**DLA Guidance Notes**

**Older children (approx. 11+)**

**About the child’s illnesses or disabilities**

**“List the child’s illnesses or disabilities in the table below.”**

Things to consider listing:

1. Down syndrome with global developmental delay and severe mental impairment

Treatment: consider whether your child receives any of the following :

Specialist 1:1 provision at school,

Speech and Language Therapy Input,

Makaton/Somerset Total Communication

How often: daily/constantly

1. Hypermobility and hypotonia

Treatment: does your child receive/require:

A daily routine of exercises

Physical support or assistance

Access to Physiotherapy team

Access to Occupational therapy team

Visits to orthotist

Use of specialist equipment

How often: daily/many times a day every day/constantly

1. Communication disorder

Treatment: does your child receive/require:

Speech and Language therapy

Makaton signing

PECS &/or other visual prompts for every day instructions, rules, routines

1. Other issues to consider including

Hypothyroidism

Any other specific medical complaints

Issues with sight – visits to orthoptist/optician/ophthalmologist

Issues with heart/bowels, including surgery and periods of hospitalisation

Hearing – grommets operations, frequent audiology tests

Severe behavioural difficulties

**Mobility**

**“Aids and adaptations”**

Does your child require any of the following:

* PECS and other visual communication aids - support from school/home to encourage use of the resources to encourage communication
* Disabled toilet/changing facilities at school – to enable nappy changing/clothing changing to be managed in a safe and private way
* Angled writing desk to help with posture and fine mobility tasks at school

**“Please tick the boxes that best describe how far they can walk without severe**

**discomfort and how long it takes them.”**

Please be aware that in the vast majority of cases, children with DS claim eligibility for the mobility component on the grounds of BEHAVIOURAL issues & not physical.

If this is the case with your child, do NOT estimate distance they can comfortably walk – leave this section blank. Tick ‘No’ (**Do they have physical difficulties walking?)** and move on to:

**“Do they need guidance or supervision most of the time**

**when they walk outdoors?”** And answer **‘Yes’**

**“If you want to tell us why you have ticked the boxes, how their needs vary or anything**

**else you think we should know, use the box below.”**

XXXX has severe mental impairment and challenging behaviour.

Questions to consider:

* Does your child need constant vigilance in order to ensure their safety?
* Is your child frequently unpredictable when out and about?
* Does s/he have an age-appropriate awareness of the danger of roads/cars/ strangers?
* Does your child frequently attempt to run or bolt when walking from the house to the car? Do you need to keep hold of your child at all times while attempting to open the car in order to keep him/her safe?
* Do they ever run off and hide? Does his/her poorly developed sense of dangers and hazards mean that s/he can often hide in dangerous places such as behind the wheels of cars?
* If the front door/garden gate is left open, is your son/daughter prone to running off?
* Does s/he constantly attempt to wriggle free from your hand or become cross and uncooperative when you attempt to bring him/her back after running off? Is physically restraining your child increasingly difficult because of their size/their younger siblings/any other reason?
* If s/he has run off, does s/he respond to a verbal request such as “Stop!” or “Come here”? Will s/he respond to the promise of reprimands or rewards? Is s/he liable to be responsive to adult persuasion when running off/refusing to move?
* Will s/he frequently sit, even in mud or puddles, and refuse to move or walk when out and about with you? Does s/he throw themselves to the floor when stubbornly refusing to co-operate?
* Does your child often mouth things s/he picks up off the floor, or touch rubbish bins, etc, and put fingers in mouth afterwards? Does his/her mental impairment make him/her prone to seeking inappropriate sensory stimulation such as licking or mouthing objects from the floor?
* Can you rely on him/her to hold your hand/a buggy handle when walking or will s/he frequently let go and run off, regardless of the dangers of roads etc.
* How good is s/he at being able to discriminate between different surfaces – eg edge of a pavement, where the ground changes level without being clearly marked?
* Is s/he so independent that it is difficult to ensure their safety (eg refusing to hold your hand while crossing the road)?
* Would loud noises (eg noisy lorry/train) make them scared and mean their behaviour is even more challenging and unpredictable?

**Extra information about mobility**

**“If you want to tell us anything else about their mobility, use the box below.”**

Additional points to consider:

* Does your child refuse to co-operate even with familiar journeys/routines when out and about? Are they liable to become even more unpredictable/ uncooperative when in unfamiliar/noisy/crowded environments?
* Are sudden noises liable to make your son/daughter bolt, regardless of dangers and hazards?
* Is s/he in constant risk because of this ill-developed sense of danger?
* Does his/her severe mental impairment mean that the potential threat of standing in front of a moving vehicle cannot be processed or acted upon without immediate adult intervention?
* Does tiredness/ill-health make your son/daughter even more liable to unpredictable/un-cooperative behaviour? Does it make him/her even more resistant to adult intervention?
* Does his/her auditory processing issues make it less likely that a simple verbal instruction such as “Stand still”, “Stop” or “Come back” will be heard, processed, understood and acted upon in time to prevent your son/daughter from putting him/herself at risk? Does it increase the number of incidences when the physical intervention of an adult is essential?
* Does even the shortest journey involve a great deal of time, verbal persuasion & encouragement? Has the behaviour ever proved so difficult to manage/proved so distressing that you have cut short/abandoned your plans? Are there places/environments/journeys that you will not attempt or that you will only attempt in the presence of two adults in order to ensure safety? Does his/her size/weight/strength mean that you will only attempt most journeys in the presence of two adults as the only means you can reliably ensure his/her safety?
* Do these difficult behaviours happen almost every time you are out and about? Does it make progress slow and distressing on almost every occasion you go out?
* Do you consider your son/daughter virtually unable to walk safely as a result?
* Is s/he independent to the point of not listening to safety instructions/refusing to hold your hand to cross a busy road?

**Care**

**“Do they need encouragement, prompting, or physical help to get into or out of or settle in bed during the day?”**

Points to consider:

* This section is only for DAY TIME naps

**“Do they need encouragement, prompting, or physical help to go to or use the toilet during the day**?”

* Does s/he suffer frequently with constipation/diarrhoea? Does this require massage/additional bathing/medication/more frequent changes and cleaning? Does it cause pain/discomfort/distress and additional soothing and reassurance?
* Does s/he need additional assistance/prompting/encouragement/adult intervention to ensure that s/he is clean after toileting? Does s/he need 1 to 1 assistance with toileting both at home and in school? Does s/he need adult intervention to help him/her out of clothes in order to use the toilet/potty?
* Does s/he need constant reminders/encouragement to use the toilet?
* Does s/he frequently refuse to co-operate with adult intervention over toileting needs? Does s/he resist/get cross/throw things? Is this becoming increasingly difficult to manage because of size/weight/strength?
* Does s/he unravel toilet rolls/throw things into the toilet/turn on taps and not turn them off/have no awareness of the risk of scalding themselves from hot water and therefore need constant close supervision when using the toilet?
* Does s/he know not to touch or play with the toilet/toilet brush/toilet paper?

**“Do they need encouragement, prompting, or physical help to move around indoors, use stairs or get into or out of a chair during the day?”**

* Does s/he require a specialist physiotherapy programme to be implemented throughout the day in order to help develop his/her ability to manipulate objects/walk/mount & dismount a chair/manage stairs? Does s/he require significantly more physical support and intervention than typically developing peers in order to encourage movement/physical activity around the house?
* Does the significant cognitive impairment make it difficult for him/her to judge the amount of space around him/her? Does s/he require adult intervention to manoeuvre him/herself safely?
* Does hypotonia make him/her unsteady on his/her feet beyond the time when typically developing peers are able and agile? Does it hinder his/her ability to negotiate steps/curbs/stairs?
* Does severe mental impairment leave him/her unable to judge the significant hazards posed by stairs? Does s/he attempt to descend a staircase in such a way as to put him/herself at significant risk? Does this poor judgement mean that constant adult supervision is required?
* Does s/he attempt to climb - eg furniture, on to window sills/rock or tip chairs when sitting in them/misjudge height of furniture and bang his/her head? Does this make unfamiliar environments even more hazardous?

**“Do they need encouragement, prompting, or physical help to wash, bath, shower and check their appearance during the day?”**

* Is your son/daughter often resistant to being showered/bathed? Does s/he get cross, refuse to bathe, run off?
* Does s/he need bathing more often due to messy eating habits and/or problems with wiping him/herself after going to the toilet?
* Is s/he safe when in the bath or does s/he try to climb on the sides? Does s/he know not to touch the hot tap or does s/he need constant supervision?
* How do they behave when they need their hair washed?
* How does s/he react when brushing teeth?

**“Do they need encouragement, prompting, or physical help to dress and undress during the day?”**

* Does your son/daughter insist on choosing their own clothes and often choose inappropriate clothing (eg summer clothing in the winter) and take some persuading to change their mind/be persuaded to wear a coat?

**Do they need encouragement, prompting, or physical help to eat and drink during the day?**

* Is s/he prone to spilling drinks by accident?
* Can they use a spoon, knife and fork successfully and independently or do they need support to develop independent feeding skills, beyond the age when their typically developing peers are able to manage without help?
* Does /he have difficulty chewing? Is s/he more prone to gagging, choking and regurgitating food? Does s/he have to be constantly supervised in order to ensure their safety?
* Does s/he need encouragement to sit and bite/chew/swallow? Does s/he need a greater degree of intervention to encourage taking manageable mouthfuls? Does his/her communication delay make it difficult for him/her to express hunger/thirst/feeling full and lead to frustration/difficult behaviour?
* Is s/he resistant to certain textures of food or to foods of mixed textures, eg yoghurt with fruit pieces in? Does s/he bite her tongue or the inside of her mouth while eating? Does s/he often push food out of his/her mouth?
* Is meal time frequently a far messier business for him/her than for typically developing peers? Does this make it difficult to eat away from the home?
* Does s/he seek inappropriate sensory stimulation – eg eating inappropriate things?

**Do they need encouragement, prompting, or physical help to take medicine or have therapy during the day?**

Therapies to consider include:

* Physiotherapy – do you follow a daily programme of exercises designed to help counter hypotonia?
* Speech and language therapy – do you follow a daily programme of activities set by a specialist SLT designed to help build communication skills and counter his/her significant speech and language delay?
* Occupational therapy – do you follow a daily programme of therapies set by a specialist OT to help with the development of fine motor skills?
* Without this constant daily implementation of therapy programmes, would his/her developmental delay/cognitive impairment be even more marked?
* Do you need to make these therapies as fun and interesting as possible in order to keep him/her engaged?

Other points to consider:

Regular medications – is s/he amenable to taking them or highly resistant? Does it take two adults to administer effectively? Is it a cause of great distress to him/her?

**Seeing**

* Does your child have a squint? Does s/he require patching for this condition?
* Does s/he need eye drops?
* Does s/he require any visual aids: glasses/contact lenses; require large print?
* If s/he wears glasses, how good is s/he at keeping track of them and looking after them?
* As is the case for many children with Down Syndrome, xxx’s eyes are anatomically different. These differences mean that his/her vision, whether supported with the use of spectacles or not, is impaired and adversely affected. This impairment results in xxx’s inability to see things as clearly as other children – and means that his visibility does not have the ‘contrast’ mechanisms which clarify vision in addition to focussing ability. xxx therefore sees things as if ‘through a fog’ with everything suffering a ‘grey over-casting filter’.
* Xxx’s brain is also unable to ‘differentiate’ between things which need to be seen and things which don’t. For example when looking through glass or windows or at a screen he is unable to filter out reflections which then proceed to interfere with his/her processing and understanding of what s/he sees.

**Hearing**

* Does your child have difficulty in hearing?
* Does s/he have grommets and still have difficulty hearing?
* Does s/he suffer from frequent ear infections/glue ear?
* Does s/he get frequent colds, which affect his/her ability to hear and if so, how does this affect his/her behaviour?
* Does s/he suffer with fluctuating hearing loss requiring constant vigilance to ensure that his/her communication doesn’t suffer and in order to avoid bouts of difficult behaviour which can result?
* Can a drop in hearing result in your child’s social withdrawal/even more challenging behaviour?

**Do they have difficulty speaking?**

* Does s/he have a specific speech and language delay? *(****All*** *children with DS can be described as having a specific S&L delay)*
* Is speech production made extremely difficult for him/her due to poor oral motor control and general hypotonia?
* Can his/her attempts at verbal communication only be understood by very familiar listeners?
* Do familiar adults need to interpret his sounds/noises for others to know what s/he is trying to say?
* Does s/he rely on makaton, gestures and body language to make her/himself understood?
* Are his/her signs often unclear or physically incorrect due to his/her difficulty with coordination and fine motor skills?
* Does this limit the social interaction s/he has directly with others?
* Does s/he get cross and frustrated if s/he cannot make him/herself understood? If so, what does s/he do - just give up and walk away; become cross or upset?
* Does s/he receive Speech and Language Therapy and have a programme of exercises and therapy which needs to be worked on constantly or at every opportunity throughout the day?

**Do they have difficulty and need help communicating?**

* Does s/he need all communication simplified for him/her?
* Does s/he need his parents/TAs to model and teach key word signs to him/her?
* Does s/he need all instructions repeated and reinforced visually?
* Does s/he have a poor short term auditory memory *in common with all children with DS*? Does s/he therefore have great difficulty retaining and processing information and following instructions in the normal way?
* Does this have an effect on his/her social interaction with peers? Does s/he find it difficult to keep up with their games and the rules?
* Is s/he not able to express his/her feelings and does this sometimes make him/her upset and confused?
* Does s/he rely on specialist resources to communicate and interact?

**Do they need to be supervised during the day to keep safe?**

* Does s/he have any sense of danger or awareness of everyday risks?
* Will s/he run off or throw himself down?
* Does s/he understand key safety concepts such as hot or burn, fast or danger?  Is s/he able to read or understand warning signs?
* Have you had to make any safety adaptations to your home in order to keep him/her safe, such as removing some of the handles on doors, putting locks on cupboards or rooms or windows?
* Can s/he be left in a room on his/her own?  Will s/he attempt to climb furniture?
* Is choking a concern? Does s/he often seek sensory stimulation through putting all types of objects in his/her mouth – eg soil, sand, stones?
* Will s/he sometimes physically hit out, kick, pinch other adults or children?
* Will s/he throw things impulsively?
* Is his/her behaviour often unpredictable?
* Do all of these things happen on a daily basis and can it take a long time to manage the challenging behaviour and get back on task?  Are there occasions on which you have to give up on your plans, get back in the car or leave a venue or go home?  Is it sometimes impossible to do ordinary everyday family things without asking for extra help from family and friends?
* Is there a real and constant risk that s/he may get lost or hurt?

**Do they need extra help with their development?**

* Xxx has global developmental delay, severe learning difficulties and specific speech and language communication difficulties.
* Does your child need support to enable him/her to interact with others?
* How does his/her language difficulties affect his/her ability to socialise with peers (eg joining in games, initiating play, responding appropriately to invitations to play)?
* Does s/he manage to keep up with his/her peers physically ?
* Does s/he need all instructions to be reinforced visually as she has a poor short term auditory memory and cannot process or retain information in the same way as other children?
* Does s/he have processing and sensory issues which mean that s/he does not make connections between actions and consequences and has no awareness of danger?

**Do they need encouragement, prompting or physical help** **at school?**

* Does s/he have a Statement of Special Educational needs?
* Does s/he require and receive 1:1 support at school throughout the whole school day?
* Is this to ensure that his/her work it differentiated, his/her attempts at communication can be interpreted and so that s/he is included socially?
* Does s/he have global developmental delay?
* Can s/he write legibly or does s/he need help to record his/her work?

**What is their behaviour like at school?**

* Is his/her behaviour unpredictable?  Can it become worse when s/he is tired?
* Can s/he become very uncooperative?

**Do they wake and need help at night, or need someone to be awake to watch over them at night?**

* Is s/he awake on and off constantly throughout the whole night, every night?
* Is it frequently extremely difficult to settle him/her to start with and then s/he is awake again before you even get to bed?
* Will s/he frequently wake startled and upset or cold during the night?  Will s/he fidget in his/her sleep, thrash around, throw off his/her bedclothes, head bang or moan in his/her sleep? Is s/he extremely restless during the night? If s/he has thrown off his/her covers and becomes cold, will s/he make the connection and re-cover himself or will s/he wake the household and need an adult to come settle him/her and cover him/her up again?
* Does s/he suffer from sleep apnoea, will s/he hold his breath?
* Does s/he frequently try to get up and wander about during the night? If an adult wasn't being constantly vigilant, would s/he be at risk of hurting him/herself - from climbing on furniture or from choking as s/he puts things in his mouth, for instance?
* Do you have additional adaptations to your home in order to help ensure his/her safety during the night, such as stair gates and extra locks?
* Does an adult need to be constantly alert to the fact that s/he will wander off during the night?
* Does s/he suffer from frequent colds - on these occasions does s/he become very congested because his/her nasal passages are smaller as a result of the Down Syndrome? Does this make it more difficult for him/her to breathe easily? Does it make him/her distressed? Does his/her nose/eyes become very crusty and messy requiring cleaning and unblocking? Does s/he need to be propped up and his/her mouth gets very dry and sore as s/he has to mouth breathe? Does s/he need to be resettled each time these things wake him/her during the night?
* Is s/he awake extremely early in the morning while the rest of the household is still asleep? Does s/he have to be encouraged to go back to bed and stay in his/her room - although then s/he just climbs on furniture of throws his/her things around? Does s/he need supervising in order to ensure his/her safety during these early hours?

**If you want to tell us anything else about their care needs, use the box below.**

* If s/he wakes crying during the night, do communication and expressive language difficulties add to his/her distress? Can this mean that you spend a significant amount of time trying to eliminate possible reasons for his/her distress? Can s/he get even more distressed when you are unable to get the cause of his problems right?
* Can more frequent health issues, such as constipation, increase the frequency with which s/he wakes in distress during the night? Is s/he unable to make it clear that s/he is in pain? Does this also add to the level of his/her distress?

**Extra information**

**Tell us anything else you think we should know about the child’s claim.**

* Does s/he have a Statement of Special Educational Needs? Does this specify that s/he requires 1:1 supervision at all times in order to ensure his academic progress, see to his personal care and to ensure his well-being and safety?
* Does s/he spend part of the school/pre-school day working in small groups on specific educational interventions such as Speech and Language, literacy & numeracy, etc?
* Does seeing to his/her needs, ensuring his/her personal safety, personal care and delivering his/her therapies and interventions make ordinary family life extraordinarily difficult?
* Does seeing to these needs demand your full attention?
* Is it becoming ever more apparent that s/he requires a high level of support, supervision and intervention simply to achieve things his/her peers take for granted?
* Is s/he frequently stubborn, refusing to co-operate either around the house or when you are out and about? Does this make ordinary outings, such as to the supermarket extraordinarily difficult to achieve?
* As s/he is getting older, does this make dealing with his/her refusal to walk/move increasingly difficult to manage? Do you spend increasing amounts of time attempting to cajole or persuade him/her to co-operate? Are there frequent occasions where no amount of persuasion or distraction works, and you have to abandon your plans accordingly?
* Does s/he often just sit when you are out and about, regardless of whether the ground is wet or muddy? Do you then take him/her to get washed or changed? Can s/he be resistant to getting up/getting changed/getting washed in this situation?
* Is quantifying the amount of time these incidents take to deal with, or the frequency with which they occur impossible? Is delivering the care, supervision and input s/he requires a constant?
* Does his/her Down Syndrome with associated global developmental delay, mental impairment and behavioural difficulties make him/her unable to do so many of the things taken for granted by other children of his/her age?
* Is s/he prone to doing the inappropriate and the unexpected at any moment therefore requiring your constant supervision both for his/her own health and safety and that of others around him/her? Does s/he simply have no understanding or awareness of danger in its many forms – traffic, strangers, hot water, scissors and sharp objects, hot cookers and ovens, mouthing dangerous objects etc.
* Will s/he run off and hide? Will s/he respond to you calling his/her name when s/he has run off or his hiding or is s/he oblivious? Is his/her safety a constant worry?
* Would s/he be able to tell anyone that he was lost or who s/he was?
* Is every minute of every day used as a learning opportunity for him/her? Do you constantly use every activity, play session, and event throughout the day to encourage his/her speech, signing, efforts at communication, thinking and reasoning, understanding, learning and ensure that s/he is constantly stimulated.
* At school/nursery is his/her school work differentiated and delivered to him via a personalised curriculum, supported with communication aids and visual resources in order to enable him to reach his potential?
* Is disturbed sleep is a constant concern? Does this means that the whole household is awake during the night? Do you worry through the night about what s/he is doing? Do you need to be with him/her to stop him/her from doing the things that put him/her in danger such as climbing on bedroom furniture or putting things in his mouth? Do disturbed nights make him/her tired, irritable and uncooperative and do they make getting him/her up and ready for school extraordinarily difficult? Does it also affect his/her behaviour at school, at home during the day or when you are out and about with him/her? Does it cause him/her to have daily tantrums?
* And don’t forget to add that your child is loved and adored by all around him/her and that his/her family will continue to ensure that s/he receives all the support and care needed to enable him/her to have every opportunity to reach his/her full potential.