

Response to Welsh Government Inquiry into the impact of the Covid-19 outbreak, and its management, on health and social care in Wales



May 2020

Response by the National Deaf Children's Society Cymru

About Us

The National Deaf Children's Society is the national charity dedicated to creating a world without barriers for deaf children and young people.

We support deaf children and young people with all levels of hearing loss from mild to profound, including those with a unilateral loss (hearing loss in one ear) and temporary hearing loss.

Our Response

Deaf children and young people already face significant social barriers in life. The effects of the Covid-19 situation and 'lockdown' are presenting additional significant barriers to all, including some specific and unique barriers for deaf children and young people.

In putting this document together, we have drawn upon a survey of our family members on their thoughts/concerns around the pandemic, experts working with deaf children across our organisation and our conversations and correspondence with professionals in Wales.

We know that the Welsh Government, public bodies and local authorities are having to make swift decisions in response to unprecedented circumstances. However, we are grateful to the Committee for bringing forward this inquiry as deaf children and young people are facing particular and unique challenges during this time, and indeed, a number of challenges that could see them disadvantaged in the longer term if they are unaddressed.

1. Newborn Hearing Screening Programme

The National Deaf Children's Society Cymru appreciates that Public Health Wales has worked hard to ensure that the Newborn Hearing Screening Wales programme continues to operate across all health boards in Wales during these very difficult times. The service has looked to redeploy staff and worked with audiologists to ensure that as many babies as possible are screened. However, given the current situation, there are many babies who are not being screened and are being referred for a behavioural screen at 8/9 months of age. The later diagnosis will have a significant impact for families, as we know that early diagnosis and support is so valuable in building a good foundation for language.

The current situation will also add to the backlog of audiology appointments for the future. This will present a further strain on services which were already facing challenges with high

caseloads and low staff numbers. We strongly urge the Welsh Government to seek to support service leads to develop costed plans for when lockdown measures subside to ensure services can take rapid action to address any backlog in identification of deaf children, providing emergency funding and additional capacity as required.

2. Paediatric audiology services

We fully appreciate the work of audiology departments during these unprecedented times and our professional networks tell us that all services are operating postal repair services for hearing aids.

However, inevitably, routine appointments have been delayed and there are risks of later diagnosis for families who have concerns about their child's hearing (around half of all deaf children are not born deaf, but acquire deafness during childhood). As indicated above, delays in diagnosis present a significant risk to a child's linguistic, educational and social development.

The cancellation of routine audiology appointments also has a number of other implications. For example, it means that audiologists can't see deaf children directly to create new ear moulds (known as an ear mould impression) for the child to use with their hearing aid. Ill-fitting ear moulds can result in feedback. The family may use hearing aids less as a result. Fortunately, audiology services are innovating to address this issue and new ear moulds for children's hearing aids are being made without impressions in some cases – using a reprint of moulds or working from a copy of an existing mould. This will work for some, but not all deaf children.

The National Deaf Children's Society Cymru is concerned about the strain that the building backlog of cases will have on our audiology services when lockdown measures ease. We are aware that, in many areas across Wales, these services were already struggling with low staff numbers and high caseloads prior to Covid19. As above, we strongly urge the Welsh Government to seek to support service leads to develop costed plans for when lockdown measures subside to ensure services can take rapid action to address any backlog in identification of deaf children, providing emergency funding and additional capacity as required.

3. Cochlear implantation and other surgeries

The NHS has stopped routine surgery to free up capacity and beds for those people who are seriously ill with Covid-19. Routine surgery for deaf children includes: grommet surgery for glue ear, bone anchored hearing aids, and cochlear implant surgery. Delays to these sorts of surgeries cause anxieties for families and result in deaf children being without effective access to sound for longer than would otherwise have been in the case. Given the importance of early intervention, this is likely to have an impact on their language and communication development, and result in the need for more intensive support later in life.

"I am writing to you about my 8-month old daughter. She was born with bilateral profound hearing loss, currently wearing hearing aids. She... was going to be implanted bilaterally this month (April). She is showing absolutely no response with the hearing aids and we are going

through an extremely stressful and worrying period, knowing how time sensitive a CI operation is and not knowing when operations will resume. We are wondering if there is anything we could do to try and get those time-sensitive operations restarted as soon as possible. Also, if you have any information on how long it will take for operations to resume after lockdown is lifted.” (Parent of a deaf child)

My child has issues with one of his cochlear implants he will only wear one and not together as it’s making strange noises and is uncomfortable to wear. He is due a tuning session to check his hearing levels. This had been cancelled because of the coronavirus. He is only able to wear one cochlear implant until we are able to get an appointment, we don’t know how long this will be. (Parent of a deaf child, Wales)

4. Mental health

The National Deaf Children’s Society UK helpline has taken a large volume of calls from families who are experiencing difficulties with isolation at this time.

“Being deaf is already very lonely and isolating. Being taken away from peers etc. is just very difficult for my son.” (Parent of a deaf child)

As with most other children, deaf children and young people are isolated at home and are disconnected from their peer group. This is a particular issue for deaf children who may rely on being able to attend clubs and events where they can be with other deaf people.

For some deaf children and young people (particularly BSL users), there is also potential isolation within the family, if the child is the only person who uses sign language.

“My daughter’s frustration is terrible as she cannot communicate, BSL needs to be more widely taught to children and young adults to stop communicate problems. If I was taught basic BSL I would know basics to help teach and communicate with my daughter.” (Parent of a deaf child, Wales)

As information and resources on Covid-19 and emotional wellbeing are not always accessible, this may cause higher levels of anxiety and stress.

“Guidance online relating to mental health and more do not have BSL versions available, which is unacceptable given the fact that deaf people are also greatly affected by issues such as mental health.” (Deaf young person)

Some deaf children may experience bereavement within the family as a result of Covid-19 and if they have delayed language skills they may find it harder to process and handle their feelings around bereavement.

Access to online and remote counselling may also present challenges for deaf young people if appropriate measures (such as a speech to text reporter or an interpreter) are not put in place. Video technology may not be of sufficient quality for lip-reading.

Overall, we believe there is a considerable risk of deterioration in wellbeing and that deaf children are disproportionately affected compared to other children.

“I am finding it really hard being away from my friends, and it is hard to speak to people using facetime when I need subtitles so it is harder to keep in touch.” (Deaf young person)

“Audiology not seeing any outpatients for 2 months at least. My son was due there the week they stopped seeing patients. He desperately needs new moulds as the feedback is horrendous. He also has a faulty aid. We have been told to send his moulds to them and they'll send them to the manufacturer which will mean no access to speech for 2 weeks minimum with a high risk that the moulds won't fit anyway. He is 14, is oral only, and would feel even more isolated if he had no hearing aids. It's awful, it's having a major impact on his mental health.” (Parent of a deaf child)

We are also mindful that parents of deaf children have also reported feeling isolated as they are missing peer support from others.

We would urge the Welsh Government to ensure that systems put in place to support the wellbeing of pupils remotely are accessible to deaf young people.

Parent views

“My son not being able to attend the deaf youth theatre which is a massive help with building his confidence especially when it comes to him using his sign as he's around other deaf young children.”

“We are very proud of the support we have here in South Wales and hope that after this pandemic that cochlear assessments are hurried and seen as absolute priority, particularly to children under five who are at the vital time of development. My daughter's frustration is terrible as she cannot communicate, BSL needs to be more widely taught to children and young adults to stop communicate problems, if I was taught basic BSL I would know basics to help teach and communicate with my daughter. I also hope that SenCom has the financial support to provide extra support to children after this crisis to make up for time lost.”

5. Face coverings

We appreciate the public health considerations underpinning the use of face masks and coverings at this time, particularly in health settings, where masks provide essential protection for staff. We understand that the Welsh Government's position is to neither mandate nor recommend the use of face masks for the general population, but to respect people's personal choice to use face coverings. We are mindful that many members of the public may choose to wear masks for their own confidence.

The use of face masks or coverings for the general public in public places will create a very significant barrier to communication for deaf people. We have received correspondence from members across the UK who are anxious about the increased communication barriers that deaf young people will encounter in light of Covid-19 and the increased use of face coverings.

Communication for virtually all deaf people, including those who use sign language, relies in part on being able to see someone's face clearly – whether this is for lip-reading, understanding facial expressions or for understanding non-verbal communication more widely (e.g. seeing whether someone is smiling or looks upset). An obstruction to the mouth makes it extremely difficult, if not impossible, for a deaf person to understand what is being said. Face masks also have the effect of obscuring and muffling speech, making it harder for deaf people to make use of any residual hearing that they have.

In order to try to address this issue, it will be extremely important for government or public health guidance or advice on face masks and coverings for the general public to highlight the barriers this introduces for deaf people, and to set out mitigating steps that can be taken. The National Deaf Children's Society has outlined some helpful communication tips (see <https://www.ndcs.org.uk/blog/the-impact-of-face-masks-on-deaf-children/> and <https://www.facebook.com/112180125505122/videos/3087775494640238>.)

We understand the need for PPE in health settings to mitigate risks of the virus and keep people safe, but we are concerned that this does present communication barriers for deaf patients and for deaf members of staff. As such, we welcome the recent letter (dated 20 May 2020) from the Deputy Chief Medical Officer raising awareness of this issue and highlighting measures health staff can take in communicating with deaf patients during these difficult times.

We would also welcome wide a reminder to staff of the All Wales Accessible Information Standards. In addition, it would be helpful to raise awareness of the availability of remote virtual BSL interpretation and access online to a remote speech to text reporter to help facilitate communication with deaf patients.

The Deputy Chief Medical Officer's letter also stated that at present transparent facemasks, which would be more accessible for deaf people, are unavailable to NHS Wales at present and that the introduction of any such equipment would face delays due to safety testing. The National Deaf Children's Society Cymru absolutely appreciates the great challenges in the commissioning and availability of protective face masks and visors at this time as well as the need for equipment commissioned and used by NHS Wales to be tested for safety standards. However, given the significant barriers that face coverings present to deaf patients, we urge that the availability and commissioning of such equipment will continue to be considered and pursued.

6. Speech and Language Therapy

The National Deaf Children's Society Cymru has recently responded to the Children, Young People and Education Committee inquiry on the impact of Covid-19. In this response, we highlighted that, while we recognise the efforts of many specialists to provide support in these very difficult times, there is a post code lottery in relation to support available.

The current lack of specialist support for deaf children and the wider family is one of the most concerning issues for our members. And for many, access to speech and language therapy is an important part of this support.

Parents are concerned that their child's educational development will be hindered by reduced or lack of access to such key support, particularly over a sustained period of time.

In addition, where support can be provided remotely, this may not be accessible to some deaf children unless additional communication support is provided – e.g. remote speech to text or sign language interpreters. Some families may not have computers/tablets to be able to access remote support.

Parents' views

“She used to have weekly visits from specialist speech and language as well as a teacher of the deaf, she also visited a deaf preschool once a week and had a one to one support in a mainstream preschool twice a week. Now the services can't visit face to face, her progress has massively declined. Her profound hearing loss means she gets next to no benefit from hearing aids, and we are praying that Covid-19 doesn't affect her development too much by the services being on hold.” (parent of a deaf child, Wales)

7. Social Care and Communities

We acknowledge that the Welsh Government has issued guidance on how social workers can continue provision during these unprecedented times, including alternative methods for child and social worker contact in the absence of face to face contact <https://gov.wales/childrens-social-services-during-covid-19-pandemic-guidance-0>.

As outlined above, while it is not for the National Deaf Children's Society to comment on the medical reasons for advising on PPE, we must highlight that these alternative communication methods can present significant barriers for deaf children young people, especially if the social worker is wearing a mask leaving the deaf child unable to lip read.

We would urge the Welsh Government to share our resources around facemask use with social workers:

- The impact of face masks on deaf children: <https://www.ndcs.org.uk/blog/the-impact-of-face-masks-on-deaf-children/>
- General communication tips around facemask use: <https://www.facebook.com/112180125505122/videos/3087775494640238>.
- DIY clear face coverings: <https://www.ndcs.org.uk/diyfacemasks>

In addition, as above, we understand the current difficulty in PPE supply, but feel it is important that options for transparent (and therefore accessible) facemasks and visors to be considered and pursued as is practically possible.

We must also emphatically stress that, as always, parents should not be used as an interpreter or communicator between social workers and the child, especially in instances where abuse or neglect is suspected. Advocates and registered interpreters should be used to ensure that the child's authentic voice is still heard. It is important that social service staff are reminded of this

and are aware of ways in which remote virtual BSL interpretation and online remote speech to text reporting can be arranged.

The current restricted application of the Social Services and Well-being (Wales) Act means that deaf young people will not be provided with the information and advice needed to sign post them to deaf friendly and supportive services in their community. As a result of this, deaf young people risk being alienated from their deaf peers and will not be supported to connect with their deaf identity. Many families of deaf children also access social services for a variety of other reasons, all which assist with their wellbeing and connection with society. Not accessing this support leaves many families in a vulnerable position. It is essential that this suspension does not, over the longer term lead to an erosion of support. It is absolutely imperative that the act resumes as soon as reasonably practical. Consideration must also be given to addressing a higher volume of work if cases have become backlogged.

Concerns around the pandemic exacerbating difficulties with abuse as well as the potential for reduced disclosures are well documented. Research demonstrates that deaf children are more vulnerable to experience abuse (see Sullivan and Knutson, 2000) and as such we share these concerns.

8. Specialist equipment

Deaf children may use specialist equipment – such as radio aids, which are often provided by local authorities. Radio aids are used with hearing aids and cochlear implants and help to amplify sound so that deaf children can hear speech more clearly, without background noise.

We believe that children who use radio aids would always benefit from using them in the home setting too since they enhance the inclusive environment and boost learning opportunities. However, during this period of home-learning, being able to use this equipment at home is particularly pertinent. Despite this, some local authorities have a policy of not allowing deaf children to take radio aids outside the school setting and do not appear to have relaxed this policy in the current crisis.

We contacted local authorities across Wales to ascertain if children were being sent home with radio aids. Of those who responded, there was a split between those who had organised this provision and those who had not. This lack of consistency across local authorities means that children in certain local authorities will be disadvantaged over others. We believe that enabling children who use radio aids to access them for home learning should be considered part of a local authority's duty under Article 23 (3) of the UNCRC.

9. Respite/support for parents and carers

Echoing the experiences of many, our parents of deaf children have informed us that they are struggling with the challenges of juggling work alongside home-schooling. However, it is also worth noting that the pressure to juggle this support can be greater for parents of children with additional needs who may require more support to complete tasks than their peers. We know

that many of our members have additional learning needs besides their deafness. Many families are finding the lack of respite opportunities physically and emotionally straining.

“Helping with school work as I don’t want him to fall behind however I am also a single parent working from home so it’s difficult trying to be mum and teacher too as my sons needs a lot of support when it comes to school work which he’s not able to get now he has to work from home.” (Parent of a deaf child, Wales)

10. Early childhood education and care

Our parent members have informed us of the detrimental effect nursery closures are having on their deaf child:

“My daughter is 3 with bilateral implants and also has selective mutism but was making good progress before the pandemic happened. I worry with her no longer getting any therapy all the progress she has made is going to be lost. She gets frustrated at the videos from nursery as she struggles to lipread the videos and understand. We sign and talk at home so I keep it going but she is struggling to understand why she can no longer go out, go to the park etc.” (Parent of a deaf child)

“Mostly missing the face to face rehab sessions with our Teacher of the Deaf. XXX was implanted 9 months ago, and early rehab is so important to help develop speech. She’s also missing nursery for interaction with other children of the same age.” (Parent of a deaf child, Wales)

11. General issues

Our Children and Families Support Officers at the National Deaf Children’s Society work directly with families to support them. Our officers tell us that many of the families they work with have felt overwhelmed by the current situation – particularly where they are caring for children with multiple or complex needs. As a result, anxieties and mental loads have increased, resulting in families struggling more in other areas such as making DLA applications.

We know that there is an increased incidence of childhood deafness in deprived regions and we have seen many of our members requiring support in these times to access food and also facing difficulties to access online learning.

12. Welfare Benefits and Employment Support

While we appreciate that welfare benefits and Access to Work are reserved matters, we wanted to highlight that our deaf young people in Wales have been facing difficulties in these areas as a result of Covid-19.

For many deaf young people, the suggestion of a telephone PIP assessment as opposed to face to face will present accessibility difficulties.

Over the past weeks, deaf young people in employment have also faced difficulties with having to submit paper claims with ink signatures from their manager, which is very difficult in lockdown

and if shielding. We have been calling on Access to Work to consider email/digital applications. There has now been some movement on this point, with Access to Work accepting printed emails from managers. However, the delays to the digitalisation of the claims process continues to make submitting claims cumbersome. The process means that (unless there is no other option), claimants are still required to make trips to the post office to post their claims, at a time when social distancing is expected. We are urging the UK Government to ensure that all Access to Work users are able to submit claims online regardless of their individual circumstances. Many deaf young people feel that the Department is being insufficiently flexible at this challenging time.

13. Good news

In amongst the current difficult times, we believe it is important to highlight instances where our members have felt well supported by their local services. We know that many of our newborn hearing screeners, audiologists and other professionals are working hard in very difficult circumstances to support children. We've gathered some feedback from parents in Wales who want to say thank you to and draw attention to the good work that is being done.

- *We usually collect batteries from our local audiology department in Ysbyty Gwynedd but given the current situation I rang my daughter's audiology department in Wrexham to ask if we should go to collect and they posted huge pile of batteries to us which should see us through a good few months so that saved us a lot of hassle.*
- *Our professionals have always gone beyond the call of duty to not only supporting our daughter but us as a family.*
- *Phone calls from different services, particularly our teacher of the deaf who thinks of activities that our daughter would enjoy and checks in regularly.*

14. Key asks

In light of the barriers and difficulties outlined within this response that deaf children, young people and their families are facing, we recommend that the Welsh Government:

1. Supports service leads to develop costed plans for when lockdown measures subside to ensure services build back stronger and take rapid action to address any backlog in identification of deaf children, providing emergency funding and additional capacity as required.
2. Ensures the needs of deaf children are included within wider Welsh Government support initiatives on the provision of equipment for home and supporting young people with their emotional wellbeing.
3. That official advice on facemasks and coverings in Wales helps to raise awareness of the communication difficulties for deaf people and of appropriate communication tips.
4. Ensures that health and social care members of staff are aware of the communication barriers that PPE presents for deaf people and are advised on appropriate communication tips and methods of booking remote interpretation or communication support.

5. Looks into the availability of PPE which is accessible, for example transparent facemasks.
6. Calls on the UK Government's Department for Work and Pensions to take steps to ensure its for Personal Independence Payments assessments and Access to Work systems are fully accessible, and to remove unnecessary bureaucracy for disabled people during this crisis.

More information

If the Committee would like any further information from the National Deaf Children's Society Cymru, please do not hesitate to contact us at campaigns.wales@ndcs.org.uk. Many thanks for taking the time to read our response.