

Valuing People with Down's Syndrome - The Toolkit

Welcome

We are delighted that you are interested in exploring how best to equip your church or school to welcome and care for people with Down's syndrome, encouraging their participation in your community. While we hope that this Toolkit is a good starting place, it is only a beginning; there is nothing like committed ongoing relationships to accelerate learning.

People with Down's syndrome are different from one another, just as all people are. The most important thing we can do, therefore, is to get to know every individual as a person; this goes for family and carers as well. It is our privilege to support them in establishing real relationships within the church and in participating in school life. Once we really get to know those with Down's syndrome in our congregations and schools all the issues around inclusion and support follow naturally; we will be thinking about them and their needs as valued members of our communities.

We hope that this toolkit will help us all to achieve the goals of welcome, participation and celebration of people with Down's syndrome.

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A Word on Terminology

It can sometimes be difficult to know which words and phrases to use and which to avoid in talking with or discussing the aspirations and needs of people with Down's syndrome. Below are a few common examples of ways in which we can change the way we talk which we hope will be helpful.

Things not to say	Preferred terminology
Risk of having a child with Down's syndrome	Chance/probability
Abnormality/problem/disorder/disease	Difference/variation/condition
Good/bad/difficult news	Expected/unexpected or different news
Normal	Typical/typical development
Suffer	Have/living with
A Down's syndrome person	A person with/who has Down's syndrome
Mental handicap	Learning disability/difficulty
Diagnose	Identify
Severely disabled	Complex needs

Throughout this toolkit we refer to 'a child or person with Down's syndrome', not 'a Down's syndrome child or person'. This is preferable as it demonstrates to all, and especially those with Down's syndrome or their parents/carers that we understand that the person is a person first, last and always and as such is equally valued with all other persons in our communities.

'Down syndrome' or 'Down's syndrome'? There is some discussion about which term better reflects John Langdon Down's identification of the condition. In practice, in the UK the term most commonly used is 'Down's syndrome' In the rest of the world and in most current

research, however, 'Down syndrome' is preferred. In this toolkit we employ the UK usage throughout.

Finally, we can get too worried about using the 'right' language at times. It is the spirit in which the words are said rather than the actual words we use that matters most. If we are unsure, we can always just ask!

A Theological Reflection

(This toolkit is intended for use primarily by churches and church schools; it is important that we take time to reflect on our faith as central to our engagement with one another)

If we are to dispel any notion that people with Down's Syndrome are in some way deficient, let alone unworthy of the gift of life, as our culture seems to increasingly be assuming, we must go back to the question; what does it mean to be a person? In Christian theology, one way of doing this is to use the Biblical idea that humanity is made in the image of God. All people, whoever they are, reflect in some way, the person of God. Yet that God is also relational, a Trinity of three persons in one. Father, Son and Holy Spirit. How do we reflect that God?

The story of the creation of humanity in Genesis shows us that human identity was incomplete when one individual was made, as that individual could not reflect God as three persons in relationship. It was only when man and woman were made in relationship that the image of God emerged. So, to be made in the image of God is not only personal but it is also relational. It is in us but it is also between us. In the story of the man and the woman, they were the same in that they were human, but they were different in that they were man and woman. They had different stories.

This leads to two basic attitudes which lie at the heart of all human relationships. The first is *recognition* of our common humanity and the second is *respect* for difference. These two attitudes lie at the heart of any Christian approach to Down's Syndrome. We are called to recognise each other's common humanity. On this is based the dignity we owe each other and the human rights each of us deserves by virtue of being human. There is no sense of relationship without it, no sense of community or welcome. Behind the glittering promises of our consumer society, there is a brooding acceptance that people themselves may have a limited value if they add little to society or need to draw on its resources to flourish. Such an erosion of human value diminishes us all.

Lack of respect for the stories of others also contributes to this malaise. We all have different stories but so often we limit the class of people who we count worthy to associate with, and listen to. With the speed of society hurrying us on, we think we must pick and choose. It seems unlikely to us that listening to someone with Down's Syndrome will add much to our lives. Yet

this is exactly what needs to happen. Society, with its stress, speed and consumerism is stripping away our humanity. We need to slow down and respect those very different from ourselves. Jesus himself, associated with an enormous range of people who felt that he heard them, as well as loving them.

Theologian, Thomas Reynolds says that it is basic to all human nature that we are *vulnerable* and *interdependent*. We are vulnerable because we are embodied and our bodies are fragile. At any point, we can find that we move from celebrity status and on the front pages of the newspapers, to being forgotten in a stroke ward. Because of this, we are interdependent. We need each other. These two elements are not the characteristics of particular individuals. They are the building blocks of what it means to be human. People with Down's Syndrome have much to tell us, about what it means to be human. They are a sign placed in our society to show us that there is another way of living.

The idea of the image of God is an extraordinarily high view of what it means to be human. We are not a chance collection of atoms but have been made with meaning and purpose. It is a statement. But it is also an invitation. Because we are all made in the image of a relational God, we are invited to look for that image in others. People with Down's syndrome may not always express themselves in the same way as us, however we should pay careful attention to what they are communicating to us simply by their very existence. We must be open to their challenge to our status quo, and be willing to examine and re-evaluate our assumptions about what it means to value others.

A senior church leader wanted to do some research on inclusion. She went to many kinds of communities but then said, 'they were all very interesting, but only one was revolutionary. I went to L'Arche, the Christian community for people with severe learning disabilities. They didn't want to know about what I'd written, preached or what committees I was on. All they wanted to know was whether I loved them. I was stripped back to the bare bones. I didn't need to pretend because they weren't interested. I was forced to come to terms with what it meant to be me. In the end, I felt liberated by their love.'

Our culture focuses on Down's Syndrome as a disability. But given the paucity of relationships in our world, people with Down's Syndrome offer us a way of being that challenges us to rediscover the nature of welcome, the beauty of difference and respect for the stories of those

who are most often overlooked. As it so often does, Christianity asks us to love others for their sake and not for ours. We receive each other as gifts from God and we are thankful that we have been privileged to enter relationship with them.

We must learn a completely new way of living. Even in our relationship with God we often relate to God because of what we think he can do for us, not for God himself. If we can come to terms with that then we can see that if we believe that we are made in the image of God we must relate to each other in the same way. If we approve of people because of what they can do for us, or despise people because of what they can't do, then we distort the divine image. But if we welcome people just because they are, then we have understood something profound about what it means to be human. As we appreciate people with Down's syndrome as they are, made in God's image, and explore their story, we will learn to understand the beauty of difference.

Parents and carers of people living with Downs Syndrome are only too aware of the difficulties and stresses which they live with every day. It is easy for those wishing to diminish the necessity of relating to people with Downs syndrome by sentimentalizing or even infantilizing them. Of course, there is much joy to be had to being with or bringing up a person with Down's syndrome but there can also be heartache, exhaustion and frustration of living in a society that often does not want to cooperate with meeting the needs of people with Down's syndrome and their families.

Each of us can be challenging as well as a blessing and this is also true of those who live with a condition such as Down's syndrome. They are no different. We need to be attentive to their own way of bringing that mix to each relationship and to society. We need to be willing to laugh and to weep when appropriate. In defending the right of people with Down's syndrome to be a full expression of the image of God in the world, we are taking it as read that they are that peculiarly human mix of a divinely inspired creation and a deeply compromised person. In other words, they are no different from the rest of us.

Discriminating against people with Down's Syndrome is therefore a serious theological issue as well as one of social justice. The church can be that welcoming community which accepts people because we are all God's children, made in the image of God. It is called to be a place where all can be at home and find a new identity. It is essential that as society begins to abandon

those who are unable to fend for themselves, the church moves in the other direction and works hard to create a community where everyone belongs.

Understanding Down's Syndrome

People with Down's syndrome have a genetic difference. This is, most frequently, an extra copy of chromosome 21 in all the cells in their body (95% of occurrences). People with Down's syndrome are not ill and while they share some common features that result from this additional chromosome, it must be emphasised that they each have their own individual abilities, needs and interests.

Prevalence: According to the Down's Syndrome Association, there are around 40,000 people with Down's syndrome in the UK (0.06% of the population; approximately one in every thousand live births). Around 750 children with Down's syndrome are born each year. While the likelihood of having a child with Down's syndrome increases with maternal age, 80% of children with Down's syndrome are born to women under 35.

Health: Some health issues are more common for people with Down's syndrome. These include heart, digestive, thyroid, hearing and vision difficulties. Most health problems can be treated successfully, with some, like acute myeloid leukaemia (AML) having better outcomes than in the general population. People with Down's syndrome also have lower incidence of solid organ tumours, hypertension and stroke. *Life expectancy of people with Down's syndrome has increased dramatically over the past century mainly due to improvements in access to cardiac surgery and better treatment of respiratory infections.* Currently, in the UK, life expectancy is around 60 years of age.

Development: Developmentally, the picture is varied. The Department of Education identifies both strengths and weaknesses for most children with Down's syndrome. Characteristic strengths including social interaction, visual learning, gesture, and reading ability. There are often delays in reaching developmental milestones, including communication and learning to walk. People with Down's syndrome also find learning from listening more difficult than learning through seeing. Advances in supported learning have meant that very many children with Down's syndrome enjoy a mainstream education with some going on to third level education.

Mental Health and neurodiversity: It is estimated that mental health difficulties amongst adults with a learning disability are quite common: approximately 40%. This is more than

double the rate of mental health difficulties in the general population. There is evidence that autism spectrum disorder occurs more frequently among people with Down's syndrome than in the general population. Dementia is also more prevalent and can have an earlier onset in their 50s and 60s. However 99% of people with Down's syndrome report to enjoy their lives, with 79% of parents saying that parenting a child with Down's syndrome has brought additional joy to their lives.

Environment: The level of physical or intellectual difficulties are factors in people with Down's syndrome achieving optimal educational, employment and social attainments, but these are also dependent upon the levels of medical, educational and social support provided to them and their families. For example, employment levels for people with Down's syndrome stand at under 20%, a figure that is not representative of either their ability or desire to work.

Some Positive Changes in Attitude Towards People with Down's Syndrome

Since Down's syndrome was classified in 1866 major medical, educational and social advances have been made, leading to greatly improved outcomes for people with Down's syndrome.

Life expectancy in 1929 was only 9 years of age, rising to 12 by 1946, 25 by 1970, 49 by 1997 and 60 today.

John Langdon Down's initial identification of the syndrome that came to bear his name was published in a work that he entitled '*Observations on an ethnic classification of idiots*', using the term 'mongoloids' to describe people with the syndrome. In 1946, Dr Benjamin Spock in his book *Baby and Child Care* asserted that that '*babies born mongoloid should immediately be institutionalized*' based on the premise that '*If [the infant] merely exists at a level that is hardly human, it is much better for the other children and the parents to have him cared for elsewhere*'. In 1965 a delegation from Mongolia successfully petitioned the World Health Organisation to stop using the terms 'Mongol' or 'Mongoloid' to describe people with Trisomy 21 as this was viewed as being objectionable to the people of Mongolia. This, rather than consideration of people with the condition, led to 'Down syndrome' or 'Down's syndrome' eventually becoming the standard descriptions of the condition by the 1970s.

In 1979, research was published that described the impact of stimulation on infants and children with Down's syndrome and compared the IQs of children raised in institutions with those raised at home. Children with Down's syndrome raised in institutions had an average IQ of 20 to 30, while those raised at home with no specific attention to stimulation averaged about 40, and those raised at home with stimulation had an average IQ of 55. Today, IQ is viewed as a questionable measurement of intelligence with models of multiple intelligence being preferred. Nonetheless, a wide range of IQ has been observed for people with Down's syndrome: while 50-60 is typical (akin to that of an eight/nine-year old without Down's syndrome) some individuals have scored well over 100. As further research is conducted into ways in which people with Down's syndrome learn and develop, higher attainments are most probable.

During this century major improvements have been made to enable adults with Down's syndrome to live independent or semi-independent lives. With support, very many adults now make autonomous choices with regard to their lifestyles and growing numbers have become self-advocates, promoting better understanding of the condition as well as increased inclusion at all levels of society.

The Department for Education has summarised the current situation: *‘It’s impossible to predict outcomes for any individual child when they are very young, but it’s important to understand that children and young people with Down syndrome in general are achieving much more than they did 25 years ago. People with Down syndrome are living longer and are learning to read, write and achieve more than was the case even 10 years ago. They often progress more slowly than other people, but if they are given opportunities to carry on learning, they can benefit from becoming lifelong learners, just like the rest of the population.*

In brief, while people with Down’s syndrome (and their families) face particular challenges, increased understanding of the condition allied with improved medical, educational and social support has transformed the outlook for very many individuals. Remaining challenges ought not to be minimised, but much progress has been made. Many people, however, remain unaware of much of this progress, relying on outdated or inaccurate information

Historical and current challenges

Less than half a century ago, people with Down's Syndrome, and people with a learning disability more widely, were locked away and kept a secret from the rest of society.

It is astonishing to think that it was only in 2009 that the last of such long-stay hospitals closed, enabling people with Down's Syndrome, and people with a learning disability more broadly, to take their rightful place in the community-living in ordinary houses, with their families or in supported living with paid carers. Attending mainstream school and college, taking part in everyday life and the life of the community are things that most of us take for granted; these have only recently become realities for people with Down's syndrome.

We now recognise that many long stay hospitals provided a totally unacceptable level of care for people with learning disabilities. Too often people's basic human rights were denied and they were treated like lesser human beings. Being locked up, having no clothes of their own and sharing everything with a large group of people are examples of the inhumane treatment some people with learning disabilities have suffered. *These memories are still vivid for survivors of this system, and the legacy of institutionalisation lives on.*

While we might think that institutionalisation of people is a thing of the distant past, it was only in 2011 that the Winterbourne View abuse scandal shone a light on the wider issue of the long-term detention of 3,000 people with a learning disability and/or autism in assessment and treatment units all over the country. Efforts continue across government and the NHS to change this, in the wake of shocking treatment that people have faced.

In other areas, challenges are no less severe. 1,200 people with a learning disability die avoidably each year when timely access to quality healthcare could save them.

Fewer than 1 in 5 people with a learning disability are in work, compared to nearly 4 in 5 of the general population.

Children with special educational needs, which includes children with Down's Syndrome, are 6 times more likely to be excluded from school, often illegally.

It is due largely to self-advocates with a learning disability, their families, campaigning organisations and a few visionary politicians, that progress has been made. Yet we must not forget that until 1971 children with a learning disability had no right to education, being seen

as 'ineducable'. It wasn't until 1995 that law was passed outlawing discrimination against disabled people- in relation to employment, using goods and services.

A focus on rights drove change: people with a learning disability should be treated as equal members of society and empowered to have choice and control over their lives. These changes are recent and we have a long way to go as a society to truly treat people with Down's Syndrome, and disabled people more broadly, as equal citizens, affording them the rights and support they need to live their lives in the ways they choose.

Unfortunately, public ignorance and awkwardness around disabled people still exist.

A large general public survey by the charity Mencap showed that only 10% of the public say they have seen someone with a learning disability featured in newspapers or magazines in the past six months and only 14% being talked about in TV news reports. This lack of visibility and exploration of disability may lead to misconceptions around learning disability. For example, 27% of the public think a learning disability is a mental illness, and an equal percentage think it isn't life-long. Both attitudes are mistaken, illustrating the lack of public understanding around disability.

When asked if people with learning disabilities are a burden on society, 61% of people strongly disagreed. It is deeply concerning that nearly 40% were unsure if people with a learning disability are a burden on society.

Clearly, there is much work still to do.

Support During Pregnancy and Birth

Currently we can screen for and identify Down's syndrome in pregnancy, and while it is rare for terminations of pregnancy to occur after 24 weeks there is no statutory limit if a foetus has Down's syndrome, which means that in exceptional circumstances a termination is legally permissible up until full-term. While this is the law, the Church of England has consistently argued that '*In the rare occasions when abortion is carried out beyond 24 weeks, 'serious foetal handicap' should be interpreted strictly as applying to those conditions where survival is possible only for a very short period*'. This is very rarely the case for children born with Down's syndrome. Further, we do not view Down's syndrome as a 'handicap' or a disability. We have also proposed that disability in and of itself should no longer provide grounds for termination of pregnancy.

In practice, if Down's syndrome is identified during pregnancy, this news is often given in a negative manner, sometimes with an outdated or overly medicalised view of what having Down's syndrome means today. Some women have reported being asked repeatedly if they would like a termination following the identification of Down's syndrome in their baby. One verified account was given during a briefing to the Department of Health in 2018 of a woman from Oxfordshire being offered a termination during labour at 30 weeks. Once a woman has made it clear that she does not want to pursue a termination, this should be noted and she should not be asked again.

Current NHS policy is to offer all women screening for Down syndrome at their first scan. This is currently 'the combined screening test' in most places, which considers the age of the mother, involves a blood test looking for two specific markers and an ultrasound scan. Women will be seen as having a low chance of carrying a baby with Down's syndrome if the probability is less than 1 in 150 and will be offered no further blood tests. If a woman is seen as having a high chance of carrying a baby with Down's syndrome, they may either be offered another more accurate screening test called NIPT (non-invasive prenatal test) or be offered an amniocentesis or a CVS (chorionic villus sampling). NIPT is scheduled to become more prevalent in the near-future but will still only return a high or low chance of the baby having Down's syndrome. An amniocentesis, or CVS are the only tests that give a definite identification of Down's syndrome if it is present.

Every pregnant woman is offered prenatal testing for Down syndrome. It is important that people considering having children are supported in thinking about whether they want

screening for Down's syndrome before becoming pregnant or before going to their first appointment.

It is essential that women are aware that it is their choice whether they wish to have screening or not and that they consider what they might do if there should be unexpected results from that screening. Results may not always offer the 'reassurance' they were expecting; dealing with unexpected news can be difficult. It is therefore wise to have thought about and discussed these issues beforehand.

The Church, in particular, ought to represent a safe, non-judgemental environment in which to talk about these issues. We must also bear in mind that there are likely to be women in our churches who have previously made challenging decisions about their pregnancies; sensitivity is required at all times.

When a baby with Down's syndrome is born

Most babies with Down's syndrome will be born without significant medical complications. Therefore, in most circumstances, when a baby with Down's syndrome is born it is entirely appropriate to say CONGRATULATIONS! This is the birth of a new baby, a baby who has, despite potential medical issues, made it into the world; he or she is a baby first. We should ask all the usual questions about their weight and name, say how beautiful he or she is (we all know that all babies tend to be wrinkly, but say it anyway!), ask how any siblings are coping, how labour was. The extra chromosome is 1/47th of the new baby. Our conversations should reflect this, but we also need to give parents the opportunity to talk about Down's syndrome and any other medical issues, if they so wish.

It is also important to be aware that new-borns with Down's syndrome are more likely to need neonatal intensive care support after birth, and so parents may have a period of days or weeks when their child is in hospital. Where there are siblings in the family, this will be a demanding time, with parents wanting to spend time at the hospital as well as having to care for other children. Offers of practical support in helping the family manage are likely to be welcomed.

Further, during the few weeks following birth, the baby will undergo tests to check for the more common medical issues that people with Down's syndrome can be more prone to. This can be a challenging time for the parents with ever-changing emotions as they adjust to new pieces of information about their child's health. It is important that we stay in touch with the parents, offering empathetic support and understanding so that they may know we are walking with them through this time.

Most siblings thrive in the presence of a sibling with Down's syndrome. It is sometimes said that if we wish to know how to treat a person with a disability, we should watch their siblings. This may not always be the case, however, and it is important throughout life, that the potential needs of siblings are not forgotten by the church. This includes enabling them to talk honestly about their feelings and experiences without judgement or censure.

Lived Experience:

We found out when I was 12 weeks pregnant. My blood test came back as 1:25 I was offered a CVS and we went ahead with it as I needed to know. 2 days later I received a call confirming baby had ds. Straight away we knew we would keep her but that didn't stop me grieving for the next few months. We were given a leaflet and told she would have learning difficulties that

could be anywhere from mild to severe. She probably would have health problems ie heart, stomach, all the negative text book information. The Fetal Medicine Unit team we're amazing but other medical staff along the way were ignorant to DS they knew nothing about it and termination was mentioned a lot. One midwife put us in touch with a friend of hers who had a son with ds. She also helped me find local support. From this meeting late in my pregnancy it changed everything for me, I finally was at ease. I was induced at 35 weeks and the care we received after delivery was great very positive although they gave me the same leaflet again.

Tracy, Sheffield.

Some Suggested Resources:

Having a copy of *More than Medical* available in the church office/library, available from the Down's Syndrome Association

Reading *Looking Forward to Your Baby* by the Down's Syndrome Association, so that you know what the parent may be dealing with. <https://www.downs-syndrome.org.uk/download-package/looking-forward-to-your-baby/>

Suggesting a resource produced by the Catholic church which may prove useful 'Because I am', a parents resource available from Redemptorist Publications.

Accessing a wide variety of stories about parenting a child with Down's syndrome at www.positiveaboutdownsyndrome.co.uk

Contacting PASS - a new non-directive advisory service for women who are pregnant with a baby with Down's syndrome

Watching and making available *Dear Future Mom*: an encouraging video made in response to a letter from a mother to be saying that she was scared of what the future held - <https://www.youtube.com/watch?v=Ju-q4OnBtNU>

Contacting Saying Goodbye (www.sayinggoodbye.org). This group offers support to women who have had terminations for foetal anomaly.

It is always good to offer connections to people and groups in church or community with children/adults with Down's syndrome. Parents might not want to make contact straight away but it is good to make them aware of who is there for support when they are ready.

Participation in Pre-school Provision and Clubs

The first few years can be full of questions, concerns, additional check-ups and hospital appointments and unless the family has a strong support network this can be particularly difficult. Realistic offers of help and making time for a chat can make a difference.

Parent and baby groups. These can be difficult places for parents of children with Down's syndrome. Other children may progress at a much faster rate, achieving developmental milestones more quickly. This can be hard for parents. Sensitivity is required by the people running and attending these groups to celebrate each tiny success of a child with Down's syndrome. They do make progress, it just tends to be in smaller steps. For example, another child may have learnt to sing a whole nursery rhyme while in that time the child with Down's syndrome might have learnt to push his or her mother's hands to make her clap at the appropriate place in that same nursery rhyme. Each step of progress is to be equally valued.

Signing. Most young children with Down's syndrome learn Makaton, which is a simplified version of British Sign Language (other sign systems such as Signalong are also used). Makaton signs can be incorporated into actions for children's songs while key words can be signed when teaching Bible stories. Makaton is particularly useful because most children with Down's syndrome are slow to learn to talk; many also can have fluctuating hearing loss. A cautionary note: some families decide not to use signing with their child. This is a very personal decision, and should be respected so it is important to check with the family if this is something they wish their child to use.

Makaton can be learned by watching *Mr Tumble uses Makaton* on the CBBC programme *Something Special*. *Prospects* provide resources in Makaton specifically for churches. If the person with Down's syndrome isn't already familiar with Makaton, or if there is no sign available in Makaton, using signs from BSL might be an option. A useful British Sign Language online dictionary can be accessed at <http://bslsignbank.ucl.ac.uk/dictionary/words/>. Local speech and language therapy services might be able to offer a short training course on basic Makaton.

Lived experience:

When I went to groups, when my daughter was young, we were just treated the same as anyone else.....to be treated the same as everyone else is the best welcome.

Jo, Aylesbury, Buckinghamshire

We tend to be treated just like everyone else at mainstream groups we go to. At one group I'm in the process of teaching the others to use Makaton which started because everyone saw Leo and I signing during song time.

Caroline, County Durham

I currently go to Baby Signing Lincoln and it's the most friendly, welcoming and inclusive baby group. There are several children that have disabilities and/or medical conditions and there are also typical children. My son isn't able to stand or walk yet like the others in the group but it doesn't matter as the activities during the class are inclusive for everyone and the other children come to him to play. The lady that takes the class also encourages the 'more confident' children to include other children, for example can you take this to Ruby and help to get the parachute out the bag together etc.

Tania, Lincoln.

Participation in Education

Schools are microcosms of society. School is often the first example children have of community and this can become the foundational model for them, particularly for those who do not attend church. As such, schools have a huge influence on children's understanding of the nature of community, including who 'belongs'.

It is useful to ask ourselves, what do our children see and what are we teaching them about community membership? Do children see children with learning differences treated as outsiders, excluded or marginalised with the unspoken message that they don't belong 'here'.

There are varying types of exclusion that children might experience: being sent to another school, being sent into the corridor to learn, being grouped together in a classroom especially for those who learn differently and occasionally being stopped from joining whole school activities.

Schools and churches are ideal places for modelling community where all children are truly treated as equal citizens.

'The image of the citizen represents persons with disabilities not as social burdens but as valued human beings. Students with Down's syndrome are not educationally segregated based on presumptions of impairment; rather, their school participation is considered essential for two reasons. First, education itself is considered to be an ever-shifting web of relationships among all members of a community. To leave even one student out diminishes the web and reduces the learning potential and experiences of all students and teachers. Second, community is recognized as the core from which individual human possibilities and capacities are realized. One's human development does not set the conditions for community acceptance; rather acceptances is the terrain on which development occurs. Citizenship, as I define it here, is an ongoing realization of each individual's value to the larger group.' (Christopher Kliever)

Parents of children with Down's syndrome often live with the constant worry that their child will be excluded or will feel excluded from school. Conversely, schools can be places of welcome, safety and participation for children with Down's syndrome, sharing responsibility with parents for loving and caring children as part of a wider family. They can be beacons of genuine inclusion.

Children with Down's syndrome make better progress socially and achieve higher educational goals when they are part of a mainstream school. Understandably, some mainstream schools do not feel they have the necessary expertise to best educate children with Down's syndrome. However, as copying behaviour is such a strength of those with Down's syndrome, an inclusive peer group provides the best environment for a child with Down's syndrome to learn.

A decision to transfer school should only ever be made because a child is unhappy or because he or she is notably disrupting other children's education despite every reasonable adjustment possible having been made on behalf of the school. Transferring to another school should never occur because the child has been unable to 'make it work'. The school is responsible for providing education, not the child, and the responsibility to make a placement 'work' should never be placed on the child.

Statutory responsibilities of schools are set out in the SEN code of practice
<https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>.

Lived Experience:

Hi, my daughter, Lillie, attends mainstream primary in year 3. She has full time support and the same two TA's have moved up through the years with her to provide consistency. The school is completely on board with her learning and promotes amazing inclusion. They provide 1-2-1 support for after school clubs to allow her and other children to try different sports and activities. Sign language and low lighting has been implemented in to assemblies and classrooms, there is a sensory garden and sensory indoor area and due to food intolerances they have even offered dairy/gluten free menu choices. Her learning is differentiated to meet her needs and they are always open to new strategies and consistently up-training staff. Can't fault them, differences are completely accepted there!

Tara, Weymouth, Dorset

My son's MS school has fully embraced DS (Down's syndrome). He's in P2 now and each year from nursery the teachers have done Makaton training and refresher. In-service days all the teachers continue to receive DS training from DS Scotland who they have a strong relationship with. Each March they have done Lots of Socks along with an assembly for the whole school on awareness of DS. They have sought & bought recommended resources designed specifically

for children with DS & altered the playground for safety to enable him to be fully inclusive. They have developed a calm room if ever he requires a break and he has an IEP which works for him. They have gone above and beyond all expectations. He's included in every aspect of activities involving the curriculum to his ability. He has appointed P7 buddies for playground times who encourage play and interactions with his peers. He has a shoulder partner who helps in class or movement around school. His peers in class initiate play (as small children do anyway) and he has some great wee friends who look out for him. Each child in his year (3classes) are taught Makaton daily and every show they have done they have sang 2 or more songs using Makaton. A little girl age 6yrs explained to me why Rudi was behaving slightly shyly one morning due to his 1:1 not being there for him and she was brilliant at reassuring him. The school got on board to have him participate in after school activities by developing relations with Sports Scotland who run Active Schools clubs.

June and Rudi, Renfrewshire, Scotland

Billy's school is very inclusive, they have just bought a weighted bow to help him play the cello in his music lessons! I talk every year to year 6 on WDS and last year i spoke to parents about the lived experience of DS. He had a personalised plan of his day at school detailing the support he needs in case his 1:1 is sick and someone needs to step in. Can't fault the school so far. He is in year 4.

Lucienne, Sutton, South London.

Special School

Hazel's school have excellent communication with families. They use Voxer messaging service which allows them/us to send each other photos of whatever Hazel might be doing. They are particularly good at spotting things she enjoys at home (eg the video I sent them of her on Small World ride at Disney) and then finding ways to bring that into her learning. They got hold of the music and also a set of Happyland figures and re-created the scene with her. The song they use from time to time (either just singing it or cd) if Hazel becomes distressed and needs calming. They also frequently share with us titles of books Hazel likes or particular types of toys that she shows interest in so that we can replicate at home. What else.....if I tell them that we are struggling with a particular issue at home eg toothbrushing, they will do their best to support this and incorporate it into Hazel's school day - they set up a daily routine with a kit consisting of towel, toothbrush, toothpaste etc and go through it with Hazel. Still lots of resistance to it - and still virtually total refusal at home but some familiarity and acceptance

of the routine is now creeping in. Same with feeding - expectation is that she sits and is offered pureed food every day at school. Lots of resistance to actually eating anything over last 3 years but we are beginning to see results - in the last 7 days she has twice managed all her lunch and not needed her milk! Huge progress but at home still lots of resistance though we can see cracks appearing in it!

Alison, Cheltenham

Secondary School

*Our MS secondary have just brought in an inclusion advisor and it's transformed our experience. They will now be setting realistic but sufficiently challenging goals every half term with all relevant parties (including us and, critically Lucas!) and reviewing at the end of the period/ assessing successes and setting new ones as appropriate. This is genuinely Lucas-centred and so positive. The Senco team have also enabled Lucas to do German as one of his options (he's in year 8 and they start them in year 9) - he loves it but the department needs a lot of help to understand it's not just about getting A*s so this is massive for us.*

Rachel, Rossendale, Lancashire

College

'My daughter is currently at a residential college about a two hour drive from us. Her college are very good, but we have had a problem with getting her to church, so have been going up every Sunday. This also means that she finds it difficult to participate in midweek groups. Recently, one young lady in the congregation took it upon herself to ask if my daughter would like to go to the midweek dance group, and arranged to pick her up from college and take her and bring her back.

Further, college finally agreed to send a member of staff to take her to church on Sundays. This was not easy as she does not have 1:1 support at college. However, it worked out, and the first week the staff member returned saying it was her best shift ever, it was a really uplifting time, and perhaps they should take more of the students!'

Colette, Oxfordshire

Some Examples of Good Practice:

Viewing the school as an example of what we want our wider community to look like in ten years' time.

Adopting the All Party Parliamentary Group on Down's Syndrome Guidelines on education for people with Down's syndrome.

Training staff in the specific learning profile of children with Down's syndrome, possibly by using the online training from Down Syndrome Education International <https://www.down-syndrome.org/en-gb/services/training/courses/> or trainers and resources from the Down's Syndrome Association <https://www.downs-syndrome.org.uk/for-families-and-carers/education/> or local Down's syndrome groups.

Utilising specialist support from external services, particularly around behaviour or following expert guidelines such as *Supporting Positive Behaviour in Children and Teens with Down syndrome - The Respond but don't react method* by David Stein.

Producing excellent Education, Health and Social Care Plans in line with IPSEA guidance.

Ensuring that legal obligations are met both within school and by related bodies such as the local authority.

Including bullying for disability in bullying and discrimination policies.

Ensuring that the school is supported and accountable in their inclusion practices. For example, exclusions and suspensions should be fully reported and support provided to prevent further disruption to the child's education.

Considering setting up Circles of Friends <https://inclusive-solutions.com/circles/circle-of-friends/> in Secondary schools.

Inviting Down's syndrome support groups/advocates to provide guest speak when genetic conditions/genetic testing is discussed as part of GCSE and A Level science curriculum or in Philosophy and Ethics courses. 'A World without Down's syndrome' can be used as a basis for discussion <https://www.youtube.com/watch?v=x16wGajCHIw&feature=youtu.be> .

Contacting ALLFIE regarding good inclusion practice. <https://www.allfie.org.uk>

Participation in Church Life

The United Nations Universal Declaration of Human Rights (1948) states that ‘*Everyone has the right to freedom of thought, conscience and religion; this right includes freedom to change his religion or belief, and freedom either alone or in community with others, in public or private, to manifest his religion or belief in teaching, practice, worship and observance*’. These rights extend to people with Down’s syndrome.

We should welcome People with Down’s syndrome into the church as they are, rather than as others may think they ought to be. This, of course, applies to all members of the congregation, however sometimes people with Down’s syndrome appear to be at increased risk of exclusion due to misunderstandings and potentially unrecognised discriminatory attitudes.

The church body is multifaceted, and when one part is missing the church is poorer for it. People with Down’s syndrome have much to offer the church. Apart from their enthusiasm for life, their desire to make friends and willingness to be included and to include, many people often also report on their innate capacity for unlimited forgiveness and living in the moment; an example to all of us.

It is very important to remember that our responsibility as the church is not just to care for people with Down’s syndrome, but to guide them in developing their faith. This is particularly important to remember as they develop into adults, and leave a Sunday school teaching environment.

It is also important to remember that most people with Down’s syndrome will remain vulnerable to exploitation throughout their lives. As such. the church will continue to have safeguarding duties towards that person. **Advice should be sought from your Diocesan Safeguarding Advisor about supporting those individuals in church life and with any safeguarding concerns.**

See also: [https://www.churchofengland.org/sites/default/files/2019-](https://www.churchofengland.org/sites/default/files/2019-10/ParishSafeGuardingHandBookAugust2019Web.pdf)

[10/ParishSafeGuardingHandBookAugust2019Web.pdf](https://www.churchofengland.org/sites/default/files/2019-10/ParishSafeGuardingHandBookAugust2019Web.pdf)

<https://www.churchofengland.org/sites/default/files/2017-11/dbs-faq-february-2017.pdf>

(Much of the following sections are applicable to school as well as to church settings.)

5-10 Year-olds

Children's church or Sunday school can be tricky places for children with Down's syndrome. In school, most of these children will have 1:1 support for lessons in which they are expected to learn something specific. This person is often needed to differentiate the work, and to help with behaviour. We should have the expectation that a child with Down's syndrome is going to learn something during Sunday school also.

It is important to remember that children with Down's syndrome:

- will learn best in an inclusive environment
- will learn through copying others
- are visual learners – use of colourful pictures and signing is essential

Their attention span can be shorter than other typically developing peers (sitting in a lecture in a foreign language where only the odd word is understood gives an idea of their experience). Several short activities are better than one long one.

It takes a child with Down syndrome a little longer to process things and therefore to respond.

A useful rule of thumb is to count to 10 before prompting: 123, the child is taking in what has just been said, 456, they are working out what it means, 789, they are working out their response, and 10, they may respond. If this process is interrupted at any point by prompting in order to help, they go them back to 1. This can feel unnatural at first, but often will result in a greater response rate from the child.

Learning through listening is extremely hard and tiring and is mostly inaccessible

Delayed motor skills can mean writing is difficult; felt tips are easier to write with than pencils.

Cutting is tricky too so it is better to try springy scissors. Glue is tasty!

We should have the same behavioural expectations of a child with Down's syndrome as a typically developing child; this will help with their inclusion. It is important to respond to behaviour, but not to react emotionally as any emotional reaction to unwanted behaviour will encourage the behaviour to continue.

It is important to try to keep children with Down's syndrome with their age peers, differentiating the work appropriately. They may be kept one year behind if that is agreeable to their parents though, where possible, it is always best to keep them with others who are in the same school year as they are.

It is also important to 'see' the parents or carers. We ought not to hold them up as some sort of superheroes, but to come alongside them in their parenting journey, recognising that they are just parents, doing their best, on what can be a different journey to the one they were expecting.

10-18 Year-olds

At this age the gap between young people with Down's syndrome and their peers may be widening. It may become increasingly important to facilitate friendships between them and others. Relationships at this age rely on general conversation, (often in groups) which can be a very difficult skill for someone with Down's syndrome to master.

One helpful intervention is to establish a Circle of Friends around a young person with Down's syndrome: a group of friends who notice if that young person 'isn't there', who will text them and include them in activities. They may think, 'it would be great to invite them to the cinema with us, but it is too difficult'. We need to offer them support to make this a reality. This might mean facilitating contact between the friends and the parents/carers of the young person with Down's syndrome, it could be offering to go with them to the cinema or finding a young adult in the church who would like to do this to help keep an extra eye on the person with Down's syndrome. At all times, safeguarding policies ought to be followed.

Some topics that we discuss in groups with young people may be thought to be too difficult to tackle with people with Down's syndrome present, e.g. death, dating and marriage, sexuality. We need to think about what we want the young person to take away from that session. It might simply be the meaning of the words, 'marriage' or 'sexuality'. It might be one phrase that explains that word, or a sentence that encourages them to think of God's perspective on a given issue. Whatever it is, it is good practice to have a discussion with parents beforehand and to try to make a topic applicable to real life. We cannot permanently shelter our young people, but they may not understand the whole topic the first time they come across it either.

Thoughts and feelings in young people with Down syndrome are as varied as that in the rest of the population. The difference is often that young people with Down syndrome do not hide them. What we see is what we get. Some behaviours, particularly around puberty, can be challenging to deal with. A person with Down's syndrome is more likely to have behaviour issues and most behaviour in people with Down's syndrome persists for longer than in a typically developing young person. This can be tricky for everyone involved. If this is true for the person with Down's syndrome in one of our communities, the church should support the young person and their family, and continually reinforce that they are a wanted and valued member of the congregation. The best ways to do this are to keep communication open, to help the parents/carers to reinforce what is and isn't appropriate behaviour and to respond to these behaviours in a way that is appropriate to the mental age of the young person. We should also remember that all behaviour is a form of communication and ask parents/carers if they know what is being communicated, and if there is anything the church can do to respond, or support the parents to respond, to the message being communicated.

For typically developing peers, it is essential that we talk to them about disability inclusion and discrimination issues in society. It is often useful to encourage them to do something positive to tackle these issues.

Urban Saints have an Additional Needs ministry, where they can offer training, and or consultancy in your setting. <https://www.urbansaints.org/campaign/additionalneeds>

We may come across young people with Down's syndrome in our work with schools. If possible, we should try to work with special schools as well as mainstream schools. While most children with Down's syndrome do start their education in a mainstream school, for a variety of reasons, they may finish it in a special school. Children with Down's syndrome educated in a special school should experience that they are as equally valued as those educated in mainstream schools.

18-30+ Year-olds

This can be a difficult time as youth provision and participation in church ends for many young people during this time. Typically developing young adults often move away either to university or for a job or stop attending church or church-based groups. This can mean that the peer group of the young person with Down's syndrome disappears. Further, as time goes on people often get married and start to have families. This may or may not happen for the young person with Down's syndrome. Only 3% of people with a learning disability live as a couple, compared to 70% of the general population: <https://www.mencap.org.uk/about-us/what-we-think/relationships-and-sex-what-we-think>

It is important at this stage, for the person with Down's syndrome to find their new place in the life of the church. If they are still at home for example, churches that organise 'small groups' or 'home groups' need to explore which group it is appropriate for them to be part of; often not the one their parents attend! It is worth considering setting up a buddy system or Circle of Friends around the person with Down's syndrome, depending on what size a home group or activity is. We all have different age friends, but it is important to include people of a similar age to the person with Down's syndrome in any circle of friends. Some useful resources that enable inclusive Bible studies that will appeal to a person with Down's syndrome and their typically developing peers can be found at <https://togethersmallgroups.org/what-is-together/>.

Some churches have found there is demand for a midweek group or an additional service for people with more complex learning difficulties. Whilst this may meet the needs of some people with Down's syndrome, we should make every effort to ensure that everyone feels they belong in all church services and in a wide range of other church activities in order that we might better reflect the true nature of the body of Christ.

As people with Down's syndrome mature, they need to be supported to find their own (not anyone else's) place in church life. One way is for them to find a specific role in church life. This might be serving communion, being on a 'welcome team', helping with children's church, or any number of volunteer roles in the church.

People with Down's syndrome often love to be invited to be part of a team. We need to find out what their interests are and what they might like to try, being happy to work through stumbling blocks with them so that they have the opportunity to serve others. We have to think 'outside the box', making sure they are given a real job, where they are valued. While they are

unlikely to be able to run a Sunday School group by themselves, they could be an assistant. Jobs that involve similar routines each time are often easier to manage, but this might not be what the person with Down's syndrome wishes to do.

Discipleship and fellowship are extremely important parts of church for many adults who attend church. The same is true for people with Down's syndrome. It is not enough simply to 'care for' them. We need to ask, are the adults with Down's syndrome in our church able to benefit from teaching and fellowship in the same way as our other members?

Some Points to Remember:

We should first find out what each person would like to do, what they are passionate about and what will fit with their gifts and abilities.

Each task or job in the church has several small steps to it. Break down these steps with the long-term aim of them being able to complete the job on their own.

'Backward chaining' is a great way to teach a new skill to people with Down's syndrome: they learn to do the final part first, and gradually increase their skills. For example, tidying up after a parent and baby group, they may be able to put the boxes in the cupboard first, then tidy a particular box and put all the boxes in the cupboard.

Don't give up. If something isn't done correctly the first time, talk to the person with Down's syndrome, talk to their parents, talk to others, and try to find a way to teach the 'correct' way of doing it.

Visual schedules and instructions given in short chunks with pictures are often useful to help a person with Down's syndrome learn and remember instructions. However, this is not always the case so it is important to speak to the person, finding out what may best help them.

Sermons can be inaccessible. Thinking of what we wish someone with Down's syndrome to take away from a sermon, and how best to communicate this to them is important. Making sure this is highlighted as a key point, either on a Power Point, or on a notice sheet is one way of doing this.

Lived experience:

Brian and Rachel Murray, a father and daughter, have found in their parish performance group a way to break down barriers between those with disabilities and those without.

Roughcast Productions was formed in 2011 in the parish, and holds two performances a year: a summer show which runs in May, and a three-night run at Christmas. The theatre group runs on a shoestring budget, and any profits are donated to the parish. Scripts are written by the parishioners, and with members including children as young as nine and pensioners as old as 85, there is somebody for every part.

This inclusive nature of the group is what attracted 18-year-old Rachel. Her mother, Lynn Murray, said she was so proud of how the group had embraced her daughter.

“She’s not just a token part: they write specific roles for her,” she said. “Some people focus on the things Rachel can’t do, but they focus on the things she can.”

Dawn O’Donnell has written a number of plays for the theatre group. She taught Rachel in nursery, and she said the teenager has brought a lot to their performances.

“Rachel immediately brought a great amount of enthusiasm and passion to our shows, and her dad has become very involved,” she said. “Rachel and Brian have now done two summer shows and two Christmas shows, and I can’t imagine not having them in the company. Everyone has something to bring, whatever age or ability. We are all different, and we are very supportive of each other and help each other throughout the whole preparation for show nights.”

The Murray family, Edinburgh.

At our church sermons always include power points and although I know a lot of it goes over Alice's head, she likes to make notes on her phone, usually copying from the screen. She doesn't write much down, but I think it helps. In some ways the church has become more aware because Alice arrived as an adult, as opposed to our old church which we were already part of when she was born - it was almost harder to get church/junior church/youth group to adapt to her needs and to think about accessibility for her as she was just Alice and had always been there.

The thing which has made a huge difference to Alice is being part of a Discipleship Group - hers is specifically for people in their 20s and 30s (ish). Alice loves it, is completely included in the group and socially and it's wonderful to see. At church someone from the group always and quite naturally has a chat with her. Alice isn't the most confident of people so this really helps her feel part of something. One of the group had an afternoon tea birthday party on Saturday, to which we were invited to but we chose not to go as we want that group to be Alice's thing so someone gave her a lift to church afterwards. When I dropped her off she seemed shy and uncertain at first, but said afterwards she'd had a really good chat with some of the girls and I could tell from her face that she meant it.

Heather and Alice, Tolpuddle

Some examples of good practice:

Appointing one of the Church leaders to take specific responsibility for participation in church life of people with Down's syndrome or other learning difficulties.

Publicly, not just privately, clergy affirming the importance of supporting the spiritual needs of people with Down's syndrome and other learning difficulties.

For 0-5 Year-olds

Using upbeat songs, having little activities sand/playdough around the hall or church.

Having room at the back of the church where he or she can go and play if wanted.

Creating a family atmosphere in church where a child can wander around.

Having activity/toy bags to occupy children if they are too young for Sunday School or it's a family service

Utilising candles if they are non-accessible to children so they can't hurt themselves if they are inquisitive.

Using Makaton in the church e.g the Lord's Prayer <https://vimeo.com/216995434> The Lords prayer is also available in British sign language <https://youtu.be/WrpjmrtF7Z0>

'Messy church' can work really well for children with Down's syndrome.

Sensory bible stories and religious rituals to make things more accessible

For Older children/young adults:

Having extra volunteers in Sunday school, as parents often feel it is too much for the person running the group to have their child as well, so they end up staying with them.

After a group meeting, making sure that we feedback positive things, as well as the challenges.

Parents/carers often get negative feedback from other professionals so while challenges may need to be mentioned, make it a positive sandwich! (Something that you loved, something you found challenging today, and something else that you love about their child/young person)

Asking how we can pray for the family, and get in touch if they have been absent more than usual.

Encouraging participation. Activities such as giving out hymn books, prayer sheets, collecting the collection all break down barriers.

Getting to know the person with Down's syndrome and their family/carers well enough to offer help.

Using Makaton for the hymns and key words/concepts in the sermon.

Using a visual timetable, so that people with Down's syndrome know what to expect during the service, and during group meetings.

Providing buddies (teens/adults) to assist when the person with Down's needs it.

Providing a sensory friendly room.

Including people with Down's syndrome in rites of passage e.g. funerals.

Asking what would help the person with Down's syndrome to access the sermon. E.g. Having someone sit next to the person with Down's syndrome and 'translate' the sermon into simple English, either through drawing pictures or simple sentences written down.

Using or having available the Easy English Bible, <https://www.easyenglish.bible/> or NIrV Accessible Edition of the New Testament.

Some Suggested Resources:

Wave Café - a social enterprise that brings people together from across the community, creating opportunities for those with and without learning disabilities to socialise and have fun together.

<https://www.wavecafe.org/>

<https://friendship.org/who/>

<https://www.stjoseph.org.uk/caritas> (from the Catholic church)

http://southwark.anglican.org/downloads/dac/all_one_in_christ.pdf

Pictorial resources:

The Lord's Prayer and creed in pictures:

http://southwark.anglican.org/downloads/dac/disability/The_Lords_Prayer_Confession_and_Creed_in_pictures.pdf

http://southwark.anglican.org/downloads/dac/disability/Pictorial_Education_Communication.pdf

<https://livability.org.uk/resources/more-than-welcome/>

<https://includedbygrace.wordpress.com/2016/11/13/teenagers-with-additonal-needs-in-the-church-needs-and-opportunities/>

https://www.reachoutasc.com/attachments/article/21/children_in_church_resource.pdf

<https://www.reachoutasc.com/churches-organisations/links-and-resources>

<https://www.new-wine.org/mission-areas/accessible-church?fbclid=IwAR0I2tPWskNKFEj1CrpNsmAiprn1xQ0stH-COh6GskgRFqfN1sRQe6GH6e0>

Some Faith Stories

Well my story is I worship the Lord with all my heart. I feel like I have a relationship with Jesus. I praise his great name. I glorify him. I give him praise. I lift up my hands to heaven and lift my voice, my Holy Spirit. I want to give my life to him and glory honour and praise.

I shout Hallelujah to him to give him thanks. I love him and I overcome by the cross and I come to the altar. And to me I make my decision to follow Jesus and no one like you Jesus. Speak to me. My redeemer lives. Shout to the Lord. I never be shaken. I will never be the same. I bring praise, I will sing to the Lord.

You ancient doors I come close to you, never let me go. You are my desire. He is coming back again. I hold nothing back. The Word of God take me, lead me to the cross glorious king. I fix my eyes on you, you are my saviour.

I believe in you to break every chain. I will praise the Lord God, make a way. Heaven and earth fade, his word still remains.

Jesus fill me afresh. In your freedom I will live. In you I feel blessed and loved and liked. I am so loved by you because you helped me because of my sins everything I done for once in my heart. And I just want prayer because I still need my care and I put my trust in him. I have plans. I gave my stressful times and I am a woman of God. I put it to practice over the years and my future.

Hear me from heaven, He is the Lord songs my soul.

Emily, 23, Rotherham

Mum: Why are you a Christian?

Because I talk about God. I pray to God. I know God. God loves me.

Mum: What does it mean to be a Christian?

“To pray to God to help in a struggle.”

To know the Bible

Because he created me and others. He made the sea and skies.

Mum: Why did Jesus die?

He died on Good Friday. Because we have sin. He took our punishment away. He came back alive. He rose again on Easter Sunday

Beth, Bullington.

Thank you for coming to my baptism and God loves me. I saw God when I was a baby and I still see him because He is light. He helps me to be kind and fills my heart with love. He said to me, I am strong I am brave and God will always help me. I want to get baptised because God loves me and I need God's help. And I need God to be on my team and I want to be on Gods team because He loves me. He is amazing and He is good. And I love God with my heart. He is mighty and loving. God helps me to clean my heart and he forgives me. I want to follow Jesus. Cookie, get on with it. Baptise me now!

Olly, 14, Surrey

I like it when I actually connect with God like in worship. Whenever I close my eyes I can picture God in my mind. I do it in worship and talk to him and say please please can you help me sort this out.

God is Jesus. Jesus is strong powerful calms me down, Holy Spirit, honest, loyal and caring and loving and a great hero and friend.

I like Holy Communion. Because it connects me with the worship, whenever I eat that bread and drink that wine it feels that God is actually touching me and wants to pray for me in that worship. Because all I feel when I am alone in that worship, it feels that something that needs to be fixed and everything that I have made mistakes, that I can take it back and keep it all hidden, then I can tell the truth to God and it will go away.

Katie, 21, Oxfordshire

Employment and Volunteering

Many people with Down's syndrome would like to work. However, this goal can sometimes be difficult to achieve as employers might find it challenging to envision employing someone with Down's syndrome (<https://livability.org.uk/resources/more-than-welcome/>). People with Down's syndrome are great employees. They are very relational and help to build team spirit, they are also often conscientious, hard-working and stay in jobs for a long time giving the employer highly valued consistency. They may need more support to learn the routines at the beginning, but then can become highly valued members of the team. The Down's Syndrome Association, MENCAP and smaller charities such as Morethan7 can offer advice and support in employing someone with Down's syndrome in your church.

Please note: receiving a salary can sometimes make a person lose benefits and therefore make them worse off financially. We need to do due diligence over this to make sure we are operating within the law but that receiving a salary does not make the person worse off. The Citizen's Advice Bureau may be able to offer advice.

Volunteer roles can often be a good way for someone with Down's syndrome to learn about work. Appropriate support still needs to be provided. Visual schedules and instructions can be useful. Being able to shadow someone else, doing a little of the job at first, and gradually building up is a helpful model to follow. By allowing someone to volunteer, we are allowing them to serve others. Often people with Down's syndrome are on the receiving end of help, it is important that they also have the opportunity to give to others.

Lived experience:

My daughter, Katherine, got a job in her local hair salon, via Down's Syndrome Association WorkFit scheme which goes into workplace and does training with staff before the person with DS goes. Then a support worker goes on the first few sessions. Katherine had a proper work interview. She had a 'buddy' at work who quickly found the best ways to work with her and she progressed from there and now she knows the job so well she just gets in with it independently. She has very hyper mobile ankle joints and low muscle tone so builds in jobs she can do sitting too. She's got Down's syndrome but doesn't let it stop her - her boss says she's just the same as

every other employee. Katherine said "People think if you have Down's syndrome you can't learn things well... but I learn things very quickly."

Katherine also has another job - receptionist at a charity which gives support to people with learning difficulties. She's paid in training courses rather than money. If anyone phones their head office on a Monday it's Katherine who answers and transfers call via computer. Amongst other things, she sorts the post and types articles.

Wendy and Katherine, Milton Keynes, Buckinghamshire.

Some examples of good practice:

Mencap's Supported Internships, Apprenticeships or Traineeships

<https://www.mencap.org.uk/advice-and-support/services-you-can-count/employment-services>

DSWorkfit Scheme run by the Down's Syndrome Association <http://www.dsworkfit.org.uk/>

MoreThan7 <https://.base-uk.uk/about/members/morethan7>

Relationships and Marriage

In the past people with Down's syndrome were often segregated, lived in large institutions and it would have been unheard of for anyone with Down's syndrome to marry.

Fortunately, this has now changed, and people with Down's syndrome are forming lifelong relationships and some are marrying. It should be remembered that people with Down's syndrome reflect the same range of sexuality as the rest of society.

People should receive the same support around sexual identity, relationships and marriage, as anyone else. It may, however, need to be differentiated in terms of language used and the way concepts are explained, so that the person involved can fully benefit from that support. Further, relationships with 1:1 carers from outside the family is an area that most other people do not have to encounter. The care and support from these people can sometimes be mistaken for sexual attraction: this is an area that needs careful handling.

We are currently not aware of relationship education programmes specifically for Christians with learning difficulties, although Southwark Diocese has some guidance on this on their [website https://southwark.anglican.org/downloads/dac/disability/love_and_marriage.pdf](https://southwark.anglican.org/downloads/dac/disability/love_and_marriage.pdf). We need to support young people to live a life in line with their beliefs. In order to do this, they need to understand and consider Christian perspectives on relationships and marriage, knowing that these may be different from what they might see happening around them with their peers and on television or streaming.

<https://includedbygrace.wordpress.com/2017/10/15/church-workers-do-you-talk-with-cyp-and-adults-with-disabilities-about-sex/>

Lived Experience

Hi I am Heidi, I am 23 and I happen to have Down syndrome but my church, Hillfields Church, Coventry, has been amazing ever since I have walked through those doors. When me and James got engaged 3 months ago, my church instantly responded with love and kindness and bought us lots of cards and presents. On behalf of me and James we want to say thank-you for the lovely presents we love them. They have made me feel valued and loved. I have made great friends at my church. They have made me a better Christian. I want to thank Peter who has

counselled us in our relationship. He has taught us to love each other in the same way as Jesus and how to have a godly marriage. I want to thank Paul for doing our marriage preparation. Now, how they have made a second home for me! Not only have I got Down syndrome, I also have coeliac disease. My church is fantastic with my dietary requirements, they always let me go first when we have lunch together. The teaching at my church is fantastic as a result of the teaching I have fallen in love with Jesus more and I have grown in my love for Jesus. Thank-you!

Heidi, Coventry

Older Adults

As parents and carers advance in years and may need care themselves, new challenges arise. Parents often look for some reassurance that their son or daughter will be well cared for when they pass away. Parents or siblings, at this stage, are often overseeing the care of the person with Down's syndrome, checking that all is well though they may not be delivering the full-time care themselves. The church can offer support to the carers also, asking what their needs are as well as recognising the needs of the person with Down's syndrome.

There are many established ways of supporting independent living and inclusion, for people with Down's syndrome. Some people volunteer as 'supporters' for self-advocacy groups, others volunteer in arts and drama groups. Some families support a person with Down's syndrome or other learning difficulty to live in their home, funded by the government's Shared Lives scheme. Still others live alongside people with Down's syndrome in a community such as those run by L'Arche or Camphill.

Adults with Down's syndrome are at increased risk of developing Alzheimer's disease in later life, with one study of people born prior to 1960, citing an average age of onset of 55yrs. This can be a challenging time for all involved, and the church should be alert to the support needed by families who are caring for siblings or offspring living with this condition.

Once parents have passed away or are no longer able to oversee their child's care an 'aunt' or 'uncle' figure could keep an eye on the services being provided, checking that everything is being done correctly and ensuring that the person with Down's syndrome remains a valued member of the church and community.

It is essential that safeguarding issues are thoroughly explored and all regulations and guidelines are followed if the church were to provide this type of support.

Supporting People Living in the Community

It is important for us to reach out to local groups that offer support to people with Down's syndrome or to people who have learning disabilities. Where possible, it is good to work in partnership with such organisations, perhaps offering a venue for groups to meet or providing volunteers to help. Many people with a learning difficulty rely on carers to do activities with them or simply feel very nervous going anywhere new on their own. This can limit the number and range of activities that they are able to enjoy. Subject to good safeguarding practice, the church could provide 'buddies' to enable wider participation in community life.

Perhaps a church could host a 'Night to Shine': a ball to celebrate the people with learning difficulties in its community (or something similar). This can be a great way of affirming people with learning difficulties, who may not often have the chance to dress up and be pampered. It is also great for those young people with learning disabilities who may not have a ball of their own at the end of their schooling, particularly if they are in a special school environment. It provides a fun evening for all involved.

Churches can celebrate World Down Syndrome Day on 21st of March each year. (It is a little-known fact that World Down Syndrome Day is celebrated on the 21st March because 21 is the number of the extra chromosome in Down's syndrome; the third month is significant because there are three copies of this chromosome.)

An Example of good practice:

Kingfisher Church in Gloucester has recognised the potential loneliness of adults with all types of learning difficulties, and offers a disco/karaoke three nights a week, every week. A local special needs college accesses this, along with other adults from the community. They also run a Learning Difficulties friendly service at 11:30am on Sunday mornings.

Resources:

<http://www.timtebowfoundation.org/ministries/night-to-shine>

Six things that you could do now

- 1.** Share the toolkit with other members of your church and its leadership (and promote it on social media)
- 2.** Prepare a sermon - either about the theology of disability, OR on any topic but with visual prompts and key concepts made accessible for a member of your congregation who has Down's syndrome
- 3.** Have a conversation with a member of your congregation who has Down's syndrome about what is working and what could be improved in church life OR make a link with a community group that supports people with Down's syndrome and investigate some form of joint working that meets the spiritual needs of their group.
- 4.** Make contact with local groups outside of church that support people with Down's syndrome (youth group/special school/residential college, assisted living services) and ask how you could support them.
- 5.** Read a book by Jean Vanier and/or Prof. John Swinton on disability.
- 6.** Speak to your church leaders about support and training regarding inclusion of people with Down's syndrome.

Online Resources

In addition to the resources mentioned at the end of each section of this toolkit, these helpful resources are also available online.

http://southwark.anglican.org/downloads/dac/disability/Open_the_Doors.pdf

<http://southwark.anglican.org/about-us/what/caring-for-our-churches/secular-legislation/disability-access>

<https://www.throughtheroof.org/supportingyou/roofbreakers/>

<https://www.throughtheroof.org/abd/wp-content/uploads/2018/01/A-Roofbreaker-Guide-to-Disability-benefits-applications-and-appeals-1.pdf>

www.ipsea.org.uk

<https://www.throughtheroof.org/supportingyou/churchresources/>

http://www.liturgyoffice.org.uk/Resources/Preparation/Valuing_Difference.pdf - catholic

<https://www.oxford.anglican.org/wp-content/uploads/2013/01/Welcome-Inclusion-Respect-June-2011.pdf>

https://www.ucobserver.org/interviews/2013/02/john_swinton/

<https://www.disabilityandfaith.org/inclusive-ministries/>

Makaton

<http://staff.prospects.org.uk/index.php/shop?action=viewcategory&id=96&slug=Makaton-Materials>

<https://inclusive-solutions.com/circles/circle-of-friends/>

<http://additionalneedsalliance.org.uk/>

https://www.researchgate.net/profile/John_Swinton/publication/288912395_THE_BODY_OF_CHRIST_HAS_DOWN%27S_SYNDROME_THEOLOGICAL_REFLECTIONS_ON_VULNERABILITY_DISABILITY_AND_GRACEFUL_COMMUNITIES/links/57ca8a1e08ae89cd1e842956/THE-BODY-OF-CHRIST-HAS-DOWNS-SYNDROME-THEOLOGICAL-REFLECTIONS-ON-VULNERABILITY-DISABILITY-AND-GRACEFUL-COMMUNITIES.pdf?origin=publication_detail