

Submission to the Joint Committee on Health: AsIAM's Response to RTÉ *Prime Time Investigates*' Findings on the Department of Health's Collection of Dossiers on Autistic Children

AsIAM received the findings from last week's *Prime Time Investigates* with dismay; the very notion that the Department of Health has been compiling dossiers on autistic children's private information towards a clandestine legal strategy sent shockwaves throughout our community. Countless families' trust in the Department and the HSE has been shattered following the programme's broadcast, at a time when relations were at an all-time low and support was needed like never before for their autistic children. Those that were involved in drawn-out legal battles with the State over its failure to provide for their children's educational needs evinces the fundamental lack of accessible services for autistic people living in Ireland, particularly those needed at a vital stage in one's life. As the Government moves to respond to these serious allegations in the days ahead, we believe several key actions must be taken as part of any fact-finding and redressive process.

It is incumbent upon the Government, first and foremost, to promptly inform the families of the (at least) forty-two children whose data is presently on file with the Department, and any others of whom may also be. Our organisation has received substantive correspondence since Thursday evening, speaking to the dread existing among families around the unknown fear that their children's information may or may not be part of such a collection of dossiers; decisively dispelling this anxiety must be among the Government's priorities going forward. In a similar spirit, any moves to notify families should, ideally, occur *before* this matter reaches the Oireachtas for public scrutiny.

Affected families, upon being informed, must be given free and unfettered access to their children's information in its entirety. Indeed, as the programme outlined, several dossiers contained significant collections of personal data, including psychiatric assessments, school reports cards, as well as photographs and video recordings. Every scrap of evidence the Department was collecting in its covert legal strategy must be returned to affected families with due regard to their privacy and dignity. There should be no further recourse for additional legal action here. Indeed, the UN Convention on the Rights of Persons with Disabilities (which Ireland ratified in 2018) sets out as much under Article 22, speaking directly to signatory States' obligation to protect the privacy of personal and health information of people with disabilities on an equal basis.

AsIAM welcomes the Data Commissioner's launching of a statutory inquiry into the matter under Section 110 of the Data Protection Act 2018. Its remit is broad, yet we would remiss if we did not impress the importance of the cultural dimension attached to any such inquiry. Whilst it may very well be the case that the Department acted lawfully in its conduct, it nevertheless highlights an underlying question of ethics around the working culture at play within it and other State agencies. This, crucially, we would argue, needs to fundamentally change. The litigation process needs to change so that its ultimate outcome is a fair resolution to legitimate grievances.

Having listened to several affected parents earnestly and courageously share their experiences in the media over the past several days, AsIAM understands that this has been an event of extraordinarily traumatic implications for so many. A clear recognition of such is required from the Government, we believe, and accessible steps taken to provide redress accordingly. Recognition of such is required from the Government, we believe, and accessible steps taken to provide redress accordingly. We would therefore recommend the setting-up of a dedicated support-line, staffed by social workers and officials from the Department of Health, along with comprehensive counselling and legal advisory services.

We are calling for an external investigation seeking to examine the impact *Prime Time's* investigation has had on families. Many families, because of last week's report, feel immensely let down, frustrated, and betrayed by the system. Trust was already at an all-time low amongst many families within our community, but last week's report has further eroded and fragmented this connection. The objectives of this external investigation should also seek to explore whether there are more families impacted by these actions. An important question that needs to be determined is whether the Department is still fighting cases where they know they are at fault. It is our view that any failure to have a full, transparent investigation will lead to a further erosion of trust and suspicion from families. There is therefore an onus on government and state agencies to ensure trust is restored so that families can have confidence in the system.

AsIAM is in a unique position when it comes to understanding families. Our organisation deals with correspondence from hundreds on an annual basis; many predominantly contact our office when they are having difficulties in accessing supports for their autistic children. Dealing with so many on a regular basis and providing advocacy and support to these families, gives AsIAM an insight into the many struggles experienced by families, particularly in relation to accessing supports from the Departments of Health and Education. In 2020, AsIAM engaged with up to 851 families alone; 23% of which engaged with our office concerned with educational issues in the form of supports, access to school placement and

resources. 17% of engagements were from those experiencing issues in accessing fundamental health services.

Given these high numbers, AsIAm is calling for a culture review of the HSE and the Departments of Health, as well as the Department of Education and its agencies, in how they deal with autistic individuals and their families. Any such audit should also be a prime task arising from any policy review that examines how we arrived at this juncture that was exposed last week. In addition, a culture audit should examine how the Departments of Health and Education and the HSE can improve their engagements with autistic people and their families. Good governance and fairness must be the watchwords of any review going forward.

Last week's investigation exposed the brokenness of our health system and the inefficiencies of our education system when it comes to supporting autistic children. One thing that was explicitly apparent from this report is the need for greater investment and better planning when it comes to state agencies engaging with members of the autism community. Our proposed Autism Empowerment Strategy, which sets out a collaborative approach for cross-departmental work and consultation with autistic services users if implemented would inform best practices and prevent malpractices like this from happening again.

The concerns of families are well documented over the course of the past week. At the centre of this debacle, families impacted by it should be prioritised and given informed answers. AsIAm is calling for an external investigation, which should seek to examine the impact this had had on families affected, and where there are more families than previously referenced involved. Such an investigation must be fully open and transparent to remove any concerns of opaqueness. Last week's reports further highlights the ongoing battle many families have had to endure when it comes to accessing supports for their autistic children; these engagements inevitably add to fatigue and exhaustion for many parents and guardian, and this practice of breaking down families must stop.