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MAINTAINING INTEGRITY AND CULTIVATING COMPASSION

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The evolution and deepening of my work as an advocate for persons with disabilities has been informed by a variety of personal experiences and the exploration of a number of different paths. A few of these may seem unique or parochial; others quite familiar and well trodden. What is a comfortable and inspiring path for some may seem foreign to others. But in the naming of where we are and why we are doing what we are doing, we can see more clearly where we have been and where we might go as advocates for devalued and disenfranchised persons.

These paths also have specific characteristics associated with them which we can learn to cultivate, if we are interested in deepening our understanding of the art of advocacy and our commitment to that path. I will try to name a few of these characteristics, or states of mind, so as to encourage those who are interested in pursuing a particular path. Finally, I want to disclaim any interest or belief in the correctness of any particular path. This is a peculiarly personal journey, walked by each of us at our own pace, in our way, for our own purposes. I have neither knowledge nor conviction of the "right" path. I do not profess to understand why we pursue different paths in search of the same goals. I only know what I have personally witnessed, and speak from that voice.

The first step on any path is a defining moment in our lives. For me, that first moment occurred at the Northampton State Hospital thirty years ago. I was invited to visit the hospital by a legal services attorney who was leaving to teach at a nearby college. My initial experience of a state hospital was profoundly disturbing and omnipresently overwhelming. I entered a large, gothic rotunda, and wondered down one hall after another, through a maze of wards and stairwells and tunnels and screened windows. My senses were soon overloaded with the sight of squalor, the smell of decay, the sound of pain, and the touch of loneliness. My heart experienced the emotional overload of relentless and pervasive suffering. When I finally returned to the rotunda, some distance from the locked wards, I stopped for a moment to recapture my energy and reflect on what had unfolded before me in the past few hours. Sitting on a wooden bench that encircled the rotunda, I heard my mind voice a vow not to leave until everyone else does. That experience and that vow was a calling of sorts, and has informed and motivated almost everything I have done since that day. It was the beginning and defining moment of my path.

Recently, there was a celebration of the closing of the Northampton State Hospital which, for me, was a fulfillment of that vow, a confirmation of that effort, and an inspiration of the next commitment. A young artist, with a similar calling about state hospitals, arranged a musical event. In her grandmother's village in Germany, the townspeople had a saying that when people die, you should open the windows to let the suffering pass out. This young woman convinced an array of state

officials that they should open the windows of the Northampton State Hospital to let the suffering out. She had the entire four story, two block long building wired for sound, and at noon on a fall Saturday afternoon, played Bach's *Magnificat* from every window in the place. Hundreds of people walked up the hospital hill and listened silently as chimes from every church in Northampton called us to remember. Then Bach spoke for the tens of thousands of people who had inhabited these buildings over the past century and a half. As I sat in the grass with my ten year old son, listening to Bach and hearing the cries of five generations of inmates, I wept and remembered a phrase from an ancient Asian teacher: "Done is what had to be done."

I want to mention four distinct paths that I have known, and walked, over the past thirty years. First, there is the path of passion. It generates inspired, focused, and fiery action directed towards someone or something. Suffering – either one's own or that of others – can be a powerful inspiration for this path. But so can be desire or other grasping emotions, such as wanting to win or to achieve some strategic objective, like closing a psychiatric institution. Similarly, passion can be motivated by anger or other negative emotions, such as revenge or just trying to have an abusive staff person fired. The path of passion can be quite pure, like the poetry of Kabir, the social justice agenda of Martin Luther King, or the steady faith of many visionaries like Nelson Mandela. It can be grounded in a compelling belief in some higher good, like justice, freedom, or the relief of suffering. Conversely, it can be quite destructive or divisive, like the scientific agenda of eugenic sterilization or the biblical agenda of Judge Moore in Alabama. What distinguishes the results of this path is the clarity of its vision and the purity of its objectives. But whatever its quality, it is a powerful and compelling path that is associated with dynamic, productive, and charismatic advocates.

Second, there is a path of service. It generates committed, dedicated, and generous action directed to the welfare of others. Appreciation of the benefits of one's own situation and the contrast to someone else's challenging circumstances is a powerful inspiration for this path. But a diminished view of one's own self-worth, or the inability to take care of one's self, can similarly propel someone to this path. The path of service is generally related to a selfless desire to assist others, as evidenced by missionaries like Mother Theresa's Sisters of Charity of Calcutta. The highest aspirations of advocacy are rooted in this path, since the very purpose of advocacy is achieving the goals and protecting the rights of those on whose behalf we advocate. It can, like all paths, be corrupted by alternative purposes, such as self-aggrandizement or a psychological need for recognition and affirmation. But if motivated by a genuine desire to help, this path of service is an extraordinarily fulfilling pursuit, commonly walked by many in our community.

Third, there is a path of the heart. It manifests as a caring and loving expression to others. It is related to, and is reflected by, actions that benefit others. Similarly, it is related to, and often expresses itself as, passion. But it is unique in its emotional roots, relational context, and out-pouring of affection. Connection and inter-relatedness is the inspiration for this path. It is rooted in the understanding that what separates those who are deemed to have a disability and those not similarly labeled is mostly a coincidence of circumstance. It is informed by the experience of leaving a locked psychiatric ward, looking back through the wired glass in the corridor door, and realizing that it is mostly the glass, not any deeper truth or difference, that separates those on the inside from those on

the outside. This recognition of circumstance and sameness is at the core of this path. Yet the undeniable difference of being confined on a locked ward as opposed to being free to move about in the community confirms the centrality of this path. The contrast between how we are all connected, and at the deepest level quite similar, with the circumstances that create the illusion of difference provides the grist for a true expression of the heart. The path of the heart is often effusive and always caring. Unlike the practice of service, it is more about all of us than only some of us. And unlike the practice of passion, it is not about ideas or strategic objectives, or winning or losing, but about unremitting love.

Finally, there is a path of the spirit. It reflects a sense of some greater power, be it the woman of the moon, the emptiness of the universe, or the all embracing love of a higher truth. It may assume specific parochial forms, or thrive in formlessness. It is beyond the Matrix. It allegedly claims an ethic of goodness, but it has been abused beyond recognition as an assertion of righteousness. For some, it is the culmination, combination, and creation of all other paths, inspiring service, generating love, and motivating passion. For others it is confusing, empty, and a cultural anathema. It is at least controversial, especially when invoked in a democracy or in the name of the rulers. But for those who have met a guide, or followed this path with care and discriminating wisdom, it is an exquisite teacher of devotion and surrender.

These paths are not mutually exclusive. Nor do you have to choose one forever. I have wandered and played on each, finding one particularly useful at one point and another creative and helpful at another, depending upon the circumstances. So what can we know about the characteristics and utility of each of these paths? And how does this all relate to our work as advocates?

I want to focus on four challenges of being an effective and enduring advocate, and explore how these different paths can assist us in meeting those challenges. The first challenge is sustaining, over a long period of time, the energy necessary to do this work. Most of us come to this work with a little fear and some uncertainty, but usually with considerable enthusiasm, even a bit of passion. We inevitably experience frustration, disappointment, defeat, and even despair. All of these experiences can whither the initial enthusiasm and sap the reserve of energy. One method for sustaining energy is to focus on maintaining a "beginner's mind." With this attitude, we try to do everything as if it was the first time, remembering the freshness and determination that we brought to that first moment. We do not try to be an expert at anything. Rather, we practice sustaining the mind of a beginner, and maintaining the energy and enthusiasm of the beginning.

Another critical source of energy is the raw determination that arises when we witness suffering, abuse, or blatant rights violations. For instance, a few weeks ago, I went to see one of the children who is a named plaintiff in a mental health class action I am litigating in Massachusetts. He lives with his grandmother in a tiny, one bedroom apartment also shared by his aunt, her husband, and their two infant children. He has profound behavioral and language challenges, strikes out frequently and hugs, a bit roughly, almost as frequently. He has much to say but can barely speak. He loves to play but has no one to play with. He is loved by his grandmother but almost no one else. As a result of his behavioral challenges, complex needs, and poverty, he is isolated, segregated, and abandoned by

most educational and mental health providers. I had been spending long hours on this complex case on behalf of the class of children and had little time left over for individual advocacy. But when I left his tiny apartment, got in my car and closed my eyes, I made a decision that I would do everything in my power to alter this desperate situation. I vowed to represent him in whatever forums, for however long, in whatever ways necessary to remedy this neglect. This recent experience, and this determination, has been the source of enormous new energy.

There is a causal connection between motivation and energy. When our passion is to win, we will almost certainly tire. When our motivation is to serve, we will most certainly be inspired. If the root of the action is negative emotions, like anger or righteousness, it will deplete energy. If it is rooted in a more selfless mind state, like dedication or generosity, it will create energy. When we focus on difference and distinctions between ourselves and others, we get discouraged or occasionally depressed by the conditions that confine them. But when we realign our hearts to dwell in the connectedness of all of us, our determination to reach out generates a reservoir of energy.

I practice this every time I begin a new case or project. Most of my seven current cases were filed over ten years ago. To begin a new class action or to invent a new project involves a commitment of at least a decade. Honoring this commitment necessarily requires a sustaining energy that you can rely on, for prolonged periods without interruption. I practice this by taking time each year to reflect on whether I am practicing what I am speaking to here. We have a policy at the Center for Public Representation that encourages everyone to take an extra week of time away from work to reflect on why they do what they do and how they can continue to do it better. Each of the paths of passion, service, the heart, or the spirit can be powerful practices for sustaining the energy necessary to do this work, mostly by focusing on the quality and merit of just the doing, rather than the outcome of the effort.

A second challenge is maintaining a sense of integrity in the midst of complex forces. Most of us come to this work without much confidence in what is right and what is wrong, exactly how to behave in the face of conflict, or how to tolerate abusive situations. But over time we develop a keen sense of both the ethics of advocacy as well as the ethics of systems. We learn the potential and the limits of law and legal remedies. We navigate the boundaries of service systems. We witness harm and affronts to dignity. We confront the raw power and intermittent gentleness of caretakers. We develop our own, experiential guidelines of what makes for constructive and effective advocacy. We create a clear vision of what is acceptable, and shape our integrity by this vision. Along the way, we may wonder whether we have been tainted by the very processes we invoke or the conditions we challenge. It is even harder to know whether more compromise or less is the better course.

A few years ago I participated in a protracted, sixty hour mediation to try and settle a complex class action on behalf of residents of nursing facilities who had mental retardation or developmental disabilities. There were numerous, competing issues to resolve: how many people would leave over what period of time, how to prevent new admissions filling up the vacated beds, what services would be provided in the nursing facility while people waited to leave, and what would happen to the people left behind. The state defendants made significant commitments on placement and nursing facility

services, but virtually none on admissions. I knew that given the current rate of admission, most of the gains achieved in the placement process could be eviscerated with a flood of new people entering these institutions. So how do you decide whether the proposed settlement, with its obvious compromises, is acceptable and consistent with the very principles and purposes of our work? In each of these difficult and potentially confusing moments, our very integrity is at stake.

But confusion can dissolve through a clear understanding of the path we are pursuing, its teachings and sign posts, and a recognition of what inspires and motivates us. Our integrity, including the critical choices we make as advocates, the lines that we draw, and the places we elect to stand are all informed by a vision of where we are going and why we have chosen this work. If we act from a well defined path, be it passion, spirit, service, the heart, or any other set of clear and relevant guidelines, our integrity cannot be threatened. In the nursing facility mediation I described a moment ago, I felt confident that ensuring the discharge and integration of almost a thousand residents was a clear expression of what most mattered. Whether the settlement would ultimately succeed in emptying the nursing facilities, I did not know and now, in hindsight, suspect will not occur. But I remain confident it was the right thing to do, that it reflected not only a clear vision of what is right but also a balanced judgment of what is possible. I am comfortable with this compromise because it did not compromise my integrity.

A third challenge is maintaining an open heart in the midst of conflict and suffering. Compassion is a term that we hear about frequently in a social justice or spiritual context. It is sometimes confused with feeling sorry for another or pity. But pity is an expression of distance or distinction. Pity reflects superiority and insulation from the circumstances that cause difficulty for the other person. Compassion, on the other hand, is grounded in a sense of connectedness and community. Compassion is not reserved for those we know, although it may be easier to experience for those we are familiar with. Similarly, compassion is not reserved for those we like, although it is certainly easier to generate for those we sympathize with. Nor is it reserved for victims of difficult circumstances, but it also can be extended to perpetrators of those circumstances.

Consider five situations and take a moment to reflect on whether each generates a sense of compassion, and whether they generate an equal sense of compassion:

- (a) you enter a hospital and see a friend who is seriously injured from an accident
- (b) you pass by several people living on the street in a large city
- (c) you see a picture of an elderly man gazing aimlessly in a refugee camp in some distant country in Africa
- (d) you observe a parent yelling and striking their child for misbehaving in a store
- (e) you see a documentary about Chinese soldiers who have harmed a Tibetan monk

In each of these situations, compassion is possible, even if it more difficult to generate in the last two scenes than the others. Compassion is an exquisite expression of the heart. It allows us to move towards, rather than withdraw, from any situation, thereby greatly enhancing our access and effectiveness. It allows us to operate from a place of equanimity and acceptance, and thus to tolerate any difficult situation. It allows us to be friends with anyone, and to build upon that friendship in an attempt to change difficult circumstances.

Compassion can be inspired through an appreciation of our own situation. When we confront, up close, the enormous pain others are forced to endure, we have great gratitude for the benefits we have received. For instance, in my nursing home case, I have spent much time in nursing institutions with young people with developmental disabilities. Many are the victims of car accidents and have suffered head injuries. Many have pictures of their former lives and families on the wall. The dramatic limitations that people with head injuries endure inspire a deep appreciation of the grace of my life.

Compassion must be cultivated and practiced. There are many techniques and methods for developing compassion, all of which can be useful under different circumstances and for different purposes. The simplest one is to pause and reflect on how it would be to be in the other person's mind and body: what would it feel like to be him. Another arises from nurturing a personal relationship with a person you serve. Laurie was a client of mine at the Northampton State Hospital. She was a twenty-five year old woman who had been institutionalized for eight years. She was afraid to talk to anyone. I spent almost a year, visiting with her at least once a week. For months we only sat quietly together. After a while we held hands, and gradually she began to respond to my questions, albeit with only a nod of her head. Eventually we started having conversations. A year later she initiated these conversations, eagerly and with a smile on her face. She told me of her abuse, and witnessing the abuse of her siblings. Eventually, as her confidant and dedicated advocate, I helped her leave the hospital and move to a community home. When she died a few years later, from choking on a hamburger at Friendly's, I cried because I had lost a dear friend. But her presence and friendship was an enormous teaching in patience and compassion.

We can cultivate compassion for different people and circumstances. We can generate compassion for ourselves. We can generate compassion for those we serve. We can generate compassion for those we oppose. In some of my cases, the opposing counsel, usually an assistant attorney general who represents state agencies, can be very difficult. In one of my cases, this lawyer was especially obnoxious. We had many conflicts and few nice conversations. He had a unique ability to make everyone, including the judge, frustrated and even angry. One day I just realized how deeply unhappy a person he was. No one liked him and he probably had few friends. All of sudden I felt a welling up of compassion for him. This realization and understanding dramatically shifted my relationship with him. I even tried talking to him about how his actions caused such difficulty for others. Although it did not convince him to change his behavior, and although he never was easy to work with, I stopped struggling with him because I truly did not want to make his life more difficult than it was. This did not mean that I compromised my integrity or my position, just that I operated from a place of compassion rather than anger or judgment.

Finally, there is the challenge of making wise decisions and acting from a place of greater understanding. Wisdom is the understanding and acceptance of how things are, and why they are so. There are many wisdom traditions from many different cultures. Native Americans understand and explain their lives as expressions of natural forces. Social justice commentators understand and explain the diminished role of certain groups as the result of political structures and power allocations. Many religions understand and explain events as expressions of divine intervention. While advocacy may be most comfortable with political and structural explanations, advocates need to find their own truth about themselves, their work, and the people they have chosen to serve.

Wisdom is uncovered not delivered. It requires effort and patience. It evolves from a commitment to explore and investigate. It is discerned from our experience, and can be enhanced by systemically reflecting on our experience. It may be useful to have a guide or a mentor, but it is a uniquely personal and subjective unfolding. One familiar truth is that the better part of wisdom is humility. Humility is a gradual settling in to what we do not know or cannot control. It is accepting the ambiguity and uncertainty of not knowing. We constantly are confronted with situations that we try to control, only to later come to see that we did not know all that we assumed.

For example, I once represented a mother with a psychiatric disability in a custody case. She had been hospitalized repeatedly for depression and suicidal thoughts. She had a four year old daughter who was in the physical custody of her former husband. When he moved for legal custody, she asked me to help her oppose the motion. After reviewing her records, interviewing her clinician, speaking with her former husband, and seeing the report of the GAL, I was convinced we had no chance of prevailing. Her former husband, who was a caring man, offered her a very generous visitation schedule if she would agree to his custody request. We had numerous meetings to discuss the case, and at each one, I advised her, more strongly than the last, to accept his offer. I was convinced I knew what was best for her, since I was convinced I knew the outcome of the proceeding. She adamantly refused and insisted on a trial.

The hearing went badly, as evidence of her psychiatric disability and self harming behavior made the judge wince. Finally, the judge called us into chambers to suggest that she assent to motion and accept the ex-husband's offer. She refused, and insisted on testifying in opposition to the motion. On the stand the judge asked her why she insisted on opposing his request. With tears in her eyes, she responded: "When I was a little girl, my mother let someone take me away, and never fought to get me back. I swore I would never do that to my daughter, if the same situation arose again." So what I thought was the best outcome – the most favorable custody and visitation arrangement – was not at all what was at stake. Instead, this courageous mother needed to tell her daughter, publicly and formally, that she would never abandon her. She taught me about not knowing, and the critical importance of remembering that at best we suspect we know what matters.

The hardest and sweetest truth is that the best part of wisdom is forgiveness. Forgiveness is perhaps the most challenging expression of both connectedness of compassion and the humility of wisdom. There are various techniques for asking for forgiveness, which help remind us to do it and

help us to actually verbalize the request.

Once I was part of a complex negotiation with a governor, her legal staff, and various state officials, in the governor's oval office. On behalf of the plaintiff class, we proposed that the governor shift funds from various accounts to mental health, and set forth convincing legal reasons for doing so. The governor's counsel took great offense at this suggestion, considering us arrogant for telling him how to manage the budget. I realized our initial, and probably only, meeting with the governor's representative had started quite badly. I regretted that he felt so offended, so I asked for his forgiveness. I did so by saying, directly to the Governor's legal counsel that if I had done anything to offend him, either intentionally or unintentionally, I was sorry and asked that he and others forgive me. The room became silent; the governor's staff were stunned and could hardly respond. When the conversation resumed, it had a distinctly different and more positive tone. The directness of asking for forgiveness allowed us to amicably resolve our legal positions.

I do not know whether any of these paths, or suggestions, will resonate with any of you. I do know that we need methods and practices to sustain our energy, to maintain our integrity, to cultivate our compassion, and to deepen our wisdom. With such methods or practices, we will surely be more effective and enduring advocates for the people and causes that we serve.