**DLA Guidance Notes**

**(Babies/toddlers)**

**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 Nursery/School,

Speech and Language Therapy Input,

Portage/Play therapy

Early Intervention Sessions,

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

Use of specialist educational toys

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

1. Communication disorder

Treatment: Does your child receive/require:

Speech and Language therapy

Portage

Makaton signing

Early intervention

1. Other issues to consider including

Projectile vomiting and reflux

Hypothyroidism

Any other specific medical complaints – eg oxygen

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

**“Aids and adaptations”**

Does your child require any of the following:

* Stair gate – to help keep your child safe
* 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

**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 wakes up because she bangs his/her head against the cot? 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/uncooperative behaviours during the morning & the rest of the day?
* Does s/he have leaky nappies in the night requiring an adult to change bedclothes/pyjamas and nappy, then resettle him/her?
* Does s/he have bad dreams and/or noisy episodes which disturb others in the house, requiring much time and energy to be spent resettling everybody?

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

* Do your child’s nappies leak at all (possibly due to constipation or diarrhoea)? Do you have to change clothes and bathe him/her or clean the furniture more than his/her peers? Is there any other inappropriate behaviour – eg smearing?
* Do they resist nappy changes? What behaviour does s/he demonstrate while requiring a nappy change (eg squirming/wriggling)?
* Do they seem to get tummy ache and often need you to ‘bicycle’ their legs/massage their tummy? Or spend time soothing or reassuring them?
* Do they need any extra medication because of their constipation?

**“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 - 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?
* Does s/he require more adult supervision – eg if you have a baby who is not yet mobile so s/he doesn’t hurt them while walking around the room?
* How is his/her behaviour when at a friend’s house? (especially if they don’t have the same safety aids –eg stair gate?)

**“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? Does s/he bite, pinch, kick or lash out while being dressed?
* Does s/he curl up his/her toes when putting on shoes?
* 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 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, wriggle, scream, cry? Does s/he bite, pinch, kick or lash out while being bathed?
* Does s/he need bathing more often due to messy eating habits and/or leaky nappies or to ease constipation?
* Does s/he soil the bath water?
* Is s/he safe when in the bath or does s/he need to be supported when his/her typically-developing peers are beginning to be a bit more independent?
* 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? Does s/he co-operate with having their teeth brushed? Does s/he attempt to run off/wriggle free/clamp jaws tightly/bite down on the toothbrush?
* 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 eat and drink during the day?**

* Does s/he need a bottle or 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?
* Do they dribble and require more changes of clothes/baths than a typically-developing child?
* Can they use a spoon 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 s/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 sand/soil/stones?

**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?
* 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?
* Here is some information you might consider using: “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?

**Speaking and communication:**

* Does s/he have a specific speech and language delay (not babbling as early as his/her typically-developing peers? *(****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?
* 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 s/he get cross and frustrated if s/he cannot make him/herself understood? If so, what does s/he do?
* 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?

**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 still open cupboards/doors/trap fingers?
* Does s/he understand key safety concepts such as hot or burn, fast or danger?
* 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 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 (eg starting to be interested in climbing equipment)?
* 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?
* Because of his/her learning difficulties does s/he get caught up in solo play or with one particular toy and need encouragement to move on?

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

* Does s/he require and receive 1:1 support at nursery?
* Is this to ensure that his/her attempts at communication can be understood?
* Does s/he have global developmental delay?

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

* 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 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?
* Do you have additional adaptations to your home in order to help ensure his/her safety during the night, such as stairgates 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 or 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 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?
* 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, hot water, scissors and sharp objects, hot cookers and ovens, mouthing dangerous objects etc. Will s/he run off and hide?
* 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.
* 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/her mouth? Do disturbed nights make him/her tired, irritable and uncooperative and do they make getting him/her up and ready for nursery extraordinarily difficult? Does it also affect his/her behaviour at nursery, 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.