition programs taught in schools by specialist staff are not as effective as actual work placement activities such as volunteer work, paid work and work experience. Adolescents with Down syndrome can expect to enjoy at least twenty to thirty years in active adulthood. Using precious and limited secondary school time focussed on teaching about work may be counterproductive. Secondary school should be devoted to the teaching of the secondary school academic curriculum because opportunities to learn that material become limited once the school years have passed. In a study investigating understanding of post-secondary options, Gibbons et al (2016) proposed suggestions for improving transition programs. Information should be provided by career counsellors on post-secondary career and study options (including tertiary studies). Parents were noted to be influential in career decisions, so methods to enable them to access this information should be provided.

#### Recommendations for high quality transition programs

- **Where** – if possible in the community (work experience, volunteer work, paid work,... (Cimera, 2010).
- **What to include**
  - information about post-secondary education, including tertiary and vocational education programs; and

- ‘intentionally assist students to not only obtain work experience, but to learn about different types of jobs, job requirements, and purposes of specific jobs’ (Gibbons et al., p. 89).
- **Who** – should be taught by mainstream teachers in schools, rather than by special education teachers. Where available, guidance officers or school counsellors who undertake career planning for students without disabilities should provide these services to students with disabilities (Gibbons et al., 2016).



## 5.3 POST SCHOOL

When they leave school, students with disabilities who have been included in regular school education are more likely to be enrolled in post-secondary education and to be employed or to live independently (European Agency for Special Needs and Inclusive Education, 2018). Learning is lifelong for all people, including those with Down syndrome. Opportunities to continue learning in both formal and informal settings may be rarer for adults with Down syndrome, so explicitly planned ongoing education may be necessary.

In this section, evidence from research, policy and practice lead to Guidelines around adult learning. In some countries, opportunities to study certificates at university are available (Hendrickson, Carson, Woods-Groves, Mendenhall, & Scheidecker, 2013; Izuzquiza Gasset, 2012; O’Brien et al., 2009; Rillotta, Arthur, Hutchinson, & Raghavendra, 2018; Ryan, 2014; Uditsky & Hughson, 2012). More commonly available are vocational training programs, many leading to trade certificates and other employment accreditation. Research specifically with participants with Down syndrome is limited, though more exists in the broader field of intellectual disability. Learning also occurs in other life contexts, such as in the workforce and in recreational activities.

### 5.3.1. Tertiary and vocational education

A common finding is the positive relationship between post-school education and employment of individuals with intellectual disability (see, for example, Grigal, Hart, & Migliore, 2011; Moore & Schelling, 2015; Zafft, Hart, & Zimbrich, 2004). Uditsky and Hughson articulate the value of inclusive post-secondary education of various forms noting that it ‘has been shown to be an important and effective means of launching students with ID [intellectual disabilities] into adulthood’ (2012, p. 298). Further, they argue that the principles arising from the research evidence supporting inclusive primary and secondary education should underpin the post-secondary sector.



Tertiary education (study at university) is increasingly possible for students with Down syndrome. As noted in section 4.2.3, in secondary school, students need to be provided with information and expectations that tertiary education exists and is an option for them, should they choose to pursue it. Identifying possible barriers, such as school exit qualifications, and working towards overcoming those barriers is an important part of transition planning.

As for members of the general population, tertiary entrance pathways can be directly from school or via formal or informal tertiary preparation programs. Therefore, there are three possible groups which might have an impact on supporting or hindering access: exiting schools, support agencies/intermediaries and the receiving university. A belief that individuals with intellectual disabilities can benefit from participating in higher education is likely to be important in the motivation to assist individuals to prepare for and gain access to courses and programs of study (Sheppard-Jones, Kleinert, Druckemiller, & Ray, 2015).

Post-secondary education can be of three types (Hart, Grigal, Sax, Martinez, & Will, 2006):

1. separate, specifically designed courses for cohorts with intellectual disabilities;
2. Audit (non-credit) programs where students with intellectual disabilities attend classes but do not undertake the assessment; and
3. Enrolment in the mainstream, where students with intellectual disabilities undertake the programs, with adjustments to course delivery and assessment as required to support students' attainment of the same learning outcomes set for all students.

Audit programs appear to be the most common option available at university level with some research emerging about the experiences of staff, students with intellectual disabilities and other students (O'Connor, Kubiak, Espiner, & O'Brien, 2012; Rillotta et al., 2018). The impact on lecturers and other students is also receiving research attention. May (2012) found that inclusive college courses encouraged positive attitudes around acceptance and appreciation of diversity amongst other students. The impact on lecturing staff was investigated by O'Connor and colleagues (2012) who noted the willingness of lecturers to develop more accessible instructional practices. This would align with research from the school years that indicates effective inclusive practice leads to improvements for all students across the school (Hehir et al., 2016).

A study by Grigal and colleagues (Grigal, Hart, & Weir, 2012) found that most programs offered in the United States emphasised independent living and employment preparation with a reduced focus on academic objectives. This is seen to contrast with university programs on offer to students without intellectual disabilities. Employment and independent living are stated goals for many people with intellectual disabilities, however, the value of learning for its own sake about topics of interest is respected by the general community and should not be discounted for people with intellectual disabilities.

Of course, there are outcomes beyond academic learning for students attending university. Students engage in university life, learn with support from mentors (academic and social) (Jones & Goble, 2012), have the opportunity to join clubs and other organisations of interest, and they may have opportunities to undertake work experience and internships. Uditsky and Hughson (2012) also note the family context may change where the member with ID acquires the identity of a tertiary or college student.

Opportunities for students with intellectual disability to study at university level are limited at the present time. Policies in many countries support inclusive practice at tertiary level but evidence from research and practice remains limited. Recommendations, subject to further investigation through experience include:

1. Establish the program. Universities may need incentives or policy imperatives to drive this as students with intellectual disability and Down syndrome specifically are not their target population.
2. Provide information about programs to students with Down syndrome and others who may influence their decisions, including parents, school career counsellors and disability support agencies.
3. Provide and train mentors for academic and social support.



### 5.3.2. Learning on the job

A benefit of employment is the continuing opportunity, and indeed requirement, to learn. Learning can happen vicariously as employees develop approaches to tasks, or explicitly, such as when a new photocopier machine is installed and staff receive training. For employees with intellectual disabilities, explicit on the job training and support has been shown to have a positive impact on employment outcomes (Kaya, 2018).

The process of supporting adults with intellectual disabilities to gain and keep a job in open employment has been studied. It was once thought that employment in segregated settings might lead to open employment, however, research indicates otherwise. “Policy makers must recognize that sheltered employment is not a stepping-stone to employment in a competitive setting” (Siperstein et al., 2014, p. 165).

Supporting an employee with intellectual disabilities in open employment can involve being trained onsite by a job coach (Noonan Walsh, Lynch, & deLacey, 1994). The efficacy of this approach has been well-researched and the value of funded support from governments or other agencies has been established (Wehman, Chan, Ditchman, & Kang, 2014).

A cautionary note is raised by Filly and Pernice (2006). Social inclusion in the workplace can be detrimentally affected by common practices. Induction or orientation training should be undertaken by staff members of the organisations and not solely by external agency coaches. Part-time rosters and casual employment can lead to exclusion from staff meetings and other workplace training, so steps should be taken to ensure all employees are included in training sessions. Similarly, performance reviews, recognition and promotion opportunities should be planned and undertaken by a supervisor in the organisation, not by an external agency. Inclusion in social functions is another aspect of employment that involves social inclusion and the opportunity to learn. Explicit planning may be needed to ensure employees with intellectual disabilities are able to take part.

Approaches to training in the workplace may require explicit teaching techniques, however, these need not be costly and need not require extensive specialist staff to implement. Becerra and colleagues (Becerra, Montanero, & Lucero, 2018) demonstrated the effectiveness of providing graphics on printed cards which, following brief training, allow the progressive development of a worker’s autonomy. This was found to be a more effective approach than verbal instructions provided on demand from co-workers.

The use of more expensive supports such as video modelling have also been studied indicating mixed results (Allen, Burke, Howard, Wallace, & Bowen, 2012; Goh & Bambara, 2013). Video modelling is a technique best supported by other techniques such as feedback and practice, as well as audio-cuing. More sophisticated training approaches using tablet computers and Bluetooth headsets were shown to be effective (Cavkaytar, Acungil, & Tomris, 2017), however the successful transfer to real-time contexts was mixed. The use of virtual reality is also emerging (Koplick & Beaumont, 2018) though research evidence is yet to be established. There may be benefits for using these technologies where learning in context is difficult or hazardous, however, as a general principle, learning in the context removes the need for additional training to transfer knowledge.

Implications for training in the workplace are:

- ongoing training should be delivered by supervisors who are staff members of the organisation, rather than by external job coaches;
- external job coaches can be helpful in supporting staff in workplaces to train an employee with Down syndrome and to monitor performance; and
- simple 'low-tech' teaching aides and techniques are effective. Visual supports, such as photographs printed on a card, allow workers to become autonomous after initial training.

### 5.3.3. Lifelong learning

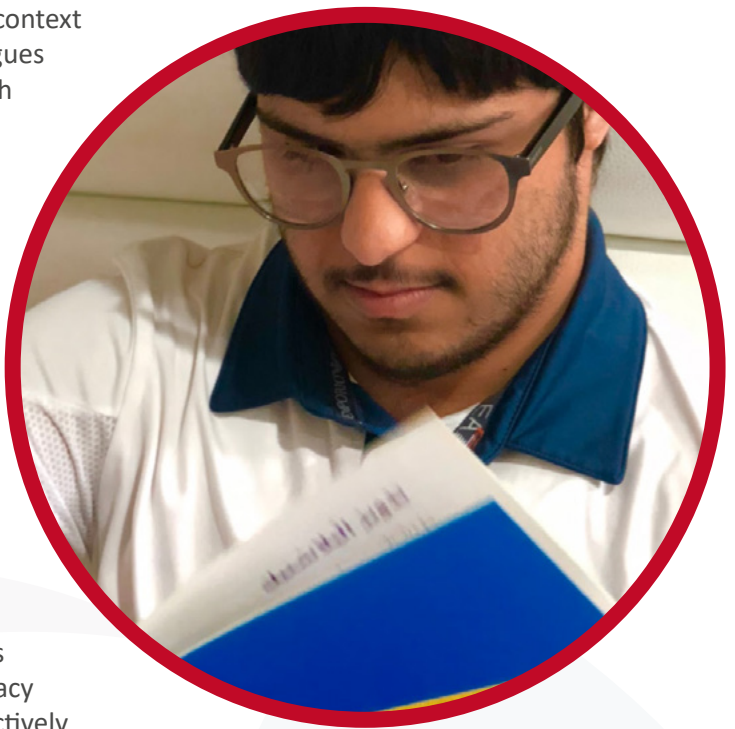
The first babies born in the post institutional era in many countries are now entering their forties. Life expectancy for this generation has expanded beyond that of past generations with one in ten now living into their seventies (Torr et al., 2010). The link between Down syndrome and dementia of the Alzheimer type has been established (Hithersay, Hamburg, Knight, & Strydom, 2017), however, aging need not have the negative connotations often promulgated (Burke, McCarron, Carroll, McGlinchey, & McCallion, 2014). Active aging, with opportunities to continue to learn, leads to enhanced quality of life for adults with Down syndrome. Lifelong learning opportunities “provide enrichment and meaningful activities that can help counteract loneliness and other feelings of discontent or boredom” (Fesko, Hall, Quinlan, & Jockell, 2012, p. 503). It has long been established that people with Down syndrome, without other complicating conditions, continue to develop intellectually throughout adulthood (Moni & Jobling, 2001).

Little research has been undertaken on which aspects of adult education would be most helpful. Some early studies have indicated the need for basic education and budgeting skills (McCausland et al., 2010; McConkey, 1998). Research undertaken with older persons with intellectual disabilities produce findings from a time when schooling for students with intellectual disabilities was limited and inclusive schooling was especially rare. The need for individual, personalised education was noted by McConkey (1998) and may be a way to identify the particular areas of life where need exists or where a person would like to develop additional knowledge or skills. Further, Faragher noted rapid technological advances occurring across society requires change to what is included in functional or lifeskills programs (Faragher, 2019).

Most studies on adult learning have explored literacy development and impacts on other aspects of life (Lynch, 2013; Moni & Jobling, 2001, 2008; Moni, Jobling, Morgan, & Lloyd, 2011; Morgan, Moni, & Cuskelly, 2013). The importance of literacy development for friendship and other areas of social inclusion imply the detriment caused if opportunities are not available for continuing literacy learning and development (Forts & Luckasson, 2011). An issue arising in adulthood (and often before) is to find developmentally and socially appropriate literacy activities (Moni et al., 2011). Moni and Cuskelly (2008) advocate the use of popular culture texts.

Adults with Down syndrome make use of a range of literacy strategies (Morgan et al., 2013) which may

have been learned either at school or in a specific context, and which are likely to have been adapted to the context in which they were used. Morgan and colleagues worked with adults with Down syndrome as research partners and found that visual texts, such as photographs beside written words, were particularly helpful in supporting the development of meaning in context. An important finding from this research is that adults with Down syndrome may continue to need assistance to use literacy strategies they may only partially have mastered at school. An example is the directionality of reading text (those in the study were observed to read words at random when the text was difficult). The study investigated literacy practices in contexts of the participants' choosing and so provides evidence for the situated nature of literacy practices. Difficulties transferring strategies learnt in school to other contexts were noted and this suggests that ongoing literacy learning in adulthood may be undertaken effectively in the contexts themselves, as the need arises, and taught by companions.



Limited studies beyond literacy exist. Faragher and Brown (2005) studied the connection between the use of mathematics in life contexts (numeracy) on quality of life. Numeracy development may require explicit planning for people with intellectual disabilities because opportunities to do so vicariously may be limited (Faragher, 2010). Financial literacy is a common concern for people with intellectual disabilities and Down syndrome in particular. Old curriculum elements such as counting coins and calculating change are not important in countries with electronic banking and digital finance (Faragher, 2019). Of critical importance are overarching concepts such as budgeting, saving, spending, earning interest and borrowing money. These should be taught as concepts, rather than relying on specific techniques that may become outdated. Use of the tools of mathematics, such as teller machines, online banking and spreadsheets removes the challenge of calculation. Almost all adults in the general community require financial advice, particularly around complex areas such as taxation and saving for retirement. So too, people with Down syndrome require advice from those they trust. Unfortunately, they are vulnerable to financial abuse and strategies should be considered to guard against the risk (Australian Securities and Investment Commission (ASIC), 2018). These include having more than one trusted advisor to oversee expenditure and to provide guidance, using a supported decision-making model, to enable the person with Down syndrome to make their own decisions with appropriate support to do so.

## RECOMMENDATIONS FOR LEARNING

31. Early intervention in inclusive settings leads to greater learning and better social outcomes than programs undertaken in segregated settings. Support children to engage in typical experiences known to promote development.
32. Professionals, such as school principals and system leaders, must support families to transition to inclusive placements.
33. Explicit and patient teaching of school routines is essential.
34. Inclusive classrooms offer opportunities for vicarious learning of culturally and age-related knowledge.
35. Students must be encouraged to attend inclusive secondary classes and be supported to remain there until the end of secondary school.
36. Secondary school should be devoted to the teaching of the secondary school curriculum because opportunities to learn that material become limited once the school years have passed.
37. People with Down syndrome have a right to be taught about relationships, sexuality and sexual health.
38. Work experience in community settings develops non-academic attributes essential for employment such as emotional and behavioural skills. Work experience in sheltered workshops or other segregated settings during the school years does not provide the necessary opportunities for learning about open employment.
39. Opportunities to continue learning in both formal and informal settings may require explicit planning beyond the school years.
40. Post-secondary education should be available to students with Down syndrome, should they wish to pursue further study. Required adjustments and supports should be provided as for other levels of education.
41. Ongoing workplace training should be delivered by supervisors who are staff members of the organisation, rather than by external job coaches.
42. External job coaches can be helpful in supporting staff in workplaces to train an employee with Down syndrome and to monitor performance.
43. People with Down syndrome, without other complicating conditions, continue to develop intellectually throughout adulthood and should have access to lifelong learning opportunities.
44. Ongoing literacy learning in adulthood is effective in life contexts, as the need arises, and can be taught by companions in those contexts.
45. Numeracy skills change with technological advances and adults with Down syndrome should be assisted to learn to use devices such as smart phones and computer applications, where they are in use by the general community.
46. Support from trusted adults to enable the person with Down syndrome to manage their finances is likely to be necessary.

## ■ 6. REFERENCES

- Ahmed, M., & Mullick, J. (2014). Implementing inclusive education in primary schools in Bangladesh: recommended strategies. *Educational Research for Policy and Practice*, 13(2), 167-180. doi:10.1007/s10671-013-9156-2
- Ainscow, M., & Sandill, A. (2010). Developing inclusive education systems: the role of organisational cultures and leadership. *International Journal of Inclusive Education*, 14(4), 401-416 doi:10.1080/13603110802504903
- Allen, K. D., Burke, R. V., Howard, M. R., Wallace, D. P., & Bowen, S. L. (2012). Use of audio cuing to expand employment opportunities for adolescents with autism spectrum disorders and intellectual disabilities. *Journal of Autism and Developmental Disorders*, 42(11), 2410-2419. doi:10.1007/s10803-012-1519-7
- Attwood, T., & Bland, K. (2012). Deployment and impact of higher level teaching assistants – how do small-scale local studies fit into the bigger picture? *Management in Education*, 26(2), 82-88. doi:10.1177/0892020611431390
- Australian Institute for Teaching and School Leadership (AITSL). (2011). *Australian Professional Standards for Teachers*. Retrieved from [http://www.aitsl.edu.au/docs/default-source/apst-resources/australian\\_professional\\_standard\\_for\\_teachers\\_final.pdf](http://www.aitsl.edu.au/docs/default-source/apst-resources/australian_professional_standard_for_teachers_final.pdf)
- Australian Securities and Investment Commission (ASIC). (2018). Financial abuse. Protecting your money from others. Retrieved from <https://www.moneysmart.gov.au/life-events-and-you/families/financial-abuse>
- Baddeley, A. D. (2000). The episodic buffer: a new component of working memory? *Trends in cognitive science*, 4, 417-423.
- Baer, R. M., Daviso III, A. W., Flexer, R. W., McMahan Queen, R., & Meindl, R. S. (2011). Students with intellectual disabilities: Predictors of transition outcomes. *Career development for exceptional individuals*, 34(3), 132-141. doi:10.1177/0885728811399090
- Baker-Ericzen, M. J., Garnand Mueggenborg, M., & Shea, M. M. (2009). Impact of trainings on child care providers' attitudes and perceived competence toward inclusion: What factors are associated with change? *Topics in Early Childhood Special Education*, 28(4), 196-208. doi:10.1177/0271121408323273
- Becerra, M.-T., Montanero, M., & Lucero, M. (2018). Graphic support resources for workers with intellectual disability engaged in office tasks: a comparison with verbal instructions from a work mate. *Disability and Rehabilitation*, 40(4), 435-443. doi:10.1080/09638288.2016.1258739
- Blatchford, P., Bassett, P., Brown, P., & Webster, R. (2013). The effect of support staff on pupil engagement and individual attention. *British Educational Research Journal*, 35(5), 661-686. doi:10.1080/01411920902878917
- Bridle, L., & Mann, G. (2000). *Mixed feelings - A parental perspective on early intervention*. Paper presented at the Supporting not controlling: Strategies for the new millennium. Proceedings of the Early Childhood Intervention Australia National Conference. <http://www.riverbendds.org/eibridle.html>
- Browder, D. M., & Spooner, F. (Eds.). (2014). *More Language Arts, Math and Science for Students with Severe Disabilities*. Baltimore, MA: Brookes.
- Buckley, S., Bird, G., Sacks, B., & Archer, T. (2006). A comparison of mainstream and special education for teenagers with Down syndrome: implications for parents and teachers. *Down Syndrome Research and Practice*, 9(3), 54-67.

Burke, E., McCarron, M., Carroll, R., McGlinchey, E., & McCallion, P. (2014). What it's like to grow older: The aging perceptions of people with an intellectual disability in Ireland. *Intellectual and developmental disabilities*, 52(3), 205-219.

Butt, R. (2016). Teacher assistant support and deployment in mainstream schools. *International Journal of Inclusive Education*, 20(9), 995-1007. doi:10.1080/13603116.2016.1145260

Butt, R. (2018). 'Pulled in off the street' and available: What qualifications and training do Teacher Assistants really need? *International Journal of Inclusive Education*, 22(3), 217-234. doi:10.1080/13603116.2017.1362478

Capio, C. M., Mak, T. C. T., Tse, M. A., & Masters, R. S. W. (2018). Fundamental movement skills and balance of children with Down syndrome. *Journal of Intellectual Disability Research*, 62(3), 225-236. doi:10.1111/jir.12458

Cavkaytar, A., Acungil, A. T., & Tomris, G. (2017). Effectiveness of teaching cafe waitering to adults with intellectual disability through audio-visual technologies. *Education and Training in Autism and Developmental Disabilities*, 52(1), 77-90.

Chapman, R. S., & Bird, E. K.-R. (2012). Language development in childhood, adolescence, and young adulthood in persons with Down syndrome. In J. A. Burack, R. M. Hodapp, G. Iarocci, & E. Zigler (Eds.), *The Oxford handbook of intellectual disability and development* (pp. 167-183). New York, NY: Oxford University Press.

Charleton, P., & Woodhouse, M. (2015). Vision and eye disorders. In R. W. Newton, S. Puri, & L. Marder (Eds.), *Down syndrome. Current perspectives*. (pp. 77-87). London, UK: Mac Keith Press.

Cimera, R. E. (2010). Can community-based high school transition programs improve the cost-efficiency of supported employment? *Career development for exceptional individuals*, 33(1), 4-12. doi:10.1177/0885728809346959

Clarke, B., & Faragher, R. (2015). Inclusive practices in the teaching of mathematics: Supporting the work of effective primary teachers. In M. Marshman, V. Geiger, & A. Bennison (Eds.), *Mathematics education in the margins. Proceedings of the 38th annual conference of the Mathematics Education Research Group of Australasia*. (pp. 173-180). Sunshine Coast: MERGA.

Cockroft, C., & Atkinson, C. (2015). Using the Wider Pedagogical Role model to establish learning support assistants' views about facilitators and barriers to effective practice. *Support for Learning*, 30(2), 88-104. doi:10.1111/1467-9604.12081

Cologon, K. (2013). Debunking myths: Reading development in children with Down syndrome. *Australian Journal of Teacher Education*, 38(3), 130-151. doi:10.14221/ajte.2013v38n3.10

Cologon, K., Wicks, L., & Salvador, A. (2017). Supporting caregivers in developing responsive communication partnerships with their children: Extending a caregiver-led interactive language program. *Child Language Teaching and Therapy*, 33(2), 157-169. doi:10.1177/0265659016650978

Committee on the Rights of Persons with Disabilities. (2016). *General Comment No.4, Article 24: Right to inclusive education*. Retrieved from <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G16/263/00/PDF/G1626300.pdf?OpenElement>

Couzens, D., & Cuskelly, M. (2014). Cognitive strengths and weaknesses for informing educational practice. In R. Faragher & B. Clarke (Eds.), *Educating learners with Down syndrome. Research, theory and practice with children and adolescents*. (pp. 40-59). London, UK: Routledge.

de Graaf, G., & de Graaf, E. (2016). Development of self-help, language, and academic skills in persons with Down syndrome. *Journal of Policy and Practice in Intellectual Disabilities*, 13(2), 120-131. doi:10.1111/jppi.12161

de Graaf, G., van Hove, G., & Haveman, M. (2013). More academics in regular schools? The effect of regular versus special school placement on academic skills in Dutch primary school students with Down syndrome. *Journal of Intellectual Disability Research*, 57(1), 21-38. doi:10.1111/j.1365-2788.2011.01512.x

Dockett, S., Perry, B., & Kearney, E. (2011). Starting school with special needs: Issues for families with complex support needs as their children start school. *Exceptionality Education International*, 21(2), 45-61.

European Agency for Special Needs and Inclusive Education. (2018). *Evidence of the link between inclusive education and social inclusion: A review of the literature*. (S. Symeonidou Ed.). Odense, Denmark: Author.

Faragher, R. (2010). Developing numeracy to enhance quality of life. In R. Kober (Ed.), *Enhancing the quality of life of people with intellectual disabilities*. From theory to practice. (pp. 401-411). London: Springer.

Faragher, R. (2014). Learning mathematics in the secondary school: Possibilities for students with Down syndrome. In R. Faragher & B. Clarke (Eds.), *Educating learners with Down syndrome: Research, theory and practice with children and adolescents* (pp. 174-191). London, UK: Routledge.

Faragher, R. (2019). The new 'functional mathematics' for learners with Down syndrome: Numeracy for a digital world. *International Journal of Disability, Development & Education*, 66(2), 206-217. doi:10.1080/1034912X.2019.1571172

Faragher, R., & Brown, R. I. (2005). Numeracy for adults with Down syndrome: it's a matter of quality of life. *Journal of Intellectual Disability Research*, 49(10), 761-765.

Faragher, R., & Clarke, B. (2016). Teacher identified professional learning needs to effectively include a child with Down syndrome in primary mathematics. *Journal of Policy and Practice in Intellectual Disabilities*, 13(2), 132-141. doi:10.1111/jppi.12159

Fesko, S. L., Hall, A. C., Quinlan, J., & Jockell, C. (2012). Active aging for individuals with intellectual disability: Meaningful community participation through employment, retirement, service, and volunteerism. *American Journal on Intellectual and Developmental Disabilities*, 117(6), 497-508.

Fillary, R., & Pernice, R. (2006). Social inclusion in workplaces where people with intellectual disabilities are employed: implications for supported employment professionals. *International Journal of Rehabilitation Research*, 29(1), 31-36.

Florian, L. (2012). Preparing teachers to work in inclusive classrooms: Key lessons for the professional development of teacher educators from Scotland's Inclusive Practice Project. *Journal of Teacher Education*, 63(4), 275-285. doi:10.1177/0022487112447112

Forlin, C., Sharma, U., & Loreman, T. (2007). An international comparison of pre-service teacher attitudes towards inclusive education. *Disability Studies Quarterly*, 27(4). doi:10.18061/dsq.v27i4.53

Forlin, C., Sharma, U., & Loreman, T. (2014). Predictors of improved teaching efficacy following basic training for inclusion in Hong Kong. *International Journal of Inclusive Education*, 18(7), 718-730. doi:10.1080/13603116.2013.819941

Forts, A. M., & Luckasson, R. (2011). Reading, writing, and friendship: Adult implications of effective literacy instruction for students with intellectual disability. *Research and Practice for Persons with Severe Disabilities*, 36(3-4), 121-125.



Gaffney, M., Bezzina, M., & Branson, C. (2014). Leading mathematics teaching. In M. Gaffney & R. Faragher (Eds.), *Leading improvements in student numeracy*. Camberwell, Vic: ACER.

Gaffney, M., Clarke, D., & Faragher, R. (2014). The numeracy challenge: Student achievement, teacher quality, school leadership and system policy. In M. Gaffney & R. Faragher (Eds.), *Leading improvements in student numeracy* (pp. 3-23). Camberwell, Vic: ACER.

Gaffney, M., & Faragher, R. (2010). Sustaining improvement in numeracy: Developing pedagogical content knowledge and leadership capabilities in tandem. *Mathematics Teacher Education and Development*, 12(2), 72-83.

Gibbons, M. M., Hyfantis, J., Cihak, D. F., Wright, R., & Mynatt, B. (2016). A social-cognitive exploration of the career and college understanding of young adults with intellectual disabilities. *Professional School Counseling*, 19(1). doi:10.5330/1096-2409-19.1.80

Goh, A. E., & Bambara, L. M. (2013). Video self-modeling: A job skills intervention with individuals with intellectual disability in employment settings. *Education and Training in Autism and Developmental Disabilities*, 48(1), 103-119.

Grigal, M., Hart, D., & Migliore, A. (2011). Comparing the transition planning, postsecondary education, and employment outcomes of students with intellectual and other disabilities. *Career development for exceptional individuals*, 34(1), 4-17. doi:10.1177/0885728811399091

Grigal, M., Hart, D., & Weir, C. (2012). A survey of postsecondary education programs for students with intellectual disabilities in the United States. *Journal of Policy and Practice in Intellectual Disabilities*, 9(4), 223-233.

Guralnick, M. J. (2013). Developmental science and preventive interventions for children at environmental risk. *Infants & Young Children*, 26(4), 270-285. doi:10.1097/IYC.0b013e3182a6832f

Guralnick, M. J. (2017). Early intervention for children with intellectual disabilities: an update. *Journal of Applied Research in Intellectual Disabilities*, 30, 211-229. doi:10.1111/jar.12233

Hart, D., Grigal, M., Sax, C., Martinez, D., & Will, M. (2006). *Postsecondary education options for students with intellectual disabilities (Research to Practice Brief No. 45)*. Boston: Institute for Community Inclusion, University of Massachusetts, Boston.

Hehir, T., Grindal, T., Freeman, B., Lamoreau, R., Borquaye, Y., & Burke, S. (2016). *A summary of the evidence on inclusive education*. Retrieved from Instituto Alana: [http://alana.org.br/wp-content/uploads/2016/12/A\\_Summary\\_of\\_the\\_evidence\\_on\\_inclusive\\_education.pdf](http://alana.org.br/wp-content/uploads/2016/12/A_Summary_of_the_evidence_on_inclusive_education.pdf)

Heifetz, R., Grashow, A., & Linsky, M. (2009). The theory behind the practice. *The practice of adaptive leadership: Tools and tactics for changing your organization and the world*. (pp. 13-40). Boston, MA: Harvard Business Press.

Hendrickson, J., Carson, R., Woods-Groves, S., Mendenhall, J., & Scheidecker, B. (2013). UI REACH: A Postsecondary Program Serving Students with Autism and Intellectual Disabilities. *Education and Treatment of Children*, 36(4), 169-194.

Hithersay, R., Hamburg, S., Knight, B., & Strydom, A. (2017). Cognitive decline and dementia in Down syndrome. *Current Opinion in Psychiatry*, 30(2), 102-107. doi:10.1097/YCO.0000000000000307

Hoskin, J., Boyle, C., & Anderson, J. (2015). Inclusive education in pre-schools: predictors of pre-service teacher attitudes in Australia. *Teachers and Teaching: theory and practice*, 21(8), 974-989. doi:10.1080/13540602.2015.1005867

Izuzquiza Gasset, D. (2012). The value of educational inclusion of young people with intellectual disabilities in higher education: the Promentor program. *Bordon. Revista de Pedagogia. [Bordon. Journal of Education.]*, 64(1), 66-80.

Janus, M., Kopechanski, L., Cameron, R., & Hughes, D. (2008). In transition: Experiences of parents of children with special needs at school entry. *Early Childhood Education Journal*, 35(5), 479-485. doi:10.1007/s10643-007-0217-0

Jobling, A., Virji-Babul, N., & Nichols, D. (2006). Children with Down syndrome. Discovering the joy of movement. *Journal of physical education, recreation and dance.*, 77(6), 34-54. doi:10.1080/07303084.2006.10597892

Jones, M. M., & Goble, Z. (2012). Creating effective mentoring partnerships for students with intellectual disabilities on campus. *Journal of Policy and Practice in Intellectual Disabilities*, 9(4), 270-278.

Jordan, A., Schwartz, E., & McGhie-Richmond, D. (2009). Preparing teachers for inclusive classrooms. *Teaching and Teacher Education*, 25(4), 55-542. doi:10.1016/j.tate.2009.02.010

Joshi, G. S., Bouck, E. C., & Maeda, Y. (2012). Exploring employment preparation and postschool outcomes for students with mild intellectual disability. *Career Development and Transition for Exceptional Individuals*, 35(2), 97-107. doi:10.1177/0885728811433822

Kaya, C. (2018). Demographic variables, vocational rehabilitation services, and employment outcomes for transition-age youth with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 15(3), 226-236. doi:10.1111/jppi.12249

Keating, S., & O'Connor, U. (2012). The shifting role of the special needs assistant in Irish classrooms: a time for change? *European Journal of Special Needs Education*, 27(4), 533-544. doi:10.1080/08856257.2012.711960

Kendall, L. (2018). Supporting children with Down syndrome within mainstream education settings: parental reflections. *Education 3-13. International Journal of Primary, Elementary and Early Years Education., online.* doi:10.1080/03004279.2017.1412488

King, F., Ni Bhroin, O., & Prunty, A. (2018). Professional learning and the individual education plan process: implications for teacher educators. *Professional Development in Education*, 44(5), 607-621. doi:10.1080/19415257.2017.1398180

Koplick, S., & Beaumont, C. (2018). *My right to an education, but does virtual reality educate?* Paper presented at the Let's shake it up, human rights for everyone! Australasian Society for Intellectual Disability. 52nd Conference, Gold Coast, Australia.

Laws, G., & Hall, A. (2014). Early hearing loss and language abilities in children with Down syndrome. *International Journal of Language & Communication Disorders*, 49(3), 333-342. doi:10.1111/1460-6984.12077

Lightfoot, L., & Bond, C. (2013). An exploration of primary to secondary school transition planning for children with Down's syndrome. *Educational Psychology in Practice. Theory, research and practice in educational psychology.*, 29(2), 163-179. doi:10.1080/02667363.2013.800024

Lynch, J. (2013). A case study of a volunteer-based literacy class with adults with developmental disabilities. *Australian Journal of Adult Learning*, 53(2), 302-325.

Maher, A., & Macbeth, J. (2013). The perspective of special educational needs coordinators working in secondary schools in North-West England. *Physical education, resources and training*, 20(1), 90-103. doi:10.1177/1356336X13496003

- Mann, G., Cuskelly, M., & Moni, K. B. (2018). An investigation of parents' decisions to transfer children from regular to special schools. *Journal of Policy and Practice in Intellectual Disabilities*, 15(3), 183-192. doi:10.1111/jppi.12238
- May, C. (2012). An investigation of attitude change in inclusive college classes including young adults with an intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities*, 9(4), 240-246.
- McCausland, D., Guerin, S., Tyrrell, J., Donohoe, C., O'Donoghue, I., & Dodd, P. (2010). Self-reported needs among older persons with intellectual disabilities in an Irish community-based service. *Research in Developmental Disabilities*, 31(2), 381-387.
- McConkey, R. (1998). Education for life? *British Journal of Special Education*, 25(2), 55-59.
- McGuire, B. E., & Defrin, R. (2015). Pain perception in people with Down syndrome: A synthesis of clinical and experimental research. *Frontiers in Behavioral Neuroscience*, 9(Article 194), 1-9. doi:10.3389/fnbeh.2015.00194
- McNeill, E., Sheehan, P., & Marder, L. (2015). Hearing issues. In R. W. Newton, S. Puri, & L. Marder (Eds.), *Down syndrome. Current perspectives*. (pp. 70-76). London, UK: Mac Keith Press.
- Mills, S., Bird, G., Black, L., Ridley, V., Heslam, S., Marsden, L., . . . Straw, F. (2015). Life with and for a person with Down syndrome. In R. W. Newton, S. Puri, & L. Marder (Eds.), *Down syndrome. Current perspectives*. (pp. 23-69). London, UK: Mac Keith Press.
- Miskolci, J., Armstrong, D., & Spandagou, I. (2016). Teachers' perceptions of the relationship between inclusive education and distributed leadership in two primary schools in Slovakia and New South Wales (Australia). *Journal of Teacher Education for Sustainability*, 18(2), 53-65. doi:10.1515/jtes-2016-0014
- Mitchell, D., Morton, M., & Hornby, G. (2010). *Review of the literature on individual education plans: Report to the New Zealand Ministry of Education*. Wellington, NZ: Ministry of Education.
- Monari Martinez, E. (1998). Teenagers with Down syndrome study algebra in high school. *Down Syndrome Research and Practice*, 5(1), 34-38.
- Monari Martinez, E., & Benedetti, N. (2011). Learning mathematics in mainstream secondary schools: experiences of students with Down's syndrome. *European Journal of Special Needs Education*, 26(4), 531-540. doi:10.1080/08856257.2011.597179
- Monari Martinez, E., & Pellegrini, K. (2010). Algebra and problem-solving in Down syndrome: a study with 15 teenagers. *European Journal of Special Needs Education*, 25(1), 13-29. doi:10.1080/08856250903450814
- Moni, K. B., & Jobling, A. (2001). Reading-related literacy learning of young adults with Down syndrome: Findings from a three year teaching and research program. *International Journal of Disability, Development and Education*, 48(4), 377-394.
- Moni, K. B., & Jobling, A. (2008). A case for including popular culture in literacy education for young adults with Down syndrome. *Australian Journal of Language & Literacy*, 31(3), 260-277.
- Moni, K. B., Jobling, A., Morgan, M., & Lloyd, J. (2011). Promoting literacy for adults with intellectual disabilities in a community-based service organisation. *Australian Journal of Adult Learning*, 51(3), 456-478.
- Moore, E. J., & Schelling, A. (2015). Postsecondary inclusion for individuals with an intellectual disability and its effects on employment. *Journal of Intellectual Disabilities*, 19(2), 130-148. doi:10.1177/1744629514564448
- Morgan, M., Moni, K. B., & Cuskelly, M. (2013). Literacy strategies used by adults with intellectual disability in negotiating their everyday community environments. *Australian Journal of Adult Learning*, 53(3), 411-435.

Noonan Walsh, P., Lynch, C., & deLacey, E. (1994). Supported employment for Irish adults with intellectual disability: The OPEN ROAD experience. *International Journal of Rehabilitation Research*, 17(1), 15-24.

O'Brien, P., Shevlin, M., O'Keefe, M., Fitzgerald, S., Curtis, S., & Kenny, M. (2009). Opening up a whole new world for students with intellectual disabilities within a third level setting. *British Journal of Learning Disabilities*, 37, 285-292. doi:10.1111/j.1468-3156.2009.00584.x

O'Connor, B., Kubiak, J., Espiner, D., & O'Brien, P. (2012). Lecturer responses to the inclusion of students with intellectual disabilities auditing undergraduate classes. *Journal of Policy and Practice in Intellectual Disabilities*, 9(4), 247-256.

OECD. (2007). *Evidence in Education. Linking research and policy*. Paris, France: OECD.

Osiname, A. T. (2018). Utilizing the critical inclusive praxis: The voyage of five selected school principals in building inclusive school cultures. *Improving schools*, 21(1), 63-83. doi:10.1177/1365480217717529

Paige-Smith, A., & Rix, J. (2006). Parents' perceptions and children's experiences of early intervention - inclusive practice? *Journal of Research in Special Educational Needs*, 6(2), 92-98. doi:10.1111/J.1471-3802.2006.00064.x

Poon-McBrayer, K. F. (2017). School leaders' dilemmas and measures to instigate changes for inclusive education in Hong Kong. *Journal of Educational Change*, 18(3), 295-309. doi:10.1007/s10833-017-9300-5

Rachubinski, A. L., Hepburn, S., Elias, E. R., Gardiner, K., & Shaikh, T. H. (2017). The co-occurrence of Down syndrome and autism spectrum disorder: is it because of additional genetic variations? *Prenatal Diagnosis*, 37, 31-36. doi:10.1002/pd.4957

Riehl, C. J. (2000). The principal's role in creating inclusive schools for diverse students: A review of normative, empirical, and critical literature on the practice of educational administration. *Review of Educational Research*, 70(1), 55-81.

Rillotta, F., Arthur, J., Hutchinson, C., & Raghavendra, P. (2018). Inclusive university experience in Australia: Perspectives of students with intellectual disability and their mentors. *Journal of Intellectual Disabilities, early view*. doi:10.1177/1744629518769421

Robinson, D. (2017). Effective inclusive teacher education for special educational needs and disabilities: Some more thoughts on the way forward. *Teaching and Teacher Education*, 61(January), 164-178. doi:10.1016/j.tate.2016.09.007

Roffey-Barentsen, J. (2014). The Voices of Teaching Assistants (Are We Value for Money?). *Research in Education*, 92(1), 18-31. doi:10.7227/RIE.0002

Rose, D. H., Gravel, J. W., & Gordon, D. T. (2014). Universal design for learning. In L. Florian (Ed.), *The SAGE handbook of Special Education* (pp. 475-489). London: SAGE.

Ryan, S. M. (2014). An inclusive rural post secondary education program for students with intellectual disabilities. *Rural Special Education Quarterly*, 33(2), 18-28. doi:10.1177/875687051403300204

Schworer, E., Fidler, D. J., Lunkenheimer, E., & Daunhauer, L. A. (2018). Parenting behaviour and executive function in children with Down syndrome. *Journal of Intellectual Disability Research, Early view*. doi:10.1111/jir.12575

Shaddock, A., MacDonald, N., Hook, J., Giorcelli, L., & Arthur-Kelly, M. (2009). *Disability, diversity and tides that lift all boats: Review of special education in the ACT*. Chiswick, NSW: Service Initiatives.

- Sheppard-Jones, K., Kleinert, H. L., Druckemiller, W., & Ray, M. K. (2015). Students with intellectual disability in higher education: Adult service provider perspectives. *Intellectual and developmental disabilities, 53*(2), 120-128. doi:10.1352/1934-9556-53.2.120
- Shulman, L. S. (2005). Signature pedagogies in the professions. *Daedalus, 134*(3), 52-59. doi:10.1162/0011526054622015
- Silverman, J. C. (2007). Epistemological beliefs and attitudes toward inclusion in pre-service teachers. *Teacher Education and Special Education, 30*(1), 42-51. doi:10.1177/088840640703000105
- Siperstein, G. N., Heyman, M., & Stokes, J. E. (2014). Pathways to employment: A national survey of adults with intellectual disabilities. *Journal of Vocational Rehabilitation, 41*, 165-178. doi:10.3233/JVR-140711
- Slee, P., Campbell, M., & Spears, B. (2014). *Child, adolescent and family development* (3rd ed.). Port Melbourne, Australia: Cambridge University Press.
- Spooner, F., & Browder, D. M. (2006). Why Teach the General Curriculum? In D. M. Browder & F. Spooner (Eds.), *Teaching Language Arts, Math, and Science to Students with Significant Cognitive Disabilities*. (pp. 1-13). Baltimore, MA: Brookes.
- Staples, K. E., & Diliberto, J. A. (2010). Guidelines for successful parent involvement: Working with parents of students with disabilities. *Teaching Exceptional Children, 42*(6), 58-63. doi:10.1177/004005991004200607
- Stein, D. S. (2016). *Supporting positive behavior in children and teens with Down syndrome. The respond but don't react method*. Bethesda, USA: Woodbine House.
- Stephenson, J., & Carter, M. (2015). Improving educational planning for students with severe disabilities: An evaluation of school-based professional learning. *Australasian Journal of Special Education, 39*(1), 2-14. doi:10.1017/jse.2015.2
- Sullivan, P., Mousley, J., & Zevenbergen, R. (2006). Teacher actions to maximize mathematics learning opportunities in heterogeneous classrooms. *International journal of science and mathematics education, 4*, 117-143.
- Swinton, J. (2012). From Inclusion to Belonging: A Practical Theology of Community, Disability and Humanness. *Journal of Religion, Disability & Health, 16*(2), 172-190. doi:10.1080/15228967.2012.676243
- Symeonidou, S. (2017). Initial teacher education for inclusion: A review of the literature. *Disability and Society, 32*(3), 401-422. doi:10.1080/09687599.2017.1298992
- Torr, J., Strydom, A., Patti, P., & Jokinen, N. (2010). Aging in Down syndrome: Morbidity and mortality. *Journal of Policy and Practice in Intellectual Disabilities, 7*(1), 70-81.
- Toson, A. L.-M., Burrello, L. C., & Knollman, G. (2012). Educational justice for all: the capability approach and inclusive education leadership. *International Journal of Inclusive Education, 17*(5), 1-17. doi:10.1080/13603116.2012.687015
- Uditsky, B., & Hughson, E. (2012). Inclusive postsecondary education - An evidence-based moral imperative. *Journal of Policy and Practice in Intellectual Disabilities, 9*(4), 298-302.
- UNESCO. (2019). Cali commitment to equity and inclusion in education. Retrieved from <https://unesdoc.unesco.org/ark:/48223/pf0000370910>
- United Nations. (2006). *Convention on the rights of persons with disabilities and its optional protocol*. Retrieved from <http://www.un.org/disabilities/default.asp?navid=15&pid=150>
- United Nations. (2015). *Transforming our world: The 2030 agenda for sustainable development. A/RES/70/1*. New York, NY: United Nations Department of Public Information.

United Nations Committee on the Rights of Persons with Disabilities. (2016). *General comment No. 4*. Retrieved from <http://www.ohchr.org/Documents/HRBodies/CRPD/GC/RighttoEducation/CRPD-C-GC-4.doc>

Vaz, S., Falkmer, M., Ciccarelli, M., Passmore, A., Parsons, R., Black, M., . . . Falkmer, T. (2015). Belongingness in early secondary school: Key factors that primary and secondary schools need to consider. *PLoS One*, *10*(9), e0136053. doi:10.1371/journal.pone.0136053

Villeneuve, M., Chatenoud, C., Hutchinson, N. L., Minnes, P., Perry, A., Dionne, C., . . . Weiss, J. (2013). The experience of parents as their children with developmental disabilities transition from early intervention to kindergarten. *Canadian Journal of Education*, *36*(1), 4-43.

Vimercati, S. L., Galli, M., Stella, G., Caiazzo, G., Ancillao, A., & Albertini, G. (2015). Clumsiness in fine motor tasks: evidence from the quantitative drawing evaluation of children with Down syndrome. *Journal of Intellectual Disability Research*, *59*(3), 248-256. doi:10.1111/jir.12132

Webster-Wright, A. (2009). Reframing professional development through understanding authentic professional learning. *Review of Educational Research*, *79*(2), 702-739. doi:10.3102/0034654308330970

Wehman, P., Chan, F., Ditchman, N., & Kang, H. (2014). Effect of supported employment on vocational rehabilitation outcomes of transition-age youth with intellectual and developmental disabilities: A case control study. *Intellectual and developmental disabilities*, *52*(4), 296-310. doi:10.1352/1934-9556-52.4.296

Wenger, E. (1998). *Communities of practice*. Cambridge, UK: Cambridge University Press.

Wilder, J., & Lillvist, A. (2017). Hope, despair and everything in between - parental expectations of educational transition for young children with intellectual disability. In S. Dockett, W. Griebel, & B. Perry (Eds.), *Families and transition to school* (Vol. 21). Cham, Switzerland: Springer.

Wishart, J. G. (1993). Learning the hard way: Avoidance strategies in young children with Down's syndrome. *Down Syndrome Research and Practice*, *1*(2), 47-55.

World Health Organization, & UNICEF. (2012). *Early childhood development and disability: A discussion paper*. Malta: World Health Organization. Available: [http://apps.who.int/iris/bitstream/handle/10665/75355/9789241504065\\_eng.pdf;jsessionid=E3D7C48A463719270508DD0B6CB37036?sequence=1](http://apps.who.int/iris/bitstream/handle/10665/75355/9789241504065_eng.pdf;jsessionid=E3D7C48A463719270508DD0B6CB37036?sequence=1).

Wright, C. A., Kaiser, A. P., Reikowsky, D. I., & Roberts, M. Y. (2013). Effects of a naturalistic sign intervention on expressive language of toddlers with Down syndrome. *Journal of Speech, Language, and Hearing Research*, *56*, 994-1008. doi:10.1044/1092-4388(2012/12-0060)

Wright, I., Lewis, V., & Collis, G. M. (2006). Imitation and representational development in young children with Down syndrome. *British Journal of Developmental Psychology*, *24*, 429-450. doi:10.1348/026151005X51257

Zafft, C., Hart, D., & Zimbrich, K. (2004). College career connection: A study of youth with intellectual disabilities and the impact of postsecondary education. *Education and Training in Developmental Disabilities*, *39*(1), 45-53.

Zimpel, A. F. (2016). *Trisomy 21. What we can learn from people with Down syndrome*. Gottingen: Vandenhoeck & Ruprecht.

## ■ APPENDIX

### International Guidelines for the Education of Learners with Down Syndrome FULL LIST OF RECOMMENDATIONS

#### KEY CONSIDERATIONS

1. In all school settings, learners with Down syndrome should be placed in the mainstream classes appropriate to their age. Students should be withdrawn from those settings as infrequently as possible.
2. Education settings for all learners, including those with Down syndrome, should be safe, welcoming and free of all forms of violence, bullying and abuse.
3. Opportunities to learn should continue beyond the school years and throughout adulthood.
4. Decisions about what is taught to learners with Down syndrome should be framed around the right to a broad and balanced curriculum and extra-curricula opportunities, on an equal basis with others, and not based on predictions about what will be needed for adulthood.
5. Academic achievement should be expected for all learners with Down syndrome with provision of appropriate learning supports.
6. Teaching staff should be aware of the high probability of vision and hearing impairments in learners with Down syndrome and that appropriate adjustments may be required to ensure effective learning and communication.
7. Speech and language therapies and other activities which promote good speech clarity and fluency should be available to learners with Down syndrome.
8. Teaching staff should make appropriate adjustments as required, given that some learners with Down syndrome may have extensive social communication difficulties.
9. Teaching should take account of limitations of verbal working memory and information manipulation in working memory.
10. Visual supports for learning (including written words) should be used.
11. Active movement and participation should be used where possible.
12. Occupational therapy can support the continued development of fine motor skills throughout life.
13. If a student displays unusual behaviour, teachers first should rule out pain as a cause.

#### LEADING

14. Leaders need to be in complete agreement with Article 24 of the UN CRPD on education, and aware of their role in driving the cultural change required.
15. Countries in the process of establishing an education system should avoid introducing a segregated special school system.
16. Leaders should provide opportunities for all staff, including learning support assistants, to undertake professional development on aspects of inclusive practice.
17. Leaders should ensure adequate planning time for teaching teams.

18. Leadership teams should be supported through the establishment of networks and communities of practice.
19. Leaders should establish a shared vision of inclusion across all levels of the educational system, working in partnerships with families and the broader community.
20. Principals should have responsibility for the selection of staff.
21. Teachers should be responsible for the learning of all students in their classes and must guide the work of assigned teaching assistants.
22. Support must be provided by the school leadership team to implement school-wide inclusive policy around learning support teams.

## TEACHING

23. Initial teacher education should prepare graduates to manage the learning of all students in inclusive classrooms.
24. At the point when a teacher is assigned a class including a student with Down syndrome, targeted professional development should be provided. It is recognised that in some countries, availability of support may be limited, however, online professional learning resources are increasingly accessible.
25. Students with Down syndrome should be given the opportunity to learn the curriculum specified for their school year level, adjusted as necessary to enable their engagement with the learning outcomes.
26. Additional supports and adjustments should be made available to all students in the class, should they wish to make use of them.
27. Where individual education plans are used, all members of the teaching team, including a member of the school leadership team, should be involved in the planning and progress of the individual education plan and its evaluation. At least one family member or advocate should be included in this process. The student should be included and supported to contribute.
28. Teaching in an inclusive classroom requires the learning needs of all students to be accommodated.
29. Behaviour is communication. It is necessary to determine the purpose behind the behaviour and act on the cause.
30. Avoidant behaviour is common and teachers need to guard against students using these strategies so that they develop persistence in learning

## LEARNING

31. Early intervention in inclusive settings leads to greater learning and better social outcomes than programs undertaken in segregated settings. Support children to engage in typical experiences known to promote development.



32. Professionals, such as school principals and system leaders, must support families to transition to inclusive placements.
33. Explicit and patient teaching of school routines is essential.
34. Inclusive classrooms offer opportunities for vicarious learning of culturally and age related knowledge.
35. Students must be encouraged to attend inclusive secondary classes and be supported to remain there until the end of secondary school.
36. Secondary school should be devoted to the teaching of the secondary school academic curriculum because opportunities to learn that material become limited once the school years have passed.
37. People with Down syndrome have a right to be taught about relationships, sexuality and sexual health.
38. Work experience in community settings develops non-academic attributes essential for employment such as emotional and behavioural skills. Work experience in sheltered workshops or other segregated settings during the school years does not provide the necessary opportunities for learning about open employment.
39. Opportunities to continue learning in both formal and informal settings may require explicit planning beyond the school years.
40. Post-secondary education should be available to students with Down syndrome, should they wish to pursue further study. Required adjustments and supports should be provided as for other levels of education.
41. Ongoing workplace training should be delivered by supervisors who are staff members of the organisation, rather than by external job coaches.
42. External job coaches can be helpful in supporting staff in workplaces to train an employee with Down syndrome and to monitor performance.
43. People with Down syndrome, without other complicating conditions, continue to develop intellectually throughout adulthood and should have access to lifelong learning opportunities.
44. Ongoing literacy learning in adulthood is effective in life contexts, as the need arises, and can be taught by companions in those contexts.
45. Numeracy skills change with technological advances and adults with Down syndrome should be assisted to learn to use devices such as smart phones and computer applications, where they are in use by the general community.
46. Support from trusted adults to enable the person with Down syndrome to manage their finances is likely to be necessary.



ISBN 978-1-78972-083-9

