GLOBAL STUDY

Inequality in Life and Death

The Duty to Investigate and Remedy the Systemic Causes of the Deaths of Persons with Disabilities under International Law

*A Lifecourse Perspective**

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* Dedicated to the memory of Professor Wanhong Zhang (Wuhan University), a giant in international disability rights law, a leader of the movement in China and a true gentleman.

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Preface.
Grard Quinn.

The idea behind this Study came about as a result of armed conflict. The armed conflict in question was the Irish War of Independence that occurred over a hundred years ago (1920-1922). My grandmother, Eileen Quinn (aged 24) was killed in that War. She had three young children, including my father (aged three at the time and a witness). She was the proverbial innocent civilian in the wrong place at the wrong time. During the war coroners were suspended and in their place were put military tribunals. The military tribunal in her case was hastily convened just four days after her killing. It whitewashed the truth. While researching how these tribunals worked, I remember asking myself, "What international standards would apply today to the investigation of 'suspicious deaths' like hers?"

To my surprise, contemporary international standards on the proper investigation of such deaths are voluminous and each region in the world has its own distinctive approach. As I unpacked these standards, a second thought occurred to me: "What is the added-value and relevance of these standards to groups in vulnerable situations, like persons with disabilities?" This was a natural question, as I have spent most of my professional life advocating for disability rights. There seems to be great untapped potential to put these standards to work for the living and not just the dead.

Death is an interesting lens on life. It can reveal the impact of a web of advantages and disadvantages one faces throughout life which is the focus of the new discipline of *social* epidemiology. Modern investigative standards focus not only on individual deaths but also on the systemic causes behind them. These systemic deficiencies are legion in the context of disability.

The UN Convention on the Rights of Persons with Disabilities (UN CRPD) lends itself admirably to this approach. For it creatively blends civil and political rights (including the right to life) with other economic and social rights (like the right to live independently and be supported in the community). As the African Commission on Human and People's Rights emphasizes, these '*conditions for life*' are just as important as the substance of the right to life. And it is these underlying '*conditions*' for life that modern investigatory bodies can and should explore. Furthermore, they can play their part in highlighting systemic deficiencies and accellerating change. The English 'prevention of future death' reporting and the Australian National Coronial Information System ('saving lives through the power of data') are good cases in point.

Theresia Degener once observed that the traditional approach to disability ended up 'problematizing' the person which meant that the individual was seen as the origin of their own problems. In a way this is reflected in the traditional view that most persons with disabilities die of 'natural causes' due to their own condition. However, the modern approach to investigations searches instead for systemic causes. One might say the modern approach to investigations - with its emphsis on systemic causes - is more faithful to the social or human rights model of disability.

This Study builds bridges between two different realms of international law - disability rights and the law governing the proper investigation of 'suspicious deaths.' It shows the

benefits of bringing two different streams together and thus reducing fragmentation in international law. It shows the benefits of moving away from a narrow medicalised conception of epidemiology toward a more *social* form of epdemiology. Additionally, it shows the benefits of a lifecourse approach to understanding disability and the impact of systemic disadvantages over time. Hopefully, it will spark a conversation about how to harness investigatory bodies as a tool for the living so that such investigations can play a more visible part in accelerating change.

This work represents a start in a new field. It does not purport to have the final word. Hopefully, it will stimulate others to consider how investigations can be adapted to reflect life circumstances and vulnerabilities faced by persons with disabilities and contribute to change. One suspects that the potential of the relevant UN and regional standards have yet to be realised for many groups in vulnerable situations including older persons.

I want to thank the International Disability Alliance (IDA) and especially Jarrod Clyne for supporting this project. I commend their vision in working to build bridges across legal different domains, using the CRPD as a cataylst to reduce fragmentation in international law. I also extend my gratitude to those around the world who provided feedback on early drafts, sharing their insights, experiences, and time. All contributors are listed in the *acknowledgements*.

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It was truly a collaborative project.

Foreword

Foreword by Nawaf Kabbara, President, International Disability Alliance (IDA)

Every person has an inherent right not only to life but to dignity, respect, and equal legal recognition. However, for many persons with disabilities around the world, these rights are tragically violated both in life and, most starkly, in death. This powerful report, "Study on Inequality in Life and Death," shines a glaring spotlight on a deeply troubling truth—persons with disabilities are not simply dying; they are being systematically failed, neglected, and ignored.

When we lose a loved one, we may find solace in the hope that lessons will emerge from our grief, preventing similar tragedies. This report calls upon duty-bearers, primarily States, to ensure that the lives of persons with disabilities that are lost due to systemic failures are not forgotten and that justice is pursued relentlessly. The testimonies within these pages illustrate vividly that the deaths of persons with disabilities often have profound, preventable systemic roots. The silence around these deaths perpetuates ongoing harm, conceals injustice, and denies dignity even beyond life itself.

As OPDs, we recognize our role not only as advocates but as custodians of truth and accountability. Persons with disabilities and our representative organizations must be central to investigative processes that aim to uncover systemic injustices. This is critical because only through our leadership can the structural barriers that perpetuate these injustices be fully understood and effectively dismantled. The powerful stories and cases presented in this study are a testament to the courage and resilience of persons with disabilities and their families who, despite profound personal loss, have fought tirelessly for accountability, reform, and recognition.

The International Disability Alliance commits unequivocally to leading this urgent charge, calling upon States, international bodies, civil society, and communities to adopt a lifecourse approach to addressing the underlying inequalities that disproportionately lead to the deaths of persons with disabilities. It is not merely about honouring the memory of those we have lost; it is about profoundly transforming systems and structures to safeguard human rights and dignity.

The depth of inequality revealed by this report must compel us all to action. Our shared humanity demands that we confront and remedy these systemic failures. Let us not allow silence or inaction to persist. The least we can do is ensure justice for those we have lost, which is also a promise for the dignity, equality, and safety for us all.

Foreword by Sasha Stevenson, Director, *SECTION27, South Africa.*

South Africa's long history of human rights violations is both tragic and well known. In our democratic era, there have been few human rights violations as egregious as the Life Esidimeni disaster. A large number of vulnerable people died in conditions of torture and neglect. The people who died were mental health care users, moved ostensibly in the name of deinstitutionalisation. Despite the circumstances of the deaths, many were recorded as being due to "natural causes".

A series of investigations and legal processes were conducted to get to the bottom of what happened, how, who is responsible, and how the disaster should be remediated and prevented from recurring. The investigations and legal processes took place only because of the relentless pursuit of justice by families of the mental health care users and their allies and lawyers. Despite this being a clear example of systemic human rights violations leading to mass deaths, no automatic investigation process was mandated by law.

The absence of a legal framework for investigation, redress and prevention of recurrence is a troubling gap. This report explores the urgency of addressing this gap and how it can be filled. If we are to respond to and reform the systems that continue to kill vulnerable people, we must heed its warnings and implement its recommendations.

Executive Summary.

Death is a definitive marker of personhood. A myriad of formalities attend to it. It often reflects how one has lived and especially the mix of advantages and disadvantages one has faced in life. When and how one dies is often reflective of these lifecourse forces.

Whenever the cause of death is unknown or 'suspicious' an investigation is generally conducted. Most countries in the world have independent investigatory bodies or create standing or issue-specific commissions of inquiry. Their primary task is to tell the truth. There is now a wealth of international (and regional) law on the duty to investigate which also spells out what the investigation should entail. Increasingly this law means that to 'protect' the right to life in the round means to 'prevent' avoidable deaths in the future. That is why international law supports the idea that investigations should go well beyond individual instances in order to probe underlying systemic causes. These underlying systemic causes could well be very potent in the context of disability. They might include neglect, abuse, violence, poor services as well as institutionalisation, and social isolation and loneliness. Seeking the truth means identifying these underlying systemic causes.

The Study examines the legal significance of death and the right to the truth. It looks at the truth expansively by adopting a lifecourse perspective on disability. This Study unpacks the various international and regional standards on the duty to investigate 'suspicious deaths' and links this to the debate about disability rights. It looks at some Public Inquiries around the world that clearly show it is unsafe to simply assume that the deaths of persons with disabilities are always down to 'natural causes.' And it examines some innovative practice that shows how investigations into 'suspicious deaths,' can, when focused on systemic causes, help contribute to a process of change for the living.

Finally, this Study makes some recommendations to try to ensure that modern investigations are properly harnessed in a disability context through a lifecourse perspective and can play their part in the broader ecosystem for legislative and policy change. Truly, a service for the living. It opens up a new domain and does not purport to have the last word. Hopefully, others will amplify its main findings and add to its recommendations.

...[the right to life]...entails a duty to protect the right to life of persons with disabilities from all acts or omissions that are intended or may be expected to cause their unnatural or premature death.

Catalina Devandas, former UN Special Rapporteur on the rights of persons with disabilities (2020).[1]

[T]he [relevant] domestic investigation *failed to address the systematic failure in the care system* which had been reported by a number of actors, including State bodies and its potential effect on the individual circumstances of Ms T.J.

European Court of Human Rights, *Validity on behalf of T.J. v Hungary,* (October 2024), at paragraph 82.

The only thing that makes sense of the loss of your loved one is that maybe lessons will be learned and the same thing will not happen to someone else...

Testimony of a parent, Andre McCulloch, to the Justice Committee of the UK Parliament hearing on the Coroners Service (2021).[2]

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1. Introduction & Purpose.

1. Inequality over a lifetime as Seen Through the Lens of Death.

This is a Study about inequality and death. It's about inequalities that build up over a lifetime and that can lead to an early death. Its chief goal is to disabuse people of the notion that most deaths of persons with disabilities are nearly always down to 'natural causes.' Instead, it urges bodies that investigate deaths to probe more closely the underlying *systemic causes* of such deaths especially as they may result from a lifetime of inequality. Just as importantly, it advocates for real learning from such investigations to eliminate the systemic causes of inequality and early death among persons with disabilities - to contribute to change for the living.

Inequality reveals itself in many different ways. Too often it is ignored. But death makes inequality stark and vivid. It cannot be ignored. For it is in death that we see the cumulative impact of deprivation, poor services, abuse, violence, discrimination and a myriad of other

[1] See the 2019 thematic report of the UN Special Rapporteur on the rights of persons with disabilities on *'The Impact of Ableism on Medical and Scientific Practice,'* at para 48. The thematic report is available at: https://www.ohchr.org/en/documents/thematic-reports/ahrc4341-rights-persons-disabilities-report-special-rapporteur-rights

[2] House of Commons, Justice Committee, The Coroner Service, First Report of Session 2021-2022 at para 185. The report is available at: https://committees.parliament.uk/publications/6079/documents/75085/default/

vulnerabilities that confront persons with disabilities. The immediate cause of death may be purely medical. But the real cause may be a lifetime in gestation. Life - and the right to life - cannot be considered apart from the socio-economic conditions that make it real. In particular, a failure to deliver rights such as the right to live independently with the services and supports needed to make it work has a slow-burning effect over time and is visible in increased rates of mortality. This Study is concerned mainly with the lifecourse impact of inequalities that compound each other over time. Unequal access to healthcare can also impact mortality but is not a primary focus of this Study.[3]

Examining the true causes of deaths – especially premature and 'excess deaths' – therefore gives us a window to appreciate anew just how devastating inequality can be in later life. Often these deaths are glossed over by asserting they are due to 'natural causes.' However, a series of high profile Public Inquiries around the world point strongly at more systemic and underlying causes and ought to at least cause investigative bodies to be more vigilant in order to reveal the same when they occur. Institutions are inherently dangerous places. Some of these Inquiries are canvassed in this Study.

For example, the 2022 Dotan inquiry in Israel revealed the intrinsic threat to life within institutions (including small group homes) for persons with intellectual disabilities. Conversely, de-institutionalisation, if done incorrectly, also causes extreme risks. The 2017 scandal in South Africa (Life Esidimeni) in which 144 persons with mental health conditions died because of an inappropriate de-institutionlisation programme reveals how poor services and bad planning can literally be life-threatening. And life in the community can be equally precarious without the right kinds of supports and services. Loneliness and social isolation are contributing factors in many deaths including those of persons with disabilities who may face isolation even in their own communities. The tragedy of the inferno at Grenfell Tower (2017) revealed just how vulnerable persons with disabilities can be when fire takes hold in buildings when there are no personal emergency evacuation plans that take account of the specific needs of residents with disabilities. These were not deaths due to 'natural causes.'

These premature deaths are always individual tragedies for the person involved and their families and survivors. But they can also hold important systemic messages. They can be important indicators that something is awry in policy and in programmes meant to advance key human rights such as the right to independent living and to adequate social supports to make it a reality. Such deaths can be the logical and even highly predictable outcome of a failing social system. What's more, they are highly likely to repeat themselves unless the cycle is intentionally broken and systemic improvements are made in underlying services.

True, many deaths of persons with disabilities are undoubtedly due to 'natural causes.' But one suspects that the natural proclivity to simply presume that this is so can conceal many systemic causes. Revealing the truth in individual instances is always important. And revealing the systemic or structural causes of the deaths in individual instances is just as important. To break the cycle - to prevent future deaths - requires learning from the truth. And learning from the truth implies a capacity and a willingness to learn.

Interestingly, and over the past 30 years or so, international law (and regional law) has developed quite sophisticated standards governing the proper investigation of 'suspicious deaths' or 'potentially unlawful' deaths in many different circumstances. And increasingly

[3] This is a specific focus of the World Health Organisation - *Health Inequality Monitor:* see, https://www.who.int/data/inequality-monitor

international law calls for a focus on the underlying systemic causes and on the positive action measures needed to ameliorate them.

However, it is striking how infrequently these standards are applied in the context of disability. This might be a result of these standards being developed with the many problems of transitional justice in mind. Political violence rather than the slow burning effect of inequality was the traditional focus. But despite the rather narrow historical origin of the standards they have tremendous potential in the domain of disability. One result is that the learning that investigations can produce in driving change is lost in the disability sphere.

This reflects the reality that, too often, the disability rights domain is hermetically sealed and viewed in isolation. One result is that key advances made in one domain often fail to cross-over into the disability domain. This is clearly so with respect to the elaborate international standards on investigations. Connecting the evolving international standards on the investigation of deaths (and their true systemic causes) to the disability rights sphere is therefore part of a larger process of integrating disability into the wider human rights sphere and indeed to contribute to that sphere. This can best be achieved by taking time to appreciate the specific threats to life faced by persons with disabilities and ensuring that the investigatory processes required by international law are attuned to them. This is a mutually enriching process.

These international standards on the duty to investigate are predicated on the right to life. They emanate from various human rights treaties of the United Nations and also within all regional bodies. The logic of the right to life requires the State to proactively protect life. This includes action to prevent the loss of life where the threats are known (or knowable) and can be dealt with. And, as Regional law makes plain, the substance of the right extends to the *'conditions for life*' which is especially important for persons with disabilities

The right to life is protected under several treaties including the International Covenant on Civil and Political Rights (ICCPR). This is of course directly mirrored in the UN CRPD (Article 10 – right to life). It makes sense to see how the standards adopted under the ICCPR can animate the relevant standards under the UN CRPD - and *vice versa*. Much of the UN CRPD deals with economic, social and cultural rights - precisely the kinds of rights that, if respected, should lead to fewer premature deaths later on in life. They go to the '*conditions'* for a dignified life. The right to life in the UN CRPD therefore gives one an important lens to view the fatal impact of deficiencies in delivering these core socio-economic rights.

These standards on investigations aren't just international. They are powerfully reflected in all regional systems: in Europe (Council of Europe), in the Inter-American system (Inter-American Commission and Court of Human Rights) and in the African Union (African Commission and Court of Human and People's Rights). In fact, regional bodies have been to the very fore in advancing the duty to investigate 'suspicious deaths' and have also become particularly active on the rights of persons with disabilities. The recent and admirable judgment of the European Court of Human Rights in *VALIDITY on behalf of TJ v Hungary* is a good case in point. Too often their amplifying effect on global standards is under-appreciated. In short, the standards on investigations are truly global and not just Eurocentric in nature.

The various standards are usefully drawn together in a series of UN policy instruments intended to guide States when crafting their own investigatory mechanisms. They include

principally the 2017 iteration of the *Minnesota Protocol on the Investigation of Potentially Unlawful Deaths* (see section 3.b.2 below). Despite its title, the *Minnesota Protocol* is not a treaty or a protocol to a treaty. But it does encapsulate and restate a large amount of treaty case law. The *Minnesota Protocol* is therefore central to the adequate investigation of 'suspicious deaths' or 'potentially unlawful deaths' and sets the benchmark for the same and will be referred to throughout. States are exhorted to take these standards into account when framing their own legislation.

The *Minnesota Protocol* has recently been complemented by the 2022 *Istanbul Protocol: Manual on the Effective Investigation and Documentation of Torture, Cruel and other Inhuman or Degrading Treatment or Punishment.* In a way, the *Minnesota Protoco*l focuses on investigations into the end result of a lifetime of inequality (premature death) and the *Istanbul Protocol* focuses on investigations into underlying deficiencies in services as well as ill-treatment that can lead to such an outcome. Both Protocols ought to be fully harnessed and applied in the disability context to help reverse systemic inequalities especially those that increase the risk of early mortality. The *Istanbul Protocol* catches much of the ill-treatment that might affect a person with a disability. However, if the failure to provide for the '*conditions'* for life does not amount to ill-treastment, torture or inhuman or degrading treatment they will not be caught. That is why I focus, for the purpose of this Study, on the right to life in its broadest sense

In addition to these standards, various Special Procedures mechanisms of the UN Human Rights Council have produced important work that adds significantly to our understanding of these investigatory standards and assists States in their application. These include the Special Rapporteur on extra-judicial killings and the Special Rapporteur on truth, justice and reparation (see sction 3.B.4) and their work will be referred to below.

There are some innovative practices around the world on how to investigate deaths especially of persons with disabilities (England & Wales, Australia & New Zealand). They will be referred to in order to show what is possible. They are not perfect by any means and require further reform. But they at least show how systems can actively learn from failures and adjust accordingly.

This Study is of direct relevance to the implementation of various core rights in the UN CRPD. It goes directly to the heart of Article 10 of the CRPD on the right to life. It expands the frame of Article 10 beyond its substance to include its more process-oriented dimension, *vis* the duty to investigate 'suspicious deaths.' It opens us up to the reality that the ingredients for the right to life rests in no small measure on how effective the other rights in the CRPD are implemented and especially those having to do with socio-economic rights. Put the other way round, deficiencies in how these socio-economic rights and entitlements are delivered can have fatal consequences.

This Study also goes directly to the core right to live independently and be included in the community (Article 19). The UN Guidelines on Deinstitutionalisation specifically mention the risk of premature death if this right is not properly implemented. Implementing this core right is not only good in itself but helps prevent avoidable deaths later in life. Furthermore, the Study should be seen as adding to our understanding of the potentially fatal consequences of violence, exploitation and abuse whether in institutions or in the community (Article 16 UN CRPD). The slow burning effect of these abuses cannot be lightly discounted and can have a direct impact on the right to life.

And this Study also goes to Article 28 CRPD - adequate standard of living and social protection. They go directly to the *'conditons'* for the right to life to succeed. In many instances, social protections and supports were originally crafted in the mid-20th century from a care or welfare philosophy, They need to be reinvented to subserve the rights of the CRPD and to honour the agency of persons with disabilities. This entails comprehensive reform of service design and delivery systems.[4] In addition, Article 19.2 CRPD effectively calls for the personalisation of services. My main point is that deficiencies in these services can become glaringly obvious in later life through premature death. In other words, these deaths provide us with a vantage point to truly grasp the import of bad supports and services over a lifetime.

An obvious and direct risk to the right to life of persons with disabilities is armed confict. Article 11 of the UN CRPD calls for respect for international humanitarian law (and international law more broadly) in the context of armed conflicts. IHL has a number of important protections fo civilians caught up in in armed conflicts. Civilians with disabilities are often in highly vulnerable situations in theatres of armed conflict and stand to lose their lives. Whatever critical civilian infrastructure there is to provide support (hospitals, clinics) is likely to be shattered in a conflict - with disproportionately devastating results.[5] In important ways, IHL protections have been under-inclusive of civilians with disabilities. Making IHL rules more inclusive of the real-life situation of civilians with disabilities is critically important. Unless that happens, civilians with disabilities will continue to suffer fatalities in greater numbers compared to the rest of the civilian population. Importantly, while it may be more difficult to implement, the duty to investigate applies equally in conflict and post-conflict suituations.

The deaths of persons with disabilities arising from armed conflict (whether between States or within States) - and the law governing investigations in these cases - is not a primary object of this Study and requires seperate in-depth analsysis. Usefully, the International Committee of the Red Cross (ICRC) in collaboration with the Geneva Academy have produced an excellent report on 'Investigating in Situations of Armed Conflict: Law, Policy and Good Practice' (2019).[6] While it was not crafted with persons with disabilities in mind, it is nevertheless a highly useful resource when coming to terms with the duty to investigate in times of conflict or afterwards.

All of the above goals of the right to life, independent living, service modernisation, the protection of persons with disabilities against violence, exploitation and abuse, the protection of civilians with disabilites in conflict situations can be materially advanced by an investigatory process into deaths (and their systemic causes and the prevention of future deaths and harm) – one that shines a light on the effects of systemic deficiencies and, in so doing, adds impetus to the need for change.

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[4] See 2023 thematic report of the UN Special rapporteur on the rights of persons with disabilities on *'Transformation of Services for persons with disabilities.'* The text of the thematic report is available at: https://www.ohchr.org/en/documents/thematic-reports/ahrc5232-transformation-services-persons-disabilities

[5] See generally the special thematic issue of the ICRC Review on 'Persons with Disabilities in Armed Conflict,' ICRC Issue 922 (2022). Full text is available at: https://international-review.icrc.org/reviews/irrc-no-922-persons-with-disabilities-in-armed-conflict

[6] See the Geneva Academy/ICRC 2019 report on 'Investigating in Situations of Armed Conflict: Law, Policy and Good Practice. Full text is available at: https://www.geneva-academy.ch/research/our-clusters/past-projects/detail/3-investigating-in-situations-of-armed-conflict-law-policy-and-good-practice#:~:text=A%20Geneva%20Academy%2DICRC%20Project&text=Proper%20investigation%20by%20militaries%20involved,in%20case%20of%20alleged%20violations

2. Outline of this Study.
This Study is divided into five parts.

Part A zooms out to focus on the legal significance of death. It frames death as significant marker in personhood. It recounts the various public interests in having a robust mechanism to investigate 'suspicious deaths.' It argues that this mechanism ought to play a decisive role in probing underlying systemic causes while also helping to alleviate them. It connects this systemic role to the notion of Government (and private corporations such as service providers) as '*learning organisations'* that are both capable and willing to learn from past tragedies. It also examines the many systemic causes that may explain the death of a person with a disability and how these vulnerabilities are experienced by different cohorts of persons with disabilities.

Part B focuses on the international standards on the duty to investigate 'suspicious deaths' or 'potentially unlawful' deaths. It focuses on treaty law and the *Minnesota Protocol* which draws these standards together as a policy guide to States. Most importantly, it recounts how these standards go beyond investigating individual instances to include a focus on '*prevention'* which essentially means to probe for underlying systemic causes and to help stop the cycle of neglect, abuse and death.

Part C focuses on how regional bodies interpret and apply these standards. These standards are now truly global going beyond the United Nations to include the Council of Europe, the Organisation of American States and the African Union. This Part unfolds these standards across the different regional bodies. Some interesting and recent caselaw involving persons with disabilities will be explored.

Part D highlights innovations around the world which shows that investigative mechanisms can play a useful role in advancing the broader socio-economic goals of the UN CRPD. First we look at some representative Public Inquiries. These are not investigations in the narrow sense of focusing on one incident but instead shine a light on multiple instances. These Inquiries reveal in striking detail that many (though certainly not all) deaths of persons with disabilities are not down to 'natural causes' but have deeper systemic roots. In this Part, I also focus on innovation in narrower investigative mechanisms (such as coroners). While they aim primarily to probe the immediate medical cause of death but thay can also be tasked (and should be tasked) to probe the underlying systemic causes (if any) and to formulate 'prevention of future death reports' or recommendations based on the lessons learned. This shows that it is entirely possible to mandate even narrowly focused investigatory bodies to go beyond individual cases and identify systemic causes. Additionally, I will examine more thematic or in-depth approach to investigating deaths in England (LeDeR programme) of particular cohorts of persons with disabilities (those with intellectual disabilities) and Australia to show that it is possible to go beyond a case-by-case approach.

Part E deals with conclusions and puts forward some recommendations. The conclusions focus on the value of applying international standards for investigating 'suspicious deaths' to persons with disabilities. If properly used to probe underlying systemic causes, these mechanisms could add urgency to the implementation of the socio-economic provisions of the UN CRPD - the *'conditions'* for the right to life. The Recommendations are geared to

ensuring that all relevant actors - including States - fully integrate disability considerations when applying the relevant international standards.

Part A:
Personhood, Death and Inequality.

2. The Legal Significance of Death and as a Lens to View the Effects of Systemic Inequality.

1. The legal significance of death and why truth is important.

Death (and the causes of death) is not always self-explanatory. Most countries have had in place for decades if not centuries, time-honoured institutions to investigate 'suspicious deaths' and to tell the truth. 'Suspicious deaths ' are deaths for which there is no clear cause of death immediately discernable.

In the Anglo-American world these investigatory bodies mainly include coroners (as in England & Wales) and sometimes medical examiners (as in some states in the US).[7] The institution of coroners goes back centuries and has a colourful history in the common law.[8] In the civil law world they include medico-legal institutions. Regardless of their title or designation, their overall purpose is the same, to tell the truth about deaths that occur out of the ordinary. Lately, they also bear an added task to recommend policy changes in order to avoid needless deaths in the future.[9]

Death is an important legal event in its own right.[10] There are many legal formalities connected with the registration of births, deaths and marriages in all countries. [11] The reason has to do with the legal idea of personhood. Generally, personhood and human agency begins at birth and ends at death. It proves crucial that important markers along life's journey are officially validated. It is not for nothing that Article 18 (2) of the UN CRPD gives children with disabilities an equal right to be registered upon birth (i.e., to have their personhood acknowledged). In other words, Article 18 (2) assures children with disabilities a legal right to their personhood. Implicitly, it concedes that this basic acknowledgement of personhood was denied in the past on the basis of disability.

Even when a person ceases to formally exist by reason of death (and cannot therefore exercise human agency) they may still have a spectral existence through their estate or property. That is to say, they can continue to have their will respected in the distribution of their property even after their death. In truth, this is less a case of exercising human agency

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[7] For a current textbook on coroners and the law see, Jarvis on Coroners, 14th Edition (Sweet & Maxwell, 2019) by Paul Mathews.

[8] See Everret Spring, '*The Antiquity of Coroners,*' 19 Law & Banker and Southern Bench and Bar Journal, (1926) 260-264.

[9] On the importance of truth in the context of human rights see the Organisation of American States, Inter-American Comission on Human Rights, The Right to Truth in the Americas, (2014) especially section 1.A, "*Relationship between Democracy, Human Rights and Truth*."

[10] See the 2024 annual thematic report of the UN Special Rapporteur on extra-judicial killings, *'Protection of the Dead*': available at - https://www.ohchr.org/en/documents/thematic-reports/ahrc5656-protection-dead-report-special-rapporteur-extrajudicial-summary

[11] See, e.g., https://www.gov.uk/browse/births-deaths-marriages

after death and more a case of having one's moral agency in life respected after death in respect of the disposal of one's earthly possessions (if one was lucky enough to have any).

The term *'civil death'* has often been applied to persons with disabilities under guardianship to highlight the reality that all the *indica* of personhood (making one's own way in the world) are stripped as a result of legal incapacity. This is a situation analogous to death. One may as well be dead - in the eyes of the law.[12] However, this is not the primary topic for analysis in this study.[13]

In the normal course of events a certificate of death is produced by some agency of the State that has tangible legal implications. A lot turns on it. It marks thre official termination of personhood. If, for example, the person has entitlements from the State or private sources (like insurance) these end upon a formal recogntion of death. Interpersonal relations (e.g., marriage), which can be thought of as a way of sharing personhood, end upon the formal recognition of death. A capacity to enter legal relations (e.g., through contract) ends upon the formal recognition of death. A capacity to exercise political rights (like the right to vote) ends on the formal recognition of death. And the capacity to control the disposition of property (generally) ends on death subject of course to the valid will of the person (assuming a will is made). So the valid legal certification of death is a very important aspect of personhood and marks the definitive legal ending of the same.

That is why a valid death certificate is so important - as well as the formalities required. Such certificates are normally generated by a State agency (usually one that deals with the registration of births, deaths and marriages). In the normal course of events, a key element of the certificate is a 'notification of death' that is produced by an attending physician who can attest, though direct and recent medical knowledge of the patient, the true cause of death. However, if there is no attending physician, or if the physician cannot determine the true cause of death (as is the case with 'suspicious deaths') then a further investigation is normally warranted which usually involves a coroner or a medico-legal functionary or a medical examiner.

Importantly, at least from a historical perspective, neither a coroner nor a medico-legal functionary have any (direct) role in establishing fault or legal liability for a death caused by third parties.[14] There are prudent reasons for ensuring that accountability mechanisms (e.g., in the criminal law) are kept separate from investigatory mechanisms if only to ensure that the former do not cross-contaminate the latter. As the impressive 2016 INQUEST (UK) Handbook states:

> The Inquest system is not there to establish who was responsible for a death. Its purpose put simply is to answer four questions on behalf of the State, who someone was, where they died, when they died, how they came to their death[15]"

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[12] See an early talk by the author linking theories of personhood with Article 12 of the UN CRPD: *Personhood and Legal Capacity: Perspectives on Article 12 of the UN CRPD,* Harvard Law School Project on Disability seminar, (February 2010). For a development of the concept of '*civil death*' drawing on the historic wrtiings of Sir William Blackstone) see Gerard Quinn & Abigail Rekas-Rosalbo, '*Civil Death - Rethinking the Foundations of Legal Personhood for Persons with a Disability,'* 56 Irish Jurist, (2019), 286-325.

[13] See now Anna Arstein-Kerslake, The Right to Legal Personhood of Marginalised Groups: Achieving Equal Recognition before the Law for All, (Oxford University Press, 2024).

[14] See UK law – IRL law

[15] The INQUEST Handbook: a Guide for Bereaved Families, Friends and Advocates (UK) (3rd Ed. 2016).

At the end of the investigation the identity of the person should be established (if unknown or unconfirmed), the date of death, the place of death and the proximate cause of death (the 'who, how, when and where' of death). Once these basics are established then a 'certificate of death' can be issued ending human agency and personhood.

Most States have a mandatory referral system to an investigatory body in some limited instances such as a violent death, an 'unnatural death' or where the deceased died while in custody or in some form of State detention.[16] Much turns on how 'unnatural death' is interpreted. If the quest is just for the immediate or proximate medical cause of death then there will be little appetite to open up the inquiry to look back at the longer-acting systemic causes. This over-medicalised approach can stymie effective investigations. Having awareness of the cumulative disadvantages faced by persons with disabilities could help counteract this.

The risk is that the true cause of death might be overlooked and the death is just put down to 'natural causes,' to the disability itself or to old age or a combination of the two. The true cause of death might in fact be due to the overuse of sedatives or chemical restraints in an institution or a nursing home.

In some systems, an inquest – a formal jury hearing or inquest presided over by a coroner or medico-legal investigator – must be convened if the referral is mandatory. This happens in a minority of cases. INQUEST – an impressive London-based NGO that supports families through the process – reports that out of half a million deaths each year in the UK about 230,000 are 'reported' to a coroner and only 31,000 lead to a full inquest.[17] INQUEST reports that only 456 inquests with a jury were impaneled in the UK in 2013. So jury inquests are the exception rather than the rule. Inquests give much more scope to probe the underlying systemic causes of death.

Inquests or their equivalent are not supposed to be conflictual or adversarial. There are no sides as such - just a quest for the truth. There is a marked tendency internationally for such investigations to become more conflictual. This is perhaps because they are seen as laying the groundwork for civil suits (especially in the realm of medical negligence).

A coroner or medico-legal investigator can order an autopsy to uncover the true medical cause of death. This is usually done by a forensic pathologist and can require a report on toxicology. The body is usually not released to the family until an autopsy (if required) is performed.

The burial of unidentified bodies can cause difficulty especially where insufficient effort is made by an investigatory body to identify and trace their families.[18] This may affect persons with disabilities who are long-stay residents of institutions in particular. A related difficulty is the donation by an investigatory body of an unidentified body to medical schools without the explicit prior consent of the deceased or next of kin. This likely affects many older persons with disabilities who have been residing in long-stay institutions and whose family ties have been broken over time.[19] Usefully the UN Special rapporteur on extra-judicial

[16] See, e.g., Section 1.(2) of the Coroners and Justice Act (UK), 2009; duty to investigte in certain cases.
[17] INQUEST Handbook: A Guide for Bereaved Families, Friends and Advisers, (2016) at p. 14.
[18] See NBC News – '*Cut Up and Leased Out: the bodies of the poor suffer a final indignity in Texas*,' Septemer 16, 2024: https://www.nbcnews.com/news/us-news/university-north-texas-corpses-dissected-unclaimed-bodies-rcna170478
[19] Ibid, at supra note 10.

killings (Morris Tidball-Binz) in a recent and important thematic report on the protection of the rights of the dead has stated that the:

> dignity of a person and the respect owed to his or her body and human remains *do not cease with death.* … Disruption of those processes, through improper protection of, or disrespectful treatment of, the dead, harms individuals and societies and, in the case of unlawful deaths, undermines or impedes the victims' rights to truth, justice and reparation. … State obligations to protect the dead are paramount to fulfilling the rights of families and to ensuring that all potentially unlawful deaths are thoroughly investigated.[20]
>
> [Italics added].

It is suggested that these observations are particularly important for persons with disabilities in search for the truth.

Outside of those limited situations under which a referral to an investigator is mandatory, referral to a coroner or medico-legal investigatory body is more or less discretionary. This usually arises if a medical doctor feels they cannot definitively pronounce on the cause of death (for whatever reason). That, in turn, means a death certificate cannot be issued to bring legal personhood to a formal close. The rates at which these discretionary cases are referred (i.e., reported to an investigatory body) vary greatly around the world. A considerable degree of discretion is allowed for each State. Of course, if too much discretion is used not to refer, then some systemic underlying causes can go undetected and unreported. Sometimes the police have the power to refer.

The outcomes of either an investigation or an inquest can take various forms. An investgator (with or without a jury) can conclude that the death occurred through 'natural causes,' through accident or misadventure, through an industrial accident, through a lawful killing or through an unlawful killing. Obviously, if the conclusion is that the death came about through an unlawful killing then this may prod the police to investigate and potentially launch a prosecution. A 'narrative conclusion' allows space for the jury or investigator to expand on their reasoning and conclusions. Narrative conclusions can be particularly useful when trying to identify systemic deficiencies that may have led to the death. An 'open conclusion' may also be reached which means that the cause of death cannot be definitively established.

Increasingly, investigators are expected to provide recommendations for changes in policy or practice to avoid further deaths in the future based on what they may have come across in the course of their investigations. This is particularly relevant in a disability context. It is an antidote of sorts to the risk which is to assume that a death is simply down to the condition of the deceased (one's status as a person wit ha disability) and not investigated any further.

Since the investigatory process is public, families and the general public have the right to attend and participate. Countries vary in terms of the transparency of the outcomes. Best practice is to make the ensuing reports of investigators available on a publicly accessible website. This is especially important with respect to investigator's reports that may contain recommendations for a change in policy or practice. Otherwise crucial lessons will be lost. If a Public Inquiry is ordered by government (e.g., in the case of a mass casualities due to a fire at an institution) then the normal practice is to suspend the medical-legal investigation until the inquiry is complete.

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[20] Id. at para 60.

In the past, investigatory bodies could be, and were, suspended during armed conflicts.[21] The duty to tell the truth could be weaponised by either side to a conflict. The pressure on investigatory bodies from all sides in a conflict could be immense. Now however, and principally because of the transcendent nature of the right to life, no such suspension is allowable at least not under international law. That places a premium on having a robust truth-telling institution that can function even under the harshest of circumstances.

2. The Public Interest/s in Having Robust Truth-Telling Institutions in the Context of Death.

Telling the truth is always its own justification. However, in addition, there are several longstanding and identifiable public policy purposes served by having a robust truth-telling institution concerning '*suspicious deaths'* and they include the following.

First of all, respect for the right to life entails a proper regard to investigate the circumstances surrounding a 'suspicious death.' This is so whether the death is at the hands of the State or purely private parties. Although the person is now dead, his/her right to life is considered transcendent. Out of respect for his/her right to life, a robust process is required to clarify the cirumstances surrounding their death if unclear. In addition, discovering the facts has its own therapeutic value and especially for the bereaved family. In an overhackneyed phrase, they have a 'right to closure'. One might call this the *'moral benefit'* of truth telling. It is no accident that all international standards in the field governing investigations have emanted from consideration of the entailments of the right to life under various human rights treaties.

Secondly, discovering the truth may sub-serve the operation of the legal system by making prosecution (and therefore accountability) more real. That is not of course, the primary object of the relevant truth-telling institutions at least in the past. That is to say, these institutions in the past were not intended or designed to find fault or to ascribe legal liability. Even so, this policy purpose can be an invaluable bye-product.[22] This second goal is most pronounced in some of the early UN policy documents on the 'duty to investigate.' That is to say, these documents emphasised the dependence of the criminal process on having a robust truth telling process investigating 'suspicious deaths.' This is presumably because the early UN policy documents were issued at a point in time (early 1990s) when the Cold War was ending and there still were still many problems (including impunity) with disapperances in authoritatrian regimes around the world leading to deaths (or presumed to lead to deaths). Of course, although the duty is felt acutely during times of emergency or conflict involving the State, it goes much wider than deaths at the hands of the State or its agents. It applies, for example, to deaths caused by the overuse of sedatives in congregated environments. One might call this the *'rule of law'* purpose or benefit of truth-telling institutions.

Third, as previously mentioned, there is a broader public interest at stake – namely the *prevention* of avoidable deaths in the future by learning the lessons from such deaths and adjusting public policy accordingly. Public policy lesson lessons drawn from investigations

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[21] Typical of legislative acts to suspend investigations during time of internal strife was the infamous Regulation 80 issued under the Restoration of Order in Ireland Act (1920). Regulation 80 suspended the work of coroners in most parts of the country and substituted Military Courts of Inquiry. This allowed for the truth to be curated.

[22] See, by way of illustration, Section 10 (2) of the Justice and Coroners Act (UK) 2009: no determination can be made of civil or criminal liability. See also Section 30 of the (Irish) Coroners Act, 1962: "*[Q]uestions of civil or criminal liability shall not not be considered or investigated at an inquest...*"

could include stricter enforcement of helmet laws for motorcyclists, improved hygiene standards in hospitals or closing service gaps that leave persons with disabilities highly vulnerable in their communities. Coroners or medico-legal instituions can and should extrapolate policy lessons from their own investigations and experience. They are in a priviliged position to see and appreciate the effects of accumulated disadvantages. Their function is *both* to tell the truth in individual instances and to perform a higher function to assist policy-makers by highligting underlying causes and thereby contributing to their amelioration.

Famously, this is what is called '*Prevention of Future Deaths Reports'* by coroners in England & Wales.[23] So individual tragedies can have broader social or policy implications. So much so that it is said that the work of coroners provides an invaluable service for both "the living and the dead."[24] One might call this a *'social engineering'* policy purpose to truth-telling institutions.

All three public interests have relevance for persons with disabilities. Life is equally precious for all and must be honoured regardless of disability. The truth counts for everybody and especially with respect to one's last moments, as they provide a revealing snapshot of one's life. Impunity must be firmly resisted, particularly given the lives of persons with disabilities are sometimes treated less seriously than others. And avoiding needless deaths in the future points to the need for continuous improvement in services, supports and in the whole de-institutionalisation process. If such improvements do not happen then the underlying inequalities will continue to manifest themselves in disproportionately high rates of mortality for groups placed in vulnerable situations like persons with disabilities.

For all these reasons and more, there is a pressing public need to ensure that the integrity of the truth-telling institution (coroners or medico-legal institutions or medical examiners) is beyond reproach and, crucially, that they can contribute to raising standards for the living - elevating the conditions of life for all.

3. ***Probing Deeper Truths: Tasking the Investigatory Process to Identify Systemic Causes and to Prevent Future Deaths.***

The third public interest above is central to this Study and requires some further elaboration.

While tragedies are deeply personal, the lessons learned can be public. As far back as 1972 one eminent judge in England speculated that one of the main reasons why accurate death certification is so important has to do with avoiding or preventing similar deaths in the future – a service to the living as well as honouring the dead.[25] He (Judge Norman Broderick) said:

> [Accurate death certification]… is important because…and this is what really matters, from the point of view of preventing avoidable deaths in the future.[26]

[23] Se BBC, 8 March 2024, '*Coroners Death Reports Reveal Rise in NHS Warnings'*: https://www.bbc.com/news/health-68425021

[24] Joint Committee on Justice, "*Report on an Examination of the Operation of the Coroner's Service" 2023 33/JC/32.*

[25] Judge Norman Broderick, '*Death Certification and Coroners,'* 1 Medico-Legal Journal (1972), 89-104.

[26] Id. at 90.

So prevention isn't just a recent invention of international law but is intrinsic to the medico-legal investigatory tradition. Judge Broderick – who chaired a public inquiry into coroners and death certification in the 1960s in England & Wales[27] – highlighted the case of five young teenage girls who each died while working in a factory. The initial cause of death was put down to pneumonia. On closer examination, it was determined that a chemical ingested by the girls while working in the factory caused the pneumonia - or caused their susceptibility to it . Adjustments could then be made to the factory process thereby saving lives in the future. This, to judge Broderick, served to underscore the importance of learing from deaths to help the living.

International law increasingly requires investigatory bodies to probe the underlying systemic deficiencies that led to a death and to make recommendations to avoid further needless deaths in the future. This is now done in several countries around the world.

Naturally, there are other bodies engaged in standard setting, in regulation and in systemic reform besides invesigatory bodies into deaths. For example, this would include the Care Quality Commission in England & Wales or the Commission on Quality and Safeguards in Australia[28] The proactive role ascribed to investigatory bodies under international law is intended to complement and not displace the work of these regulatory bodies. In other words, the unique data points provided by investigatory bodies can add to, and give extra gravity to, the analysis and recommendations of these regulatory bodies. Optimally, they should work closely together to ensure that the learning is put to good use. The policy feedback loop is complete when all public bodies that should know (and act on) the analysis and recommendations of investigatory bodies into 'suspicious deaths' are properly apprised.

It is therefore entirely possible to use 'suspicious deaths' as an occasion to investigate poor practices that, if left unchanged, can lead alnost inevitably to deaths. And it is therefore logical to ask what kind of course correction might be needed to avoid these deaths. Here the investigatory system can be a genuine 'learning system' - learning from patterns of individual tragedies to avoid policies or practices that generate inevitable deaths. This is critically important - and surprisingly undereveloped - in a field like disability where key violations of core rights like the right to live independently are still rife throughout the world and where inadequate services and supports often characterise the field.

Medico-legal systems in place around the world are now innovating with mechanisms to go beyond reporting on the cause of death to also issue reports to Government on the policy changes needed to avoid further deaths. Sometimes these changes involve small tweaks (like changes in surgical practices in hospitals). And sometimes they require more systemic change - like a move away from congregated living arrangements (institutionalisation) that will predictably expose the residents to needless risk. A good illustrative example is the '*Prevention of Future Death'* (PFD) reports done by coroners in England & Wales (see below).[29] This is only an illustrative example and the UK system definitely bears improvement. Yet, in order to protect the right to life and prevent needless deaths, all States should have something akin to it. This is one way of avoiding needless deaths due to a

[27] The Committee on Death Certification and Coroners, (UK, 1965-1971).

[28] The Care Quality Commission regulates health and social care in England: see, https://www.cqc.org.uk

[29] See Coroners and Justice Act, UK (2009), Schedule 5 (Powers of Coroners) Para. 7 'Action to Prevent Other Deaths) and Regulations 28 and 29 of the Coroners (Investigations) Regulations (2013). A precursor to this is to be found in the Coroners Act (1962) in Ireland S. 31.2 "*…recommendations of a general character designed to prevent further fatalities may be appended to the verdict at an inquest."*

variety of factors affecting persons with disabilities including poor services and institutionalisation.

4. The Potential 'Sytemic Causes' of the Deaths of Persons with Disabilites - the cumulative effect of a lifetime of inequality: A Lifecourse Approach.

One suspects that most of the deaths of persons with disabilities are almost routinely put down to 'natural causes' or even to the disability itself. This is probably especially so when disability is combined with old age. In the result, deaths that ought to be investigated are sometimes left un-referred to an investigatory body. Small wonder then that the systemic causes are left unexamined and under-reported.

If so, the 'problem' then arises from the person's condition and not from the social or other conditions under which they have had to live through during their lives. It is exactly this kind of easy supposition that the UN CRPD is designed to unzip. Theresia Degener has called this the 'problematising' of persons with disabilities. The promise of the social or human rights model of disability was to flip this in order to focus instead on the systemic causes of deprivation.

Of course, the death of a person with a disability may well be down to 'natural causes'. But the easy supposition that it is can hide a myriad of factors. Once you do peel away the easy suppositions there are a myriad of possible systemic causes of death in the disability context that deserve to be investigated - if only to rule them out.

Institutionalisation itself poses a distinct set of risks. It is often said that the best form of protection for anyone is to have a friend.[30] But the isolation and segregation of institutional life tends to sever ties with the outside world - with both family and friends. One is therefore left almost incommunicado and at the mercy of staff and others in institutions. Unfortunately, there is ample evidence that all manner of deprivations are possible in institutional settings including violence, sexual abuse, excessive physical restraints, over-medication, poor medical care, bad nutrition and ill-treatment.[31] Sometimes, as shown by the Dotan Report, these accumulated risks can arise even in small group homes.[32] The solution is not better regulation of these spaces. The solution is to close them down and invest instead in making life in the community more sustainable.

It is striking that the UN CRPD Committee's 2022 Guidelines on deinstitutionalisation not only highlighted the risk of violence within institutions but has also called on States to recognise institutionalisation itself as a form of violence (para 6). It called out the heigthened risk of women in institutions to violence. And the Committee specifically called on States to adhere to minimum international core standards even in emergencies to, *inter alia,* avoid preventable deaths in institutional settings (para 108).

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[30] See generally, Jon Wittrock, '*A Human Right to Friendship, Dignity, Autonomy andf Social Deprivation,'* International Journal of Human Rights (2022)., 1590-1607. See the Oddfellows Foundation, 'The Protective Power of Friendship,' (2023): see - https://www.oddfellows.co.uk/news/the-protective-power-of-friendship/#:~:text=The%20support%20that%20good%20friends,problem%2Dsolving%20skill%20set."

[31] The many threats to the right to life posed by instituonalisation are well set out by Janos Fiala-Butelo (extensively discussed later in this Study): *'Disabling Torture: The Obligation to Investigate Ill-Treatment of Persons with Disabilities.'* 45 Columbia Human Rights Law Review, (2013), 214-280.

[32] A summary (in English) of the Dotan Report (Summarised Report for the Commission of thee Examination and Structuring of the Management and Operation of Residential Facilities for Persons with Disabilities) is here: https://www.bizchut.org.il/post/summary-of-the-dotan-commission-report

Even when one is living independently in the community there are many issues having to do with the quality of services that pose a real risk to life.

First of all, the State might not adequately fund services. This inevitably creates gaps in services. The resulting cracks may be tolerable for some but can impact persons with disabilities quite severely. These gaps can pose critical risks for persons with disabilities who may depend on consistent and uniform coverage of services to live successfully in the community. In *extremis* these gaps can pose a risk to mortality.

Second, a lack of coherence across social support programmes may also generate real risks of mortality. Ensuring coherence across the whole range of social support porgammes is one of the constant problems in designing social support systems. For example, housing may be provided. But sufficient support in the form of personal assistance to enable one to live in the housing may not be provided. Conversely, adequate social support night be available but with no housing. And the housing, though provided, may be isolated from the community. Or, worse, it may be physically situated in the community but the community itelf is not 'visitable' due to an inaccessible environment. The resulting social isolation and loneliness arising from policy incoherence carries its own set of risks to mortality.

Most often, the State does not provide direct support. It funds intermediary service providers who may work according to outdated paradigms. This lack of person-centredness might serve to further isolate the person and make it unlikely that critical risks to mortality will be spotted and dealt with. Poor staff training and the absence of coherent workforce development programmes might lead to a failure to spot risks. Indeed, since many countries increasingly rely on imported labour, there may well be language and cultural barriers rendering it difficult to identify and respond to threats as they arise.

Strong links have been posited between social isolation and loneliness with early mortality.[33] Humans are social animals and persons with disabilities are no different. It is not for nothing that Article 19 of the UN CRPD includes being included in the community alongside living independently. Social connections are one of the keys to good health. Poor health behaviour can be associated with loneliness causing life-shortening illnesses and conditions. Loneliness affects many persons with disabilities especially when family relations are sundered due to institutionalisation or when community engagement is poor. Here, service providers have a crucial task - to build bridges into the comnunity. That, however, is not a traditional goal of service provision and ramains a key 21st century challenge.

Violence and abuse create real risks for mortality.[34] They can often go unnoticed especially where the individual is compromised in terms of their communicative ability. The effects could build up over time. They can be both psychologically intimidating as well as life-

[33] See Wang, *et al*, *A Systemic Review and Meta Analysis of 90 Cohort Studies of Social Isolation, Loneliness and mortality,* 7 Human Nature Behavior (2023), 1307-1319. See also Kirsten Rogers, *Loneliness or Social Isolation linked to serious health outcomes, study finds*, CNN, 24 December 2023: https://edition.cnn.com/2023/06/19/health/loneliness-social-isolation-early-death-risk-wellness/index.html

[34] See the impressive analysis and detailed recommendations of the (Australian) Royal Commission into Violence, Abuse, Neglect and Exploitation of Persons with Disabilities (2013): https://disability.royalcommission.gov.au/system/files/2023-11/Final%20report%20-%20Executive%20Summary%2C%20Our%20vision%20for%20an%20inclusive%20Australia%20and%20Recommendations.pdf

threatening. Sexual violence can be all of the above as well as soul destroying.[35] Particular categories of persons with disabilities, such as those with Albinism, can be especially vulnerable to violence and even death.[36]

The phenomenon of legal incapacity means that many would-be victims either cannot (legally) air their suspicions about abuse or will simply not be believed. Thus, if their voice is not respected then the risks even to their mortality will simply accumulate. Apart from its intrinsic violation of the core right to personhood, the guardianship system also operates to cast a shroud of secrecy over the systemic risks.[37] It serves to indecently conceal the risks as if the person did not count.

In addition, bad medical practices can also enhance risks to mortality. For example, consent forms may be ambiguous and too broadly cast. They may include overly-broad umbrella clauses that would allow a visiting or attending physician in, e.g., in a small group home, to prescribe sedatives or chemical restraints without any effective limit. The build-up of toxins could be fatal over time. Chemical restraint is probably one of the least researched aspects of restraints but one suspects that its abuse is rampant.[38] Addiction may even result from bad prescribing practices which can pose long-term threats to life.

Some medical practices continue around the world that can pose a direct threat to life. They include Electro Convulsive Therapy[39] (ECT) and compulsory sterilisation which the WHO has described as a form of torture.[40] Some point to the emergence of a *new eugenics* in the context of disability.[41] What is really meant by this is that the right to life of a person with a disability is heavily discounted. And some point to the trend toward medically assisted dying legislation in many countries - as applied to disability - as an example of this trend.[42]

In addition, mental health issues - especially in the context of unreformed systems - may materially aggravate the risks. To be clear, it is not the mental health as such that causes the

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[35] For a review of the literature see, Amylee Mailhot Amborski, *et al,* '*Sexual Violence against Persons with Disabilities - a Meta Analysis,'* 23 (4) Trauma Violence and Abuse (2022), 1330-1343.

[36] See the African Committee of Experts on the Rights and Welfare of the Child, Report of thr Investigative Mission on the Situation of Children with Albinism in Temporary Holding Shelters: Tanzania (2016): "[T]he situation clearly leaves the children (in Tanzania) in a situation where their health is severly endangered which could eventually result in a significant number oif deaths. " (p.16). On the systemic causes of the early deaths of persons with Albinism see the report of the UN Special Expert on the Rights of persons with Albinism, *A Preliminary Survey of the Root Causes of Attacks and Discrimination against Persons with Albinism,* (2016), A/71/255.

[37] Interestingly, the link between legal incapacity, violence and death was explored in the context of older persons by the US National Centre for Elder Abuse, *Guardianship: Remedy Vs Enabler for Elder Abuse,* (2021): available at - https://pfs2.acl.gov/strapib/assets/NCEA_Guardianship_Remedy_VS_Enabler_f667a4f83c.pdf
More research is needed on the link between guardisnhip and the early mortality of personos with disabilities,

[38] It would appear that chemical restrints are sometimes used simply to pacify thus making life mroe convenient for carers. Much more research is needed on iots prevalence and efects. See, Equality and Human Rights Commission (England & Wales), *Human Rights Framework for Restraint: Principles for the Lawful Use of Physical, Chemical, Mechanical and Coercive Interventions* (2019)

[39] See,e.g., the thematic report of the UN Special Rapporteur on torture (2008), *Protecting Persons with Disabilities against Torture,'* at para 61 (Electroconvulsiove therapy): available at
https://documents.un.org/doc/undoc/gen/n08/440/75/pdf/n0844075.pdf

[40] See, Eliminating Forced, Coercive or otherwise Involuntary Sterilisation: an Interagency Statement, OHCHR, UN Women, UN AIDS, UNDP, UNFPA, WHO, (2014): available at
https://iris.who.int/bitstream/handle/10665/112848/9789241507325_eng.pdf?sequence=1

[41] See generally Sam Bagenstos, *The New Eugenics*, 71 Syracuse Law Review, 3 (2021) and Robyn M. Powell, *Confronting Eugenics Means Finally Confronting its Ableist Roots,* 27 William & Mary Journal of Race, Gender and Social Justice (2020-2021) Issue 3.

[42] See generally forthcoming book, 'Unravelling MAiD in Canada: Euthenasia and Assisted Suicide as Medical Care,' McGill University Press (2025).

risk. It is the persistence of old medical models of care and support and the failure to move to a new paradigm.[43] Suicide in mental health institutions appears to be a problem worldwide. It is of course hard to definitively put down a suicide to the quality of treatment (or ill-treatment) but it is fair to surmise that it has at least some contributory effect. Many investigations into premature death around the world tend to focus on persons with mental health conditions. Again, the focus is not so much on the mental condition itself but on the quality, range and depth of the supports and services available.

Curiously, just as invisible are the legions of informal carers - a legion only because of inadequate State support for services. They can die prematurely and are constantly stressed by the lack of forward planning for the care of their family member.[44] They die without any certainty about how their family member will be supported after their own demise. They constantly dread institutionalisation for their loved one as a lazy default option for the State. This causes its own set of anxieties which no doubt can contribue to an early death. Demographic shifts in many countries mean that the informal support networks that were relied on by States in the past are now fraying. If so, a re-balancing is necessary between formal and informal supports.[45] Without it persons with disabilities and their carers face even higher risks to their mortality.

Of course, the risks are only obvious if they are properly examined or investigated. The first barrier is the supposition that all deaths by persons with disabilities are almost always due to 'natural causes.' Most probably are. But those that aren't are left largely unexamined. One might consider this omission to be a function of ableism. Interestingly, in her thematic 2020 thematic report on ableism, the former UN Special Rapporteur in the rights of persons with disabilities grounded her analysis of ableism under the heading '*Lives Not Worth Living*.' She goes on to emphsise the importance of the right to life in the CRPD and asserts that:

> ...this enails a duty to protect the right to life of persons with disabilities from all acts or omissions that are intended or may be expected to cause their unnatural or premature death.
>
> [para 48].

This linking of ableism with gaps in the protection of the right to life for persons with disabilities would apply equally to gaps in investigations.

If that first barrier (an assumption that 'natural causes' are always responsible) is surmounted then a related barrier has to do with joining the dots to form a convincing picture about the underlying systemic causes (if they exist). There may be resistance to doing so when it comes to marginalized groups like persons with disabilities. However, these blockages have to be overcome if investigations are to work properly and play their part in reducing the risks for the living.

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[43] See WHO on new models: Mental Healthm Human Rights and Legislation: Guidance and Pracrice (2013). The new Lampard Commission of Inquiry into excessive deaths in mental helth care in a part of England is at: https://lampardinquiry.org.uk/#:~:text=The%20Lampard%20Inquiry%20is%20an,mental%20health%20inpatients%20in%20Essex. See generally, C. Tess Sheldon, *et al, Uncovering Laws' Multiple Violences at the Inquest of the Death of Ashley Smith,* in Violence, Madness and Power, (University of Toronto Press, 2019).

[44] There is now a wealth of research on the health (and mortality) impacts of caring. Typical of this is P.L. Zwart, *et al, 'Will you Still Need me, Will you still Feed me when I am 64: the Health Impact of Caring to One's Spouse*,' 26 (S2) Health Economics, (2017), 127-138. Much more research is needed to iron out some contradictory findings.

[45] See, e.g., World Economic Forum, White Paper: The Future of the Care Economy, (2004): available at https://www3.weforum.org/docs/WEF_The_Future_of_the_Care_Economy_2024.pdf

A recent study on the UK, found that the median age of death for persons with intellectual disabilities was 13 years younger than that for the rest of the population.[46] While acknowledging the 'natural' health difficulties that might arise with aging for a person with an intellectual disability, it asserted:

> there are other broader determinants of health relating to the environmemnt, provision of care and access to health care services that might contribute to premature death.
>
> (p. 889).

A scoping paper conducted by the Faculty of Medicine at the University of New South Wales (UNSW) in 2019 reported that "a recent systematic review of mortality among people with intellectual disability...found that the group dies, on average, 20 years earlier than the general population."[47] The scoping paper also reported - citing to the work of Walker *et al*, that persons with mental illness "have a significantly higher mortality rate than comparison populations with a median of 10 potential life years lost."[48]

The gender dimension of mortality risks seems to have been considerably under-researched. First of all, the intersectional disadvantages experienced by women and girls with disabilities throughout their lives may magnify the risks and account for higher rates of mortality. Secondly, their relative invisibility might mean that investigatory processes may not be primed to genuinely examine the true causes of death and instead may put them down too readily to disability or old age or a combination of the two. That is to say, they can be relatively invisible even in processes designed to shine a light on the truth. Thirdly, a history of ill-treatment or abuse (and a related history of impunity) can too easily enhance the risk of early death for women and girls with disabilities. And finally, the added burdens often assumed by women and girls with disabilities, especially in the home, might impact on their overall health and wellbeing and contribute to their untimely death.

Other intersectionalities can be extremely potent. Indigenous and First Nations and racialised minorities with disabilities are often subject to institutionalisation in the form of prisons or forensic mental health institutions which create real risks to mortality. In an important 2024 thematic paper on indigeneous persons with disabilities, the United Nations Special Rapporteur on the rights of indigenous peoples has called attention to the systemic causes of disproportionately higher rates of disability among indigenous populations.[49] He identified structural racism and the remnants of colonialism as underlying causes. He alludes to other forms of systemic disadvantage including extreme poverty. And he highlights the high rate of mortality in maternity care for indegenous women. Although mortality was a not a core focus of his paper, it is fair to infer that the many structural disadvantages he highlights have a material impact on mortality. It would be interesting to explore to what extent investigative

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[46] See e.g., Pauline Heslop et al, T*he Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK - a population based study,* 383, No 8, The Lancet, 2014.

[47] UNSW Faculty of Medicine, Department of Developmental Disability Neuropsychiatry, *A Scoping Paper of Causes and Contributors to Deaths of people with Disability in Australia,* (2019) citing to O'Leary *et at, Early Death and Causes of Death of People with Intellectual Disabilities, a Systematic Review,*' (31)3 Journal of Applied Research in Intellectual Disabilities, 325-342.

[48] Walker *et al*, *Mortality in mental disorders and global disease burden: a systematic review and meta-analysis,* 72(4), JAMA Psychiatry (2015).

[49] United Nations Special Rapporteur on Indigenous peoples, thematic report, *Indigenous Persons with Disabilities,* (October, 2024): available at - https://www.ohchr.org/en/documents/thematic-reports/ahrc5747-indigenous-persons-disabilities-report-special-rapporteur. See also: Dying from Improvement: Inquests and Inquiries into Indigenous Deaths in Custody, Sherene Razack, (University of Toronto Press, 2015).

processes with respect to 'suspicious deaths' are alive to these systemic disadvantages in the lifecourse of indgenous persons with disabilities. One suspects they are not.

5. Learning from Death to Improve Life for the Living - Government and Private entities as 'Learning Organisations.'

International law is not the only reason to use investigations to probe the underlying systemic causes of 'suspicious deaths.'

Interestingly, the gradual extension of the tasks of investigatory bodies to include an examination of underlying systemic causes (and making recommendations for changes in policy or practice) not only fits with an expansive view of the right to life under human rights treaties (and the duty to migitate or prevent risks) but also with contemporary understandings of public agencies and indeed the State itself as a type of 'learning organistion.'[50]

This is all about the transfer of knowledge from within an entity (whether public or private) or between one entity and another in order to constantly improve performance. Looking at investigatory bodies not in isolation but as part of a broader public policy ecosystem, means enabling and empowering each part of that system to learn from the other. In this way a knowledge loop is created between the investigatory bodies and other regulatory bodies (or the ultimate regulator - the State) to enable problems to be clearly identified and to enable change to happen. This serves to materially advance the 'conditions' for the right to life.

Private corporations have a very real interest in becoming sucessful 'learning organisations.' It may give them an advantage in their efforts to protect their existing market share and to increase it. Being agile and nimble is necessary in a market context lest underachievers are left behind.

Public bodies may have less of an incentive. At one extreme, they may be perversely motivated to hide the truth in order to avoid responsibility. They may view the truth as inconvenient. That is why the theory and practice of Government as a 'learning organisation' is so important since it forces the State to grasp reality and not to ignore it - and to change policy and practice if it requires changing.[51] This should incentivise States to perfect their learning ecosystems so that the lessons to be gained form investigations can be put to good use for the living.

Garvin *et al* asserts that there are three critical building blocks that determine the success of a 'learning organisation':

> a supportive learning evironment, concrete learning processes and practices, and leadership behaviour that provides reinforcement.

All three factors are important in determining the success of investigatory bodies. It is the nature and quality of the information loop that matters most. All of which serves to

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[50] See a classic statement of the idea of a learning organisation, Peter Senge, The Fifth Discipline: the Art and Practice of the Learning Organisation (Doubleday, 2006). See also David Garvin, Amy Edmundson, Francesa Gino, '*Is Yours a Learning Organisation,'* Harvard Business Review Magazine, (March 2008).

[51] Change is never a unilinear process. To sustain change there needs to be an underlying re-orientation of the primary narrative about disability. On the variables at play, see Gerard Quinn, keynote address, *Change and Disdability - the Researcher as Policy Entrepreneur,* Disability Advocacy and Research in Europe final event (DARE), 12 May 2022, Brussels, (on file with the author).

emphasise the organic link between the learning - and the entity that does the learning such as an investigatory body - and the State and its regulatory agencies. If, (if) States are serious about being a 'learning organisation' then it is important that investigatory bodies are not only allowed to do their work but that the learning derived from their work is put to good use in the public interest. Interestingly the English in-depth and thematic studies of the deaths of persons with intellectual disabilities (LeDeR - see section D.B.1 below) is self-branded as a '*service improvement programme.'*

Part B:

The Evolution of International Standards on the Duty to Investigate 'Suspicious Deaths' and to Probe Systemic Causes.

Most of the more important international and regional standards have emerged from case law under international and regional treaty law protecting the right to life. Regardless of their source, cumulatively, they all underpin the necessity for a robust and independent mechanism for discovering the truth about 'suspicious deaths' and exploring their systemic roots. Failure to put in place such a robust system of investigation is itself considered a separate violation of the right to life.

International law and policy have evolved considerably in the last 30 years or so regarding the need for and the adequacy of truth-telling institutions in order to discern the truth surrounding 'suspicious deaths.' While these standards were not developed with marginalised groups in mind, they nevertheless have considerable potential. What follows is a brief account of these international standards.

3: The Duty to Investigate in the United Nations System.

The Evolution of the Duty to Investigate in the UN treaty system.

1. The International Covenant on Civil & Political Rights, Article 6 and General Comment 36 on the right to life (2019).

Prominent among the relevant UN treaties is the International Covenant on Civil and Political Rights (ICCPR). Article 6 of the Covenant protects the right to life. [52] The relevant part reads:

> 6.1 Every human being has the inherent right to life. The right shall be protected by law. No one shall be arbitrarily deprived of his life.

The 'protection' of the right is interpreted to mean that the State has a proactive duty to mitigate risks and to prevent the loss of life. So prevention, as a goal is encoded in Article 6.

The remainder of Article 6 deals with the death penalty. This is, of course relevant to those persons with disabilities who find themselves ensnared in the criminal process. Indeed, many of the issues dealt with by Special Procedures in the UN human rights system have dealt with the high number of persons with disabilities subjected to the death penalty.[53] The death penalty is not a primary focus of this study.

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[52] See Stuart Casey-Maslen & Christof Heynes, The Right to LIfe under International Law: an Interpretive Manual, (Cambridge University Press, 2021).

[53] The issue of the death penalty as applied to persons with disabilities is contentious. The traditional view, supported by famous judicial decisions such as the US Supreme Court decision in *Atkins v Virginia* (2002) holds that the imposition of the death penalty on a person with an intellectual disability is cruel and unusual punishment. Another view driven by equal treatment suggests that persons with disabilitieds should be subject to what ever penalties others are subjected to no matter how harsh. The issue needs to be more fully explored and discussed. See, The Arc, *Understanding the Fight to Protect People with Intellectual Disability from Execution,* August 5, 2024: available at - https://thearc.org/blog/understanding-the-fight-to-protect-people-with-intellectual-disability-from-execution/

As is usual, the relevant treaty monitoring body, the UN Human Rights Committee, issues, from time to time, General Comments setting out its understanding of the nature of the obligations inherent in articles such as Article 6. These General Comments lack specific legal standing. However, they are highly authoritative guides to the interpretive approach of the relevant treaty monitoring body and are thus highly relevant to adjudging a country's record.

An early General Comment on the right to life was released by the Human Rights Committee in 1982 (No 6). As was the emphasis of the time, much of it focused on the link between political violence, involuntary disappearances and violations of the right to life as well as the death penalty. The 'duty to investigate' was mentioned in General Comment 6 in the context of involuntary disappearances but not developed more broadly.

More recently, General Comment No.36 (2019) was issued by the Human Rights Committee on the right to life and could be considered a necessary update of the 1982 General Comment in light of the Committee's experience.[54] It starts by emphasising the central importance of the right to life:

> the right to life is the supreme right from which no derogation is permitted, *even in situations of armed conflict and other public emergencies that threaten the life of the nation*.[1] The right to life has crucial importance both for individuals and for society as a whole. It is most precious for its own sake as a right that inheres in every human being, but it also constitutes a fundamental right, the effective protection of which is the prerequisite for the enjoyment of all other human rights and the content of which can be informed by other human rights.
>
> [Italics added. Para 2].

So the right to life is of transcendent importance and also serves more instrumental purposes that underpin all other human rights. And it applies even during times of war. This entails that the 'duty to investigate' also applies in times of war.

Interestingly, General Comment No 36 asserts:

> The right to life is a right that should not be interpreted narrowly. *It concerns the entitlement of individuals to be free from acts and omissions that are intended or may be expected to cause their unnatural or premature death, as well as to enjoy a life with dignity.* Article 6 of the Covenant guarantees this right for all human beings, without distinction of any kind, including for persons suspected or convicted of even the most serious crimes.
>
> [Italics added. Para 3].

Therefore, apart from enjoining the State and its agents not to violate the right, Article 6 extends to require concrete steps to *protect* the right to life against actions that are not directly attributable to the State and even extends to persons not employed by the State. Note in particular the use of language like actions or omissions likely to '*cause their unnatural or premature death*.' This hints strongly that investigations should be calibrated to contribute to the prevention of future deaths.

Those held in captivity by the State or its agents are of especial concern in General Comment No 36. This would obviously include prisoners with disabilities of those institutionalised. Importantly for our purposes:

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[54] ICCPR General Comment no 36, Article 6; Right to Life (2019): available at - https://www.ohchr.org/en/documents/general-comments-and-recommendations/general-comment-no-36-article-6-right-life

> The obligation of States parties to respect and ensure the right to life extends *to reasonably foreseeable threats and life-threatening situations that can result in loss of life*. States parties may be in violation of article 6 even if such threats and situations do not result in loss of life.
>
> [Italics added, Para 7.].

A *'reasonably foreseeable'* threat might have to do, for example, with inadequate services and supports for a person with a disability trying to exercise their right to live independently and in the community. Although it predates General Comment No 36, one might interpret the production of '*Prevention of Future Death Reports'* in England & Wales as a way of implementing this general obligation (see section D.B.1 below).

Importantly, the 'duty to protect' is said to explicitly encompass a duty to investigate:

> ...where they [the State] know or should have known of potentially unlawful deprivations of life, to investigate and, where appropriate, prosecute the perpetrators of such incidents, including incidents involving allegations of excessive use of force with lethal consequences

[Para 27].

The duty to investigate is not confined to instances where the State is itself directly responsible for the threat. The duty would extend to cover, e.g., service providers for persons with disbilities.

Usefully, with respect to investigations, General Comment No 36 proceeds in Para 27 to state;

> Investigations and prosecutions of potentially unlawful deprivations of life should be undertaken in accordance with relevant international standards, *including the Minnesota Protoco*l on the Investigation of Potentially Unlawful Death, and must be aimed at ensuring that those responsible are brought to justice, at promoting accountability and preventing impunity, at avoiding denial of justice and at drawing necessary lessons for revising practices and policies with a view to avoiding repeated violations…

This is useful language since it emphasises the centrality of the *Minnesota Protocol* in designing an investigatory system as well as the many important public policy purposes served by having a robust investigatory mechanism (see section B.B. 2) below. Crucially, as to the character of the investigations, General Comment No 36 states (para 28):

> Investigations into allegations of violations of article 6 must always be *independent, impartial, prompt, thorough, effective, credible and transparent.*
>
> [Italics added].

Much of the *Minessota Protocol* specifies exactly what these characteristics require.

And:

> States parties need to take, among other things, appropriate measures to establish the truth relating to the events leading to the deprivation of life…

One might surmise this to mean that the structural guarantees of the independence of coroners and medico-legal systems for telling the truth are a vital aspect of respect for Article 6 ICCPR. They are quintessential 'truth telling' institutions.

As to the standing of families and next of kin, General Comment 36 usefully provides (para 28);

> States parties should also disclose relevant details about the investigation to the victim's next of kin, allow the next of kin to present new evidence, afford the next of kin legal standing in the investigation, and make public information about the investigative steps taken and the findings, conclusions and recommendations emanating from the investigation, subject to absolutely necessary redactions justified by a compelling need to protect the public interest or the privacy and other legal rights of directly affected individual.

This would give considerable standing to the familiy in the relevant investigations. One of the main historical complaints in the past was that families - including families of persons with disabilities - have been an afterthought. In fact, they are one of the more important consumers of the 'truth' with a clear stake in the integrity of the process. A pressing issue around the world for families is the right to legal representation at the relevant hearings.

A brief and admittedly unscientific review of some of the more recent Concluding Observations of the Human Rights Committee on Article 6 reveals the following.

In its 2024 Concluding Observations on India and with respect to Article 6 ICCPR the Human Rights Committee focused very much on the issue of the death penalty.[55] Its relevance to persons with disabilities was not in focus. In its 2024 Concluding Observations on Malta and with respect to Article 6, the Committee focused on the issue of migrant deaths at sea.[56] Interestingly, the Committee referred to 'possible deprivations of life [of migrants at sea] that have not been investigated" (para 22).

The Human Rights Committee drew attention to the allegedly high rate of extra-judicial killings in Guyana in its relevant Concluding Observations.[57] It stated that:

> (25) The State party should ensure that all allegations of extrajudicial killings are promptly, impartially, transparently and thoroughly investigated

And that:

> [T]he State party should take all measures necessary to prevent extrajudicial killings in the future

Interestingly, the Committee specifically referenced both the *Istanbul Protocol* (investigations of torture and other forms of ill-treatment) and the *Minessota Protocol* (investigations of potentially unlawful deaths) in its 2024 Concluding Observations on Namibia.[58] In its 2023 Concluding Observations on the Islamic Republic of Iran, the

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[55] Human Rights Committee, 2024 Concluding Observations on the fourth periodic report of India (2024) at paras 31-32. Available at - https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CCPR%2FC%2FIND%2FCO%2F4&Lang=en

[56] Human Rights Committee, 2024 Concluding Observations on the third periodic repor tof Malta (2024) at para 22: available at - https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CCPR%2FC%2FMLT%2FCO%2F3&Lang=en

[57] Human Rights Committee, 2024 Concluding Observations on the thrid periodic report of Guyana at paras 22-25: available at https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CCPR%2FC%2FGUY%2FCO%2F3&Lang=en

[58] Human Rights Committee, 2024 Concluding Observations on the thrid periodic report of Namibia at para 19.d: available at - https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CCPR%2FC%2FNAM%2FCO%2F3&Lang=en

Committee focued on the death penalty and high rates of such deaths.[59] It also stated that it [the Committee]:

> …is concerned by the *apparent lack of independent, impartial and transparent investigations into deaths and injuries following incidents of excessive and lethal use of force* and firearms by law enforcement officers, by the lack of prosecution of, and sanctions handed down to, perpetrators and by the lack of remedies for victims, which create a de facto climate of impunity.
>
> [italics added].

It specifically recommended that the State party:

> Ensure an impartial, independent, prompt and transparent investigation into the death of Ms. Amini.
>
> [Para 26.c].

In its 2024 Concluding Observations on Indonesia the Human Rights Committee focused on the abolition of the death penalty.[60] And its 2024 Concluding Observations on the United States of America the Committee focused on the death penalty as well as on death by drone strikes in the context of conflicts.[61] It specifically recommended that the State party:

> *Conduct independent, impartial, prompt and effective investigations of allegations of violations of the right to lif*e and ensure that those responsible are prosecuted and, if convicted, punished with appropriate sanctions…
>
> [Para 33.c].
>
> [Italics added].

This underscores the importance of investigations in the context of conflicts. Its set of 2024 Concluding Observations on the following countries did not seem to include any direct treatment of the right to life: Chile, Syrian Arab Republic, Serbia.

In sum, the ICCPR, as interpreted by the Human Rights Committee, requires proactive measures to 'protect' the right to life which includes prevention. And it demands an independent investigation into 'suspicious deaths' - investigations that are genuinely independent, effective, prompt and inclusive. These obligations obtain for all - but assume particular importance for persons with disabilities whose deaths seem too eaily ascribable to 'natural causes.' The Human Rights Committee does not, as such, specify that one of the tasks of such investigations is to probe the underlying systemic causes of deaths. But it does emphasise prevention which seems unachievable without actually probing the underlying or systemic causes.

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[59] Human Rights Commitee, Concluding Observations on the fourth periodic report of the Islamic Republic of Iran at paras 23-26: available at - https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CCPR%2FC%2FIRN%2FCO%2F4&Lang=en

[60] Human Rights Committee, 2024 Concluding Observations on the second periodic report of Indonesia at paras 24-25: available at - https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CCPR%2FC%2FIDN%2FCO%2F2&Lang=en

[61] Human Rights Committee, 2023 Concluding Observations on the fifth periodic report of the United States of America at paras 29-35: available at - https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CCPR%2FC%2FUSA%2FCO%2F5&Lang=en

2. The UN Convention on Enforced Disappearances (CED) and its potential relevance to disability.

This treaty was adopted by the UN General Assembly in December 2006 (the same month as the adoption of the UN CRPD) and came into force in 2010.[62] It is canvassed here because of its potential relevance in the context of deaths of persons with disabilities because involuntary or enforced disappearances are often causally linked to deaths or are presumed to give rise to deaths when the person cannot be located. In as much as some persons with disabilities might be considered 'disappeared' this is relevant to this Study.

The set of Principles that preceded the CED (adopted in the early 1990s) specifically stated that enforced disappearances "violates or constitutes a grave threat to the right to life' (Article 1.2, UN *Declaration on the Protection of all Persons from Enforced Disappearances*).[63] The CED treaty makes it incumbent on States to use the criminal law to penalise enforced disappearances. It emphasises that there can be no derogation from the freedom even during armed conflict. It obliges States to search for the disappeared and investigate their disappearance. Of course this investigation may easily become an investigation into a 'suspicious death.' And it obliges States to keep a full registry of those deprived of their liberty and prohibits secret detentions.

Persons with disabilities detained in institutions may or may not qualify. If they are secretly detained they clearly fall under the treaty. If they are effectively abandoned then a question mark may arise as to whether they fall under this treaty. And if their death in an institution is concealed (or fraudulently put down to 'natural causes') then arguably the treaty applies. It could at least be argued that a person with a disability who is a victim of plenary guardianship is effectively treated as one of the (legally) disappeared. These potential applications have not been tested yet before the relevant treaty monitoring body (the Committee on Enforced Disappearances or CED).

Article 7.2.b of the CED creates a discretion on the part of States parties to punish 'aggravated' cases which would include the death of a disappeared person. Article 15 pledges the States parties to cooperate, *inter alia*, in locating the bodies of dead or missing persons. Article 17.3.b. requires the States parties to maintain a registry of the disappeared and "[I]n the event of death during the deprivation of liberty, the circumstances and cause of death and the destination of the remains." This necessarily requires an investigation.

Only one General Comment has been adopted by the relevant treaty monitoring body (CED). That focued on the subject of deaths of the disappeared in the context of migration (2023).[64] Of course, this might encompass the deaths of persons with disabilities displaced by armed conflicts.

The CED Committee has the capacity to entertain 'urgent requests' and has indeed done so on many occasions. Effectively, this is a request from the Committee to a State party to urgently search for, locate and protect a disappeared person. This might plausibly apply to a person

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[62] International Convention for the Protection of All Persons from Enforced Disappearance (2006): see egenerally - https://www.ohchr.org/en/treaty-bodies/ced/background-international-convention-protection-all-persons-enforced-disappearance

[63] UN Declaration on the Protection of All Persons from Enforced Disappearance, General Assemby Resolution 47/133 (1992): available at - https://www.ohchr.org/en/instruments-mechanisms/instruments/declaration-protection-all-persons-enforced-disappearance#:~:text=of%20international%20law.-,Article%206,duty%20not%20to%20obey%20it.

[64] See: https://www.ohchr.org/en/treaty-bodies/ced/general-comment-no-1-enforced-disappearances-context-migration

with a disability who, e.g., might be effectively incarcerated in a secret or distant institution. So far, the treaty does not seem to have been used for this purpose but it has that potential.

3. UN Convention on the Rights of Persons with Disabilities (CRPD) and the right to life.
Famously, the UN CRPD blends economic, social and cultural rights with civil and political rights. This was quite deliberate.[65] One might even say that the text is more faithful to the original intent behind the UN human rights system before it separated out both sets of rights in two different treaties in the 1960s (ICCPR and ICESCR). So one might expect it to be even more naturally attuned to the *'conditions for life'* as well as to the substance of the right to life itself.

The right to life is protected under Article 10 CRPD:

> **Article 10 Right to life**
> States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.

This wording pledges the State to take '*all necessary measures*' to ensure the '*effective enjoyment*' of the right by persons with disabilities. This is particularly strong language. What's more, by the use of langauge like '*on an equal basis with others*' it pegs that level of protection to prevailing international standards including those of the ICCPR and the Human Rights Committee. How then has the CRPD Committee interpreted Article 10?

The CRPD Committee has not yet adopted a General Comment focused on Article 10. Since there is no 'fragmentation' of norms between the ICCPR and the CRPD it may be presumed that the CRPD Committee would generally follow the overall approach of the Human Rights Committee. All the more so since the language of Article 10 CRPD is, if anything, stronger than the languiage in Article 6 ICCPR.

Revealingly, and with respect to State reporting. the CRPD Committee *Guidelines on State Reporting* (2016) state the following under Article 10[66]:

> **Right to life (art. 10)**
>
> 12. States parties should provide information on the following:
>
> (a) Legal and other measures adopted to recognize and protect the right to life of persons with disabilities on an equal basis with others, including to ensure that persons with disabilities are not subject to arbitrary deprivation of life;
>
> (b) Measures adopted for the early identification of, combat against and eradication of practices that infringe on the right to life of persons with disabilities, such as: the neglect, abandonment, concealment, destitution and life-threatening starvation of persons with disabilities, particularly children and adults with disabilities still living in institutions; the violent deaths of persons with disabilities, intentional killings of children

[65] The creative interplay between civil and political rights with economic, social and cultural rights in the UN CRPD was explored in Quinn & O'Mahoney, *Disability and Human Rights: a New Field in the United Nations,* in Krause, Caterina & Scheinin, Martin (Eds.), International Protection of Human Rights: A Textbook (2nd revised edition, Abo Akademy Press, 2012).

[66] UN CRPD Committee revised *Guidelines on peroidic state reporting to the Committee on the Rights of Persons with Disabilities, including under the simplified reporting procedure*, CRPD/C/3, (2016): available at - https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/3&Lang=en

with disabilities by their parents and termination or withdrawal of medical treatment without the consent of the person concerned;

(c) Legal and other measures adopted to eradicate harmful practices, including ritual killings, "mercy killings", mutilations, trafficking in organs and body parts, infanticide or intentional killings of persons with disabilities;

(d) Measures adopted to promote an understanding that the lives of persons with disabilities are of equal value to those of others and eradicate attempts to disseminate ideas that life as a person with disabilities is "not worth living";

(e) Measures to ensure that the lives of persons with disabilities are guaranteed to be equal to those of others, that all decisions regarding medical treatment in life-threatening situations are made on the basis of free and informed consent.

What is interesting in the above is the understanding that the threats to life for persons with disabilities are many and varied and can include '*neglect'* (12.b).

While the Guidelines do not directly address the issue of investigations, they might nevertheless be inferred from its emphasis on the '*eradication of practices*' that might threaten life. Its hard to eradicate a practice unless it is known and revealed through an investigation. What is also striking in the Reporting Guidelines is the CRPD Committee's keen understanding that institutionalisation poses heightened risks to the right to life.

It can be safely assumed that the CRPD Committee would follow the jurisprudence of the Human Rights Committee in dealing with the right to life. That it has done so can be seen in many of its recent Concluding Observations.

Interestingly, in a series of recent Concluding Observations on State reports the CRPD Committee has specifically pointed to the need for '*preventative measures*' and robust investigations. Again, it is hard to see preventive measures in the absence of investigations that probe systemic causes. What follows is a brief - admittedly unscientific - account of some of its more recent Concluding Observations of the CRPD Committee under Article 10.

For example, in its 2024 Concluding Observations on Sweden, it recommended that it (Sweden)[67]:

> [D]evelop a comprehensive approach to *prevent* avoidable deaths among persons with disabilities still in institutions, including by providing training to all professionals working with persons with disabilities, such as health, social, education and community workers, and ensure that criminal acts are effectively prosecuted.
>
> [para 24.b].

What is striking is the emphasis of the Commitete again on prevention. And because the Committee was (and is) very concerned with the continuation of institutionalisation throughout the world, it emphasised deaths occurring in institutions. This is of course where all or most of the scandals happen. But it does not exhaust the threats to life faced by persons with disabilities who may equally be at risk in the community especially if supports and services are not adequate or if they suffer abuse.

[67] UN CRPD Committee 2024 Concluding Observations on the combined second and thrid periodic reports of Sweden at paras 23-24: available at https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2FC%2FSWE%2FCO%2F2-3&Lang=en

In its 2024 Concluding Observations on Zambia,[68] the Committee recalled its jurisprudence with respect to several individual complaints (communications) under the CRPD Optional Protocol and specifically recommended that it (Zambia):

> [T]ake immediate and urgent legal and policy measures to *safeguard and protect* persons with disabilities and persons with albinism from abduction and murder and to ensure that all perpetrators are brought to justice.
>
> [para 20.b].

In terms of its jurisprudence under the CPRD Optional Protocol, the Committee referred to three individual petitions in its Concluding Observations with respect to Zambia.

In *X v United Republic of Tanzania*, (2017)[69], the complainant, who had albinism, had one of his arms chopped off by young men. No prosecution was ever brought. He claimed violations by the State of Articles 5 (equality), 15 (freedom from torture, inhuman or degrading treatment or punishment) and 17 (protection against violence, exploitation and abuse). On the merits, the Committee found:

> ...that the State parties authorities have not taken the *necessary measures to ensure an effective, impartial and complete investigation a*nd prosecution of the perpetrators and that no preventive or protective measures have been implemented with respect to the protection of persons with albinism.
>
> [Para 8.2].

With respect to Article 15 the Committee recalled that the States' obligation to prevent and punish torture, inhuman and degrading treatment applies to acts committed both by State and non-State actors. Its conclusions under Article 17 were similar. Here, the CRPD Committee parallels the approach of the Human Rights Committee.

In its Concluding Obsersations on Zambia the Committee adopted its reasoning from *X v United Republic of Tanzania* to engraft a similar obligation of prevention with respect to the right to life (Article 10 CRPD). It would have been useful if the Committe referred to the *Minessota Protocol* since it is even more specific to the right to life and investigations thereof.

In a companion case - *Y v United Republic of Tanzania* - a myriad of claims were put forward based on the horrific treatment of the complainant who also has albinism under Articles 4, 5, 7, 8, 14, 15, 16, 17 and 24 of the UN CRPD. The claim under equality (Article 5) was to the effect that the complainant was discriminated against because, unlike others without albinism, no steps were taken to prevent violence or abuse in their case.[70] That, it was claimed, amounted to actionable discrimination. The Committee concluded that the State Party authorities;

> ...had not taken the necessary measures to ensure an *effective, complete and impartial*

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[68] UN CRPD Committee 2024 Concluding Observations on the initial report of Zambia at paras 19-20: available at - https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2FC%2FZMB%2FCO%2F1&Lang=en

[69] CRPD/C/18/D/22/2014,Communication 22/2014, *X v United Republic of Tanzania:* available at - https://www.ohchr.org/sites/default/files/Documents/HRBodies/CRPD/CRPD-C-18-DR-22-2014.pdf

[70] CRPD/C/18/D/23/2014, Communcation No 23/2014, *Y v United Republic of Tanzania:* available at - https://documents.un.org/doc/undoc/gen/g18/327/11/pdf/g1832711.pdf?OpenElement

> *investigation* of the perpetrators and that no preventive or protective measures have been implemented in that regard.
>
> [Para 8.2].

A third complaint - *Z v United Republic of Tanzania* - also involved the horrific treatment of a single mother with albinism.[71] This time round Article 10 was included in the complaint. However, because it was not substantiated in the pleadings, the Committee held that this claim was inadmissible. This is a pity since an explicit ruling on Article 10 would have been useful. A suitable case awaits.

In its 2024 Concluding Observations on Azerbaijan,[72] the UN CRPD Committe concluded that the State should:

> Prevent the arbitrary deprivation of life of persons with disabilities still living in institutions, including by *periodically monitoring the registries of deaths in institutions*, setting up early warning mechanisms in institutions and ensuring the investigation of deaths, prosecutions and, where appropriate, the conviction of perpetrators.
>
> [Para 22.b].

This is very useful langauge as it refers specifically to the monitoring of registries of deaths. Bearing in mind the insights of Judge Broderick (above), the validity and veracity of death certificates is crucial in avoiding or preventing future deaths. The duty to investigate is clearly an antidote to the temptation to hide the truth about deaths in institutions.

In its 2024 Concluding Observation on the report of Kazakhstan (2024) the Committee voiced concern about[73]:

> Reports about deaths of persons with disabilities who were still living in residential institutions, including in psychiatric settings and detention facilities, and in special social service centres for children, particularly in the eastern and southern regions, and about the *limited number and scope of investigations* into and insufficient accountability for actions leading to death or threats to life...
>
> [Para 21.a].

The Committee's Concluding Observations on Germany focuses on that country's recent legislation prohibiting discrimination with respect to the triage of persons with disabilities in medical emergencies. It recommended a change in the law to make it crystal clear that there should should be no discrimination against the right to life - either direct or indirect - on the ground of disability in the context of the policy response to COVID-19.[74] Interestingly, the Concluding

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[71] CRPD/C/18/24/2014,Communiction No 24, 2014, *Z v United Republic of Tanzania*: available at - https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2FC%2F22%2FD%2F24%2F2014&Lang=en

[72] UN CRPD Committee 2024 Concluding Observations on the combined second and third periodic reports of Azerbaijan at paras 21-22: available at https://documents.un.org/doc/undoc/gen/g24/061/26/pdf/g2406126.pdf

[73] UN CRPD 2024 Committee Concluding Observations on the initial periodic report of Kazakhstan, paras 21-22: available at - https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2FC%2FKAZ%2FCO%2F1&Lang=en

[74] For a brief review of discrimination with respect to medical triage responses to disability during COVID see Gerard Quinn, *COVID-19 and Disability - a War of Two Paradigms*, ch. 8 in Morten Kjaerum, Martha Davis & Amanda Lyons, COVID-19 and Human Rights, (Routeledge 2020).

Observations of the CRPD Committee on Costa Rica, Austria and Mongolia did not contain anything on Article 10 (April, 2024).

Despite some uneven treatment of the issues it is plain that the CRPD Committee is well aware of international law on the need for investigations and the need to use such investigations to contribute to the *prevention* of future deaths. It is equally plain that the Committee is most concerned about the heightened vulnerabilities of persons with disabilities in institutional settings where, *inter alia*, the accurate certification of death cannot be guaranteed. This jurisprudential base could be extended further by looking at the disparate impacts on mortality rates for persons with disabilities that arise due to poor services in the community. In other words, it could be expanded to look at the systemic factors that explain high mortality rates.

In its 2023 decision in *Bellini v Italy,* the Committee expanded its consideration of Article 23 on 'respect for home and the family.' [75] It had been thought that this Article primarily gave rights to persons with disabilities themselves to enter, participate and leave the family. *Bellini* expanded this to include at least some consideration of support to families and especially carers. In keeping with the spirit of *Bellini,* the UN CRPD Committee might also usefully look at the mortality rates of carers (usually women) and the adequacy of investigations into them and the need for proactive policy measures to avoid them in the future. This phenomenon is hidden and hardly ever talked about. But it is precisely those areas that the Committee can and should be encouraged to shine a light on.

UN Soft Law Instruments on Truth and the Duty to Investigate.

1. Truth as a Foundation for Human Rights - 2006 Study of the UN High Commission for Human Rights.

Why is truth so important? And what kinds of truths should be actively probed, explored and shared?

A valuable UN OHCHR Study on Truth was prepared in 2006 and is still instructive despite the passage of time.[76] The Study asserts that the right to the truth:

> ...is an inalienable and autonomous right, linked to the duty and obligation of the State to protect and guarantee human rights, to conduct effective investigations and to guarantee effective remedy and reparations. The right is closely linked with other rights and has both an *individual and a societal dimension* and should be considered as a non-derogatable right...
>
> (p. 2, Italics added)

The 2006 Study makes it plain that the initial impetus for a right to truth came from international humanitarian law. The Geneva Conventions of 1949 and the Protocol of 1977

[75] *Bellini v Italy,* CRPD/C/27/D/51/2018, decision the UN CRPD Committee of October 2022: available at - https://juris.ohchr.org/casedetails/3604/en-US On the nexus between family support and disability rights see Gerard Quinn, *Disabilty and the family, Opinion piece* (anticipating the need for an expansive interpretation of Artile 23 CRPD), COFACE Brussels (2020): available at - https://coface-eu.org/opinion-disability-and-the-family/ See generally Like Clements, *A Landmark UN Carers Decision,* blogpiece, (2002): availabe at - https://juris.ohchr.org/casedetails/3604/en-US

[76] UNOHCHR, Study on the Right to Truth, (2006), E/CN.4./2005/91: available at - https://www.ohchr.org/en/transitional-justice/rule-law-right-truth See generally Melanie Klinker, Howard Davis, The Right to Truth in International Law: Victim's Rights in Human Rights and International Criminal Law, (Routeledge, 2020).

impose various obligations with respect to 'missing combatants' and 'missing persons.' The ICRC has asserted that the right to the truth (about missing combatants or family members) is a customary international law norm applicable to both international conflicts as well as non-international conflicts (i.e., internal or civil wars). From these beginnings, the right to the truth got extended to gross violations of human rights. This Study carries that one extra step by looking at the importance of truth beyond conflict situations and outside of gross human rights violations to look at the need for truth about neglect and insufficient support for persons with disabilities.

This initial focus of the right to the truth on gross violations of human rights (mass killings, enforced disapperances, extra-judicial killings) was understandable given the problems of the 1970s and 1980s with the transition from authoritarian to democratic systems around the world. At that point a truthful accounting for the recent past was (rightly) considered foundational to reconstruction, reconciliation and justice. That is to say, no sustainable process of reconstruction could be built unless the truth about mass or gross violations of human rights was adequately investigated and exposed. As Principle 2 of the 2005 UN Principles for the 'protection and promotion of human rights through action to combat impunity' states:[77]

> [E]very people has the inalienable right to know about past events concerning the perpretrators of heinous crimes and about the circumstances and reasons that led, through massive or *systemic* violations, to the perpetration of those crimes.
>
> [Italics added, P. 4].

It is interesting that the word *'systemic'* was added, which presumably extends to incoude the systemic causes of the deaths of persons with disabilities.

So, the truth is important to individuals to understand the past (especially if family members were implicated) and to come to terms with it. And the truth is important in the eco-system of democracy in providing a factual basis on which to look back as well as look forward. A democratic system's key strength is the ability to learn from the past and adjust accordingly for the future. It is simply not possible to do so without the truth.

Of course, the search for the truth can be framed differently. It could be narrowly focussed on a specific event at a paticular point in time. That wouldn't reveal much. Alternatively, it could be take a longer view - a lifecourse perspective. Should the right to the truth concern only the immediate causes of death? If the right to the truth is at its highest when violence, in its many forms has happened, then is not a lifetime of inequality in itself a form of violence? Or does the right to the truth stretch back to the underlying systemic causes that may have taken a lifetime to manifest themselves? The true causes - the systemic causes - are likely to be missed by superficial investigations that focus on *synchronic* events (what caused a particular death at a particular point in time). Instead, the lens needs to be intentionally broadened to a *diachronic* lens - to enable investigators to 'see' the systemic truth over time and to report and react accordingly. Only then, can the deeper truth be fully understood.

Truth is therefore crucial not just for understanding the past and present but also for shaping the future. Moreover, the right to the truth is not confined to classic gross violations of IHL or

[77] UN E/CN.4/2005/102/Add 1.

human rights. While it is, of course, critical with respect to the same. Yet, the truth is elusive and is often evaded when it comes to marginalised or invisible groups like persons with disabilities - and it is just as important for facing the past and re-imagining the future. Part of that entails looking at obvious violations. But part of revealing the truth - the deep truth - must also look at uncovering systemic issues that help explain vulnerabilities and, for the purpose of this study, early death.

An important element of revealing and respecting the truth is the memorialising those hidden places where violations have occurred against persons with disabilities - so-called *'sites of conscience*.'[78] Through these sites the violations can be named, publicly acknowledged and communicated to future generations in order to keep the lessons alive. This process honours those who have suffered and benefit future generations. Truth needs to be actively transmitted, otherwise, collective memory fades and important lessons are lost. Indeed, truth is foundational to 'moral repair.'[79] The pioneering and extensive work of Linda Steele on moral repair in the disability context deserves special mention.

Truth, in all its dimensions, is therefore pivotal to justice and enabling societities to learn and move forward. It is just as vital for persons with disabilities as it is for others.

2. Truth Telling and Death: The Minnesota Protocol (2019) on the Duty to Investigate Potentially 'Unlawful Deaths.'[80]

Soft UN standards have also been evolving in light of case law under treaties such as the ICCPR. Although they purport to draw together this jurisprudence, these soft standards are highly relevant to the process of domestic law reform.

The origin of these soft standards can be traced back to the 1989 ECOSOC *Principles on Prevention and Investigation of Extra – Legal, Arbitrary and Summary Executions* (1989/65). These Principles provide guidelines for the effective prevention and impartial investigation of extra-legal deaths in order to protect individuals from potentially unlawful killings.[81] As is obvious from the title, the main concern is the State - or emanations of the States - as the alleged cause of death. Nonetheless, it sweeps in all threats whether from the State or from other private parties. It is clear that the second public interest identified above (rule of law) was the primary concern of these standards. ECOSOC formally welcomed the principles and the UN General Assembly endorsed them.

Once again, these principles highlight the need for an impartial, thorough investigation of all reports or indications that suggest an un-natural or unexplained death. The purpose of the investigation should be to determine the cause, manner, and time of death, as well as the circumstances that may have brought about the death.

Paragraph 9 of the ECOSOC principles is to the effect that there:

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[78] See Elisabeth Punzi & Linda Steele (Eds.), Sites of Conscience: Place, Memory and the Project of Deinstitutionalisation, (Chicago University Press, 2024). See generally, 65 NOMOS (2023), American Society for Political and Legal Philosophy, thematic issue on *Reconciliation and Repair.*

[79] See generally Linda Radzik, Making Amends: Atonement in Morality, Law and Politics, (Oxford University Press, 2011).

[80] For an excellent and detailed historical background to the *Minnesota Protocol* see Christof Heyns, Stuart Casey-Maslen, Toby Fisher, Sarah Knuckey, Thomas Probert, Morris Tidball-Binz, '*Investigating Potentially Unlawful Death under International Law: the 2016 Minnesota Protocol,* 52 (no 1) The International Lawyer, (2019).

[81] United Nations Economic and Social Council, 'Principles on Prevention and Investigation of Extra-Legal, Arbitrary and Summary Executions' (24 May 1989) UN Doc E/RES/1989/65.

> ...shall be thorough, prompt and inpartial investigatuiion of all suspected cases of extra-legal, arbitrary and summary executions, including cases where complaints by relatives or other reliable reports suggest unnatural death in the abive circumstances.,
>
> [Italics added].
>
> The purpose of the investigation shall be to determine the cause, manner and time death, the person responsible and any pattern or practice which may have brought about that death.

Curiously, this would appear to allow for the apportionment of blame ('the person responsible') which contradicts the history of the relevant truth-telling institutions at least in the common law world. And interestingly, it hints at future innovations by focusing attention on any *'pattern or practice'* which may have brought about the death (like inadeqtare services). This hints at a concern for systemic causes.

Interestingly, Paragraph 11 of the Principles is to the effect that where:

> …the established investigative procedures are inadequate because of the lack of expertise or impartiality….Governments shall pursue investigations through an independent commission of inquiry or similar procedure….In particular [the Commission of Inquiry] shall be independent of any institution, agency or person that may be the subject of the inquiry…

Of course, such in-depth investigations might also be instituted in situations other than 'lack of expertise or impartiality.' They might also be required where a particular cohort has specific vulnerabilities like persons with disabilities. In such instances, a standing commission of inquiry might be created like the English LeDeR, which has conducted 8,500 inquiries into the deaths of persons with intellectual disabilities.

The 'investigative authority' shall have the power to obtain ‘all the information necessary to the inquiry’. Those persons conducting the iunvestigation shall have at their disposal 'all the necessary budgetary and technical resources for effective investigation.' (para 10).

Interestingly, the 1989 ECOSOC set of principles also deals with autopsies. In particular, "the body of the deceased person may not be disposed of until an adequate autopsy is conducted by a physician who shall, if possible, be an expert in forensic pathology" (para 12). Of course, an autopsy may not be needed and its wisdom is always a judgment call for the deciding body.

The autopsy shall:

> ...at a minimum attempt to establish the identity of the deceased and the cause and manner of death...The autopsy report must describe any and all injuries to the deceased including any evidence of torture' (para 13).

Those conducting the autopsy 'must be able to function impartially and independenly of any of any potentially implicated persons or organizations or entities' (Para 14). The focus seems to have been on regulating too close a connection between the autopsy process and agencies of the State.

Families are given particular standing under the 1989 Principles document:

> Families of the deceased and their legal representatives shall be informed of, and have access to, any hearing as well as to all information relevant to the investigation, and shall be entitled to present other evidence.
>
> [para 16].

A receptiveness to such engagement is seen as critical. At the end of the process "a written report shall be made within a reasonable period of time on the methods and findings of such investigations. The report shall be made public immediately" (para 17).

Interestingly the 1989 ECOSOC Principles proceed to deal with 'legal proceedings' (i.e., criminal prosecutions) that may follow from an investigation (paras 18-20). This is a bit unusual given the history of coroners and medico-legal institutions as bodies that do not generally establish legal liability. Again, it is perhaps explained by the times it was written in at the end of the Cold War when the main concern was arbitrary action by authoritarian States (and impunity).

The 1989 ECOSOC Principles document reflected the priorities of the times when arbitrary action by the State and its agents was the main object of concern. Nonetheless, it laid a foundation for more elaborate and extensive guidelines that would cover both State and non-State action and deal with 'suspicious deaths' due to more systemic human rights violations by either public or private parties.

The rather narrow priorities of the 1980s were broadened by the 2000s. In 2016 the United Nations updated the 1989 ECOSOC *Principles* in the *Minnesota Protocol.* The use of the term 'protocol' is somewhat of a misnomer since there is no underlying treaty and therefore no legal protocol as such. However, the name was likely intended to signal the seriousness of the endeavour. Forensic developments alone justified an update of the early Principles.

The *Minnesota Protocol*, formally titled, '*The Revised United Nations Manual on the Effective Prevention and Investigation of Extra-Judicial, Arbitrary and Summary Execution,*' extends beyond its rather narrow title. It is in reality a collection of international guidelines formally endorsed by the United Nations that aim to standardize the approach to prevention and investigation regardless of whether the death was at the hands of the State or not.

The *Minnesota Protocol* has been formally acknowledged by a number of authorities, including the European Court of Human Rights.[82] It has been described as " a comprehensive restatement of the procedural component of the right to life" that is intended:

> ...to assist a range of actors, including States, investigators, civil society organizations, and rights-holders themselves, to ensure that [the] proper investigations of suspected unlawful killings are conducted."[83]

It is now joined by the *Istanbul Protocol* (2022) wth deals with the duty to investigate alleged instances of torture, inhumane or degrading treatment.[84] This is especially relevant to persons

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[82] See, e,g, *Machalikashvili and Other v. Georgia,* App no 32245/19 (ECtHR, May 22 2023).

[83] Christof Heyns *et al, 'Investigating Potentially Unlawful Death under International Law: The 2016 Minnesota Protocol,'* (2019) 52(1) The International Lawyer 47–80 (print) at 4.

[84] *Istanbul Protocol: Manual on the Effective Investigation and Documentation of Torture, and Other Cruel, Inhuman or Degrading Treatment or Punishment*, (2022): available at - https://www.ohchr.org/sites/default/files/documents/publications/2022-06-29/Istanbul-Protocol_Rev2_EN.pdf See generally, Janos Fiala-Butora, '*Disabling Torture: The Obligation to Investigate Ill-Treatment of Persons with Disabilities,* 145

with disabilities who face an increased risk of abuse due to inadequate services and congregated living arrangements.

The stated purpose of the *Minnesota Protoco*l is (1)1:

> To protect the right to life and advance justice, accountability and the right to a remedy by promoting the effective investigation of potentially unlawful death or suspected enforced disappearance.
>
> [Para 8].

Again, note the link drawn between proper investigations and the 'rule of law' (not a traditional concern of meico-legal investigations). Protection of the right to life is said to mean:

> preventing the arbitrary derivation of life, including through an appropiate framework of laws, regulations, precautions and procedures. It also requires accountabiity

The focus on precautionary measures is a clear and direct link to more systemic concerns in avoiding future needless deaths.

The 'duty to investigate' applies where the death may have been caused by direct acts or omissions of the State, where a death occurred when a person was held in detention by the State or where "the death occurred where the State may have failed to meet its obligations to protect life" (1(2)c. The *Minnesota Protocol* states:

> There is also a general duty on the State to investigate any suspicious death, even where it is not alleged or suspected that the State caused the death or unlawfully failed to prevent it.

This is important since it makes it plain that if the State can apprehend a threat caused by third parties and that it bears a duty to take preventive steps and a duty to investigate. States are also encouraged to "take appropriate steps to incorporate Protocol standards into their domestic legal systems and to promote it use by relevant departments and personnel…."

With respect to the *Elements and Principles of Investigation*, the Protocol emphasises that international law "requires that investigations be: (i) prompt, (ii) effective and thorough and (iii) transparent." [D]. An investigation must be "carried out diligently and in accordance with good practice (para 27)." Importantly,

> Investigations, and investigative mechanisms must be, and must be seen to be *independen*t of undue influence. They must be *independent institutionally*, and formally as well as in in *practice and perce*ption, at all stages.
>
> [Italics added.]

Institutional independence is therefore critically important. This aspect of institutional independence is emphasised in contexts where the State or its agents may have been the

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Columbia Human Rights Law Review, (2013) 214-280. On the Istanbul Protocol see: Adolpho Azcuna, '*The Law on Torture and the Istanbul Protocol*,' 52 Issue 3 Ateneo Law Journal (2007), 722-729. See also Emily Julia Kakoulis, *Monitoring Mechanisms designed to serve Persons with Intellectual Disabilities: exploring the implementatik omf Article 16 in Cyprus*,' (inadequate mechanism to prevent torture or abuse for persons with disabilities), 15 International Journal of Law in Context (2019).

perpetrators: “Investigations must be independent of any suspected perpetrators and the units, institutions or agencies to which they belong (para 28).” Furthermore, independence means:

> …more than not acting on the instructions of an actor seeking to influence an investigation inappropriately, It means that that the investigation’s decisions shall not be unduly altered by the presumed or known wishes of any party (para 29).

In a way this prohibits an investigatory body from anticipating what result would suit the State and deciding accordingly. Additionally, the participation and protection of family members in relevant legal proceedings are highlighted in the 2016 *Minnesota Protocol*. Family members:

> have the right to seek and obtain information on the causes of a killing *and to learn the truth* about the cirumstances, events and causes that led to it. In cases of potentially unlawful death, families have the right, at a minimum, to information about the circumstances, location and condition of the remains, and insofar as it has been deterined, the cause and manner of death.
>
> [Italics added, Para 11].

This is important for families of persons with disabilities who may have passed away in unexplained circumstances.

Further:

> Determining the final whereabouts of [a] disappeared person is fundamental to easing the anguish of family members caused by the uncertainty of their disappeared relative. A violation [of the right to life] is *ongoing* as long as the fate or whereabouts is not determined.
>
> [Para 12].

Importantly, the public interest in the right to know is cast broadly:

> *The right to know the truth extends to society as a whole*, given the public interest in the *prevention* of, and accountability for, international law violations.
>
> [Italics added, Para 13].

So society has a right to know and this right to know is directly connected with the goal of 'prevention.' This may be especially relevant in a disability context since society has tended to avoid the truth in the past. A particular concern of the *Minnesota Protocol* is when death happens in the custody or care of the State:

> this must be reported without delay, to a judicial or other competent authority that is independent of the detaining authority and mandated to conduct prompt, impartial and effective investigations into the circumstances and causes of such deaths.
>
> [Para 17].

This would arise in mental institutons, hospitals and general institutions. Interestingly the 'duty to investigate' is said to arise even when the State "cannot be held responsible for failing to prevent such deaths" (Para 18). That sweeps in deaths caused by private parties even though they could not have been stopped by the State.

Paralleling the jurisprudence of the Human Rights Committee, the duty to investigate is also said to arise under the *Minnesota Protocol* equally in "peacetime, situations of internal disturbance and tensions, and armed conflict" (Para 20). This is important with respect to the many civilian casualties with disabilities that often result from armed conflict. Indeed, the duty still arises even when there is no suspicion of a violation of International Humanitarian law (laws of war). The *Minnesota Protocol* acknowldeges that many practical difficulties that might arise in conflict/post conflict situations. But these diffculties must be recorded and publicly acknowledged. If a purely military object (as distinct from targeting civilians) was pursued during an attack and civilian casualties arise then a:

> post operation assessment should be conducted to establish the facts, including the accuracy of the targeting...
>
> (Para 21).

If there are reasonable grounds to suspect that a war crime has been committed then the State "must conduct a full investigation and prosecute those who are responsible" (Para 21).
The character of the investigation is also provided for in the *Minnesota Protocol*. Specifically it has to be "(i) prompt, (ii) effective and thorough, (iii) independent and impartial and (iv) transparent" (D).

The requirement for promptness arises in part from the fragility of the evidence and the need to act while sufficient lines of inquiry are available to the forensic pathologists. Having said that, the need for promptness does not justify a rushed or unduly hurried investigation "which might easily miss (whether by intention or not) key evidence." If no investigation has been carried out promptly then the State still bears untimate reponsibility to investigate (even at a later date). In other words, the overall duty to investigate does not fade with time.

An 'effective and thorough' investigation requires it to "collect and confirm all testimonial, documentary and physical evidence" (Para 24). Interestingly, investigations must be capable of "*...preventing future unlawful death[s]."* This strongly hints at a higher public interest in investigations to avoid similar deaths in the future.

Investigations shall aim to "(i) identify the victim[s], (ii) recover and preserve all material probative of the cause of death...(iii) identify possible witnesses and obtain ther evdence in relation to the death...(iv) determine the cause, manner, place and time of death, (v) determine who was involved in the death and their individual responsibility for the death." This last requirement is again strikingly at odds with the traditional functions of coroners in the common law world who do not typically stray into issues of liability.

The *Minnesota Protocol* aserts that an autopsy would, in many cases, be necessary. Any decision not to carry one out should be subject to judicial review.

Importantly, the investigation should:

> seek to identify any failure to take *reasonable measures which could have had a real prospect of preventing the death.* It should also seek to identify policies and systemic failures that may have contributed to a death and to idenity patterns where they exist"

(Para 26).

Again, this language echoes the analysis of the Human Rights Committee and speaks directly to a higher public interest in investigating death linked to systemic failures (e.g., inadequate services) which may affect distinct cohorts such as person with disabiities.

On the criteria of independence and impartiality the *Minnesota Protocol* demands that they

> must be and must be seen to be independent of undue influence. They must be independent insitutionally and formally as well as in practice and perception, at all stages.
>
> (Para 28).

A particular concern is independence from suspected perpetrators (especially if they are agents of the State). Also of concern is independence from politial parties and powerful social groups. This reflects a concern that political parties may have an incentive to hide the truth. And maybe this hints at a concern that private actors - like some service providers - will also have an vested interest to hide the truth. Unfortunately, the language of the *Minnesota Protoco*l, does not elaborate.

Independence requires:

> more than not acting on instructions from adecisions shall not be unduly altered by an actor seeking to influence an investigation inappropriately. It means that the investigations decisions shall not be unduly altered by the preumed or known wishes of any party.

(Para 29).

Investigators themselves:

> must be able to perform all their professional functions without intimidation, hindrance or harassment or improper interference and must be able to operate free from the threat of prosecution or other sanctions for any action taken in accordance with recognised professional duties, standards and ethics.

This is important as it acknowloges the centrality of standards of professional ethics arrived at autonomously by the various professional bodies. That is why the ethical standards set by these bodies are an important part of the policy mix.

The investigative process and its outcomes must be transparent including through openness to scrutiny by the general public and of victims' families. Some limitations on transparency are allowable, e.g., to protect the integrity of further investigations.

Family participation (and protection) is of particuar concern:

> The State must enable all living relatives to participate effectively in the investigation, though without compromising its integrity. Family members should be granted legal standing and the investigative mechanism of authorities should keep them informed of the progress of the investigation during all its phases in a timely manner. Family members must be enabled by the investigating authorities to make suggestions and arguments as to what investigative steps are necessary, provide evidence and assert their interests and rights throughout the process.

Importantly, this section proceeds:

> Where necessary to ensure that the family members are able to participate effectively, the authorities should provide funding for a lawyer to represent them.

(Para 29.)

Funding for legal representation of families in investigative processes turns out to be one of the Achilles' heels of the process worldwide. The *Minnesota Protocol* does acknowlede certain limitations on the rights of the family particularly where they - or members of the family - are suspected as perpetrators.

The *Minnesota Protocol* acknowledges the specific rights of families in the context of human remains. Indeed, families should be notified of an impending autopsy and entitled to have a representative present during the autopsy. After all investigations are completed the remains should be released to the family for disposal in accordance with their beliefs. The *Minnesota Protocol* suggests that a family liaison should be appointed.

The *Minnesota Protoco*l provides valuable detail on the actual process of investigation (Paras 50-79). Further Detailed Guidance also is given with respect to crime scene investigations, interviews, excavation of graves and autopsies. These detailed guidelines have less to do with the overall shape of law and policy and more to do with how particularly important tasks - like autopsies - should be carried out. This reflects the fact that the *Minnesota Protocol* was a product of lawyers and public policy specialists working collaboratively with forensic specialists.

Overall, the *Minnesota Protocol* is a central reference document that should underpin domestic law and policy on investigations. Particularly notable are the detailed criteria governing the constitution and operation of investigatory bodies (independence, effectivenss, promptness, and family involvement). And of especial note for our pruposes is the focus on *prevention*. In the disability context, this points strongly to the need for investigatory bodies to probe underlying systemic causes of deaths and to provide recommendations for change in the public interest. Unlike its origins, the current *Minnesota Protocol* is relevant not merely to political regimes in transition and to mass violations of human rights - it is also relevant to the often hidden or invisible systemic causes of the deaths of groups in vulnerable situations like persons with disabilities.

3. Truth about Ill-Treatment: The 2022 Istanbul Protocol on the Effective Investigation and Documentation of Torture, and other Cruel Inhuman or Degrading Treatment or Punishment - its relevance to disability.

The right to freedom from torture - like the right to life - cannot be derogated from during a war or a state of national emergency.

It was previously emphasised the importance of the link between torture, inhuman and degrading treatment and death. Of course such ill-treatment may not lead to death and is obnoxious in its own right. But there may well be a causal link betwen such ill-treatment and death. So, a duty to investigate ill-treatment may well be foundational to the proper investigation of a death that may eventually result.

It is to be recalled that the former UN Special Rapporteur on torture, Manfred Novak, had opined that the civil commitment of persons with psychosocial disabilities might itself amount to a *per se* form of torture.[85]

In a pioneering 2013 essay in the Columbia Human Rights Law Review, Janos Fiala-Butelo laid out the myriad of circumstances in which torture, inhuman or degrading treatment might arise for persons with disabilities.[86] He cites institutionalisation, inhuman and degrading living conditions, lack of privacy, inadequate healthcare, a failure to meet special needs, violence, restraints, and forced medication as classic examples of ill-treatment in the disability context. He says:

> ...persons with disabilities continue to suffer ill-treatment on a massive scale. Many still live in horrible conditions in large, segregated, institutions, where various forms of abuse take place. Practices that would otherwise constitute torture are justified on medical and economic grounds. Chemical and physical restraints, "corrective" medical interventions, physical and sexual violence, and facilities not adapted to their needs, all form part of the daily experience of persons with disabilities.
>
> [p. 216.]

He critiques the existing international law (as of 2013) on the 'duty to investigate' as failing to fully embrace disability since it was developed in a non-disability-specific context. Worse, he asserts that:

> Inaccessible procedures and remedies, and legal mechanisms created with the non-disabled in mind, *foster ill-treatment* and protect perpetrators instead of helping victims.
>
> [Italics added, p. 218].

And he points to the UN CRPD as a corrective to this invisibility, noting that it could help give reality to the latent potential of the general duty to investigate. He takes a close look at how the European Court of Human rights defines the constituent elements of torture, inhuman treatment and degrading treatment and considers how all the above ill-treatment in the context of disability ought to qualify.

Interestingly, he also points to the direct link between such ill-treatment and high mortality rates for persons with disabilities in institutions:

> Amnesty International reports that 27 residents of the Dragash Voyvoda home, which houses over 140 individuals, died between 2001 and 2002, mostly due to a lack of medical treatment.
>
> [p. 229].

Similarly, he points to an outrageous event leading to death in Slovakia:

> In that case, an intellectually disabled resident of the Rokytovce Nad care home was beaten to death on January 6 2006. The victim was punished for his attempted escape by one of the staff members who tied him to a bed and told three other residents to beat him with sticks and then left the room. Upon

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[85] UN Special Rapporteur on Torture, 2008 thematic report on '*Protecting Persons with Disabilities From Torture*,' especially at para 44: available at - https://www.ohchr.org/en/special-procedures/sr-torture/annual-thematic-reports-special-rapporteur

[86] Janos Fiala Butora, *Disabling Torture: The Obligation to Investigate Ill-Treatmen of Persons with Disabillities,* 45 (1) Columbia Human Rights Law Review, (2013) 214-280.

> returning the staff member realised that the victim had died. A criminal investigation against the staff member was reluctantly initated after the media exposed the events. Journalists emphasised what a great employee he has been and how he cared about his family, suggesting that the life of a 'crazy resident' whom nobody would miss was not worth the hassle.
> ...
> The prejudicial belief that the life and health of persons with disabilities are worth less than that of others, and that therefore violence against them is more acceptable, is a recurring theme of institutional care and often in life in the communtiy as well.
>
> [p, 232-233].

In 1998, the European Court of Human Rights fashioned a general 'duty to investigate' whenever an 'arguable case' of ill-treatment was raised by a complainant on the facts.[87] Thus, a 'procedural dimension' to the right was created, in part, to get round some procedural blockages to valid claims. States could easily hide the damning information thus making it almost impossible to mount a sucessful claim. One way around this was to flip the evidentiary burden and to place a positive obligation on States to investigate. Fiala-Butelo asserts that the European Court followed its own jurisprudence under Article 2 (right to life) and engrafted the 'duty to investigate' from the Article 2 ECHR caselaw onto the domain of torture, inhuman and degrading treatment (Article 3 ECHR). So the right to life case law enriched and informed the case law under Article 3 ECHR (freedom from torture).

Fiala-Butelo outlines the criteria the European Court of Human Rights uses to assess the adequacy of an investigation under Article 2. They largely overlap with the criteria of the *Minnesota Protocol* (independence, effectiveness, prompt, inclusiveness and public scrutiny). He critiques each of these criteria as they apply to disability (as of 2013). And he notes the many difficulties persons with disabilites face in trying to take advantage of the Court' caselaw on the procedural obligation under Article 2.

Article 3 of the ECHR is mirrored by Article 15 of the UN CRPD. It reads:

> **Article 15**
> **Freedom from torture or cruel, inhuman or degrading treatment or punishment**
> 1. No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected, without his or her free consent to medical or scientific experimentation.
>
> 2. States Parties shall take all effective legislative, administrative, judicial or other measures to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading or punishment.

One of the main historical problems highlighted by Fiala-Butelo is that:

> Persons with disabilities often do not have adequate access to investigatory mechanisms because they enjoy limited support by their social supports and are disadvantaged by procedural rules.
>
> [p. 276].

He links effective enjoyment of the procedural rights in Article 15 CRPD (freedom from torture and the duty to investigate) to Article 13 CRPD (access to justice and the right to an

[87] *Assenov and others v Bulgaria,* 91/1997/874/1086, October 1998: available at - https://hudoc.echr.coe.int/eng#{%22itemid%22:[%22001-58261%22]}

effective legal remedy). He concludes in language that could equally apply to the procedural dimension to the right to life as it does to freedom from torture:

> ...in investigation proceedings, the state should be under an obligation to provide information to persons with disabilities about their rights in an accessible format. Investigative bodies and judges should also be educated on disability issues and trained to communicate with persons with disabilities. The state should be required to provide similarly trained and specialised legal representation...
>
> [p.277].

He continues:

> Associations and other organizations of persons with disabilities shopuld be acknowledged as an important source of support. They should have adequate rights in the investigation proceedings as well, by participating either on behalf (as representatives) or in support of complainants with disabilities...
>
> [p. 277].

And he concludes;

> The most important lesson from this [law review] Article is that when it comes to ill-treatment, law is to a great extent the cause of this vulnerability. Instead of providing them effective protection, the law provides for procedures and remedies that are largely inaccessible to people with disabilities. Legal mechanisms created with the non-disabled citizen in mind foster ill-treatment and protect its perpetrators instead of helping the victims. It is precisely these outdated doctrines that the Convention on the Rights of Persons with Disabilities should help to correct and overcome so that the prohibition of torture becomes a reality rather than simply an aspiration for people with disabilities.

The *Istanbul Protocol* was first proclained in 2001, then 2004 and the current iteration was proclaimed in 2022. It aims to address the many problems and obstacles identified by Fiala Butelo. It is grounded on a series of *'Istanbul Principles'* which set out minimum standards according to which medical or medical legal investigations of claims of torture and other cruel, inhuman or degrading treatment or punishment should be carried out.

The *Istanbul Principles* overlap considerably with the *Minnesota Protocol*. The purpose of an investigation is stated to include clarification of the facts. Significantly, another purpose is:

> ...the identification of measures needed to *prevent recurrance*...[1.b].

Again, that is hard to do without an in-depth investigation of systemic causative factors. A third major purpose is to facilitate prosecution and the need for full reparation and other remedies [1.c.]. States are enjoined to carry out investigations 'promptly and effectively.' Apart from a formal complaint, they should be initiated 'if there are other indications that torture or ill treatment has occurred.'[2].

That is to say, investigations should not wait for a formal complaint. The powers and capacities of the investigatory body are prescribed under the *Istanbul Principles* and include having the power to obtain all the information required with adequate budgetary and technical resources and the power to compel witnesses. Witnesses should be protected from violence, the threat of violence and intimidation. Anyone potentially implicated in torture or

ill-treatment should be removed from any position of control over investigations. Alleged victims have a right to access to all information put before the investigation and to attend any hearing.

Curiously, the *Istanbul Principles*, like the *Minnesota Principles,* envisage a situation in which establised investigation procedures are inadequate and a commission or other inquiry may be needed. This may happen becasue of 'insufficient expertise or bias, or because of the pattern of abuse or for other substantial reasons.' It is submitted that another legitimate '*other substantial reason*' might have to do with the relative invisibility of the cohort in question and a history of discrimination and abuse against them. A good case can be made to institute a standing commission of inquiry into the deaths of persons with disabilities akin to the LeDeR programme in England.

As with the *Minnesota Protocol*, the independence of such a commission is stressed. Whether the investigation is done by an ordinary investigatory body or by a commission of inquiry it should compile a report and make it public.

All clincial and other experts appoined to assist the investigatory process are required to meet the highest professional ethical standards. This underscores the importance of these independent professional ethical standards in complementing the *Istanbul Protocol* (and indeed the *Minnesota Protocol*).

The role of clinical experts is itemised and include:
1. Compiling a report icluding details about any interview with the alleged victim, a history of the case
2. Record of the physical or psychological examination,
3. Expression of a professional opinion as to the link between the examination and ill-treatment
4. Signing and authoring reports which remain confidential to the alleged victim and the investigatory body.

In sum, the Istanbul Protocol should inform how investigations of abuses against persons with disabilities should occur. It does not capture the full breadth of neglect that night at least contribute to the death of a person with a disability. Nevertheless, it is important in the context of disability and ought to be more fully utilised. And the space it creates for commissions of inquiry should be more fully utilised.

4. Toward More Effective Truth Telling: Thematic report of the UN Special Rapporteur on Extrajudicial, Summary, or Arbitrary executions on Effective Investigations (2022).

Among other tasks, including the monitoring and implementation of international safeguards to prevent extrajudicial, summary, or arbitrary executions, the UN Special Rapporteur on extra-judicial, arbitrary or summary executions submits annual thematic reports to the UN Human Rights Council. These reports generally highlight current or topical challenges and suggest practical solutions for States.

In 2022 the Special Rapporteur issued a very valuable thematic report to the UN Human Rights Council on '*medical legal death investigations*.'[88] He received many submissions from around the world to assess the state of investigatory mechanisms. He begins by referencing a report by the previous Special Rapporteur:

> In a 2015 report, a former Special Rapporteur, Christof Heyns, noted that the right to life cannot be considered fully protected unless thorough and effective investigations are conducted into any situation in which it may have been violated. States must conduct such investigations with reference to as much forensic expertise as necessary.[89] *Thus, a failure to conduct a proper investigation is regarded, in itself, as a violation of the right to life.*
>
> [Italics added.]

This is interesting as it conflates inadequate investigatory mechanims as a *per se* violation of the right to life. In his summary of typical problems around the world the Special Rapporeur asserts:

> 28. Legislation governing medico-legal death investigations is often inadequate to comply with standards, including those recommended in the Minnesota Protocol, or to meet contemporary challenges in death investigations.

This serves to make the need to make the *Minnesota Protocol* central to any process of law reform. While the Special Rapporteur does not focus extensively on the criteria for independence of the system, he does state:

> 31. In many contexts, medico-legal death investigations systems are not fully independent, including where they are part of police or security forces, which also raises questions on the objectivity and impartiality of the investigations under their responsibility.

Interestingly, he asserts:

> The *structure of an organization* can support or undermine its independence. *Subordinating forensic medical services to the police, prosecutors or judges, or placing services in departments where they have little priority, is unlikely to promote independence*. Providing an independent oversight body, such as a commission or board with a membership consisting of respected senior individuals from the health, justice, education and community sectors, can help to protect forensic medical services from improper pressure and empower them as independent entities. This type of structural protection exists in some contexts, as exemplified by medical examiner offices in the United States.
>
> [Italics added].

The place of the investigatory authority in the hierarchy of institutions is clearly important. Preferably these entities should not be slotted into an existing hierarchy but be located outside them.

Among his many practical recommendations to States are the following:

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[88] UN Special Rapporetur on extra judicial, summary or arbitrary executions, 2022 thematic report '*Medico-Legal Death Investigations,*' A/HRC/50/34: available at - *https://www.ohchr.org/en/documents/thematic-reports/ahrc5034-medico-legal-death-investigations-mldis-report-special*

[89] A/70/304, para. 63.

Independence of medico-legal death investigations

81. States should protect professionalism, safeguard reliability and promote public confidence in investigations into all potentially unlawful deaths by ensuring that medico-legal death investigation systems are fully independent. Models of best practice exist to help to guide the legislative, institutional and other reforms required in this regard.

82. States should ensure that the laws governing medico-legal death investigations are up to date and reflect applicable international standards, including those set out in the Minnesota Protocol. The law should delineate the duties and functions of forensic doctors in a way that enables them to give full expression to their professional skills, in compliance with international standards and in the best interest of reliable investigations, without undue pressure or conditions.

This is an important thematic report and especially the Rapporteurs' insight that the *Minnesota Protoco*l has yet to be given effective legisative and policy grounding around the world. It is also important since the rapporteur emphasises the structural preconditions for the efffective independence of the truth-telling institutions.

Probably the main challenge in a disability context is that investigatory bodies are perhaps prone to be to overly deferential to third parties, such as service prpoviders. Greater awareness among investigatory bodies as to the particular vulnerabilites that persons with disabilities can find themselves in would be one corrective to ensure genuine independence.

5. Truth Telling in the Context of Transitional Jusrice - Thematic Report of the UN Special Rapporteur on the promotion of truth, etc., on International Legal Standards underpinning the Pillars of Transitional Justice (2023).

This UN Special Rapporteur - commonly known as the Special Rapporteur on transitional justice - issued an especially interesting and useful thematic paper in 2023 on the legal values and doctrines underpinning the broad concept of transitional justice. [90]

In this report, he identified the five main pillars of transitional justice as follows; (1) truth seeking, (2) justice, (3) reparation, (4) memorialisation and (5) guarantees of non-recurrence. Each pillar is highly relevant in the context of persons with disabilities who, like their fellow citizens, have often lived through conflict, turmoil and transition as well as systemic neglect and abuse. These pillars are especially crucial in the context of truth-telling on death.

He emphasises that all pillars are inter-dependent and must be implemented in a non-discriminatory and victim-centered manner. One intepretation of this principle is that they should be each sensitive to the particular vulnerabilities confronting distinct cohorts like persons with disabilities. This, it is argued, is especially important when it come to truth-telling in the context of disability.

The truth pillar is critically important. It is central to combatting impunity and "consists oin the inalienable right of victims and their families to know the truth about past events...and about the circumstances that led, through massive or systemic violations...(to crimes)." (para 17). The failure to properly investigate such systemic causes could give rise to a separate

[90] UN Special Rapporteur on the promotion of truth, justice, rep[aration and guaruantees of non-recurrance, *International Legal Standards Underpinning thre Pillars of Transitional Justice,* A/HRC/54/24, (2023); available at - https://www.ohchr.org/en/documents/thematic-reports/ahrc5424-international-legal-standards-underpinning-pillars-transitional

violation of international law (para 17). He ties the search for truth with the international legal duty to investigate gross violations of human rights and serious violations of international humanitarian law. Actually, the legal duty to investigate extends beyond those extreme realms to encompass a duty to investigate all 'suspicious deaths' whether caused by the State and its agents or by private parties.

With respect to conflicts more generally, both the Unitied Nations and each regional system view the right to life is a non-derogable human right. That is to say, it applies with equal (if not especial) force during times of emergency and conflict. It follows that the duty to investigate applies in both peacetime and in times of conflict – either between States or withing States. Of course, the range of war crimes – or breaches of international humanitarian law – are wide and include such things as reprisals, use of human shields and wonton homicide. However, given that 'suspicious deaths' often increase during conflict, it is imperative that effective investigations are carried out.

Usefully, the Geneva Academy has produced clear guidance on this issue in its 2019 publication, ***Guidelines on Investigating Violations of International Humanitarian Law: Law, Policy and Good Practice***.[91] It begins:

> Legal sources for a duty to investigate can be found in both treaty and customary international law, *inter alia*, in the obligation of the High Contracting Parties to the Geneva Conventions of 1949 and their Additional Protocol of 1977, applicable to international conflict, to enact any legislation necessary to provide effective penal sanctions for persons suspected of having committed or ordering 'grave breaches' of their obligations.
>
> [Para 12].

The Geneva Academy Guidelines distinguish between administrative and criminal investigations. The latter would apply to grave breaches of international humanitarian law which include homicide. Here the Guidelines assert:

> 128. It is submitted that States should have a law enforcement agency outside the chain of command (within the military or civilian police), that conducts investigations into suspected war crimes committed by members of the armed forces in order for criminal investigations to be independe3nt and impartial and be seen as such.

It continues:

> 129. Structural guarantees contributing to the independence and impartiality of a military law enforcement agency will in include the way in which its members are appointed, their tenure and rank and the relevant reporting structure.

The Venice Commission published a report in 2020 amidst the COVID-19 pandemic on Respect for Democracy, Human Rights and The Rule of Law during States of Emergency.[92] Public Emergency situations sometimes involve derogations from human rights (but not the right to life). However it has been reaffirmed by the Venice Commission that these

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[91] ICRC & Geneva Academy, *Guidelines on Investigating Violations of International Humanitarian Law: Law, Policy and Good Practice (2019): available at - https://www.geneva-academy.ch/research/our-clusters/past-projects/detail/3-investigating-in-situations-of-armed-conflict-law-policy-and-good-practice#:~:text=A%20Geneva%20Academy%2DICRC%20Project&text=Proper%20investigation%20by%20militaries%20involved,in%20case%20of%20alleged%20violations*

[92] European Commission for Democracy through Law (Venice Commission), *Report on Respect for Democracy, Human Rights and the Rule of Law during States of Emergency*, Reflections (2020) 014 (Strasbourg, 19 June 2020): available at - https://www.venice.coe.int/webforms/documents/default.aspx?pdffile=CDL-AD(2020)014-e

emergency powers must be governed by the principles of necessity, proportionality and temporariness. In addition to this, an earlier report published by the Venice Commission in 2006 specifically emphasized the obligation on States to take positive steps to implement measures and procedures that minimize the loss of life during emergency situations.[93]

[93] European Commission for Democracy through Law (Venice Commission), Opinion no. 359/2005, *On the Protection of Human Rights in Emergency Situations*, adopted at the 66th Plenary Session (Venice, 17-18 March 2006) 27.

Part C:
Regional Standards on The Duty to Investigate Suspicious Deaths and its links to Disability.

What follows is a brief overview of the duty to investigate in three regional organisations: the Council of Europe, the Organisation of American States and the African Union.[94]

What is useful to bear in mind are the different contexts in which the duty to investigate might arise: systematic and widespread human rights violations, violations motivated by hatred (e.g., against LGBTQ or women), forced disappearances and extra-judicial killings, politically motivated crimes, war crimes (crimes against International Humanitarian Law), crimes against humanity (e.g., genocide) and 'ordinary situations' (e.g., the deaths of persons with disabilities either in institutions or in the community. Some of these contexts are more pronounced in some regions compared to others or may vary in intensity over time.
The duty to investigate applies to all contexts but may be more pronounced when it comes to systemic violations.

One thing that binds all three Regional Organisations together is the overarching need to reveal the truth. And the duty to investigate deaths has emerged as a function of the interaction between general Articles or provisions in an underlying treaty to make human rights effective with the right to life.

Council of Europe Standards

Council of Europe Treaty System on the duty to investigate

1. European Convention on Human Rights (Article 2 on the right to life).
Beginning in the 1990s the European Court of Human Rights has developed a general duty to investigate in circumstances where there are 'suspicious deaths' (potentially) contrary to Article 2, credible allegations of mistreatment (potentially) contrary to Article 3 and a well-founded fear of disappearences (potentially) contrary to Article 5 (liberty) of the European Convention.[95]

Much of the case law was fashioned against the backdrop of political instability in Northern Ireland, Turkey and Russia. However, it can be lifted and generalised from this context and applied to the 'suspicious deaths' of persons with disabilities regardless of political strife.

This jurisprudence is now highly developed and continally evolving. Doubtless, one of the motivating concerns was the arbitrary exercise of State power. However, the caselaw has now moved far beyond the State and its agents and is highly relevant to both older persons and persons with disabilities. The general 'duty to investigate' should therefore be read across

[94] On these three systems compared see generally Philip Leach, Rachel Murray & Clara Sundoval, '*The Duty to Investigate Right to Life Violations Across Three Regional Systems: Harmonisation or Fragmentatuoin of International Human Rights Law?',* chapter 1 in In C. Buckley, A. Donald, & P. Leach (Eds.), *T*owards Convergence in International Human Rights Law: Approaches of Regional and International Systems (2017, Brill Academic Publishers).
[95] See generally Alistair Mowbray, *Duties of Investigation under the European Convention on Human Rights*, 51 ICLQ, (2002) pp 437-448.

Articles 2, 3 and 5 of the European Convention. For the sake of brevity, I will focus on the Article 2 standards (right to life).

Article 2 of the European Convention (right to life) reads as follows:

1. Everyone's right to life shall be protected by law. No one shall be deprived of their life intentionally save in the execution of a sentence of a court following his conviction of a crime for which the penalty is provided by law.
2. Deprivation of life shall not be regared as inflicted in contravention of this Article when it results from the use of force which is no more than absolutely necessary:
   (a) in defence of any person from unlawful violence
   (b) in order to effect a lawful arrest or to prevent the escape of a person lawfully detained;
   (c) in action lawfully taken for the purpose of quelling a riot or insurrection.

Our focus is on the 'procedural' aspect of the Article 2.1. Protocol 13 (2002) to the ECHR prohibits the use of the death penalty, which has the effect of qualifiying paragraph 1 (second sentence) of Article 2.1. Interestingly, the European Court has extended the scope of the first sentence in Article 2 to go beyond 'intentional' or suspected 'intentional killings.' This specifically includes deaths due to negligence or neglect in healthcare settings (see below). This is potentially extremely relevant to future litigation involving persons with disabilities.

The evolution of European standards governing the duty to investigate 'suspicious deaths' can be traced back to the 1995 landmark case of *McCann and Others v United Kingdom.*[96]

This seminal case concerned the killing of suspected IRA terrorists by British army personnel in Gibraltar, otherwise known as the "*Death on the Rock*" case. The UK Government 'declared' in 1953, upon ratification of the ECHR, that its provisions would extend to Gibraltar since the UK was responsible for its international relations.

In the *McCann* case case it was accepted by the Strasbourg Court that the obligation of state parties to protect and respect the right to life under Article 2 of the European Convention should encompass both a substantive dimension (the lawfulness of a killing) as well as a procedural dimension (a duty to investigate 'suspicious deaths'). Indeed these two dimensions are separable. The 'duty to investigate' is not confined to cases where there is clear evidence of an unlawful taking of life. It arises even no such evidence exists.

In the 2013 case of *Hemsworth v United Kingdom*, Judge Mahoney opined in his concurring opinion that a procedural violation of Article 2 is separable from a substanitve concern and is capable of forming a separate and independent violation of Article 2.[97] In his concluding observations, he stated that:

> the extant of this obligation means that on the international level an application alleging a procedural violation must be examined on its merits by this Court even where the substantive violation, for its part, has been, or is susceptible of being, acknowledged and compensated for at national level.[98]

What this means, in effect, is that a procedural defect (e.g., a clear lack of independence in the investigative process) can give rise to a separate and seperable cause of action at the

[96] *McCann and Others v United Kingdom*, Application No. 18984/91 (ECtHR, 27 Sep 1995). For a detailed overview of the caselaw see: Guide to Article 2 of the European Convention on Human Rights, Right to Life, Registry of the Court (2023), Section IV 'Procedural Obligations'.
[97] *Hemsworth v United Kingdom,* Application No. 58559/09, (ECtHR, July 16 2013).
[98] Ibid.

international level. One might say that the procedural aspects are as important as the substantive.

For example, in the 2001 inter-State case of *Cyprus v Turkey* the European Court found that there was no evidence that the 1,485 missing persons who went missing after the Turkish invasion and occupation of northern Cyrpus in 1974 had actually been unlawfullly killed. Nevertheless, the duty to investigate arose even in the absence of this evidence. The European Court stated that the duty to conduct an effective investigation also arises:

> ...upon proof of an arguable claim that an individual who was last seen in the custody of the State, subsequently disappeared in a context that might be seen as life threatening.
>
> [para 132].

Effectively this means that when there is reason to believe that disappearances may be 'life threatening' the duty also arises. This might apply to ‘disapperances’ effected by the person themselves (i.e., by escaping from an institution or nursing home).

Interestingly, the duty to investigate has been gradually extended to include circumstances where the State or its agents are not even indirectly implicated in a death. In its 2001 decision in *Ergi v Turkey* the European Court held that the duty to investigate under Article 2 arose where it had not been established that the death was caused by an agent of the State. This means that a death that occurs in a private institution or nursing home is also subject to the duty to investigate. The relevance of this case law to persons with disabilities is direct. Most of their services - though funded by the State – is effectuated through private intermediaries (service providers).

Furthermore, it is not necessary for the family of the bereaved to lodge a formal complaint to trigger the duty:

> In the case under consideration, the mere knowledge of the killing on the part of the authorities gave rise *ipso facto* to an obligation under Article 2 of the Convetnion to carrry out an effectuve investigation into the circumstances surrounding the death.
>
> [para 82].

What then counts as an 'effective investigation' in the eyes of the European Court of Human Rights?[99] The nature of the required investigation will depend on the circumstances. After all, this is a Court fashioning its jurisprudence in response to the cases presented unlike, e.g., the more prescriptive detail contained in the *Minnesota Protocol.*

The landmark case dealing with the general criteria of effectiveness in investigations is the 2001 decision of the European Court in *Kelly & Others v United Kingdom.* Four sets of criteria were outlined in *Kelly* and applied and developed in subsequent cases.

First of all, the independence and imparitality of the invesigation is a particular concern of the European Court. In *Kelly* the European Court stated:

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[99] The recent UK Supreme Court decision under the 1998 Human Rights Act (legislation domesticating the European Convention on Human Rights into UK law) in *R (Maguire) v. His Majesty’s Senior Coroner for Blackpool & Fylde and Another,* [2023] UKSC 20, is worth studying. Three different types of procedural requirements were identified: basic, enhanced and redress.

> it may generally be regarded as necessary for the persons responsible for and carrying out the investigation to be independent from those implicated in the events...This means not only a lack of hierarchical of institutional connection but also a practical independence...

Again, practical independence might mean freedom from deference and assumptions about the deaths of persons with disabilities. The European Court found that insufficient independence arose in the 1998 case of *Gulec v Turkey.*[100] In that case the investigating authority had the same institutional status of the gendarmerie who were accused of involvement of the death of a protestor. In *Kelly* the European Court found that the fact that an investigatory police force had been involved in the events that led to the deaths of nine persons as a result of an ambush conducted by the British army (*Kelly & Others*) detracted from their independence. As one eminent commentator says of this decision:

> The ruling indicates that the Court demands a strict institutional independence of investigators from the State agents implicated in the killing and it is to be welcomed as such a strutural separation will contribute to the objective independence of the investigation and the public's acceptence of its legitimacy.[101]

The degree of independencee required will very much depend on the naure and circumstances surrounding an investigation (*Tunc v Turkey*). As the Registry Guide on Article 2 states;

> Where the statutory or institutional independence is open to question, such a situation, although not decisive, will call for a stricter scrutiny on the part of the Court of whether the investigation has been carried out in an independent manner.
>
> [p.35].

The Registry Guide cites many examples where the European Court has found insufficient independence including in situations where the investigators themselves "were potential suspects," where the investigators were "direct colleagues of the persons subject to investigation" or where the investigators were "in a hierarchical relationship with the potential suspects."[102] A recent example is *Jasinkis v Latvia* (2010). There, the same police department that allegedly neglected Mr Jasinkis and contributed to his dealth had carried out the investigation. This was a clear breach of the requirement for independence.

Secondly, the European Court has also emphasised that the investigation must be *effecive* in the sense that:

> it is capable of leading to a determination of whether the force used in such cases was or was not justified in the circumstances...This is not an obligation of results but of means. The autorities nust have taken reasonable steps available to them to secure the evidence concerning the incident, including, *inter alia*, eye witness testimony, forensic evidence and, where appropriate, an autopsy which comprises a complete and accurate record of injury and an objective analysis of clinical findings including the cause of death...Any deficiency in the investigation which undermiines its ability to establish the cause of death or the person responsible will risk falling foul of this standard.
>
> [para 96].

In effect, the investigation must be fit for purpose which is to gather and anlyse

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[100] *Gulec v Turkey,* 54/1997/838/1044, ECtHR, July 1998.
[101] Alistair Mowbray, *Duties of Investigation under the European Convention on Human Rights,* 51 ICLQ (2002).
[102] See Registry Guide to Article 2, p. 36.

all the evidence available as to the circumstances surrounding a 'suspicious death.' For example, in its 1998 decision in *Gulec v Turkey* the European Court found that the investigating officers' approach was 'not thorough' enough since he failed to interview some key witnesses. One imagines that many investigations might lack the required rigour when it comes to disabillity.

Sometimes, the European Court focuses on the integrity of the process of gathering and analysisng the forensic evidence. In its 1998 decision in *Kaya v Turkey*[103] the European Court found that the prosecutor had not ordered key forensic tests including an examination of the scene of death. The Court has insisted that the investigating body should use 'well recognised' methods of forensic science. In this regard, the European Court pays particular attention to instances where autopsies (and indeed exhumations) are required with the proper personnal and also to the integrity of the overall autopsy process.

In the 2013 case of *Hemsworth v United Kingdom*, Judge Mahoney opined in his concurring opinion, that a procedural violation of Article 2 is separable from a substanitve concern and is capable of forming a separate violation of Article 2.[104] In his concluding observations, he stated that:

> the extant of this obligation means that on the international level an application alleging a procedural violation must be examined on its merits by this Court even where the substantive violation, for its part, has been, or is susceptible of being, acknowledged and compensated for at national level.[105]

What this means, in effect, is that a procedural defect (e.g., a clear want of independence or effectiveness in the investigative process) can give rise to a separate and seperable cause of action at the international level. One might say that the procedural aspects are as important as the substantive.

Therefore, in addition to protecting the right to life and securing the effective implementation of domestic laws, the Court has emphasised that investigations must effectively hold those accountable where there are grounds to suspect that State agents or bodies may have been the perpetrators (see *Vachkovi v. Bulgaria*).[106] Although it is not the duty of a coroner to hold individuals criminally or civilly liable, it is vital that they are able to carry out their function to the highest attainable standard in order to be able to sustain any potential criminal investigation. Without proper empirical evidence, any subsequent investigations might be significantly held back or compromised.

Thirdly, the European Court has emphasised the need for *promptness* as an aspect of the duty to investigate. It stated:

> A requirement of promptness and reasonbable expedition is implicit in this context...It must be accepted that there may be obstacles or difficulties which prevent progress in an investigation in a particular situation. However, a prompt response by the authorities in investigating the use of lethal force may generaly be regared as essential in maintaining public confidence in ther adherence to the rule of law and in preventing any appearence of collusion in or tolerence of unlawful acts.

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[103] *Kaya v Turkey,* 148/1996/777/978, ECtHR, February 1998.
[104] *Hemsworth v United Kingdom* Application No. 58559/09 (ECtHR, July 16 2013).
[105] Ibid.
[106] *Vachkovi v Bulgaria,* Application No. 2747/02 (ECHR, 8 July 2010).

The European Court has emphasised that reasonable expedition is necessary in order to maintain public trust and confidence in an Article 2 investigation (see *McDonnell v United Kingdom*).[107] This is particulry important when the State or its agents may have been involved in the death. For one thing, it is unlikely that some forms of forensic evidence would survive a prolonged period. Witness accounts may become more unreliable as time progresses. A delay of two years to initiate an investigation failed this requirement (*Tas v Turkey,* 1998).[108] The European Court has held against the effectiveness of investigations in circumstances where "the forensic investigation was defective… [where] the authorities accepted the version of facts presented by the accused State without hearing any further witnesses, [where] the investigation into the contract killing of an investigative journalist focused only on a single line of inquiry without exploring other allegations." [p. 38].

Fourthly, public confidence is served by allowing for, and enabling, effective public scrutiny as well as family involvement in the investigative process. The European Court has emphasised:

> ....there must be a sufficient element of public scrutiny of the investigation or its results to secure accounability in practice as well as in theory. The degree of public scrutiny required may well very from case to case. In all cases, however, the next of kin of the victim must be involved in the procedure to the extent necessary to to safeguard his or her legitimate interests....

In *Gulac v Turkey*, for example, the European Court held against Turkey in part because the family were not allowed participate in the investigative process. The European Court has held that the the obligation to investigate promptly was not satisfied in cirumstances where inquest proceedings commenced 8 years after a death, an investigation into a death following a protest was pending 23 years later and where there were 'inexplicable delays' in proceeding with an investigation.

Hate crime attracts particular attention by the European Court. If it appears that a death has resulted from a hate crime directed against a member of a minority group then the obligation to conduct an independent, effective and timely investigation becomes all the more crucial. This could be extremely important in the context of disability. Here the "authorities should react with special diligence in carrying out the [investigation]."[109]

The case law of the European Court has focused on racially motivated violence leading to death. However, the same should hold true for other grounds of hate crime including hate crime directed against persons with disabilities. A good example of the former would be the horrible knife attack on residents of an institution in Sagamihara, Japan.[110] Apparently, the perpetrator said shortly after the incident "it is better [that] the disabled disappear." Indeed, the European Disability Forum has called for EU intiatives on hate speech and hate crime directed at persons with disabilites.[111] Even though no cases involving death as a result of hate crime directed at persons with disabilities have yet come before the European Court of Human Rights there is ample space in the caselaw for this to happen in the right case.

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[107] *McDonnell v United Kingdom* App no 19563/11 (ECHR, 9 Dec 2014).
[108] Tas v Turkey, Application No. 24396/94, ECtHR, November 2000.
[109] European Court of Human Rights, Registry Guide on Article 2, p. 42.
[110] See Justin McCurry, *Japan Knife Attack: stabbing at care centre leaves 19 dead*, The Guardian, 26 July, 2016.
[111] See EDF: https://www.edf-feph.org/content/uploads/2021/04/EDF-position-and-recommendation-on-hate-speech-and-hate-crime.pdf

As mentioned above, the European Court has extended its jurisprudence that requires an investigation to go beyond 'intentional' killing. Agents of the State and indeed purely private parties may contribute to or cause death unintentionally through, e.g., negligence in a legal sense or neglect more broadly. As the Registry's Guide to Article 2 states:

> …the Court has extended the scope of the procedural obigations under Article 2 to circumstances where individuals have sustained life-threatening injuries or where lives have been lost due to negligence.
>
> [p. 44].

What seems to be uppermost in the eyes of the European Court is the need to provide an adequate means of investigating such deaths that would offer a realistic prospect of a remedy (mainly in civil law). In the context of healthcare the Registry Guide in Article 2 states:

> …the Court has interpreted the procedural obligations of Article 2 as requiring States to set up an effective and independendent judicial system so that the cause of death of patients in the care of the medical profession, whether in the public or the private sector, can be determined and those responsible made accountable.
>
> [p. 45].

The need of an independent means to establish the truth about such non-intentional deaths has been held by the European Court to arise "in the context of dangerous industrial accidents, [and] in the context of a denial of healthcare", etc. [p. 46 of the Regiostry Guide]. In the context of healthcare:

> This requires not only a lack of hierarchical or institutional connection but also that all parties tasked with conducting an assessment in the proceedings for determining the cause of death of patients enjoy formal and *de facto* independence from thiose implicated in the events.
>
> [p. 46].

This *de facto* independence could be crucial in a disability context. There is a growing body of case law dealing with the procedural obligation of Article 2 in the context of deaths by negligence. Negligence is of course a relatively narrow legal concept. What of the broader notion of neglect which can sweep beyond negligence? And what if the neglect concerns inadequate funding or provision on the part of the commissioning authority (e.g., a public authority commissioning services)? Thus far, the caselaw of the European Court does not extend this far. However, there is nothing in principle that suggests that it cannot be so extended. This would of course be a major benefit to groups like persons with disabilities. If the intention behind Article 2 is the adequate *prevention* of deaths then this would make sense.

The jurisprudence of the European Court does not yet explicitly embrace the need for an investigating body to go beyond narrow determinations of the cause of death in individual instances to include policy prescriptions for the avoidance of such deaths in the future. It is submitted that such an obligation would be consistent with one of the underlying aims of Article 2.1 which has to do with the *prevention* of deaths. Certainly, such an obligation where it already exists (e.g., 'prevention of future death' reports under the UK Coronors & Justice Act, 2009) does not fall foul of Article 2. And, in the right case, it is entirely open to the European Court to embrace this policy-oriented function of an investigatory body as required by the deep logic of Article 2.

Unsurprisingly, there have been a number of cases before the European Court of Human Rights on the right to life and the duty to investigate the deaths of persons with disabilities. *Jasinkus v Latvia* (2010), mentioned above, involved a young man who was deaf and mute and who died in police custody. He had been drinking before his death. He went to to a nearby school after drinking with some friends. While there he was knocked to the ground and briefly lost consciousness for a few minutes. Security personnel at the school called for an ambulance and the police. The police, who were told of his injuries and that he was deaf and mute, did not wait for an ambulance and brought him straight to the local police station to initiate proceedings for hooliganism and public drunkenness and to sober him up. No medical examination was carried out upon admission to police custody. They thought he was behaving aggressively when in fact he may simply have been trying to communicate. The police had taken away his notebook which he usually used to communicate with others who did not understand sign language.

When the ambulance crew communicated with the police they were told there was no need for medical attention as he was just sobering up. In the morning, when he showed signs of unresponsiveness another ambulance crew initially refused to take him to hospital claiming he was 'faking it.' When he was later brought to hospital he was (mis)diagnosed with 'severe intoxication.' A post mortem examination revealed multiple injuries to the brain probably from the fall. This, the forensic specialist concluded, was the probable cause of death.

The European Court had little difficulty finding a violation of the right to life (Article 2) as well as a separate violation concerning the independence of the investigation carried out by the police. The Court stated:

> [P]ersons in custody are in a vulnerable situation and the authorities are under a duty to protect them. When the authorities decide to place and maintain in detention a person with disabilities they should demonstrate *special care in guaranteeing such conditions as correspond to his special needs resulting from his disability.*
>
> [para 59)

While the language above is not particularly apt ('*special needs resulting from his disability*'), it nevertheless conveys the point that due consideration should be given to the particular challenges in protecting the right to life of persons with disabilities in such circumstances. It is submitted the same logic should apply to all other forms of 'detention' including institutionalisation.

The case of *Nencheva and Others v Bulgaria* (2013) involved the deaths of 15 children and young adults in a home for children with severe intellectual disabilities.[112] The Court found that the authorities had not taken swift, practical and sufficient measures to prevent the deaths. This was despite having specific knowledge of the dangers (cold, lack of food, lack of medicine and lack of basic necessities). The European Court also found that the investigations into the deaths was inadequate and amounted to a separate violation of Article 2 due to a lack of promptness. This case vividly highlights the risks of institutionalisation mentioned in Section 2.2 above.

[112] *Nencheva and others v Bulgaria,* 48609/06, ECtHR, (2013).

The 2014 decision of the European Court in *Centre for Legal Resources (CLR), Campeanu, v Romania* involved the mis-placement of a man with HIV, other co-morbidities and an intellectual disability in a psychiatric hospital where he died.[113] He was abandoned at birth and institutionalised all his life. The core argument of the CLR was that :

> ...as a result of their inappropriate decisions concerning Mr Campeanu' transfer to institutuons lacking the requisite skills and facilitiies to deal with his condition, followed by inappropriate medical actions or ommissions, the authorities had contributed directly or indirectly, to his untimely death. [para 115].

When he died in custody a compulsory *post mortem* examination was required by law but not carried out. His death certificate mentioned HIV and his status as a person with an intellectual disability as contributory causes of his death. Many international bodies had already pointed to the severe deficiencies of the relavant institutions (including the Council of Europe Committee against Torture - CPT). The Court concluded:

> [T]he Court finds that..in the present case the domestic authorities' response to the generally difficult situation at the PMH [the institutiuon in question] at the relevant time was inadequate, seeing that the authorities were fully aware of the fact that the lack of heating and appropriate food and the shortage of medical staff and medical resources, including medication, had led to an increase in the number of deaths during the winter of 2003. (para 143)

In a sense, the Court took judicial notice of a pattern of deaths to inform its judgment (reputedly 129 deaths in a two year period). The Court concluded that the placement of Mr Campeanu in PMH:

> ...notwithstanding his already heightened state of vulnerability the domestic authoriies unreasonably put his life in danger.(para 143).

The Court reviewed the various investigations into Mr Camopeanu's death and the failure to carry out a mandatory autopsy. It also reviewed domestic legal proceedings (a District Court decision) which it cited as 'terse.' On the procedural ground of Article 2 it concluded that"

> the authorities have failed to subject Mr Campeanu's case [death] to the careful scrutiny required by Article 2 of the Convention and thus to carry out an effective investigation into the circumstances surroinding his death.
>
> [para 147].

More recently in October 2024 the European Court handed down its landmark decision in *Validity Foundation on behalf of T.J.v Hungary.*[114] T.J was born in 1973 with a severe intellectual disability and was unable to communicate verbally and sometimes prone to aggressive behaviour. In 1983 (when she was 10 years old) she was placed in the Topaz 'social care institution' in God (Hungary). In 1996 she was deprived of her legal capacity and placed in the guardianship of her mother. Because her mother was deemed incapable of exercising legal capacity, the guardianship was moved successively to various agents of the State. Her guardian towards the end of her life was also appointed guardian over dozens of residents and visited the institution once a week for one hour. Although T.J. could not communicate verbally she did socialise and managed to make herself understood. Over time she had acquired many injuries 'caused by falling or being pushed or by hitting herself' (para

[113] *Centre for Legal Resources on behalf of Compeanu v Romania*, 47848/08, ECtHR, July 2014.
[114] *Validity Foundation on behalf of T.J. v Hungary*, Application no. 31970/20, ECtHR, October 2024.

8). When Validity Foundation observed her during a monitoring visit in April 2017 she was tied to her bed and emaciated. She died some months later in 2018.

In May 2017 Validity published a report based on their visit to the institution. It reported violence as well as over-use of restraints. In May 2017 the Hungarian Ministry for Human Resources carried out an inspection of Topaz. The findings included overcrowding, windows and doors that could not be opened, bathrooms lacking privacy and an unsafe environment. The Ministry reported that understaffing, hindered the provision of a 'professional care programme.' The use of both chemical and physical restraints was reported. The report specifically mentioned the situation of Ms. T.J. (even before her death). It stated that she had become more aggressive since 2016 and that it was recommended that she be fed with baby formula. After a number of falls it was suggested that she should be restrained for her own safety. In May 2017, a doctor recommended that she should be restrained while lying in bed due to the 'low number of caregivers.'

Complementing the reports of Validiy and the Human Resources Ministry was another report on conditions in Topaz from the Hungarian Commissioner for Human Rights. The European Court summarised this report as follows:

> The professional work in the institution is sloppy. The residents' rights are infringed to an impermissible extent. The institution gives the impression of neglect and abandonment. There is a failure to ensure a clean and sanitary environment. Mental health activities are lacking, or are not capable of aiding rehabilitation or maintaining residents' limited physical and mental functions.

Medicine and food past their expiry date were found. Care records were incomplete.
On 17 August 2018, Ms T.J. was transferred to hospital where she was diagnosed with pneumonia and treated. When she was about to be released her condition deteriorated and she died on 25 August 2018. An autopsy was carried out on 30 August 2018 and the cause of death was described as 'bacterial pneumonia.'

After its 2017 report Validity launched proceedings to be allowed access to the residents to offer them legal service. They were initially refused by the instutution. Validity also initiated criminal proceedings alleging that "multiple counts of unlawful deprivation of liberty, endangering of minors, causing gross bodily harm, sexual violence and professional misconduct had been committed in Topház." Validity subsequently amended (expanded) its criminal suit to allege:

> ...that two further deaths – those of Ms T.J. and K.K. – had occurred in the institution because of the professional misconduct of the staff. Relying on the evidence submitted in its criminal complaint of 2 May 2017, Validity Foundation argued that there were grounds to believe that the inadequate conditions of care indirectly contributed to the death of Ms T.J. and K.K. Validity Foundation reiterated that based on the testimony of another resident, Ms T.J. had been tied up and was severely malnourished.
>
> [para 21].

The criminal complaint was dismissed in January 2019. According to police files, the residents had died because of their 'severe disabilities.' Apparently, seven residents had died in 2017 alone. Effectively, the police and the courts took an extremely narrow view of the 'cause of derath' - pinpointing it to a specific medical event. The applicants on the other hand wanted a broader review of the treatment regimen to assess whether the known deficiencies in services were a contributing factor (or even a major causative factor) in the death. This

naturally poses the question: what should the investigative body be looking for and how broad or deep a remit should it have when there is a reasonable suspicion that there are systemic factors at play?

Validity asked for the care plan of T.J. and supected, based on the testimony of another resident that she had been severely malnourished. The Police Department concluded that Ms T.J. died of 'severe disabilities.' The criminal complaint was dismissed. Validity appealed on the basis that the investigation had not probed the conditions under which Ms T.J. was treated. In other words, they challanged the scope of the investigations for being too narrow and failing to capture underlying systemic issues. The District Prosecutors' Office ordered the investigation to be re-opened. A new medical expert opinion was sought by the Police on the cause of death and the question whether the use of restraints had contributed to it. The new medical opinion stated that she died of pneumonia and could not have been saved.

Eventually, the Police Deparment discontinued the investigation. No causal link was found between the restraints used on her and her death. Validity then applied for a Collective Complaint (a civil law suit) against the social care home, the Ministries responsible for supervision and local government bodies claiming a violation of the resident's peronality rights and a failure to supervise the institution properly. An application for interim orders (precautionary measures) was dismissed on the basis that sufficient improvements had been made in the interim. The Budapest High Court ruled in February 2024 that the Ministries affected had failed to exercise their oversight responsibilities and stated :

> They had maintained a humiliating and degrading environment, restrained the liberty of the residents in an inhuman manner, exposed the residents to indecent sanitary conditions, had not provided human living conditions, had not provided education, rehabilitation, participation in sport, cultural and social life, had not provided appropriate care and development and had not ensured the resident' right to access to healthcare.
>
> [para 32].

The heart of Validity's claim under Article 2 (right to life) was that:

> [M]s T.J., who had been placed in a State-run social care institution, had died there from long-term neglect and inadequate care. Validity Foundation also complained that the investigation into Ms T.J.'s death had concentrated on potential medical negligence on the part of the personnel in carrying out their duties and had not addressed the question of whether the death had been caused by the inadequate conditions in the social care home.
>
> [para 35].

It was claimed that the authorities had failed to "address the *systematic deficiencies* in Ms T.J.'s care and to adopt appropriate measures to safeguard her life" (para 60). More specifically it argued " that the investigation into Ms. T.J.'s death had been insufficient, since it had not inquired into the circumstances of her care and the use of physical restraints which could have contributed to her death" (para 63). A forensic report was only initiated after Validity complained. The forensic report relied on narrow (medical) documentary evidence and had not consulted witnesses as previously stipulated by Validity.

The European Court of Human Rights ruling on Article 2 (right to life) in *Validity & T.J.* on both substantive and proecural limbs is revealing. Substantively, the European Court reiterated its longstanding jurisprudence to the effect that States are required to

> make regulations for hospitals, whether public or private, to adopt appropriate measures for the protection of their patient's lives. This applies especially where patients' capacity to look after themselves is limited.
>
> [para 72].

The latter reference to limited capacity is a bit odd given the Court's overall positive posture toward 'supported decision-making.' What the Court is probably trying to say is that the positive obligations inherent in Article 2 to protect life are heightened with respect to groups who find themselves in vulnerable situation like many persons with disabilities. This positive duty obliges States to "take preventive measures of [a] practical nature to protect the individual against opthers..." (para 72).

The European Court took judicial notice of the fact that Ms T.J. had lived most of her life institutionalised and that her loss of connectedness with the outside world had heightened her dependency. It emphasised that especial regard was to be had to the right to life of persons like Ms. T.J. who have a disability. Interestingly the Court took notice of the reality that her guardian was not consulted to give informed consent to medical treatment. In other words, in as much as guardianship is to be used only in a person's 'best interests,' this was simply not possible in this case since she was not consulted. The net effect was to leave such persons with no legal protection.

A fascinating part of the European Court's judgement reads:

> The Court observes that according to the autopsy report Ms T.J. died of pneumonia (see paragraph 26 above) for which she had been treated in hospital (see paragraph 15 above). While this clarified the direct cause of Ms T.J.'s death, the Court refers to its findings in paragraph 104 below that the domestic investigation *failed to address the systematic failure in the care system* which had been reported by a number of actors, including State bodies and its potential effect on the individual circumstances of Ms T.J. However, it was for the authorities to account for Ms T.J.'s treatment and to demonstrate that her life had been adequately protected in the care home.
>
> [Italics added. para 82].

In other words, if there are reasonable grounds to believe that there are systemic causes of a death they ought to be investigated and covered by existing investigative bodies or mechanisms. The circumstances affecting Ms T.J went beyond mere negligence and affected many more residents. In effect, it was systemic. The many reports into the social care institution, the Court ruled, "makes it implausible that the decline of Ms T.J.'s health and her death were sudden, isolated or unpredictable events which the authorities could not have prevented" (para 89). Unsurpiringly, the European Court found that there had been a violation of the substance of Article 2 on the right to life (failing to prevent a predictable death in full knowledge of the deficiencies of care at the social care institution).

As to the second or 'procedural' limb to Article 2 (the need for an effective investigation) the European Court found that:

> 102. [T]he police investigation was focused essentially on establishing the *direct cause* of Ms T.J.'s death and whether the restraint measures used on her had contributed causally to her death. The domestic authorities d*id not establish the facts concerning the level and quality of care in Topház,* and did not examine the adequacy of Ms T.J.'s living conditions or whether there were shortcomings in her medical and therapeutic care.

> 103. Consequently, they did not carry out any assessment of whether those alleged shortcomings had a bearing on Ms T.J.'s death and whether any crime had been committed in that regard.

Essentially, Hungary was found in violation of the procedural limb of Article 2 because the relevant investigations did not go deep enough to probe the causal link between the deficiencies in care and her death.

This is indeed a remarkable decision. It indicates that the European Court is inclined to the view that when persons in especially vulnerable situations die in suspicious circumstances that the relevant investigation ought to take full account of the systemic factors that led to the death.

The impressive jusisprudence of the European Court on the duty to investigate is still evolving. It chimes very well with the main features of the *Minnesota Protocal* particularly with its insistence on independence, its focus on the integrity of the process to secure the evidence and reach actionable conclusions, in the link between the investigatory process and the criminal law and on the necessity for public and especially family involvement.

The recent and remarkable ruling in *T.J.* shows that the Court is fully alive to the need to probe the underlying systemic causes of death. The case in point - *T.J.* - involved a death in a State institution. But, it is submitted, the rationale of the decision could be broadened to encompass deaths in the community when it is equally forseeable that a death can occur due to other systemic reasons like a lack of adequate supports or defects in regulatory law or policy. One factor the Court took into account in *T.J.* was a pattern of deaths in the institution (indicating deeper problems). It is submitted that similar patterns affecting persons with disabilities living in the community should also trigger heightened scrutiny. How advocates build on T.J. in future cases will be interesting to watch.

Council of Europe Soft Law Instruments on the duty to investigate.

1. Committee of Ministers Recommendation 1999(3) on the harmonisation of Medico-Legal Autopsy Rules.

The Committee of Ministers of the Council of Europe often acts to amplify rulings of the European Court of Human Rights and propound coherent policy guidance for law reform on a European level. This is the primary purpose of Committee of Ministers' Recommendations. Given that they represent the Committee's understandings of the logical entailment of major ECtHR decisions (like *McCann*) and that they are intended to guide harmony in approaches in law reform across the continent, they are highly relevant to domestic law reform debates and are a key point of departure in the same.

Recommendation (1999)3 of the Committee of Ministers [115] is entitled *"Harmonization of Medico – Legal Autopsy Rules."* As the title suggest, it is mainly concerned with the actual process of autopsies. Interestingly, one of the triggers for an autopsy according to the Recommendation is 2. (c) "[a] violation of human rights such as suspicion of torture or any other form of ill treatment." Of course, institutuonalisation and inadequate services would count as a human rights violation, especially when the UN CRPD is taken into account.

[115] Council of Europe, Recommendation Rec(99)3 of the Committee of Ministers to Member States on the Harmonisation of Medico-Legal Autopsy Rules (Council of Europe Publishing, 1999).

Interestingly, coming as it did at the tail end of the Cold War, Recommendation (1999)3 highlights the political character of some deaths:

> [A]ware of the importance of proper autopsy procedures, in particular with a view to bringing to light illegal executions, and murder perpetrated by authoritarian regimes.

A recital to Recommendation (1999)3 emphasises:

> the need to protect the independence and impartiality of medico-legal experts as ell as to make available the necessary legal and technical facilities to carry out their duties in an appropriate way…"

As well as highlighting the necessity for independence and impartiality of the medico–legal investigation, the Recommendation invites Member States to establish quality control systems to ensure that the performance of the investigations adhere to the proper international standards, by way of legal and technical facilities and appropriate training to ensure the appropriate function of the experts.[116]

Of particular relevance is Recommendation 3 which states:

> Medical-legal experts must exercise their functions with *total independence* and impartiality. They should not be subject to any form of pressure and they should be objective in the exercise of their functions, in particular in the presentation of their results and conclusions".[117]
>
> [Italics added].

In addition to this, the Committee of Ministers of the Council of Europe stressed the underlying importance for international co-operation to guarantee the progressive harmonization of rules and procedures on autopsies at a European level.

The Recommendation pointed to the increasing mobility of the European population which brings fresh challenges to the internationalization of judicial proceedings. It cites to the difficulties of implementing the Council of Europe Agreement on the Transfer of Corpses (ETS 80). Although a pertinent consideration in the year 1999, it is now more pressing than ever with increasing mass migration.

A Recommendation that sets out the policy and legislative parameters for the proper investigation of the suspicious deaths of persons with disabilities and their underlying systemic causes would be a positive step. And it would build on the VALIDITY ruling.

5. The Evolution of the Duty to Investigate in the Organisation of American States.

A: The OAS Treaty System on the Duty to Investigate

1. Inter American Convention on Human Rights.

"When the right to life is not respcted, all other rights are meaningless'
Inter-American Court of Human Rights, J*uan Humberto Sanches v Honduras* (1993).

[116] IbiCL d at 2.
[117] Ibid at 3.

The American Declaration on Human Rights was adopted in 1948 (Bogota) and protects the right to life in Article 1. This is a non-binding political instrument. Article 1 reads:

> [E]very human being has the right to life, liberty and the security of his person.

The Inter-American Commission can entertain complaints under the Declaration with respect for OAS States that have not ratified the Convention. Decisions by the Commission under the Declaration can be an important source of jurisprudence.[118]

Disability is specifically mentioned in Article 16 of the 1948 Declaration to the effect that any person with a disability whose disability makes it 'physically or mentally impossible for him to earn a living' has a right to social security. This language reflects an outdated medical or welfare model of disability.[119]

In contrast, the American Convention on Human Rights (Pact of San Jose, 1969) is a legally binding treaty for those States that have ratified it.[120] Some OAS States have not ratified the Inter-American Convention and therefore the original 1948 Bogota Declaration remains relevant for them. That is to say, the processes of the Commission remain relevant for them including the United States which has not ratified the Convention. Our focus in this Study is on the caselaw under the Inter-American Convention.

The Inter-American Convention contains an important unbrella clause at the beginning (Article 1) pledging States Parties to '*ensure'* that all persons in their jurisdiction can exercise the rights and freedoms contained therein and without discrimination. This is crucial, as it underscores that rights are not to be illusory and positive action may be required to fully implelent them.

Likewise, Article 1 assures to rights holders the equal and non-discriminatory enjoyment of those rights. As will be seen, innovations in the jurisprduence means that the lens has been broadened to take account of indirect discrimination. This broader approach could prove important in sensitising investigatory bodies to the accumulated disadvantages affect persons with disabilities.

The right to life is protected under Article 4 of the Inter-American Convention.[121] The relevant part reads:

> 4.1. Every person has the right to have his life respected. This right shall be protected by law and from the moment of conception. No one shall be arbitrarily deprived of his life.

The remainder (the bulk) of Article 4 deals with the death penalty. Article 27(2) stipulates that the right to life is one of those rights that cannot be suspended during armed conflict. Therefore it - and the intrinsic duty to investigate - are effectively non-derogable.

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[118] Francisco Bariffi, 'La Declaración Americana de Derechos y Deberes del Hombre y la Comisión Interamericana de Derechos Humanos' *Revista Electrónica Iberoamericana*, Vol. 13, Edición Especial, 2019.

[119] Christian Courtis, 'Los derechos de las personas con discapacidad en el Sistema Interamericano de Derechos Humanos' *Tratado sobre Discapacidad*, R. de Lorenzo & L. Cayo (Coord.), Thomson Reuters Aranzadi, 2007.

[120] American Convention on Human Rights, adopted in San José, Costa Rica, on 22 November 1969. OAS Treaty Series nº 36.

[121] Carlos Ayala Corao y María Daniela Rivero, 'Artículo 4 Derecho a la Vida', *Convención Americana sobre Derechos Humanos Comentada*, Christian Steiner & Patricia Uribepp (Coord.) Fundación Konrad Adenauer, Programa Estado de Derecho para Latinoamérica, 2014, pp. 112-130.

The organs of the Inter American system are the Inter American Commission on Human Rights (IACHR - based in Washington DC)[122] and the Inter American Court of Human Rights (IACtHR - based at San Jose, Costa Rica).[123] They have each produced landmark decisions on the right to life of relevance to this Study. The Commnission traces its existence back to the Charter of the OAS. The Court is a creature of treaty law.

The main roles of the Commission are to raise awareness, to conduct thematic studies, to conduct on-site visits, to hear individual petitions under its jurisdiction (provided the State in question has lodged a declaration allowing such petitions against it) and to make recommendations to the political organs of the OAS. A petition may be brought by individuals, groups of individuals or organisations.

If a petition is deemed admissible the Commission endeavours to facilitate a friendly settlement between the parties. If a State does not respond or only responds in part to a recommendation of the Commisison it (the Commission) may transmit the petition to the Court (provided the State in question has ratified the American Convention).[124] An individual petition therefore starts in the Commision and may be transmitted by the Commission to the Court.

The main roles of the Court are to adjudicate contentious disputes and to issue legally binding judgments, to issue advisory opinions and, in cases of 'extreme gravity and urgency' to issue orders for provisional measures to be taken by States to avoid irreparable harm. Only States Parties or the Inter-American Commission have standing to transmit a case to the Court. Article 29.b of the Convention, on its face, merely suggests that the American Convention shall not be used to dilute obligations emenating from other treaties to which the States are parties. However, it seems to have been used as an invitation by the Court to take into account external treaties and their interpretation by the relevant treaty monitoring bodies (like the CRPD Committee) when interpreting the American Convention. This provides a natural bridge between the American Convention and the UN CRPD (and ther European Conventio no n Human Rights as well as the African Charter).

Addtionally, Article 4 (right to life) is complemented by:
1. Article 3 (right to juridical capacity)
2. Article 5 (right to humane treatment)

This is highly relevant since violations of Article 5 (which includes a prohibition against torture, inhumane or degrading treatment) may lead to threats to the right to life. In fact much of the relevant case law on the duty to investigate includes both Article 5 and Article 4.

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[122] https://www.oas.org/en/iachr/Default.asp

[123] https://www.corteidh.or.cr/index.cfm?lang=en

[124] On the evolution of the broad disability jurisprudence of the Inter American Commision and Court see, Diana Guarnizo-Peralta, *Disability Rights in the Inter-American system of Human Rights: an Expansive and Evolving Protection,* 36(1) Netherlands Quarterly of Human Rights (2018) and Ying Chen & Paul McDonagh, *Upholding Disability Rights in the Americas: Role of the Inter-American Institutions,* 50(3) Georgia Journal of International and Comparative Law (2022). See also, Perez & Rincon, *The Inter-American Systm fothe Protection of Human Rights and Persons with Disabilities: Challenges and Perspectives Beyond the Non-Discrimination Rule*, Juridicas (18)2 (2021).

A puzzling part of the American Convention (Article 26) deals with the nature of obligations that attach to economic, social and cultural rights ('achieve progressively'). This is puzzling because the Convention does not contain such rights. It may be a way of qualifying the economic and social rights contained in the original Charter. Or it may be a way of suggesting that in as much as the civil and political rights contained in the Conention require positive action then the relevant obligations are subject to 'progressive achievement'. That is to say, the positive duties that emanate from the penumbra of the core civil and political rights are subject to the duty of 'progressive achievement.'

The American Convention is complemented by an Additional Protocol on Economic, Social and Cultural Rights (Protocol of San Salvador).[125] This provides for a right to social security (Article 9) and also contains a right on the 'protection of the handicapped' (Article 18). Notably, Article 18 seems grounded on a welfare philosohy that would not fully align with the CRPD's emphasis on human agency and autonomy.

Nevertheless, the Inter-American system has all of the essential elements to align with the CRPD with equal emphasis on civil and political rights - like the right to life and protection against torture, inhuman or degrading treatment - and the full spread of socio-economic rights (either as a logical emanation of the core civil and political rights or as provided for in a sepatate Protocol).

How then has the right to life been interpreted in the Inter-American system?[126] Giovanna Frisso explains that the background to the caselaw is a tradition of impunity for killings arising from political upheaval and the halting transition from states of emergency to democracy in the Americas. The Court, in her view, developed the duty to investigate in order to avoid repeat violations and inpunity. Hence, the duty to investigate was tied to the fight against impunity and the need for criminal sanctions to be effective. Only effective investigations and the disclosure of truth could break the cycle of violations that fueled ongoing political violence.

Article 4 of the Convention primarily addresses state responsibility.[127] The State - or emanations of the State - must not directly pose a threat to life. Just as important, the State has a responsibility to protect life. In this regard, the obligation of prevention is fundamental regardless of whether the threat is posed by public or private actors. Of course, the obligation is heightened when the individual is in some form of State custody (such as a prison or mental institution).

Precautionary measures were awareded in *Irene v Argentina* (2016)[128] to reverse some cutbacks in inclusive education that impacted a girls right to life and personal integrity. However, the ruling on precautionary measures did not establish how deficiencies in inclusive education affected the girls' right to life. Peralta points to some dissonance between the rulings of the Commission on precautuionary measures and the UN CRPD

[125] Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social, and Cultural Rights: "Protocol of San Salvador": Signed at San Salvador, El Salvador, on November 17, 1988, at the Eighteenth Regular Session of the General Assembly. OAS. Official records; OEA/Ser.A/44) (Treaty Series no.69).
[126] See generally Giobvanna Maria Frisso, '*The Duty to investigate violations of the right to life in armed conflicts in the Jurisprudence of the Inter-American Court of Human Rights*,' 51(2) Isreal Law Review (2018).
[127] Cuadernillo de Jurisprudencia de la Corte Interamericana de Derechos Humanos No. 21: *Derecho a la vida,* Corte Interamericana de Derechos Humanos. San José, C.R.; Corte IDH, 2021.
[128] Resolution No. 38/16, PM 376-15 - Irene, Argentina. Inter-American Commission on Human Rights, available at: https://www.oas.org/es/cidh/decisiones/pdf/2016/mc376-15-es.pdf

Committee on issues of legal capacity as applied to the death penalty. However, the Commission has done a good job at linking deficiencies in social and economic entitlements to deaths. The Commission published a thematic report in 2014 on *The Right to Truth in the Americas.*

In the case of *Valasques Rodrigeuz v Honduras* (1988)[129] the Inter American Court stated that States had an obligation arising the convention to 'prevent, investigate and punish' any violation of the rights in the Convention including the right to life. There the Court said:

> 176. The State is obligated to investigate every situation involving a violation of the rights protected by the Convention. If the State apparatus acts in such a way that the violation goes unpunished and the victim's full enjoyment of such rights is not restored as soon as possible, the State has failed to comply with its duty to ensure the free and full exercise of those rights to the persons within its jurisdiction. The same is true when the State allows private persons or groups to act freely and with impunity to the detriment of the rights recognized by the Convention.

The Court went on to emphasise that an investigation must be undertaken in a serious manner and 'not as a mere formality preordained to be ineffective.' Furthermore, ' [W]here the acts of private parties that violate the Convention are not seriously investigated, those parties are aided in a sense by the government, thereby making the State responsible on the international plane.' (para 177).

In the case of *Juan Humberto Sánchez v Honduras (2003)*,[130] the IACtHR established that States must implement effective procedures to thoroughly investigate any circumstances where the right to life might be at risk. This was a case of forced disapperance and extra judicial killing. Honduran citizens were often suspected of supporting the Sandinistas guerrillas in El Salvador. Mr Sanchez was detained twice by the Honduran army on suspicion of an alleged association with a terrorist organisation. He was found dead, badly mutilated, bound and tied in a river some days after his second detention.

There was no autopsy conducted to establish the cause of death. The Inter-American Commission had previously entertained a petition on the case and recommended that the authorities should "conduct a serious, impartial and exhaustive investigation of the facts...with the aim of establishing the criminal responsibility of all the perpetrators." Note, the linking of investigative measures with criminal liability.

The Commission also recommended that Honduras 'adopt such measures as might be necessary to prevent' future similar occrances.' A sting hint that 'protection means 'prevention.' There was interesting testimony from a psychiatrist on the effects of the death on the mental health of the survivors.

The case in the Court turned on several Articles in the Inter-American Convention including Article 1.1 (general obligation to respect rights) alongside Article 4 (right to life). The Court emphasised that Article 4 generated both negative obligations on the part of a State (not to violate the right) and positive obligations to 'prevent' foreseeable deaths.

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[129] I/A Court H.R., Case of Velásquez Rodríguez v. Honduras. Merits. Judgment of July 29, 1988. Series C No. 4.
[130] I/A Court H.R., Case of Juan Humberto Sánchez v. Honduras. Preliminary Objection, Merits, Reparations and Costs. Judgment of June 7, 2003. Series C No. 99.

With respect to Article 4 the Court concluded that there was sufficient evidence to ground a finding that this was a case of extra judicial killing on the part of the forces of the State and tolerated by the State. The Inter-American Court referred approvingly to the judgment of the European Court of Human Rights in *Hugh Jordan v United Kingdom* (2001) to the effect that "

> The obligation to protect the right to life under Article 2 [of the European Convention], read in conjunction with the State's general duty [...] to "secure to everyone within their jurisdiction the rights and freedoms defined in [the] Convention", requires by implication that there should be [an] effective official investigation when individuals have been killed as a result of the use of force. [para 105]

What is interesting - and useful - in the *Sanchez* judgment is the distinction between negative and positive obligations under the right to life and the duty to prevent foreseeable threats. The case also provided for a duty to investigate using the rationale provided by the European Court of Human Rights.

The Inter-American Court has described the obligation to investigate as an 'obligation of means'. This places a spotlight on process and on the integrity and effectiveness of the process. In a way this imports the general requirements of the *Minessota Protocol* (independnce, effectivess, timeliness and inclusion) without saying so.

An unusual feature of the duty to investigate in IACtHR jurisprudence is that it is also grounded in Articles 5 (right to humane treatment) and 25 (right to judicial protection) of the American Convention which, when combined, guarantee a right to acess to justice. Again, this reflects the reality that the duty to investigate was crafted with conflicts and painful transitions to democracy primarily in mind. This is quite similar to the *Minnesota Protocol* with its emphasis on the link between investigations and the criminal law However, the duty itself can be separated out from criminal liability (important though that is) and treated as an end in itself.

If a State is found not to have carried out an appropriate investigation then the Inter-American Court can order such an investigation as a form of 'reparation.' The passage of time may make this inappropriate. However, in some cases the Court has ordered an investigation even 20 years after the original death.[131]

The duty to investigate does not depend on action taken by the family or others. It arises whenever facts arise that point to a 'potentially unlawful death' as broadly understood in the *Minnesota Protocol.* This duty applies irrespective of whether the State (and its agents) is suspected of direct involvement.

The case of *Ximenez Lopes v Brazil* is particularly instructive as it involved deficiencies in investigating the death of a person with a disability in a mental institution (2006).[132] Brazil, at the time, was undergoing a transition away from mental hospitals to community based centres for support. However, the transition was not fast enough to benefit Mr Lopes.

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[131] I/A Court H.R., Case of the Massacres of El Mozote and surrounding areas v. El Salvador. Merits, Reparations and Costs. Judgment of October 25, 2012. Series C No. 252; and I/A Court H.R., Case of Cruz Sánchez et al. v. Peru. Preliminary Objections, Merits, Reparations and Costs. Judgment of April 17, 2015. Series C No. 292.

[132] I/A Court H.R., Case of Ximenes Lopes v. Brazil. Merits, Reparations and Costs. Judgment of July 4, 2006. Series C No. 149.

The victim was admitted twice to a private mental institution by his mother (in 1995 and October 1999). The institution was poorly maintained, lacked a resident doctor and was infrequently inspected. On the first ocassion, he returned home with brusies. His mother was told they were self-inflicted while trying to escape. The second admission in 1999 proved fatal. While there he suffered violence at the hands of the staff (and seemingly other mental health patients). Only four days after his second admission, he was found dead.

The Inter-American Court acknowledged the general "situation of the vulnerability" of persons with mental illness and the special obligation of the State to provide protection to individuals held in [mental] health facilities (para 3)." A finding of vulnerability as such seems to fiunction to elevate and solidify the obligations of States Parties. Particularly powerful expert testimony was given tio the Court by Eric Rosenthal (Disability Rights International).

An autopsy was performed but it seemed highly inadequate. The brain (which evidently suffered trauma) was examined at the autopsy but the results were evidently not reported on. One expert witness (a psychiatrist) stated that 'a diagnosis of violent death caused by a skull and brain traumatism could be established based on the patient's clinical evolution.' (p.18). She concluded that Mr Lopes "had a violent death caused by extrinsic agents as evidenced by the victim's traumatic body lesions" (p. 18).

One issue in the *Lopes* case was the liability of the State for the actions of a private entity (the private mental health hospital). This was disposed of easily under the longstanding jurisprudence of the Inter-American Court to the effect that the State has the responsibility to properly regulate such places to prevent predictable harms to individuals. In any event, the hospital in this instance was deemed not to be not a purely private body. As the Court explained "the acts performed by any entity, either public or private, which is empowered to act in a State capacity, may be deemed to be acts for which the State is directly liable, as it happens when services are rendered on behalf of the State." Such was the case with the hospital in question. The Court found that persons with disabilities who reside in psychiatric institutions "are particularly vulnerable to torture and other kinds of cruel, inhuman or degrading treatment" (para 106).

Interestingly, the Inter-American Court referred to the Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities (CEDDIS)[133] as a 'source of interpretation' to assess the depth and breadth of State duties under the American Convention. The Inter-American disability conventiion pre-dates the UN CRPD. But it does come from a non-discrimination and social model of disability. CEDDIS does not, as such, directly protect the right to life. However, it frames disability within a human rights perpective, which assists the Court in applying the norms of the American Convention to persons with disabilities in acordance with both CEDDIS and the UN CRPD.

A recurring issue was the use of both physical and chemical restraints and indeed reliance on other patients to restrain Mr Lopes. His mother visited him on 4 `October 1999 and:

[133] The Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities was adopted in 1999 within the Organization of American States. It calls on states to facilitate the full integration of persons with disabilities into society through legislation, social initiatives and educational programmes. It entered into force on 14 September 2001.

> found him bleeding, with bruises, his clothes torn, dirty and smelling like excrement, with his hands tied backwards, having difficultybreathing, agonizing and shouting and calling out to the police for help. Mr.Ximenes-Lopes was still under physical restraint, which had been applied the night before.
>
> [para 112.9].

She asked for him to be bathed and receive medical attention. Apparently a physican prescribed medication without examining him and then left the hospital. He died later that morning after being medicated and without any medical attention. As the Court said ' as a result of this lack of care, the patient was at the mercy of all kinds of life-threatening accidents and aggression' (at para 112.11).

After his death, a doctor examined the body, declared him dead and reported that the body did not show any external injuries stating that the cause of death was 'cardiorespiratory arrest.' The next of kin requested an autopsy but the physician conducting it reported 'no signs of internal traumatic injuries' and the cause of death was 'unknown.' During civil proceedings an exhumation was ordered but the doctor who performed it similary concluded that the cause of death was 'unknown.' This was hardly credible.

During the hearing before the Court the Inter-American Commission argued that the State had failed to adequately protect Mr. Lopes' right to life, failed to conduct an effective investigation and punish those found liable (if any). It also argued that the mere admission of patients to such a facility amounted to inhuman and degrading treatment contrary to Article 5 of the American Convention. Additionally, it argued that the 'physical containment' techniques used in the hospital (i.e., restraints) were not in accordance with prevailing international standards (which have moved on a lot since 2006).

The Court found that the death took place against the backdrop of violence and indeed that most employees of the hospital were not in fact trained. It found that the overall conditions of the hospital were 'an offence to the dignity of the patients.' (para 120). For example, there were no showers, washbasins were broken, toilets were dirty, medical attention was given only fleetingly and at the public entrance to the building, the emergency room lacked basic facilities, medical records were patchy and poorly maintained. It found that when his sister visited on the 4th of October '

> [he]...was bleeding and had bruises all over his body, his clothes were torn, he was dirty and reeking of feces and urine, his hands were tied at the back, and he was breathing with difficulty, in the throes of death, screaming and asking for help to the police.
>
> [para 121].

The Court found it proven that 'the death occurred in violent circumstances' (para 121). The Court's analysis of the obigations of States under Article 4 (right to life) are revealing. It held that States 'have the duty to ensure the creation of the conditions required to prevent the violations of this inalienable right'. (para 125). This goes to one of the core theses of this Study - namely the civil right to life depends in no small measure in how or whether States provide for socio-economic rights and entitlements. Further, the Court stated that the State should adopt;

> ...such measures as may be necessary to create a legal framework which allows deterring any threat to the right to life; to establish an effective system of justice which can investigate, punish, and redressany act of deprivation of life by the State agents or private individuals...
>
> [para 125].

The Court found that the use of restraints 'poses a high risk of doing harm to the patient or causing his or her death' (para 133). This is useful since the Court directly links mistreatment with death. With respect to the duty to investigate the Court held:

> the State has the duty to commence *ex officio* and without delay, a serious, fair, and effective investigation which is not undertaken as a mere formality condemned in advance to be fruitless.124 Such investigation should be carried out with all available means and should be designed to establish the truth and to investigate, prosecute, and punish all the persons who are liable for the facts, particularly when State officials are or may be involved.
>
> [para 148].

On the concept of truth, the Court opined:

> The knowledge of the truth in human rights violations such as those in the instant case is an inalienable right and an important means of reparation for the victim and, if applicable, for their next of kin, and it constitutes a fundamental way of learning the truth that allows a society to develop its own methods of reproach and deterrence.
>
> [para 245].

The victim's relatives, as such, have a right to the truth. Here, usefully, the Court links truth with the need for preventive steps. For it is the truth that allows for learning - and change. On the facts the Inter-American Court found that the various investigations were wanting.

On the issue of precautionary measures, the Commision has come very close to linking premature deaths to deficits in the delivery of economic and social rights. As Peralta highlights, in the cases of the *Patients at the Neuropsychaitric hospital v Paraguay* (2003) *and Federica Mora Hospital v Guatamala* (2012), the Commission considered that severe deficiencies at the hospitals endangered not only the wellbeing of the patients but their lives too.[134] Peralta also recounts two additional cases of precautionary measures awarded in 2014, where poor health conditions for persons with disabilities in prisons "endangered their possibility to stay alive."[135]

The 2016 case of *Chincilla Sandoval v Guatamala* decided by the Inter-American Court is illustrates the issues that may arise.[136] Mrs Sandoval was convicted of murder and aggravated larceny in 1995 and imprisoned for 30 years.[137] She had uncontrolled diabetes with many associated ailments. She had one limb amputated and lost the sight of one eye.

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[134] Peralta at p. 52.

[135] Pralta at p.53.

[136] I/A Court H.R., Case of Chinchilla Sandoval et al. v. Guatemala. Preliminary Objection, Merits, Reparations and Costs. Judgment of February 29, 2016. Series C No. 312.

[137] See, Handbook published by the Inter-American Court in 2017 on The Rights of Persons Deprived of their Liberty: https://www.corteidh.or.cr/tablas/r34109-2017.pdf Section 4.4.3 deals with the investigation of deaths in custody. See also Inter-American Commission, Principles and Best Practices on the Protection of Persons Deprived of Liberty on the Americas (2022): https://www.oas.org/en/iachr/jsForm/?File=/en/iachr/mandate/basics/principlesdeprived.asp

Given the prison's inaccessibility, she could move around only with great difficulty in her wheelchair. She also had suspected cancer.

Her daughter had to bring in medicines and install a small refrigerator in her cell for the insulin (which she also supplied) as the prison did not have the capacity to do so. Her ailments progressively deteriorated. She had to go through a complicated process of getting permission to attend many out-patient appointments (icluding de-bridment surgery) in a local hospital but the prison infirmiry was not equipped or staffed to deal with her underlying condition and its associated ailments. While trying to negotiate some steps she fell and died (25 May 2004). Prior to her death she moved some unsuccessful motions in court for an early release based on having a 'terminal illness.' While it was plain that her condition was not necessarily terminal in the accepted sense, the various motions gave the courts ample opportunity to assess the inappropriateness of imprisonment in her case.

An autopsy was carried out and her cause of death was put down to pulmonary edema and hahmoragic pancreaticitis. The Proscutor's Office ascertained there was no need to continue (with an investigation or prosecution) since the facts did not indicate a crime had been committed.

The Inter-American Commission found that her right to life under Article 4(1) had been violated, that her right to personal integrity had been violated (Article 5(1)) and that her right to judicial protection had been violated (Articles 1, 8, 25, and 2).

In a long and very detailed judgment the Inter-American Court eseentially agreed with the conclusions of the Commission and put its own gloss on the obligations of the State in such circumstances. It benefitted from several detailed *amicus curia* briefs including one from the Harvard Project on Disability. Echoing the African Court on Human and People's Rights, the Inter-American Court emphasised that "[S]tates have the obligation to *create the conditions required* [for the the full enjoyment and exercise of the rights in the Convenion]..." (para 166). This includes the right to life. It reasoned that the general obligation to respect rights in Article 1 meant that special obligations can be derived according to "the particular needs for protection [of the individual]...either owing to his personal situation or to the specific situation in which he finds himself." (para 168). In this case the person in question had a disability and was placed in a closed environment over which the State had direct control.

In the context of imprisonment generally the Court reiterated it longstanding jurisprudence that the State had an obligation under Article 5 (humane treatment) "to safeguard the health and wellbeing of those deprived of liberty and to ensure that the manner and method of deprivation of liberty does not exceed the inevitable level of suffering inherent in detention." (para 160). The Inter-American Court emphasised that "[H]ealth should be understood as a fundamental guarantee for the rights to life and personal integrity..."[para 177]. It asserted that persons with serious or chronic health conditions should not remain in imprisonment unless States can ensure thay have adequate medical facilities either on site or easily accessible. For a variety of reasons the Inter-American Court concluded that the State had not provided adequate health care, medicines or supervision in the prison and that access to outpatient health care was not flexible enough contrary to both the right to life (Article 4) and the right to humane treatment (Article 5).

A related question before the Court was whether there was an adequate investigation into the death. Interestingly the Court observed:

> [W]ith regard to the investigation conducted after Mrs. Chincilla's death, the Commission noted that there was no inquiry into the possible responsibility of State officials, including prison staff, doctors or the courts, for their alleged failure to fulfill the duty to guarantee Mrs. Chioncilla's right to life...for the omissions related to her prison conditions, the lack of adequate medical treatment and the factors that could have contributed to her death.
>
> [para 228].

In other words, in the eyes of the Inter-American Court, the investigation was configured too narrowly just to look at the proximate medical cause of death instead of the major contributing factors. The Commission asserted that:

> ...the failure to conduct an official investigation ...meant a failure to disclose the truth, with the result that...there is still no judicial determination as to whether or not Mrs. Conchilla's death was caused by her illness or by the lack of adequate medical attention.
>
> [para 228].

The Inter-American Court interrogated the various court proceedings leading up to the death of Mrs. Conchilla. It did not just examine compliance with domestic law and procedure but also compliance with the Inter-American Convention holding that the domestic courts must exercise '*conventionality control'* (meaning the domestic courts must take due account of the Inter-American convention in their proceedings). The Court ruled that the various legal proceedings prior to death had not met the onus on courts under the Convention to balance the need to enforce imprisonment with the medical needs of this particular inmate. As to the actual investigation of the death itself, and in a curiously terse section of its judgement (paras 256-260), the Court concluded the State was not responsible for any flaws in the investigation. This is curious since the argument of the Inter-American Commisison was not that the investigation was improper or flawed in its execution but that its focus was too narrow. It is submitted that this was a missed opportunity for the Court to clarify how wide or narrow such investigations should be. The Inter-American Commission's view is the better view.

A 2016 case did not directly involve death or the investigation of death but is nevertheless relevant because it involved a disappearence from a mental institution and therefore at least a suspicion of death (*Gauchala Chimbo et al v Ecuador)*. In this instance there was a lingering suspicion that death ocurred in the institution and was covered up by staff. It was mentioned in a previous section that disapperances are taken seriously in part because they can lead at least potentially to death. In this case a young man in his early 20s was admitted by his mother to a mental hospital in Quito. He had severe epilepsy and was not fully medicated in the community due to a lack of financial resources. He either escaped from the institution on January 17, 2004 or died. On January 19 a discharge sheet was issued for him stating that he had abandoned the hospital. Various legal investigations were initiated to no avail. Some years had now passed since his disappearence. The case in the Inter-American system basically involved compulsory detention on the ground of mental disability (civil commitment), the right to treatment, his disappearance and the adequacy of the investigations thereto.

Before the Court the Inter-American Commission argued that hospitalisation and compulsory treatment are symptoms of a discriminatory system and that the hospital in question was influenced by outdated stereotypes abhout disability. It also criticised the lack of supported

decision-making in such circumstances. In other words, in the eyes of the Commission, structural discrimination against persons with disabilities played a large part in his treatment and disappearance. Interestingly, although the case could probably have been decided on much narrower gounds, the Court entertained the Commissions' argument about structural discrimination fully. The Inter-American Court held:

> 91. The Court considers that, in the case of Luis Eduardo Guachalá Chimbo, if the diverse grounds for discrimination alleged in this case are verified, different factors of vulnerability or sources of discrimination associated with his condition as a person with disabilities and his financial situation – owing to the situation of extreme poverty in which he lived – *had coalesced intersectionally*. Thus, the Court stresses that the lack of financial resources may hinder or preclude access to the medical care required to prevent possible disabilities or to prevent or reduce the appearance of new disabilities. Based on the foregoing, the *Court has indicated that the positive measures that States must take for persons with disabilities living in poverty include those necessary to prevent all forms of avoidable disabilities and to accord persons with disabilities preferential treatment appropriate to their condition.*
>
> [Italics added].

In effect, in the eyes of the Inter-American Court, an expansive concept of indirect discrimination sweeps in the 'conditions' for life. This certainly bears further development.

One particularly interesting and potentially highly useful concept developed by the Court has to do conpensation for the loss or interference with with ordinary or expected 'life plans.' It adds to the existing heads of damages, It is described thus by the Court:

> The concept of a "life plan" is akin to the concept of personal fulfillment, which in turn is based on the options that an individual may have for leading his life and achieving the goal that he sets for himself. Strictly speaking, those options are the manifestation and guarantee of freedom. An individual can hardly be described as truly free if he does not have options to pursue in life and to carry that life to its natural conclusion. Those options, in themselves, have an important existential value. Hence, their elimination or curtailment objectively abridges freedom and constitutes the loss of a valuable asset, a loss that this Court cannot disregard.[138]

This is potentially very relevant in the context of disability not just because of the constriction of one's life chances due to poor services and especially institutionalisation but also because of the resulting reduction of life years. In the instant case (which did not pivot on disability) the Court reckoned that the negative impacts on the facts:

> alter[ed] the course in which life was on, introduce new and hostile circumstances, and upset the kinds of plans and projects that a person makes based on the everyday circumstances in which one's life unfolds and on one's own aptitudes to carry out those plans with a likelihood of success.
>
> [para 149].

It is not hard to imagine this arising in a relevant disability case concerning early mortality due to poor services and institutionalisation. It should be plain that persons with disabilities have hopes, dreams and lifeplans of their own just like everybody else.

[138] *Loayza-Tamayo v. Peru* (27 November, 1998) judgment on reparations & costs. para 148.

2. *The Inter American Convention on the eliminationn of all forms of discrimination against persons with Disabilities (CIADDIS).*

This convention was adopted before the UN CRPD in 1999. It entered into force in 2001. It was the first international treaty wholly dedicated to the rights of persons with disabililites. It is grounded on the non-discrimination idea. It does not, as such, outline or specifiy or tailer the substance of individual rights (like the right to life) but it applies the non-dicrimination norm to all of them. This was actually a drafting option at the UN CRPD nergotiations. But the drafters of the CRPD opted to go one further by specifying and then tailoriing all rights and obligations (like the right to life).

Further, the CIADDIS applies a definition of disability that falls short of the social or human rights model in the UN CRPD (Article 2.1). Over time, the Commision and Court have moved more toward the model provided by the CRPD.[139]

More useful is the definition of discrimination in CIADDIS which is close to the UN CRPD and which incorporates classic US approaches to disability discrimination (Article 2.1.a) . Hence it includes those with a previous record of a disability (e.g., a heart attack in the past) or those whom it is assumed have a disability but do not (the so-called attitudinally disabled). Both groups are likely to be discriimated 'as if' they have a disabipoity even though they don't. Article 1.2.b creates space for positive action measures compatible withthe non-discrimnation idea which is also useful to the Commission and Court.

There is no complaints or petitions mechanism under CIADDIS which is unfortunate. States Parties (and they are limited) have to submit periodic reports on progeress made and obstacles encountered in implementing the treaty every 4 years under Article 6.3 to a Committee for the Elimination of All Forms of Discrimination against Persons with Disabilities. This Committee is composed of one representative *per* each ratifying party. They seem to be drawn mainly from national administrations. The reports of the Committee (their conclusions on State reports) seem to be published only in Spanish. The last meeting of the Committee seems to have been in 2017. The Committee has adopted interesting reports of a working group on legal capacity which in which it aligns itself with the UN CRPD Committee. But, so far, it does not appear to have done any work on the right to life and the duty to investigate or its connection with background socio-ecomomic rights. Indeed, it does not appear to produce General Comments on the core obliagations of the convention (unlike the UN CRPD). It may well have the inherent jurisdiction to do so.

The OAS announced that disability was one of its priority issues in its 2019-2021 Strategic Plan. To that end, it created a Unit on disability matters in the secretariat of the OAS. Apparently, that became a thematic Rapporteurship on disability in 2019. It does not appear as if the Rapporteur has adopted any thematic reports of his own. It is suggested that his office might produce a thematic report on the right to life and especially the many connexions made by the Commission and Court linking the right to life with deficiencies in economic and social rights and applying the impressive OAS standards on the proper investigation of 'suspicious deaths' to disability. Cognate rapporteurs in the OAS system on Memory, Truth and Justice as well as on Economic, Social, Cultural and Environment rights could be good allies and resource in putting such a thematic report together.

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[139] Francisco Bariffi, '*Human Rights and Disability Reinterpreting Disability within the OAS in Light of the CRPD*', Disability Law and Policy: An Analysis of the UN Convention, Charles O'Mahony & Gerard Quinn (Ed.), Clarus Press, Dublin, 2017.

What can be gleaned from the following is that the Commission and the Court are very well aware of global standfards on the right s of persons with disabilities. They strive to interpret the American Convention in a way that aligns with and benefits from these standards. Its early inisstence with the duty to investigate was tied to the prevailing prob;lems in the Americas - especially inpunity and the need to break the cycle of political violence. However, the duty can be applied outside the domain of political violence to apply to 'ordinary' deaths for example in mental health institutions or otherwise. What is particularly helpful in the caselaw is the line drawn by the organs of the Inter-American system between the right to life and the conditions obtaining, e.g., in mental health institutions.

The OAS seems to lack any equivalent to the *Minnesota Protocol.* Yet all the essentials are there. And the overall approach helps to reinforce the notion that investigative mechanism should be alive to probing systemic and cumulative disadvantage - or 'situations of vulnerability' as the Court calls them.

B: Soft Law Instruments in the OAS on the Duty to Investigate.

Some soft law instruments of the OAS have some utility in the dfisability field even though not fashioned with disability in mind. An example is the 2008 OAS *Principles and Best Practices on the Protection of Persons Deprived for their Liberty in the Americas.* Of course, full complaince with the CRPD would deny any restriction of the right to liberty based solely on disability.

The 2008 OAS Principles aim to protect the right to life as well as to regulate conditions of confinement. Interestingly Article III.3 of the Principles deals specifically with 'special measures for persons with mental disabilities.' It essentisally calls for de-institutionalisation. Even before the UN CRPD Committe, it asserts "[T]he mere existence of a disability shall in no case justify deprivation of liberty."

6: The Evolution of the Duty to Investigate in the African Union.

The African Union (AU) traces its history back to the Organisation of African Unity (OAU) which was founded in 1963. Recently, in *Agenda 2063, The Africa we Want,*[140] the AU has set forth its aspirations for the future of the continent. Prominent among them is Aspiration 3 - an Africa of good governance, democracy, human rights, justice and the rule of law.[141]

Several older African human rights treaties dealing with children, women and the internally displaced mention disability but mostly from within a medical model.[142] There are approximatly 89 million persons with disabilities on the Arican continent.

1. The African Charter on Human and Peoples Rights and the right to life.

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[140] African Union, *The Africa we Want, Agenda 2063*: available at - https://au.int/sites/default/files/documents/33126-doc-06_the_vision.pdf

[141] The African Disabiity Rights Yearbook is a good source for information on the jurisprudence of the African Commision and the Court on disability matters. A search of the database revealed no articles or notes on the duty to investigate as applied to disability.

[142] For an elaboration of the medical model in the traditional African human rights instruments (on children, women and internal displacement) see Dianah Msipa & Paul Juma, *The African Disability Protocol: 'Toward a Social and Human Rights Approch to Disability in the African Human Rights System,'* (especially '*Section on A Deficient Approach to Disability in the African System Prior to the African Disability Protocol*). 5-9 in Springer Handbook on Disability (2021).

The African Charter of Human and People's Rights was adopted in 1981 by the Organisation of African Unity (OAU). Interestingly, and useful for the purposes of this Study, the preamble to the Charter states:

> Convinced that it is henceforth essential to pay a particular attention to the right to development and that civil and political rights cannot be dissociated from economic, social and cultural rights in their conception as well as universality *and that the satisfaction of economic, social and cultural rights is a guarantee for the enjoyment of civil and political right...*
>
> [Italics added].

This, if anything, undercores the linkage between the right to life and the satisfaction of socio-economic rights like those contained in the UN CRPD.

The Charter contains a prohibition on discrimination with respect to the enjoyment of the rights contained therein (Article 2). The prohibition did not include disability as one of the proscribed grounds. This was not unusual in when the Charter was being drafted. It is, of course, interpreted to include disablility.

Article 4 of the African Charter protects the right to life:

> Human beings are inviolable. Every human being shall be entited to respect for his life and the integrity of his person. No one may be arbitrarily deprived of this right.

Unlike the ECHR or the Inter-American Convention, there are no detailed provisions on the death penalty contained in Article 4. Article 4 is complemented by Article 5 that, *inter alia,* prohibits torture as well as all forms of cruel, inhuman or degrading treatment.

Article 18 of the Charter on the family deals specifically with the rights of persons with disabilities:

> 18.4. The aged and the disabled shall also have the right to special measures of protection in keeping with their physical or moral needs.

This was in keeping with the philosophy of the time and was reflected, e.g., in Article 15 of the original European Social Charter (Council of Europe) of 1961. The African Charter is unusual in also stipulating the duties of individuals. Interestingly, one of the duties of an individual is to support his/her family (Article 29.1).

Part III of the Charter sets up the African Commission on Human and People's Rights (ACHPR) to promote the human rights and ensure their protection. The mandate of the Commission is set out in Article 45 of the Charter. It became operative in 1987 and is based in Banjul (the Gambia), The Commission can create subsidiary mechanisms such as working groups, special rapporteurs and committees. A working group on older persons and persons with disabilities was created in 2007 (see below). Article 66 of the Charter allows for additional or optional protocols to be adopted. One such protocol is the Protocol on the Rights of Persons With Disabilities in Africa which came into effect in 2023 (see below).

With respect to 'promotion' three core tasks are ascribed to the Commission. First of all it shall conduct studies and assemble research and, if the need arises, formulate its views or recommendations to Governments (Article 45.1.a). Secondly, it can formulate general

guidelines ('principles and rules') aimed at 'solving legal problems related to human and peoples rights' to form a basis for legislation among the States Parties (Article 45.1.b). Third, it can cooperate with other regional bodies or international organisations with respect to the same. The Commission shall 'ensure the protection of the rights 'under conditions laid down by the present Charter' (Article 45.2). The Commission can also interpret the Charter at the request of a State Party or organ of the OAU (Artilce 45. 3). And the Commission can perform any other task entrusted to it by the organs of the OAU. The Commission is empowered to resort to any 'appropriate method of investigation' to achieve the above and 'hear from any other person capable of enlightening it.' (Article 46).

There is an Inter-State complaints mechanism envisioned by the Charter (Articles 47-54). 'Other communications' (i.e., individual or group complaints) can also be laid before the Commission under certain conditions such the exhaustion of domestic remedies (Article 56). The Commission can strive to achieve an amicable settlement between the Parties. In default of that it can lay its report with recommendations (if any) before the organs of the OAU. All matters remain confidential unless and until the Heads of State and Government decide otherwise.

The African Court on Human and People's Rights was provided for in a 1998 Protocol to the Charter. The Court was formally launched in 2004 (in the middle of negotiations on the UN CRPD) after sufficient ratifications to the Protocol were received. The Court complements the Commission and especially in its protective mandate (Article 2 of the Protocol). The jurisdiction of the Court extends to "all cases and disputes submitted to it concerning the interpretation and application of the Charter, this Protocol and any other relevant Human Rifhts instrument ratified by the States concerned" (Article 3 Jurisdiction). This would certainly include the Protocol on the Rights of Persons with Disabilities (see below) and possibly even the UN CRPD (if ratified by the State/s concerned).

The Court can issue Advisory Opinions at the request of the AU, its organs or a Member State on "amy legal matter related to the Charter or any other relevant human rights insruments" provided that the same matter is not pending before the Commission (Article 4.1. of the Protocol). Access to the Court - i.e. to present a contentious case - is confined to the Commission, a State Party which has initiated a case before the Commsion, a respondant State Party before the Commission, a State Party whose citizen is a victim, and an African Intergovernmental Organisation (Article 5.1 of the Protocol). In effect, all disability cases have come from the Commission.

The Court 'may' entitle relevant NGOs with consultative status before the Commission and individuals to institute cases in compliance with Article 34.6 of the Protocol. Article 34.6 basically entertains such NGO or individual cases provided at the time or ratification (or at any time thereafter) States Parties have made a declaration to the effect that they accept such a jurisdiction. It seems that twelve AU States have made the relevant declaration.[143]

As to sources of law, the Court can take into account - besides the Charter - "any other relevant human rights instruments ratifed by the States concerned." (Article 7 of the Protocol). This would certainly include the UN CRPD provided the respondent State has ratified it. The Court might try to reach an amicable settlement.

[143] See: https://www.african-court.org/wpafc/declarations/

If the Court finds there has been a violation of the Charter it may make "appropriate orders to remedy the violation, including the payment of fair compensation or reparation" (Article 27.1 of the Protocol). Furthermore, in cases of 'extreme gravity and urgency' the Court can/shall adopt such provisional measures as it deems necessary (Article 27.2 of the Protocol). This would certainly apply to persons with disbailities whose lives are at risk. Like in the Council of Europe system, the political arm of the AU - the Council of Ministers - "shall monitor the execution of judgments" on behalf of the Assembly of the OAU (Article 29.2 of the Protocol). Interestingly, the Court istelf has the right to propose amendments to the Protocol (Article 35.2). An updated set of the Rules of the Court were adopted in 2020.[144]

A specific provision in the Charter allows the Commission to take account of prevailing international treaty law (Article 60). Undoubtedly, this includes the UN CRPD. Each State Party has to submit a report at two yearly intervals on the legislative measures taken to implement the Charter. The Charter says nothing about an assessment of these reports by the Commission.

A series of cases shows the range and depth of the duty to investigate in the African system - some of which involve disability issues.

While there have been many cases on the duty to investigate deaths, disapperances and violence, there has only been one full case on disability so far: *Purohit and Moore v The Gambia* (2003). [145] It involved the treatment of persons with mental disabilities in the Gambia and engaged, *inter alia*, Article 2 (non-discrimination), Article 16 of the African Charter on the right to the highest attainable standard of health and Article 18(4) on the right of the disabled to 'special measures of protection.' At issue was the compulsory detention of persons with mental health disabilities (through civil commitment law) as well as the underlying legislation that allowed such civil commitment (Lunatics Detention Act 1917 as amended in 1964). The complaint alleged that the grounds on which a person could be detained seemed vague and overbroad and there was a critical want of *due process* in the process.

The African Commission implicity ruled that the non-discrimination provision (Article 2) included disability under 'any other status.' The Commission then adopted a fulsome human rights-based approach to disability (in contrast to the text of previous AU treaty instruments). It ruled:

> The African Commission maintains that mentally disabled persons would like to share the same hopes, dreams and goals and have the same rights to pursue those hopes, dreams and goals just like any other human being 10. Like any other human being, mentally disabled persons or persons suffering from mental illnesses have a right to enjoy a decent life, as normal and full as possible, a right which lies at the heart of the right to human dignity. This right should be zealously guarded and forcefully protected by all States party to the African Charter in accordance with the well established principle that all human beings are born free and equal in dignity and rights.
>
> [para 61].

The lack of therapies was deemed a separate violation of Article 18. The decision in this complaint signifies that the Commission is in a good place to assess disability rights under

[144] See: https://www.african-court.org/wpafc/wp-content/uploads/2021/04/Rules-Final-Revised-adopted-Rules-eng-April-2021.pdf

[145] *Purohit & Moore v the Gambia*, Inter African Commission Application 241/01, 2003.

the Charter provided the right cases are laid before it. This is remarkable given that the decision of the Commission came 3 years before the adoption of the CRPD. It is hoped that more disability-specific cases will be brought.

More specifically on the right to life, in *Forum of Conscience v Sierra Leone* (1998) the African Commission described the right to life as the 'fulcrum to all other rights" or, as the Commission described it later, as the "foundational or bedrock human right."

In the case of *Commission Nationale des Droits de l'homme et des Libertes v Chad,*[146] the Commission stated that:

> The Charter specifies in Article 1that the states parties shall not only recognise the rights, duties and freedoms adopted by the Charter, but they should undertake...to adopt meadures to gove effect to them. In other words, if a state neglects to ensure the rights in the African Charter this can consitute a violation, even if the state or its agents are not the imediate cause of the violation"
>
> [Communication 74/92, para 20].

This would certainly apply to the deaths of persons with disabilities whose death is not caused directly by the State or its agents.

Application 279/03 -279/05 *Sudan Human Rights Organisation & Centre on Housing Rights and Evictions (COHRE) v Sudan,* was an application before the African Commnission.[147] At issue was the political violence - incuding deaths - arising in the Darfur region of Sudan in the early 2000s. There was an allegation that the Government sponsored a militia (Janjaweed) that terrorised the black inhabitants of Darfur causing many deaths and enforced disappearances. The Government did not appear to deny this but sought to suggest that a peace agreement should provide sufficient relief. The Commision's decision on the merits asserted that the right to life (and other substantive rights) entailed the necessity to conduct effective investigations when the State has been implicated in a death, to deter (prevent) violations by third parties, and to:

> establish law enforcenent machinery for the prevention, suppression and investigation and penalise breaches of the criminal law.
>
> [Para 147].

The African Commission continued that State responsibility was engaged by the acts of third parties causing death:

> ...not becauise of the act itself but because of the lack of due diligence on the part of the State to prevent the violation or for not takig the necessary steps to provide the victims with reparation.
>
> [para 148].

The complainant alleged that no effective investigations were carried out into the relevant killings. In this regard the Commission recalled its previous holding on the merits in *Amnesty International, et al v Sudan* (2003) to the effect that:

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[146] *Commisaion des Droits de l'homme et des Liberte v Chad,* 74/92, (1995).

[147] *Sudan Human Rights Organisation & Centre on Housing Rights and Evictions (COHRE) v Sudan* 279/03-296/05, (2009).

> investigations into extra judicial killings must be carried out by entirely independent individuals, provided with the necessary resources and their findings muct be made public and prosecutions initiated in accordance with the information uncovered.
>
> [para 150].

Given that the relevant investigations had led nowhere and general justice initiatives (on uncovering the truth) had similarly failed to reach the truth the Commission had no trouble concluding that this lack of investigations led to a violation of Article 4 of the African Charter.

At issue in *Amnesty International v Sudan*,[148] (1999) were mass arrests effectuated after the 1989 coup in Sudan. The arrestees were allegedly kept in 'ghost houses.' Allegations were made of various types of torture (including mock executions) and ill-treatment whilst detained. Some extra judicial killings were also alleged on the basis of evidence supported by the UN Special Rapporteur on Sudan. It was alleged that such killings took place after summary and arbitrary trials and that some innocent civilians were also killed. Other killings were reported which were not at the hands of the military. The African Commission asserted that even if the killings were not carried out by the military or other arms of the State that the Government nevertheless "has a responsibility to protect all people residing under its jurisdiction" (at para 50).

With respect to the adequacy of investigations into the deaths so far the Commission stated:

> Investigations must be carried out by entirely independent individuals, provided with the necessary resources, and their findings should be made public and prosecutions initiated in accordance with the information uncovered. Constituting a commission of the District Prosecutor and police and security officials, as was the case in the 1987 Commission of Enquiry set up by the Governor of South Darfur, overlooks the possibility that police and security forces may be implicated in the very massacres they are charged to investigate. This commission of enquiry, in the Commission's view, by its very composition, does not provide the required guarantees of impartiality and independence.
>
> [para 51].

Importantly, the Commission held that if the respondant Government - any respondant Government - does not contradict the evidence put before it then the Commission will "take it as proven, or at the least probable or plausible." The Commission concluded that there was a breach of Article 4 (right to life) among other provisions.

In *Noah Kazingachre et al (represented by the Zimbabwe Human Rights NGO Forum) v Zimbabwe*[149](2012) the issue involved four separate deaths of young persons at the hands of the police. One issue that arose was the lack of a remedy in the form of compensiation for 'wrongful death' in Zimbabean law. An inquest was held into at least one of the deaths and the presiding magistrate ruled that the death was caused bu gunshot wound but that "nobody ios to be prosecuted as the accident was justified" (para 75).

In its decision on the merits the Commission referenced Article 60 of the African Charter which allows it to take into account opther internationa instruments where relevant to the interpretation of the Charter. The reference to 'other instruments' of the United Nations in

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[148] *Amnesty International and others v Sudan*, Communication 148/90, 50/91-52, 91-98/93 (1999).

[149] *Kazingachre et al (represented by the Zimbabwe Human Rights NGO Forum) v Zimbabwe,* Communication 295/04, (2012).

Article 60 could easily apply to the *Minessota Protocol*. In this case the Commission specifically drew inspriatuion from the *UN Principles on the Effective Prevention and Investigation of Extra-Legal, Arbitrary and Summary Execution*s (1989). This, combined with other soft law instruments, made it plain that the use of force by the police or the army that caused death could only be done upon an objectively reasonable apprehension that the right to life of others was at stake and that the use of force was proportionate. Neither of these conditions applied in the four deaths on the facts in the instant case.

According to the *Basic Principles and Guidelines on the Right to a Remedy and Reparation for Victims of Gross Violations of International Human Rights Law and Serious Violations of International Humanitarian Law* (2005) remedies should include "the victim's right to adequate, effective and prompt reparation for the harm suffered" (para 130). That was said to also include 'moral damage' for the loss going beyond compensation.[150]

The African Commission refered to the caselaw of the Inter-America Court in the *Velasquez Rodriguez* case. One of the deaths was apparently at the hands of the army acting outside its 'normal' duties. Following *Rodriguez,* the Commission held that international legal liability can nevertheless fall to the State in such circumstances "not because of the act itself [the killing] but because of the lack of due diligence to prevent the violation or respond to it" (para 133). The Commission recommended law reform (to allow for full compensatory and other damages) to bring domestic law into conformity with Article 1 of the Charter and to pay full compensatory damages to the heirs and survivors of the deceased.

The African Commission adopted General Comment No 3 (2015) on the right to life. It is a remarkable document and reinforces the core thesis of this Study.

First of all, life is to be understood and interpreted in a broad sense to include a consideration of the *conditions* (especially socio-economic rights) that go to underpin a dignified life (para 3). In General Comment 3 the Commission ties both civil and political rights with economic, social and culural rights to underping the right to life.

Secondly, the right to life is said to explicitly embrace *'preventive measures'* that can forestall theats to life (para 3). And States have an added obligation to do so with respect to 'groups who are frequently targeted or particulaly at risk.' The General Comment references the grounds of discirimation contained in Article 2 of the Charter (gender etc). Even though, Article 2 does not specifically mention disability it is assumed to be incuded under 'other status.' Therefore, the heightened duty toward those whpo are particularly at risk would also embrace persons with disabilities.

Third, the State has an obligation to 'conduct prompt, impartial, thorough investigations into [any violations']...(para 7). And it is the duty of the State (upon proof of a violation) to provide for an effective remedy and reparation for the victim or victims or, where appropriate, their immediate family and dependents' (para 7). The General Comment envisages commission of inquiry (on top of ordinary investigative mechanisms). Importantly accountability is said to encompass 'measures such as reparation, *ensuring non-repetition ,* disciplinary actions, making the truth known, institutional review and, where applicable,

[150] See Pierre Jourdain, '*Les Reparations non-Pecuniare dans la practique de la Court Africain des droits des l'homme et des peuples',* 7 African Yearbook of Human Rights (2023), 116. See also African Court of Human and Peoples' Rights, Comparative Study on the Law and Practice of Reparations, (2019).

reform. (para 17).' The emphasis on '*non-repetition'* is important since it assumes that a State has a process to learn from the turth and from institutions designed to reveal the truth.

Fourth, and importantly for our purposes, a State:

> ...can be held responsible for killings by non-State actors it it approves, supports or acquisces in those acts or if it fails to exercise due diligence to prevent such killings or to ensure proper investigation and accountability.
>
> [para 9].

The notion of '*due diligence*' in preventing such killings means learning from the investigations and acting to avoid future similar deaths.

A heightened obligation to protect and prevent the right to life applies to persons held in any form of State custody. The General Comment specifically states that such persons should be given the necessary conditions for a dignified life including 'food, water, adequare ventilation, an environment from from disease, and the provision of adequate healthcare (para 36). This would certainly apply to mental health or other institutions for persons with disabilities where they exist (notwithstanding that they should not exist).

With respect to deaths at the hands of private parties the State is said to have responsibility 'for those deaths where the authorities knew or oought to have known of an immediate threat and failed to take meadures to avoid those deaths (para 38).' Further, the General Comment asserts that the State is reponsible for killings at the hands of private individuals 'which are *not adequately prevented* (para 39).' This would certainly include the deaths of persons with disabiities at the hands of third parties such as institutions or bad service providers.

Furthermore, the right protects those who are threatened. The resonsibilities of the State are said to be heightened when 'an *observable pattern* has been ignored or overlooked such as is often the case with....harmful practices (Italics added, para 39).' This would most assuredly be the case with respect to a pattern of suspicious deaths experienced by persons with disabilities.

The General Comment strongly asserts a clear linkage between the right to life and other rights:

> Given the role of the State in the enjoyment of a number of other rights which might, collectively, *be constitutive of the condition of life,* especially a dignified life, its *progressive realisation of various economic, social and cultural rights* will contribute to securing a full and dignified life. Violations of such rights may in certain circumstances, therefore, also entail violations of the right to life.
>
> [Italics added, para 43].

This goes to the fundamental thesis of this study, which is the interlinkage between the right to life and the other socio-econimc rights in the CRPD. A breach of these rights isn't just regrettable - it jeopardises the right to life.

2. Protocol to the African Charter on the Rights of Persons with Disabilities in Africa.[151]

[151] See Dianah Msipa & Paul Juma, *The African Disability Protocol: Toward a Social and Human Rights to Disability in the Agfrican Human Rioghtd System*, in Marcia Rioux et al, Handbook of Disability (2023, Springer).

Complementing the African Charter is a Protocol focusing on the rights of persons woth disabilities. It was adopted in 2018 and came into force in May 2024. It comprises the legal pillar of the African Union Disability Architecture.

The AU Disability Protocol is a corrective to the medical and welfare model of disability found in the older AU human rights treaties and it adds greater regional specificity to the rights. For example, it adds a provision dealing with harmful practices. Unlike the OAS disability convention, it is not purely a non-discrimination measure but instead covers the full substantive spectrum of both civil and political rights as well as economic and social rights.

Article 8 of the African Protocol deals with the right to life. It reads:

> 8. Every person with a disability has the inherent right to life and integrity. States Parties shall take effective and appropriate measures to ensure:
>
> a) Protection, respect for life and the dignity of persons with disabilities, on an equal basis with others;
> b) That persons with disabilities have access to services, facilities and devices to enable them to live with dignity and fully realise their right to life.

Interestingly, the text directly links the right to life with services and facilities. The Protocol came into effect in May 2024 (after the deposit of 15 ratifications). Article 8 explicitly enables the Commission and the Court to probe more fully the underlying determinants of the right to life.

States Parties to the Protocol pledge to cooperate internationally and regionally, including by sharing research as well as good practices. This could significantly drive change. States Parties also pledge to assist the African Commission in setting up an *ad hoc* Advisory Council on Disability to facilitate implementaion and follow-up of African policies on disability (33.d). States Parties are required to include in their periodic reports under the Charter to ionclude information on laws, polcied and programmes to implement the Protocol. The African Commission is tasked to interpret the Protocol and, in appropriate cases, referring matters to the Court concerning the Protocol (Article 34.3 & 34.4).

Article 8 (right to life) is complemented by:

- Article 10: Freedom from torture, inhuman, or degrading treatment or punishment.
- Article 11: A groundbreaking provision on harmful practices.
- Article 30: Focuses on older persons with disabilities, including their right to supported decision-making.

B: Soft Law Instruments on the Duty to Investigate in the AU

The African Protocol is a key pillar (the legal pillar) of the African Union Disability Architecture (AUDA) which was adopted in 2013.[152] In addition to the Protocol, AUDA also contains:

- A Programmatic Pillar (Disability Strategic Framework / Social Policy Framework on Disability).

[152] African Union Disability Strategy, EX/CL/DEC/750 (XXII), text on file with the author.

- An Institutional Pillar (AU Disability Institute, intended to replace the African Rehabilitation Institute).

1. The African Union Disability Architectire.

The AUDA came about as a result of two successive African Decades of Persons with Disabilities (1999-2009 and 2010-2019) and was adopted by the African Union Executive in 2013.[153] This is significant since there are approximately 80 million persons with disabilities living on the continent of Africa – the majority of whom are women and girls living in rural areas.

The Disability Strategic Framework is fascinating and impressive in itself and in the scope of its ambitions. It acknowledges that persons with disabilities experience 'systemic discrimination' and extreme poverty (preamble). It also acknowledes that 'vulnerability to disability increases throughout the lifecycle,' suggesting that disadvantages accumulate and intensify over a lifetime posing risks to mortality.

The new strategey aims to 'catalyse action that shall accellerate the achievement of the continental vision of an inclusive society.' It is intended to guide legislative, policy and other actions of the Member States.

Key provisions include:

- A biennial report on disability, produced by the AU Social Policy Department, to highlight emerging issues and continuing challenges (para 5.e).
- A recognition that addressing the structural and socio-economic drivers of exclusion is essential to achieving social inclusion (Executive Summary).

The Strategy has 10 focus areas: (1) strenthening the capacicy of OPDs, (2) reducing poverty and enhancing economic empowerment, (3) strengthening social protection systems, (4) inclusive education, (5) ensuring gender equality, (6) improving access to health, (7) improving access to rehabilitiation, (8) improving access to the built and virtual environment, (9) improving the reliability of data, (10) improving access to justice.

Many of these focus areas go directly or indirectly to the socio-economic determinients of mortality. For example, focus area no. 6 (health) expressly acknowledges the risk of early mortality for persons with disabilities. Focus area 5 (gender) acknowledges the vulnerability of women and girls with disabilities to violence and abuse which of course can impact mortality rates.

Focus area 9 (data and statistics) is particularly relevant to this Study. It calls for national and comparative data 'to support the design and monitoring of inclusive policies and programmes.' That is to say the emphasis is not on the prevalanece of disability as such. The emphasis is on using data to learn about barriers and obstacles to inclusion facing persons with disabilites. Data is a tool to give visibility to challenges so that they may be tackled rationally.

[153] See Lars Wissenbach & Thomas Ongolo, *The African Union Disability Architectire (AUDA): Reflections on a Project to Strengthen the Disability Policy Framework in Africa*, 32 Disability and International Development (2021), 10-18.

One of the Targets under this focus is that there would be a one-stop research hub in the form of the new African Research Institute on data. It is suggested that this would be an ideal platform to develop common strategies for mining data across all invesitgatory bodies in Africa on the early mortality of persons with disabilities using Austtralia and New Zealand as a model. The stretegy also proposes the creation of a Special Rapporteur in the AU on the fights of persons with disabilities. In this it would follow the OAS.

Other parts of the Strategy deal with the responsibility of the African Commission and the new (yet to be established) African Disability Institute. Interestingly, the Strategy emphasies a 'learning agenda' on disability matters which could certainly include a wider remit for investigatory bodies.

The Pan-African Parliament is a body composed of representatives sent forward by national Parliaments (like the Parliamentary Assembly of the Council of Europe). In 2019 it adopted a *Model Law on Disability*. It is a model for law reform in the AU's Member States. Section 8 deals with the right to life and, like the Charter, ties the right to life together with its underlying determinents or conditions. It contains a detailed right to health (Section 23). A very useful cluster of provisions is added dealing with gender, ageing and disability (Sections 39-42).

An interesting section is added on data and statistics (Section 36). It requires States to establish an 'inter-ministerial epidemiological surveillance system on disability' (Section 36.3.a). It is suggested that investigative mechanisms on 'suspicious deaths' should be a key part of this platform. Section 36 also deals with the need to generate research based in the data. Again this would be an ideal opportunity to generate research on mortality and to learn lessons from the accumulated disadvantages faced by persons with diabilitiues in their lifecourse. Interestingly Section 45(4) converts medical negligence into criminal offence if it causes disability.

7. Conclusions on Regional Standards on investigations and the duty to go beyond narrow medical causes of death.

All three regions have developed their own rationale for the duty to investigate deaths. Both the African Union and the Organisation of American States have produced significant case law in applying these obligations to persons with disabilities. As Murray *et al,* state in their comparative assessment of the duty to investigate in the three regional organisations:

> Overall there is a striking similarity in the broad approach of the three regional systems in their interpretation and application of the duty to investigate in right to life cases. Although the systems have employed differing wording to describe the essential nature of the duty to investigate (requiring either ‘due diligence’ or an ‘effective official investigation’), each identifies six core elements. The investigation must be undertaken on the state’s initiative; be effective; be conducted with promptness and reasonable expedition; be independent and impartial; be open to public scrutiny; and ensure the involvement of next of kin. There are some differences in wording which do not, however, actually indicate a divergent approach (such as the Inter-American and African requirement for a ‘serious’ investigation).
>
> [p.64].

To a greater or lesser degree these standards have been applied to the 'suspicious' or 'potentially unlawful' deaths of persons with disabilities. So far, they have been applied particulary well in the context of various forms of institutionalisation or State incarceration especially in the mental health context. While this is a positive development, their application must be broadened to include: hate crime, systemic violations, disapperances, violations of IHL as well as to 'ordinary' deaths of persons with disabilities that may well have more systemic causes.

Here, the recent judgment of the European Court of Human Rights in *Validity on behalf of TJ v Hungary* is most welcome. The concept of protection or prevention can and should extend more to probing the underlying systemic causes of the deaths of persons with disabilities and using the truth to drive change.

The three regional courts, the European Court of Human Rights - the Inter-American Court of Human Rights and the African Court of Human and Peoples Rights - have begun cooperating (San Jose Declaration 2023). This is welcome. This cooperation entails an 'exchange of conceptual and jurisprudential standards from each court for the mutual of their respective systems'. It is suggested that disability rights generally - and specifically the duty to investigate - should form the focus of a periodic exhange. After all, all of them are in the process of interpreting or reinterpreting their own underlying human rights treaties to make positive space for the UN CRPD. It would be good to do so having common understandings of the requirements of the UN CRPD and to take fuller account of each other's rich jurisprudence in this regard.

Part D:

Case Studies - Using Investigative Institutions to Reveal Systemic Causes of the Deaths of Persons with Disabilities.

A: Public Inquiries that Demonstrate that Systemic Causes are often at Play.

The main focus of this study is on the investigation of individual deaths and what they reveal about the systemic causes and their reversal.

Public inquiries are of a different order. They typically look at a plurality of deaths (as in a natural or man-made disaster) or a particularly controversial incident. Some more recent public inquiries are covered here mainly because they demonstrate the level and depth of systemic causes. That being so, they highlight the necessity to go beyond 'natural causes' as a ready explanation for many deaths of persons with disabilities.

We cover below the Dotan Commission Inquiry in Israel, the Life Esidemini Inquiries in South Africa and the Grenfell inquiry in England. They were not selected scientificially They were selected because they are illustrative of the risks to mortality faced by persons with disabilities.

There are many such inquiries around the world. One ongoing Public Inquiry deserves to be closely watched - the Lampard Inquiry which is an independent statutory inquiry into the unusually high rate of mortality for mental health inpatients in Essex (England). [154]

1. Deaths of persons with disabilities in insitutions and small group homes - 2023 Dotan Commission of Inquiry (Israel).

Institutionalisation itself can be a significant cause of 'excess deaths' for persons with disabilities.

The Dotan Commission of Inquiry was set up by the Minster for Social Welfare of Israel in 2022. It came about, in part, due to the deaths of three residents at a small group home. The immediate medical cause of death was attribued to food poisoning. However, there was clamour to look behind the immedaite causes to trace the core problem back to institutionalisation itself.

The title of the resulting inquiry was: *Commission for the Examination and Structuring of the Management and Operation opf Residential Facilities for People with Disabilities.* There are three kinds of institutions in Israel: *Meonot* (large scale institutions that might house up to 200 residents), *Hostels* (group homes for 24 residents) and '*Shared Accommodation'* (small group homes).

An essential backdrop to Dotan was the findings and recommendations of an International Advisory Committee in 2011: *Integrated Comunity Living for People with Intellectual Disabilities in Israel.* [155] It advised against maintaining these institutions and recommended

[154] On the background to the Lampard Commission on deaths oin mental health services see: https://lampardinquiry.org.uk

[155] The Committee was led by professor Arie Rimmerman and included Peter Blanck (USA), Meindert Haveman (Germany) and the author.

instead a deinstutionalisation programme in line with the UN CRPD (which Israel ratified in 2012). Its analsyis was grounded on Article 19 (right to live independently), Article 12, (right to make one's own decisions), Article 8 (awareness raising) and Article 16 (freedom from violence, exploitation and abuse).

Article 19 was invoked by the International Advisory Committee because it was central to the de-institutionaliosation agenda. Article 12 was invoked because the introduction of suported decision-making would be justifiable in itself and would also materially assist the process of deinstitutioanlisation by giving people real freedom on their own homes and lifes in the community. Article 8 was invoked because the process should be accompanied by education for the community at large. Indeed, the International Advisory Committee recommended that there should be follow-up research to track not just changes in person's lives but changes in attitudes in the community. This, it was felt, would make the process more sustainable. And Article 16 was invoked because of the continuing risk of violence and abuse in all kinds of institutional settings. Article 10 (right to life) was not directly invoked but was nevertheless implicit.

The International Advisory Commitee recommended that all institutions close within ten years (by 2021). It did foresee some small joint living arrangements but on the strict proviso that they were by choice and provided they contained a mix of persons with disabilities and others such as in house-sharing partners (but not support workers). This was not intended as a pretext for the continuation of mini-institutions. It also recommended legal capacity legislation to advance supported decision-making and also a mapping study to assess and strengthen community-based support services. It also recommended personalised and individualiused budgeting for persons with disabilities.

While there was some progress in implemening these recommendations - but clearly not enough. Legislation on legal capacity and supported decision-making was enacted in 2016 (Amendmemt 8 to the *Legal Capacity and Guardianship Law).* And significant legislation was enacted to provide a right to live in the community with the services and supports that this necessitated (*Welfare Services for Persons with Disabilities Law, 5782-2022*). It has yet to be fully implemented.

A TV *expose* in 2022 exposed incidents of abuse in an institution with 200 residents. And three deaths arising from food poisioning in an institution with 210 residients also ocurred in 2022. The Dotan Commission was not confined to the investigation of these incidents. Rather, it undertook to undertake a deeper systemic review of institutionalisation in Israel.

A summary of the Dotan Commission report is available in English and will be referred to here. The Dotan Commission saw the deaths as inextricably linked to the pattern of institutional abuse. A common or instinctual reaction around the world to institutional violence is to seek better ways of regulating life within such places. The Dotan report is strikingly different. Instead, it saw such abuse (including deaths) as *instrinsic* to the nature of institutionalisation. No amount of future regulation would solve that problem in the absence of a robust process of deinstitutionalisation. The Commission felt that the incidents that gave rise to its appointment were far from isolated:

> Out-of-home housing facilities, especially hostels and boarding residences (‘Meonot’), are the scenes of unimaginably shocking, intolerable practices that neither the heart nor the mind can countenance. This inconceivable systemic reality, falling somewhere between insufficient quality of life and abuse, includes poor treatment to the point of violence and abuse, medical neglect, widespread and

> uncontrolled use of restrictive measures, poor sanitation and hygiene conditions, improper living and residential conditions, buildings and infrastructure in a state of disrepair (such as courtyards surrounded by fences similar to animal enclosures, peeling walls, broken cabinets), limited and extremely inadequate care services, limited options for exercising choice and autonomy, and residents having to pass their day idly and meaninglessly.
>
> [p. 2 of Summary].

A wide varierty of institutional abuses were reported by the Commission including rape, indignities such as shared under-garments (male and female), unexplained bodily injuries that were not inevestigated, un-monitored use of psychiatric drugs, extensive use of all manner of restraints, lack of privacy (e.g., in shared shower-rooms, male and female) lack of accessibility (internalising 'an implicit asumption that residents do not need to move from one place to another'). Violence perpetrated by staff was also highlighted. Furthermore, the Commission highlighted reports it recieved on the prevalence of 'unnatural death' in institutions.

The Dotan Commission concluded from the above that "the underlying cause of this shocking reality is the extensive use of the institutional approach.' (p. 5 Summary). The Commision doubted that the 2022 *Welfare Services Law* (that promises community-based services) 'will ever be fully implemented' in the absence of structural change. Among the many obstacles to change it cited "a failure to internalise the principles of the UN Convention and the importance of deinstitutionalisation.'

The Commision recommended the adoption of a national action plan on deinstitutionalisation and a parallel plan on housing and community support services. It recommenced setting up an evaluation process involving independent academics. And it recommended many changes to the underlying Ministry (Ministry of Social Welafer) to ensure progress. In sum, the Dotan Commission was emphatic on the linkage between the various abuses it identified (including 'unnatural deaths') and the very idea and practices of institutionalisation.

2. Deaths of persons with disabilities as a result of a failed de-institutionalisation programme (Life Esidemini series of Public Inquiries, South Africa).

"Mental Health care users were dehumanised and their families treated callously."
Justice (ret) Moseneke.

The South African example highlights the fatal consequences of a deinstitutionalisation programme that is inadequately concieved, planned and executed.

On the direction of a Member of the Executive Committee ("MEC") Qedamai Mahlangu, the Department of Health in the province of Gauteng in South Africa, decided in 2015 to deinstitutionalise over 2,000 persons with mental health conditions residing in a group of institutions (Life Esidemini or LE). The contract with LE was long-standing (over 30 years). This was announced as a contribution to the countries' stated commitment to de-institutiuonalization. As part of the justification it was said that the quality of care at LE was not acceptable. The process began in 2016. An attempt to apply to court have curators

appointed to represent the interests of mental health care users in December 2015 and to forestall the plan through litigation in March 2016 failed. [156]

It appears the decision to transfer patients and close LE was really an effort at cost reduction. Very little preparation was made to ensure a smooth tranfer of patients from the LE to private service providers (confusingly called NGOs) in the community. To her credit, one medical consultant resigned rather than be complicit in a botched process. Many of the NGOs (service providers) were not licensed. Despite assurances given after litigation that the level of care would be equivalent, if not higher, than in the LE this did not happen. Many explicit warnings from advocacy groups and others were given that people's lives were at risk. Families were not happy with the process and were not kept informed. The first among those who were moved to die was Deborah Phetla (at Takalani centre - a service provider for children) who was found with brown paper and plastic in her stomach. Between May and June 2016 1,300 service users were moved out of LE.

In the result, at least 94 of the patients who were moved died in the immediate aftermath of the process. That number is now estimated at 114 deaths.[157] It appears that some of the the service providers simply turned up at LE and choose whom to take. There were no assesments of the fit of the persons with the services. Indeed, no proper discharge process was followed. Sometimes the service providers would turn up in an open truck (a Bakkie). Sometimes they were moved around from one service provider to another without any identity documents. The lack of identity documents made prescribing medicine difficult if not impossible once they arrived at the service providers and, in any event, there were no clinicians based at them. An arbitrator stated that "[C]linical records, medication and other belongings did not move with the mental health care user." (p.30).

The National Minister for Health asked the Health Ombudsperson (Professor Makgoba) to carry out an inquiry. The report of the Inquiry was issued on 1 February 2017. Just one day before publication, the Gauteng MEC for Health resigned. The report was scathing about the process : **The Report into the Circumstances Surrounding the Deaths of Mentally Ill Patients: Gouteng Province - No Guns, 94 Silent Deaths and still Counting.** Professor Makgoba found that persons with mental health conditions who were moved from LE died at a substantialy higher rate than would ordinarily be expected. He drew on the expertise of a panel of experts in the mental health field. He requested the Statistics Office of South Africa to assist with a detailed 'death analysis.'

Professor Makgoba asserted that:

> The NGOs where the majority of patients died had neither the basic competence and experience, the leadership/managerial capacity nor ‘fitness for purpose’ and were often poorly resourced. The existent unsuitable conditions and competence in some of these *NGOs precipitated and are closely linked to the observed ‘higher or excess’ deaths of the mentally ill patients*. [1.4].
>
> [Italics added].

That is to say he drew a direct causal link between the botched de-instutionalisation process and the excess deaths of persons with disabilities. He continued:

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[156] *The South African Depression and Anxiety Group and Others v Member of the Executive Council for Health, Gauteng and Others*. Case number 08904/16, (2016).

[157] See Harriet Perlman & Mark Lewis, Life Esidimeni, Portraits of Lives lost, (Jacana Media, 2024).

> The project demonstrated clearly that basic professional care skills for community mental health care, cannot be acquired through seminars or workshops but through professional education, training and qualifications.
>
> [para. 1.4].

This strongly echoes the UN CRPD Committees' De-institutionalisation Guidelines:

> 94. *States parties should ensure that institutional staff are trained in an approach to deinstitutionalization that is human rights-based, reparative and person-centred.* Trusted persons, who may include family members, friends and others, should be involved in planning processes in accordance with the will and preferences of the persons concerned. Peer support for institutionalized persons and survivors of institutionalization should be facilitated as part of planning and transition to promote full inclusion. Family members of persons who have been institutionalized should be provided with information and guidance, as well as economic and administrative support and dedicated services, to address the harms caused to their relatives by institutionalization and to prepare to constructively support them when leaving institutions.
>
> [Italics added].

One of the death certificates described in the Health Ombudspersons' report explicitly stated that one of the residents had died of 'natural causes' (para 4.1.1). This was clearly not the case. The circumstances surrounding his death was concealed on the basis that it was 'confidential information.' Two hours before his death, he 'apparently had a wound to his head, blisters around his ankles and a sore on his nose' (para 4.1.1). Many families remained unaware that their relatives had been transferred, had passed away, or even the wherabouts of the corpse.

Professor Makgoba stated: 'the notion of 'natural death' on cerificates was very confusing to many relatives: it needed explanation.' (para 4.1.2). He asserted that 'some corpses had unexplained bruises on their bodies.' He concluded that "[M]oney to follow the user principle was not followed" which led to 'increased mortality.' The SA Federation for mental health testified that there was a "lack of understanding of duty bearers for de-institutionalisation." It was critical to acknowledge the deaths and to upgrade community services to to enable independent living.

The relevant service providers (NGOs) were, in the main, residential facilities. Many were not properly licensed and were "without suitable infrastructure and not for fit for purpose" (para 5.1.1.). Some security risks compounded the lack of suitability. Few Service Level Agreements had been concluded. This held up payments for vital supplies and services. It wasn't even obligatory to provide adequate meals (para 5.2.4). Out of the 25 service providers visited during the course of the investigation "twenty two did not have the capacity, skill or competence to deal with the influx of mentally ill patients" (para 5.4.1.). They started recruiting staff 2-3 months *after* patients had been recieved. And payments did not start until 2-3 months into the contract which meant that basic facilities were lacking. The deinstitutionalisation plan was rushed in three months - when in fact it could and should have taken 5 years. 95% of the deaths took place in these service providers.

The service providers did not keep medical records and it appears that no medical examinations took place prior to displacement. Staff at the service providers did not have the

medical skills required to carry out assessments. One result was the lack of coordinated handover with respect to medications. The Report assessed the factors leading to death as:

> [A] Majority of deaths occurred in newly established NGOs some of which existed for less than six (6) months and lacked previous experience in caring for mentally ill patients. The following factors were observed to be challenges in those NGOs:
> - Lack of capacity in relation to skills, knowledge and competence to manage patients, particularly mentally ill patients;
> - Lack of financial resources;
> - There were no patient care and management systems in place, particularly medication administration, control and storage;
> - Delays in identifying need for and seeking medical attention.
> - Infrastructural constraints resulting in restricted patients' movement, security risk, lack of patients' recreational space.
>
> [para 5.9.13)].

Based on an analysis of documentary evidence and testimony, the Ombudsperson's Report concluded that the true concept of de-institutionalisation was not achieved through the Marathon programme (para 5.11). Instead, the NGOs (service providers) were

> lured into what appeared as a business opportunity not to be missed and as such received patients knowing that they neither had capacity, expertise, nor the requisite infrastructure.
>
> [para 5.10.5].

A key finding was:

> ...that the GDoH (relevant provincial department of health) overlooked and/or failed to properly anticipate the consequences that may arise from the rushed transfer of patients and that the negligent conduct led to making unsound decision that did not seek to prioritise the health care and safety of patients and the quality, thereby putting the life of patients at risk.
>
> [para 5.10.8].

The decision to relocate patients from LE was taken ostensibly on the need for de-institutionalisation. In reality, it was a cost-cutting measure (para 5.6.1.).' However, it was misplaced. The Report stated:

> If cost was the rationale for the termination of contract and transfer of MCHUs from LE to NGOs...one has to ask what quality health care service can be delivered anywhere for an estimated cost of R112 per day. This surely must represent a serious form of neglect and denial of quality health care to one of the most vulnerable population of our society. p
>
> [at p.35].

The Report explicitly linked this flawed decision to the resulting deaths. It stated:

> Omissions to carry out critical patient care steps...created clinical and safety risks that would result in [the] deaths of patients...
>
> [para 5.9.1].

The report concluded that "it was the cumulative impact of deviation from the normal course, starting from a flawed decision along a 'chain of events' that led to "the higher number or excess deaths" of patients at NGOs" (p. 26). The chain of events included the decision, planning, implementation, monitoring and intervention. It continued:

> Let's first state the obvious i.e. the goal of de-institutionalisation is the corner stone of the MHCA 2002. This is universally accepted and was confirmed throughout this investigation by the testimony of almost every witness. The difficulty was not the concept itself but how the concept was translated in reality on the ground. The selective interpretation and usage of the legislative framework and strategy was at the heart of the Project. The project which was aptly named 'the Gauteng Marathon Mental Health Project' instead became the 'Gauteng sprint'!
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> [at p.26].

The Report counteracted the argument that the decision to deinstitutionalise could be disassociated from the deaths. It stated plainly: "the decision (to move patients from LE) and the deaths are inextricably linked..." (at p. 28).

The Health Ombudsman concluded that the patients died under unlawful circumstances.

Among the more important recommendations of the report of the Health Ombuds were the following: that the Marathon Project should be immediately discontinued, that senior officials responsible for the decision and its planning should have disciplinary proceedings brought against them, that the National Minister for Health should ask the South African Human Rights Commission to launch an inquiry into human rights standards and mental health,[158] that appropriate legal proceedings should be taken against those NGOs (service providers) who had been operating unlawfully and in which service users died, that service providers that do not meet minimum health standards should be de-registered, that all those illegally placed in service providers should be repatriated, that de-institutionalisation henceforth should be based on developing appropriate community-based services and supports, that the National Minister of Health should issue a public apology and institute an Alternative Dispute Resolution mechanism to deal with reparations and redress.

The Report of the Health Ombudsman is anchored in a health care perspective - as one might expect from a Health Ombudsperson. The right to health and its core ingredients figure prominently. While this is not a criticism, it be strengthened by considering Article 19 of the UN CRPD and the UN CRPD Committee's De-institutionalisation Guidelines, which expand the health care dimension to embrace a right to live in the community with more personalised supports (including but going beyond access to traditional health care).

The Alternative Dispute Resolution mechanism recommended in the final report by the Healh Ombudsman was duly instituted by the Minister and the province. Retired Justice Moseneke was appointed as the arbitrator in February 2017. Most public hearings were televised and remain available on Youtube. The Arbitration began in October 2017 and the judgement (award) was released in March 2018.[159] The award judgment makes for compelling reading.

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[158] See now South African Human Rights Commission, *Report of the National Investigative Hearing into the Status of Mental Health Care in South Africa,* (2017). It pointed to a 'treatment gap' in mental health care: available at - https://www.sahrc.org.za/home/21/files/SAHRC%20Mental%20Health%20Report%20Final%2025032019.pdf

[159] *In the Arbitration between Families of menal health care users affected by the Gauteng Mental Health Marathon Project (claimants) and National Minister for Health of the Republic of South Africa, Government of the Province of Gauteng,*

The core issue was "the nature and extent of the equitable redress, including compensation, due to mental health care users and their families who were negatively affected by the Marathon Project" (at p.4).

An arbitration agreement was concluded between the parties before the process begun. The arbitration agreement empowered the arbitrator to reach conclusions as to: appropriate compensation, where possible the provision of information to families regarding the circumstances and cause of death of their loved ones as well as the location of their final resting place, appropriate apologies, an appropriate monument in their memory, and any other equitable redress deemed appropriate (at p.4 of the award).

The arbitration agreement also stipulated that the "deaths were not natural but caused unlawfully and negligently" and that "liability for the loss of the affected families falls to the Government" (p.6). So liability itself was not in question in the process. The Government, in essence, conceded the need for equitable redress with repect to funeral expenses and "common law general damages arising from pain, suffering and emotional shock and nothing else."

For their part, most of the claimants sought reparations for "the pervasive, egregious, uncaring and wanton violations of the constitutional rights of all mental health care users affected and their families, [and called for]... for equitable redress which must include constitutional damages." This was resisted by the Government. This was the core net point left to the arbitrator. One set of claimants asked that the arbiration proceeding and conclusions be formally transmitted to the South African Police Service for possible further action in the form of criminal investigations and prosecutions.

All arguments in favour of the decision to close LE and institute the Marathon programme were rejected. An argument was made that it aimed to deliver on the countries' commitment to de-institutionalisation as et out in the National Mental Health Policy Framework and Strategic Plan (Policy Framework - 2013-2020). The arbiter concluded that "...the Marathon Project was not the deinstitutionalisation the Policy Framework imagined." (p.19). He added "deinstutionalisation may not be and ordinarily is not a cost saving measure" and that "numerous research studies have shown that displacing patients from institutions should not be used to save money as this inevitably results in people with mental illness being further abused, increased hospital admissions and early mortality." (at p.19).

He continued:

> [T]he new living environment at non-governmental organisations was no less restrictive than a hospital but significantly more disadvantageous. Most mental health care users were moved to non-governmental organisations far from their family homes, removing them from the communities into which they were supposed to be integrated. Some of the non-governmental organisations were far from any community.
>
> [p. 20].

Cost effectivness and especially the need to end *'evergreen contracts'* was expressly rejected by the arbitrtor as an argument for closing LE. A report from the Health Advanced Institute which had been commissioned by and provided to the provincial department before the decision was taken made clear

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Premier of the Province of Gauteng, member of the Executive Council of Health, Province of Gauteng (respondants), Award, 19 March, 2018.

that the old LE contact provided good value for money. Representatives from the National Treasury argued that the Government had never demanded that core costs be cut and that mental health was core. This undercut the arguments of the Provincial Government. The arbitrator concluded that cost savings could not be the real reason behind the closure of LE. And in any event he stated:

> resource constraints cannot constitute an acceptable justification for the failure to protect and realise constitutional rights."
>
> [p.23].

As to the transportation of the residents to the service providers the arbitrator stated:

> On ...instructions, the patients were loaded on buses or open trucks and driven to non-governmental organisations unknown to the patients of their families. Patients tightly held their meagre personal belongings. The evidence suggests that the patients were visibly harassed or anxious and some were conveyed with their hands or feet or both tied. On all accounts the conveyance was cruel, inhuman and in a degrading manner. All this without prior and continuous clinical assessment of the patients; without useful or any medical records; without access to clinical and other medical care and without access to appropriate or prescribed medication.
>
> [p. 31].

As to the conditions they met once transferred the arbitrator stated:

> The chaotic process of moving mental health care users to non-governmental organisations; the lack of appropriate assessment to ensure sufficient, qualified staff, decent infrastructure and programmes; and the late payment of non-governmental organisations meant that conditions at the non-governmental organisations were poor and entirely unsuited to the care and medical needs of mental health care users.
>
> [p. 32)].

Many lacked adequate clothing and reports of abuse or suspected abuse surfaced at some service providers. The arbitral award decision recites many of these heart rendering individual cases. When a man sought his mother he was brought out the wrong person although she was wearing his mother's name tag:

> Ms Mangena's brother did not recognise his mother at first because of the amount of weight she had lost. He had to walk around the hall a second time before he found her. She was sitting in a corner shivering, without any socks or jersey. Her feet were swollen and she was extremely hungry. The nurse with whom Ms Mangena's brother spoke was new and had no experience caring for mental health care users. The patients at Takalani were receiving the same medication despite having different mental health conditions. If mental health care users could not walk or talk for themselves they would not get what they needed, including their food and medication. Ms Mangena's brother insisted on seeing where his mother slept. There were no enough beds for all of the patients. Some of the mental health care users slept on benches or on the floor without mattresses. He was taken to a bed, but he knew that it was not his mother's bed because there were pictures of another person's family on the wall by the bed.
>
> [p. 33].
>
> And:
>
> > Mrs de Villiers received no sympathy from the staff when she enquired about her brother's wellness. She said that she was physically prevented from entering the ward where her brother

> slept. When she phoned to enquire about her brother's condition she was told that there was no patient by the name of Mr Jaco Stols. She explained how she had to intervene to ensure that her bother was admitted to hospital and how she was informed that he was severely dehydrated and underfed and that his condition was critical. An autopsy was performed but that she never received the findings nor did the South African Police Service in Cullinan revert to her over the formal charge she had laid at the Cullinan Police Station.

The arbitraror concluded that all top officials and the Minister knew of the death toll but refused to acknowledge it. Further, they each claimed that the deaths were a direct result of their mental health condition and not caused by the move. This the arbitrator specifically rejected and labelled as 'misinformation.' He said "[A]ll evidence points to unnatural casuses of death." (at p. 40.) He added:

> The circumstances of all of the deaths were questionable and indicated, at the very least, cruel, inhuman and degrading treatment. The causes of death as reflected on the death certificates varied but include pneumonia, neuroglycopenic brain injury, chronic hepatitis which caused liver failure, septicaemia, and severe dehydration. Despite the circumstances of the deaths, most were classified as being due to "natural causes". The result was that post-mortem examinations were not conducted in the vast majority of the deaths.

The causes were anything but 'natural.' And yet, because they were put down to 'natural causes,' no further investigations happened even though they were fully warranted. The State conceded that the deaths were not 'natural deaths' but were caused by the unlawful acts or omissions of the MEC and her officials.

It appears that a lot of the bodies had decomposed beyond recognition by the time the families had located them which the arbitrator described as amounting to cruel, inhuman and degrading treatment for the familites. To dispose of the bodies, the service providers (NGOs) apparently shunted them from one mortuary to another without the knowledge or consent of the families. Extensive testimony was taken in the arbitration hearing not only about the dead and also about the survivors in their own words and from their families. All such testimonies were searing.

The arbitrator canvassed international human rights standards as well as those of the South African Constitution and the African Charter of Human and Peoples' Rights. The most important rights canvassed were the right to life, the right to be free from torture, inhuman and degrading treatment, the right to an adequate standard of living and the right to health. The arbitrator stated that the UN CRPD was of immediate relevance. He also referenced the 1991 UN *Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Car*e. These principles are primarily grounded on a medicalised approach to mental health care. He particularly referenced (under the 1991 Principles) the preservation of autonomy, the necessity for consent, the necessity to follow medical ethics and the right to appeal any course of treatment prescribed.

During the hearing, the justice also directly challenged the MEC on her failure to meet the obligation under the UN CRPD to consult with persons with disabilities

before the decision was taken to cancel the LE contract.[160] The justice implied a material breach of Article 4.3 of the UN CRPD.

It is unfortunate that he did not reference important WHO policy documents on the need for a new paradigm in mental health. Subsequent to his otherwise excellent arbitration judgment, the WHO issued its 2023 *Mental Health, Human Rights and Legislation: Guidance and Practice* on the need to move away from an overly-medicalised approach. His focus on the narrow medical issues was perhaps understandable given that the main concern was with deteriorating health care conditions (and death in extreme cases) and reparations therefor. However, one senses that an opportunity was lost to ground the de-institutionalisation process on a different footing than in the past.

The reasoning of Justice Moseneke under the Constitution mirrored his approach to international law. The service providers were said to have assumed constitutional obligations. Justice Moseneke stated:

> These [constitutional rights and obligations] include their inherent human dignity, right to life; freedom and security of the person, especially the right not to be tortured in any way; and not to be treated or punished in a cruel, inhuman or degrading way. Mental health care users were entitled to have access to adequate health care services and sufficient food and water. (p. 65).

Furthermore, the democratic project of the State "sets admirably high principles for officials in the public service." These include:

> ...a high standard of professional ethics, using public resources in an efficient, economic and effective manner; providing services impartially, fairly, equitably and without bias; and being responsive to people's needs and engaging and encouraging the public to participate in policy-making.
>
> [p. 65].

Justice Moseneke went on to specify provisions of national legislation of relevance. They included the National Health Act and the Mental Halth Care Act and the National Mental Health Policy Framework and Strategic Plan (Policy Framework). The Policy Framework aligns well with international law and specifically warns against rushed de-institutionalisation programmes, a warning that appears to have been ignored in the Mararon Project (para 2.5 of the Policy Framnework). The Mental Health Review Board, which could have intervened, was described as 'moribund' and as seeking to preserve its own status and remuneration above all else. What stood out for Justice Moseneke was:

> ...the breadth and depth and frequency of the arrogant and deeply disgraceful disregard of constitutional obligations, other law, mental health care norms and ethics by an organ of state, its leaders and employees.
>
> [p. 73].

The only question remaining was the basis for redress and its extent. Justice Moseneke allowed the claim for breach of constitutional rights. He said that the reasons put forward by

[160] Arbitration hearing, 25 January 2028: available at - https://www.youtube.com/watch?v=InQtYsktdfg

the MEC and her officials for the termination of the LE contract were "untrue and false" and "fabricated and patently false" (p.73). The setting aside of the contract was irrational and "in blatent breach of the law and the constitution." The death and torture of the residents of LE "stemmed from the irrational and arrogant use of public power" (p. 74). Justice Moseneke decried the fact that the MEC and her officials blamed each other for a collective decision. None took direct responsibility and the true reason for the decision to terminate the contract remained unknown. The decision caused so much trauma and pain that it "amounted to a very serious breach of constitutional obligations by the State and its servants." (74). He continued:

> The violations of the right to dignity here are as many as they are plain to see. Not only were the mental health care users stripped of their dignity, in life and in death, but their families were also treated as sub-human and devoid of any worth. Their entitlement to participate in the decisions about the health care of their loved ones was disregarded, as was their right to information. Their grief was brushed off. Their emotional distress arising from the trauma they went through was undermined and used to marginalise them.
>
> [p. 75].

One expert witness before the arbitration process (Ms. Trotter) asserted:

> [Torture].. is a strong term. I think once you've decided that a group of people is undesirable and you dehumanise them, then actually you are in the terrain of torture. So if you take a group of people who didn't know the move was coming up, weren't prepared for it and they are moved on the backs of trucks, tied with sheets, without supervision, without identity documents, without wheelchairs, without medical files, this is no longer a human endeavour, that in itself is a torture. This was done inhumanely and so now we are in the terrain of torture. And then that doesn't stop, because the patients are moved into these filthy dangerous environments as if they are not people.
>
> [p. 77].

An Inquest were initiated by the National Minister for Justice in 2021 under the Inquests Act (1959) and it concluded hearing evidence in 2023. Normally inquests happen before official inquiries and normally they focus on the cause of death and not on liability.

The Inquest was chaired by Judge Teffo (High Court) and reported on 10 July, 2024.[161] Judge Teffo was at pains to point out that an inquest is wholly separate from criminal proceedings. Interestingly, one of the issues raised was the admissibility of evidence tendered at the Arbitration since those who testified were not notified that their testimony might be relevant in future proceedings that might lead to criminal prosecution. In a detailed and impressive judgment, Judge Teffo admitted the evidence produced during the Arbitration. Judge Teffo ruled:

> [W]hen conducting an inquest, every single piece of information and evidence is vital as each piece of information and evidence plays an important role in conducting a thorough investigation and uncovering the truth and circumstances surrounding unsolved death not due to natural causes. Allowing the arbitration record into evidence is consistent with the purpose and mandate of an inquest and plays an important role in furthering the objective of conducting an inquest.
>
> [para 40].

[161] *In the High Court of South Africa (Gauteng Division, Pretoria), In the Matter Between Life Esidemini Inquest,* Case 2001/21, Teffo J., 10 July, 2024.

Some fascinating evidence was tendered to the inquest by Professor Leslie Robertson, a psychiatrist specialising in community-based care. She recalled the origins of the de-institutionalisation movement in South Africa from the early1990s. She said one of the reasons for the National Policy Framewortk was the pressing need to develop community-based care services as distinct from standalone hospitals. And she usefully recalled that the National Policy Framework explicitly warned against de-institutionalisation without laying the groundwork for commiunity care services.

Judge Teffo had to work in unusual circumstances. She conceded that, since autopsies were not carried out on most of the deceased, she had to conclude that "the [narrow] medical cause of death of each deceased is therefore unknown" (at para 419). Judge Teffo rejected the argument that there were intervening acts (*novus actus interveniens*) of third parties that, uncoupled from the original decision to terminate the LE contract, caused the deaths. "[E]verything that happened after the terminaion of the LE contract until the deaths was a continuous process"(at para 548). Judge Teffo held that the MEC and the chief official in charge of the project had "created circumstances in which the deaths of the deceased were inevitable" (at para 573). The Inquest found that some of the deaths were caused by the negligence of Minister Mehlangu and one of her senior officials Dr. Manamela.[162]

As of December 2024, no criminal proceedings have yet been instituted against any of the main protagonists.

What the sad events of LIfe Esidimeni show are the following. Many of the deaths were initially put down to 'natural causes' when in fact the causes were anything but natural. The heightened vulnerability of the deceased meant they were largely invisible. Even their families and advocates failed to halt the move that led almost inevitably to death. The de-institutionalisation process had not been meticulously planned as is needed to ensure that adequate care in the community that makes community living successful. Domestic law (including the Constitution) and international law were violated. Indeed, the implicit post-Apartheid social contract that the Arbitrator rightly pointed to, was ripped up.

However, one has to be impressed with the dogged determination of the families and their advocates and equally impressed with the truth-telling institutions of the State: the Health Ombudsperson, the Arbitration process and the High Court Inquest. They did not rest satisfied with suppositions about the 'natural' causes of death but probed all the underlying determinative factors - a model of sorts for inquiries for the rest of the world.

3. Deaths of persons with disabilities due to inadequate evacuation measures in social housing (Grenfell Tower UK).

The UK enjoyed a period of rapid house building in the immediate aftermath of the Second World War. Many of the newer houses took the form of high rise apartment blocks. Most of them were not insulated, since building standards were not as developed in the 1950s or 1960s as they are today. In the last two decades, an intensive effort has been made to retro-fit

[162] Umamah Bakharia, I*nquest Finds Former MEC Mahlangu Causes Life Esidemini Deaths*, 10 July 2024, Mail & Guardian: https://mg.co.za/news/2024-07-10-inquest-finds-former-health-mec-mahlangu-and-former-head-of-mental-health-manamela-guilty-of-life-esidimeni-deaths/

these apartment blocks to ensure a modicum of insulation. However, the way this was done exposed the inhabitants to further risks, particularly fire hazards.

External cladding was generally added to the outside walls. Unfortunately, this cladding was combustible. This meant that a localised fire on, e.g., a third floor apartment could easily apread to the outside cladding which then spread the fire vertically upwards on a tower block which might have 15 stories. Once the fire spread upwards on the external wall, it blew in windows on the upper floors, lit curtains and attachements and therefore spread the fire to upper floor apartments. Thus, a fire that could previously be localised to a third floor apartment posed a substantial risk to all appartments in the building with this external cladding no matter how high. The spread of the fire could take only a matter of minutes.

Much of this was highlighted in an inquest that concluded in 2013. In 2009, a fire killed six people in a 14-storey tower block in Camberwell, London (Lakanal House). An inquest was held into their deaths. The coroner (Frances Kirkham) made several recommendations to the fire brigade of London, to the Lord Mayor of London, to the Secretary of State and to the local Borough. They included raising awareness about the fire risks posed by external cladding, improvements in building regulations to ensure a reduction of the risks of cladding, an improvement in fire brigade command and control (a big issue in Grenfell) and better guidance on evacuation during an emergency.[163]

Interestingly, very few of the coroner's recommendations were implemented. This, of course, powerfully reinforces the proposal of INQUEST that a National Oversight Mechanism is needed to coordinate implementation of such coronial recommendations.

The Grenfell Tower fire took place on June 14, 2017 after a refurbishment using the cladding in question. The inquiry set up to investigate the events produced two reports: the first report (published on October 2019) looked at the events leading up to the fire.[164] The second (final) report was published in September 2024 and looked at the underlying or systemic causes of the fire, where mistakes were made and produced recommendations to ensure that similar events could not happen in the future.[165] The chair referred to the deaths as 'all avoidable.'

Nearly half of the residents who died had a disability (32 out of 72 deaths). Volume 6 of the Final Phase report contains details of the individual residents who died including those with disabilities. One statement produced by Disability Rights UK said:

> Disabled people knew they were sitting ducks should there be a disaster. They raised safety concerns which were dismissed time and again. The Inquiry has heard from residents who said they were "bullied" and "stigmatised" when they raised such concerns. The disproportionately high death rates of children and Disabled people in the Grenfell Tower fire is truly shocking and heart breaking. [166]

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[163] For the coroners' report on Lakenal see See: https://www.lambeth.gov.uk/about-council/transparency-open-data/lakanal-house-coroner-inquest

[164] *Grenfell Tower Inquiry: Phase 1 Report (*2019): available at - https://assets.grenfelltowerinquiry.org.uk/GTI%20-%20Phase%201%20full%20report%20-%20volume%201.pdf

[165] *Grenfell Tower Inquiry: Phase 2 Report (2024): available at - https://www.grenfelltowerinquiry.org.uk/sites/default/files/CCS0923434692-004_GTI%20Phase%202%20Volume%201_BOOKMARKED_0.pdf*

[166] Disability Rights UK, Statement, *'Almost Half of Grenfell fire deaths were disabled people and children,*' 30 March 2021. See also Neha Gohil, *Disabled High Rise residents 'Still at Risk' seven years after Grenfell fire*, The Guardian 30 June, 2024.

None of them had a personal emergency evacuation plan. A longstanding demand from disability OPDs in the UK has been for 'personal emergency evacuation plans' (PEEPs) which would include personal aids and devices to ensure safe evacuation in times of emergency like a fire.[167] One result is that residents with disabilites are particularly vulnerable in high-rise apartment buildings with combustible cladding. A slogan used by one of the campiagn groups reads "no one deserves to be cremated alive."

One of the recommendations made in the second or final report was that a publicly accessible database should be created to bring together the recommendations of public inquiries and coroners. This would generate added pressure for implementation. This is what INQUEST has been calling for. INQUEST observed in its 2023 Report: **No More Deaths: Learning, Action and Accountability, the case for a National Oversight Mechanism:**[168]

> The Grenfell Tower Inquiry exposed the fact that many of the Lakanal House recommendations were not implemented before the fire. Implementation was not considered to be urgent and was instead included in a medium to long term programme of work.

Had the Lakanal inquest recommendations been heeded then Grenfell may not have happened or would not have had such catestrophic results. The Phase 2 Report (2024) specifically acknowledged that "[D]isabled people were particularly affected by the speed and ferocity of the Grenfell fire (14.2).

What Grenfell shows is that persons with disabilities are placed in highly vulnerable situations when their particular safety needs are not considered or met. The risk of death posed to them can be magnified many times over when there is a failure to consider their particular needs. These design failures in the built environment aren't just regrettable as a failure to achieve universal design - it can pose a tangible risk to life.

One imagines this issue is not confinded to the UK. Many persons with disabilities across the world rely on social housing. It is fair to infer that many are at risk since the housing stock in many countires is quite old. The Grenfell Inquiry did a great public service in highlighting these vulnerabilities. It is a pity that the 'prevention of future death' recommendations of the Lakanal coroner were not heeded in time to prevent Grenfell.

[167] See the views of an NGO dedicated to the rights of persons with disabiliites in social housing - CLAD DAGH (Leaseholder Disability Action Group): https://claddag.org

[168] INQUEST, No More Deaths: Learning, Action and Accountability - the case for National Oversight Mechanism, (2023): availabe at - https://www.inquest.org.uk/no-more-deaths-campaign

Part E:

Innovative Practice that Empower Investigative Bodies to Probe Systemic Causes and make Policy Recommendations for Change.

1. Innovative Practice - 'Prevention of Future Death' Reporting by Coroners in England & Wales and the in-depth thematic reviews of the deaths of persons with intellectual disabilities in the NHS LeDeR programme.

The UK (England & Wales) is an interesting case-study on how an exploration of underlying systemic deficiencies in services and supports can be brought to light by investigatory bodies and reported to Government and other agents of the State for action. There are of course other standard-setting and investigatory bodies such as the Care Quality Commission and in many respects the work of coroners in producing PFD reports complements their work.

The obligation to go beyond individual instances can be traced back to Rules introduced by the Lord Chancellor in 1984 under longstanding coroners' legislation (Coroners Act 1926). Rule 43 of the 1984 Rules was to the effect:

> A coroner who believes that action should be taken to prevent the recurrence of fatalities similar to that in respect of which the inquest is being held may announce at the inquest that he is reporting the matter in writing to the person or authority who may have power to take such action and he may report the matter accordingly.

A similar provision was contained in Irish legislation dating back to 1962[169] (Coroners Act 1962)[170] and indeed in New Zealand legislation in 1980. The relevant provision in the Irish Act stated:

> Section 31 (2): Notwithstanding anything contained in subsection (1) of this section, recommendations of a general character designed to prevent further fatalities may be appended to the verdict at any inquest.

This assumed that an inquest actually took place and it further assumed that a coroner could not otherwise issue such recommendation in the course of his/her own investigations. Although there are many anecdotal accounts of pointed recommendations being made by Irish coroners, it appears that no comprehensive study has yet been done in Ireland to gauge the extent of the use of this legislatiive option and its impact.[171] Now would be a good time to commission such a study since the legislation is due for renewal.

The relevant part of the New Zeland Act (Coroners Act, 2006) reads:

> **57.A. Recommendations or comments by coroners**
> (1) A responsible coroner may make recommendations or comments in the course of, or as part of the findings of, an inquiry into a death.

[169] Coroners Act (Ireland), 1962 at Section 30.2
[170] See also Section 57a and Section 57B of the Coroners Act of New Zealand (2006).
[171] Several such coroners policy 'recommendations' are on file with the author from some leading coroners in Ireland.

(2) Recommendations or comments may be made only for the purpose of reducing the chances of further deaths occurring in circumstances similar to those in which the death occurred.
(3)Recommendations or comments must—
(a) be clearly linked to the factors that contributed to the death to which the inquiry relates; and
(b) be based on evidence considered during the inquiry; and
(c) be accompanied by an explanation of how the recommendation or comment may, if drawn to public attention, reduce the chances of further deaths occurring in similar circumstances.

Section 57B requires a coroner in New Zealand who is contemplating making a recommendation to consult with interested parties before doing so. Note, the New Zealand Act allows for 'recommendations' to be made. This language is somewhat stronger than in the UK Rules. However, unlike the situation in the UK, the matter giving rise to concern must be 'clearly linked' to the death under investigation. This is much narrower than the UK legislation. Interestingly, the Coronial Services of New Zealand publishes every three months a summnary assessment of the main 'recommendations' made by coroners.[172] This is exceptionally useful to policy-makers and advocates. The coroners service of New Zealand also publishes 'findings of public interest.'

The 1984 Rule in the UK (England & Wales) appeared to suggest that only in cases where an inquest was convened that this power could be exercised. An inquest would not be convened in every case. Furthermore the language of Rule 84 suggested that this power was discretionary and not mandatory. Nevertheless it appears that considerable practice evolved under it.

Section 32 of the UK Coroners and Justice Act (2009) now deals with the 'Powers of Coroners.' Schedule 5 to the Act amplifies those powers. It contains a highly interesting provision that further develops the old Rule 43 of 1984 as follows:

Action to prevent other deaths
7(1)

Where—

(a) a senior coroner has been conducting an investigation under this Part into a person's death,
(b) anything revealed by the investigation gives rise to a concern that circumstances creating a risk of other deaths will occur, or will continue to exist, in the future, and
(c) in the coroner's opinion, action should be taken to prevent the occurrence or continuation of such circumstances, or to eliminate or reduce the risk of death created by such circumstances,
the coroner must report the matter to a person who the coroner believes may have power to take such action.

(2) A person to whom a senior coroner makes a report under this paragraph must give the senior coroner a written response to it.

(3) A copy of a report under this paragraph, and of the response to it must be sent to the Chief Coroner.

The resulting reports are called '**Prevention of Future Death**' (PFD) Reports. Several features of paragraph 7 of the above schedule are noteworthy. The discretionary nature of the old 1984 Rule is now gone and, in the right circumstances, the coroner is now under a 'duty' to report (7.1.c). And, unlike the old Rule 43, a written response from the addressee (usually

[172] See e.g., https://www.coronialservices.justice.govt.nz/findings-and-recommendations/recommendations-recap/

a Government Department or an agency of State or a service provider) is now needed under Schedule 5 (7.2). Further, the Schedule at least hints at a new supervisory role for the Chief Coroner (7.3).

Annex A to Schedule 5 contains a template to be followed by coroners for PFD reports Further useful Guidance on Schedule 5 was given by the Chief Coroner in 2013 (**Guidance No 5 - 'Reports to Prevent Future Deaths'**).[173] The Guidance asserts:

> Broadly speaking, reports should be intended to improve public health, welfare and safety. They should not be unduly general in their content; sweeping generalisation should be avoided. They should be clear, brief, focused and meaningful and, wherever possible, designed to have practical effect. [para 5].

With respect to the duty to report, the Guidance asserts that the coroner is not confined to matters arising in an inquest (if there is one) but the cause of concern may arise at any stage of an investigation. The concern:

> is that circumstances creating a risk of future deaths will occur, or will continue to exist, in the future. (10.3).

If such a concern arises, then the coroner has a duty to report "to a person or organisation who the coroner believes may have power to take such action" (10.5).

The Guidance insists that a PFD reporting regimen should not lengthen the time needed for an investigation nor lead to a widening of its scope (14). A PFD is essentially 'ancillary' to the primary purpose of an investigation which is to "determine the statutory determinations, findings and conclusions relating to the death as recorded in the Record of the Inquest." A PFD is essentially 'ancillary' to the primary purpose of an investigation which is to "determine the statutory determinations, findings and conclusions relating to the death as recorded in the Record of the Inquest."

The PFD need not dwell on anything specific in the investigation. It is sufficient that the *'matter of concern'* arises during the investigation. Indeed, the matter of concern need not be probative of the cause or potential cause of death in the immediate instance.

The coroner is supposed to list his/her concerns (part 5 of the Template). Part 5 of the Template has been described as the essence of PFD. The Guidance states:

> The coroner should state clearly, simply and in neutral and non-contentious terms,the factual basis for each concern.
>
> [para 23].

It proceeds:

> In some cases the action to be taken following the coroners' concern will be obvious. But it is not for the coroner to express precisely what action should be taken. **A PFD report is a recommendation that action should be taken, not what that action should be.** The latter is a matter for the person or organisation to whom the PFD report is directed.

[173] Chief Coroner of England & Wales, Guidance No 5 - Reports to Prevent Future Deaths: available at - https://www.judiciary.uk/wp-content/uploads/2013/09/guidance-no-5-reports-to-prevent-future-deaths.pdf

(para 24. Emphasis in original).

Furthermore, in keeping with the history and tradition of the role of coroners (including the baseline legislation) the report need not dwell on causation (or potential causation) of the matter that is of concern with respect to the specific death under investigation. It is sufficient that it arises in the course of the investigation. Therefore a matter that is peripheral to the instant case under investigation but nevertheless likely to lead to deaths in the future is covered. All PFD reports are in fact published on the Judiciary website since 2013 in the UK and are fully searchable.[174]

In keeping with the history and tradition of the role (including the baseline legislation):

> Reports should not apportion blame, be defamatory, prejudice law enforcement action or the administration of justice, affect national security, put anyone's safety at risk or breach data protection. (26).
>
> And:
>
> Coroners should not make any observations of any kind, however well intentioned, outside the scope of the report. Such observations are an expression of opinion wider than is permissible…
>
> (para. 27).

As to the recommended action to be taken the Guidance insists that "[I]t is not for a coroner to make recommendations as to what specific should be taken". (31) It appears that New Zealand law allows more specific recommendations to be made.

The addressee (which could be a service provider) has a duty to respond to the PFD report (as per the Template). The Template states:

> Your response must contain details of action taken or proposed to be taken, setting out the timetable for action..Otherwise you must explain why no action is proposed.

The Schedule states that the Chief Coroner 'may' publish a response either in full or in a redacted (where needed) or summary form. A cursory search has not yielded such responses on the website of the Judiciary. That is a pity as it impacts on the capacity of third parties to gauge compliance and developments.

Importantly, the Chief Coroner asserts in the Guidance that they have a role in "taking some reports (and responses) further." This is very welcome since publication of a PDF (with or without a response) may have no impact in a field without further prodding.

There have been many calls for this system to be further improved. The Justice Committee of the House of Commons published a Report in 2021 on '**The Coroners'**

[174] Visit: https://www.judiciary.uk/?s=&pfd_report_type=&post_type=pfd&order=relevance

Service.'[175] Part 7 dealt with *'Prevention of Future Deaths.'* Giving testimony to that inquiry Deborah Coles (director of INQUEST) said:

> An inquest can try to ensure public scrutiny and hold people to account, but also identify false, dangerous and harmful practices, which, if put right, could prevent people from dying or being injured in the future.

The Committee commented on the wide divergence of practice between different coroners as to both the scope of their investigation and the range of evidence admitted. The Coroners' Society attested that 'local variations can affect the depth of coroners investigations' which means that PFDs – even where needed – may not be produced. The 'independence' of expert witnesses was also called into question on some testimony. For example, this allegedly happens when one side of a health trust (not the side responsible for the death) is called to give evidence against another side. The impact on bereaved families in particular was highlighted.

The limited or uneven impact of PFDs without further change was also highlighted. Coroner Andrew Tweddle testified:

> I have written many Prevention of Future Death reports over the years [...] There is a lack of a proper central hub to properly monitor such reports and to follow them up and to try and secure change. It is not the function of the coroner to suggest what improvements to a situation should be, just to highlight shortcomings, and so someone else needs empowering to take matters forward.

In this regard Deborah Coles (director of INQUEST) said:

> The very least that families are owed is that, where a report is made, those to whom it is made should make sure that they report back to families on what they have done or not done. I find it simply astonishing that we have a system that thinks it is acceptable not to keep families in the loop.

Another witness, Lisa O Dwyer, added:

> If you have a good, robust investigation process that the coroners' courts certainly can deliver on, which produces a prevention of future death report, what happens is that the report is made and you get a response. There is no independent body following that up. There is no independent oversight. There is nobody policing or monitoring it, and that is almost a waste of resources.

Sometimes, it is reported that potential addressee (typically a State agency) tries to pre-empt the issuing of a PFD report by setting out a programme of actions they propose to undertake. Of these Lisa O Dwyer said:

> Those action plans are as valuable as the prevention of future death reports themselves, and they too should be collated and publicised, and they really do need the same monitoring, policing and follow-up as a prevention of future death report.

Many witnesses commented on the limited searchability (at that time) of the relevant website that carried the PFD reports. Witnesses pointed to the better presentation and searchability of data on the Australian National Coronial Information System (NCIS).

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[175] See: https://committees.parliament.uk/publications/6079/documents/75085/default/?_gl=1*1eadcdt*_up*MQ..*_ga*MjAzOTQ5Mjg4Mi4xNzIzNzQzMDkw*_ga_9684J19FT4*MTcyMzc0MzA4OS4xLjAuMTcyMzc0MzA4OS4wLjAuMA..

The House of Commons Committee concluded:

> 207. The system for the Coroner Service to contribute to improvements in public safety is under-developed. The absence of follow up to coroners' 'prevention of future deaths reports' is a missed opportunity. The Ministry of Justice should consider setting up an independent office to report on emerging issues raised by coroners and juries; and liaise with regulators, (for example the Health and Safety Executive, the Independent Office for Police Conduct, the Prisons and Probation Ombudsman, the Care Quality Commission, Highways Authorities, and Air and Rail safety bodies) and others, to follow up on actions promised to coroners and to report publicly where insufficient action has been promised or implemented. As an alternative a new Coroner Service Inspectorate could be given this role.
>
> 208. The current arrangements for publishing coroners' reports and responses to those reports require improvement. The information published is the bare minimum and is difficult to search and analyse. The Ministry of Justice should provide funding so information about the risks to public safety discovered by coroners and inquest juries is freely available online, along with the actions that have been proposed in response. The MoJ should ensure that this information is well-organised and easily searchable.

A new Committee of Justice (House of Commons) inquiry into progress made since the its 2021 recommendations was launched in November 2023.[176] Its terms of reference included the following:

> Whether more can be done to make best use of the Coroner Service's role in learning lessons and preventing future deaths. In particular (a) are Coroners across England and Wales making consistent use of their power to issue Prevention of Future Death (PFD) reports? And (b) could the way PFD reports are being used to help prevent future deaths be improved?

The Centre of Evidence-Based Medicine at Oxford University (now at King's College London) has a '*Preventable Deaths Tracker*' project.[177] It claims that one in five deaths in the UK each year are preventable. It further claims that 12% of preventable harms result in disability. And it claims that "wider communication of coroner PFD reports, and the actions taken or proposed, could help prevent thousands of deaths." The Centre developed a web-based tracker. The rationale for the project is expressed as follows:

> While many recognise the important lessons outlined by coroners in PFDs, the lack of communication of the lessons and the insufficient auditing of the statutory requirement of responding to PFDs and taking action limits their use. As a result, our researchers created the Preventable Deaths Tracker, which is trying to change this by making it accessible to all. The Tracker also shares systematic analyses of this information, to warn against repeat hazards and highlight important lessons to improve public safety, reduce avoidable harms, and prevent premature deaths. Its Preventable Deaths Database collates and displays the data from PFDs in a visual, filterable, and searchable format that others can use to affect patient outcomes.

This Tracker is indeed a very valuable research resource and a useful model for what can be achieved in all countries that have (and should have) the equivalent of PFD reporting.

What follows is a sampling of the some of the PFD reports in the UK of relevance to persons with disabilities and older persons. It is by no means scientific but merely illustrative of the kinds of issues that can be highlighted through the PFD process.

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[176] See House of Commons, *Justice Committee Launches a New Inquiry into the Coroner Service to Examine Progress*, (November 2023): visit - https://committees.parliament.uk/work/8029/the-coroner-service-followup/news/198557/justice-committee-launches-new-inquiry-into-the-coroner-service-to-examine-progress/

[177] See https://www.cebm.ox.ac.uk/research/preventable-deaths

The relevant website (Judiciary) is searchable across domains like mental health or community care.[178] It is not directly searchable using groups like persons with disabilities. It is nevertheless a useful window into the issues that arise since many of the domains disproportionaly affect persons with disabilities and older persons.[179] From time to time the media reports on worrying trends in PFD reports.[180]

The Preventable Deaths Tracker (PDT) project reports that 30% of PFD reports have received no 'response.' Therefore it is impossible to detect if any change has happened as a result of the PFDs in these cases. And the project also categorises the type of PFD.[181] The first major set of concerns touch on hospital care (2,137 PFDs). The fourth is community health care and services (554 PFDs). The fifth is mental health care (501 PFDs). The seventh is care homes (residential institutions) and services (301 PFDs).

The issue of concern in *Re: Mavis Dewey* (August 12, 2024) was that staff failed to read a detailed care plan for Mrs Dewey (89 years old with multipe disabilities) whilst in the care of a community care home.[182] The matter of concern was reported by the coroner as "the admitted failure of agency staff, on occasion, to read care plans such that there can be confidence that residents are safe." This highlights the inadequacies of services and supports in an institutional environment.

In Re: *James Capstick* (aged 83 with multiple health conditions), the incorrect use of a defibralator in a care home led to injuries that contributed to his death. There was a suspicion that important file notes seemed to have been fabricated. The case highlights the added risks of being in a care home.[183]

In Re: *Shahide Khan* the lady in question was a resident in a care home. Lethal levels of a toxic medicine were given that hastened her death.[184] An area of concern expressed by the coroner in a PFD was "[I]n the absence of an explanation [for the administration of the drugs] there is a risk of a further recurrence where those in the care of the staff are administered toxic and fatal quantities of medications." Again, this shows the heightened risks of institutionalisation.

In Re: *Rose Holllingsworth*, the lady in question (aged 83 with many co-morbidities or disabilities) was living at home with the support of a community care service provider. Poor care provision in the home was identified as a contributing cause of death. One matter of concern expressed by the coroner in a PDF was that "[T]he failings demonstrated a poor standard of care which in other circumstances could have delayed potentially lifesaving intervention and treatment." Additionally, the carer may have had language difficulties which may have impeded her ability to communicate effecticely with Mrs Hollingsworth. This case

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[178] See https://www.judiciary.uk/courts-and-tribunals/coroners-courts/reports-to-prevent-future-deaths
[179] See Qungyang, Zhang & Georgia C. Richards, '*Lessons from web scraping coroners' Prevention of Future Death reports*,' 91.3 Medico-Legal Jourtnal (2023).
[180] See e.g., Jim Reed, Harriet Angerholm & Alison Benjamin, '*Coroners' death reports reveal rise in NHS warngings*,' BBC news webpage (8 March 2024) at: https://www.bbc.com/news/health-68425021
[181] See: https://preventabledeathstracker.net/database/death-categories/

[182] https://www.judiciary.uk/prevention-of-future-death-reports/mavis-dewey-prevention-of-future-deaths-report/
[183] https://www.judiciary.uk/prevention-of-future-death-reports/james-capstick-prevention-of-future-deaths-report/
[184] https://www.judiciary.uk/prevention-of-future-death-reports/shahida-khan-prevention-of-future-deaths-report/

highlights the importance of quality support services when an individual excercises their right to live in her own home, independently and in the community.

In Re; *Hazel Pearson* (aged 83) the lady in question had a food allergy.[185] The staff of the care home where she resided were repeatedly informed by her family of this. Nevertheless they administerd food with gluten that caused or contributed to her death. Its seems clear that if she had continued to live with her family in her own settings this would not have happened. Again this shows the added risks of living in an institution. One of the coroners' concerns in a PFD report was:

> There were other incidences of gluten ingestion at Ysbyty Maelor and Deeside Community Hospital. On the at least 4 occasions at Deeside Community Hospital there were no Datix reports completed at the time. I was provided with no evidence that additional training, refresher training or induction training deals with when such reports should be made. I cannot be satisfied and reassured that all staff are aware of when to make a Datix report and how to complete this.

A Datix report is an online report that is supposed to be prepared by staff that outlines incidents and risks.

In Re; *Anthony Friend,* (2023), the gentlemen in question was living at home and was suffering from a brain tumor.[186] There was a handover of care support from one care provider to another. Apparently, important information having to do with the proper use of a sling was not passed on between the two care support groups. He sustained a significant head injury as a result of slipping through the sling and subsequently died. The case highlights the need for seemless support to enable persons with disabilities to live independently in their own home. One of the care providers responded in part by saying:

> As a Trust we recognise that at the time of the incident we did not have a robust policy and procedure in place to support our staff in the community with regard to the removal of unsafe equipment. Since the inquest we have formulated a working group to design a new policy around equipment provision and this will cover the necessary steps and procedures for our staff, around timely removal of unsafe equipment from a patient's home.[187]

This at least shows an awareness of the issue and a commitment to do better in the future. Such an awarerness would make the right to live independently and in the community more viable.

There are several proposals for law reform of the PFD system. One is to create a new independent body to to "audit hundreds of reports each year, and to make sure recommendations are implemented."[188] Of course, the 'recommendations' are not really directives for action. Nevertheless, the point remains that there is no real follow-through on PFDs. To optimise their usefulness some form of follow-through would appear vitally necessary.

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[185] https://www.judiciary.uk/prevention-of-future-death-reports/hazel-pearson-prevention-of-future-deaths-report/

[186] https://www.judiciary.uk/prevention-of-future-death-reports/anthony-friend-prevention-of-future-deaths-report/

[187] https://www.judiciary.uk/wp-content/uploads/2023/09/2023-0336-Response-from-Herefordshire-and-Worcestershire-Health-and-Care.pdf

[188] BBC…report

In his 2023 Annual Report[189] the Chief Coroner of England & Wales asserted:

> 2.21 Individual coroners occasionally come under pressure from interested P{ersons or others to monitor the outcome of their PFD reports. In my view, this pressure is generated by the absence of any system or mechanism to oversee responses.

The Preventable Deaths Tracker project is a clear step in the right direction. To make the project viable, beyond a certain point, the users have to make a payment. Many concerned citizens probably cannot afford to do so. Although much has been achieved, more could probably be done to make the official website more searcheable. Indeed, assessments of the common challenges found across PFDs should be done and cross tabulated with the work of cognate bodies like the Care Quality Commission. A much more systemised approach to the learning would appear needed to optimise the benefit of PFDs to the reform of systems. There is a need for publications that assess PFDs domain by domain and which summnarises the basic challenges and way forward. The idea of an independent mechanism to do this has much merit.

An important policy document and associated campaign on the future of the PDF system was launched by INQUEST in 2024 called **No More Deaths.** [190] It calls for an end to preventable deaths by setting up a National Oversight Mechanism to oversee implementation of PFD reports. It covers investigations, inquests, inquiries and official reviews. It recommends that such a body be independent and accountable directly to Parliament, that it would have an advisory panel made up of families, that it would produce an annual report, that it would be empowered to highlight a lack of follow-up to PDFs and similar recommendations, that it would be given power to seek further information about failure to follow-up and that its activities should be informed by non-discrimination. It envisages that the National Oversight Mechanisms be given three key tasks:

(1) **Collation** (bringing all the information together),
(2) **Analysis** (understanding what the information represents and where the underlying systemic problems arise) and
(3) **Follow-Up** (which may entail liaising actively with bodies such as the Crown Prosecution Service, Health & Safety Executive, and the Equality and Human Rights Commission).

This is a very serious proposal and, if implemented, would mark a logical progression from the existing system.

An exceptionally interesting programme in the NHS (National Health Service, England) is the ***Learning from Lives and Deaths - People with a Learing Disability and Autistic people*** (LeDeR) programme.[191] This is an intensive review process (going beyond what coroners do). It is not confined in point of time to the death but can investigate lifecourse issues that may have evolved over the years.

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[189] Annual Report of the Chief Coroner (2023): https://assets.publishing.service.gov.uk/media/664c5701f34f9b5a56adcb16/chief-coroner-annual-report-2023.pdf at p. 16.

[190] See No More Deaths Campaign and associated docuemnts (including the key Briefing) at: https://www.inquest.org.uk/no-more-deaths-campaign

[191] Visit: https://www.england.nhs.uk/learning-disabilities/improving-health/learning-from-lives-and-deaths/

Several kinds of deaths are potentially reportable to the review process. It seems to be used mainly with respect to persons with learning disabilities or autism who die in NHS services or supports. That is to say, it does not apply generally to all persons with disabilities nor to those who are not in the care of the NHS.

The reviewer is from the NHS but is separate from and independent of care delivery services. The reporting of deaths for a LeDeR review is not mandatory. Families can submit a request for a review. An initial review is first carried out. If it does not reveal concerns or a potential for significant learning that can be applied across the board then the review is completed. If a further in-depth or Fucused Review is required then matters move to the next level where it may be conducted with the assistance of a multi-disciplinary team (if particularly complex). Reviews should be conducted and reported within six months from when communicated. Fucused Reviews are mandatory for certain categories of persons with learning disabilities or autism including Black, Asian or other minority backgrounds.

LeDer started as a pilot programme in 2017 and emerged from a Confidential Inquiry into Premature Deaths of People with a Learning Disability. Up to 8,500 deaths of persons with learning disabilities and autism have been reviewed between 2017 and 2021.

In 2021, the NHS issued policy guidance on LeDeR to put it on a more permanent basis. In the policy document it is described as a:

> ...service improvement programme which aims to improve care, reduce health inequalities and prevent premature mortality of people with a learning disability and autistic people by reviewing information about the health and social care support peopoe received. [p.4].

Local integrated care systems (ICS) within the NHS are responsible for carying out the reviews and ensuring that actions recommended are implemented. This allows learning across the regions when recurring themes emerge.

Once a year the NHS (England) produces an ***Action from Learning Report*** which looks at good practice and changes in systems that emerge from LeDer. The 2019-2020 ***Action from Learning Report*** states[192]:

> We know that too many people with a learing disability die too young and as the programme [LeDeR] continues we understand more about the circumstances that led up to those deaths. There is much more we need to do and the LeDeR programme gives us the largest body of evidence in the world about the deaths of people with a learning disability reviewed at an individual level.

One interesting case reviewed in the 2018 Report had to do with the inappropriate use of Do not Resusitate (DnR) orders (specifically Do Not Attempt Cardiopulmonary Rescusitation - DNACPR). It stated that "[the 2018] report raised concerns about instances in which a learning disability was cited as the reason for making a DNACPR". The result was that the National Medical Director of the NHS wrote to all staff in the NHS reminding them "that a learning disability is not fatal and should never be used as a cause of death or the rationale for a DNACPR order." (p. 19).

A core priciple of LeDer is the direct involvement of people with learning disabilities and autistic people as well as their family involvement.

[192] Visit: https://leder.nhs.uk/resources/action-from-learning-reports

The examples above from England & Wales show how a system designed to investigate individual instances can neverthless be operationalised to raise concerns about systemic issues. It is not perfect and there are many calls for improvement. But it at least shows what can be done. The LeDer programme is an excellent example of targeted thematic studies of the deaths of persons with particular disabilities placed in vulnerable situations (e.g., persons with learning disabilities). Further research is needed into how LeDer works and especially its link to reform. Nevertheless, the idea behind it - that the deaths of particular cohorts of persons with disabilities deserve heightened scrutiny above and beyond individual investigations - is probably one worth emulating elsewhere in the world. Indeed, if it was, that would enable a database to emerge linking many countries and this enabling deeper learning to take place.

2. Innovative Practice - Data Mining of Coroners' Reports in Australia & New Zealand to generate Recommendations for Policy Change & recent advances.

The combined approach of Australia and New Zealand builds on the English precedent. Coroners there have the option to make their own recommendations which are primarily aimed at preventing future deaths. But the Australian and New Zealand system goes one step further.

It has often been observed that there may well be an in-built bias and unevenness in the English system in that it is very much left to the discretion of individual coroners whether to provide PFD reports. Some will 'see' systemic issues and some will not. Another way to come at this is to require all reports of coroners to be uploaded onto a combined database (combining Australia and New Zealand) and to then to mine that database to search for systemic issues. Because their social systems are quite close it makes sense to combine the databases.

The mission of the National (really international) Coronial Information System (NCIS) is 'saving lives through the power of data'.[193]Set up in 2000, the database is available on request to researchers and families. It was set up to enable coroners to share data and has grown into 'an evidence base for research into preventable death.' The database contains demographic details of the deceased, contextual details of the death, cause and manner of death and searchable midico-legal reports.

On the NCIS website is a 'fatal facts' database. Essentially it allows one to search any recommendations made by coroners since 2013 to prevent future deaths. The NCIS does not undertake research of its own accord. It - the database - is predominantly used for research by Government agencies and other organisations such as research bodies and *bona fide* NGOs. Direct access may be given to approved investigators. Organisations such as OPDs and NGOs can request a data report from the NCIS. Such reports can contain aggregate statistical data and de-identified case summaries

Usefully, the NCIS website contains references to and links to the many research reports (including by third parties) done on the basis of the data contained in the database. The website organises these reports thematically. One of the thematic headings has to do with mental health. Pearse and Dakin have listed several policy areas where reform has come

[193] Visit: https://www.ncis.org.au

about as a result of research grounded on the NCIS database.[194] As yet, there is no disability sub-theme to the database - but that is entirely possible.

Interestingly, the Australian State-based Disability Services Ombudsmen have published a series of papers on the deaths of persons with disabilities based in part on the NCIS coronial database. For example, the Victoria Disablity Services Commissioner published a review of deaths of persons with disabilities receiving services (2017/2018). The NSW Ombudsman has published several reports on the deaths of persons with disabilities in residential care. And the Queensland Office of Public Advocate published a review of deaths of persons with disabilities in care based on coronial reports as well as other data points (2009-2014).

The National Disability Insurance Scheme (NDIS) of Australia has introduced a Quality & Safeguards Commisson.[195] Service providers enrolled in the national scheme are under an obligation to report all deaths and other serious incidents to the Commission. Based on the data, the Commission asked the Australian Institute of Health and Welfare (AIHW) to conduct a study on mortality patterns among people using disability support services in Australia. [196] The 2020 AIHW report found that persons with disabilities using disability services had a higher rate of mortality compared to the general population and that many of these deaths were preventable. An interesting and innovative study was published by Professor Bill Mitchell in 2018 using the NCIS database to link elder abuse in institutions with death.[197] Apart from its intrinsic interest, this points the way and shows the potential for more disability-themed studies grounded on the NCIS database.

The NDIS Quality and Safeguards Commission commissioned an independent review of its functions after the death of an NDIS service recipient who died of neglect. And the Commission collaborated with the Australian Human Rights Commission to produce a Human Rights Guidance framework for thr operation of the NDIS and service delivery (2023).[198]

Australia recently established a National Disability Data Asset (NDDA) agency. Its primary purpose is to act as a repository of data connected with the lives of persons with disabilities. An impressive submission to the Royal Commission on Violence, Abuse, Neglect and Exploitation of persoins with disabilities suggested that the NNDA should be the principal source of data and researeh about the deaths of persons with disabilities.[199] It was suggested that the NCIS database might be too narrow as it only includes deaths ocurring in services registered under the NDIS. If the NDDA undertakes this work it could be a formidable source of deep data and might provide a model around the world.

The above Royal Commission made over 200 recommendations. One was for the creation of disability death review schemes in each State and territory (Recommendation 11.14). Among other things, these schemes should, based on the data, formulate recommendations

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[194] Jessica Pearse & Leeann Dakin, *The National Coroner Information System: Contributing to Death and Injury Prevention,* 36 No.2 Health Information Management Journal (2007), 54-57.

[195] Visit: https://www.ndiscommission.gov.au

[196] See https://www.aihw.gov.au/reports/disability/mortality-patterns-of-people-using-disability-serv/contents/summary

[197] Bill Mitchell, *Identifying Institutional Elder Abuse in Australia through Coronial and other Death Review Processes*, (2018) 18 Maquarie Law Journal, 35.

[198] See https://www.ndiscommission.gov.au/sites/default/files/2024-03/Human%20Rights%20Guidance%20Paper.pdf

[199] Submission to the Disability Royal Commission, *Review of Deaths of Persons with Disabilities,* from Jim Simpson, Council for Intellectual Disability and Julian Troller, Department of Developmental Disability and Neuropsychiatry (UNSW Sydney), 24 March 2023: available on the website of the Royal Commission.

for changes in policy or practice to 'prevent or reduce' reviewable deaths and to prevent or reduce risk factors. Such bodies when created should be able, in the view of the Royal Commssiion, to conduct own inquiries into individual or group deaths and analyse data with a view to detecting trends. Importantly, the Royal Commission essentially agreed with the submission from Troller *et al* to the effect that the NDDA should have a role in gathering and analysing disability death data.

The approach of Australia and New Zealand shows the power of data to identify sytemic issues, to learn from past mistakes and to put that learning to good use in formulating and revising policy. It is a model of sorts for the rest of the world and especially in systems that aspire to be true 'learning organisations.'

Part E
Conclusions & Recommendations.

1. Conclusions.

Several important conclusions seem warranted by the above analysis.

First of all, how one ends one's life is just as telling as how one has lived it. For it is in death that we can see the cumulative impact of deprivations that, over time, affect mortality. Therefore the right to life - properly understood - is deeply affected by the *conditions for life*, the social and economic supports that give meaning to life.

The UN CRPD seems naturally attuned to this nexus between life and the conditions for life. That is because it carefuly blends rights like the civil right to life with a wide variety of economic and social rights. These socio-economic rights go to the determinants of a long life without a premature death. There is much speculation in the abstract about the relationship between civil and political rights on the one hand with economic and social rights on the other. After all, the 1993 Vienna Declaration[200] famously stated that all human rights are 'universal, indivisible and interdependent.' This interdependence actively invites us (and policy makers) to draw links and to search for interdependencies between rights – whether civil and political or economic, social and cultural. Seldom does a field present itself that so graphically demonstrates this classic interdependence. This is the case with respect to deaths (loss of the *civil* right to life) due to inadequate services and institutionalisation.[201] Persons with disabilities seem to suffer disproptionately when social support services are not adequate or when they exposed to the added risks inherent in institutions or during armed conflicts.[202] That is to say, persons with disabilities and are prone to suffer premature death (loss of life) as a result of these systemic failures.

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[200] Vienna Declaration and Programme of Action on Human Rights (1993): available at - https://www.ohchr.org/en/instruments-mechanisms/instruments/vienna-declaration-and-programme-action

[201] Inadequate services in the context of disability have been extensively commented on by the UN Special Rapporteur on the rights of persons with disabilities in his 2023 thematic report *Transformation of Services for Persons with Disabilities:* available at - https://www.ohchr.org/en/documents/thematic-reports/ahrc5232-transformation-services-persons-disabilities

[202] See generally with respect to the risks faced by older persons, Clarissa Bryant, *Beyond Bedsores: Investigating Suspicious Deaths, Self-Inflicted Injuries, and Science in a Coroners System*, 7 National Academy of Elder Law Attorneys NAELA Journal, Issue 2, (2011).

Secondly, there is an added advantage for adding a perspective to disability rights from the lens of a core civil right - namely the right to life. Advocacy for social and economic entitlements from the 'ground up' and based on economic, social and cultural rights alone sooner or later bump up against the same argument from States in practice: resource scarcity. But what if the arguments for change come additionally from the top-down – namely the need for the improvement of social entitlements in order to avoid a fundamental breach of the right to life. That certainly adds moral (and political) urgency to the need for change. To be sure, it won't directly help all – only those who stand in direct jeopardy of their life. But this extra spur for change from the 'top-down' may help galvanise the need for broader systemic change. And, as the evidence shows, sooner or later all persons with disabilites stand in jeopardy of their lives if poor services and institutions are allowed to fester. No matter how resilient, the human condition cannot outrun the long-term effects of deprivation or abuse.

Third, the fine filigree of international and regional standards on the investigation of 'suspicious deaths' or 'potentially unlawful deaths' is quite impressive. But these standards were not crafted with persons with disabilities in mind and the kinds of systemic risks thay are exposed to over a lifetime. And they are hardly ever applied consistently in the investigation of the deaths of persons with disabilities. This is not a criticism of the standards as such, but it points to the need for more work to tailor these standards to the situation faced by persons with diabilities and to add value to the dynamic of change.

Fourth, perhaps the biggest barrier in getting the best from these investigatory standards is the easy assumption that the death of a person with a disability is almost always down to 'natural causes.' A related temptation is to investigate only the most immediate medical cause of death without exploring the backstory. And the backstory may be quite revealing indeed in the life of a person with a disability. This assumption hides the many systemic factors that may be at play. Much greater awareness of the life stories and lifecourse of persons with disabilities is needed on the part of medical professionals and investigators to counteract this. Only then will investigatory mechanisms become alert to the possible systemic factors underlying a particular death. The various Public Inquiries canvassed in this Study have shown that death certificates do not always tell the truth.

Finally, international law strongly supports the idea that investigations can play a part in reform - a system for the living as well as the dead. Systems can and should learn from individual instances which, no matter how isolated, can shine a light on systemic deficiencies. And as shown in some of the examples of innovation in State practice, this learning can be put to good use in highlighting underlying problems and accellerating reform. As emphasised earlier, this is not only good in itself as it respects the letter and spirit of international law, but it demonstrates the capacity of Government to be a true 'learning organisation.'

2. Recommendations.

To States:

- States should design and implement independent and effective investigatory systems to inquire into suspicious or potentiallly unlawful deaths if they do not exist already. The *Minessota Protocol* ought to be their guide.

- States should specifically task these bodies not only to investigate individual instances but to probe the underlying systemic causes of death if the same are suspected.
- Where systemic causes or contributory causes are suspected, investigatory bodies should report back to Govenment on how similar deaths might be prevented into the future. Government and others have to learn from the analysis and change practice if required.
- Investigatory bodies should receive regular disability sensitivity training to make them aware of the lived reality and lifecourse of persons with disabilities. The reflex of the past - the implicit assumption that most causes of the deaths of persons were due to 'natural causes' - should be replaced by a curiosity into and a search for deeper systemic causes where they exist. The genuine 'indepenendence' of investigatory bodies would seem to require this training.
- The Investigatory bodies should be coordinated with other relevant regulatory bodies to ensure that the knowledge learned in their processes is used to inform the work of these regulatory bodies and can lead to an overall agenda for change.
- States should compile a composite and accessible database of such investigations. This database should be publicly accessible. Relevant disability authorities (e.g., Disability Services Ombudsman and the like) should be specifically tasked to mine the database to identify systemic risks and report to Government accordingly with recommendations on how to avoid these risks.
- An oversight body should be set up to ensure that the recommendations of investigatory bodies are tracked and implemented. This oversight body should be answerable directly to Parliament.
- States should be aware of, and motivated to learn from and improve, innovations such as the 'prevention of future deaths' reporting in England & Wales and the combined databases of Australia and New Zealand).
- States might also consider the in-depth thematic studies of deaths conducted by the UK NHS LeDeR programme as a model for how such standing commissions of inquiry into the deaths of persons with disabilities might work. It is to be noted that the *Minessota Protocol* creates space for such commissions to function alongside nornal investigatory bodies. Such a standing commission might focus on groups at particular risk which may differ from country to country.
- States should adhere to the *Istanbul Protocol* with respect to the proper investigation of suspected torture, inhuman, cruel or degrading treatment. They should apply this with great sensitivity to the treatment of persons with disabilities whether in intitutional settings or in the community. The link between such abuse and the early mortality of persons with disabilities should be frankly acknowledged and more fully explored.
- The mortality rates of carers is a particular concern. States should pay closer attention to the conditions experienced by carers and the need for support to avoid needless deaths. The decision of the CRPD Committee in *Bellini* (right of family carers to support) needs to be taken as a fresh cue to re-think how carers are supported to enable persons with disabilities to live their own lives independently.

To UN TreatyBodies:

- The UN Human Rights Committee might further develop its concept of '*prevention*' with respect to the right to life in the context of disability to ensure that investigations

- to be effective - should probe the underlying systemic risks faced by persons with disabilities.

- The concept of a '*reasonably forseeable*' threat to the right to life in the jurisprudence of the UN Human Rights Committee might be further developed in a disability context to include matters that are particularly relevant to their lives such as inadequate services and supports.
- The UN Committee on the Rights of Persons with Disabilities should consider drafting a General Comment on the right to life (Article 10 of the UN CRPD). Such a General Comment could usefully draw attention to the '*conditions for life'* as well as the substance of the right itself. In so doing, the Committee could help develop further and contribute to the international debate about the interdependency of civil and political rights (in this instance the right to life) with economic and social rights which go to the *'conditions for life*.'
- The UN Committee on the Rights of Persons with Disabilities should develop further the so-called procedural dimension to the right to life; *vis* the obligation to carry out an investigation into suspicious or unlawful deaths of persons with disabilities. It should make clear that this includes an obligation to probe underlying systemic causes - if suspected - and to report this learning back to Government for action.
- The UN Committee on the Rights of Persons with Disabilities should routinely probe States Parties in their periodic reports on mortality data affecting persons with disabilities and the reasons why variations occur as between groups and over time .
- The UN Committee on the Rights of Persons with Disabilities should consider using a more intentional lifecourse perspective on the rights protected by the UN CRPD. This perspective should be informed by the cumulative impact of even minor inequalities over a lifetime and its contributory effects on the mortality of different cohorts of persons with disabilities.
- The UN Committee on the Rights of Persons with Disabilities should continue to be vigilant about threats to life presented in institutions. It should also develop an understanding of broader and insidious threats to life in the community including social isolation and loneliness that may go unreported and under the radar.

To the UN Hnman Rights Council:

- The UN Human Rights Council should consider holding a day of discussion on the threats to the right to life for persons with disabilities and especially the risks that arise from the effects of inequalities over a lifetime.
- The UN Human Rights Council should consdier adopting a Resolution on the duty to investigate the deaths of persons with disabilities and to tailor such investigations to probe systemic causes and contribute to the process of change.
- The Special Rapporteur on extra-judicial, summary and arbitrary executions might consider drafting a thematic paper on the investigation of the suspicious deaths of persons with disabilities focusing in particular on systemic causes.
- Complementary thematic work on the deaths of other marginalised groups (and the quality of investigations into them) might usefully be carried out by other Special Mechanisms including the UN Special Expert on the enjoyment of all human rights by older persons.

To Regional Organisations.

African Union

- The African Disability Institute (proposed in the African Union Disability Strategic Framework of 2019) could play a hugely useful role in helping to design investigatory mechanisms across Africa and ensuring that they are used effectively to probe the underlying systemic causes of the mortality of persons with disabilities. It could help provide the protocols for connecting the databases of individual countries to a future merged continental database that could drive meaningful policy-oriented research in the future using the combined Australian/New Zealand database as a model.
- The African Commission on Human and People's Rights might further develop its very positive notion of the *'conditions'* for the right to life under the African Charter to include, specifically the 'conditions' of life considered essential for persons with disabilities.
- The proposal in the African Union Disability Architecture to create an inter-ministerial epidemiological surveillance system is welcome and should be used to generate useful social epidemiological research on the systemic causes of the deaths of persons with disabilities across Africa.

Organnisation of American States

- The jurisprudence of the Inter-American Commission and Court to the effect that the conditions for life must receive attention is welcome and should be built on.
- The OAS Special Rapporteur on the rights of persons with disabilities might consider doing a thematic study on the right to life of persons with disabilities and focus particularly on how investigations should be conducted and how they might reach and report on underlying systemic causes in keeping with the Inter-American Court's emphasis on the *conditions* for life.
- The concept of compensation for the interruption of 'life plans' in the caselaw of the Inter-American Court should mean compensation for the loss of the lives of persons with disabilities due to inadequate or poor services and supports (the essential *conditions* for life). More caselaw is welcome.
- The expansive reading by the Inter-American Court of the obligation of non-discrimination in *Gachala Chimbo* as applied to disability has tremendous potential. It too can be extended to include a consideration the *conditions* for the right to life whether in institutional or community settings.

Council of Europe

- The Committee of Ministers of the Council of Europe might consider adopting a Recommendation (policy guidance) to its Member States on the proper investigation of suspicious deaths of persons with disabilties based on the caselaw of the European Court of Human Rights. It should highlight the need to use the investigatory system to probe underlying systemic causes and to use this learning to inform meaningful change. This would build positively on the recent impressive ruling of the European Court of Human Rights in V*alidity, T.J. v Hungary (*2014). The emphasis by the European Court in *T.J.* on the absence of an investigation into the *systemic* causes of death should be the essential departure point in any new Recommendation.
- In his country visits, the High Commissioner for Human Rights should query states on their data concerning the mortality of persons with disbilities. He should examine how robust the investigatory mechanisms are and whether they are configured properly to get at the underlying systemic causes. He might consider adding to his important disability thematic work by examining such investigatory mechanisms.

- Member States or the Secretary General of the Council of Europe should consider requesting the Venice Commission for Democracy through Law for an opinion on the optimal arrangements for investigations into the deaths of marginalised groups like persons with disabilities in line with best practice internationally and geared specifically to highlight underlying systemic causes and help remedy them.

To OPDs and NGOs.

- OPDs should engage with investigatory mechanisms to ensure that the voices of persons with disabilities are actively listened to and to ensure that the systemic causes of deaths affecting persons with disabilities are adequately probed and fully reported on.
- OPDs should follow-through on reports from investigatory bodies that highlight risks confronting persons with disabilities and that propose recommendations for change. These reports should be kept in the public eye with a view to maintaining the momentum for positive change.
- OPDs should partner with NGOs involved in these investigatory processes to ensure mutual learning and to ensure the very best outcomes.
- NGOs generally involved in investigatory processes that affect persons with disabilities should familiarise themselves with the lived realities of persons with disabilities and liaise actively with their representative organisations.
- Public Inquiries into the deaths of persons with disabilities afford a unique opportunity to highlight systemic issues and should therefore engage maximum attention. All outcomes should be built on in the advocacy strategies of OPDs.

To Research Bodies

- Further research needs to be done on the specific risks confronting different cohorts of persons with disabilities adopting a lifecourse and intersectional perspective. Such research should be intersectional with a particular focus on sub-groups most at risk such as persons with intellectual disabilities, persons with psychosocial disabilities, indigenous persons with disabilities, as well as women and girls with disabilities and carers.
- While paying attention to the risks attached to various forms of institutionalisation it should also probe the many risks faced by persons with disabilities in the community arising from poor services and supports and including the long term effects on mortality of social isolation and loneliness.
- This research should not focus primarily on the particular health risks arising from the condition of the individual due to their disability. It should focus primarily on the risks arising from their overall conditions of living and especially over a lifetime using insights from s*ocial epidemiology* - the study of the patterns of advantages and disadvantages in life that affect health and mortality.
- This research should be communicated effectively to Government and to the private sector as relevant (including service providers) to ensure that key risks are identified, prioritised and rectified.
- Such research should be conducted in a collaborative and participatory manner with the cohorts of persons with disabilities directly affected and their representative organisations. Researchers may not be aware of the myriad of sometimes invisible yet highly potent inequalities that may predispose one to an early death. Such active

collaboration would play a significant role in sensitising them (and Government) to the real variables at play.

- Research should always aim to be policy-oriented with the goal to add value to the process of change.