

# SUPPLANTING THE *PRAIRIE* FOR *PASTURES* ANEW

Scientific Advances and Forensics of The Perplexing Minority  
Complex Health Presentations / Rare Diseases / THE HUMAN CONDITION  
versus

The Fii Flawed Model of Child Protection or Safeguarding

Westminster Health Forum Policy Conference

## PRIORITIES FOR RARE DISEASE RESEARCH, DIAGNOSIS, AND CARE IN THE UK

When Health and Education Collide, what are the Priorities for Children and Young People?

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*“Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.”* (WHO 1946)

*“The test of the morality of a society is what it does for its children.”* — Dietrich Bonhoeffer

*“One cannot educate a dead or unhealthy child.”* — Janet Willicott

*“In 1939, Hitler implemented acting on T4, which led to the murder of 3000 disabled people while sterilising an additional 400,000; the secret program developed the gas chamber technology used in concentration camps during World War II; the history of disabled lives has slowly been forgotten. Many of those lives were Children.”* — Ashley Eakin

*“My government is here to protect me; it’s not about me, having to protect myself from my government.”* — Janet Willicott

This article is written where possible as an easy read – accessible for all.

To comprehend the gravitas of my article, the reader must first understand that the UK Government has two primary legal dut: caringing for its citizens.

A. To keep safe all of its citizens from harm/undue harm.

B. To keep all of its citizens healthy by virtue of The Health Principles:

**9 HEALTH PRINCIPLES 1946 – Ratified by our Sovereign State – into UK Legislation, in which said State has a wide Margin of Appreciation.**

1. *Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.*
2. *The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.*
3. *The health of all peoples is fundamental to the attainment of peace and security and is dependent upon the fullest co-operation of individuals and States.*
4. *The achievement of any State in the promotion and protection of health is of value to all.*
5. *Unequal development in different countries in the promotion of health and control of disease, especially communicable disease, is a common danger.*
6. *Healthy development of the child is of basic importance; the ability to live harmoniously in a changing total environment is essential to such development.*

7. *The extension to all peoples of the benefits of medical, psychological and related knowledge is essential to the fullest attainment of health.*
8. *Informed opinion and active co-operation on the part of the public are of the utmost importance in the improvement of the health of the people.*
9. *Governments have a responsibility for the health of their peoples which can be fulfilled only by providing adequate health and social measures.*

#### **CARE:**

- the process of protecting someone or something and providing what that person or thing needs (Cambridge Dictionary)
- the provision of what is necessary for the health, welfare, maintenance, and protection of someone or something. (Oxford Dictionary)

#### **THE SIX PRINCIPLES OF CARE / SAFEGUARDING**

First introduced by the Department of Health in 2011 but now embedded in the Care Act 2014, these six principles apply to all health and care settings.

##### **1. Empowerment**

People being supported and encouraged to make their own decisions and informed consent

##### **2. Prevention**

It is better to take action before harm occurs.

##### **3. Proportionality**

The least intrusive response is appropriate to the risk presented.

##### **4. Protection**

Support and representation for those in greatest need.

##### **5. Partnership**

Local solutions through services working with their communities. Communities have a part to play in preventing, detecting and reporting neglect and abuse.

##### **6. Accountability**

Safeguarding is everybody's business. Everyone must accept that we are all accountable as individuals, services, and organisations. Roles and responsibilities must be clear so that people can see and check how safeguarding is done.

Have [we] the modern homo sapiens not learnt? Has [society] not learnt? Why do we teach history? What is the purpose of history? It is to document something for the sake of it. What is medicine? What is Science? More importantly, what is Health? Why do we have Jus? [Law] and are we, the so-called 'new homo sapiens', actually or really that advanced?

Are we regressing or devolving for that path of renewal - How are we to know? However, the author does know that science seems to be an agenda for renewal or regression. If science is that much of a plan, why does our government not even consider it when setting the political framework for underpinning health and safeguarding? Why is science referred to as being the

holy grail, when medical, legal and educational professionals ignore it? Is emergent science a priority in terms of understanding the human construct?

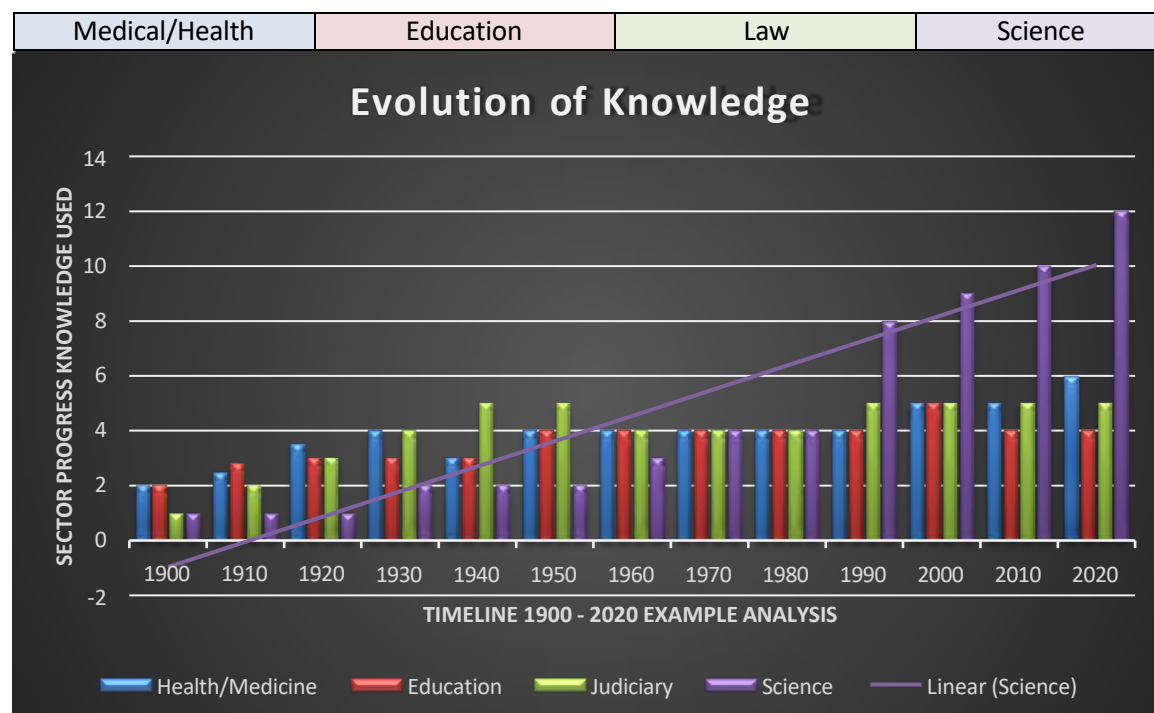
At this point, the author senses the reader becoming confused...or even *perplexed* about the relevance of the article topic; are the first two paragraphs under 'accountability' about the priorities for Rare, Complex, Perplexing Diseases or Conditions, which often give rise to disabilities or differing-abilities?

Moreover, what is the relevance or link to the latest 'kid on the block', i.e., the exponential acceleration of Fii (Munchausen's by Proxy) and course, imprisoning parents, in particular, [mothers], especially when their children struggle to attend 'school' or have complex health anomalies?

Every corner of our planet is intrinsically linked; life is a series of micro and macro links that form intricate chains, holding life together. So, before a government addresses *their* priorities, the author, as an independent professional and society's minority, must also have **their preferences** heard.

A rare disease is a life-threatening or chronically debilitating disease that affects five people or fewer in 10,000 and requires special, combined efforts to enable patients to be treated effectively. (*UK Strategy for Rare Diseases DfH 2013*)

Let's demonstrate the lack of links or rather the lack of progress that links the four main sectors together, most notably the sectors that create a betterment of society:



The author has used a simple graph, where she plots her research findings based on her interactions with Disabled Parents and Children or those with Rare Diseases and Complex or Perplexing Children within the UK School Framework. The parameters used to determine the discrepancies of progression are found within the sectors of Health/Medicine, Education, Judiciary (The Law) and Science. The plot uses a simple example number, with (1) being a general starting block of knowledge and (10) being the current position of expertise within each sector.

It is very clear from the data above that new science (linear), i.e., Genetics / DNA analysis, is emerging and rapidly at that; however, the co-reliant sectors that need this scientific data haven't or rather don't apply this emerging data for their sector improvements and progressions. It is this very ignorance that allows for the 'minority' who are not a priority to continue to receive disproportionate care and support, let alone understanding.

One of the departments for children within the health and medicine sector is the under-resourced Child and Adolescent Mental Health Service (CAMHS), which routinely fails children simply because it uses subjective analysis and not the linear emerging hard science. [They] routinely state that the parenting skills at fault or the overanxious mothers' reliance on Dr Google give rise to 'complex presentations'; however, according to most professionals, the child 'looks fine'. This approach could be seen to bypass the understanding of complex and or perplexing presentations. The patient then leaves the services without supportive therapy, and their needs go unmet.

The government is trying to prioritise these rare diseases or known/unknown complex conditions as are the sectors. Still, it is not like disabled people and or complex and or perplexing humans have never existed before. MASH agencies, including NHS, CCG, Local Authorities, Primary Care Trusts, and Schools, should and must coordinate care and support effectively but regrettably fail to share accurate reports or data appropriately. Personalised health records are not easily accessible by healthcare professionals; more worryingly, the patients' records are inaccurate, but even more alarmingly, those who produce documents that contain erroneous information are often not trained or are specialists in complex or perplexing conditions.

These subjective medical opinions or views, along with inaccurate records, are passed onto Social Workers, who assume that these Professional Safeguarding Leads are accurate. There is no independent analysis to determine whether these records that social workers rely upon are correct. General professionals generally do not understand complex conditions.

Safeguarding guidance or the forensic safeguarding models do not support or serve Children/Young People with these very complex conditions. These very children who need support and care are removed under safeguarding processes.

It is not all about genetics either; not all conditions can be 'tested for', hence why we have perplexing or complex behaviours. There are no genetic or definitive diagnostic tests, so no curative or effective symptomatic treatments exist. Therefore, following this 'no cure' or 'nothing wrong' with these patients, by lack of evidence, allows patients to be dismissed.

Their phenotypes (expressions or behaviours) of the known or unknown condition are not taken seriously or dismissed as a fabrication. Concernedly, this dismissing means the person or persons are never afforded their right to effective treatment or support. Most parents (mothers) are now being accused of Munchausen's by Proxy or Fii (Fabricating Inducing Illness) when their children are unable to attend school due to these very perplexing and or complex phenotypes. Some mothers end up being criminally prosecuted, have their children removed and have also committed suicide because of the impact of wrongful decisions.

Patients or the people living with these complexities are, in fact, the experts; they are living with their symptoms. Rare diseases and all complex or perplexing health concerns all share the same link...(not enough data), or clinical, therapeutic or medical professionals don't know enough about the complexity. Patients' records are then left incomplete, treatment is often denied, and the patient is left to suffer.

This incompleteness or lack of data allows educationalists and social workers to fill in the gaps. These gaps or lack of evidence are then recorded as safeguarding concerns, leading to more allegations of Fii. The children/young people are then placed under child protection and or are removed under the guise of needing protection.

The below list is not exhaustive; however, it details some of the participant's unique, complex and perplexing conditions, which are now regarded as fabricated by ill-informed or non-specialist professionals.

▪ Allergies	▪ Mast Cell
▪ Anxiety	▪ ME
▪ AUTISM	▪ Mental Health
▪ Bowel and Gut Disorders	▪ Mobility Disorders
▪ Catatonia	▪ PANDA - Paediatric Autoimmune Neuropsychiatric Disorder Associated with streptococcal infections
▪ Chronic Pain – CRPS – Regional Pain	▪ PANS - Paediatric Acute-onset Neuropsychiatric Syndrome
▪ EDS – Ehlers-Danlos syndrome	▪ POTS
▪ Fibromyalgia	▪ SETD 5
▪ Genetic Rare Syndromes	▪ Sleep Apnoea
▪ Hidden Disabilities	▪ SWAN
▪ Lyme Disease	▪ Trauma (C-PTSD/PTSD)

Most of the above conditions or complexities require several or repeated investigations. This very (several or repeated) notion triggers a safeguarding red flag. This red flag is a criterion embedded into the Safeguarding / Child Protection Model used by the professionals mentioned above to 'safeguard'.

This very 'model' that should protect children or young people is, in effect, causing them to be harmed by the very government that needs to protect them. The Human Condition and its innate, intrinsic intuition that's hard-wired into the human genome has, by all accounts, been omitted from the safeguarding guidance.

Whether human or found on the roaming plains of Africa, mothers are all the same. All living organisms can be placed in one of six different animal kingdom classifications. We humans are part of the animals. The Animal = A kingdom of complex multi-celled microorganisms that do not produce their food. This kingdom contains all living and extinct animals. Examples include elephants, whales, and humans.

Therefore, mothers are hard-wired to pick up on every subtle nuisance their offspring express for protection and survival. Mothers instinctively know when something is 'not quite right' with their children, yet sometimes they lack articulation when explaining the 'not quite right' expression. Then, the health/medicine sector needs to listen rather than dismiss the mothers' concerns.

The new Rare Disease Framework 2021 (January 2021), which supersedes the previous [Strategy for Rare Diseases 2013], specifies that all professionals involved in a person's care must work together. The Rare Disease Framework includes all conditions, i.e., rare and unique conditions, complex or perplexing conditions, conditions without a name, phenotypes still being studied under genetic services, etc.

The UK NICE Guidelines offer specific clinical reference support pathways, but again, there remains a funding discrepancy, thus giving rise to scientific researchers struggling to complete their findings; therefore, data never being submitted for professional use. It must be known for the record, as was stated in this conference, that those with rare diseases are seen as a minority, hence lack of funding, which equates to a clear: **those with complexities are not a priority.**

Priorities must be afforded to **all** patients with complex and perplexing presentations in that children and young people's behaviour is understood for suitable education/schooling. As an independent researcher, I continuously observe health professionals, which includes the **one** named GP Lead and the **one** named Paediatrician Lead. These **two** leads are often untrained in complex/perplexing conditions, thus causing **significant harm** in that the very children they are trying to protect are torn from their families and removed into care.

The judiciary, educational and health sectors have not linked the scientific evidence to the underpinning of why these complex presentations occur. Therefore, the secondary priority for Rare Disease pathways must include amending the safeguarding model thresholds so that children / young people are not removed from parental care. The current and outdated model of child protection is built around a theory made famous by the often referred to disgraced *Meadows*. Regrettably, Meadow's approach has gone on to infiltrate rare diseases and complex and perplexing conditions in that the most vulnerable of humans are now left severely harmed or without treatment. It is time to seek *pastures* anew.

Rare diseases/complex or perplexing conditions do not cause safeguarding but instead, give rise to patients needing to be understood, listened to, and supported.

Why does it have to take an independent researcher to join the dots? Where has person-centred care and support gone? Whatever happened to individualised care? The priority is so great that it requires national orchestration and facilitation of and by all professionals, including the NHS Digital Network, to challenge the status quo.

The scientific knowledge is there; it is simply not accessed. Scientific analysis is rising exponentially; why then is it a 'culture' of – we have not done it this way, for it to be an excuse not to apply science? Why is science not married to the outdated education, law and health sectors? The Sector 'Systems' mentioned above are no longer fit for modern mobility.

Whilst we are not murdering our disabled under a '*T4 Euthanasia Programme*' [Nazi Germany], little has changed, as really, euthanasia has transferred into ignorance and dismissing of the disabled by ill-trained professionals, thus causing those with complexities, to end up dead or severely harmed anyway eventually.

The collective MbP / Fii ignorance was based on a theory by a known disgraced doctor (well documented), only to become unravelled; sadly, lives were lost because of Meadow's unprofessional approach.

The author asked @Prof Dame Hill - how she or rather the NHS propose to support the Judiciary in their understanding of Complex Health matters / Rare Diseases - especially when children and or young people are being removed from their families because their parents (mothers) are simply seeking support for their child's complexities.

The author further stated that the High Court (Family Division) must be trained to understand rare diseases/complexities so that a framework is established to prevent mothers from being accused of Munchausen's by Proxy / Fii. Moreover, professionals speaking at this conference stated that a Rare Diseases/Complex Presentation Passport would likely become necessary to help support the 'minority' having a voice.

***[Janet Willicott – Independent Public Health Combined Forensic Scientific Fellow - Legal Researcher for SEND Educational and Health Outcomes and Neuro Plasticity Models. Poor PhD Student & APPG SEND Adviser. Woman, Mother, Carer and Outspoken Campaigning – Political Advocate for ALL children. Hobbies: Educational Neuroscience, Hoarding Mint Chocolate, Ultra Running.]***

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Key priorities for rare disease research, diagnosis, and care in the UK.

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