

Ongoing communication with the Department of Health regarding inequalities in physical healthcare for adoptees in Northern Ireland

The below email was sent to Matthew O'Toole, South Belfast MLA within the SDLP party:

Request for support re. healthcare for adopted adults

Chris Tennyson

To:

- matthew.otoole@mla.niassembly.gov.uk

Sat 03/08/2024 13:52

Dear Matthew,

My name is Chris Tennyson, and I am writing to you as a South Belfast constituent to request your support with an issue related to healthcare equality for adopted adults in Northern Ireland. I was recently interviewed for an article related to this issue, following my own personal experiences:

<https://thelead.uk/dodging-bullets-dark-genetic-risks-kept-hidden-adoption-rules>

[Like dodging bullets in the dark: the genetic risks kept hidden by adoption rules](https://thelead.uk/dodging-bullets-dark-genetic-risks-kept-hidden-adoption-rules)

Hundreds of thousands of adoptees and their family members lack vital health history - as even NHS numbers are changed after adoption.

thelead.uk

This article briefly summarises the issues I faced, but prior to this, I have had extensive correspondence with both the Belfast Trust and Southern Trust (Post-adoption Social Work service) where they have acknowledged shortcomings in their policies and procedures, as well as “unconscious bias” in relation to how adoptees are supported within physical healthcare settings. Whilst there was some talk of service improvements, it was my experience that I had to work against significant resistance to attain full acknowledgement of the issues and an apology. This resistance, combined with my own background as a healthcare professional, makes me acutely aware that service reform can often fall down the list of priorities, and therefore I feel that having support from political representatives is likely to be hugely beneficial in setting change in motion.

Since the article was published, a number of people have reached out to share similar stories. I believe that had it not have been for my professional background and experience working within the medico-legal sector, I would not have had the same success in ensuring the Trusts acknowledged and apologised for my treatment, so this certainly seems to be an area of great need and an opportunity

to ensure social justice for all those affected. In light of ongoing, parallel movements about the impact of Mother and Baby Homes in Northern Ireland, I think this is an area which merits further consideration.

I would be more than happy to share more details about my correspondence with the health trusts to give some further context, but would welcome your views on what actions could be taken to support developments in this area.

I look forward to hearing from you about options for progressing this enquiry at your earliest convenience.

Many thanks,

Dr Chris Tennyson

Following on from this email, a meeting was convened with the SDLP, and the put the following questions to the Minister of Health on 04/09/2024:

aims.niassembly.gov.uk					
om - Tennyson Psychology Services Mail			MLA Details: Mr Matthew O'Toole		
AQW 14449/22- 27	Mr Matthew O'Toole (SDLP - South Belfast)	To ask the Minister of Health to detail any plans to make information sharing between adoptees and birth parents easier in relation to genetic health conditions.	04/09/2024	To be answered by 19/09/2024	
AQW 14448/22- 27	Mr Matthew O'Toole (SDLP - South Belfast)	To ask the Minister of Health to detail any engagement his Department has had with adoption organisations in relation to potential genetic conditions that adoptees may face.	04/09/2024	To be answered by 19/09/2024	
AQW 14447/22- 27	Mr Matthew O'Toole (SDLP - South Belfast)	To ask the Minister of Health to detail the current provision for adoptees to access healthcare records pertaining to their birth parents and any medical conditions that might impact them.	04/09/2024	To be answered by 19/09/2024	

The response to all three questions was the same, see below:

When considering adoption for a child, an adoption agency is required by law to obtain and keep a record of information about the child's health. It is also required to arrange any physical/medical examinations and screening for the child and—as far as reasonably

practicable (dependent on parental engagement and consent) - the child's birth parents, as may be recommended by the agency's medical adviser. As far as it is practicable, a birth family health history should also be obtained, including details of any serious physical or mental illness and any inherited and congenital disease. This information is required to be placed in the child's case record and preserved for at least 75 years.

The adoption agency has discretion to disclose information to adopted adults seeking access to their information. The release of information will take into account the need to balance the welfare and interests of the adopted person with those of any third parties whose information may be held.

Any medical information held in adoption records may be limited to information which was known at the time of adoption. When a child is placed for adoption, he or she is issued with a new Health and Care number. Processes are in place to advise relevant health care settings of the child's new name and health and care number, and to arrange for the transfer of relevant medical records. Through the ongoing development and implementation of a digital health and care record system, the Department is working to ensure that a continuous record of care both pre- and post-adoption is maintained, while at the same time ensuring that all necessary steps are taken to respect the privacy of the adopted person and their family.

To assist those who have been adopted to access their adoption record, including any information it contains relating to the health records of birth parents, my Department issued 'Access to Birth Records and Adoption Agency Case Records for Adults Impacted by Adoption to Health and Social Care Trusts and Adoption Agencies – Practice Guidance' on 29 November 2023, for immediate implementation. This guidance was developed by experts by experience, including adoptees and birth mothers, working alongside experienced adoption organisations. It provides clear processes and best practice guidelines which aim to ensure that people affected by adoption have access to as much information about themselves and their families as possible; and that access is provided in a fair, balanced and transparent way.

My Department also engaged with adoption organisations throughout the passage of the Adoption and Children Act (Northern Ireland) 2022, which introduces a new legal framework for disclosure of information. When implemented, it will provide for a new and more consistent approach to access to information held in adoption agency records and by the Registrar General about adoptions which take place after the Act comes into operation.

For adoptions, which took place before the relevant provisions of the Act come into operation, it will introduce intermediary services to assist adopted adults and their birth parents to obtain information about their adoption (including health information) and to facilitate contact between them and birth relatives. In addition, intermediary services will be available to persons with a prescribed relationship to an adopted person (for example, the adopted person's children or grandchildren) to facilitate contact between them and birth relatives. Regulations will prescribe who will be able to access such services. The Act also empowers the Department to put in place regulations making clearer and more up-to-date provision about how adoption agencies must respond to requests for disclosure of, or access to, adoption records information that they hold.

Work is ongoing to implement the provisions in the Act on a phased basis, and new regulations will be subject to consultation. In the interim, the current Adoption Agencies Regulations (Northern Ireland) 1989 will continue to apply, which provide adoption agencies with the discretion to disclose information, as appropriate, in accordance with the published practice guidance.

Based on review of this answer, and analysis of the documents mentioned, a letter was prepared by myself and the SDLP representatives regarding this, detailed below:

Matthew O'Toole MLA
South Belfast



Matthew O'Toole MLA
30 University Street
Belfast
BT7 1FZ

30 September 2024

Dear Minister

Our Ref: Adoption services

I am writing to you in relation to the AQW 14449/22-27, AQW 14448/22-27, AQW 14447/22-27 which you have provided answers for to follow up and request some additional information on, on behalf of a constituent. I really appreciate your responses so far.

In your response you outline that any medical information held in adoption records may be limited to information which was known at the time of adoption and also that there is ongoing implementation and development of a digital health and care record system which is working to ensure that a continuous record of care both pre and post adoption is maintained. I am writing to ask if there have been any considerations given to the creation of a confidential link being made between the adopted person and birth family to ensure alerts are placed on the system in respect of vulnerability to health conditions which become known following the adoption.

In your response to the questions you mentioned 'access to Birth records and Adoption agency case records for adults impacted by adoption to Health and Social Care Trusts and Adoption agencies – practice guidance'

This guidance states that 'adoption is not a one off event. It is an evolving life-long process for all involved...' In this way I am writing to ask if you might be able to provide some guidance for any potential amends that can be made to the current legislation and practice which only appear to exist for access to family health/medical information from a single point in time.

Further to this, there are references made to the medical adviser of each adoption agency.

- What guidance does the Medical adviser work from
- What is the view of the medical adviser on the need for updated health information to be accessible to adoptees throughout the course of their life

Matthew O'Toole MLA
South Belfast



Kind Regards,

Doire Finn
Office of Matthew O'Toole MLA

Having spoken with the SDLP representatives, they stated they are keen to continue to advocate on behalf of adoptees in respect of this issue, but noted that the case for such advocacy could be strengthened by more adoptees coming forward to share their experiences of any similar issues.

I would be more than happy to discuss this with anyone else affected by the issues, or to stay in touch if people are happy to go ahead and write to their own political representatives. It has been drawn to the attention of Colin McGrath, who is an SDLP MLA in South Down, and is the SDLP rep on Stormont's health committee, and again, he is also keen to support the issue.

Any questions, feel free to give me a shout,

Chris Tennyson

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Email: enquiries@tennysonpsychology.com or ctennyson587@hotmail.co.uk