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Newborn hearing screening debacle in Scotland: how does Australia compare?

Independent review finds 'horrendous' failings over a nine-year period. Repeated errors in identifying hearing loss have long-term consequences for the speech and language development of the children involved.



Mining sites pose higher occupational health and safety hazards

Noise generated from the constant operation of heavy machinery and drilling can cause hearing damage to mine workers. An efficient way to monitor air quality and noise levels in mining sites is with wearable instrumentation. "There have been remarkable developments with technology in recent years which allow for hands-free dust and noise assessment."



Limits of hearing aids

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How deaf creatives make films better

More deaf creators are getting behind the camera and changing the industry. "A director, if they're hearing and they don't know sign language... how would they be able to capture those little nuances, the facial expressions, the signing, the pausing? That's where we as deaf people come in."

Currently **one in six** Australians suffer from some form of hearing loss. This may increase to one in four by 2050. *Access Economics 2006*

Deafness Forum of Australia is a Voice for All. It is the peak body representing the views and interests of the 4 million Australians who live with hearing loss, have ear or balance disorders, people who also communicate using Australian Sign Language, and their families and supporters. Our mission is to make hearing health & wellbeing a national priority in Australia.



Bianca Birdsey is a doctor and mother of three in South Africa.

“Up until eight years ago, I hadn’t given hearing loss a second thought. I didn’t know anyone d/Deaf or hard of hearing personally, nor did I appreciate the complexities of language and communication.

“One day, when my twin daughters were already three years old, I discovered that they were both deaf. All the dreams for our family’s future seemed to shatter under the weight of overwhelming uncertainty. Four months later, we learned that our youngest daughter, who was 20 months old at the time, was deaf too. As a medical doctor, I felt like I had failed the most important test in my life. I had missed all three of my daughters’ hearing loss, and the consequences could be dire.

“Today, eight years later, I consider the journey that was set before me not one I chose, but one chosen for me. It has been hard! I’ve had to learn more than I could have ever obtained from a library of textbooks and unlearn a whole lot of preconceived ideas about disability and differences. I have learned that child deafness is invisible and that raising a deaf child is multifaceted and requires intentional effort and ongoing advocacy. Consequently, families need holistic support.

“Meeting other families on a similar journey has been an enormous source of encouragement. Meeting deaf adults who embodied my subconscious definition of success was a game changer to the way I viewed the future for my daughters. Those dreams that had once shattered slowly started to take shape again, but this time they were bigger and swollen with purpose.

“My children are still young, so we have much of this journey ahead of us. We face an unequal education system, which coupled with injustices such as late identification and inadequate intervention and access, threatens the ability for a deaf child in my country and many other parts of the world to dream. I refuse to accept this for my children and desire to support as many families as possible, so that they too can commit to seeing their deaf child thrive.”

Bianca is a Changemaker who supports the call in the World Report on Hearing for hearing care for all, now. Join the [Changemakers' Facebook group](#).

National Health Service says sorry to families after independent review finds ‘horrendous’ failings over a nine-year period

By [Libby Brooks](#) Scotland correspondent for [The Guardian](#)



Scottish health secretary Humza Yousaf, pictured here on a visit to a hospital, called on NHS Lothian to enact the report's recommendations 'as a matter of urgency'. Photograph: Jeff J Mitchell/AFP/Getty Images

A Scottish health board has apologised for “horrendous” failings after an independent review found that deaf children missed out on vital cochlear implant surgery because of mistakes and delays in diagnosis.

NHS Lothian apologised to the families involved as the report set out repeated errors in identifying hearing loss and admitted the delays would have long-term consequences for the speech and language development of the children involved.

An independent investigation of NHS Lothian's paediatric audiology service uncovered “significant failures” over a nine-year period in 14% of cases after sampling more than 1,000 patient records, in particular among the under fives.

Experts agree that early identification and correct care are vital in helping deaf children develop language and communication at this crucial age. Cochlear implants expose hearing-impaired children to the sensation of sound.

The report was commissioned by the health board after criticism about the care of a child with hearing difficulties and was carried out by the British Academy of Audiology. It highlighted the average age of diagnosis of hearing loss at NHS Lothian between 2009 and 2018 was 1,653 days, or 4.5 years old, compared with 109 days in England.

The report also found that 12 children who were eligible for cochlear implants faced significant delays, to the extent that five missed out on getting them altogether; 49 children had a delayed identification of hearing loss or the fitting of their hearing aid; and 30 were not offered the correct hearing aids.

Responding to the report, chief executive at the National Deaf Children's Society Susan Daniels said the findings in the report represent a real-life nightmare for the families involved.

"They placed their trust in a service that was supposed to help, only to be completely let down. Some will be left with life-changing consequences, while many others across Scotland will now be facing the very real fear that the same thing could happen to them."

Following the report, the charity called for an urgent country-wide review, warning that thousands more children treated at NHS Lothian could have been affected.

"This means we need urgent action from the Scottish government, starting with a thorough review of children's audiology services across the country. Until we have national leadership, better data collection and mandatory standards that services must comply with, thousands more deaf children could be at risk and families won't be able to rest."

The review found no evidence that national protocols on hearing tests for children had been followed "at any point since 2009" and that delays had gone "unreported and unnoticed."

Scotland's health secretary, Humza Yousaf, called on the health board to enact the report's recommendations "as a matter of urgency" and apologised directly to the families involved. "I am deeply disappointed at the unacceptable failures this report has highlighted, and I have already made my views unequivocally clear to NHS Lothian," he said. "The service provided to children affected and their families was simply not good enough."

Tracey Gillies, medical director at NHS Lothian, said: "We are very sorry and saddened to learn that there are some children whose conditions were not diagnosed correctly, or as early as possible, as a result of testing that was not up to standard."

"We have already written to the most severely affected families individually to offer support and a face-to-face meeting to discuss their child's condition. We have also arranged appointments for those children that the review recommends should be tested again."

How does Australia compare?

All States and Territories in Australia have universal neonatal hearing screening. It is widely acknowledged that delays in the identification and treatment of permanent childhood hearing impairment may profoundly affect quality of life in terms of language acquisition, social and emotional development, and education and employment prospects.

There is clearly a need for a National Framework for universal neonatal hearing screening and early management of interventions in Australia. A national approach aims to screen all babies in Australia for potential permanent childhood hearing impairment and provide access to interventions to minimise the impact of hearing impairment.

The National Framework focuses on having standardised screening pathway guidance across Australia, supported by evidence-based standards of practice. It is a joint initiative between the Australian and state and territory Governments in collaboration and partnership with specialists in the field of paediatric hearing and in consultation with families of children with hearing loss. Read the [National Framework for Neonatal Hearing Screening](#).

Effective noise and dust monitoring essential to worker safety



[Australian Mining](#)

Mining sites pose higher occupational health and safety hazards compared with many other working environments, and among those risks are dangerous exposure to dust and noise.

One of the most common causes for concern is dust inhalation in a mine site. Likewise, the noise generated from the constant operation of heavy machinery and drilling can cause hearing damage to mine workers. Often this damage goes unnoticed until it's too late and hearing loss or other conditions such as tinnitus have resulted from over-exposure to excessive noise.

Which is why monitoring is essential for both dust and noise exposure in mining. Employers need to know that their control measures, including personal protective equipment, are keeping workers safe. They also need to ensure they are complying with the relevant state or territory workplace health and safety (WHS) legislation.

Thermo Fisher Scientific Australian product manager for gas and industrial hygiene instrumentation, Nick Taylor, says an efficient way to monitor air quality and noise levels in mining sites is with wearable instrumentation.

"There have been remarkable developments with technology in recent years which allow for hands-free dust and noise assessment," Taylor says, who has worked with customers in the Australian mining segment for over 15 years.

"These portable devices can be worn with ease and because they have wireless Bluetooth connectivity, the reporting data can be accessed remotely by the site safety manager. In conjunction with the built-in motion sensor, this also enables the manager to remotely check that the device is being used and is working properly on any given individual."

"It's peace of mind for employees and regulatory compliance for employers, and technology such as the Casella range of wearable devices and calibration system simplifies the process of collection, assessment and servicing of equipment on site."

Limits of hearing aids

Many people will think that if you suffer from hearing loss, a hearing aid will fix the loss. Just like glasses do for those with vision impairment. While correctly prescribed glasses can restore vision to 20/20, this isn't true for hearing aids.

How can hearing aids help me? Any problems with the external and middle ear will usually result in sound not getting through to the inner ear (a blockage), where it can be transmitted to the brain for processing. This will cause what's called a conductive loss. A conductive loss can usually be overcome by more volume or power to get the sound through. This is where hearing aids can help and, once the sound is amplified, we expect good results in most cases. This is dependent on the level of conductive loss and the ability of the hearing aid.



No solution for inner ear problems. When the problem is in the inner ear, things become more complicated as there is often damage to some structures that process sound. Hearing aids cannot repair this damage. Other devices can attempt to address this damage, such as cochlear implants and bone conduction devices.

It takes time to get used to hearing aids. If we understand that hearing aids can only attempt to approximate a person's hearing - and that there are issues and limitations with that approximation - we must also understand that it will take a while for new wearers to get used to hearing aids.

Read the full article at the [Better Hearing Australia website](#).



[Disability Gateway](#) was created by the Australian Government to help people living with disability, their family, friends and carers find information more easily and connect them to services in their area.

It is a website, phone line and social media channels. The Disability Gateway will:

- improve the navigation to access relevant information and services
- span multiple sectors including health, housing, employment, transport and everyday living
- exist as a central point of entry for referrals to disability information, services and programs

You can access [translated fact sheets & videos](#) and [translated brochures](#) in various spoken languages, and a list of [frequently asked questions](#).

More deaf creators are getting behind the camera and changing the industry

By Scottie Andrew, [CNN](#)

In Siân Heder's award-winning coming-of-age film "CODA," the Rossi family living room is a place the foursome gathers for big conversations, from the difficult and awkward to the celebratory.

The cozy sea-green space is where teenage Ruby, the sole hearing member of a deaf family, chides her parents for engaging in cacophonous intercourse while a crush is visiting. (Her position in the family gives the film its title - it's the acronym for "[child of deaf adults](#)").

When Alexandria Wailes and Anne Tomasetti, the film's directors of Artistic Sign Language (that is, [deaf experts of American Sign Language](#) who choreograph signing for screen and stage performances), and actress Marlee Matlin walked on set to shoot those scenes, they immediately started rearranging the room's furniture, Heder remembered.

Heder, the film's director and screenwriter, said she and her production set designer initially placed the furniture "where it seemed to fit" in the characters' coastal Massachusetts home, "kind of ignoring the fact that this was a deaf family."



Troy Kotsur and Marlee Matlin are two of the deaf stars of "CODA."

Wailes, Tomasetti and Matlin swiftly corrected that. They turned one of the seats so it would face the door and arranged the furniture in a circle so the Rossi family could easily sign to each other. The family room's layout is one of the grounding details in a film full of them -- moments that may not have been possible without the constant collaboration of deaf crew members.

["CODA"](#) is one of several projects released this year to star deaf actors and skirt stereotypical deaf stories -- Lauren Ridloff stole scenes as a speedster superhero in Marvel's ["Eternals"](#) Millicent Simmonds helped defeat monsters in ["A Quiet Place Part II,"](#) while Matlin and her family fought to save their business in "CODA." Their deafness isn't always central to the plot, but when it is, those storylines are handled with care and nuance -- because, in most cases, they were developed with the help of deaf consultants and experts of American Sign Language (ASL).

Douglas Ridloff, who served as an ASL coach on "Eternals" (in which his wife Lauren starred) and "A Quiet Place" (parts I and II), said in a conversation with CNN and interpreter Ramon Norrod that

more productions are incorporating deaf crew members into the filmmaking process from the very beginning -- steps that even five years ago were rarely taken.

"They start to realise the value of the deaf person's perspective and the input into their film production," Ridloff said of filmmakers and production crews. "It just shows that they value the deaf person's perspective and they want more of that."

How deaf creatives make films better

Involving deaf creators at every step of the production process -- from ASL coaches for actors to consultants on story elements and blocking-- improves both the story the production is telling and the set atmosphere for deaf cast and crew, said Ridloff.

Deaf consultants, directors of Artistic Sign Language and coaches of ASL all bring their experiences to their work, Ridloff said, something that would be impossible for a hearing person to replicate.

"A director, if they're hearing and they don't know sign language -- how would they be able to capture those little nuances, the facial expressions, the signing, the pausing?" he said. "That's where we as deaf people come in."

Ridloff said he likes to be involved in a film's creation from the very beginning. He'll translate lines in a script from spoken English to ASL, choosing the signs and techniques that correlate to a character's development, and will recommend actors who can pick up signing quickly. On set, he'll watch a scene through a monitor, taking note of how the camera picks up an actor's signing and whether the actor is signing correctly. And then, once a film has wrapped, he'll assist its editors in selecting shots that keep an actor's signed lines in the frame in a way that preserves the nuance of what they're signing. He'll correct subtitles, too.

Not all productions are that collaborative, but Wailes, in a conversation with CNN and interpreter Heather Rossi, said that Heder's willingness to cooperate on "CODA" while adhering to her original vision was what made the film so strong in its portrayal of deaf characters -- and such a trusting atmosphere for its deaf actors and crew.



['Coda' is a small movie that hits all the right notes](#)

Wailes went through Heder's script line by line before production started. Not every line in spoken English had an ASL equivalent, so they would rework a line that kept the character's intent and translated easily to ASL.

"We were just gardening," Wailes said of the pre-production experience. "We laid the seeds and we were letting it all grow."

Deaf audiences' take on deaf actors in mainstream film and TV

Recent films and TV series that incorporate deaf characters, played by deaf actors, have been received warmly by many deaf and hearing audiences.

Three of the central roles in "CODA" went to deaf actors -- Matlin, an Oscar winner and perhaps the most famous working deaf actor in the US, Troy Kotsur as her gruff fisherman husband and Daniel Durant, who plays her son. "Eternals" cast Lauren Ridloff, a mixed-race actress, as a character who in the comics was a [hearing white man](#).

These works don't satisfy all deaf audiences, though: In the case of "CODA," [some deaf viewers took issue with](#) the film's focus on music -- in one scene, Ruby's family attends her concert and the sound drops from the film to show their perspective -- plus the seeming burden it is for Ruby to interpret for her family. The casting of Riz Ahmed as the lead in the Oscar-winning "Sound of Metal," as a heavy metal drummer who loses his hearing throughout the film, also [offended some viewers](#), though some deaf and hard-of-hearing audiences who, like Ahmed's character, lost their hearing later in life, were [moved by his performance](#).



Siân Heder (center) worked closely with deaf collaborators before, during and after filming "CODA."

Not all film sets have been accommodating to deaf creatives

Ridloff and Wailes believe that the first mistake a production can make when telling stories about deaf characters is casting hearing actors in deaf roles.

"Someone else trying to wear that language -- you can't," Wailes said. "It's in our bones. It's who we are ... they're trying to imitate, and that's not going to work."

"La Famille Bélier," the French film "CODA" was loosely based on, notably cast hearing actors as the protagonist's deaf parents, a decision that was [widely condemned](#) by [critics](#). Heder knew to avoid

missing the same opportunities of honestly portraying a deaf family and child of deaf adults, she needed to involve deaf creators from the beginning.

"I have a lot of faith in my abilities as a storyteller," she told CNN. "But I knew in order to get it right that I was amplifying the voices of my actors and my collaborators who knew what it was like to live and move through the world [as a deaf person]."

Ridloff said he's been a part of projects where ASL consultants are more of an afterthought, where there aren't enough interpreters for him to communicate efficiently with directors and actors, or a deaf character's storyline wasn't as true as it could have been had it been written by a deaf person.

Wailes chalks up those challenges to a lack of funding, little research, short production time frames and, perhaps most prohibitive, fear -- the fear of not being able to communicate with a deaf person. That fear often keeps storytellers from even attempting to produce films or TV series about deaf characters, she said.

Overcoming that fear or emphasising just how much a production can improve if deaf crew members are involved "can be a dance," she said, but it's a process that's steadily improving.

Where the future of deaf-led films is headed

Heder was drawn to the story of "CODA" because there were so few films that had focused on a deaf family in that way.

"It was important to me to show how free and comfortable deaf spaces can be, and then how different that is once you introduce the barrier that the hearing world puts up," she said.



Siân Heder said she was open to collaboration throughout the filmmaking process to make "CODA" stronger.

But to continue to improve a production's portrayal of deaf characters, Ridloff has a few guidelines that begin with hiring deaf people -- actors, crew members, writers, producers -- in the first place, and making sure deaf people are involved at every level of the production process. Hiring at least two to three deaf consultants and ASL coaches is key, too, he said, as is employing enough interpreters so everyone is able to communicate efficiently. All of these guidelines come from a place of wanting a story to be the best, truest version of what it could be, he said, and if hearing and deaf collaborators keep that spirit in mind, they'll be set up for success.



Voice for All

A Strategic Plan for 2022 – 2024

Deafness Forum recently completed a strategic planning process for the next 3 years.

It aimed to be inclusive, engaging and stimulating, using evidence - particularly the evidence from lived experience - to guide the development of a new Strategic Plan.

Active supporters were engaged through personal contact, views were captured in a strategic survey, and the board held two professionally facilitated workshops to ensure this plan meets the voiced needs of our Members and other constituents.

Read [Deafness Forum Australia – Voice for All – Strategic Plan 2022–2024](#).

Hearing test educational videos

UsherKids Australia shares its Hearing Test Educational Videos with the Usher syndrome and wider deaf and hard of hearing communities.

These short educational videos have been produced in collaboration with UsherKids Australia, Hearing Australia and the Cochlear Implant Clinic at the Royal Victorian Eye & Ear Hospital with funding provided through the Deafness Foundation Grants Scheme.

UsherKids Australia aims to reduce the long-term mental health and well-being disparities found in both adults with Usher syndrome and those that care for them through the provision of information and resources specific to the condition.



<https://www.youtube.com/watch?v=T7M4vHqYtl8>



https://www.youtube.com/watch?v=bpxIM1Ou_q4

World Hearing Day

3 March 2022

**To hear for life,
listen with care!**



World Hearing Day will be observed on 3 March 2022 with the theme,

“To hear for life, listen with care”

Through this theme, we can focus on the importance of safe listening as a means of maintaining good hearing throughout our lives.

The key messages in 2022 will be:

- It is possible to have good hearing across the life course through ear and hearing care
- Many common causes of hearing loss can be prevented, including hearing loss caused by exposure to loud sounds
- Safe listening can mitigate the risk of hearing loss associated with recreational sound exposure

Deafness Forum joins the World Health Organization in its calls on government, industry partners and civil society to raise awareness for and implement evidence-based standards that promote safe listening.

The World Hearing Day 2022 will mark the launch of:

- The 'Global standard for safe listening entertainment venues and events'
- A Safe Listening handbook
- A media toolkit for journalists

Keep visiting [our website](#) for updates and resources.

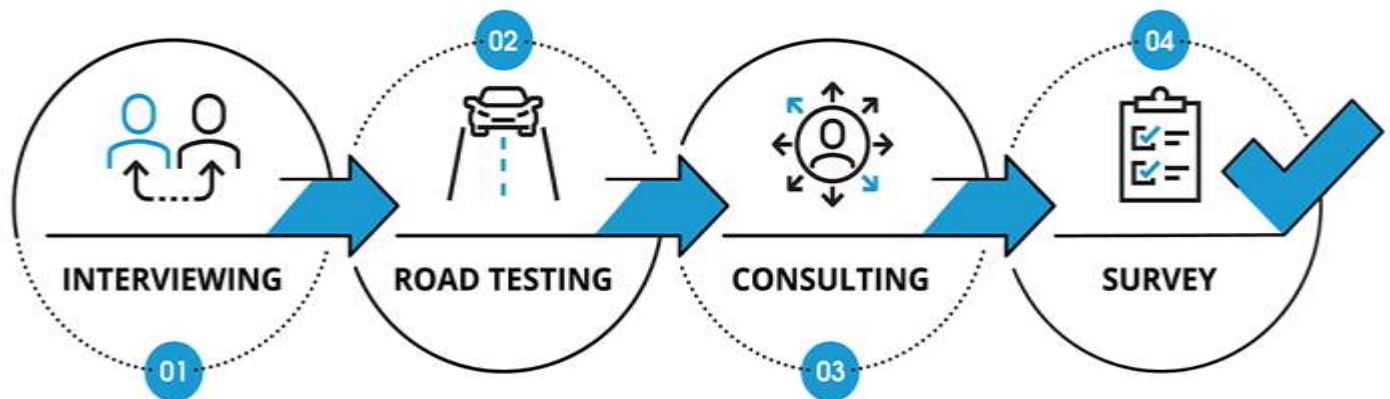
Teleaudiology guidelines

From June to August 2021, the hearing health sector had its say on draft guidelines for delivering hearing services using telehealth (teleaudiology).

The [Teleaudiology Guidelines Working Group](#) and Audiology Australia thank those who contributed a consumer perspective through focus groups or in writing. Read the consultation findings [here](#).

The guidelines are now being tested using interviews, focus groups and a survey, as illustrated below.

TELEAUDIOLOGY GUIDELINES TESTING PROCESS



If you would like to contribute to developing a consumer resource about teleaudiology in February 2022, please contact the Guidelines project manager [Karen Barfoot](#).

To find out more about the project, visit www.teleaudiologyguidelines.org.au

Good design at the heart of normalising disability

[The Conversation](#). By [Sally Britnell](#), Senior Lecturer in Nursing, Auckland University of Technology.

While working as a nurse in a busy hospital I began to use a magnifying glass, as I could no longer read the small print on medication vials. I regarded this adaptation as a part of my professional responsibility to keep patients safe.

Others didn't see it the same way. I was asked to stop using the magnifying glass because it apparently reduced public trust in the care I provided patients and families.

This is just one personal example of how those with a disability are often forced to confront negative language, values and beliefs to engage with the world personally and professionally.

New Zealand's Minister for Disability Issues Carmel Sepuloni says the new ministry will 'replace a fragmented system where there is no single agency responsible'.

Historically, disability was identified as an individual health problem, rendering invisible the variety and normality of living with a disability. So the creation of a Ministry for Disabled People, and the principles set out in the Accelerating Accessibility in New Zealand cabinet paper, offer a unique opportunity for progress.

The new ministry aims to place disability alongside gender, age and ethnicity in terms of state representation. It should help raise the profile of disabled people while normalising their need for access to things others take for granted.

But while the ministry can potentially change the narratives around disability at a structural level, the challenge will be in shifting societal and individual attitudes.



People with disability face an employment crisis due to their low “visibility” in the community and consequently low societal expectations that in turn reduce their opportunities.

Improving visibility and accessibility at a practical level will depend to a large extent on good design. Take the NZ COVID Tracer app, where accessibility relies on the environment in which it’s used. How often have you seen the QR code for shops or cafes placed high up on a window or counter?

For those with restricted mobility these are impossible to scan independently. People who are blind or have low vision have difficulty finding the QR code and lining up their smartphones to scan. While guidelines for the placement of QR codes are specific, the environment they’re used in often precludes better accessibility.

Improvements such as near field communication technologies (currently being tested by the Ministry of Health) and size reduction of QR codes all help. But imagine a world in which the built environment was designed from the outset for accessibility. Everyday activities like scanning a QR code should not be a challenge for disabled people.

New Zealand could learn from the UK and US, where equity for the disabled is being pursued through regulation and legislation. In 2019 I attended several conferences in London and travelled to meet friends and family. While accessible design was not always perfect, the acceptance and normalisation of disability at community and professional levels was profound.

So, while it’s exciting to see the new ministry’s plans to change the narrative around disability, it remains to be seen how this will filter down to reach everyday New Zealanders. Perhaps now is the time to take the government at its word and expect opportunities for people with disabilities to participate meaningfully in reshaping that narrative. With this in mind, perhaps the new ministry could be renamed the Ministry for Possibility.

Disability Royal Commission publications

The Disability Royal Commission released two new publications that show how hard people with disability, advocates and activists have fought for the same rights as others, and to gain the protections offered by equality, inclusion and justice.

Disability in Australia – Shadows, struggles and successes

This report explains how, for hundreds of years, society viewed people with disability as different and told them they didn't fit in. This influenced the way the community and government treated people with disability regarding access and needs.

Agents of our own Destiny – Activism and the road to the Disability Royal Commission

This report is about the disability rights movement and the history of disability activism and advocacy in Australia. It outlines the history of disability activism, including the passage of the Disability Discrimination Act 1992 and covers the campaign for the National Disability Insurance Scheme. In 2019 the Disability Royal Commission was established.



Know someone who deserves their own copy of One in Six?

Drop us a line to hello@deafnessforum.org.au

Contact us to receive this publication in an alternative file type.

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