

**Health Advice: Education Health & Care Plan**

*For all queries on this document please contact the Team on EHCPqueries@alderhey.nhs.uk*

**Child/Young Person’s Details:**

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| **Child’s Name:** | Gwendolyn Vials Moore | **D.O.B:** | 22/08/2014 |
| **Parent/Carer Name(s):** |  | **NHS Number:** | 7010571422 |
| **Home Address:** | 2 Coronation Drive, L23 3BN | | |
| **Contact Number:** |  |  | |

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| **Name:** | Dr Natalie Daniels |
| **Role:** | Consultant Neurodevelopmental Paediatrician |
| **Speciality:** | Neurodevelopmental paediatrics |
| **Email:** | EHCPqueries@alderhey.nhs.uk |
| **Date Completed:** | 31/5/2022 |

**What are the child’s health needs (specifically relating to your speciality)? How do these health needs impact on the child’s education/learning?**

Gwen has complex medical and developmental needs requiring a high level of support and constant supervision to maintain her safety. She has the following confirmed medical background:

1.Trisomy 21 (Down’s syndrome)

2. Hearing impairment - history of mild to moderate hearing loss and will remain under audiology until she is 18

3. Visual impairment - Bilateral hypermetropia & previous recurrent iritis (previous lactimal

probing and syringing January 2019)

4. Autism Spectrum Disorder (ASD) with pathological demand avoidant profile

5. Mobility problems requiring right sided osteotomy in March 2020, followed by a left patella stabilisation surgery in April 2022 and subsequent splint use and wheelchair use. Gwendolyn has permanent mobility issues, such as a limp.

6. Possible absence seizures (normal EEG 2021) and a seizure while in the burns unit at Alder Hey

7. History of gastroesophageal reflux disease (Upper GI endoscopy and biopsies January

2019 with normal range, however, stone cobbling found to her airways, Ph and

impedance study February 2021 showing evidence of minimal gastroesophageal reflux).

8. Cardiac arrhythmias likely neurogenic in origin (PDA and PFO at birth, now resolved)

9. Tachy-brady Syndrome

10. Obstructive sleep apnoea (weaned off CPAP February 2019 and discharged from LTV

Physio, but remains under respiratory and is overdue a sleep study)

11.History of recurrent upper and lower respiratory tract infections, prophylactic antibiotics

12.Intra-capsular tonsillotomy and adenectomy

13. Isolated early menarche

14. Behavioural issues with refusal to void her bladder in school, constipation and lack of independent skill to toilet and clean without help.

15. Gwen is also considered a child in need owing to her complexity

Gwen has complex medical and social needs. These are long standing and will require long term ‘round the clock support’ to ensure Gwen is safe, happy and thriving; ensuring her physical and emotional needs are met. Any support plans in place need to take the above complexities into consideration along with her challenging behaviour profile and autism which impacts on her mood and behaviour which negatively affects her ability to access a learning environment. Given her medical complexities, Gwen attends multiple health appointments which may impact on her access to learning. Gwen has had a number of operations and her health needs are ongoing. She has required the input of community Occupational Therapy and Physio for her to be able to safely return to School. Most recently with a 2:1 for toileting in addition to her normal 1:1.

Children with Down syndrome usually have an IQ in the mild to moderate low range. Gwen’s learning needs should be identified and managed by the school.

**What intervention will be offered to address these needs? Who will provide this? How often and for how long will you offer this intervention?**

Gwen has follow up from a range of medical specialties to include a Neurodevelopmental Paediatric Clinic at Alder Hey on an at least yearly basis until transition to adult services.

Gwen requires consistent caring relationships which are especially important to her emotional wellbeing and enabling her to develop lasting secure relationships with peers and carers. Gwen requires a robust framework of support that caters for her needs and ensures she is empowered to reach her academic and social potential. Whilst Gwen is headstrong, she benefits from being challenged to learn/develop and maintaining a consistent and routine approach to most things in order for her to feel comfortable and have a sense of control over life and events. Even with this consistency, Gwen can display challenging behaviour which can compromise her safety and the safety of others. Escalation in challenging behaviour can be minimised/avoided by ensuring she has a consistent routine and a sense of involvement and control over decisions. Gwen benefits from consistent support and familiar faces in her 1:1 or 2:1 provision.

**Support with health needs:**

***Trisomy 21 screening*** – Gwen is at increased risk of health complications of Trisomy 21 and so has condition specific screening on a yearly basis.

***Hearing*** - Gwen has a history of mild to moderate hearing loss. A hearing test is completed annually. Gwen is inconsistent in her response to sound which is thought to be due to her concentration and attention difficulties. She would therefore benefit from prompting to maintain focus and stay on task.

***Vision*** - Gwen has worn glasses since 2018 and is under ophthalmology/orthoptics follow up regularly. She has good functioning visual fields, but the possibility raised of visual field inattention or processing difficulties which will be monitored.

***Communication*** - Gwen can talk in sentences but reverts to using noise and growls when distressed/for comfort. She can make her needs known and can be very headstrong. Gwen can make a structured choice - i.e. ‘this or this?’, but would not be able to respond accurately to ‘what would you like?’. Gwen can go rigid and dislocate her joints when stressed.

***Mobility*** – Gwen has had mobility problems from birth owing to hypotonia and being hyperflexive. She regularly dislocates her joints leading to an osteotomy in 2020, which left Gwen with a significant limp. Gwen’s bones are flat not typically round in profile. This is not a feature of Downs Symdrome generally. Gwen has turns in her feet. Gwen can walk but has always required a wheelchair for any distance. More recently Gwen required the exceptionally rare procedure of left patella stabilisation in April 2022, performed by the head of orthopaedics and complex needs team at Alder Hey. Subsequently she has required a plaster then splint use and wheelchair use. Prior to this, Gwen could walk around the house - slow and unsteady, but determined and generally successful in her movement, yet experiencing trips and falls every day. Gwen is determined to move under her own steam at home even when she was in a non weightbearing cast. Following her surgery, Gwen is full time in a wheelchair at school and has a physiotherapy plan in place to help recover mobility, however, she will never walk typically. Gwen is not suitable for a self-propelling/directed wheelchair and currently has a bespoke Mojo. Gwen has follow up with physiotherapy and orthopaedics.

***Sensory*** - Gwen does not feel or does not care about pain typically and will inflict it on herself in a sensory seeking manner and will not report it, therefore requires supervision to keep her safe from herself.

***GI related problems*** – Gwen has reflux and constipation requiring medication and follow up by the gastrointestinal team.

***Respiratory related problems*** – Gwen has a history of recurrent infections for which she takes prophylactic antibiotics and had previous sleep apnoea. Gwen has follow up by the respiratory team.

**Activities of daily living:**

***Personal care*** - Gwen requires help with personal cares daily and this should be included in all support plans to maintain her physical health and wellbeing. Gwen needs full assistance in washing, dressing and teeth brushing. Gwen cannot fully dress or undress and she needs to be taken to the toilet as she either has no insight into needing the toilet or refuses to go in order to avoid day to day demands placed on her, the urinary play team are now involved with her care owing to this and are providing her with a special watch to assist her to know/be in more healthy control of her toileting. Gwen experiences constipation and behavioural challenge around voiding her bladder. In view of this she experiences wetting and soiling requiring full care in the toilet and with hand washing, with at least 1:1 but sometimes 2:1, due to both mobility and challenging behaviour. Gwen also has early menarche and bleeds on a monthly basis, although she hasn’t bled since February 2022, Gwen is under both Endochronology and Gynaecology who are clear that they are likely to return. Gwen has no capacity to tend to this herself. This requirement for care has previously led to her being kept off school and denied access to education – this is not acceptable and it is understood that the inclusion team is/has worked with School to put a policy in place to allow her to attend. The policy should be shared with parents.

***Eating and drinking*** – Gwen will put anything in her mouth and try to eat things which are not edible. Gwen is obsessed with food and was referred to CAHMS owing to poor behaviours around food, such as drinking a teachers’ drink at School and then vomiting and spoiling another child’s lunch by trying to take it from them. Her preference would be to eat the same foods, rather than a wide variety of foods- being obsessed with ham and cheese (although not being able to properly digest dairy). Gwen can eat with a spoon and fork if food is cut up into small pieces and can finger feed. She often shovels food at her face, and so is a messy eater and is at risk of aspiration. She needs constant supervision. Gwen can drink from a tommy tippy cup and can now drink from a cup without a lid, but almost always requires a straw, she again requires supervision with this as she will spill liquids. Gwen does not drink enough and seems to confuse thirst with hunger. Gwen does not appear to ever feel full and is under the care of a dietician.

**Social and behavioural support:**

Gwen is a child in need and has a disability Social Worker who supports the family and provide 50 hours of funding on a 2:1 basis owing to her complexity and the challenges in keeping her safe.

Gwen accessed Claire House Children’s Hospice also on a 2:1 basis when outside the setting and a 1:1 inside at all times.

Gwen cannot access ‘Jets’ before and after school provision owing to her medical complexity and needs, it being unsafe in their assessment for her to attend without a 1:1 which they refused to provide.

Gwen attends Aiming High provision on a 2:1 basis following their assessment of her needs.

Gwen is a loving and caring child, who can form relationships over time and can behave very well in routine and a highly structured environment with consistent support. She is headstrong and fixed in her approach to everything and therefore struggles a great deal with change that she does not understand, transition and with demands placed on her. In the hospital setting, Gwen has recently required sedation due to unsafe behaviours and risk of harm to herself from sensory seeking as well as impulsive behaviour. She has required a constant 1:1 and a low demand approach to completing the most basic of tasks. In recent weeks, Gwen’s behaviours have caused a large number of hospital trips and her behaviour while in hospital has required specialist input and sedation. It is noted her compliance is deteriorating with age and she is becoming more demand avoidant. To maintain her safety, even with structure, at least 1:1 is required at all times.

As time has passed, Gwen has required more support and provision has increased in every area of her life. This is required to continue to keep her safe, happy, healthy and meeting her potential. Gwen would thrive with familiar and highly structured support with a low demand approach.

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| **What is the anticipated outcome for the child/young person?** | | | |
| **Health Needs** | **Outcome** | **Provision**  **Resources and monitoring** | **By whom and how often?** |
| Under our service, Gwen has Trisomy 21/Down syndrome for which she requires condition specific monitoring as per recommendations by UK Down syndrome interest group | For Gwen to remain fit and healthy and to achieve her maximum potential | Condition specific monitoring | Neurodevelopmental paediatrician- annual review, Alder Hey |

**These recommendations are based on Gwendolyn’s current level of need, and therefore are likely to change as there is progresses and needs change. Any amendments to the level of support will be based upon clinical need and will be discussed with the child/young person, parents and the setting, and documented in a report.**