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Winks, Blinks, Squints, and Twitches:
Looking for Disability and Culture through Our Son's Left Eye

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For most of modern Western history, the “official” reasons to study intellectual disability have been to learn more about how to make it disappear. As a medical condition it has been something to prevent or cure. As an educational deficiency, it has been something to remediate or overcome. As an economic and social burden, it has most often been something to rehabilitate or at least remove from society’s view. Recently, however, the emergence of the disability rights movement has challenged this predominantly clinical approach in areas as wide-ranging as personal experience, social policy, and cultural interpretation. As a result of this movement, many of us are re/cognizing disability for the first time as both a complex social construction and a significant personal identity. That is, we are simultaneously recognizing and rethinking (literally re-cognizing) the interaction of self, culture and disability in the lives of individuals. With this new approach, now known as “disability studies,” the reason to study disability is to make it more visible, not less; more valid as an ongoing part of the human experience; and more legitimate as a topic of study across the humanities and social sciences.

One of the hallmarks of this still emerging field of disability studies is the exploration, recovery, and celebration of a “culture of disability.” What this phrase might actually mean is by no means settled, of course. Indeed, it is precisely in the move from talking about culture *and* disability to talking about the culture *of* disability that a tension between “same” and “different” most clearly emerges. This chapter will argue against hasty attempts to resolve this tension by imposing one orientation or another upon those who wish to do engage in the in the interdisciplinary practice of disability studies. We will look in particular at two movements at the heart of disability advocacy over the last several decades or so: independent living and inclusion. Central to our discussion is a consideration of what it might mean to speak of a “culture of intellectual disability.” Other questions quickly follow: Is there such a thing? Should there be? How might it compare to cultures of deafness, blindness, physical disability? And what forms and approaches should attempts to answer these questions take? That is, what should disability

look like? Finally, throughout the chapter, we will ground our reflections on these topics within a narrative approach to events from our son's life.

Blinking Away Definitions: Seeing Disability Through Our Son's Left Eye.

Our son, Ian, just turned 45 years old and has multiple disabilities. Over the years he has collected a variety of labels that supposedly specify what those disabilities are: severe intellectual disability, spastic quadriplegia, and developmental disabilities. Predictably, the educational and adult service systems involved in his life have given labels only to his perceived limitations; there have been no clinical diagnoses for his mixture of odd talents and personal quirks that are the main images we share of him now. What is the technical term for an aficionado of sound effects tapes? Which professional would assess his ability to identify TV sitcoms by the first four or five notes of their theme songs? When does he get graded for the terrific laugh he shows along with a warped sense of humor? The scary stereotypes and diagnostic categories that lie behind the official labels can easily swallow up our son's individuality. But after 45 years, most of what matters to us about Ian is not touched by terms like "intellectual disability" and "cerebral palsy." Certainly, the physiological realities giving rise to those terms are there to be reckoned with. Many things that most 45 year olds find easy to do are impossible for Ian without intensive supports. Moreover, the very need for those supports challenges us to discover what adulthood - and the self-determination that is normatively associated with adulthood - might mean for Ian. However, after all these years observing his progress and frustrations in dealing with those limits, the question that really bothers us is one that may at first seem superficial: How should we describe what Ian is doing when he "winks"?

The story goes like this. A number of years ago, someone taught Ian to squeeze together the eyelids of his left eye in a rough approximation of an acceptable wink. If you ask him to wink, he will usually do this behavior. If he sees someone else "wink," he might imitate that action even without being prompted. On rare occasions he might actually produce his winking behavior spontaneously. He usually

laughs or smiles when he does this, and it usually evokes smiles and laughter by those around him as well.

So, a brief summary of the situation might note that Ian can close his eyelids together on one eye: he knows the mechanics of winking. He also does this behavior when asked to “wink.” That is, he apparently associates the work “wink” with the same physical action (roughly speaking, he is not very coordinated about it) that the rest of us do. He even apparently understands at some level that something about the physical action is humorous, because he usually laughs when he does it. However, the question remains: Is Ian really winking? It seems more volitional than an uncontrolled twitch would be, but is he really doing some learned behavior: a squint or blink more than an actual wink? Perhaps his actions could be described as imitating a wink, but without any intentionality behind the physical behavior similar to that which motivates others to wink (indicating that one is joking, acknowledging some sort of conspiratorial understanding with another person, flirting, etc.). Alternatively, does Ian’s disability overwhelm any cultural context to such an extent that a thick behavioral description of eyelids closing is all that remains available for careful observers?

These are not new questions, of course. Although he never mentions disability, Clifford Geertz’ classic essay on “thick description” (Geertz, 1973) relies upon the complexity of winking (admittedly borrowing from the philosopher Gilbert Ryle’s original discussion) to illustrate how even the simplest physical behavior can become quickly embedded in layers of cultural interpretation as we “thicken” the context surrounding that behavior (from twitching, to winking, to imitating a wink, to practicing imitating a wink, etc.)¹. This connection with Geertz is purposeful. Geertz is not so much interested in winks as he is in how to interpret them as symbols full of cultural meaning. His discussion has relevance to disability studies as well. As a way to explore the interactions of self and culture within the context of disability

¹ Geertz also uses an extended discussion of mock sheep raids in Morocco to make his case for cultural interpretation. However, to our knowledge, Ian has never participated in a sheep raid, so we have decided to stick with winking as our primary example.

studies, an elaboration of “thick description” encourages us to collect and interpret the narratives within which cultural meanings of disability are initially embodied.

What might go into a thick description of whether and how someone like our son could be understood to be actually winking? The larger questions that emerge from this involve the changed interaction of personal perspective and cultural context – all of the dimensions that help make a description thick instead of thin – when the participant’s very capacity for intentional behavior is somehow questioned, or at least inaccessible.

So, from Ina’s winks, we are led to two basic questions. First, what is it that Ian is doing when he closes his eyelids, and how is it similar or different to what others do? Second, what is it that we are doing when we try to understand what Ian is doing, and how is that similar to or different from what has been done in the past? We take the first question to involve, at least partly, an attempt to define intellectual disability. We take the second question to involve, at least partly, an attempt to define disability studies. Obviously, with both question, then we are emulating Geertz’ use of the mundane behavior of winking to open up a much broader and more abstract consideration of disability and culture.

Asking for definitions – of disability or disability studies – is often misleading. As often as not, the questions send us off into an epistemological wilderness, hunting for some conceptual trophy that we can mount on the wall at home for all to study and admire. A definition seems to imply an essence – some common meaning that, in turn, refers to a discrete piece of shared reality possessed by all those objects to which the term correctly applies. However, a search for definitions need not involve such a commitment to essentialism. The philosopher, Ludwig Wittgenstein, reportedly advised his students to avoid this trap by framing the question differently: “Don’t ask for the meaning, ask for the use” (cited in Wisdom, 1965, p. 87). In other words: Give up the quest for some smooth but slippery essence that strips away particularities of context in the push for linguistic common ground. Instead, Wittgenstein advises, “move to the rough ground” of practice (Wittgenstein, 2001, p. 40) and recognize how people actually interpret their lives in language. Don’t define literature for us; tell us some stories. If we notice some family resemblances among the examples, then so much the better.

So, what we hope to do in response to our two questions is not so much to define disability in general or intellectual disability in particular. Much less do we desire to pin down some prescriptive rules for how to do disability studies “correctly.” Our goal is simpler: to tell some stories, look for relationships, and find enough traction to move forward our cultural interpretations of intellectual disability.

From Twitch to Wink: Finding the Self in Culture

You can’t wink (or burlesque one) without knowing what counts as winking, or how, physically, to contract your eyelids. . . . But to draw from such conclusions that knowing how to wink is winking . . . is to betray as deep a confusion as, taking thick descriptions for thick, to identify winking with eyelid contractions. (Geertz, 1973, p. 12)

One way to rethink (“re-cognize”) intellectual disability is to describe how the complex array of possible meanings for a person’s behaviors seems drastically curtailed. The social construction of the meaning of language and behavior initially leads to a potentially infinite variety of interpretive possibilities. (Objectivist critics of such constructivist approaches to meaning (Anastasiou & Kauffman, 2011) argue that this relativism cannot be escaped, leaving us with interpretive anarchy where there are no rules to prefer one meaning as more valid than any other.) We move from the babble of possible meanings to the precision of communication through a complex interplay of cultural location, historical period, subgroup conventions, specific elements of immediate context, and personal intention. We are arguing that one useful way to approach intellectual disability is to see it as a preemptive constriction of this communicative process.

To a certain extent, Ian’s eyelid movement is just an eyelid movement because it is taken out of this interpretive interplay. It is not suspended in the same “webs of social significance” (Geertz, 1973, p. 5) that the rest of us spin for ourselves. At its most profound, intellectual disability seems to remove the element of personal agency or psychological intent that pushes the behavior from twitch to wink. It is difficult, for example, to think of Ian as a sexist when he winks, objectifying women as sexual objects by

knowledgeably participating in a traditional behavior of men. It is equally hard to impute an ironic or deceptive sensibility to Ian's behavior. In the same way, it is hard to envision someone thinking of Ian as a racist, or a capitalist, or any number of other categories typically available to those interpreting the behavior of adult white males in our society. To the extent that we all believe, or behave as if we believe, that some personal understanding of the cultural norms and traditions is important to such interpretations of specific behavior, then those meanings seem less available to Ian than to others.

The crisis of representation spoken of so frequently these days in postmodern discussions of social science and the humanities (Schwandt, 2007, p. 49) seems superseded here by an earlier crisis of presentation. The "crisis" arises not from our inability to provide direct access to Ian's understanding of his world but rather from an uncertainty that a fully furnished world is there to be accessed.

Telling Stories: Describing Cultural Context

For us, the answer to this crisis of presentation comes dressed in the metaphors of the humanities rather than the sciences. We try to "read" Ian's story within a symbolic "discourse" that changes behaviors into actions. It is important to recognize what makes intellectual disability so different in what is still the dominant approach to disability. It is not so much that we do not see a "person" or "a real human being" when we encounter someone with so-called "profound" intellectual disability. It is rather that we do not see any culture. We see no meaning to the behavior: there are words but no discourse; events but no story. In a way, the challenge for interpretation is that *all* we see is an individual: Rousseau's noble savage, a single person in a cultural void, as close to a decontextualized existence as possible. The physiology seems to overwhelm the social. We see no religion, no politics, no racial awareness or class identity, no moral stance, no economy. We have trouble admitting any intentional awareness of these cultural components that the rest of us use to define each other. What potentially impedes interpretation of Ian's "winking," then, is not an absence of self but an absence of culture.

Without such a cultural context, people with significant intellectual disabilities are neither the same as, nor different from, the nondisabled population. There is no comparative context within which to make the judgment.

However, the instant that anyone begins to try and interpret Ian's behavior – the minute it becomes worthy of notice – then culture flows in. By representing our son's life to others we invest it with a narrative. We inscribe his actions with a temporal sequence that starts to transform his eye twitches into winks. When we told the story earlier of how Ian came to learn to close an eyelid when asked to wink, we were contributing to an enculturation of his life through narrative. In short, Ian cannot wink unless someone wonders aloud if he can. It makes culture relevant to his life, and starts the search for further interpretive symbols. That may not be sufficient, but it seems a necessary interpretive leap for questions of similarity and difference to have meaning to the lives of people with intellectual disabilities. The poet may be right that the world will end not with a bang but a whimper; we argue only that it begins with a wink. I wink, therefore I am.

A brief aside may be appropriate here. This analysis seems to us to show a path to a conceptual intersection between hardheaded interpretivists and soft-nosed behaviorists. The evolution among enlightened professionals from simply shaping discrete skills to embedding those activities in inclusive, home and community-based settings with natural reinforcement and functional relevance is – in its largest sense – a partial recognition of the importance of cultural context in behavioral support (Lucyshyn, Dunlap, & Albin, 2002). At the same time, many disability studies scholars have worked to avoid the impression that the successful enculturation of people with significant intellectual disabilities is purely an interpretive exercise in collective pretending (Corker & Shakespeare, 2002; Hughes, 2002). If Ian did not learn some approximation of closing his eyelids, then no amount of “as if” stories would create a persuasive wink. Talking of the necessity of cultural emplotment (Landsman, 2007), demands the translation of behavior into meaningful, not the invention of behavior that no one else can see. The process is one that researchers have noted in the narratives (Roets, Goodley, & Van Hove, 2007),

metaphors (Van Hove et al., 2009), and “behavior sculpting” (Goode, 1980; 1995) that individuals with intellectual disabilities and their families use to describe purposeful actions where others see mere random sound or movement.

Reading Stories: Explaining Cultural Context

Once human behavior is seen as . . . symbolic action . . . the question as to whether culture is patterned conduct or a frame of mind, or even the two somehow mixed together, loses sense. The thing to ask about a burlesqued wink or a mock sheep raid is not what their ontological status is. It is the same as that of rocks on the one hand and dreams on the other – they are things of this world. The thing to ask is what their import is: what it is . . . that, in their occurrence and through their agency, is getting said.
(Geertz, 1973. p. 10)

What gets said, of course, depends on who is listening and in what cultural context. It is not enough to tell stories about people with intellectual disabilities. We must also learn how to explain them. Asking if Ian can wink, and what that might mean, begins the story, identifies his behavior as part of asocial discourse. The cultural hermeneutics behind Geertz’ treatment of thick description allows us to interpret the “said” of Ian’s behavior not merely what he did or did not mean to say. Ian’s wink becomes a social text with multiple meanings.

For people with significant intellectual disabilities, this social dimension is crucial. Ian’s ability to wink is not only temporal, it is situational. Ian has to be around people who believe he can wink – in some sense of that term that is meaningful to them. Sartre was wrong. His famous quotation that “hell is other people” conveyed the crushing sense of finitude that simply recognizing the presence of other active humans created for cranky existentialists. We interpret his remark to refer more to spatial limitations than to hints of mortality. The simple awareness of the existence of other conscious actors was enough to defeat one’s comforting conceit of solipsistic control of the world and its interpretation. As academics,

we know well the desire for solitude and autonomy that grows especially strong after the third committee meeting of the day. How rewarding it would be to think our own thoughts, do our own deeds, and act on our own beliefs. For Ian, though, For Ian, such separation seems profoundly wrong and even dangerous. Other people are Ian's salvation; they are essential to the daily elaboration of who he is. Even more than for most of us, other people are a crucial part of who Ian is. Intellectual disability is not the absence of self; it is the absence of other people.

There are two explanatory components to this social expansion of Ian's narrative. First there is the importance of Ian's community membership, surrounded by supportive friends and family who join him in a choral presentation (as it were) of his personal story. Ian's story must be told by groups with multiple voices. The historical isolation and segregation of people with intellectual disability from precisely this kind of community affiliation are part of what has deprived them of a cultural voice. Stories of Ian's presence in the community, his enculturation, if you will, thicken the explanation of how he acts in the world. Using the interpretive metaphors of social text allows us to have Ian's friends tell their stories as well. Ian's story must be explained – translated -- by those around him.

The second dimension of explanation has to do with a type of conceptual thickness. Not only must Ian have other people help tell his stories. He must also have his story placed in a critical, socio-historical context. The thick explanation of why Ian can or cannot wink would have to attend to the opportunities for people with intellectual disabilities to be perceived as winking by others members of the culture. Interpreting Ian's winking as part of a larger, macro-level commentary on the emerging social challenge to the medical model of intellectual disability reflexively invests his action with greater explanatory richness than he could ever imagine (Watson-Gregeo, 1991). That Ian does not bring an especially acute political consciousness to his action does not prohibit such application: “[W]here an interpretation comes from does not determine where it can be impelled to go. Small facts speak to large issues, winks to epistemology, or sheep raids to revolution, because they are made to (Geertz, 1973, p. 23).

This socio-historical context for explanations of Ian's life also locates some important differences between cognitive and other types of disabilities. Trying to supply a cultural context for critical explanations of Ian's place in society soon confronts the issue that there is no alternative culture or subculture available to replace or resist the absent culture of dominant society. In this regard, at least, significant intellectual disability differs from a disability such as deafness. Whether or not Deaf people choose to (or are allowed to) locate themselves within such a community, there exists an impressive and distinct tradition of language, heritage, and shared values that is demonstrably different from the mainstream culture (Van Cleve & Crouch, 1989). There is a potential of "me as a DEAF person" that such individuals may develop and present to the world. Simultaneously, reflexive interpretations of an alternative culture by members of the Deaf community themselves provide a thick explanatory context for others to study and interpret as well.

What we are suggesting is that there may be little use in trying to speak of an "intellectual disability culture" in the same way that it makes perfect sense to speak of a "Deaf culture," or a "Blind culture," or even a "Physical Disability culture." There probably is something that might be called a "professional" or "bureaucratic" subculture that often engulfs people with intellectual disability (Rapley, 2004). One can find evidence of such patterns of life in many residential programs operated for people labeled "developmentally disabled" (Ferguson, Ferguson, & Wehmeyer, 2013). It is a life of rules and programs, and procedural rigidity that turns a home where disabled people live into a facility where support staff work. There is perhaps even something of a "family/advocate" subculture. A kind of "support group" identification can emerge among family members, for example, that becomes a haven of familiarity for parents and others who grow tired of explaining, defending, and advocating to a seemingly indifferent outside world. However, we would argue that these examples are more about people who surround those with significant intellectual disabilities than a culture arising *from* the intellectually disabled population itself. At most, people with significant intellectual disabilities have been offered the options of fragile assimilation into, or paternalistic parodies of, the dominant culture.

This is a complicated issue, and one that not received the scholarly attention it deserves. It is an issue that touches on the elaboration of a truly inclusive theory of disability itself (Goodley, Hughes, & Davis, 2012; Rapley, 2004). There are important differences in cultural experience relating to how significantly intellectually disabled someone is. However, the logic of our argument suggests that a distinct and authentic intellectual disability culture will probably never be a persuasive reality. If intellectual disability is appropriately understood as the absence (or the progressive diminution) of culture, then the unavailability of an alternative culture uniquely identifiable with intellectual disability (rather than the bureaucracy surrounding it) seems implicit as well.

Winking at Adulthood: A Relational Approach to Intellectual Disability

Let us pursue these cross-disability comparisons by shifting our focus to stories about something more obviously fundamental to our son's life than winks and twitches. Specifically, we point Ian's transition to adult several decades ago in order to examine the cultural implications embedded within two of the more influential policy reforms of that same period: the Independent Living Movement (ILM) and the Community Inclusion Movement (CIM). These two reform movements provide interesting case studies in the different cultural histories of intellectual and physical disability. They seem to us to offer helpful examples of the conceptual tension between core concepts of "sameness" and "difference" that run throughout the evolving relationship of disability and culture.

The ILM is perhaps the more familiar of these two reform efforts as it has gained prominence internationally as the disability rights movement has spread from country to country. It fundamentally challenges the assumption of public support policies that equate disability with dependence and end up excluding people from access to the types of support needed to live active lives of autonomy and independence. Whether through flexible funding, personal assistance services, accessible housing and workplace accommodations, or any number of other reforms, the ILM has pushed to reshape disability policy to help adults gain control of their lives and the decisions that most affect them.

The CIM is, perhaps, less familiar (at least by this name). Inclusion is a term that is used more often exclusively in connection with educational policy than community life in general. However, at least in the United States, the move to include students with disabilities in general education schools and classrooms can actually be seen as an outgrowth of a larger struggle to create places for people with disabilities throughout all the domains of life. Whether it be the classroom, the neighborhood, the workplace, the city park, or the house of worship, the CIM has argued that people with disabilities should be present and included. In its earliest version in the United States, the CIM led to a massive transfer of people with even the most significant intellectual disabilities from large institutional settings into neighborhood settings of apartments, houses, and other typical housing arrangements. In the employment the analogous effort has been to move people with disabilities from segregated sheltered workshops into settings where people without disabilities do their jobs. At its best, the CIM has challenged our notions that intensity of support must always be in direct proportion to the separateness of setting. The more intense a person's support needs were, so the previous logic has held, the more segregated did the support program have to be (Ferguson, 2013). The CIM has sponsored policy reforms and programmatic restructuring that has overturned that logic and helped build inclusive communities for all citizens.

Briefly, to forecast our argument, we find assumptions of both essential sameness and essential difference implicit in the discourse surrounding both the ILM and the CIM, although they emerge within separate dimensions of adulthood. The unintended consequence of this persistent essentialism is to risk the continued ghettoization of people with the most significant intellectual disabilities to the margins of both the disability community and mainstream culture. We believe the comparison suggests the potential strength of a relational approach to disability and culture that chips away at the frozen distinctions of essentialism without dissolving our legitimate differences in some sort of mythical melting pot.

As before however, we want to ground our discussion in a story about our son's life. In many ways, Ian's experiences of the last several decades or so, exemplify a generation of dramatic changes in social policy and professional practice in dealing with people with his level of intellectual disabilities.

When he was 5 years old, Ian was legally excluded from the public schools in the state where we lived. One year later, 1975, (and more than 20 years after the *Brown* school desegregation decision) the original version of the *Individuals with Disabilities Education Act (IDEA)* guaranteed for the first time Ian's right to a "free, appropriate public education." During his school years, Ian benefited from professionals advances in how to combine a focus on functional skills with an emphasis on keeping him in the most integrated educational settings possible. Finally, just as he got ready to leave school, there was a renewed professional attention to effective planning and coordination to make sure that transition to adulthood went as smoothly as possible (Wehman, 2006).

These changed perspectives followed Ian (and others of his generation) as he left school and tried to make his way as an adult. Over the last several decades, there has been a dramatic change in how many families and professionals have approached the challenge of designing effective services to help people with disabilities similar to Ian's lead an adult life embedded in the community as fully as possible. Through a vocational policy called "supported employment," (Test & Mazzotti, 2011) Ian has been able to avoid the segregation of sheltered workshops. An analogous policy in the residential domain – "supported living" – offered Ian a greater variety of living arrangements to choose from than traditional group homes or other forms of congregate care (Ferguson & Ferguson, 2011).

The Day the Canary Died: The Fragile Status of Adulthood

However, translating these reforms into concrete and durable improvements continues to be a frustrating challenge. Just as the promise of a home of his own was to be achieved, Ian and Phil encountered the quintessential disastrous week during which 3 years of planning and work by all of us seemed dangerously close to collapse. The pieces had finally seemed in place for Ian to move into his own home, making all of the transition plans, policy waivers, redesigned support strategies, and searches for flexible support seem worthwhile. A selective chronology from one day of the week when Phil was keeping the journal:

- 9:00 AM: Ian's van dies. His personal assistant cannot get it started even with the jumper cables. This means Ian misses work, and is effectively stuck at our house with no transportation. I get the call and come home. The personal assistant is right: the van won't start.
- 10:30 AM: The mortgage seems critically ill. I get a call from the loan officer handling the mortgage for Ian's new house. Despite a preapproved loan arranged for months with a special trust arrangement for Ian to participate in home ownership, the previously happy investor had suddenly developed cold, and would not the closing to go forward with Ian's name anywhere on the mortgage.
- 12:45 PM: The pay system collapses. I call in from the car repair garage to my phone messages (yes, this was before cell phones). I hear from the person who is coordinating Ian's support plan that the system of flexible state support dollars we had helped design over the past 18 months is falling apart. It looks as though Dianne and I will have to cover salary commitments to Ian's support staff or risk losing them to other jobs that actually pay wages.
- 1:30 PM: The refrigerator won't work. The man delivering the refrigerator to what is supposed to be Ian's new house calls to tell me that it will not fit. It seems that the extra-wide door built to handle Ian's wheelchair changed the dimensions for the refrigerator space. No one thought to re-measure. I am ready for cold storage.
- 3:45 PM: At a previously scheduled meeting with Ian and his support staff, I review the day's events. Ian is in a lousy mood from missing work. His helpers are in lousy moods because their pay arrangements still seem unsettled. We abandon plans to move Ian into his house over the weekend. The meeting adjourns with yet another ad hoc plan for the coming week. I am supposed to be optimistic and cheerful.

8:00 PM: I find Ian's pet canary, Lucy, lying very still on the bottom of her cage. I think of the old stories about coal miners using canaries as an early warning system for the presence of explosive gases. After years of digging our way through the bureaucracy, I wonder if everything is about to blow up.

We survived the week (well, except for Lucy), and prospects soon improved. However the sequence of events and our own growing sense of futility and frustration during that week reinforced an awareness that the longer all of those disruptions and delays persisted, the more fragile Ian's adulthood seemed. Whether the issue is winking or adulthood, too often the main feature of Ian's disability is how contingent his cultural status seems on events that are largely out of his (or our) control.

We need to be clear about the issues we are raising here. First, it is the cultural status of adulthood that seems fragile, not whether Ian is an adult or not. Being an adult and securing the symbolic status of adulthood within the dominant culture are two very different achievements. In many ways, it is precisely in the gap between the two where intellectual disability resides. The second cautionary note flows from the first: the causal direction is important. It is not, we think, the type and severity of Ian's multiple impairments that have cumulatively *caused* his adulthood to be so at risk. Just the reverse: it is the multiple social barriers placed in the way of his adulthood – the breakdown of the narrative rather than any physiological impairments – that construct and define the nature and severity of his disability.

Most frustrating of all, perhaps, is that Ian's difficulties with concepts and language mean that he is largely unable to challenge these threats to his adulthood in his own words. All of us, disabled or not, have had days similar to the one described above. Certainly, everyone with a disability can recite their own horror stories of dealing with a bureaucracy that seems intent on perpetuating their dependence and poverty. What is different in Ian's experience (and others with significant intellectual disabilities) is in how he responds to such barriers. Even if he does in some way recognize a challenge, his opportunity to respond effectively can be limited by both his communication and social skills. In other words, part of the

issue surrounding his adulthood is how it continues to require his parents (and other advocates) ongoing translation of his complaints and desires.

Finally, we do not want to deny or neglect the very real gains that our son, and many others with similar disabilities, has derived from policy reforms directly attributable to either the ILM or the CIM or both. His life is embedded in a circle of friends who help tell the stories of his adulthood to a larger society that often remains uncomfortable with his presence. Clearly Ian's battles to maintain a job and live in a home of his own are very tangible signs of a generation of disability advocacy to create a recognized place within those personal and cultural dimensions where the status of adulthood seems to dwell. And in winning some of these battles, however fragile and few the victories seem, Ian and many of his peers have lives today than we dared envision 45 years ago. In fact, despite dead canaries, many more of Ian's days follow a comfortable and predictable round of work, shopping, and chores around the house and yard, punctuated by dinner parties, concerts and movies, travels and other such events and explorations any of us enjoy. However, despite these gains, we want to argue that this cultural terrain will remain contested by the dominant society until the essentialist assumptions of both movements are recognized and reframed.

Independent Living, Self-Determination and the Personal Dimension of Adulthood

Personal autonomy is the meaning or dimension of adulthood that has probably received the most attention from the fields of special education and adult services. Having control over where we live and with whom we work are perhaps the most common markers in our personal lives of our independent living and self-determination. It is this personal connotation of adulthood that educators and human service professionals usually mean to convey when they speak of the "transition from school to adult life." Over the past decade, the expansion of formal planning for this transition has most often focused on those domains of life most clearly associated with personal independence in our society (Storey, Bates, & Hunter, 2008; Wehman, 2006).

From its outset, the strength of the Independent Living Movement has also been to concentrate on the personal dimension of adulthood. Perhaps the central contribution of the ILM has been to relocate the sources of economic and social isolation from personal impairments inherent to the disability to cultural and environmental barriers constructed by society. The movement has stressed the values of self-determination and autonomy as well within reach of people with disabilities if only the full range of creative adaptations and accommodations were made available. The key value has seemed to be personal control: over where one lived; what one did for a living; how one got around from place to place.

In in most common formulations, the main argument of the ILM has been to argue that people with disabilities could succeed in the dominant society if allowed to use alternative means to achieve the same ends. The social critique most often presented by the movement has focused on the barriers to these hallmarks of Western individualism – autonomy and self-sufficiency – not with the goals themselves. In the words of one of the earliest interpreters of the movement:

While disabled persons have been excluded from full participation in the American economic-political system, they still subscribe to the system's most cherished values and assumptions. They still want to become a part of the system. (De Jong, cited in Williams, 1983, p. 1004)

Adulthood, the argument goes, is essentially the same for disabled people as everyone else. It is the environmental accommodations that need to be different. Consequently, the rules of this predominantly economic game have often gone unchallenged; disabled people were simply demanding a place at the starting line.

Within the disability rights community, some would argue that it is precisely this politically moderate agenda that is behind what partial success of the movement there has been, at least in terms of official policy and rhetoric (Williams, 1983). Certainly, it could be argued that the attitudes and programs flowing from the ILM have helped produce a major shift in how our culture thinks of adults with

disabilities. The epitome (at least rhetorically) of that shift may be contained in the language of the *Americans with Disabilities Act*: “[T]he Nation’s proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals” (Section 2.a.8).

There is, nevertheless, a danger in this success that flows from the very core of the ILM. If the argument is that disabled people are essentially the same as everyone else, then once the barriers to full adulthood are removed, any remaining differences are reified into equally essential “facts of life.” Since the ILM infrequently challenges the social rules of rugged individualism, then if there is a remnant that continues to fail even when access is expanded, its exclusion from culture appears more justified than ever (Ferguson, 1994; Ferguson & Ferguson, 1986). If Ian has to continue to earn his way into adulthood by the measures of personal productivity and self-determination, then his social participation will always remain persistently fragile at best or overtly denied at worst. For people with the most significant intellectual disabilities the ILM has unintentionally created a logic that helps legitimize their marginalization as the exceptions that prove the rule of essential sameness for other disabled people. Once more, it is the essentialist assumptions of an either-or ontology that reinforces the supposedly inherent “otherness” of some by claiming the inherent familiarity of most.

Deconstructing the discourse surrounding the ILM shows how this exclusionary logic was present from the earliest descriptions of independent living. It is not only the limited success of the ILM that potentially justifies the continued exclusion of intellectually disabled people from the status of adulthood. That exclusion originated in the terms and definitions of who was even acknowledged as disabled in the first place. One of the open secrets of the early years of the disability rights movement was its often obvious discomfort with sharing the disability label itself with the so-called “mentally retarded” population. Just as with the internationally recognized graphic symbol for “disability” (the stick figure in the wheelchair), so did some of the most prominent spokespersons for independent living place physical disability and disability as a whole in a synecdochical relationship where the part stands for the whole. So,

in both terminology and practice, the ILM made physical disability synonymous with disability itself. One way to understand the unnoticed implications for people with intellectual disabilities of the essentialist logic within the ILM is that the very terms of the movement did not seem to recognize such individuals as disabled in the first place.

This exclusionary discourse continued even when the first flush of success prompted calls for attention to groups who had previously been excluded from the movement's analyses. When one of the earliest promoters of "independent living" (De Jong, 1984) described the progress of the ILM, he admitted that its "core constituency" (p. 40) had thus far been limited to young adults with a limited range of physical disabilities. The groups that found "notably absent" (p. 41) from the movement were elderly people and racial minorities with physical disabilities. At that point, the absence of people with significant intellectual disabilities was not even "notable."

Again, our point here is not that early – much less recent – proponents of the ILM have intentionally adhered to an essentialist defense of personal autonomy as a way to distinguish themselves from undesirable association with intellectually disabled people. The attractions of searching for some common essence, some objective reality that grounds our identity, are often as unnoticed as they are irresistible. They can be found in equal force, and equal dangers, within the advocacy movements that have explicitly focused on people with significant intellectual disabilities as well.

Community Inclusion and the Cultural Dimension of Adulthood

The cultural dimension of adulthood is certainly related to such indicators of personal autonomy as employment and residence, but it also goes beyond such concrete personal circumstances. It is also perhaps even more problematic than the personal definition of adulthood for individuals with the most significant intellectual disabilities. It involves a more symbolic dimension of citizenship, membership, and reciprocity that we invoke when we speak of someone being "a responsible adult," or "a good citizen."

Unlike the Independent Living Movement, many of the strongest early proponents of the Community Inclusion Movement came from the ranks of advocates for people with the most significant intellectual disabilities. The focus of the CIM on how to secure full adulthood for disabled people also changed. While inclusion is often seen as a call for educational integration of students with disabilities, the language of inclusion has now been expanded by most of its interpreters to extend to other domains of life (e.g., Ferguson, 2013; Ferguson, Ferguson, & Wehmeyer, 2013), including adulthood. Unlike the ILM, however, the calls for community inclusion of disabled adults have emphasized adulthood over the personal.

Instead of a vocabulary focused on personal qualities of autonomy and self-determination, the CIM has often seemed to focus on the symbols of membership and participation. The argument, however, has remained familiar. People with intellectual disabilities are *essentially* the same as everyone else. They deserve acceptance as full citizens of their communities in recognition of this essential sameness. Indeed, it is largely through the social dimensions of assimilation that full adulthood is to be achieved. As part of the analysis of the symbols of adulthood, the avoidance of symbols associated with disability has often seemed equally important.

Perhaps the clearest demonstration of this argument is the calls for “people first” language that many self-advocates, and others within the developmental disabilities community in the United States, have made. At least part of the obvious impetus behind the adoption of such terminology is the assertion that whatever differences reside behind the labels of intellectual disability, they should be inconsequential compared to our essential humanness. The call for linguistic reform is consistent with an implicit ontology that relies on a shared human nature that emerges when the cultural barriers to inclusion are removed. Our argument here looks only at the ontology behind the call for “people first” language. There may well be ethical and/or political arguments that counterbalance these conceptual abstractions. The history of abuse, incarceration, and even extermination at the hands of people who denied their humanity,

and which has fallen especially hard and especially often on those with the most severe intellectual disabilities, makes those additional areas of argument particularly relevant.

The risk in the cultural essentialism of some versions of inclusion is that its implicit denial of essential differences from the dominant culture can also deny intellectually disabled people access to the alternative cultures and traditions that the larger disability community is beginning to celebrate. In our struggle to surround Ian with the cultural symbols of adulthood, to have him fully included as an adult in his community, we worry that we may simultaneously isolate him from the equally important benefits of being included within the larger disability community as well.

If, as we have argued, intellectual disability can be seen as the absence of culture, then gaining the benefits of the alternative cultures emerging within disability studies seems just as potentially valuable as creating affiliations within the mainstream culture for Ian. There are unique strengths, traditions, role models, values, and relationships that are available to Ian because he is disabled at a time when that is becoming a source of pride. Surely the status of adulthood for intellectually disabled people should be available without sacrificing a constructed identity as a disabled person as well. Indeed, the dichotomy seems to exist only as long as an essentialist logic posits them as incompatible concepts in the quest for the Truth about the nature of disability.

The Relational Approach to Disability and Adulthood

Essentialism in disability studies is like a fundamentalist religion: the security of the doctrine conceals the leaps of faith required to maintain belief. We seem to need the Manichaeian dichotomy of devils and deity. Of course, whether one finds difference to be divine and similarity to be the road to hell, or vice-versa, the solace comes from the clarity of conviction. What is truly hellish in such a theology is a tolerance of ambiguity and change. What is left for an interpretivist agnostic who has doubts about heaven and hell? If both the personal and the cultural dimensions of adulthood have been captured by essentialist assumptions embedded in the most prominent branches of the disability reform movement of

the last 40 years or so, where should an interpretive approach to disability and culture look for difference and similarity in adult life?

For us, the issue becomes one of how to advocate for Ian's adulthood in ways that do not, through the very acts of advocacy, emphasize how he differs from other adults (including those with other disabilities). Do we emphasize his differences and try to avoid the conclusions of inferiority that society had traditionally attached, or do we emphasize his sameness and risk perpetuating the same social rules and expectations that have already unfairly excluded him? Should Ian's adulthood look the same or different from the dominant cultural models, or from any alternative models presented by other parts of the disability community?

All of these issues are similar to ones that legal and feminist scholars such as Martha Minow (1990) and Anita Silvers (1995) and others have written about. How should we emphasize the differences that seem constitutive of Ian's identity as a disabled adult without unintentionally perpetuating the grounds for exclusion that the dominant culture has traditionally used to rationalize its denial of our son's adulthood? Minow has summarized this "dilemma of difference" with explicit reference to how it affects people with significant intellectual disabilities and those who advocate on their behalf:

Social, political, and legal reform efforts to challenge exclusion and degradation on the basis of assigned traits continually run up against the danger either of recreating differences by focusing upon them or of denying their enduring influence in people's lives. This dilemma of difference burdens people who have been labeled different with the stigma, degradation, or simple sense of not fitting in while leaving the majority free to feel irresponsible for, and uninvolved in, the problems of difference. . . . [D]ecisions about housing, education, and employment for individuals with severe mental disabilities add to the dilemma of difference the difficulty of learning what the individuals most affected would themselves want. (Minow, 1990, pp. 47-48)

We can only suggest the outlines of an answer here, and it is not original with us. We find the answer in relationships instead of essences, in the ambiguity and messiness of daily interactions. Much of Minow's "social relations" approach seems a promising way to avoid the negative consequences of the "difference dilemma" quoted above, without trying to actually dissolve the tension. Ironically, for intellectually disabled people inclusion within the independent living movement one of the practical examples of how this relational advocacy could work. If intellectual disability is characterized as the absence of culture, then moving to secure the status of those who have that label in either an alternative or a dominant culture might accomplish the same end of mitigating the negative consequences of being denied a cultural context. Instead of removing or dissolving the tension between sameness and difference (independent living or inclusion, disability culture or community integration), the relational approach avoids the essentialism implicit in the assumptions of the dichotomy.

We must, then, start to approach disability as relational, not essential. To our way of thinking that does not diminish disability, it does not discredit its centrality to our lives. Everything that tells us who we are -- how we are the same and how we are different -- is suspended in the webs of, relationships that construct our culture. To interpret disability as relational simply shows us where to look not what we should see. It only begins our search. When we look, we find disability in our affiliations with each other, our celebrations of difference, our struggles for equality. We find it in our cultural achievements and shared aspirations. We find it in our friendships and mutual supports. We find it in the history of our differences and our similarities. We even find it in our debates over who can really participate in the search for meaning in those relationships: who is "us" and who is "them"?

We find it most of all in the stories we tell each other about our lives. We find it especially in the stories our son helps us hear and see. We find it, in short, in the wink of an eye.

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