Down Syndrome Ireland

Dual Diagnosis

Down Syndrome

Autism

Information for Parents & Teachers

2021

Contents

Background Information

Given that autism is very common in children with intellectual disability, with rates reported at around 40%, it should not be surprising that the proportion of children with Down syndrome who are screening positive for autism, is also high. However, the expectation set by early medical textbooks, is that Down syndrome actually reduces the risk of having autism. The fact that Down syndrome is diagnosed very early in an infant's life may play a part in low rates of the dual diagnosis. Thus, once the diagnosis of Down syndrome is made, medical professionals generally do not seek other explanations as to why the child is not following a typical developmental pattern. In other words, other conditions are not looked for. However, if a child with Down syndrome also has an additional disorder, such as autism, this diagnosis can be very helpful in ensuring access to dedicated support e.g. autism specialist schools.

For many years, the possibility of a co-occurrence of autism and Down syndrome was considered to be very rare. However, over time, researchers began to take note of the possibility that some children with Down syndrome could also be challenged by an additional behavioural diagnosis i.e. autism.

Given that autism is very common in children with intellectual disability, with rates reported at around 40%, it should not be surprising that the proportion of children with Down syndrome screening positive for autism is also high.

Autism

There is some information we need to know about autism spectrum disorders before we can begin to comprehend what autism might look like in a child with Down syndrome:

- **Autism is a developmental disability identified by a developmental and behavioural evaluation process. There is no medical test for autism. Therefore, it is extremely important for personnel evaluating the child to be skilled and experienced.**
- **Autism involves disorders of the development of the nervous system, including the brain.**
- **Autism in a child may involve many of the child's biological systems e.g. gastro-intestinal, vision, immune etc.**
- **The specific cause of autism is not known, but scientists feel that the condition is strongly genetic.**
- **The biological aspects of autism have not been found to exist in any one part of the brain, but are more likely to involve problems in the way the brain can send and integrate messages across different regions of the brain.**
- **There is an increase in the percentage of children with autism throughout the developing world. Research in 2013 found that 1 in 91 children had autism. This is significantly higher that the estimates generated in 2005, of 1 child in every 2500 children having autism.**
- **Autism is reported to occur in children of all races, ethnicities and socio-economic groups. It occurs more often in males, with an approximation of 3 boys diagnosed for every 1 girl.**
- **Clinicians and researchers would say the disorder is 'heterogeneous' or 'having a lot a variability'. Possible sources of differences in how autism presents in different children are outlined in the following table.**

Sources of Individual Differences in Symptom Presentation in Autism

	How Differences Impact Symptom Presentation
Chronological Age	Younger children show different forms of social, communicative and behavioural differences than older children. Children with autism under 3 years of age might not understand what simple gestures, such as pointing, mean, and they are less likely to follow an adult's pointed finger with their eyes. However, most children with autism will have learned to do this before they begin primary school. Therefore, failing to follow a point is an important symptom in pre-school children and toddlers. However, this symptom does not differentiate children with autism from other children in their primary school years.
Overall Developmental Level	A child's overall developmental level is an important consideration in setting expectations for the development of social and communicative skills.
Patterns of Cognitive Strengths and Weaknesses	Some children with autism are better at solving problems without language, others are better using verbal reasoning. Some children with autism learn better with visual supports. Other children learn better through auditory supports, for example, listening, while others learn better with kinaesthetic supports, for example, moving or doing.
Temperament	Children with autism tend to respond to situations in predictable ways.
Activity Level	Some children with autism are very active and constantly moving. Other children are more lethargic and may seem slower to respond.
Emotional Intensity	Some children show strong emotional feelings, while others have less reactive responses to situations and experiences.
Adaptability or 'Behavioural Flexibility'	Some children with autism are better able to adjust to changing situations or experiences. Other children have great difficulty with any requirement for change or flexibility.
Persistence or 'Mastery Motivation'	Some children persevere to complete a task while other children give up more easily. They can show varying levels of persistence, particularly with tasks they are interested in.
Distractibility	Some children are very easy to distract, or become unfocused, while others are difficult to distract from what they may be doing. Some children demonstrate both of these traits at different times.

A diagnosis of autism is only relevant, if difficulties in social functioning and nonverbal communication are less developed than would be expected for the child's development level, not the child's chronological age.

Features of Successful Intervention Strategies for Children with Autism

- **A combination of behaviourally oriented strategies with developmental and educational approaches relevant to the individual child's profile of skills and deficits**
- **Recognition of the need for structured teaching programmes, with a particular emphasis on visually based cues - these provide the child with a predictable and readily understandable environment, which helps to limit confusion and distress**
- **A focus on the development of social-communication and play activities, especially with peers, and if possible the implementation of specialist training programmes**
- **Acknowledgement that many so-called undesirable behaviours are a reflection of the child's limited behavioural repertoire or poor communication skills - a focus on skill enhancement is therefore often the most effective means of reducing difficult and disruptive behaviours**
- **Understanding of the importance of obsessions and rituals, not just as an underlying cause of many behaviour problems, but also as having a vital role in reducing anxiety and as powerful sources of motivation and reinforcement**
- **Treatment approaches that are family-centred rather than exclusively child-oriented**
- **Management strategies that can be implemented consistently without excessive sacrifice of time, money and other aspects of family life.**

Structured Teaching Programmes

Focus on Skill Enhancement

Family Centred Approaches

Down Syndrome

Basic Facts about Down Syndrome

- **The majority of cases of Down syndrome are caused by 'nondisjunction' or failure in cell division. Three copies of Chromosome 21 are found instead of two copies.**
- **Down syndrome affects over 300 genes and therefore affects multiple systems.**
- **Down syndrome is associated with specific facial features.**
- **Down syndrome is associated with a specific cognitive profile.**
- **Down syndrome may predispose some children to specific behavioural issues.**

Down syndrome is a genetic condition caused by the presence of an extra chromosome 21 in a baby's cells. The impact of the additional chromosome 21 varies considerably from child to child as they grow and develop. Children with Down syndrome have developmental delays in all areas of functioning, although the degree of delay varies greatly from child to child. Developmental delays will result in children having some level of additional needs but again, the degree and impact of those needs will be different for each child. While children share some common physical characteristics, their personalities are unique. Just like any typically developing child, they can be very sociable or very shy, well-behaved, or difficult to manage.

Children with Down syndrome develop more slowly than their peers, but can make progress in all areas of development. Recurring patterns in the development of children with Down syndrome, when considered as a group, have been identified and can be considered a Developmental Profile of characteristic strengths and weaknesses associated with the syndrome. Good social interaction, visual learning and reading ability are among the strengths attributed to children with Down syndrome. Weaknesses include delays in motor, speech and language skills, with impaired short-term memory skills. More detailed information can be viewed in the following tables. This profile is quite distinctive and different to the profile exhibited by children who have a similar level of learning disability, but do not have Down syndrome. However, children can also share some characteristics with children who have General Learning Disabilities.

Developmental Profile Associated with Down Syndrome

Learning Strengths
Social Understanding and Social Interactive Skills
• Able to form friendships. • Can enjoy learning with and from peers. • Can acquire age-appropriate behaviour and show concern for others.
Non-Verbal Communication
• Able to understand and use gestures, eye contact and facial expression. • Usually quick to pick up on non-verbal signs of emotions, such as anxiety or disapproval.
Visual Processing and Memory
• Can learn effectively from visual information. • Sight word reading uses visual skills so often an area of strength.

Learning Needs

Speech & Language Development

- Receptive language more advanced than expressive.
- Specific speech production difficulties often exacerbated by hearing problems.
- Spoken vocabulary delayed but grows progressively.
- Tendency to talk in key words rather than complete sentences.
- Grammar is often an area of difficulty.
- Limited expressive language makes it difficult to express feelings and negotiate social situations.

Motor Skills

- Low muscle tone and loose muscle joints affect the acquisition of gross and fine motor skills, especially in the early years. These improve with practice as the child grows older.
- Gross motor skills can become an area of strength.

Verbal Short-Term Memory and Verbal Processing Skills

- Specific impairment in ability to process and retain verbal information leads to problems in following verbal instructions, sequencing skills, and remembering rules and routines.

Motivation

- Can be hard to motivate, particularly when new skills are introduced.
- May display low levels of persistence and a tendency to drop out of more demanding tasks.
- Task avoidance may be caused by fear of failure and lack of problem-solving skills.

Additional Learning Needs Associated with General Learning Disabilities

Attention

- May have short attention span.
- Can find it difficult to focus on relevant aspects of learning situations.

Transfer and Generalisation Skills

- Typically have problems applying knowledge and skills in new learning situations.

Retention and Maintenance of Learning

- May take longer to master new skills.
- Performance tends to be inconsistent – varies from day to day.
- Previously learned knowledge and skills often lost – overwhelmed by new learning.

Self-Management Skills

- May find it hard to organise materials, to recognise when to look for help and to check work for errors.
- Inclined to depend on others for direction and support.

Dual Diagnosis

of

Down Syndrome

&

Autism

Making a Dual Diagnosis

There is no doubt that autism is more prevalent (around 5 per 100) among those with Down syndrome than in the general population (around 1 per hundred), but diagnosis presents problems, particularly for professionals with little prior experience of the very distinctive behavioural and developmental patterns associated with the syndrome. The hallmarks of the disorder are:

- **impairments in social interaction**
    - **social communication (including speech and language)**
    - **imagination**
- **repetitive behaviour patterns**
- **resistance to change in routine**

Bearing in mind that it is normal for children with Down syndrome to be delayed in developing speech and language and pretend play, that many like doing the same things over and over again, and that both oppositional and opting out behaviours are common, it can be quite difficult to disentangle what is normal development for a child with the syndrome and what is abnormal.

Autism should be considered, but is not necessarily the cause in any preschool child with Down syndrome who is failing to make expected progress in speech, language, communication and social skills, or in any older child who shows regression of these skills.

One point stressed by Dr George Capone is that in Down syndrome, autism may be first recognised at a later age (between 3 and 7 years old or sometimes even in the teenage years) than is usual in other children (usually by age 2-3 years).

In these later onset children with Down syndrome, the hallmarks of the disorder are:

- **loss of speech**
- **social withdrawal**
- **lack of initiative**
- **a general air of not being interested in anything**
- **just not wanting to be bothered about anything or by anyone – the intense need for 'aloneness' as described by Kanner.**

It is critically important that autism, when present in a child with Down syndrome, should be recognised as early as possible because the dual diagnosis has implications for education and management which will carry through into adult life.

Often a diagnosis of autism may be more important as far as educational placement is concerned, than the fact of a learning disability. Unfortunately, because of a lack of training and knowledge of the syndrome by some healthcare and educational professionals to whom a child may be referred, it is not unusual for the diagnosis to be missed. Once suspicion has been raised, the child is usually referred to a specialist multidisciplinary team who will take a detailed history from the parents, observe the child in a clinic setting and often at home with family members, in school or nursery or some other group situation with which the child is familiar.

A variety of special diagnostic tools – questionnaires, interviews and observational schedules – will usually be used in parallel with history taking and clinical observation, but these tools are never used in isolation to establish a diagnosis. They do not in themselves provide a definitive answer to the question, 'Does my child have autism?' A specialist will take all the information together to advise you of their opinion

Frequently Asked Questions

Is Autism more common in boys with Down syndrome?

Many research studies have shown that autism is more common in boys, with rates reported at around four times higher than in females. Although previous research into autism in Down syndrome has not reported a gender difference, it was found that boys were around twice as likely as girls to meet the autism screening threshold. However, the difference is not as pronounced as typically seen in autism.

Is the profile of Autism characteristics the same in children with Down syndrome?

There are several characteristics, including offering comfort, social smiling and eye gaze that are better developed in children with Down syndrome who screen positive for autism compared with people with autism only. On the other hand, the children with Down syndrome and autism tend to have more severe compulsions and rituals.

Are there behavioural differences?

When the behaviour of the children with Down syndrome who met the threshold for autism was compared with that of other children with Down syndrome, there were higher rates of emotional symptoms, conduct problems, hyperactivity and peer problems in the first group. Levels of conduct problems and hyperactivity in the Down syndrome and autism group were just as high as in an autism-only group. In contrast, they showed fewer emotional problems than the autism-only group.

Parents also reported that children with Down syndrome and autism tended to have more communication and social relating difficulties, (although they often had good eye contact), as well as being more self-absorbed. Teacher reports echoed these findings. However, teachers tended to describe more anxiety and disruptive behaviours at school. It might be that context plays a part in how anxious or disruptive children are, or it could be that the interpretation of behaviour differs between parents and teachers.

Although levels of communication and socialisation difficulties in children with Down syndrome and autism were similar to those with autism alone, the pattern of these difficulties often differed. For example, the children with Down syndrome were more likely to approach others, but they had more limited vocabulary than children with autism only. They also tended to have poorer daily living skills i.e. in self-care, and domestic tasks etc.

What is the Impact of a Dual Diagnosis on the Family?

Several studies have shown that having a child with autism can be stressful and affect parental wellbeing. On the other hand, stress levels in parents of children with Down syndrome are reported to be no higher than those of other parents. There is a risk that the pressures of raising a child with Down syndrome and autism go undetected, given that the formal dual diagnosis is rare. The parents of children with Down syndrome and autism reported a higher level of stress than those with Down syndrome only. It seems that the often challenging behaviours of children with Down syndrome and autism may contribute to stress levels. Lack of perceived support may also have an impact, although to a lesser extent.

Communication Issues

Communication is one person conveying a message, verbally or non-verbally, to another. Interaction happens when one person responds to the other person's communication. Children with autism may have the ability to speak or sign, read and write, but find it harder to use these skills effectively to interact with others in a sociable way. The National Autistic Society (NAS) has a useful article which gives some advice about communicating and interacting with a child who has autism. They suggest that it is important to observe the ways in which the child communicates, in order to identify their communicative strengths and needs, and to be able to respond to and interact with them effectively. It is also important to understand why the child is communicating. By understanding the purpose of their communication, NAS suggests that you can help them to find more ways and reasons to communicate.

Additional Resources

- Down Syndrome & Autism
  https://www.ndss.org/wp-content/uploads/2017/11/2017-DS-Autism-rv3.pdf
- Autism Society of America
  www.autism-society.org
  Improving the lives of all affected by autism
- Autism Speaks
  www.autismspeaks.org
  An organization with the goal to change the future for all who struggle with autism spectrum disorders
- Down Syndrome-Autism Connection
  www.ds-asd-connection.org
  An organization committed to providing education and support to individuals facing the unique challenges caused by co-occurring Down syndrome and autism
- National Association for Dual Diagnosis
  thenadd.org
  An association for persons with developmental disabilities and mental health needs.

BOOKS

- When Down Syndrome and Autism Intersect. Froehike, R.N., Zaborek, Robin. Bethesda, MD: Woodbine House. (2013)
- Dual Diagnoses: The Importance of Diagnosis and Treatment. Patterson, B. (1999).

ARTICLES

- Down Syndrome and Autism Spectrum Disorder: A Look at What We Know. Capone, G. (1999). Can be found at www.kennedykrieger.org/patient-care/outpatient-programs/down_syndrome_autism_spectrum_disorders
- More than Down Syndrome: A Parents View. Gurthie Medlen, J. (1999). Can be found at www.kennedykrieger.org/patient-care/outpatient-programs/parents_views_down_syndrome

Hannah Patterson, Access Project Practitioner and Vanda Ridley Communications Manager. Down Syndrome Association, who have developed a series of focus meetings for parents who have children with a dual diagnosis of Down syndrome and Autism Spectrum Condition (DS/ASC).

Communication and interaction' along with others on social isolation and social skills, can be found on the NAS website www.autism.org.uk

Educational Programmes for Children with Down Syndrome & Autism

School Communities

Relationships are key to making the journey as successful as possible

The School

Teachers need to see the child, not just the label. Sometimes, from the parent's perspective, it takes persistence. At other times, it may take additional steps:

- **Network with other parents about which teachers they have found to be collaborative and open**
- **Always check in with the principal**
- **Stay positive and be persistent**
- **Participate in support groups.**

School Leadership

The first relationship to build is with the principal of the school. They set the tone for the school community. If they value children with disabilities, children with a dual diagnosis will be valued too. If principals do not take ownership for every child in their school, then they are not modelling that belief for the entire school. Many principals' hesitancies are founded on fear and in their own uncertainties. Building a relationship with the principal is extremely important. It is crucial that the principal knows both parents and child, and understand that they will be a positive force in the school for all children. The neighbourhood school will always be the ideal for the sense of community and belonging.

Parent Expertise

The importance of valuing the expertise of parents cannot be overstated. They know their children best and have thousands of hours of experience. They know the child's likes and dislikes, their subtle and obvious

forms of communication, what makes them smile, become angry, fearful or calm. Information should be shared between parents and school. Make sure to include parents' insights, recommendations and ideas in any formal or IEP meeting. Parents should inform the school about their child - who their child is within the family, as part of the family rather than just defining them in terms of disability, the child's strengths and weaknesses, interests and favourite things, their dreams for their child and their vision for the future.

Parental expertise must be valued

Include parents' insights & ideas

Vision for their child's future

Building Relationships

Special education traditionally comes from the medical model, which is very different from the educational model. As a result, the focus is often on the disability, rather than the whole child. We should bring a team together that keeps the whole child at the heart of their work. We need to know that when we create learning environments that focus on the many ways children learn, we are enriching the experience for all children. Many teachers feel that they do not have the expertise to work with children with a dual diagnosis and other disabilities, but when teachers have a 'heart' for children, they are good instructors and educators for all children. Good teachers are those who ask questions and keep learning. This will enhance children's success. Teachers need to be asked for their input in relation to the child with any Special Educational Need (SEN), to identify the child's strengths as they see them and what they would like the child to learn. Teachers also need to learn how to value the child in their class, to include them in the class and to value any contribution they make. Teachers need to encourage the development of friendships in their class. It is also vitally important to support teachers' needs and to ensure they are aware of how important they are in the child's life. Their preferences for communicating with parents should also be respected.

Team Roles & Responsibilities

It is too easy to make assumptions as to who will do what. It is important not to make assumptions about this and to know which team member to approach for key information. Decisions must be taken about the input of all team members in developing the IEP; in giving information to parents; in ensuring successful curriculum access; in providing visuals to support the child; in ensuring that the whole team knows how to use visuals, strategies and prompts to help children achieve success. Decisions must also be taken in relation to collating data and reviewing the child's progress; and organizing training for all the team about Down syndrome and autism. All students in the school must be encouraged to create a welcoming, inclusive classroom community, while learning to value diversity and difference

Team Communication

Establishing a communication system with the whole team will help everyone be and stay on the same page. As a starting point, it is worth brainstorming to discover what the team will need to know about home, and what the family will need to know from the school day. A home-school communication book is useful, with key ingredients in an easy-to-use 'tick' system, with a few blanks to add any extra notes needed. Decisions must also be taken on the methods of sharing private data or information between team members, or with the home.

- ## In the Classroom

What does research say about creating successful learning opportunities for students with Down syndrome and autism? The potential of children with a dual diagnosis is often hidden and lost because of what assessments do not measure, and because the labels often get in the way of people seeing possibility and setting expectations to match.

Key Points

- **Visual supports, schedule, maps etc. are extremely important because they provide ongoing and consistent information for students. They provide non-intrusive support and provide time to process information. Visuals enhance communication and organisation and promote connections and interactions.**
- **Enlist typically developing peers in the development of visual supports and use the interests of the child to promote value and meaning.**
- **Find communication systems that work. Having multiple modes and ways for students to receive information and to express themselves is critical, such as, sign language, picture systems, and verbal and electronic devices. It is best to try out a variety of systems first before investing money in one. This is also another place to enlist the involvement of typical peers, by helping the child to learn how to use the system and how to respond.**
- **Get augmentative communication and assistive technology assessments done to identify functional and relevant tools. Do this early and continuously throughout the school to ensure the child is getting the appropriate tools. It is important as well, to have support for the whole team to learn how to use these tools effectively. Follow up consistently to ensure that they remain the best tools as the child grows and learns.**

- Ensure that the curriculum is modified and accommodated specific to the child. It is about breaking the expectations down to smaller pieces. Once a team learns how to make modifications and accommodations, they will begin to see that it benefits more than just one child, as every classroom has diverse learners and there are no 'typical' classrooms.
- Pay attention to positive behaviour support planning.
- The school staff need to work to ensure that the child has natural supports, such as reciprocal friendships and connections with their typically developing peers.
- Offer plenty positive reinforcement and visually reinforcing rewards for behaviours you want to encourage.
- Arrange team training in the school and include parents in this training. Any training should look at best practices, knowledge of the individual's learning styles, working as a team, defining the adult roles and responsibilities, positive behaviour planning curriculum accommodations, modifications and much more.
- Use social stories and try video modelling, taking videos of desired behaviours and actions.
- Emphasize the importance of the child learning independent skills, such as self advocacy and self-monitoring, to prevent learned dependency and learned helplessness.
- Data collection and progress monitoring will help ensure that the child is growing and that the instruction provided is producing the results the team desires.
- Encourage continuous team planning, problem-solving and celebration.

Inclusive Best Practices

Inclusion when done well with commitment, researched best practices and heart, makes all the difference in the lives of children. Inclusion is about valuing every person, every child and every student. Every child should respected and welcomed, not just be present in the classroom. By setting up the necessary support services and activities to include putting plans in place, the child with Down syndrome and autism can be a successful participant and learner with a genuine sense of belonging. We need to ensure that we have the right supports in place. We need to be sure that the team is trained. The bottom line is to ensure the plan is about what adults will do to support the child, not how the child should change to fit what adults want.

- **Building Friendships and Communication with Typical Peers**

What can parents do to promote friendships?

- Make your home the place to be!!
- Welcome other children with snacks, games and things the child and the other children enjoy.
- Notice what the other children do, where they hang out, music they like, activities they enjoy.
- Get the child involved in community groups and activities with neighbourhood children at the same age.
- Help your child to reach out, phoning, inviting children over to go shopping or on family outings
- Invite two or three children to keep the things moving and help everyone to build friendships.
- Show others how your child can participate and demonstrate ways to make your child feel comfortable and safe in new situations. Then step back and let the children be together.
- Keep adults presence and interference to a minimum in the day-to-day routines.
- Speak up and get involved. Let other people see you and your child in the neighbourhood and in the community.

What can teachers do to promote friendships?

- Have regular class meetings or circle time for sharing feelings and problem solving.
- Use co-operative learning strategies with the whole class to teach communication and teamwork.
- Set up buddy systems that facilitate students working with each other.
- Go to students to suggest solutions.
- Role-play with all students to teach new skills and to increase self-confidence.
- Look for ways to involve every child in the curriculum. Break down the task and let each child have a role, using his or her strength, for example, using the calculator to check maths work or be a time keeper for a quiz.
- Make sure all students have the same opportunities with routines and procedures, homework, report cards, test presentations.
- Communicate, and model respect and valuing of the child in your interactions and your behaviour.

- Do not forget to include appropriate goals in the IEP related to co-operation and communication and friendships.
- Teachers cannot make friendships happen but they can create welcoming classroom communities that foster respect and belonging, and create a natural environment for friendship to grow.

- ## Positive Behavior Planning

  Sometimes, the missing piece in behaviour and dealing with behaviour issues, is that we truly do not get down to what a child is trying to tell us. We sometimes make assumptions and miss the point. So what should we do? We need to take time to gather people together, include peers, to give them a chance to meet or brainstorm. We need everybody to come together and discuss how we might do things differently. Finding the real reason behind the behaviour is important. We often focus on the difficult behaviour and what we will do when it occurs. Instead we should focus on the specifics of the behaviour. Put yourself in the child shoes and make 'I' statements of what the behaviour may be saying. Then, instead of the process being adult driven, it becomes child-centred. With clear 'I' statements, we can better plan what the need is and how to support the child. The outcomes are different when you try to look through the eyes of the child. You also start to see a theme. Then, it becomes the responsibility of the team to not only create the tools and visuals, to give the student the voice but also to be sure that the tool is always available to the child. We must listen to children!

  The collection of data is critical so that we know who was there, what the activity was, what the behaviour looked like and how everyone responded. It is important too, for parents to see this data. We can use very simple forms with just key headings listed that will paint the picture of what is happening. If the data does not give us clues, then we might not have enough data or accurate enough data. Parents can also collect data at home if they are seeing a concerning behaviour. The more specific the data, the more information we will have to work through. When behaviour seems to be the biggest concern, the key is to ask for observations to be completed, for the team to track the questions listed, and then get people together to look more deeply at the data. We can then try to figure out what to do differently, what to add to the supports, what to change rather than all the time considering that the child is the problem.

- ## The Role of Additional Adults

  The role of additional adults in the classroom can be extremely difficult. The SNA can have multiple supervisors and directions, along with a huge desire to do right by the child. So, when the team is planning for student support, a crucial point to remember is that every team member has an important role. When

the rules are clarified, the needs of the students must be kept at the forefront. Once the teacher understands the role of the SNA, they take ownership for every child. Sometimes, the SNA with the best will in the world, can be causing difficulties for the child with disabilities. Some examples of this include an SNA sitting between two students with disabilities, helping them with their lessons, moving to help others when they came to her, but when two other students came to her and asked her which snack the student with Down syndrome and autism wanted, it should have been a red flag! They could have asked the student themselves. The students without disabilities had come to believe that the SNA was there for the students with disabilities and was that student's voice. It is not what the team wanted to happen and it demonstrates the importance of looking for signs of what the SNA role was becoming.

Another red flag could be identified if the student with disability does not really need to do anything because the SNA is sitting with them all of the time. The student did not need to raise their hands to ask for help, to look for the teacher or to even consider what to do for themselves, because if they look puzzled or were not working, the SNA, with the best of intentions jumps in, directs or prompts. This is how learning dependency starts. If instead, the SNA moved around the class, helping others, coaching peers to give directions or information, the scene becomes very different and we can see the student's independence and confidence growing. That is why the role of the SNA and promoting student independence are so closely related. We need SNAs to see themselves as facilitators for students, to look after their care needs, in addition to helping students to learn to listen and to focus on the teacher, to access the curriculum, to check in with a peer. SNAs should refer a parent to the teacher and not discuss the child themselves. They should follow the teacher's lesson plans, record progress data for the child, if required, but continually step back to promote student independence.

- **IEPs**

Prior to the IEP meeting, it is important to set an agenda and to set a timeline; decide who will be at the meeting; what are the assessment results, progress updates and goals. Ensure that all of the team will have time to read this, prior to the meeting. Be sure that the agenda gives an opportunity for every team member to discuss the child's strengths, along with their work samples and examples of the strategies and instructions that are helping the child to learn. An IEP could include data about the student's present levels of performance; how progress is monitored; whether the goals change from year to year, if they are the same every year, and if this is the case, to question why it is the case. An IEP should include parental input, along with ideas, progress and information from the teachers. Goals and objectives need

to make sense to the student and must be achievable, reflecting the goals for every child. The goals should be tied to the core curriculum for the student's class and show how we will know when the goal is reached. They should also include goals that teach co-operative skills with other children in their class.

- ## Transition Planning

Everyone planning for the child's transition must have a vision that is bigger than what life has been for most students with Down syndrome and autism in the past. Our young people are now going to college, they can have jobs they like. It is everybody's job to hold the same kind of dream for the child with Down syndrome and autism as they do for every other child. It means listening to the person, their friends and their same age peers and giving them the way to voice their dreams. Part of the discussion about transition from primary to post Primary School is thinking about what will happen in post primary school. One of the key questions to ask is what all the other post-primary students are doing. Is the student with Down syndrome and autism out of classes and away from their friends all the time? The recommendation is, to do with a child with Down syndrome and autism just as we do with every other students. Let them experience post primary school and learn all they can then because, remember, work and life after school will always be there. It is important to remember that any transition plan is a work in progress and it is a team approach. Remember to rejoice and enjoy who the child is and the uniqueness they bring. Do not ever let labels, difficulties and uncertainties take the joy out of the child's presence in the school or classroom.

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Buckley, S. et al, (2001)
Down Syndrome and Autistic Spectrum Disorder: A Look at What We Know
George T Capone
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