The following Paper has been accepted for presentation at the European Group for Organisational Studies (EGOS) Conference in Sweden in July 2011 and contains some ideas and concepts that I think are highly relevant to the Productivity Commission's current Inquiry into the Longterm Care and Support needs of people with disabilities. This paper will be further developed prior to the Conference and I am happy to supply an updated version of the paper to the Commissioners by the end of May should you think that will be helpful.

As a parent of a young man who faces life with significant disability-related challenges, I have an active and personal interest in the current Inquiry. As an organisational and management academic I attempt to actively and creatively observe and analyse dynamics within the disability sector in the hope that fresh ideas will be considered and tried in order to achieve different and better outcomes for people such as my son.

The attached paper is one such attempt. In this paper, I apply the concept of 'governance' to how persons with disability can create and manage their own meaningful and self-directed lives – especially individuals whose lives are affected by the particular challenges of intellectual or developmental disabilities. Despite the best intentions of family members, loved ones and service providers, these individuals are frequently and routinely treated as if they have no rights to even say what they would like to happen in both large and small aspects of their lives, much less to *decide* what they would like to happen in their lives. Too frequently, the ruling assumptions are that such individuals are incapable of understanding what is said to them or what is happening to them and/or that they are unable to express a meaningful choice even if they do understand.

Whatever recommendations the Productivity Commission makes as a result of this Inquiry, it is paramount that it supports a significant shift of power away from service providers, specifically directing more power to those individuals whose lives are directly affected by disability. In the context of the current disability systems in Australia (not to mention the societal assumptions which reinforce these systems), this will be revolutionary and highly challenging to implement. Nonetheless, anything less than such a shift runs the extremely high likelihood of reinforcing the current system dynamics which routinely disempower people with significant disabilities by disregarding their voice and rights. Across Australia, there are examples of visionary individuals and families taking the lead in trying to craft new alternatives. A recurring theme with these examples is that they are routinely underfunded and under-resourced primarily because they are initiatives brought into being by families and individuals rather than disability-sector professionals.

I also suggest that the Commissioners will do well to study successful examples that have been in existence and growing in Canada for more than twenty years. These include PLAN Canada (Personal Lifetime Advocacy Networks); Vela Microboards (www.microboards.ca) and the Alberta Association of Community living.

Towards better lives: Applying the concept of governance at the level of the individual

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ABSTRACT

People who live with intellectual disabilities are among the most marginalised and silenced citizens in many developed countries. The rights and opportunities for many to make or even participate in decisions that directly affect their own welfare and life experiences are systematically undermined or extinguished and depend largely on the drive and commitment of family members. This paper explores how applying the concept of governance at the level of such individuals' lives may be a successful social innovation. Rather than being the passive recipients in a system of care, they can become the empowered directors of their own lives in ways that are typical for most other citizens. Such a development repositions them to make their own meaningful contributions to the societies in which they live. This potentially includes contributing to reforms in public policy in the field of human services.

Imagine that you are living your life essentially in darkness, a darkness that is possibly caused by a significant visual deficit. In this darkness you are unable to speak. You depend on others for assistance with many of the most basic functions of daily living. You can communicate with others only by writing or drawing on a large pad using a single pen that you have been given. You are free to write or draw anything you want in communicating with others. This includes responding to questions, making requests, expressing your thoughts and feelings, and exploring and expressing your creativity.

Over time, you notice that there is a low correlation between what you write or draw and what happens to you. In the morning, you are asked if you would prefer eggs and bacon or cereal for breakfast. You write 'eggs and bacon' but are served a bowl of cereal and forced to eat two pieces of fresh fruit. In a short space of time, you also note that those some of the people who care for you have become detached and are no longer as empathetic as they initially seemed to be. They rarely ask you about your preferences for things that matter to you and they never directly engage with you about what you may be thinking or feeling. They pay scant attention to your pad. Sometimes they give it a cursory glance, but more often than not they don't even look at it – even when they ask you a direct question and you write an immediate response.

Your life becomes an endless repetition of being rushed through functional activities like eating or showering so that you can be taken to activities like ten-pin bowling with people whose disabilities and communication challenges mirror your own. On some occasions, you hear your carers telling others how much you enjoy these outings as opportunities for you to socialise with people who are like you. Your carers are clearly oblivious to your inability to meaningfully communicate with these other people without assistance.

You endure this existence. It is tiring and tiresome. It is dehumanising. You live in a state of perpetually high anxiety and complete disempowerment. You often feel highly frustrated and you frequently get angry about some of the things done to and for you. People consistently speak to you as if you are a child. You have no real decision making power in your life and you never feel as if you truly belong anywhere or to anyone. You are bewildered about what role love should play in your life. It is clear to you that no-one who has power or influence in your life believes that you have either a need or a capacity for intimacy. They clearly assume that you are incapable of sexual relationships.

What you don’t know, what you can never know in this bizarre world you inhabit, is that your pen has no ink. A pen that can actually write is considered to be unnecessary for someone like you.

This metaphor expresses the reality for many of the people whose lives are directly affected by intellectual disability. They exist in the powerless and voiceless margins of civil societies, unable to exert any meaningful influence in key domains of their own personal lives. The social construction of the world in which they live, predicated as it is on a dominant market economy worldview, means that many of the quality of life gains made in recent decades are now receding (Cocks 1998). Funding formulas combine with the erosion of community in contributing to the systematic and systemic reinforcement of assumptions that such an existence is “normal for these people”. The horror (for that is what it is) of such lives would never be tolerated by those who have voices and connections to power in so-called civil societies. It is therefore, beyond time to give such people a pen that has ink. An important first step is to reposition them from the margins to the centre of decision-making processes that affect their lives.

In this paper, we argue that applying the concept of governance at the level of an individual's life has the potential to effect significant change. As a social innovation, this may empower people who are frequently treated as voiceless recipients of care to become the architects of their own meaningful lives. Despite abundant rhetoric to the contrary, many such people are currently treated as if they are not fully human (Leipoldt 2011).

Defining Governance

In both academic literature and popular parlance, governance is defined in many and varied ways. The term is applied to a range of different contexts. In recent decades, the concept has been popularised in the context of 'corporate governance', a phrase that first appeared in 1981 (Siedel 1981). High profile corporate collapses and crises over recent decades have focused the attention of regulators, policy makers and academics on corporate governance arrangements and practices (Mason and O'Mahony 2008). Harper (2007, 20) defines corporate governance as 'the accomplishment, manner or system of directing and controlling the affairs, policies, functions and actions of an organization.' In corporate and other business settings, overall responsibility for governance is typically the province of Boards of Directors. The Directors collectively authorise executive officers to use power within certain limits, and to make and execute decisions that are guided by the goals or mission of the organisation (Brajesh 2010). It is important to note that good governance includes attending to the structures, the processes and the mechanisms by which power is exercised, decisions are made and subsequent actions are taken (Korhonen, Hiekkanen and Lahteenmaki 2009, 66).

In order to apply this conceptualisation of governance to the level of an individual person's life it is necessary to make conscious and intentional decisions to do so given that conceiving of one's life in terms of governance arrangements is something of a novelty. The assumptions underlying the structures, processes and mechanisms that influence how power is exercised, decisions are made and actions taken in individual lives are not commonly brought to light for examination within this frame of reference. While these assumptions are certainly subject to culturally determined influences, there are many domains of life in which the unspoken governance arrangements assume each individual's right to make their own decisions and to act accordingly. In reality however, things are rarely so straightforward. As a result, complexity science will be used as the theoretical framework in which this proposed solution is explored.

Complexity science approaches to understanding the world of human affairs are steadily gaining currency, including within the fields of management and organizational studies (Goergen, Mallin, Mittleton-Kelly, Al-Hawamdeh and Chiu 2010; Kuhn 2009; Shaw 2002). Complexity science is a systemic and systematic lens for making sense of one's experience of the world based on a constructivist epistemology. As a theoretical framework for the study of complex systems, complexity science brings system dynamics into focus in a way that positivist approaches frequently do not (Griffin, Shaw and Stacey, 1999). While the multitude of variables that exert influence in complex systems can never fully be measured or explained, complexity science examines the patterns of interaction of these variables and attempts to identify how these patterns exert influence at multiple levels of the system (Kuhn 2009). Consequently, concepts such as emergence, fractality, self-organising, interdependence, connectedness, feedback, exploration of possibility space and edge of chaos are centrally important to explaining observed dynamics and behaviour (Goergen, Mallin, Mittleton-Kelly, Al-Hawamdeh and Chiu 2010; Kuhn 2009).

There is a certain logic to using such a framework for sensemaking in the context elaborated here. For most families and individuals, direct experience of disability most frequently arrives in one of two ways: 1) with the birth of a baby who exhibits some form of disability at delivery or soon after; or 2) through the interruption of a life event which results in a family member acquiring a disability. In both scenarios, direct entry into the world of disability usually comes as an unexpected shock, triggering a range of emotional and behavioural responses which are typically influenced by factors in the local 'disability industry'. Cocks (1998) and Leipoldt (2011) convincingly demonstrate the importance of understanding systemic influences on the lives of individuals with disability and their families for both the development of public policy initiatives and the delivery of appropriate and effective support services.

When individuals' lives and communicative capacities are significantly affected by intellectual disability, it is commonly the person's family members (most frequently one or both parents) who exercise considerable power and influence over what happens in the individual's life. In effect, such family members constitute the governance arrangements. It is the espoused and enacted beliefs and assumptions held by these family members and other friends and professionals which have the greatest impact on the person's ability to have a meaningful say about aspects of their life and circumstances. These beliefs and assumptions directly affect the degree to which the family members and others use meaningful two-way communication with the person and create opportunities for the person to make their own decisions in a largely normalised manner (Gorenflo and Gorenflo 1991; Lennox, Taylor, Rey-Conde, Bain, Boyle and Purdie 2004). Systemic influences such as the philosophy underpinning the design of human services, public policy frameworks, funding and resourcing decisions, and community attitudes all play an iterative role in reinforcing or challenging beliefs and assumptions about persons with intellectual disabilities (Cocks 1998; Leipoldt 2011). It is common to hear comments made by family members and professionals which seem to dismiss any possibility that the person could comprehend or meaningfully communicate a preference or opinion on a subject. In many cases, it is evident that creative approaches to communication or using assistive technology are both possible and likely to make a difference. However, in many such instances these are either not used, or the cost of acquiring them is beyond the resources of families and funding agencies. Technical incapacity is rarely the most limiting factor. Indeed, recent research has demonstrated that some longterm “vegetative” patients maintain a capacity to meaningful respond to yes/no questions despite the absence of outward signs of their responsiveness (Monti, Vanhaudenhuyse, Coleman, Boly, Pickard, Tshibanda, Owen, and Laureys 2010).

Michael Kendrick (2003) is a widely acknowledged global thought leader in the area of self-determination for persons with intellectual disabilities. He identifies numerous ways in which systemic factors interact to undermine a person’s ability to make their own decisions about both important and trivial aspects of their own lives. Quite frequently, family members and organisations will espouse the rights of persons with intellectual disabilities to be self-determining. Yet at the same time, they will often make or enact decisions in ways that institutionalise arrangements that actually limit the individual’s ability to be self-determining (Kendrick 2003; Westley, Zimmerman and Patton 2006). Leipoldt (2011) details some of the ways that well intentioned human service agencies are thwarted by systemic factors such as those that relate to self-preservation of the institution or complying with government or funding bodies’ metrics and guidelines. This paper proposes that by intentionally considering each of the elements of governance described earlier, a decision making model can be enacted which will lead to things being done in different ways for many such people.

In many countries, there are numerous past and present examples of individuals and organisations attempting to achieve better lives for people with intellectual disabilities. However, very few are using an approach that is consistent with consciously applying governance concepts. One example of such an attempt originated in British Columbia and is now being replicated in other countries including Ireland and Australia. It involves incorporating a not-for-profit Society (called a microboard) around a single individual who has disabilities. A microboard (micro=small, board=group of friends and family) is composed of five to ten people who know the person and have a strong, unpaid, reciprocal relationship with them. The microboard exists to help the person to achieve their goals, dreams and wishes (Malette 2002). As legal entities, each microboard's objects are solely focused on meeting the needs of, and benefiting, that one individual. The Vela Microboard Association (VMA) of British Columbia is the overarching organisation that has supported and overseen the establishment of more than 700 individual microboards in British Columbia since 1989. Several core principles, all premised on strong, unpaid, reciprocal relationships between the individual and the members of the microboard, underpin all microboards and include:

- Relationships are the heart of the microboard and must be honoured above all other activities;
- All people have the capacity for self-determination; and
- Paid services are customised to meet the needs of the individual, not on the availability of the service or the needs of a service agency (Malette 2002).

With the strong emphasis on relationships at the core, establishing a legal entity that focuses on benefiting just a single individual potentially creates a sound structure within which the concept of governance can be applied (Featherstone 2010; Jay and Schaper – in press). However, it is the relationship-based processes within microboards which expand the possibility space within which an individual's communication preferences and decision making capabilities can be enhanced and honoured (Malette 2002). This in turn, ensures that their choices and preferences are known and respected in decisions made by others about their lives. It is conceivable that such relationship-based processes can successfully be applied outside the context of a legal entity such as a microboard with sufficient intentionality.

In conclusion, it is important to note that the normalised experience of most members of civil societies is that they desire more than to simply have their preferences and choices known and respected. The desire to contribute to the world in more significant and meaningful ways forms part of the human condition. Accordingly, applying a governance framework in the lives of individuals with intellectual disabilities can potentially open even greater possibility space. It is in this space that the person, along with their friends and family, can consider a multitude of ways in which they can make their own meaningful and valuable contribution to the world, as is typical for citizens who live without intellectual disabilities (Westley and Antadze 2010).

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