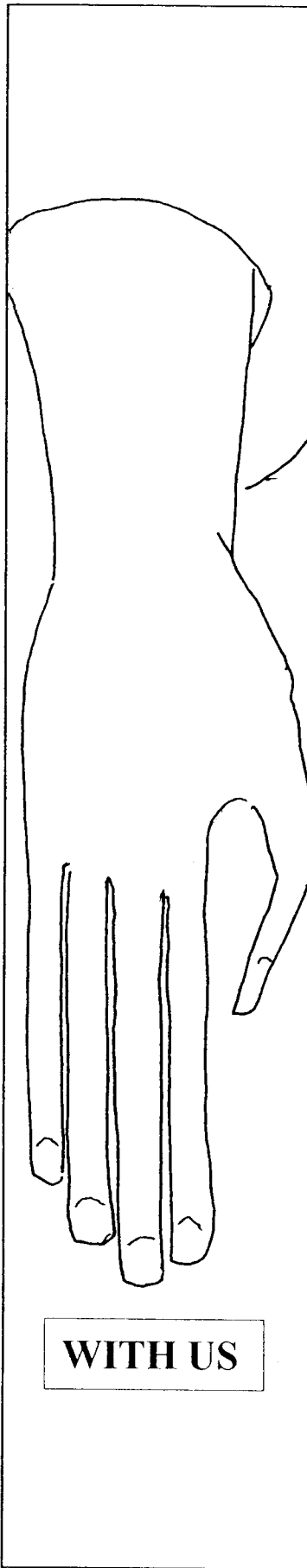


It was a snow storm, four to six inches had already fallen and more was promised. The parish Spred group decided not to put the families and catechists at risk, so the Spred session was cancelled. All the persons involved were contacted and informed by phone - except one family whose phone was out of order. Surely they would know and not come. Not the case. They arrived with the child who requires extensive care. The child's sister found the parish door to be locked. All the lights were out. The sister went back to the car and told her mother. The child with disabilities - who does not speak except to make a strident sound or bellow and has a visual impairment - grasped the situation and blew up her own stormy tantrum. It continued on the way home, and into a good part of the night. Her Spred outing was cancelled and somehow she knew and registered her disapproval. Somehow she knew.

I can see the room I was in forty years ago at St. Cecilia rectory. I remember the light in the room. I was reading a series of letters exchanged between Fr. Dan Berrigan and Dr. Robert Coles. It was such a turbulent year with the war on, the assassination of Dr. Martin Luther King and Robert Kennedy, the riots, a cultural upheaval in process - and the catechetical renewal in a frenzy and on the brink of collapse. The air was electric. In that context I stumbled on a line of Berrigan's six words: "Hope is reductionary; despair is inflationary." It branded my psyche. The staff and I had been blessed with a method of catechesis for persons with developmental disabilities, yet we struggled over a scaffolding for disseminating its riches in a human way. Such was the birth of a central maquette of an environment along with one way viewing mirrors so people could actually see us work with persons with disabilities of different ages. We wanted to establish a center to validate the method and make our catechetical work credible. Then brick by brick, parish by parish, we were able to replicate what we were doing. There were not five year plans, nor self-lacerating recriminations because the growth was slow. Converting the Catholic culture would be slow, tedious - but hopeful.

Dr. John Swinton wrote an article that is worth applying to persons with developmental disabilities. Swinton argues that the representation of personhood in the way our society often does is to misunderstand at a fundamental level what it means to be human and to live humanely. Persons are not to be defined by what they *do*, but by what they *are*, or perhaps better by *whose* they are. His notions of personhood as they relate to those with developmental disabilities, argue for a revised understanding centered on God's commitment to human beings who are not defined by doing but by being with and for the other. He argues for the fullness of personhood of people in all circumstances. We need to take seriously the possibility that there is always something more if we take the time, slow down and look for it.



Swinton recounts “a narrative of sadness.” In his psychiatric nursing training, he realized that he worked in a context which seemed to assume that the people before him were no longer worthy of more than basic care and minimal respect. It was a system, and sometimes “those of us who sought to offer care within the system, frequently ‘forgot’ people’s status as unique persons created to be in meaningful loving relationships with others and with God. WHY do we struggle to remember this and hold on to the personhood of people and establish models of care and support that reflect this?”

Swinton then examines the importance of the demographics, the sheer number whose life experiences are of growing importance for both church and world. Medical diagnoses are vital for professional discourse but often offer only a narrative of pathology and loss. Definitions are not comprehensive - certainly in terms of the experience of the person and the family. When one begins to reflect on the question of what it means to be a person, the influence of culture answers by de-personalizing individuals. Swinton examines the liberal assumptions of the Australian ethicist Peter Singer as well as John Locke’s perception, “a person is a thinking intelligent being that has reason and reflection and can consider itself as itself.” These ideas emphasize function as definitive of personhood. Human beings find their worth in terms of what they can do, or cannot do. Human beings with significant cognitive disabilities have little or no moral status. More ominously, they can turn into non-persons. It is not enough to be. But I remember my own near-death experience after three months in the hospital, how much the statement of Abraham Joshua Heschel meant to me: “Just to be is a blessing. Just to live is holy.”

Swinton marshals likeminded others who are rethinking this narrative of persons with disabilities. He cites an English psychologist, Tom Kitwood, who would see a person, not in terms of functionality but in terms of relationship. Personhood is a gift of community, not an achievement. Human beings are not isolated, individual monads who create their own personhood, Rather, persons emerge from and are shaped by the types of relationships that occur in some form of community. Additionally, Swinton cites John Macmurray, a Scottish philosopher, who develops his understanding of personhood as persons-in-relation, in opposition to Rene Descartes’ dictum “I think, therefore I am.” - a formulation profoundly cognitive, focused primarily on intellect and reason. However the mind is not a box as Descartes conceived it, but rather as Macmurray considers thought - a subordinate component of human experience. The mind develops in dynamic bodily interaction between self and the other.

The neurologist, Sir John Eccles, also holds the necessity of human relationships in the development of personhood. Emotional and intellectual development is essentially communal and physical from the earliest stages of infancy. Relationships have neurological as well as psychological and spiritual significance. Macmurray advocates moving away from the medicalization of persons with disabilities toward a model that takes seriously the relationality of persons and the natural interconnectivity of body, mind and soul. It would shift the focus. *I am because we are: we relate therefore I am!*

Swinton pushes his confreres further, and argues for the transcendent in the understanding of relationality. What happens to those whom others refuse to recognize as persons, who are deprived of relationships-in-community? Do they cease to be persons?

Swinton puts forward a relational conception of the human being based on Trinitarian theology, i.e. that human relationality is to be viewed as analogous to Divine relationality: the inherently relational nature of human emerges from the nature and relational shape of the God in whose image they are created.

Human beings are created from and in loving relationships, for loving relationships. God is love.

Further, Swinton incorporates the Christological perspective of Dietrich Bonhoeffer to understand how God remains with us and for us even when we can no longer cognitively be with and for God. If God is with and for persons with disabilities, then those who claim to follow God are called to be with and for persons with disabilities.

The very being of Christ is his being-for-humanity. Christ can only be thought of in relational terms. "Being- there-with-and-for-us" is the manner of his existence and presence. Christ exists "as community." Human beings can only be understood as they relate with one another and with God.

There are some implications: God remains with and for the person with disabilities even when the person can no longer be with and for God. We might forget God, but God will not and indeed cannot forget us. God remembers us even when we can no longer remember God.

From Kitwood's hypothesis on the development of the brain, we simply do not and cannot know the cognitive level that people are working at or indeed have the potential to function at. Their outward appearance may well reflect chaos and loss - still, there may well be hidden depths to a person's experience which could reveal new and healing perspectives on their situation. None of this, however, is intended to minimize the very real pain and suffering by people whose loved ones face a disabling condition.

Remember the snow storm and the child who was upset that there would be no parish Spred session. She has been in a Spred group for three years. She would break things. For most of the time she worked on the floor, as did her caring catechist. Now they can sit at a table but we still need to keep alert. Now she can stay in the celebration room for a little while. In another three years she may remain for the whole catechesis.

Spred works incrementally. We let life unfold without insistence. It is the small signs of participation we relish. After all, "hope is reductionary."

Rev. James H. McCarthy
Director, Spred Chicago

1 Notes on Forgetting Whose We Are: Theological Reflections on Personhood, Faith and Dementia, by John Swinton, PhD, in Journal of Religion, Disability and Health. Vol. 11, Number 1, 2007, The Haworth Pastoral Press, Binghamton, New York, (www.HaworthPress.com)

