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**The search for a societal catalyst with the capacity
to motivate the inclusion of people with cognitive disabilities.**

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The disability rights movement has made tremendous strides forward over the past thirty years in advancing the rights of people with disabilities in Canada and around the world (Roehrer Institute, 1996; Canadian Healthcare Association [CHA], 2009). While these political achievements are significant, full social inclusion and acceptance of people with disabilities has not actualized on a broad scale, particularly for those with profound cognitive disabilities (Hennen, 2006b; Reinders, 2008; Cameron & Valentine, 2001; Prince 2004; Crichton & Jongbloed, 1998). Hans Reinders (2000), an ethics professor, argues that political developments are ineffective in achieving a better quality of life for people with profound cognitive disabilities if society decides that the disabled life is “burdened with a deficit of meaning” (p.206-207). Reinders (2000) explains that “all of us hold certain views about what makes our lives worthwhile and it is on the grounds of these views that we come to evaluate the meaning of disability” (p.10). Regardless of what political rights have been ascribed in government documents and regardless of what material benefits have been bestowed, disabled people, especially those who are profoundly cognitively disabled, are usually seen by society “first and foremost as an economic burden” (Vanier, 1997, p.8). Sumarah (1987) confirms this perception when he writes that severely disabled people are perceived to be “the antithesis of the present day Western notion of production, materialism, and competition” (p.166). On what grounds then, can society be motivated to facilitate full integration and inclusion of people with profound cognitive disabilities?

I will examine three philosophical and theoretical positions that attempt to provide a rationale for the full societal inclusion of people with cognitive disabilities. The three positions stem from the normalization and social role valorization model, the rights-based model grounded in liberal individualism, and the L’Arche model which is centered on mutual and reciprocal relationships and community living. I argue that it is the L’Arche model and philosophy which is best equipped to provide the necessary motivation to inspire society to positively engage with some

of its most vulnerable members. This argument is fraught with tension however, since L'Arche draws on a rationale which is beyond the realm of social science. In order to resolve this tension, I will provide empirical evidence that clearly demonstrates the potential for social change when the currently non-disabled form mutual, reciprocal friendships with people with disabilities. Finally, I will conclude by arguing that it is when one moves beyond theories and words to engage in real, interpersonal relationships with people with disabilities, that one may spontaneously discover the *motivation* which will compel them to work toward social inclusion for some of society's most vulnerable members.

Over the past thirty years many of Canada's large residential institutions have been shut down (CHA, 2009). The people with cognitive disabilities that were previously housed in these institutions have found alternative housing arrangements. This movement has been labeled the *deinstitutionalization movement*. While the detrimental effects of institutional living arrangements are widely acknowledged, transitioning toward more community-based residential models has not been a seamless, problem free process (Sienstra & Wight-Felske, 2003; Hennen, 2006b). Making the transition is not simply a matter of logistics. In fact, "closing an institution is a complex process of social change. It represents a challenge to policy-makers, service providers and community developers" (Roehrer Institute, 1996, p.32). Deinstitutionalization involves a shift in the conceptualization of disability. The process of deinstitutionalization has come to necessitate that the term incorporates "as fundamental to its meaning, the development of community" (Roehrer Institute, 2000, p.2). Milner and Kelly (2009) critique the 'policy understanding of inclusion' when they write,

perhaps to escape the shadow of the total institution, service providers rhetorically cite values like 'community inclusiveness', 'full participation', and 'participatory citizenship', which bear little relationship to the social segregation of people with disabilities or the experiences of families and others who support them. (p.53)

This quote highlights the role of society in the deinstitutionalization process. Milner and Kelly (2009) believe that “the sense of community connectedness through relationship represents the heartland of life quality” (p.53). If non-disabled members of society are unmotivated to contribute to this ‘community connectedness’, it cannot be forcefully constructed.

Hennen (2006a) states that “the adoption of ‘normalization’ as the rallying cry for the advocates of persons with developmental disability was the primary force behind the promotion and implementation of the deinstitutionalization process” (p.18). Normalization and its reincarnation as social role valorization (SRV), is considered by many to be “one of the most significant human-service reform movements of the last-quarter-century” (Flynn & Lemay, 1999, p.4). Normalization theory was first developed by Nirje in Scandinavia in the sixties, and then was developed further by Wolfensberger in Canada during the seventies. To act on the basis of the normalization principles would mean making it possible for people with disabilities to practice “those patterns of life and conditions of everyday living that are as close as possible to, or indeed the same as, the regular circumstances and ways of life of their communities and culture” (Nirje, 1999, p.17). Normalization and SRV theories broke new ground when first introduced. These theories shifted the conceptualization of disability away from the medical and rehabilitation model toward the social model by promoting society’s responsibility to facilitate the integration of people with disabilities. However, there was still an emphasis on changing the disabled individual to make them more acceptable. Normalization adherents recognized the need for deinstitutionalization and the responsibility of society to provide more opportunities for people with disabilities, but they also believed that people with disabilities must make adjustments to themselves – their appearance, behavior, speech – in order to be fully accepted and valued by society (Yates, 1999, p.122).

SRV asserts that people evaluate and interact with other people according to their ‘role’ or ‘position’ in society and that these roles can be either valued or devalued. SRV strives to change the

role of the person with a disability from a devalued role to a valued role. Devalued people are low status members of society and can be considered second-class citizens, or even worse, sometimes they are relegated to subhuman roles (Yates, 1999, p.136). I applaud the contribution that normalization and SRV theories have made to the deinstitutionalization movement, but these theories are not able to demonstrate what will motivate non-disabled members of society to create valued roles for people with disabilities. Yates (1999), a proponent of normalization / SRV, appears to ask this question without ever satisfactorily answering it when he writes, “how can we broaden the public’s definitions of who is okay, who is acceptable, who is welcome, who is included?” (p.121).

Michael Oliver disagrees with normalization and SRV theories. Oliver is one of the leading British scholars on the social model of disability and a passionate activist within the disability rights movement. A debate between Wolfensburger and Oliver, captured in an edited book by Flynn and Lemay (1999), highlights the differences between normalization / SRV and a rights-based perspective grounded entirely on the social model of disability. Oliver (1999) believes that normalization / SRV “as a social theory is inadequate” (p.172) and his reasons for this claim are as follows:

Normalization theory offers disabled people the opportunity to be given valued social roles in an unequal *society that values some roles more than others*. Materialist social theory offers disabled people the opportunity to transform their own lives and in so doing to *transform the society in which they live into one in which all roles are valued*. As a disabled person, I know which of those choices I prefer, and I also know which most of the disabled people I meet prefer. (p.172, emphasis added)

Oliver clearly is a materialist theorist with Marxist orientations and he believes that society will only be transformed through struggle and conflict by the “oppressed grouping themselves against the forces that oppress them” (Oliver, 1999, p.171). He insinuates that the motivations of Wolfensburger and Nirje are less than honorable with their attempts to make disabled people

'normal' (Oliver, 1999, p.170). In response to Oliver's criticism, Wolfensburger (1999) claims that Oliver's argument is supra-empirical and beyond the realm of social science. Wolfensburger (1999) considers himself a realist and he believes that social devaluation will always exist. He criticizes Oliver for focusing primarily on power imbalances and structural factors. Wolfensburger writes, "I consider that to be a naiveté. What I have taught is that how people relate to each other will be very heavily influenced by what is in their minds" (1999, p.176). Unlike Oliver's rights-based approach, which Wolfensburger accuses of being utopian and naïve, Wolfensburger (1999) argues that normalization / SRV are practical and realistic theoretical tools that can be applied to real-life situations in order to better the lives of some disabled individuals and achieve an "occasional abeyance in oppressive social stratification" (p.179).

Unlike the normalization approach which advocates for conformance to a norm, L'Arche philosophy celebrates difference and unabashedly embraces eccentricities (L'Arche Canada 2010a; Cushing, 2002). The first L'Arche community was founded in 1964 in France by Jean Vanier and L'Arche Canada was founded shortly afterwards in 1969 (L'Arche Canada, 2010b). L'Arche Canada has currently founded about 200 homes and workshops or day programs for people living with cognitive disabilities, and these homes and workshops are grouped into 27 communities located across the country (L'Arche Canada, 2010b). L'Arche communities are heavily influenced by L'Arche's philosophical framework which emphasizes mutual relationships and community life (L'Arche International, n.d.). L'Arche's founder, Jean Vanier (1997), describes L'Arche as communities "rooted in the relationship of love and trust between people with handicaps and those who have chosen to live with them" (p.194). L'Arche communities aim to reduce "the expected distinction between caretakers and patients" (Angrosino, 2003, p.944). Although L'Arche communities appreciate and value individual independence, in contrast to the rights-based individualistic approach, L'Arche philosophy prioritizes *interdependence* over independence.

Christine Kelly (2007) asserts that “the most apparent counter-cultural value of L’Arche communities is the rejection of the idea that ‘independence’ is the ultimate goal for people with disabilities” (p.26). Close relationships between staff and residents at L’Arche are encouraged and the values of interdependence are nourished. In a book about long-term care in Canada, the authors describe the concept of interdependency:

tackling the notion of individual failure means tackling the very idea of independence and individual responsibility. Although Western liberal thought has long stressed the importance of self-reliance, interdependency is part of the human condition. We vary significantly in the extent of our capacities and contributions, but we necessarily depend on others for food, clothing, shelter, jobs and joy. The dependency that may come with old age and with disability does differ from other forms in that it often requires personal, intimate kinds of care for people unable to manage aspects of daily maintenance along. But this too is part of the human condition, a part we accept in infancy, but too often reject at older ages. (Armstrong et al., 2009, p.21)

This quote is referring primarily to the aging process, but I believe it also applies to people with profound cognitive disabilities who often find it necessary, more so than non-disabled persons, to be dependent on others for their wellbeing. In our contemporary society being dependent on others is often seen to be a sign of weakness and failure even though the experience of dependency is an inextricable part of the human condition. Embracing our interdependency “is critical to our health, our quality of life, our sense of belonging, our peace of mind, our security” (Etmanski, 2002, p.44). L’Arche chooses to honor and prioritize interdependence and mutual relationships above all other values, setting itself apart the rights-based movement and distinguishing itself from many other group home models which adhere to normalization / SRV principles (Angrosino, 2003).

L’Arche philosophy is different from normalization / SRV in that it does not try to change people with disabilities so that they can measure up to some social standard or earn a valued role in society. Instead the L’Arche philosophy believes that people with profound cognitive disabilities are intrinsically worthy and that they have much that they can share and contribute to society through

the vehicle of relationship. Genuine relationships are only possible when “nondisabled people learn to attend to the distinctive ways of being in the world of people with intellectual disabilities” (Cushing & Lewis, 2002, p.177). This perspective stands in contrast with normalization and SRV theories which argue that “people relate to each other largely on the basis of social roles, rather than on the basis of their inherent value” (Yates, 1999, p.140). Wolfensberger (1999) accused Michael Oliver for basing his theories on the supra-empirical ‘religious’ realm, beyond the realm of social science, and Wolfensberger could easily make the same accusation about the L’Arche philosophy. Normalization / SRV theory does not pretend to “speak to question to the value of persons” (Yates, 1999, p.141) as this question is above the empirical realm. Yates (1999), however, does not deny that

religious and ideological decisions *must* be made in human services. But such decisions must be made before, so to speak, one undertakes to apply Normalization or SRV. Only *if* one decides that such people should be positively valued does Normalization/SRV *then* make any sense, because it can tell one what to do that has the best chance of bringing that about. But SRV cannot provide one with a reason for wanting devalued people to be valued in the first place. Only ‘a religion’ can do that. (p.157)

In this way, normalization / SRV attempts to detangle itself from any philosophical question about the meaning and value of human life. Instead, it asserts itself as merely a social science theory that accepts the world as it exists and works with reality to better the lives of people with disabilities.

In 1971, Wolfensberger (1973) discovered the L’Arche movement for the first time and he writes, “fancying myself somewhat of an expert in mental retardation, I was stunned by the magnitude of what it was that I had missed all these years” (p.10). Wolfensberger’s reflections on L’Arche are fascinating to analyze as they provide insights into both theories and philosophical positions. Wolfensberger (1973) was very intrigued by the quality of life he discovered at L’Arche and his surprise is obvious when he writes, “I can scarcely begin to define what I mean by joy in the lives of the retarded, because one has to experience this phenomenon to understand it” (p.12). He

attributes this joy he discovered at L'Arche to "a feeling of being valued and esteemed by the others in one's life. . . and occasions at which one meets in a relaxed and free social atmosphere devoid of certain of the tensions and drives so common in the mainstream of our society" (Wolfensberger, 1973, p.12). He also appreciated the lack of power imbalances evident in the interactions between staff and residents. Wolfensberger (1973) did not believe the L'Arche model offered a comprehensive and practical solution to integrating people with disabilities into society on a broad scale, but he saw "the movement of *qualitatively* vast importance to the future" (p.14, emphasis added). He found this qualitative value in its ability to inspire both staff and the local public by demonstrating a different way to engage with people with disabilities. Wolfensberger predicted that "the presence of a L'Arche establishment can have profound effects upon a local public, by interpreting mental retardation to them in a compelling fashion, and by involving them constructively in the lives of the mentally retarded" (Wolfensberger, 1973, p.16). Nevertheless he recognized that L'Arche's philosophy advocated for an approach to disability that conflicted with normalization/SRV, since L'Arche perceived "the current structure and direction of the mainstream of our society as being one that we should not impose upon the retarded" (Wolfensberger, 1973, p.15). Although Wolfensberger was impressed with the L'Arche model and recognized its ability to inspire people to respond to people with disabilities in new ways, he maintained his belief that in order to establish a dignified life in society for large numbers of people with disabilities, they must learn to adopt socially valued roles (Wolfensberger, 1973, p.15).

Angrosino (2003), a cultural anthropologist, notes that in general, L'Arche has not been interested in affecting change in society by joining the disability rights movement in lobbying politicians. Angrosino (2003) writes, "L'Arche prefers not to immerse itself in the prevailing political culture but rather to stand apart and. . . demonstrate the possibility of living by alternative values" (p.934-938). These alternative values place L'Arche at odds with the rights-based,

individualistic approach to disability because L'Arche emphasizes *interdependence* over the *independence* typically associated with the rights-based movement. Kelly (2007) observes that L'Arche typically engages in “‘lived’ advocacy rather than formal political protest” (p.26). L'Arche communities in Canada contribute to broader social change primarily by being a lived example of interdependent community living and an inspiration to society members who are witness to their community life. Is Wolfensberger correct in arguing that this is an ineffective approach to creating widespread social change? Could L'Arche's community and friendship model be applied on a broader scale in society? The following three examples demonstrate how the development of respectful, reciprocal relationships between people with and without cognitive disabilities is directly related to the quality of life for people living with a cognitive disability. These friendships also deeply enrich the life of the non-disabled friend. The development of these types of genuine and reciprocal friendships is key to achieving sustainable societal change because they have the power to change the attitudes and values of those in the broader community.

The first of these examples is illustrated by a participatory action research project undertaken by Milner and Kelly (2009), which explored understandings of community participation among twenty-eight adult, New Zealand vocational service users who had disabilities. Milner and Kelly (2009) critique political understandings of inclusion and argue:

Although. . . public policy has increased their presence in community spaces, three decades later people with intellectual disabilities remain absent from the intimate social and interpersonal relationships characteristic of community membership and belonging for other community members. . . . Various disability writers have described people with disabilities as living ‘*in*’ but not ‘*of*’ their local community. (p.48, emphasis added)

Through focus groups and semi-structured interviews with people twenty-eight people with disabilities, Milner and Kelly (2009) clearly illustrate how a lack of “‘intimate social and interpersonal relationships’” greatly detracts from the quality of life for someone with a disability

(p.51). Participants who had only a few friends expressed a greater sense of marginalization and compromised life quality, while participants who discovered safe and comfortable environments that offered them many opportunities to develop genuine friendships, expressed a higher level of self-esteem and quality of life (Milner & Kelly, 2009, p.51). Milner and Kelly (2009) recommend having an ongoing dialogue between people with disabilities and others in society to “broaden our understanding of inclusion” and “leave space for the alternative imaginings of people with disabilities” (p.59). Milner and Kelly’s participatory action research project gave voice to people with disabilities who clearly indicated that interpersonal relationships with others in society increased their quality of life. It emphasized the importance of having welcoming places in our society where these friendships can develop and proliferate.

Pottie and Sumarah utilize qualitative methodology to explore the nature of friendships between persons with and without cognitive disabilities in a L’Arche community (2004). They document the challenges inherent in these types of friendships, like the challenge of learning how to communicate with a person with a disability who does not express themselves verbally. Their interviews clearly demonstrate how these friendships are possible even as the friends struggle with the power imbalance between them. Vanier believes that a non-disabled person can enter into friendship with a person with a disability on an equal plane if the non-disabled person recognizes their own weaknesses. Vanier (1997) writes, “when we deny our particular inner weaknesses, we remain an illusion. . . we are all wounded on different levels” (p.207). This is an essential first step in understanding our common humanity and enabling genuine friendship to grow. In light of this understanding, Sumarah (1987) writes, “L’Arche, then, is not simply a facility *for* persons with mental handicaps. It is a community where people come together to grow in greater bonds of fellowship *with* each other” (p.166, emphasis added). Pottie and Sumarah (2004) provide evidence through their qualitative research, that the non-disabled friends in the four ‘dyads’ they studied were

personally nourished and encouraged by their relationships with people with disabilities which demonstrates the reciprocity of the friendships. This reciprocity was able to occur because the friendships were built on “the belief that the other has something equally important to give in return and a recognition of their interdependence” (Pottie & Sumarah, 2004, p.64). Pottie and Sumarah (2004) acknowledge that the contextual environment of a L’Arche community helped these friendships to flourish and that the “community’s vision, values and structures provided a supportive environment for friendships between persons giving and receiving care” (2004, p.64). This example provides empirical evidence that friendships between people with and without disabilities have the potential to be reciprocal and rewarding for both individuals. If the welcoming environment of L’Arche communities were to be duplicated and nourished on a broader scale in different social contexts, there would be more opportunity for these types of friendships to flourish naturally.

Finally, the last piece of empirical evidence comes from an evaluation conducted by the Roeher Institute in 2000. It is an evaluation of deinstitutionalization projects mounted in six Canadian provinces. Using a wide variety of methodologies including case studies, surveys and interviews, the evaluation examined deinstitutionalization projects according to five commonly used outcomes to indicate quality of life. One of these five measures is referred to as “supportive personal relationships” (Roeher Institute, 2000, p.i). The evaluation results clearly indicate that “supportive personal relationships were found to be an integral element of community inclusion because they provided a context in which individuals’ and families’ new-found status was promoted, valued, and respected” (Roeher Institute, 2000, p.6). Non-disabled people who had befriended a person with cognitive disabilities after their deinstitutionalization, reported dramatic shifts in their attitudes and perceptions toward people with disabilities – a change they attributed to

their newfound friendships that blossomed when they came to know an individual with a cognitive disabilities in a personal way (Roeher Institute, 2000, p.19).The evaluation report describes how

one community member reflected that it wasn't until she got to know the individual that she began to recognize possibilities for him: *I learned he is a person, he has talents and characteristics. He's made me appreciate that those with disabilities – they want to be like everyone else. His personality has come through as I have come to know him. He has a unique personality.* (Roeher Institute, 2000, p.11)

Families of people with disabilities also noted significant changes in the way they viewed their family member when they had a chance to build a relationship with them outside an institutional setting (Roeher Institute, 2000, p.14). This evaluation provides carefully documented evidence that interpersonal, reciprocal friendships between people with and without disabilities can create dramatic attitudinal shifts among non-disabled members of society who previously may not have perceived people with disabilities as equal human beings. As these types of friendships proliferate there is the potential to achieve sustainable social change as the attitudes and perceptions of those in the broader community are transformed. The evaluation report states:

Relationships also changed others in communities by transforming their beliefs about the capacities and value of people with intellectual disabilities. It is on the groundwork laid by the exercise of self-determination and supportive personal relationships that broader community support for inclusion was built... *The extension of people's lives into the social, economic, and political spaces of their communities would not have been possible without the fundamental restructuring of personal supports* that many examples from the evaluation illuminate. (Roeher Institute, 2000, p.13, 34, emphasis added)

This evidence conflicts with normalization / SRV theory, which states that only when people with disabilities manage to obtain a valued social role are they then able to achieve full inclusion. The evaluation of deinstitutionalization projects by the Roeher Institute demonstrates that full inclusion *begins* with interpersonal, reciprocal relationships where each person in the relationship comes to accept the other as a contributor and an intrinsically valuable human being.

I now return to my initial question: how can society be motivated to facilitate the full integration and inclusion of people with profound cognitive disabilities? Wolfensberger (1999) would argue that we must begin by first applying normalization / SRV to assist people with cognitive disabilities so they can improve themselves in order to earn valued roles and convince society of their worth. Oliver (1999) believes that social inclusion and equality would actualize if the political, economic and other structural barriers were removed, while L'Arche identifies friendship as the vehicle for social change and inclusion. Reinders believes that appeals to people's cognitive capacities will not succeed in creating change in society because it is motivation that matters, and this motivation depends on the cultivation of our moral resources which is nourished by interpersonal relationships with dependent others. Reinders (2000) writes,

there is no compelling rational ground why *we* ought to try to share our lives with them, should we be inclined not to do so. In case we consider society to be the space of exchange between moral strangers, we can leave it up to our institutions to care for whoever needs to be taken care of . . . The reason for maintaining social responsibility for mentally disabled persons is grounded in an understanding of ourselves as *relational selves* who receive our lives and its potentialities from one another's hands. Although *this understanding grows out of and is nourished by interpersonal relationships*, it can provide us with *motives* to exert our moral imagination for the sake of dependent others through social institutes and practices. (p.154, emphasis added)

Instead of locating the key to motivating society within a detached philosophical or theoretical position, I argue that it is the lived experience of genuine and reciprocal friendships between people with and without cognitive disabilities that is capable of prompting profound shifts in society's perception and attitude. Reinders (2000) describes how 'the skeptical outsider in liberal society' would not be able to appreciate how parents could commit to caring for a severely disabled child if they had never had a similar experience (p.205). Finding meaning in human life is not something that can be forced; it simply happens as our moral self "discovers itself within a network of social relationships" (Reinders, 2000, p.17). Reinders does not admonish society to 'try harder' to become

more inclusive to people with disabilities by drawing on rational scientific reasons *or* supra-empirical reasons founded on assertions about the intrinsic value of human life. Instead Reinders (2000) suggests that one simply begin building relationships with people with disabilities directly as there is no other solution, but “to expose oneself to the vulnerability of meaning and to accept the other as a fellow creature with whom one can share one’s life and do the best one can” (p. 208). This can be encouraged through the fostering of welcoming places in society where disabled and non-disabled are in close proximity and friendships can spontaneously develop at their own pace, without being forced.

I can speak from my personal experience to the effectiveness of direct engagement with people with disabilities. I had never had direct interaction with people with profound cognitive disabilities before I visited a L’Arche community for two months in the summer of 2009. For the first few days I was awkward, ill at ease, and I did not know how to interact with people who seemed so different than me. This is a common experience which Cushing and Lewis describe as follows:

Most people without disability that come to L’Arche carry with them some degree of socially pervasive perceptions about the weaknesses of people with intellectual disabilities... Thus, they initially have limited language to describe or think about how a person with an intellectual disability could be a friend or teacher as well as one’s charge. Before moving toward mutuality, the caregivers have to unlearn normative beliefs and stereotypes surrounding people with developmental disabilities as ‘passive recipients of care’. (Cushing & Lewis, 2002, p.182)

During my first few days at L’Arche I was acutely aware of my negative perceptions of the community’s residents and no amount of cognitive or emotional reasoning with myself was able to adjust these perceptions. It was only by sharing my life with these individuals and building relationships with them that my perception of them dramatically shifted. This process was so subtle I was almost unaware that it was occurring. When I left the L’Arche community after two months,

my perceptions and way of interacting with people with disabilities had been radically altered.

Similarly another author, C. Pottie (2000), writes about the eleven years that he spent in L'Arche communities and he refers to this time as being "personally transforming" (p.3). Vanier (1997), the founder of L'Arche, writes,

if we are really to understand the important and paradoxical role of people with handicaps it seems to me necessary to have some experience. Words and theories are not enough. The things that I suggest *may seem naïve, utopian*; they may even seem a way of trying to make sense of difficult lives, of finding meaning where there is none. But these not just words. These are things that I have learned by living. (p.xii, emphasis added)

This quote compels us to move *beyond* rights-based approaches, normalization and SRV theories, and even the seemingly naïve and utopian philosophy of L'Arche. In the lived experience of sharing life with a person with a disability we may discover unwittingly, that the moral self that has been there all along.

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