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Assignment: Supporting Children with Additional Learning Needs - Webinar.

Part 1: Poster – CMV – Cytomegalovirus; cCMV – Congenital Cytomegalovirus.

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Page 2: Script – Written script of ALN webinar

Page 11: Reference list

AI Statement:

Throughout the duration of this assignment I acknowledge the use of the following

- <https://copilot.microsoft.com/chats/uWfmGxnT1d6Cv1bTnZhjv> using the following prompts:
 - To check my own text for grammatical and syntactical mistakes and for suggestions to rephrase my own work.
 - Find and summarise data in relation to CMV – Cytomegalovirus and cCMV – Congenital Cytomegalovirus.

Script

Introduction:

Welcome everyone and thank you for attending this evenings Webinar. We'll just run through initial introductions from our presenters and then we'll make a start –

- Kirstie Harding - Understanding Tourette's Syndrome
- Amy Cox - Navigating ADHD: Diagnosis, Barriers and ALN Provision in Education

Thank you both my name is

- Jo McDonough - CMV – Cytomegalovirus & cCMV – Congenital Cytomegalovirus

Just a small reminder you are welcome to take notes and there will be time at the end of each presentation for questions, and back to Kirstie to start us off.

Kirstie – presentation

Amy – presentation

Jo -

- **Cytomegalovirus (CMV)**

Cytomegalovirus (CMV) is a common and usually harmless herpes virus that remains dormant for life. Most healthy individuals experience no symptoms or only mild, flu-like illness with no long lasting effects (NHS, 2023; Abdullah; 2023; CDC, 2025). Transmission occurs through infected bodily fluids and is commonly acquired by children in childcare, or reinfection with a different strain (Tommy's, 2026). Widespread CMV poses particular risk to immunocompromised individuals and pregnant women (NHS, 2023; CDC, 2025).

- **Congenital CMV (cCMV)**

cCMV is the most common congenital infection worldwide (Jones *et al.*, 2023; Nguyen and Shorman, 2025). Many babies show no symptoms at birth, yet asymptomatic infants may later develop progressive hearing loss or speech and language delays (Rochat *et al.*, 2024). Primary maternal infection carries the highest risk of transmission, though non-primary infection also contributes to global

prevalence (Nguyen and Shorman, 2025). Postnatal transmission is rare, however can occur during birth or via breast milk, with particular risk for premature or low birth weight babies (CMV Action, 2022).

- **Prevalence and prognosis** cCMV is highly prevalent worldwide,
- *Around 1% of all live births result in cCMV, with a global rate of 7 in 1000 births (CDC, 2025; NHS Scotland, 2025).*
- *In the UK, 1 in 200 babies are born with cCMV with*
- *1 in 5 affected infants experiencing birth defects and/or complex needs (Tommy's, 2026; NHS, 2023).*
- *10-15% develop long term medical or developmental difficulties (NHS Scotland, 2025; Jones et al., 2023; Nguyen and Shorman, 2025).*
- *cCMV accounts for 25% of childhood hearing loss and is a major cause of childhood disability (CMV Action, 2022; NHS, 2023; CDC, 2025)*
- *It's also associated with longer hospital stays, increased medical issues and lifelong therapy needs (Nguyen and Shorman, 2025; LeWine 2024).*
- *Pregnant women working with young children or caring for young families face increased exposure (NHS, 2023).*
- *And tragically 5 in every 1000 babies born with cCMV die at birth or IN early childhood (Action Medical Research, 2024).*

- **Screening and Diagnosis –**

UK National Screening Committee (Tommy's, 2026) and the National CMV Foundation (2025b) do not recommend routine antenatal or newborn screening. Maternal blood tests cannot reliably predict foetal infection and outcomes remain uncertain (Kalogeropoulou *et al.*, 2025). Ben Shoham *et al.* (2023) similarly concludes that that routine antenatal screening offers limited value in high prevalence areas.

Symptomatic women or those with concerning ultrasound findings may receive antibody testing, with confirmed infection requiring ongoing monitoring, including foetal brain MRI at 28-31 weeks (National CMV Foundation, 2025b; Tommy's, 2026). US studies are evaluating dried blood spot testing to identify infants at highest risk of long term complications (CDC, 2024a) Meanwhile, Professor Vincent Teng is

developing a low-cost, highly sensitive bedside diagnostic device with accuracy exceeding current gold standard methods (Action Medical Research, 2024).

Rochat *et al.* (2024) report typical ages of first diagnosis for CMV-related conditions:

- hearing deficits at 0.84 years,
- vision deficits at 1.2 years,
- neuromuscular problems at 1.8 years,
- with all qualifying conditions identified by age 3.

Leruez-Ville *et al.* (2024) recommend monitoring children infected in the first trimester, or where timing is unclear, until at least age six, with high-risk children receiving neurodevelopmental assessment at 24–36 months.

- **Barriers to diagnosis**

As cCMV is little-known among pregnant women, families and healthcare providers, early symptoms, may not prompt timely medical advice, and many cases go undetected without routine screening (Jones *et al.*, 2023). Diagnosis is further hindered due to unreliable testing, practitioner awareness and pregnant women rarely knowing when to seek testing (Tommy's, 2024; LeWine, 2024). Interpretation of results are also challenging due to false positives, time dependent testing and the need for specialist review (Kalogeropoulou *et al.*, 2025).

Definitive foetal diagnosis is also delayed, as amniocentesis is only reliable from around 21 weeks with foetal infection unreliable in predicting neonatal outcomes. After birth, diagnosis is highly time-sensitive, testing within the first 2–3 weeks of life is essential to distinguish congenital from postnatal infection (CMV, 2024; National CMV Foundation, 2025b; Nguyen and Shorman, 2025).

Global awareness remains low, contributing to inequity and delayed diagnosis particularly in low- and middle-income countries (WHO, 2024; UNICEF, 2026). This reflects a persistent gap between the high burden of disease and very low public and professional awareness, reinforcing the need for coordinated international education and screening strategies.

UK awareness is particularly low, with studies and national consultations showing that most pregnant women and healthcare practitioners have never heard of cCMV,

leading to frequent reports of missed or delayed diagnose due to limited professional awareness (GOV UK, 2025; Greiner et al., 2025a).

Despite cCMV being more prevalent than Down syndrome or spina bifida and the leading cause of childhood hearing loss, it is rarely discussed in antenatal care (Action Medical Research, 2024). With NICE only recommending pregnant women be informed of CMV within the last 5 years (NICE, 2021). This persistent lack of awareness contributes to preventable long-term outcomes, including hearing loss and learning difficulties, underscoring the need for improved health messaging and professional training.

- **Treatment and prevention**

There is no curative treatment for CMV in pregnancy (NHS, 2023; NHS Scotland, 2024). Newborn treatment is specialist led and depends on severity. For infants with significant neurological or systemic involvement antivirals in the first 12 weeks may reduce transmission and limit progression of hearing loss and further complications (LeWine, 2024; NHS, 2023). Leruez-Ville *et al.* (2024) recommends a further six months of antiviral therapy for symptomatic infants. However evidence is limited and offers no proven benefits once the foetus is infected, overall, antivirals may reduce serious complications however do not cure CMV (Tommy's 2026; NHS, 2023).

The National CMV Foundation and LeWine (2024) emphasise behavioural prevention, particularly for pregnant women including frequent handwashing, avoiding saliva contact from young children, not sharing food, or utensils and reducing exposure in childcare settings by working with older age groups.

Nguyen and Shorman (2025) describe clinical prevention strategies, such as preventative medications and CMV safe blood products, newer antivirals for prevention in high-risk cases and strict infection-control measures and patient education in healthcare settings.

- **ALN Outcomes**

Schleiss (2024) and NHS Scotland (2025) confirm that cCMV is the leading infectious cause of permanent childhood disability, especially sensorineural hearing loss. WHO (2024) and UNICEF (2026) identify it as a major but under-recognised cause of neurodevelopmental impairment. Newborns may present with prematurity,

low birth weight, microcephaly, seizures, neurological impairments, hearing loss and jaundice, reflecting the virus's capacity to disrupt development and cause long-term disability or death (LeWine, 2024). Rochat *et al.* (2024), NHS (2023) and the CDC (2025) also report additional associated disabilities including, intellectual, orthopaedic, speech-language and visual impairments, as well as autism. cCMV is the most common infectious cause of neurodisability in high-income countries (Kalogeropoulou *et al.*, 2025).

In Wales, ALN is identified when a learner has a learning difficulty or disability requiring provision beyond what is ordinarily available (Welsh Government [hereafter WG], 2021). cCMV aligns with this framework, as its associated hearing, communication and neurodevelopmental needs often require Additional Learning Provision consistent with the ALN Act 2018 and ALN Code (WG, 2021).

- **Impact of the ALN**

Families consistently report significant emotional, practical and financial strain, with parents commonly experiencing shock, anxiety, guilt and uncertainty, intensified by low public and professional awareness (Vandrevala *et al.*, 2020; Dollard *et al.*, 2021). Diagnostic delays are frequent, leaving families feeling dismissed and worried that earlier intervention might have improved outcomes (Greiner *et al.*, 2025a).

Children with cCMV may require input from up to 20 professionals across health, social care and early years services, disrupting employment, finances and family routines, while low awareness contributes to social isolation and emotional fatigue (Rawlinson *et al.*, 2017; Vandrevala *et al.*, 2025; Greiner *et al.*, 2025b).

The economic impact is substantial: cCMV costs the UK an estimated **£750 million annually**, including £330m to services and £420m in family-borne costs such as lost work, private therapies and specialist equipment (Action Medical Research, 2018).

In Wales, inequity, missed prevention opportunities and rising ALN demand heighten disadvantage (Gov UK, 2025). Persistent low awareness contributes to delayed diagnosis, reduced access to early antiviral treatment and inconsistent professional knowledge, all linked to poorer developmental outcomes and greater long-term reliance on health, education and social care systems (NICE, 2021; Greiner *et al.*, 2025; CMV Action, 2024).

- **Inclusion -**

Inclusion is grounded in the principle that all learners have equal worth and are entitled to high-quality education regardless of disability, need or background. It rejects deficit views and places responsibility on systems and educators to remove barriers and ensure meaningful participation, belonging and fairness (UNESCO, 2017; WG, 2021). Key inclusive models:

- Medical model – views disability as an individual deficit requiring clinical intervention (Shakespeare, 2018; WG, 2021).
- Charity model – reinforces dependency, limits agency and positions disabled people as passive (Retief and Letšosa. 2018).
- Social model – locates disability in environmental, attitudinal and systemic barriers, requiring changes to practice, pedagogy and environments (Barnes, 2019; WG, 2021).
- Rights-based model – grounded in the UNCRPD, positioning inclusion as a legal entitlement, requiring reasonable accommodation and proactive planning (UNESCO, 2017; WG, 2021)

This aligns with the Salamanca Statement, framing inclusion as a systemic responsibility and rejecting segregation in favour of mainstream participation (UNESCO, 1997). UNESCO further emphasise that inclusion extends beyond disability to children facing wider educational, including those with EAL, HIV/AIDS and Gypsy/Traveller backgrounds (UNESCO, 2017). Collectively these highlight that inclusion is not about ‘fixing’ the child but transforming systems to ensure equity and uphold children’s rights.

- **Barriers to support**

Despite strong policy frameworks, practitioners continue to face significant systemic barriers. They carry responsibility for adapting curriculum, pedagogy and environments, often with limited time, shifting guidance and inconsistent specialist support (Norwich, 2023; Murphy *et al.*, 2024). ALN Cos report mixed compliance with ALN reforms, with legacy SEN practices persisting (Murphy *et al.*, 2025). Workload pressures, staffing shortages, rising ALN complexity and fragmented multi-agency pathways further constrain capacity, while long waits for health services delay early

intervention (Greiner *et al.*, 2025; Murphy *et al.*, 2024; Corbett-Symmons, 2025). Funding and research limitations also challenge provision, with support often difficult to sustain once initial reform funding ends (Corbett-Symmons, 2025).

A persistent policy–practice gap remains, with some settings identifying as inclusive while still relying on withdrawal, segregation or uniform teaching approaches (Graham, 2023; WG, 2025a). Estyn and WG reviews highlight significant variation in ALN Code implementation, signalling the need for clearer guidance, stronger multi-agency integration and greater national consistency (Corbett-Symmons, 2025; WG, 2025b). Communication, coordination and environmental barriers continue to slow assessment and support processes (WG, 2025a). International evidence shows that meaningful inclusion requires coordinated policy, sustained training and long-term investment at system level (UNESCO, 2017; Ainscow, 2020). Nonetheless, recent reviews note improvements in person-centred practice, family engagement, ALN visibility in leadership and broader school-based provision (Corbett-Symmons, 2025; WG, 2025b).

Despite strong legislative protections, discrimination continues to shape access, participation and outcomes. This includes direct discrimination, indirect discrimination, and discrimination arising from disability, where unfavourable treatment is linked to disability-related needs such as fatigue, sensory differences or communication barriers (Equality Act, 2010; EHRC, 2023). These patterns persist through deficit-based assumptions, inflexible teaching methods and inconsistent reasonable adjustments (Knight *et al.*, 2023).

- **Support Strategy**

ALN and health related outcomes are common in children with cCMV, making early identification and ongoing monitoring essential (Rochat *et al.*, 2024). NHS Scotland (2025) recommends audiology reviews to age six and neurodevelopmental assessments for at least two years from six months, reflecting that fluctuating or progressive hearing loss and neurodevelopmental differences are the most frequent long-term outcomes (CDC, 2024).

Given this variability, multimodal communication, such as sign-supported speech [hereafter SSS], is particularly important for maintaining consistent access to language and learning (Marschark and Knoors, 2024). SSS provides a visual

scaffold that supports comprehension, reduces communication breakdowns and can stimulate spoken language. Research on Makaton, a SSS programme, shows that pairing speech with signs increases basic communication, social interaction and inclusion (Kravchenko and Boychuck, 2021). The visual component of SSS offers stable access for children with ALN and fluctuating hearing loss, particularly when auditory input is inconsistent or processing demands are high with consistency across settings strengthening outcomes (Broadly, 2023).

SSS also aligns with behaviourist principles of modelling and reinforcing language acquisition (Skinner, 1957), and sociocultural theories of scaffolded, socially mediated language learning (Vygotsky, 1978). Practitioner challenges, include consistency, gesture complexity and workload (Sin, 2020), yet SSS reduces frustration, supports early language, engagement and emotional regulation (Kravchenko and Boychuck, 2021). It is particularly effective for mixed-ability and multilingual groups, as many children process visual information more effectively than auditory input (Sin, 2020; Bednarski, 2016).

For Welsh practitioners, SSS directly aligns with the ALN Code for Wales (2021), which emphasises removing communication barriers and ensuring meaningful participation. SSS supports these statutory expectations by reinforcing key vocabulary, reducing cognitive load and enabling more independent engagement. Sin (2020) found that SSS was widely viewed as an effective multimodal approach that strengthens understanding, participation and emotional security. While highly effective for fluctuating hearing loss and mixed ALN profiles, children with profound hearing loss still require BSL as the primary approach, with SSS as supplementary (Marschark & Knoors, 2024) .

In summary cCMV is common, preventable and often overlooked, yet early awareness, diagnosis and support can significantly reduce its lifelong impact on children and families.

QUESTIONS

Jo for Kirstie - Can you tell us more about the parliamentary discussion.

Jo for Amy – Was there any information in relation to gender based diagnosis?

Amy for Jo – Why CMV?

Kirstie for Jo – You've mentioned BSL could you tell us some of the key differences.

To Close - We'd like to thank everyone for their input this evening and for attending and we hope you enjoy the rest of your evening.

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