



Affirming Presence: Spiritual Life and Friendship with Adolescents with Developmental Disabilities

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My first impression of Galen immediately brought to mind the description of Dr. James Mortimer by Sir Arthur Conan Doyle in *The hound of the Baskervilles*: “He had large, quivering fingers as agile and restless as the antennae of an insect” (Doyle, 579). While the logic of the antennae’s movement is inscrutable to the observer, they are busily working to determine moisture, discern scents, taste surroundings, locate food or detect enemies. Galen’s motions are often as erratic to me, but I know they are purposeful.¹ Galen has an intellectual disability and autism which manifests itself physically through the typical repetitive motions and rituals (often involving wads of string or glasses) and peculiar responses to the variety of sensory stimuli that are part of the wallpaper of our lives. He has severely impaired reciprocal interaction and, therefore, has had a difficult time entering into friendships. To understand Galen primarily through his autism, however, does him a disservice and may cause one to miss what it is to know him as a friend.

If you desire a meaningful conversation with John, a young man with Asperger’s syndrome, and to engage him in a two-way conversation, you will need to talk to him while you assemble a 1200-piece puzzle together. The activity occupies his brain and has a calming effect on him that allows him to stay, more or less, on topic. I was recently evaluating a joint event with the

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activities coordinator of an organization that does a wonderful job providing community activities and advocating on behalf of persons with intellectual and developmental disabilities in our community. We were discussing what activities we should keep, drop and what needs improvement to make it a better experience, more suited to those involved. She was describing one activity, a game that she believed needed to be dropped because one of her “clients” did not understand the game and spent the whole time doing the wrong thing. This client, however, was John, my friend, and I happen to know that, in his mind, he was playing the game precisely as it is to be played. She could never have known this because he was a client to her. Friendship opens us up to participating in others’ lives and connecting with them beyond the model of caregiver and patient, or service provider and client. The medical model is concerned with issues of aetiology, diagnosable signs and symptoms and is always interested in finding technical solutions to the problem of disability. The patient, therefore, is related to in terms of a specific, definable pathology, an individual problem to be eliminated—this model does not address the human as a person set in the context of a web of relations. The client of the social services provider receives services, training, benefits or opportunities—there is no need to share life with the person who happens to also be a client. In contrast, as John Swinton² has succinctly put it, “The priority of friends is the personhood of the other and not the illness” (Swinton 2000, 37). Friendship recognizes the disabled other not in terms of a patient with a pathology, or a client who receives good and services, but in terms of mutuality, and mutuality is essential to the experience of spirituality.

While Galen’s mother is pleased with the progress made in the United States with respect to disability rights and the many institutional barriers that have opened the way for him to be present in our society, she knows that legislation cannot address the

deeply entrenched cultural and community barriers that deny him the experience of belonging – the intimacy of friendship. One aspect of the disability rights movement that opened doors for Galen included opening up the exit doors of institutions, the deinstitutionalization which made it possible for people with intellectual disabilities to enter into the kind of relationships with others that made intimate connections and the development of a healthier identity possible. According to Amos Yong, it was important then, as it is vitally important now, that “this new paradigm emphasized social services professional support networks, and most importantly, the cultivation of genuine friendships” (Yong, 57). Hans Reinders, a professor of ethics and mental disability at the Free University of Amsterdam has made the same point:

The practices and politics of inclusion will not create a lasting change for persons with disabilities unless there will be people willing to invest in friendships with them. Without true friendships, disabled persons will enjoy the new opportunities created by their equal rights most likely as ‘strangers in a strange land.’ (Reinders, 187)

If spirituality is, among other things, a matter of “connectedness,” then how do we nurture Galen’s Christian spirituality? Can we discern it, measure it or foster it? Friendship is one important Christian model of spiritual connectedness that finds its origins in the initiative of God. In Christian theology people do not make friends with God; by an act of self-revelation God makes friends with people, offers them an affirming presence, and invites them to participate in the divine life. The issue is central to Reinders’ work:

I wish to confront the longstanding convictions in the Christian tradition with implications of exclusion that have never been properly questioned. . . . Every

human being is worth of being chosen as a friend simply because that is what God does – choose us to be friends. . . . friendship with fellow creatures is our vocation. (Reinders, 162)

For the congregation that is serious about including adolescents with special needs in its corporate life, friendship is the first practice in providing an affirming presence. The practice of friendship is a spiritual practice that provides a tangible way that we can nurture the spiritual lives of adolescents with developmental disabilities by extending to them a wider range of connectivity. It is also a practice that challenges contemporary understandings of what it means to be human and created in the image of God.

The Problem

When we attempt to assess spirituality in others, what do we look for? We could look at the manifestation of one's spirituality in terms of age-appropriate moral growth or verbal affirmations of faith. The assumption is that along with the spiritual encounter, adolescents will develop in their moral convictions with the complexity, intentionality and responsibility that is appropriate to other persons their age. But it must be considered that spiritual growth is not strictly tied to human development. It is also true that at different times, related to different intellectual and emotional capacities, the process of spiritual growth will take on different manifestations, as Kenda Dean has made clear in her work on the faith responses of adolescents. For example, adolescence opens up new possibilities for spiritual formation with the introduction of formal operational thinking, the ability to consider abstract possibilities, and the surge of passion that leaves them looking for something worth dying for. All of these new resources are activated in the spiritual encounter. But what happens to those who don't develop along the predictable course and don't seem to have

these capacities?

Karen-Marie Yust's observations about faith in children could be aptly applied to spirituality among adolescents with developmental disabilities. Consider the implications of this statement for understanding the spirituality of adolescents with disabilities:

My call for defining faith as a gift from God rather than a set of beliefs or a well-developed cognitive understanding of all things spiritual is, then, an attempt to encourage us to take seriously this tension from the "grace" side of the equation so that children are recognized as fully [spiritual] beings from birth. If we hold this definition of faith as an act of grace, then we make room for children to be actual people of faith rather than just potential people of faith in need of further development before they can truly engage in a spiritual life. If faith is not something we do but something we are given by God, then anyone can be a recipient of faith and respond with faithfulness, even if that person is incapable of rational reasoning. (Yust, 7)

At each age and stage of development children have certain abilities and primary activities. While developmental theory seems to push us forward to the next, emerging stage of spiritual development, Christian educators who are interested in spiritual formation must be attuned to the capabilities that emerge in each stage through which kids can embody their faith. But what if those capacities never emerge? Certainly spirituality is a multisensory experience, but what if you have sensory integration issues? A program of spiritual nurture that relies on the cognitive exercises of memorizing and repeating doctrine seems insufficient to the task. In the historic practice of Christian catechism, catechesis means to teach by word of mouth or, more literally, to "echo back". In order for Christian catechism to be inclusive, kids with

developmental disabilities need to be afforded a space in which they can “echo back” according to their own capacities and abilities and in their own manner. We cannot limit our expectations and impressions of the spiritual vitality of adolescents with developmental disabilities simply because they don’t proceed through the expected stages of human development. Instead, through participating together in Christian practices we allow a certain freedom for spiritual encounter and create an atmosphere or environment in which the adolescent with special needs can interiorize the symbols, respond to spiritual realities and experience community in their own way, according to their own abilities and disabilities, like everyone else.

Christian Practices as “Habitations of the Spirit”

I am arguing that by participating together with adolescents with developmental disabilities in Christian practices, especially the practice of friendship, we open up spaces where their spirituality and ours will be nurtured. While the past two decades have seen a proliferation of literature on Christian practices, Craig Dykstra is certainly a doyen of the practices discussion and my understanding of Christian practices is deeply influenced by his theology of Christian practices.³ Dykstra draws on Alasdair MacIntyre’s conception of practices as explained in *After virtue* and Edward Farley’s phenomenological theology.⁴ Dykstra draws upon MacIntyre’s theory of practices to make the distinction between a practice and actions, even strategic and patterned actions, carried out by professional agents to create change in other persons using social-scientific theories outside of larger moral considerations. Such a mechanical view of practice misses the transformative element of habitus. There is another meaning of practice, argues Dykstra, which is historically elongated and is a social

and communal way of responding to fundamental human conditions. Any normative moral tradition participates in, modifies and extends practices through which individuals and communities are able to realize goods that are internal to that tradition. These realities, the goods internal to the practice, become known in the context of participating in certain practices. To MacIntyre’s insights, Dykstra adds Farley’s appropriation of Edmund Husserl’s studies in phenomenology that tie the apprehensions of the realities of faith, or in our instance, spirituality, to a community. Farley’s notion of a pre-reflective, preconscious perceptivity that is brought into existence as it is mediated through the Christian community, what Farley calls *ecclesia*, has epistemological consequences. Whether or not one completely agrees with Farley’s argument, one can certainly agree that participation in a community of faith can have a transformative impact that may have more to do with intuition and impression and does not necessarily correspond to our intellectual or psychosocial development.

The communities’ life consists in practices that are historical, social, universal, local and transformational. Practices like healing, hospitality and Sabbath-keeping are entrusted to us from our living traditions and we shape them in the present to address our particular circumstances. Our practices persist in the present and are extended into the future because they find expression in social forms of embodiment. Our practices are universal in that they address fundamental human needs that are experienced across the globe yet they are contextualized such that each practice is shaped to fit each culture. The practice of healing outside of the city in a sub-Saharan African country like Malawi, for example, while maintaining a family resemblance to the practice of healing in my home town of Williamsburg, Virginia, is textured and informed by the fact that it is practiced in a setting that includes a wider world of ancestral spirits, superstition and witch

doctors.⁵ Whether in Malawi or Virginia, however, the practice of healing addresses the issues of illness, frailty and finitude. Finally, and most importantly for this essay, Christian practices have a transformational quality related to a spiritual reality such that participating in Christian practices puts one in a position to recognize, experience and participate in God's active presence for the world.

In Dykstra's own words, Christian practices are constitutive of "the kind of community life through which God's presence is palpably felt and known" (Dykstra 2005, 53) and "place us where we can receive a sense of the presence of God" (63). Participation in Christian practices opens the door for new ways of knowing through a kind of experiential knowledge that does not depend on one's cognitive capacities or developmental stage:

[I]n the context of participation in certain practices we come to see more than just the value of the "good" of certain human activities. Beyond that, we may come to awareness of certain realities that outside of these practices are beyond our ken.

Engagement in certain practices may give rise to new knowledge. (Dykstra 1991, 145)

From the standpoint of their capacity to create a space in which adolescent spirituality is nurtured, Christian practices are "habitations of the Spirit, in the midst of which we are invited to participate in the practices of God" (Dykstra 2005, 78). For Dykstra, and in this regard I certainly follow Dykstra, the practices create spaces or arenas that put us in a position where we can be formed spiritually and, I would add, are particularly suited for the spiritual nurture of persons with developmental disabilities.

The Practice of Friendship

The specific practice that I am advocating in this essay is the practice of friendship with adolescents with developmental disabilities. Along the lines of Dykstra's appropriation of MacIntyre's theory of practices, Swinton presents friendship as a practice. "Friendship," Swinton explains, "is not something that we embark upon on our own. Friendship is a skill that is learned in community and in turn contributes to the formation of a specific type of community. . . . The meaning and praxis of friendship can be understood only within the context of the particular community within which it is being practiced, and the specific moral tradition within which it is rooted" (Swinton 2000, 50). This is a nice MacIntyrian description of the practice of friendship, but what fundamental human need or experience does the practice of friendship address?

If healing addresses finitude and fragility, the practice of Sabbath-keeping attends to the fact that we are creatures who abide in time, and hospitality addresses the fact that we are all at one time or another the stranger, what fundamental human experience does friendship address? Loneliness and negation. Practical theologian James Loder addresses the concept of negation in terms of loneliness, rejection, embarrassment and disorientation or a sense of meaninglessness that stretches through our lives. The negation of such negation, argues Loder, is the key to transformation. Loder sees in the trauma of birth the psychoanalytical roots of existential negation. All of the newborn's activities are an attempt to adapt to this situation and to find postnatal equilibrium in the face of this crisis of birth. "What the child is seeking instinctively (as opposed to consciously)," explains Loder, "is a center around which to integrate this multiplicity of new activities and emerging competencies" (Loder, 170). This attempt to deal with an existential problem (our precariousness) with a functional solution (the employment of new competencies) fails us and the presence of a

face (a person who is present) becomes an interpersonal center of focus. In the caretaker the foundations of future trust are being laid. But there is always the fear of abandonment. The absence of the face has produced mistrust. A functional maneuver, adaptations in psychosocial development, cannot deal with an existential problem. Loneliness haunts us and we long for an affirming presence. As Loder explains:

The face-to-face relation is prototypical [of the transformation of existential negation at birth] because it embodies both the process and the ontology of religious experience. That is, the transformational process is affected by a cosmic ordering, self-confirming impact from the presence of a loving other. (173)

What intellectual capacities are required for this to happen? I would argue, none. Simply the self-confirming impact from the presence of a loving other:

Through the practice of spiritual friendship, a person with profound learning disabilities is no longer a member of an amorphous group – “the mentally handicapped” – excluded and alienated from sources of value and positive self-worth. Rather, in and through the gift of friendship, the learning disabled are enabled to develop a new identity as “persons in relation” with whom others desire to relate and are prepared to strive to find ways of relating, which operate beyond the boundaries of cognition and intellect. (Swinton and McIntosh 2000, 184)

The practice of friendship creates a space in which persons with developmental disabilities can experience the spiritual reality of being connected to God and others. This friendship is not utilitarian or instrumental to some other goal, but is simply “place-sharing”—

sharing life together and affords them a new identity.

I get the term “place-sharing” from Andy Root’s *Revisiting Relational Youth Ministry*. Root builds on Dietrich Bonhoeffer’s approach to ethics to make the case that relationships, according to the model of the humanity of Jesus Christ, require that we take responsibility for the other and stand with him or her as an advocate. This place-sharing is not instrumental to some other goal, like evangelism, but is a reflection of the place-sharing God. Furthermore, place-sharing has a revelatory, sacramental aspect. Root quotes Clifford Green to make his point:

God’s transcendence is not remote otherness or absence; God’s otherness is embodied precisely in the other person who is real and present, encountering me in the heart of my existence with the judgment and grace of the gospel. (Root, 140)

As this relates to the argument of this essay, place-sharing is a form of affirming presence or spiritual friendship – a practice that creates a space in which a spiritual encounter occurs.

Franklin doesn’t run until he is sure you have seen him. When you look away for a second to respond to a question or return a greeting or pick up a Frisbee, you will notice that he is standing about 15 yards away from you. But he won’t run until you make eye contact and move toward him. Then he knows he has you. He knows you will come for him because you are his friend. He gives a coy smile and connects with your eyes and soul in a way that he rarely does in any other circumstances—then he runs, smiling, giggling, bouncing. In that moment you understand each other—you have communicated. You have experienced a deep spiritual connection. He only runs from those he loves. He knows you will come for him.

Conclusion

We are all connected. John Swinton draws on Scottish philosopher John Macmurray to insist, “It is a person’s relationships that constitute who they are as persons. I exist as an individual only in personal relation to other individuals” (Swinton 2003, 74). This connectedness is a reality, but the spiritual experience of this connectedness is something that so many with developmental disabilities never encounter. Our faith communities continue to participate in spiritually formative exercises that exclude those with special needs (Carter, 6–8). Those with intellectual disabilities get to be the “holy innocents”—understood to be close to God as a matter of course, but are rarely engaged in the mysterious self-revelatory spirituality of friendship. What would happen if people with developmental disabilities were not merely accepted or accommodated in our congregation’s spiritual life, but were instead included and invested in it through the practice of friendship?

When you ask 17-year-old Galen, “What is God like?” he will answer confidently, “He is a man.” This is a very concrete, physical and anthropomorphic response that is commensurate with his intellectual development, the typical response of a kindergartener or elementary school student. But his description of God does not account for Galen’s spirituality. It is his spirituality that informs his answer to the next question, “What does God think about you?” Having practiced his faith and been in the spaces that afford him a sense of God’s presence, a palpable reality, and having had the experience of friendship with some loving young men and women who have intentionally transgressed social boundaries to connect with him, Galen can answer, “He thinks I’m nice. He is my friend.” Theologically speaking, Galen has experienced a specific type of Christian connectedness called communion.

Notes

- ¹ Rosalind Picard is developing technological tools that can “bridge the chasm between internal feelings and external display” (Picard, 3576). She explains the difficulties in gauging the emotional temperature of persons with autism and describes how, according to her research, their repetitive motions can actually function to calm the autonomic nervous system.
- ² John Swinton is chair in Divinity and Religious Studies and Professor in Practical Theology and Pastoral Care at Kings College, University of Aberdeen. He is particularly situated to speak to this issue because, aside from his theological credentials, he holds a RMN (Registered Mental Nurse) and a RNMD (Registered Nurse for People with Learning Disabilities).
- ³ Craig Dykstra, in his role as a practical theologian and as senior vice-president, Religion of the Lilly Endowment, Inc., along with Dorothy Bass, has supported the Practicing Our Faith conversation, which has resulted in several books on the topic of Christian practices. The standard definition of practices according to this discourse is the following: “By ‘Christian practices’ we mean *things Christian people do together over time to address fundamental human needs in response to and in the light of God’s active presence for life of the world*” (Volf and Bass, 18, emphasis in original).
- ⁴ MacIntyre’s approach to practices is found in his *After Virtue: A Study in Moral Theology* and Farley’s phenomenological theology is articulated in *Ecclesial Man: A Social Phenomenology of Faith and Reality*.
- ⁵ See, for example, Janet Brown’s work on HIV/AIDS in Malawi in: *HIV/AIDS Alienation: Between Prejudice and Acceptance*.

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