2019 JCU SPEECH-LANGUAGE PATHOLOGY STUDENT SHOWCASE

COMMUNICATION & HUMAN RIGHTS WITHIN SPEECH PATHOLOGY

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Bill Mitchell, Principal Solicitor

Townsville Community Legal Service Inc.

ACKNOWLEDGEMENTS

I acknowledge that we are gathered on the lands of the Bindal people. I pay my respects to their elders, past, present and emerging. With your consent I will use the diminutive 'speechie'.

I thank Professor McLeod for her introduction. She contends "everyone should uphold others' right to communicate as they interact with people in daily life in order to enhance equality, justice and human dignity" (McLeod, 2018). Professor McLeod understands that human rights is a lens through which we see distinct visions of Australia. At its widest aperture, you see whether our notion of a 'fair go' is rhetoric or reality. When focused on the individual, their lived experience becomes visible. We gather here tonight to sharpen your focus.

INTRODUCTION

On 1 January 2020 the *Human Rights Act 2019* (Qld) (the Act) will commence. It will bind all persons, including the State and to a lesser extent the Commonwealth. It took us 70 years after the 1948 Universal Declaration of Human Rights to legislate in Queensland. We join the ACT and Victoria as the third Australian jurisdiction to protect human rights. The Universal Declaration was born out of the atrocities of the World Wars and was the first truly global human rights document. It is a common standard of achievements and aspirations for all peoples and all nations. It set out the fundamental human rights to be universally protected.

The Queensland Act draws on the Universal Declaration and other instruments for its content. It begins by noting that "Human rights are essential in a democratic and inclusive society that respects the rule of law." The Act cautions that human rights should be limited only after careful consideration, and only where justifiable in a free and democratic society based on human dignity, equality, freedom and the rule of law.

Section 3 sets out three main objects, which are like strategic goals:

- to protect and promote human rights;
- to help build a culture in the Queensland public sector that respects and promotes human rights;
- to help promote a dialogue about human rights.

The Act uses a 'dialogue model' between the three arms of government:

- the Courts through interpretation of laws and adjudicating rights;
- the Parliament through making and scrutinising laws; and
- the Government through developing policy and administrative decision making.

Each of these three processes is assessed against the 23 human rights in the Act.

Your profession is part of this dialogue in three ways.

Firstly, you work for entities exercising public functions that must comply the Act. Secondly, a human rights approach is best practice. Thirdly, your dual role: as providers of allied health services, and as human rights defenders.

Let's set the scene.

COMMUNICATION CAPACITY

Large group studies of children with communication support needs report lower academic performance, reading difficulties, more bullying, poorer peer relationships, and higher rates of psycho-social difficulties (McCormack, 2018).

The Senate's (2014) Speech Pathology Report noted these impacts continue into adulthood:

> *Failing to treat childhood speech, language and communication disorders contributes to significant lifelong problems. These include limited employment options often leading to periods of unemployment, a dependence on welfare, the psychological and emotional distress to the sufferer and their family and carer, and in many cases interactions with the justice system. Accordingly, diagnosing and addressing speech, language and communication problems in childhood are crucial to an individual's wellbeing and to the level of services and supports that society must provide.*

The Senate did not mention human rights but drew a roadmap for your profession. You engage at both ends of the life course, and throughout. You see those destined for disadvantage, and the later life outcomes of that predestination. You see the social determinants of health play out in mid-life when things like strokes or brain injuries occur. O'Halloran (2017) cleverly said, you see "the consequences of the consequences". Lawyers see legal issues clustering around these consequences. We are all seeing the co-morbidity of life course issues. Recognising what we are seeing matters a great deal for how we do our work.

I mentioned the wide aperture earlier so let's begin with the big picture.

1.2 million Australians have some level of communication disability, ranging from those who function without difficulty in communicating every day but who use a communication aid, to those who cannot understand or be understood at all (ABS, 2015). Australia's growing and ageing population means those with communication support needs is increasing. The importance of communication rights goes beyond just enabling freedom of opinion, expression and language. Communication rights enable people to realise other rights. Speechie's work enables communication, asserts communication rights and thereby guarantees other rights.

Santow (2018) described the importance of communication rights:

> *Humans cannot live or thrive in isolation. We are inherently social. As such, communication is essential to our humanity. It is important to our expression and self-determination as individuals, our sense of belonging within a community, our inclusion and participation within society, and in acknowledging the meaning and value of ourselves and others.*

Communication rights are ‘cross-cutting’ ‘enablers’ of other rights. Through your work you move people from objects of charity to rights-bearers. Communication rights encompass a broad concept of communication capacity. It includes the totality of a person’s social connectedness, and limitations and enhancements of that capacity (Hopf, 2018).

The impact of your work is felt widely given Australians with communication support needs are at least 5% of our population. Within this cohort, over two-thirds also have mobility limitation and almost half have self-care limitations. More than one third reported schooling or employment restrictions (ABS, 2015). Estimates suggest up to 20% of the population could benefit from communication support. However, this figure does not include those with literacy difficulties. The potential population of Australians with communication support needs rises considerably if we include low literacy, and culturally and linguistically diverse backgrounds. Children with communication disorders were the second highest area of learning need at 13% (APH, 2014). This is in addition to other learning needs that might involve a speechie (APH, 2014).

Your clients are from all age cohorts but obvious groups are children and older persons. Both groups’ identities are socially constructed by reference to their chronological age. Both experience blurring around their social identity. Blurring that creates conundrums about autonomy and independence, legal capacity and agency and builds barriers to equality and non-discrimination. Barriers to communication access include environmental, structural, attitudinal, informational and temporal. That serious barriers to equality exist is borne out by the data: Almost half with communication support needs did not have their needs met (ABS, 2015). Three out of five were children.

Those with communication support needs had significantly lower labour force participation rates than other disability (ABS). The only area where labour force participation was higher than both ‘other disability’ and ‘without disability’ was in physical labouring (ABS). Three-quarters experienced employment restrictions; more than one-quarter had difficulty changing jobs or getting a preferred job, and 16% were restricted in the number of hours. Forty percent reported they were permanently unable to work because of their condition(s) (ABS).

People with communication support needs earn less, experience social isolation, loss of autonomy, restricted activities and stigmatisation. They are at greater risk of violence, poverty and homelessness. They lead poorer lives in all respects.

DYSPHAGIA

Another primary concern for you is dysphagia. It gives rise to a range of human rights issues. One sufferer described dysphagia as akin to waterboarding - an infamous style of torture, but all day, every day (Nelson, 2016). The general prevalence is 16- 23% but much higher for older persons (Smithard, 2016). Recent studies show as many as 1 in 4 independent (65+ years) and 1 in 2 dependent (85+ years) suffer dysphagia (Igarashi, 2019).

Choking and aspiration are major public health issues for institutional and home care. It requires a careful balance of rights including autonomy, dignity of risk and nutrition (Cichero, 2018). Dysphagia is both a contributing factor to frailty and a consequence of it (Hathaway, 2014).

Now we know what your big picture looks like, let's consider your 3 engagements with human rights, beginning with speechies in the public entity space.

SPEECH-LANGUAGE PATHOLOGISTS AS PUBLIC ENTITIES

Speechies who are employees of entities exercising public functions will have to comply with the Act. Public entities must act in a way compatible with human rights. This includes the public service, local government, and agencies with public functions. Public functions include public emergency, health, disability and education services. It also includes National Disability Insurance Scheme (NDIS) providers.

Speechies work in a range of public entities. Your occupation's demand has doubled in five years, but supply is tight. The NDIS has increased opportunities but has revealed a disconnect between health and disability sectors. I think this disconnect includes some of the inherent tensions between the medical, social and human rights models of service provision.

The NDIS gives some insight into the human rights approach. The NDIS' objects include to "give effect to Australia's obligations under the Convention on the Rights of Persons with Disabilities". The NDIS reinforces the social model of disability with a human rights focus.

It is important to note the differences between the various approaches:

> *While the medical model of disability reduces the disabled individual to her impairment, the social model dissects disability as a social construct and debunks exclusion and denial of rights on the basis of impairment as ideological constructions of disability. The human rights model builds on the social model in that it is built on the premise that disability is a social construct but it develops it further.* (Degener, 2016)

The human rights approach has some critical differences:

- Universal human rights do not require a certain health or body status.
- Human rights include civil, political, economic, social and cultural rights that are indivisible and interrelated.
- Human rights treats impairment as a condition that might reduce the quality of life on one hand but belongs to humanity and thus must be valued as part of human variation.
- Human rights values different layers of identity and acknowledges intersectional discrimination.

I want to emphasise the importance of a global approach by a brief example. At a recent Royal Commission hearing, a woman's personal narrative included a lifetime of mixed and changing diagnoses: hearing impairment, speech disorders, dyslexia, psychiatric disorder, autism, personality disorder. Overwhelmingly, her principal needs, as she identified them, were communication support

needs. She said: no-one would listen, and when they did, they did not understand. Consequently, the system didn't respond to her progressively worsening educational attainment, and later on her limited work prospects and growing poverty. Nor did the system intervene in the cycle of violence that enveloped her. Her case was not unique or even rare in my experience.

Her story typifies how communication support needs cannot be approach solely through a medical model, and its assessments and diagnoses or even the social model of disability. A human rights approach ignores labels; it says rights are universal and inherent to us all.

HUMAN RIGHTS PRACTICE IS BEST PRACTICE

My second point is that even if your practice is not part of a public entity, a human rights approach is still best practice. Speech Pathology Australia has a myriad of policies that reflect this approach: scope of practice, principles of practice, parameters of practice, charters, code of ethics, clinical guidelines and position statements. SPA's key guiding ethical principles align with well-established human rights principles:

ALIGNMENT OF HUMAN RIGHTS WITH SPA PRINCIPLES	
Human Rights-Based Approach	**Spa Key Guiding Principles**
Participation	Autonomy
Accountability	Integrity
Non-discrimination and equality	Fairness
Empowerment	Beneficence and non-maleficence
Legality	Truth

Speech Pathology Australia's Key Purpose Statement recognises the rights of individuals to possess an effective form of communication and swallowing. While this statement underplays your impact in the community, its use of rights-language is critical. Doell (2018) suggests a human rights lens provides an opportunity to specifically focus on the impact on children with communication disorders and families receiving the service. Children are empowered when adults support them to express their needs, aspirations and dreams and seek to understand their perspectives and lived experiences (Doell, 2018).

Your practice approaches already include understanding and applying intersectional methods. The benefits of combining lenses of inquiry furthers the pursuit of social justice and creates a stronger focus on deconstructing social barriers of exclusion (Smyser-Fauble 2015). It recognises the value of experiential knowledge and patient narratives. Intersectionality recognises the importance of communication access for social inclusion and well-being. Communication access is a critical manifestation of autonomy. Last year in the UN I argued that if human rights are steps in a ladder, autonomy is the bottom rung without which further steps cannot be reached. Communication access is part of that bottom rung.

SPEECH-LANGUAGE PATHOLOGISTS ARE HUMAN RIGHTS DEFENDERS

Thirdly, you are already human rights defenders. This includes as health service provider and cross cutting enabler. There is a third involvement – that of human rights advocacy. Clearly speechies are best placed to advise policy-makers about Australia's communication support needs. You just need to speak up! Wickenden (2013) suggests speechies could broaden their lens and become much more political animals and get more involved in changing understanding and attitudes about people with communication disabilities (Wickenden, 2013). This preventative advocacy work fits neatly within a public health or socio-ecological model.

Returning to your dual roles.

Firstly, you work within entities performing public functions such as education, health or disability services. The public entity's and your actions and decisions must be compatible with and considerate of the 23 human rights under the Act. In doing this you will be at the coalface of human rights work.

Secondly, your work as an enabler. I am going to work my way through this list of human rights from the Act and give examples of your likely engagement. I have dealt with them in clusters.

We have begun to understand that many human rights guarantee aspects that are linked to selfhood. Accordingly, the first cluster is **autonomy, agency and identity**.

Freedom of expression rights (s.21) are fundamental rights that contain a personal and a social dimension. They are indispensable conditions for the full development of the person (Howie, 2018). These rights are highly contextual. For example, Lundy (2007) suggests children's right to participation includes four elements: space, voice, audience and influence (Lundy, 2007). Audience suggest the child's voice must be listened to, and influence suggests it must be acted on. By contrast, legal guarantees about free speech in recent High Court decisions emphasise that free speech rights are not a right to force an unwanted message on those who do not wish to hear it.

Free speech is hotly debated but poorly understood. Even more poorly understood is the right to be able to communicate. The distinction is paramount. Most who trumpet free speech rights don't have to worry about their ability to speak. The right can be conceived in three parts: 1. the right to communicate (share ideas and information with others), and, by implication, 2. the right to be able to communicate (to have a mode of communication) and 3. be understood (McCormack, 2018). The right also implies the right to information in accessible written forms, known by many terms. This is a challenge for all professions.

Many of your clients have difficulty **taking part in public life** (s.23) engaging with our democratic processes – voting, engaging in political activity – things we value and take for granted. Studies show that persons with communication support needs can achieve full participation in society with resourcing and support (Rvachew, 2018). The use of social media has been explored as a method of improving participation (Hemsley, 2018)

It is vital that we do not presume people communication support cannot engage in democratic processes. In the US, voting by persons with disability surged 8.5% in 2018 though those with mental or cognitive impairment were still lowest among all groups at 37% (Schur, 2018).

Recognition and equality before the law (s.15) requires that people are treated equally before the law. It promotes inclusion, non-discrimination and legal capacity. This right is the universal recognition of legal personality of the human being.

Hersh (2018) suggests that people with Aphasia lack identity, even within the disability sector. She argues we need to take a range of steps including understanding how aphasia intersects with social determinants of health. We need strategies in place so that people with aphasia can be equal partners in research, and within the disability movement and determine their own agenda (Hersh, 2018). Projects like the AphasiaBank show progress is being made by speechies to further the identity of those with Aphasia (MacWhinney, 2018).

Guardianship systems can deny equality rights to individuals and you must be cautious of your involvement in assessment procedures that diminish autonomy such as capacity testing. Speech-language pathologists have specialised skills and knowledge in communication and human interaction, both central elements of supported decision-making practice, making them ideally placed to facilitate practice in this area. General Comment No.1 (2014) to the Disability Convention already expects this. It suggests support can include the development and recognition of diverse, non-conventional methods of communication, especially for those who use non-verbal forms of communication to express their will and preferences. The Comment states "A person's mode of communication must not be a barrier to obtaining support in decision-making, even where this communication is non-conventional, or understood by very few people." Your role will always include helping to reach an assessment of capacity but ought to much more proactively include maximising and supporting capacity in daily interactions.

Cultural rights (s.27) include cultural expression and use of language. This clearly becomes even more complex for persons with communication support needs where English is not their first language. I have worked with refugees with communication support needs and recovery from trauma and torture and re-settlement is far harder for them. Our society's lack of tolerance for different cultures doesn't help. This is where you can work effectively with other disciplines such as CaLD experts, interpreters and settlement workers. Your role in helping people be understood transcends the mere act of communication. Communication enables understanding which in turn enables dignity, respect and tolerance.

Cultural rights for **Aboriginal peoples and Torres Strait Islander peoples** (s.28) include the right to live life as an Aboriginal or Torres Strait Islander person who is free to practise their culture. This includes the right to enjoy and maintain identity and culture, to maintain and use Indigenous languages, to maintain kinship ties and the freedom to teach cultural practices and educations to their children.

The maintenance of these rights is closely linked to other rights such as the right to education. Speechies contend that some aboriginal students ought to be recognised as multilingual in the

context of systemic expectations and that reports that have overlooked fact that the developmental language and literacy milestones of these students are different to the national benchmarks based on the typical development of monolingual English-speaking students (Freeman 2018, Martin 2019).

PERSONAL LIBERTY & SAFETY

Let's move to those rights that protect the integrity of the person and the body.

The **right to life** (s.16) includes obligations to protect the lives of people in care and have effective investigations into their deaths. This is exemplified by choking, aspiration and asphyxiation deaths in aged care. Deaths of older person from choking will increase with population ageing and the rising prevalence of neurodegenerative conditions that impair swallowing (Roy, 2007). Ibrahim's (2017) forensic research found choking accounted for 8% of deaths in aged care. He and others argue that choking is a preventable event.

Various coronial inquests have found that a speechie's mealtime management plan might be the difference between living with quality of life and choking to death. Your specialist assessment and intervention to prevent choking and aspiration and asphyxiation deaths is of critical importance.

Additionally, we should never undersell the critical importance of meals as part of our quality of life. It is embedded within our cultures and or lives. It reminds us of family and community. Recent Royal Commission evidence has highlighted the undignified and unwholesome nature of some nursing home meals. The provision of inadequate, insufficient and inappropriate meals is a clear breach of numerous human rights.

Freedom from **torture, cruel and inhuman or degrading treatment** (s.17) in institutional settings is critically important. Those with communication support needs are particularly vulnerable to this. I foresee a time when speechies will be more proactively consulted in situations where human rights norms require far more critical and careful assessment of informed consent. And where informed consent will depend on the possible human rights ramifications of the actual treatment.

I want to give two examples of this.

Firstly, forced, involuntary or compulsory treatment, such as some forms of psychiatric treatment (e.g. electroconvulsive treatment) must be balanced with rights to equality, fair hearing, and freedom from cruel and inhuman or degrading treatment. Many persons with mental health issues also have complex communication support needs.

The use of restrictive practices or restrictive interventions is a second example. Up till this point in time, aged care residents have been treated with a cocktail of sedatives and psychotropics, physical and environmental restraints, locked doors and behavioural modifications. Where communication support needs are met, institutions are less likely to use restrictive practices. A wide range of human rights standards point to the abolition of restrictive practices in all but the most extreme cases.

Both examples will be different with the intervention of a speechie. My point is that communicating will, preferences and values in clinical and treatment settings is essential. Treatment can enable or

disable dignity and in the busy and understaffed halls of institutions, the time, facilities and expertise needed to obtain and communicate informed consent can be lost. The time needed to understand a person's needs is often lost in the hubbub. Or worse still where communication rights are ignored because that is the cheaper and easier path.

The **protection of families and children** (s.26) is a critical area. Risks of sexual and gender-based violence increase for women with communication disability (Marshall, 2018). The World Health Organization reported that women with communication impairments are severely hampered in their ability to disclose their abusive experiences. Women with communication support needs are more at risk of violence and less likely to receive protective or remedial support from police or the justice system. This is a group you need to look out for carefully.

ACCESS TO JUSTICE

This cluster of rights reveals some truly frightening issues. It illustrates how speechies are critical to preserving civil liberties. Communication support needs include police interaction, court processes and victim support processes.

The right to **liberty and security of the person** (s.29) and **fair hearing** (ss.31-33) are often compromised for Aboriginal and Torres Strait islander persons. Imagine how things play out in high stress interactions where the actors lack mutual trust and respect and may in fact be driven by negative emptions such as fear and hate. Add to this language issues such as the differences between standard Australian English and aboriginal English.

Similar issues arise for non-aboriginal persons with communication support needs. For example**,** police and correctional staff training around communication support needs is critical and yet the frontlines still receive little training. (Burn, 2019) Just think about how important it is for police to understand the impacts of communication disorders.

Research shows that police response to communication difficulty generally means a reliance on modifying verbal communication. Police most frequently simplified language or slowed their rate of speech. Offering pen and paper, reading written material, and writing down verbal messages were also identified as strategies (Burn, 2019).

Despite this many with communication support needs languish in the criminal justice system – misunderstood, misrepresented, wrongly convicted and improperly incarcerated. Their communication support needs impact on their interactions with police, lawyers, court officials and court-appointed experts.

We ought to be very concerned about this issue from both perspectives: the rights of victims of crimes and the rights of those questioned about or accused of crimes. A failure to deal with communication support needs can mean a failure to provide proper community policing and safety on one hand and miscarriages of justice on the other.

Young offenders in custody provide a stark example.

60% of young offenders within institutional settings have communication support needs, but only 5% were diagnosed before entry into youth corrections. (Martin, 2019) Half of young people in custody in New South Wales had severe core language difficulties, and severe single word reading difficulties, and three-quarters had severe reading comprehension difficulties. (Martin, 2019) Speech-language pathologists have a unique ability to assist young people with neuro-disabilities, complex trauma and attachment difficulties, and social, emotional and behavioural difficulties, common among the youth justice population. (Martin, 2019)

Finally to the **economic, social and cultural rights** including two of great importance to speechies: education and health services.

Right to education (HRA, s.36)

The Act guarantees a right to education. You are clearly at the vanguard of this critical human rights issue. Inclusive education depends on your profession to turn the rhetoric and ideals of the Disability Convention into the reality of better inclusion, outcomes and consequently better lives. If education is critical to life success, speechies are an essential part of attainment.

Article 24 of the Disability Convention demands inclusion. The Committee on the Rights of Persons with Disabilities' General Comment No.4 sets out the importance of access to communication support:

> *"(d) Learners with communication impairments must be provided with the opportunity to express themselves and learn using alternative or augmentative communication. This may include the provision of sign language, low- or high-technology communication aids such as tablets with speech output, voice output communication aids or communication books. States parties should invest in developing expertise, technology and services in order to promote access to appropriate technology and alternative communication systems to facilitate learning;*
>
> *(e) Learners with social communication difficulties must be supported through adaptations to classroom organization, including work in pairs, peer tutoring, seating close to the teacher and the creation of a structured and predictable environment.* (UNCRPD, 2016)

The committee's baseline requirements include "most appropriate languages, accessible formats and modes and means of communication." (UNCRPD, 2016) Your own literature reinforces the importance of the Committee's comment. The 2018 International Journal of Speech Pathology Human Rights Edition carries many examples of this. Some examples include:

- A heightened focus on children's preferred outcomes (Doell, 2018);
- Children's participatory and communication potential beyond linguistic expression (Gillett-Swan, 2018); and
- Children's own narratives as part of inclusive practice (Murphy, 2018).

Right to health services (HRA, s.37)

I finish tonight looking at the Act's guaranteed right to health services. This includes those provided by you and others through your facilitation.

You are the canary in the coal mine. Lest this metaphor be missed, let me spell it out. Before proper testing equipment was available, miners used lived canaries to detect carbon monoxide. Canaries are a sentinel species: an animal more sensitive to the colourless, odourless carbon monoxide and other poisonous gases than humans. If the animal became ill or died, that would give miners a warning to evacuate. Speechies have a unique role as first identifier. They may not be first responder or primary clinician but they will be the first to unlock communication from which proper identification of other health or social needs will flow.

Proper clinical care needs the answers that only people can give themselves. One cannot derive will and preferences, values, views and beliefs from blood tests, angiograms, magnetic resonance or x-rays.

Let's come back to Aphasia within the health services setting as an example before we conclude. Research on success and failure of communication with persons with communication support needs across the continuum of health care shows that when people and providers establish shared meaning, positive health care outcomes are likely. Conversely, communication breakdowns lead to negative health outcomes, increased hospital stay, higher rates of readmission, increased costs, an increase in negative events, and a reduction in patient satisfaction. Without access to appropriate and relevant communication support, people with aphasia may experience a reduction in their capacity to express their health care needs and actively participate in decisions regarding their own health care.

Poor communication access within health care can lead to damaging and negative experiences for people with aphasia, including a reduction in the reported satisfaction with the health care experience, an increased risk of inappropriate or inadequate service provision, and an increased likelihood of the occurrence of adverse events.

CONCLUSIONS

Speechies' voices and philosophies are already underpinned by human rights.

There are big issues facing your profession, including future resourcing considerations for the speech pathology sector. The resourcing of speech language pathology services will come under scrutiny soon. The human rights implications of failing to fund this critical work can only draw positive attention to the needs of the communication access community.

McCormack (2018) summarised what you face very neatly:

> *The impact of childhood communication disorder shows how other rights fall out of place when the right to communicate is challenged by the child's lack of an effective communication mode. Thus, we begin to see the importance of supporting individuals with*

communication disorder; not just to provide them with a voice, but so they may use that voice to participate in daily life.

I hope the 'we' in her statement includes Government and policy-makers. Just as you have seen a shift from the medical model to the bio-psychosocial model (Nippold, 2012), so too will you see a shift to a human rights approach. While the rhetoric of human rights is that they are inherent to us all, the reality of the Human Rights Act takes the question beyond doubt.

Human rights are not the sole domain of lawyers. I rely on the words of Eleanor Roosevelt:

Where, after all, do universal human rights begin? In small places, close to home – so close and so small that they cannot be seen on any maps of the world. Yet they are the world of the individual person; the neighbourhood he lives in; the school or college he attends; the factory, farm or office where he works. Such are the places where every man, woman and child seeks equal justice, equal opportunity, equal dignity without discrimination. Unless these rights have meaning there, they have little meaning anywhere...

I hope tonight's lecture gave you some insight into the small places you will find human rights and the ways in which you can make sure they have meaning.

I'd like to acknowledge Gareth Lloyd for his excellent work in organising this lecture.

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