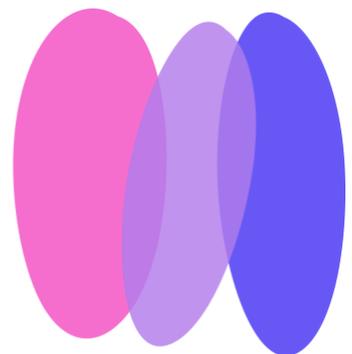


Evidentiary Summary  
Document to support the  
formation of the  
Down Syndrome Bill

National  
Down Syndrome  
Policy Group  
CHANGING THE NARRATIVE



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## Preface

The [National Down Syndrome Policy Group](#) (NDSPG) is a voluntary and not-for-profit organisation formed in 2021. The group comprises people from a wide range of charities and support groups: all with the common aim of ensuring that the voice of people with Down syndrome is heard in society and reflected in government policy. The NDSPG also acts as the Secretariat to the [All-Party Parliamentary Group on Down Syndrome](#).

The NDSPG is delighted to provide this document to aid the research and analysis of the provision of support and services for individuals with Down syndrome (DS).

The document serves three purposes:

- To act as a depository of references of research carried out across a number of fields, principally Healthcare, Education, Social Care and Employment.
- Where clear evidence and best practice is demonstrated through the research material, to summarise and highlight this within the document
- To highlight key areas for consideration and discussion with a view to aiding the Secretary of State's consultation process, following the enactment of the Down Syndrome Bill.

The intention of this document is to capture a broad cross-section of research, including input from educational, health and social care practitioners as well as academics and other interest groups. As such we expect the contents and references contained herein to be updated and expanded upon as the Bill progresses through the various stages of the Parliamentary process. As such we seek to emphasise the dynamic nature of this document.

Where possible the references are from peer reviewed journals, respected opinion pieces from experienced professionals or experts by experience. However we offer no guarantee about the accuracy or efficacy of any references.



## GENERAL

### What is Down Syndrome?

Down syndrome (Trisomy 21) occurs when there is additional full or partial copy of chromosome 21. Down syndrome can cause varying degrees of intellectual disability (usually mild to moderate) as well as possible physical disabilities and associated medical issues, but this can vary from individual to individual.

### What it Means to Have Down Syndrome

People with Down syndrome are achieving more than ever before and leading full, semi-independent lives. With appropriate support and intervention, individuals can be successfully included in everyday activities, they attend mainstream school and pass exams, gain employment and make positive contributions to their communities.

The average life expectancy for people with Down syndrome has significantly increased to 58 years, but this continues to be well below typical life-expectancy. There should be an expectation that with better awareness and inclusion, and improved health and social care, that this figure will continue to rise.

Like everyone, people who have Down syndrome have:

- their own personalities
- things they like and dislike
- things that make them who they are

### What are the medical conditions commonly associated with Down syndrome?

There are some medical conditions that are associated with Down syndrome, but they are not restricted only to people with Down syndrome.

The medical conditions and disabilities that commonly affect people with Down syndrome are:

- Learning Disability – all children have some level of learning disability
- Heart disease
- Obesity
- Leukaemia
- Stomach and bowel problems
- Alzheimer and dementia – a high proportion of people with Down syndrome will have early on-set Alzheimer or dementia.
- Hearing and sight problems



- Problems with the Immune system
- Speech and hearing problems

*It should be noted that not all people with Down syndrome will have all these medical conditions & disabilities and many children grow up to lead healthy lives.*

## UK POPULATION

The estimated number of people with Down syndrome living in the UK in 2015 was 41,511<sup>1</sup>. The Down's Syndrome Association put their estimated population at 47,000 people in the UK with the condition, so there is possibly a great variation in actual population numbers today.

Research and data collection around birth can be variable and there is room for improved data reporting. Recent papers on European and UK numbers can be found summarised here<sup>2</sup>

Region/country	Number
<b>Western Europe</b>	<b>111,304</b>
Austria	4,716
Belgium	5,646
France	35,684
Germany	47,465
Luxembourg	243
Netherlands	13,309
Switzerland	4,241
<b>Northern Europe</b>	<b>69,760</b>
Denmark	2,887
Estonia	679
Finland	4,130
Iceland	234
Ireland	6,557
Latvia	1,226
Lithuania	2,020
Norway	3,725
Sweden	6,792
United Kingdom	41,511

<b>Southern Europe</b>	<b>96,075</b>
Albania	1,729
Bosnia and Herzegovina	2,063
Croatia	2,232
Greece	5,146
Italy	38,330
Malta	423
Montenegro	440
North Macedonia	780
Portugal	6,421
Serbia + Kosovo	5,275
Slovenia	913
Spain	32,323
<b>Eastern Europe</b>	<b>139,997</b>
Belarus	5,161
Bulgaria	2,879
Czech Republic	3,299
Hungary	3,463
Poland	21,328
Republic of Moldova	2,041
Romania	8,736
Russian Federation	69,220
Slovakia	2,396
Ukraine	21,474

*Table excerpt: The estimated number of people living with Down syndrome in European countries in 2015<sup>3</sup>*

<sup>1</sup> <https://docs.downsyndromepopulation.org/factsheets/down-syndrome-population-europe-factsheet.pdf>

<sup>2</sup> Mai, C. T., Isenburg, J. L., Canfield, M. A., et al. [National population-based estimates for major birth defects, 2010–2014. Birth Defects Research. 2019; 111: 1420–1435.](https://doi.org/10.1038/s41431-020-00748-y)

[Estimation of the number of people with Down syndrome in Europe](https://doi.org/10.1038/s41431-020-00748-y) de Graaf, G., Buckley, F. & Skotko, B.G. Eur J Hum Genet 29, 402–410 (2021).

[SUPPLEMENTARY MATERIALS](https://go.downsyndromepopulation.org/europe-supplement) <https://go.downsyndromepopulation.org/europe-supplement>

<sup>3</sup> [People living with Down syndrome in Europe: BIRTHS AND POPULATION](https://doi.org/10.1038/s41431-020-00748-y) de Graaf, G., Buckley, F. & Skotko, B.G.



The lack of precise numbers and geographical distribution of people with Down syndrome impacts support and service provision in a number of vital ways:

- Planning for training for Antenatal and Postnatal care (i.e. midwives) and Health Visitors
- Planning for Early Intervention Services effectively to meet need.
- Planning for education services
- Recruitment of specialists in all areas.
- Social Services: current inability to plan appropriate housing or social care provision.
- Work: Job creation.
- Support groups planning their activities.
- Research viability, is there a big enough cohort where regionally do we find them.
- Variation in regional attitudes towards having a child with DS.



## TOPIC: HEALTHCARE

People with Down syndrome are living longer than ever before due in large part to the fact they are being brought up in families and are accessing medical procedures previously denied them. Yet they still receive poorer care than age matched individuals in the general population. Lack of understanding and low expectations of people with Down syndrome rooted within medical education has contributed to under or over-treatment of their health issues. Famously, there is a lack of speech therapy input and specialist guidance around Down syndrome, yet as the Royal College of Speech and Language Therapist tells us, speech, language and communication needs can have a direct impact on children's development and educational outcomes, health and wellbeing and if left unaddressed, they can adversely affect children across their lifespan.

It is also vital that expectant and new parents need to be provided with accurate and balanced information, and be treated with unbiased compassion when a baby may have/has Down syndrome from staff who need to be well-informed and aware of their public health equality duty. There needs to be greater awareness and accurate knowledge about life with Down syndrome in wider society if antenatal screening for DS is to continue.

The Government's vision is that people should live well and live for longer. Investment in research and focussed healthcare for people with Down syndrome will go hand in hand with increased prevention of health issues and avoidable deaths, thus increasing health and wellbeing to help make Government vision a reality for this group.

## BACKGROUND

- Currently, the healthcare journey of someone with Down syndrome from antenatal care to the timely end of life can be very variable and there is much room for standardisation and equity.
- Make the right start: the pregnancy screening programme could allow the specific health needs of this group before, during and after birth to be met in a more targeted and timely way.
- Down's Syndrome Medical Interest Group UK :*"People with Down syndrome on the whole do not have medical problems that differ from those in the general population. However some medical conditions are overrepresented. Most of these are treatable disorders which, if undiagnosed, impose an additional but preventable burden of secondary handicap"*<sup>4</sup>.

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<sup>4</sup> <https://www.dsmig.org.uk/information-resources/guidance-for-essential-medical-surveillance/>



- Poor access blocks people with Down syndrome getting the healthcare they need. These barriers include<sup>5</sup>:
  - a lack of accessible transport links
  - staff having little understanding about Down syndrome
  - lack of any toolkit to aid meaningful communications, diagnosis and true confidence in the outcome for all involved parties.
  - lack of joint working from different care providers
  - inadequate aftercare or follow-up care.
  - Diagnostic Overshadowing is common within the care of those with Down syndrome (*once a diagnosis is made of a major condition there is a tendency to attribute all other problems to that diagnosis, thereby leaving other coexisting conditions undiagnosed.*)
- Difficulties being a part of the national health screening programmes i.e., breast, colon due to the reasons above, not receiving invitations to attend, support to take part or other factors.
- Lack of consistent health screening programmes for conditions they are at increased risk of e.g., thyroid conditions, leukaemia. This leaves it to chance if a person is under a pro-active 'Down syndrome-aware' clinician or a carer who is advocating for their needs. GPs or physicians specialising in Learning disability would be a valid option.
- Referrals for screening for other neurodevelopmental conditions that people with Down syndrome may have e.g., autism, ADHD or processing disorders are not prompt or timely leading to children's needs not being fully understood, misdiagnoses and distress to the child/adult and families. I.e. labelled as challenging behaviour or 'naughty'.
- Care for adults, with their increased risk for dementia or other difficulties, need improved service provision and specialist care in place. Advances in research are opening valid avenues for early treatment for Alzheimers in Down syndrome<sup>6</sup>.

*“Greater focus is needed on the prevention and treatment of ailments that develop in middle and older age, so that increased survival can be matched by an increased quality of life.”<sup>7</sup>*

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<sup>5</sup> [Heslop et al. 2013](#); [Tuffrey-Wijnes et al. 2013](#); [Allerton and Emerson 2012](#)

<sup>6</sup> [Stagni, Fiorenza et al. "Timing of therapies for Down syndrome: the sooner, the better." Frontiers in behavioral neuroscience vol. 9 265. 6 Oct. 2015. doi:10.3389/fnbeh.2015.00265](#)

<sup>7</sup> [Bittles AH, Glasson EJ. Clinical, social, and ethical implications of changing life expectancy in Down syndrome. Developmental Medicine and Child Neurology. 2004;46\(4\):282-6](#)



## IMPACT

- Higher rates of stillbirth for babies who have Down syndrome despite pregnancy screening programmes in place<sup>8</sup>.
- Life expectancy of people with Down syndrome has been consistently climbing as healthcare has been afforded to them.
- Still shorter life spans for people with Down syndrome who die about 28 years earlier than others in the general population.
- Research spending per person with Down syndrome per year into treatments is about £5 pp<sup>9</sup>
- Healthcare professionals lacking support to help this group live their best lives.
- Higher rates of hospitalisation and length of stays for people who have Down syndrome.
- Inappropriate DNR situations for people (children and adults) with Down syndrome, simply because they have Down syndrome<sup>10 11 12 13</sup>. A sign of the bias in health care towards this group.

*“It is unacceptable for clinical decisions – decisions which could dictate whether someone’s loved one gets the right care when they need it most – to be applied in a blanket approach to any group of people.”*

Rosie Benneyworth, Chief Inspector of Primary Medical Services and Integrated Care<sup>14</sup>

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<sup>8</sup> [Muglu J, et al. Risks of stillbirth and neonatal death with advancing gestation at term: A systematic review and meta-analysis of cohort studies of 15 million pregnancies. PLoS Med. 2019;16\(7\):e1002838.](#)

<sup>9</sup> [Freedom of Information request ‘Spend on research into Down’s syndrome and titles of studies funded since 2010’](#)

<sup>10</sup> [Dyer C. Family of man with Down’s syndrome takes legal action over “do not resuscitate” order BMJ 2012; 345 :e6246 doi:10.1136/bmj.e6246](#)

<sup>11</sup> [Down’s Syndrome: Do Not Resuscitate Orders Volume 767: debated on Tuesday 15 December 2015,](#)

<sup>12</sup> [CQC finds that combination of increasing pressures and rapidly developing guidance may have contributed to inappropriate advance care decisions](#) Dec 2020

<sup>13</sup> [Down’s syndrome teenager offered do not resuscitate order](#) [Times 2021](#)

<sup>14</sup> [CQC finds that combination of increasing pressures and rapidly developing guidance may have contributed to inappropriate advance care decisions](#) Dec 2020



## EVIDENCE OF PRESENT OUTCOMES

- Better Health for All  
<https://publichealthmatters.blog.gov.uk/2018/11/05/better-health-for-all-a-new-vision-for-prevention/>
- Speech and language therapy for children with Down syndrome  
<https://library.down-syndrome.org/en-gb/news-update/02/2/speech-language-therapy-down-syndrome/>
- Survival and patterns of hospitalisation for children and young people with Down syndrome in Scotland over a 25-year period  
<https://www.sldo.ac.uk/our-research/children-and-young-peoples-health/down-syndrome-survival-and-hospitalisation-rates/>
- [The Learning Disabilities Mortality Reviews \(LeDeR\)](#) and Government responses.
- [Increased mortality during the Covid-19 pandemic of those with Learning Disabilities](#) (including those with Down syndrome)
- Early death and causes of death of people with Down syndrome<sup>15</sup>

With thanks to MENCAP [Health Inequalities reports](#)

### Legal obligations

- Article 24 (Education) of the UN Convention on the Rights of Persons with Disabilities (UNCRPD 2009) Equality Act 2010
- The Special Educational Needs and Disability Regulations (2014)
- The Children and Families Act (2014)
- Disability Discrimination Act 1995

### Existing guidelines

#### Antenatal:

- [PERSONALISED ANTENATAL CARE OF PREGNANCIES SUSPECTED OR DIAGNOSED WITH DOWN SYNDROME PATHWAY](#), 2021 St George's University Hospital NHS Foundation Trust, London

#### Children:

- [Basic Medical Surveillance Essentials for children with Down syndrome -Down's Syndrome Medical Interest Group BEST PRACTICE GUIDANCE -NEONATAL](#) (January 2018 updated Sept 2018)

<sup>15</sup> <https://pubmed.ncbi.nlm.nih.gov/29573301/>



- UK [Down's Syndrome Medical Interest Group Surveillance Guidelines:](#)
  - Cardiac disease
  - Thyroid
  - Hearing
  - Ophthalmic problems
  - The appropriate monitoring of growth.
- [PAEDIATRIC SERVICE SPECIFICATION Services for Children and Young People with Down Syndrome](#) draft The Royal College of Paediatrics and Child Health 2015
- [Nottingham Guidelines for the Management of Children with Down Syndrome](#) Nottingham University NHS Trust & Childrens Hospital 2017
- [American Academy of Pediatrics Clinical Report: Health Supervision for Children with Down Syndrome](#) Marilyn J. Bull, MD; the Committee on Genetics Pediatrics (2011) 128 (2): 393–406.

#### Children & Adult:

- [Down's Syndrome Pathway](#) - antenatal to end of life guidelines, Hull NHS Clinical Commissioning Group rev 2020
- [Care Pathway for Children and Adults with Down's syndrome Birth to adulthood.](#) University Hospitals of Leicester and Leicestershire Partnership NHS Trusts 2020
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#### Adult:

- [The GLOBAL Medical Care Guidelines for Adults with Down Syndrome](#) 2020 Global Down Syndrome Foundation
- USA Down Syndrome Medical Interest Group [Co-occurring medical conditions in adults with Down syndrome: A systematic review toward the development of health care guidelines.](#)<sup>16</sup>

## POSSIBLE OUTCOMES

- Funding promising research to improve morbidity and mortality across the lifespan of people with Down syndrome.
- Improved access to clinical trials and involvement in protocol design of trials could all lead to less reliance on hospitals services and increased life expectancy for people with Down syndrome. Covid 19 has highlighted these issues for this group.
- Centres of Excellence and better dissemination of expertise in condition specific health screening for said conditions and their treatment in people with Down syndrome e.g. hypothyroidism.
- Improved communication skills for better health and wellbeing.

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<sup>16</sup> Capone GT, et al DSMIG-USA Adult Health Care Workgroup. Co-occurring medical conditions in adults with Down syndrome: A systematic review toward the development of health care guidelines. Am J Med Genet A. 2018 Jan;176(1):116-133. doi: 10.1002/ajmg.a.38512. Epub 2017 Nov 12. PMID: 29130597.



- Professionals who have expertise in working with people with additional needs which would inform the testing, assessment and treatment to suit the individual in front of them. E.g., expertise in running sleep studies, or in the nuances of treating thyroid conditions in Down syndrome
- Informed, confident Healthcare professionals supporting patients who have Down syndrome to better health.
- With improved access to healthcare and timely identification and treatment of additional health issues people with Down syndrome can hope to live longer, fuller lives.

## POINTS FOR CONSULTATION

- Guidance for pregnant women whose baby has Down syndrome.
- Learning Disability and autism training expanded to include Down syndrome.
- Mainstream medical guidance around care and consideration of people with Down syndrome.
- Increased commitment to research for Down syndrome in line with vision for prevention of additional conditions where appropriate or early identification.
- Guidance for speech therapy intervention or further research if deemed necessary.
- Guidance and specialist annual health screening programme for Down syndrome.
- Implementation of LeDer and Government recommendations with review.

## POSSIBLE TIMELINES

- Guidance for women continuing pregnancy could be delivered in months.
- Expansion of Learning Disability Training could be delivered in months
- Specialist Health screening programmes could be delivered within 3 years.
- Guidance for health issue prevention and speech therapy for Down syndrome within 2 or 3 years.
- By 2030 in line with Millennium Goals for health.



## TOPIC: EDUCATION

Over 25 years of Educational research on differences in how children (and adults) with DS learn has now been amassed. We can now confidently describe the way that education needs to be adapted to optimise the outcomes for children and young people.

However, education professionals in all settings do not routinely receive the specialist training they need to give them a thorough understanding of the specific learning profile associated with Down syndrome (DS) and the best educational practice which would enable them to successfully include young people with Down syndrome and meet their global needs.

We estimate the number of children aged 4-18 at school in the UK with DS at any one time is approximately 10,000<sup>17</sup> <sup>18</sup>.

## BACKGROUND

- Legacy of historic exclusion of people with DS from the education system/mainstream education.
- No modules about Down syndrome are routinely taught as part of teaching/PGCE courses, with limited modules about Special Educational Needs and Disabilities (SEND) in general, no government led, evidence-based guidelines.
- Lack of knowledge/out-dated views in society about Down syndrome/institutional direct and indirect discrimination.
- Ignorance surrounding the specific learning profile, visual/kinaesthetic/multi-sensory educational strategies and the speech, language and communication profile. A recent paper by Dr Burgoyne summarises the need for SALT in people with DS<sup>19</sup>.
- Limited specialist training about DS, schools unwilling to undertake and implement training.
- The term 'specialist' training is open to interpretation and misrepresentation.
- Schools rely on support from special schools who are often not specialists in DS and who are not specialists in mainstream inclusion.
- School budget restrictions: training overlooked for staff working with pupils with DS.
- Lack of clarity surrounding differentiation of the curriculum and lessons.

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<sup>17</sup> Gert de Graaf, Frank Buckley, Brian G. Skotko - *European Journal of Human Genetics* (2021) 29:402–410 Estimation of the number of people with Down syndrome in Europe ([nature.com](https://doi.org/10.1038/s41431-021-00400-0)) Department for Education

<sup>18</sup> <https://explore-education-statistics.service.gov.uk/find-statistics/school-pupils-and-their-characteristics> (June 2020)

<sup>19</sup> [Down's syndrome: language development and intervention](#) 2020, Dr Kelly Burgoyne, Royal College of Speech and Language Therapists Bulletin



- Absence of government led, centrally produced, evidence-based guidance for practitioners on Down syndrome.
- Restricted educational and health resources, and provision Eg. Speech and Language Therapy (SALT), Occupational Therapy.
- Bureaucratic and budget driven approach to Education and Health Care Plans (EHCPs).
- Inconsistent support/ ineffective deployment of additional support, including Learning Support Assistants (LSAs).
- Learning Support Assistants lacking in relevant skills and experience.
- Teaching staff are overly dependent on LSAs to differentiate and deliver the curriculum.
- Individuals with DS are not recognised as a 'unique group' so numbers are estimated
- Numbers of pupils with DS are not specified in the school census.
- Issues surrounding attitudes to inclusive practice and ethos particularly at secondary level.
- Social isolation. Unwillingness particularly at senior level to scaffold friendships and set up buddy initiatives.
- Unwillingness to make reasonable adjustments.
- Lack of knowledge behaviour management and the strong relationship between behaviour and communication challenges.
- Unfamiliarity of access arrangements for public exams/suitable exam boards.
- Pupils removed from lessons deemed too difficult or inappropriate eg. Relationship and Sexuality Education.
- Lack of Specialist transition support, including opportunities for work experience.

## IMPACT AND EVIDENCE

Inappropriate educational approaches have a negative impact on pupils in all areas of social and educational development and achievement, speech and language development, frustration, confidence, relationships, friendships, isolation, independence, wellbeing/mental health, qualifications and work experience – the negative stereotype is perpetuated.

This could result in possible behavioural issues (communication issues – behaviour used as a form of communication, lack of provision/resources/knowledge) particularly around times of transition. It should be noted that behavioural issues do not automatically arise from having Down syndrome.



## ***Evidentiary Summary Document to support the formation of the Down Syndrome Bill (ver.1)***

Staff feel frustrated and can question the appropriateness of inclusion if there is not adequate provision. Belief that inclusion = negative outcome.

Inclusion rates vary from region to region. The majority of children with DS (estimated 80%) are included in mainstream primary. This falls significantly at secondary level where it is estimated only 25% of pupils with DS transition to mainstream secondary schools<sup>20 21 22</sup>.

There is a cost advantage to mainstream for local authorities (combined with better outcomes for the student, their peers and inclusion as a whole) but each placement should be based on the specific needs of the individual pupil/parent choice rather than budget driven decisions.

The average annual cost to a council of a SEND placement in 2017/18, was £6,000 per pupil per year in a mainstream school, compared with £23,000 per pupil per year in a maintained special school, and £40,000 per pupil per year in an independent or non-maintained special school<sup>23</sup>. Local authorities are unable to effectively budget, plan and allocate provision and resources if they do not know specific numbers Eg. SALT provision

Studies clearly demonstrate that there are distinct academic advantages to inclusive education for pupils with Down syndrome who work at a significantly higher academic level in all areas of the curriculum than their peers in special schools, particularly language (2.5 years) and literacy (3.3 years), with still greater gains in social development, behaviour and speech<sup>24</sup>.

Furthermore, studies show the more delayed children with Down syndrome still benefit from mainstream inclusion. They outperform the more able pupils in special educational settings<sup>25 26</sup>.

Research proves that specialist interventions improve outcomes<sup>27 28 29 30</sup>.

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<sup>20</sup> S. Lorenz: *Making Inclusion Work for Children with Down Syndrome* (1999) <https://assets.cdn.down-syndrome.org/pubs/a/practice-149.pdf>

<sup>21</sup> Dr K. Burgoyne, R. Baxter: *Educational Experiences of Pupils with Down syndrome in the UK* (2020) Publication due 2021

<sup>22</sup> Cuckle, P. (1997). *The school placement of pupils with Down syndrome in England and Wales*. *British Journal of Special Education*, 24(4), 175-179.

<sup>23</sup> (LGA Special Educational Needs and Disability Funding, House of Commons, Jan 2020)

<https://www.local.gov.uk/sites/default/files/documents/29012020%20LGA%20briefing%20-%20SEN%20support-WEB.pdf>

<sup>24</sup> Buckley, S., Bird, G., Sacks, B. and 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. doi:10.3104/reports.295

<sup>25</sup> G de Graf, E de Graf: *Development of Self-Help, Language and Academic Skills in Persons with Down Syndrome* (June 2016)

<sup>26</sup> G. Graaf, G. Van Hove, M. Haveman: *Effects of Regular V Special School on Students with Down Syndrome: A systematic review of studies* (2012)

<sup>27</sup> Burgoyne, K., Duff, F. J., Clarke, P. J., Buckley, S., Snowling, M. J., & Hulme, C. *Reading and Language Intervention* (2012)

<sup>28</sup> Bird, G. & Buckley, S. (2001). *Number skills for individuals with Down syndrome – an overview*. Portsmouth, UK: Down Syndrome Education International.

<sup>29</sup> Wing T, Tacon R. *Teaching number skills and concepts with Numicon materials*. *Down Syndrome Research and Practice*. 2007;12(1);22-26.

<sup>30</sup> Buckley, S. & Bird, G. (2000). *Education for individuals with Down syndrome - An overview*.



LSAs will also need speech and language training as they will be required to regularly deliver the pupil's speech and language programme throughout the pupil's education<sup>31</sup>.

There is a disproportionate use of sanctions and exclusions.

Students with DS are consistently denied meaningful Further Education, both for continuing skills development and for work experience.

Opportunities to attend university are severely limited.

Extremely low employment rate for individuals with Down syndrome. No figures available for Down syndrome specifically but 5.6% of adults (18-64) with a learning disability in England were in paid employment in 2019-20<sup>32</sup> with only 4.2% in Scotland.

Learning disability training was made mandatory in the health sector in 2019 and had a positive reception<sup>33</sup>.

#### Legal obligations

- Article 24 (Education) of the UN Convention on the Rights of Persons with Disabilities (UNCRPD 2009) Equality Act 2010
- Education Act 2011
- The Special Educational Needs and Disability Regulations (2014)
- The Children and Families Act (2014)
- Disability Discrimination Act 1995

#### Existing guidelines

- SEND code of practice (guidance): 0 to 25 years Dept of Education (2014)
- [APPGDS Education Guidelines 2012](#)
- [Educational Guidelines for the Education of Learners with Down Syndrome \(Down Syndrome International \(2020\)\)](#)

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<sup>31</sup>Buckley, S, and Le Prèvest, P. (2002) [Speech and language therapy for children with Down syndrome. Down Syndrome News and Update, 2\(2\), 70-76. doi:10.3104/practice.171](#)

<sup>32</sup> [British Association of Supported Employment](#) and [SCLD](#) 2018

<sup>33</sup> [https://www.ndti.org.uk/assets/files/HEE\\_report\\_summary\\_18th\\_May\\_Final\\_v2\\_2020-08-06-143959.pdf](https://www.ndti.org.uk/assets/files/HEE_report_summary_18th_May_Final_v2_2020-08-06-143959.pdf)



## OUTCOMES

- Update APPGDS Education Guidelines as priority; government led, centrally produced evidence based.
- Children with DS should be recognised as a unique group (like autistic children, deaf children) so specific data is available to inform policy, funding and provision.
- School census to include numbers of pupils with Down syndrome.
- Down syndrome identified as separate classification on EHCP.
- Better outcomes and achievements in all areas for pupils, school and staff. Wider recognition that inclusion can and does work with the right provision, mainstream becoming the norm.
- Where pupils with DS are included, there should be mandatory specialist training for staff in mainstream and special school setting, and for the whole school community delivered by specialists in Down syndrome (mandatory learning disability training in the NHS).
- Definition of what constitutes a ‘specialist’
- Training prior to child starting school or at the beginning of term followed by annual training for staff and school community.
- Research surveys to fill gaps in information and provide up to date, relevant data eg. numbers of children with DS included in mainstream at primary and secondary level.
- Training should include a general overview, positive terminology, inclusion and legislation, the specific learning profile and research based educational strategies to meet specific needs including visual and kinaesthetic strategies and whole word approach to reading alongside phonics, the language and communication profile associated with DS, exam pathways, access arrangements and alternative methods of recording and assessing, age-appropriate topics such as RSE, behaviour management and sanctions, effective differentiation, resources, and effective deployment of additional support including Teaching Assistants.
- Training should be relevant to all age settings eg. Early years, primary etc. Down syndrome specific training to be included in relevant teaching/university courses.



## POINTS FOR CONSULTATION

- Consultation with families, school staff, DS specialists, Down Syndrome Policy Group, local authorities, APPGDS, Dept of Education.
- Research surveys required to fill gaps in information and provide up to date data including numbers in special school/mainstream, gender, staff attitudes and knowledge, access to support and training.
- Create guidelines for training. Identify resources required for effective delivery.
- DfE approves and publishes guidelines and recommends implementation – widely circulated to all educational settings.
- PR and awareness campaign nationally and in groups, schools etc.
- Feedback from implementation and criteria for success, monitoring
- Campaign for guidelines to be made legislation and adopted as best practice throughout the UK.
- Training forms part of larger and more comprehensive Education Guidelines/Policy for Pupils with DS; government led, centrally produced and evidence based.

## POSSIBLE TIMELINE

Immediate implementation of training guidelines approved and published by the Dept for Education recommending specialist training in all educational settings where a child with Down syndrome is included, ahead of legislation being passed for this to become mandatory training.



## TOPIC: SOCIAL CARE

There are an estimated 40,000+ people living with Down syndrome (DS) in the UK. Better health and social care have greatly improved life expectancy. However, people with DS die earlier than others even within the group of those with Learning Disability and for reasons we do not know. Throughout their lives there are low expectations for this group for whom social care has to become social empowerment. Parents are challenged by low expectations within society.

We must also acknowledge the research gaps that exist, particularly across the later years of the lives of people with DS and their family. How can they best take part in and enrich the society they live in as they also face unique challenges in their employment, health and relationships?

## BACKGROUND

- Individuals with DS are not recognised as a ‘unique group’ so population data isn’t available. We don’t know which local authority people with DS live in, and how needs are being met within that.
- Educational context of poorer educational outcomes and segregated childhoods.
- Lack of knowledge about what people with Down syndrome can do or be taught to do.
- Expectations that adults will not become independent particularly where there are additional diagnoses/‘co-morbidities’.
- Social work resources are scarce and professionals don’t undergo training around how people with DS are impacted by the condition and how they can be more empowered.
- Current mediation/redress services place undue pressure on families/carers.
- Parents/carers often consulted around next steps are steered towards what has historically happened for people with DS and therefore adults with DS aren’t meaningfully engaged in the process. They require a person-centred approach.
- Social workers require training to:
  - understand how living with DS impact lives
  - develop a thorough understanding of the specific issues
  - learn how to best communicate with people with DS
  - have knowledge of the best practices which would ensure good health and wellbeing for those children and adults with DS.



- No specialist modules about DS are routinely provided to Social Worker professionals.
- Lack of knowledge of the specific benefits of inclusion and the negative effects of social isolation.
- Lack of knowledge of the specific learning profile and the speech and language and communication profile.
- Restricted health resources and provision E.g., Speech and Language Therapy (SALT), Occupational Therapy.
- Often a bureaucratic and budget driven approach to Social Care.
- Lack of professional knowledge about the strong relationship between behaviour and communication challenges.
- Greatly increased risk of developing early onset dementia akin to Alzheimer's disease, we don't yet understand why this occurs, social circumstance could be contributory.
- People with DS and dementia may be defined by these factors rather than their individual needs.
- There is no clear Social Care pathway for people with DS.
- Lack of suitable accommodation for adults.
- Lack of suitable placement and support for those with early onset dementia i.e. Often people who develop dementia are then placed in elderly care facilities in their 40s or 50s.

## IMPACT AND EVIDENCE

Local authorities are unable to effectively budget, plan and allocate provision and resources if they do not know specifics. UK Population estimates are now effectively out of date.

Early death and causes of death of people with Down syndrome: A systematic review  
<https://pubmed.ncbi.nlm.nih.gov/29573301/>

Existing regional care pathways for Down's syndrome could shape national care pathway  
<https://www.leicspart.nhs.uk/wp-content/uploads/2020/02/LPT-Combined-care-pathway-for-DS.pdf>

Lack of socialisation, stimulation and employment has a detrimental effect in areas of social and personal development and responsibility, communication, confidence, relationships, friendships, independence, wellbeing/mental health. Person-centred planning is key  
<https://www.unitedresponse.org.uk/resource/person-centred-support/>



Lack of opportunity for meaningful Further Education, both for continuing skills and personal development and for work experience.

Extremely low employment rate for individuals with DS. No figures available for DS specifically but 5.6% of adults (18-64) with a learning disability in England were in paid employment in 2019-20 (British Association of Supported Employment) with only 4.2% in Scotland (SCLD 2018)

Possible behavioural issues (communication issues – behaviour used as a form of communication). It should be noted that behavioural issues do not automatically arise from having DS however this may feed the notion that professionals must manage a situation instead of changing the situation.

<https://bmcp psychiatry.biomedcentral.com/articles/10.1186/s12888-014-0266-z>

As things stand, adults with DS may be more prone to depression. Down syndrome and dementia: is depression a confounder for accurate diagnosis and treatment?<sup>34</sup>

There is a disproportionate use of detention in institutions. Assessment of mental health problems in people with Down syndrome: key considerations<sup>35</sup>.

Supported housing for people with Down syndrome<sup>36</sup> *“There had been a mean of 2 years delay between application and securing accommodation. The large number of people providing care at home who wished their family-member to move into supported living suggests that there is a large unmet need for this type of accommodation.”*

There is a cost advantage for local authorities who invest in support to avert future crises e.g., elderly carers becoming unfit.

Learning disability training was made mandatory in the health sector in 2019<sup>37</sup>

#### Legal obligations

- Mental Health Act (1983)
- Health and Social Care Act 2008
- Article 24 (Education) of the UN Convention on the Rights of Persons with Disabilities (UNCRPD 2009) Equality Act 2010
- Mental Health Act 1983

<sup>34</sup><https://www.scie-socialcareonline.org.uk/down-syndrome-and-dementia-is-depression-a-confounder-for-accurate-diagnosis-and-treatment/r/a1CG0000003ZML5MAO>

<sup>35</sup><https://www.scie-socialcareonline.org.uk/assessment-of-mental-health-problems-in-people-with-down-syndrome-key-considerations/r/a1CG0000000GO35MAG>

<sup>36</sup><https://www.scie-socialcareonline.org.uk/supported-housing-for-people-with-downs-syndrome/r/a1CG0000003YkfdMAS>

<sup>37</sup> [https://www.ndti.org.uk/assets/files/HEE\\_report\\_summary\\_18th\\_May\\_Final\\_v2\\_2020-08-06-143959.pdf](https://www.ndti.org.uk/assets/files/HEE_report_summary_18th_May_Final_v2_2020-08-06-143959.pdf)



## ***Evidentiary Summary Document to support the formation of the Down Syndrome Bill (ver.1)***

- The Special Educational Needs and Disability Regulations (2014)
- The Children and Families Act (2014)
- Disability Discrimination Act 1995
- Equality Act 2010
- Care Act 2014

Existing guidelines

Health and Social Care Act 2012: fact sheets

<https://www.gov.uk/government/publications/health-and-social-care-act-2012-fact-sheets>

Build Back Better: Our Plan for Health and Social Care

<https://www.gov.uk/government/publications/build-back-better-our-plan-for-health-and-social-care/build-back-better-our-plan-for-health-and-social-care>

## **OUTCOMES/POSSIBLE OUTCOMES**

- Better understanding of the needs and of the benefits of societal inclusion, resulting in targeted services and improved health and wellbeing outcomes.
- Emphasis on the concept of lifelong learning where learning may be delayed.
- Improved access to Needs Assessment and follow-up.
- Improved mediation services.
- National census.
- National Social Care Pathway.
- Early support for those with DS and Alzheimer's and their carers.  
Better outcomes and achievements in all areas.
- Mandatory specialist training for professionals.
- Research surveys to fill gaps in information and provide up to date, relevant data around life outcomes.
- Professionals reverting to DS charities for support.

## **POINTS FOR CONSULTATION**

- Data collated to include local authority and employment status.
- Research surveys required to fill gaps in information and provide up to date data including outcomes for adults with DS and service provision.
- Expanded Oliver McGowan Mandatory Training in Learning Disability and Autism to include understanding of how living with DS can impact lives, providing a thorough understanding of specific issues.
- Develop a National Social Care Pathway.



- Training forms part of larger and more comprehensive Guidance for social care workers.
- Improved redress.
- Impose duties on local authorities to better respond to needs.

## POSSIBLE TIMELINE

- Data collated to include local authority and employment status.
- Research surveys required to fill gaps in information and provide up to date data including outcomes for adults with DS and service provision.
- Expanded [Oliver McGowan Mandatory Training in Learning Disability and Autism](#) to include understanding of how living with DS can impact lives, providing a thorough understanding of specific issues.
- Develop a National Social Care Pathway.
- Training forms part of larger and more comprehensive Guidance for social care workers.
- Improved redress.
- Impose duties on local authorities to better respond to needs.

*“The increasingly long life span in Down syndrome is among the most important of all advances in the field of developmental disabilities. And yet, while such a change is worthy of celebration, increasing life spans bring about a need to understand many aspects and components....*

*Beyond the individuals themselves, we need to understand co-occurring changes in their parents, the group that—in many cases—continues to provide day-to-day care within the family home. So too do we need to pay attention to the adult siblings who often take on care once parents can no longer do so.*

*Yet just as increasing longevity fosters research interest and leads to policy implications, so too do we need to connect longer lives to the adult’s surrounding environments. From transition and early adulthood, to later aging while living with aging parents, adulthood in Down syndrome features certain aspects that are similar to—and others that differ from—adulthood among others with intellectual disability.*

*It is time to fill in the many gaps in our knowledge, thereby helping these individuals and their families to experience more connected, fulfilled lives.”*

From Transition Through Old Age: Caring for Adults With Down Syndrome Robert M. Hodapp, Kelli A. Sanderson, and Maria Mello



## TOPIC: EMPLOYMENT

There is a limited expectation for people with Down syndrome (DS) to be in employment and as a result individual are being denied the opportunity to earn a regular salary, have a sense of identity, be challenged, learn new skills, meet new people, understand the world better, enhance their sense of meaning and purpose, make a positive contribution to their communities; in short be a full participant in adult life.

Young adults with Down syndrome who work in open employment have higher levels of overall functioning, particularly in the areas of self-care, community, and communication skills<sup>38</sup> and fewer behaviour problems<sup>39</sup>.

## BACKGROUND

- Poor educational outcomes.
- Segregated childhoods.
- Lack of knowledge about what people with Down syndrome can do or be taught to do.
- Very limited work experience opportunities to allow someone with Down syndrome to find a role they are suited to and enjoy.
- No structured work experience opportunities offered by schools or specialist apprenticeship positions.
- Major barriers to further education.
- Historic failure by authorities to break down the barriers to employment for people with DS, and a denial of their human right to work.
- Government employment schemes are not sensitive to the needs of people with learning disabilities compared to physical disabilities.
- Lack of specialist training and support to ensure that a job placement is accessible to people with Down syndrome.
- The legacy of historically low life expectancy has created an environment where there was no consideration to make the job market accessible for people with Down syndrome.
- Fear by employers of being accused of discriminatory behaviour if they have to fire someone if the employment doesn't work out.
- Too many employers think they are 'doing a favour' by hiring someone with Down syndrome, rather than wanting to embrace diversity and bring in a new customer

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<sup>38</sup> [Foley, K.-R., Jacoby, P., Girdler, S., Bourke, J., Pikora, T., Lennox, N., ... Leonard, H. \(2012\). Functioning and post-school transition outcomes for young people with Down syndrome. \*Child: Care, Health, and Development\*. 39, 789–800.](#)

<sup>39</sup> [Foley, K.-R., et al. \(2014\). Day occupation is associated with psychopathology for adolescents and young adults with Down syndrome. \*BMC Psychiatry\*. 14, no. 266.](#)



base and an additional mix to their staff base, so they don't spend enough time looking to make the employment a success.

- Recruiters have an unconscious bias towards people with a learning disability.
- No job fluidity for employees, so little chance to practise interview skills, deal with rejection.
- Lack of meaningful work opportunities.
- Limited opportunities for career development if in employment.
- Fear of losing benefits or falling out of the benefit system and then not having enough money to access the necessary support – this fear is held by the individuals, their families, social workers, and advisors.
- Time spent reapplying for benefits and waiting times for processing benefits.
- Assumption individuals with DS are looking for work, but a person with DS is likely to need support to apply for and find work.
- Abuse of system - some organisations employ/train people with LD for short-fixed terms to tick boxes, with no long term offer of permanent work, some people with DS pay their employer for the privilege of working, some feel that the only option is unpaid volunteer work.
- No specific employment data exists for people with Down syndrome.
- Employers are not getting themselves 'skilled up' on what people with Down syndrome can do, and so no jobs are being created.
- When promoting disability diversity, there is a bias towards learning disabilities in favour of physical disabilities.
- Limited flexibility eg. part-time, flexi-hours, job-share
- Some employers may fear the extra time and costs associated with hiring someone with a learning disability eg. sick leave, hospital appointments, specialist resources, making spaces accessible, review of safety procedures

## IMPACT AND EVIDENCE

- 5.6% of adults (18-64) with a learning disability in England were in paid employment in 2019-2020 (source British Association of Supported Employment)<sup>40</sup>.
- Only 417 employment opportunities for people with Down syndrome created by the DSA since 2011.
- 6% of adults with a learning disability known to their LA in England are in paid employment<sup>41</sup>. 4.2% in Scotland<sup>42</sup>.
- 52% of people aged 16-64 with any disability in UK are in paid work<sup>43</sup>.

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<sup>40</sup> Source Mencap – Employment – research and statistics

<https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/employment-research-and-statistics>

<sup>41</sup> source NHS Digital 2018

<sup>42</sup> SCLD 2018

<sup>43</sup> Source ONS 2019a, source ONS 2019b



- 76% of 16-64 of general population in England are in paid work<sup>44</sup>.
- No employment trainers/coaches who have Down syndrome
- The United Nations Convention on the Rights of Persons with Disabilities said that people with a learning disability have a fundamental right to full and active participation and inclusion in society<sup>45</sup>.

#### Legal obligations

- Article 24 (Education) of the UN Convention on the Rights of Persons with Disabilities (UNCRPD 2009) Equality Act 2010
- Education Act 2011
- The Special Educational Needs and Disability Regulations (2014)
- The Children and Families Act (2014)
- Disability Discrimination Act 1995

## OUTCOMES

- A detailed specialist support package put into place to create work experience opportunities for schools to access – this has to include mainstream employers – the government could take the lead on this.
- FE colleges to develop strong partnerships with employers
- Specialist training of employers to fully support their employee and ensure their work-place and job is accessible – understanding the learning profile and providing resources
- A register of companies promoting diversity who offer work experience, internships and permanent jobs for people with Down syndrome.
- An obligation on large employers to review their workforce and see what jobs could be offered to people with Down syndrome.
- A simplification of the benefits system for people with Down syndrome – for example, no benefits change for those earning less than £20,000 pa
- A better understanding of the value of the ‘disability pound’ by government and employers
- Better universal outcomes for individuals and community: increased financial and social independence, improved confidence and skills, social opportunities, positive contribution to their community, wellbeing and mental health, breakdown in inclusion barriers

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<sup>44</sup> Source ONS 2019a, source ONS 2019b

<sup>45</sup> Source - United Nations, 2006

<https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/stigma-and-discrimination-research-and>



- Source Gov.uk - Get support in work if you have a disability or health condition (Access to Work) <https://www.gov.uk/access-to-work>

## POINTS FOR CONSULTATION

- Consultation with specialist organisations, employers, DWP, DfE, to create a register of employers and a network of support and training organisation.
- Consultation with DWP and HMRC to provide simplification of benefits to avoid over dependency on social workers and third parties by people with Down syndrome. All benefits could be processed through payroll.
- Centralise support for employers through the National Down Syndrome Policy Group to support placements and individuals and identify persistent issues.
- Create a register of people with Down syndrome and find out more about the types of jobs they would like to do.
- Run a PR and awareness campaign to promote the opportunities and to promote people with Down syndrome.

## TIMELINE

Immediately set up the consultation processes and identify willing employers and job roles for dissemination within the DS community.

Coordinate a census of people with Down syndrome across the lifespan to understand need and plan services and implementation in governmental and third sector groups.



## APPENDIX 1 HEALTHCARE REFERENCES

### Summary Publications

#### Books

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Mac Keith Press [ISBN: 9781909962477](#) 2015

[Mental Wellness in Adults with Down Syndrome: A Guide to Emotional and Behavioral Strengths and Challenges](#) Dennis McGuire, Ph.D. & Brian Chicoine, M.D.isbn

978-1-60613-285-2 / 2021

[The Oxford Handbook of Down Syndrome and Development](#) 2020 (in progress)

Edited by: Jacob A. Burack, Jamie O. Edgin, and Leonard Abbeduto ISBN: 9780190645441

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### Existing Guidelines

#### Antenatal:

- [PERSONALISED ANTENATAL CARE OF PREGNANCIES SUSPECTED OR DIAGNOSED WITH DOWN SYNDROME PATHWAY](#), 2021 St George's University Hospital NHS Foundation Trust, London



Children:

- [Basic Medical Surveillance Essentials for children with Down syndrome -Down's Syndrome Medical Interest Group BEST PRACTICE GUIDANCE -NEONATAL](#) (January 2018 updated Sept 2018)
- UK [Down's Syndrome Medical Interest Group Surveillance Guidelines:](#)
  - Cardiac disease
  - Thyroid
  - Hearing
  - Ophthalmic problems
  - The appropriate monitoring of growth.
- [PAEDIATRIC SERVICE SPECIFICATION Services for Children and Young People with Down Syndrome](#) draft The Royal College of Paediatrics and Child Health 2015
- [Nottingham Guidelines for the Management of Children with Down Syndrome](#) Nottingham University NHS Trust & Childrens Hospital 2017
- [American Academy of Pediatrics Clinical Report: Health Supervision for Children with Down Syndrome](#) Marilyn J. Bull, MD; the Committee on Genetics Pediatrics (2011) 128 (2): 393–406.

Children & Adult:

- [Down's Syndrome Pathway](#) - antenatal to end of life guidelines, Hull NHS Clinical Commissioning Group rev 2020
- [Care Pathway for Children and Adults with Down's syndrome Birth to adulthood](#), University Hospitals of Leicester and Leicestershire Partnership NHS Trusts 2020
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Adult:

- [The GLOBAL Medical Care Guidelines for Adults with Down Syndrome](#) 2020 Global Down Syndrome Foundation
- USA Down Syndrome Medical Interest Group [Co-occurring medical conditions in adults with Down syndrome: A systematic review toward the development of health care guidelines.](#)

Self Advocacy and Voices of the Community

**What a patient with a learning disability would like you to know**

BMJ 2016; 355 doi: <https://doi.org/10.1136/bmj.i5296> (Published 05 October 2016)Cite this as: BMJ 2016;355:i5296v

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Virji-Babul N, et al [Use of health care guidelines in patients with Down syndrome by family physicians across Canada](#). Paediatr Child Health. 2007 Mar;12(3):179-83. PMID: 19030356; PMCID: PMC2528699.

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**Sleep- see Healthcare appendix**

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# APPENDIX 3 SOCIAL CARE

## Books



[From Transition Through Old Age: Caring for Adults With Down Syndrome](#) Robert M. Hodapp, et al. in *The Oxford Handbook of Down Syndrome and Development* Dec 2020

[The Oxford Handbook of Down Syndrome and Development](#) 2020 (in progress)  
Edited by: Jacob A. Burack, Jamie O. Edgin, and Leonard Abbeduto ISBN: 9780190645441  
DOI: 10.1093/oxfordhb/9780190645441.001.0001

## Family Systems

**Families of children with Down syndrome: What we know and what we need to know.** Cuskelly, M., Hauser-Cram, P., & Van Riper, M. (2009). *Down Syndrome Research and Practice*, 12, 105-113. <http://www.down-syndrome.org/reviews/2079/?page=1>

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## APPENDIX 4 EMPLOYMENT

Mencap – Employment – research and statistics

<https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/employment-research-and-statistics>

[Down's Syndrome Association WorkFit Programme](#)

[British Association of Supported Employment](#)

[SCLD 2018](#)

[How to Support People with Down Syndrome in the Workplace, 2021 Careers with Disabilities](#)

Down Syndrome Australia has a suite of resources

[https://www.downsyndrome.org.au/resources/employment/Down syndrome in the workplace,](https://www.downsyndrome.org.au/resources/employment/Down%20syndrome%20in%20the%20workplace)

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## APPENDIX BACKGROUND FACTS AND FIGURES

### POPULATION DATA

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See last table on this summary doc. for population

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