

# DLA Guidance Notes

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

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

Things to consider listing:

- a) 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 Nursery/School,  
Speech and Language Therapy Input,  
Portage/Play therapy  
Early Intervention Sessions,  
Makaton/Somerset Total Communication

How often: Daily/Constantly

- b) 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  
Use of specialist equipment

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

- c) Communication disorder

Treatment: Does your child receive/require:

Speech and Language Therapy  
Portage  
Makaton signing  
PECS &/or other visual prompts for everyday instructions, rules, routines  
Early intervention

- d) Other issues to consider including

Projectile vomiting and reflux  
Hypothyroidism  
Any other specific medical complaints  
Issues with sight and/or hearing

### **“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.
- Buggy –encouragement to remain in buggy because of behavioural issues when out and about/to safeguard against running off/stepping into the road/refusal to walk
- Disabled toilet/changing facilities at school – to enable nappy changing/clothing changing to be managed in a safe and private way
- Bed Rail – to prevent the child from falling out of bed during their sleep
- Stair gate – to help safeguard against the child’s instability on stairs/poor awareness of danger/low tone
- Sleeping bag instead of blankets or duvet – to maintain body temperature during their sleep/to prevent them from throwing off bedding during their sleep/because they toss and turn to a considerable degree during their sleep
- High chair/booster seat/wedge for seat – to safeguard against the increased risk of falling from an ordinary chair because of low tone & poor core stability/poor sense of danger/constant attempts to wriggle out of or rock the chair
- Supportive waist band/belt – OT prescribed in order to help develop greater core stability

## **Mobility**

**“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.”**

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 unco-operative when you attempt to bring him/her back after running off? Do you find yourself having to lift and carry frequently because of unsafe or unco-operative behaviour when out and about? Does your child frequently resist being picked up, either by going stiff or extremely limp? Do they bite, pinch, scratch, kick or lash out at you or passers by? Is physically restraining/picking up your child increasingly difficult because of their size/their younger siblings/any other reason?
- Do you find yourself having to rely upon a buggy, beyond the age when typically developing peers no longer require one, because of unsafe/unco-operative behaviour when out and about?
- 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? If 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.

## 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/unco-operative 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?
- Do you carry more than parents of typically developing children have to because of delayed toilet training/increased likelihood of soiling clothing? Does this add to the difficulties of physically restraining an unco-operative child when out and about?
- 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 an 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?

## 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:

- Does your son/daughter easily settle for a daytime nap/night’s sleep? Does s/he rely on adult intervention/support/encouragement/presence? Does s/he rely upon a strict pre-sleep routine in order to settle for sleep successfully? Does reliance on a strict routine make any unforeseen changes to that routine extremely difficult to manage?
- Does s/he frequently get out of bed instead of settling for sleep? If an adult is not constantly vigilant, is s/he at risk of endangering themselves by throwing/climbing/mouthing?
- Does s/he toss and turn during his/her sleep to a significant degree, so that s/he frequently falls out of bed/bangs his/her head against the wall? Does s/he frequently wake him/herself up when this happens? If s/he wakes too soon, does an adult need to repeat the pre-sleep routine in order to settle them back again?
- Does your son/daughter frequently/almost constantly suffer from severe congestion? Does s/he have great difficulty breathing properly when lying down in bed for daytime naps/settling down for the night? Does s/he need to be propped up as a result? Do you need to get him/her off to sleep in an upright position because of this?
- Upon waking is the congestion sufficient to cause distress and discomfort? Does this require additional support/reassurance/intervention?
- Does poor sleep impact on his/her behaviour during the day/upon waking? Does tiredness frequently result in difficult/unco-operative behaviours during the morning & the rest of the day?

**“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?”**

- Is s/he still unable to safely sit in a chair without restraint because of his/her significant developmental delay and hypotonia? Does s/he need propping up/a wedge/special equipment in order to enable him/her to sit because of hypotonia? Is s/he able to successfully manipulate objects with his/her hands when in an upright position? 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/roll/sit/crawl/pull to standing/stand/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 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 furniture/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 dress and undress during the day?”**

- Does hypotonia/hypermobility make your son/daughter ‘floppier’ than typically developing children? Is it more challenging for him/her to dress alone/to assist you when being dressed by pushing arms & legs through clothing? Do you have to take extra precautions to ensure that his/her arms & legs are not bent awkwardly because they are unable to do so themselves while being dressed?
- Is your son/daughter often resistant to being dressed? Does s/he get cross, wriggle, run off? Does s/he bite, pinch, kick or lash out while being dressed?
- Does your son/daughter insist on dressing themselves, in spite of difficulties in managing to pull on clothing, deal with fastenings, zips etc? Does dressing therefore take a great deal of time and require a lot of prompting, encouragement & patience?
- Does your child’s poor muscle tone result in more mess on clothing following meal times/increased dribbling? Do they more frequently suffer from diarrhoea? Do they therefore need their clothing changed more frequently than their peers? Does dressing your child take up a great deal more of your day than it might otherwise do?

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

- Does s/he need a lidded cup? Does s/he throw or deliberately spill or because of poor motor skills are they more prone to spilling drinks by accident?
- Do they struggle to use a straw? 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 /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?

**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?
- Portage/play therapy – do you follow a daily programme of specially designed games & activities set by a portage worker, designed to help build on specific areas of developmental delay?
- 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?

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?

**Speaking and communication:**

Does Oliver 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 due to his poor oral motor control and general hypotonia?

Can his 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 he was trying to say?

Does he rely on Makaton, gestures and body language to make himself understood?

Are his signs often unclear or physically incorrect due to his difficulty with coordination and fine motor skills?

Does this limit the social interaction he has directly with others?

Does he get cross and frustrated if he cannot make himself understood? If so, what does he do - just give up and walk away; become cross or upset?

Does 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 he need all communication simplified for him?

Does he need his parents/TAs to model and teach key word signs to him?

Does he need all instructions repeated and reinforced visually?

Does he have a poor short term auditory memory in common with all children with DS?  
Does he, therefore, have great difficulty retaining information, processing information and following instructions in the normal way?

Does this have an effect on his social interaction with his peers? Does he find it difficult to keep up with their games and the rules?

Is he not able to express his feelings and does this sometimes make him upset and confused?

Does he rely on specialist resources to communicate and interact?

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

Does he have any sense of danger or awareness of everyday risks?

Will he run off or throw himself down?

Does he understand key safety concepts such as hot or burn, fast or danger? Is he able to read or understand warning signs?

Have you had to make any safety adaptations to your home in order to keep him safe, such as removing some of the handles on doors, putting locks on cupboards or rooms or windows?

Can he be left in a room on his own? Will he attempt to climb furniture?

Will he sometimes physically hit out, kick, pinch other adults or children?

Will he throw things impulsively?

Is his 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 he may get lost or hurt? **Do they need encouragement, prompting or physical help**

at school or nursery?

Does he have a Statement of Special Educational Needs?

Does he require and receive 1:1 support at school throughout the whole school day?

Is this to ensure that his work is differentiated, his attempts at communication can be interpreted and so that he is included socially?

Does he have a global developmental delay?

Can he write legibly or does he need help to record his work?

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

Is his behaviour unpredictable? Can it become worse when he is tired?

Can 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 awake on and off constantly throughout the whole night, every night?

Is it frequently extremely difficult to settle him to start with and then he is awake again before we even get to bed?

Will he frequently wake startled and upset or cold during the night? Will he fidget in his sleep, thrash around, throw off his bedclothes, head bang or moan in his sleep? Is he extremely restless during the night? If he has thrown off his covers and become cold, will he make the connection and recover himself or will he wake the household and need an adult to settle him and cover him up again?

Does he suffer from sleep apnea, will he hold his breath?

Does he frequently try to get up and wander about during the night? If an adult wasn't being constantly vigilant, would he be at risk of hurting himself - from climbing on furniture or from choking as he puts things in his mouth, for instance?

Do you have additional adaptations to your home in order to help ensure his safety during the night, such as stair gates and extra locks?

Does an adult need to be constantly alert to the fact that he will wander off during the night?

Does he suffer from frequent colds - on these occasions does he become very congested because his nasal passages are smaller as a result of the Down Syndrome? Does this make it more difficult for him to breathe easily? Does it make him distressed? Does his

nose/eyes become very crusty and messy and needs cleaning and unblocking? Does he need to be propped up and his mouth gets very dry and sore as he has to mouth breathe? Does the need to be resettled each time these things wake him during the night?

Is he awake extremely early in the morning while the rest of the household is still asleep? Does he have to be encouraged to go back to bed and stay in his room - although then he just climbs on furniture or throws his things around? Does he need supervising in order to ensure his safety during these early hours?