One out of a hundred:
Providing Chaplaincy in State Schools to People with Mental Retardation

Robert L. Hendricks

The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) calculates the prevalence of mental retardation (MR) in the general population at about 1 percent. DSM-IV indicates that the degree of MR can be observed on four descending levels: mild, moderate, severe, and profound. In the world of the remaining 99 percent, verbal wars are fought, relationships are built, deals are made, prayers are offered, spiritual healing is made available, financial strategy is implemented, songs are sung, love and anger are exchanged, and grief is expressed. It is no different in the world of the 1 percent.

When I came to San Antonio (Texas) State School seven years ago, I had had almost no experience working or living with people who are mentally retarded. I began my research at the city public library with the DSM-IV. Diagnostic criteria for MR include the following: a functioning IQ level of approximately seventy or below; deficits or impairments in two areas of daily life—communication, self-care, home-living, social/interpersonal skills, self-direction, functional academic skills, work, leisure, health, safety and use of community resources; onset before age eighteen. MR is an Axis II entry in the DSM-IV.

Books devoted to understanding MR were surprisingly few in number and reflected the legal aspects of guardianship for those needing special services or the benefits of placement into a community home. The public library offered no real studies on the spiritual aspects of living with MR or how those aspects could be addressed in an institutional state school. One author, a sociologist who seemed to be writing for shock value, wrote that there were no biblical references to mental disabilities. To the contrary, from the Pentateuch to the Revelation, God is present for the weakest among us as well as the smartest and wealthiest.

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In contrast to a biography written several years ago by a popular celebrity, people with MR are not angels. To name them as such is to take away from their God-given humanness as well as to ignore a variety of behaviors. It is the equivalent of revising John Newton's "Amazing Grace," to say "how sweet the sound that saved a swell person like me." It is far better to demythologize MR rather than to disguise it with platitudes. Most recently, the descriptive term used by some groups changed from mental retardation to mental disabilities. This is an unfortunate trend because it dilutes issues experienced exclusively with MR.

The philosophical and clinical debate among those who treat MR has been polarized through the years, moving from the practice of warehousing severely retarded people with no effort to habilitate them, to the theory that all institutions are bad and should be closed. It is from the former that we hear horror stories; however, over the last fifty years, many institutions have created and refined progressive developmental techniques—either voluntarily or because of litigation. It is also true that at any given time, there are people who are so severely retarded that they cannot function in a community home or a private center without institutional preparation.

Ronnie, a middle-aged African American with poor socialization skills, was admitted to the state school less than two years ago. Almost nonverbal at the time of admission, his affect was nearly catatonic. Much of his life had been spent in seclusion, and his psycho- logical assessment suggested he was agoraphobic. However, with newfound freedom, he began to walk trance-like at the end of each day from his dormitory to the opposite side of the campus where he sat at a picnic table and watched the cars and people in the parking lot. As he gained vocational training skills in the school's developmental center, he began to communicate in short sentences and to walk to the picnic table with a friend. He eventually enjoyed liberal freedom of movement as well as participation with friends in numerous on- and off-campus activities.

After about eighteen months, Ronnie began appearing at Sunday worship in the chapel, partly in anticipation of the cookies served at the end of service. Satisfied just to look and listen, he would worship by sitting in the middle of the sanctuary. Within a few weeks, he became one of the first people to arrive at the chapel; his chosen role was to acknowledge the arrival of others. He learned to serve as an acolyte, pass out bulletins, to sing songs, and to join in responsive reading and prayer—and he began to smile. He now assists with the distribution of the elements during Holy Communion. His future is promising.

The causes of MR include, but are not limited to, Down Syndrome, brain damage due to physical trauma, Fetal Alcohol Syndrome, and Fragile X Syndrome. In fact, more than two hundred causes have been documented. Despite this statistic, the cause often is unknown. Slow motor skill development in infancy frequently is a first sign. If MR is mild, the body may develop normally through adulthood. If MR is more severe, the body still may develop normally but with stark behavioral consequences. As the body matures biologically, the mannerisms and social skills can remain infantile. A fully-grown adult male may prefer to crawl or sit in the middle of a busy hallway. A woman may giggle loudly or squeal to make a point in what should be a quiet situation. Inappropriate public sexual behavior may become a problem for either gender. Everything from personal hygiene and meals to education and transportation must be addressed exhaustively on a daily basis.

It is important to note that MR is a condition, not a disease; people with MR do not have a sickness that can be cured with surgery or a drug. As previously noted, MR is an Axis II entry in the DSM-IV. Some persons with MR also are diagnosed with Axis I mental health issues, e.g., schizophrenia, self-injurious behaviors (SIBs). Understandably, communication problems make Axis I diagnoses difficult. Assault or mal-adaptive sexual behavior by persons with dual diagnoses often bring them before a judge in the public court.

David is a forty-five-year-old Hispanic male, who was admitted after a series of unsuccessful group home placements. His mother reportedly received prenatal care with no problems noted. However, she was treated with antibiotics for a severe ovarian infection during the pregnancy. David was a "blue baby," who required oxygen at birth, and she attending physician advised her that he had suffered brain damage. His developmental milestones were delayed: he walked between ages three and four, did not talk
until he was four, and was not toilet trained until past age five. He was diagnosed with MR at age twelve.

David demonstrates anxiety and nervousness. His speech pattern is rapid; he often must repeat himself to be understood and continues to receive speech therapy. Despite these handicaps, he has completed the general equivalency diploma course (GED) and is able to manage small amounts of money and to make minor purchases. In addition, he has had varying degrees of success with employment at janitorial services and grocery stores. David enjoys movies, dancing, music, and basketball. He dislikes being Redirected by females, playing soccer, and eating spaghetti.

David was a charter member of the chapel services, which were begun at the school seven years ago. His desire to wear multiple layers of clothing was satisfied with the opportunity to wear a choir robe. He frequently arrives at the chapel with a long, noisy key chain dangling from his jean vest pocket. David’s motor skills are such that he can use a candle lighter for altar candles without much prompting. He enjoys congregational singing and is a joy to the choir director because he follows direction. Though speech does not easily come to David, he can be heard reciting the Lord’s Prayer. David is proof positive that spiritual growth is not exclusive to the 99 percent world.

Once their child is diagnosed with MR, parents most likely will receive a referral from the school district to a local mental retardation authority (MRA), which will provide a menu of options and services depending on funding from the state or commonwealth and the severity of the MR. The MRA ensures that a “permanency plan” is developed for each child and reviewed every six months. If the condition is mild, the child may stay in the home well into adulthood. The individual’s independence may be encouraged through placement in a group home or even in an apartment. If the condition is more severe, the legally authorized representative (LAR) must make difficult decisions. Caring for people with MR in their home of origin can be exhausting to parents. At some point, they often must make the heart-wrenching decision to place their child in a group home or a state school.

Texas has eleven state schools with populations ranging from 295 to over 600. These state schools receive federal funding as intermediate care facilities for mental retardation (ICF-MR). The word school is something of a misnomer. In the past, these facilities enjoyed independent school district status, but today, most residents are well above school age, and those who are enrolled in special education classes are bused to the nearest high school. Because they receive ICF-MR funding, state schools must undergo an annual survey similar to Joint Commission for the Accreditation of Healthcare Organizations (JCAHO) inspections.

When individuals arrive at the school, whether by placement or court order, they first attend an admissions meeting that includes the interdisciplinary team which will monitor and supervise their care throughout the length of their placements. Every aspect of their lives becomes an object of treatment and concern. A caseworker will already have been assigned along with a psychologist who will develop a behavior modification plan (BMP). A social history is documented with input from family members. Vocational potential is determined. Health and medical concerns are addressed by doctors and nurses employed by the school. Physical, occupational, and speech therapists are available. Pastoral care addresses religious needs. Other issues considered include the person’s vision, hearing, mealtime habits, diet modifications, communication methods, reinforcers, need for bathroom assistance, likes/dislikes, required level of supervision and mobility, e.g., ambulatory, non-ambulatory. Once the admission is formalized, individuals meet with a smaller interdisciplinary team within the dormitory. This team includes the home supervisor, case worker, psychologist, and specialists called active treatment providers. These titles differ from school to school and state to state. An annual review assesses the individual’s progress toward personal goals, which may be as simple as daily teeth brushing or as detailed as vocational objectives.

Vital to the life of a person in a state school is the promotion and protection of basic human rights. These rights include the right to make decisions regarding medical treatment and finances; to vote; to send and receive unopened mail; to make and receive confidential phone calls; to receive visitors; to wear, keep and use clothing as well as other personal possessions and personal hygiene items; to have access to, keep, and spend money; to freely move about the home and neighborhood. Residents have the right to a voice in program development and placement decisions, and above all, they have a right to
privacy, and the right to participate in religious services of their choice.

Rix is a tall, fifty-eight-year-old Caucasian male, who has lived in state schools since 1960. His father was an attorney, his mother an administrative assistant for his father's firm. He has a younger brother. After a normal delivery at term, Rix developed as expected up to thirty months of age. At that time, he had a serious reaction to a vaccination which resulted in severe disability. Testing ultimately revealed a very low I.Q. and low socialization skills. His parents initially cared for him at home. He was admitted to a child development center in San Antonio and later to state schools in Austin and Travis before coming to San Antonio State School in 1980.

Rix became a recognizable fixture on campus. Staff learned his self-help skills were his strength: he could eat and drink neatly, wash and dry himself, use toothpaste, and perform other helping tasks. His periodic self-injurious behavior (SIB) required medication, which unfortunately produced severe side effects. Eventually, a behavioral modification program helped to refine his self-help skills and to improve his impulse control and inter-personal skills.

His vision was impaired in his left eye due to cataract development, and a few years ago, Rix lost sight in both eyes. Tasks that were difficult before now became impossible without constant attention and care. Rix's father has died, but his devoted mother continues to visit him every week. On Sunday morning, Rix will walk with other residents from his dormitory to the pavilion where chapel services are conducted. One, sometimes two, active treatment providers guide him across a street and up a sidewalk to the entrance of the building. If staff members are not available, Rix's mother makes the 75-yard walk to and from the dormitory to make sure that he has an opportunity to worship.

Once seated in the chapel, Rix responds to the people around him and the activities of the worship service. He enjoys the "clapping songs" and tries to become a part of the festivities. Sometimes without warning he will stand and exclaim, "Chocolate!" in anticipation of the chocolate candy his mom gives him after the service. At Communion time, the bread and cup are taken to Rix. His mother whispers into his ear why the chaplain is there and receives the bread and the cup with him.

In the Genesis story we read that creation came out of chaos. Caring for people with extreme mental and physical disabilities twenty-four hours a day is an attempt to control chaos. At San Antonio State School, it takes approximately six hundred employees to provide necessary services for three hundred residents.

Chaplaincy services is a part of the interdisciplinary approach to treatment, and each of the eleven state schools in Texas has one chaplain. With ever-declining budgets, only five schools provide full- or part-time assistants. Though state schools must conform to ICF-MR facility and state regulations, they are fairly autonomous in the manner in which they carry out the mission. Likewise, each pastoral care director adapts to the needs of the individual institution.

Chaplains at state schools love the works of the Roman Catholic scholar Henri J. M. Nouwen, in part because his final ministry, to the shock of many, was to be chaplain of the L'Arche-Daybreak Community for people with MR in Toronto, Canada. In Reaching Out: The Three Movements of the Spiritual Life, Nouwen reminds all in the healing business that they do not own the people for whom they care: "The great danger of the increasing professionalism of the different forms of healing is that they become ways of exercising power instead of offering service ... many people who suffer — view those who are helping them with fear and apprehension. Doctors, psychiatrists, psychologists, priests, ministers, nurses, and social workers often are looked up to by those in need as if they are endowed with a mysterious power." During the first five years of my ministry to people with MR, I often underestimated their abilities. Now I often hope for more than can be expected.

Chaplains ministering in state facilities work within a political where employees sometimes raise the red flag of "separation of church and state" and resist religious programming or even interdisciplinary involvement. However, I have never seen a parent, family member, or guardian of a client with MR do this. If chaplains retain integrity and professionalism, their ministry will at least be endured, if not accepted.

In addition to the standard orientation, the best way for a chaplain to begin an assignment is a state facility is to wear out the shoe leather. Rounds at a state school are unlike rounds at a hospital because residents are not acutely sick and may reside at the institution for decades. The most important aspect is face time, or what chaplains call "ministry of presence." This assures both residents and staff that the chaplain does not appear only on Sunday. Opportunities for work in the interdisciplinary setting.
abound and usually increase over time. As a department head, the chaplain is included in institutional management and participates in the admissions process, not only because this is the first "hello" to the resident, but also because it alerts staff that pastoral care is an essential part of the treatment process.

As with health care institutions, chaplains may be members of or chair the ethics committee. State schools utilize a human rights committee which monitors, approves, or disapproves changes in a resident's behavioral management program. I serve on a volunteer state "surrogate decision making" committee which convenes in special circumstances for an individual whose LAR cannot exclusively make a decision for the individual, often for a medication change or a medical procedure. Committee members usually will include a physician, attorney, and a MR worker closely familiar with the individual. Chaplains also may act in liaison with area churches, clergy, and volunteer organizations. Many state schools utilize their chaplains in either a critical incident stress management (CISM) team or some other grief counseling model. As these responsibilities multiply, care must be taken not to blur the boundaries between administrator and pastor.

The "family association" of each state school is crucial to its well-being. This group not only generates projects to benefit residents of the school, it also networks with other family associations, which as a single organization can then lobby legislators. As employees of state schools and therefore employees of the state, chaplains would not normally join family associations and by law cannot lobby legislators on state time. However, for family members, the pastoral care director symbolizes the spirituality of the facility. Thus, family associations and chaplains are mutually supportive.

Larger state schools may have medical clinics to treat residents. Smaller schools have physicians and a nursing staff to dispense drugs; however, emergencies, surgeries and acute medical concerns are directed to area hospitals. A state school chaplain soon realizes that an assessment of a school resident often will not be similar to an assessment in a medical center. Many times the resident will be nonverbal and nonambulatory. Unless a family member or school employee is in the patient's room, communication becomes the nurse's responsibility.

In my first six months at the school, I visited a resident with a dual diagnosis who had been hospitalized for about two weeks and was fairly verbal. He expressed loneliness during his two weeks in the hospital. I noticed there were no get well cards or flowers displayed in the room, an occurrence not uncommon for school residents. As a result of that encounter, I began a simple system of providing cards for residents when doing rounds. Though the patient may not even realize a card is in the room, the tacit message to hospital staff is that the mentally retarded person in the bed is important to others.

Most state school chaplains compare their work to parish ministry. The tenure for most residents of a MR facility is much longer than that of patients at a medical center or even a mental health hospital. The chaplain's role is highly relational because of the trust factor with facility staff. For each of us, the positive indicators are likely to be personal. For instance, I knew I had arrived as my school's chaplain when staff of various faiths and ethnic backgrounds, or with no particular religious background, began calling me their pastor.

The worship service at a MR facility is the most visible spiritual outlet experienced on a regular basis. In this safe place, people with MR can express their faith and hope without fear of rejection. The chapels at most state schools in Texas were built with private funding. Some are quite elaborate with stained glass and large choir lofts. One chapel building was donated and moved to the campus from another location.

When possible, residents are encouraged to attend churches or temples in their communities. Some state schools work closely with Jewish representatives to make this a reality. However, few churches have the knowledge or the patience to accommodate people with severe MR. I know of one church outreach program that seated people with MR in the cry room where there was no opportunity for them to experience congregational worship or for the congregation to experience them. I once wrote a brief article for a church association newsletter asking for volunteer help. Though the newsletter went to about fourteen hundred addresses, there was not one inquiry.

At San Antonio State School, the first Sunday worship service commences in a general purpose pavilion. The assembly hall converts into a worship center in an hour. A communion table with casters for easy movement doubles
as an altar. Brass altar ware, paraments and artificial flowers decorate the table. An attractive oak podium stands to the right of the altar. Plastic chairs are arranged in curved rows with a large middle aisle to accommodate wheelchairs. Colorful felt banners hang at the front of the stage area.

The stage is used only for special programs. All chapel furniture is at floor level. The space to the left of the altar is the designated choir area with one microphone coveted by some of the choir members. For congregational singing, many state schools use an overhead projector to project words onto a large screen. Because of the time factor in converting a large room into a worship space, San Antonio prints a soft-sided “hymnal” that has a shelf life of about six months. Since the songbooks must be replaced so often due to wear and tear, new songs and liturgy can be added easily thanks to Microsoft Word. Currently, the hymnal contains thirty-eight songs and four pages of an easy-to-follow liturgy. Hymns range from the oldest favorites to praise songs and “El Shaddai,” an often requested song.

The Order of Worship reflects the vocational training philosophy of repetition, one goal of which is to prepare residents to participate in congregational worship should they be able to move into the community. Many residents take on duties, reminiscent of conventional church congregants, e.g., one man has assumed the role of the deacon who thinks he should control every aspect of the service; a woman has become the matriarch who expresses approval or disapproval of chapel social activities.

Bulletins are distributed with the weekly Order of Worship, which begins with a prelude, welcome announcements—including birthdays. The service incorporates at least six songs sung by the congregation as well as special music provided by the choir. Prayer requests are invited and followed by a pastoral prayer and the Lord’s Prayer. A responsive reading, Scripture and either message or Holy Communion round out the service.

The birthday recognition is extremely important to people living in a state institution as it is the special day that separates them from everyone else. Half the worship may be devoted to music as people with MR love to sing. They also are wonderful audiences, projecting confidence to performers who are not really too sure of themselves. Songs are selected from the hymnal in numerical order, i.e., 1, 2, 3, or 5, 6, 7, because this makes it easier for residents to locate them. Scripture is followed by a “message” that is really more of a single object lesson. I struggled for six months over whether or not to institute the Holy Communion as probably 95 percent of the resident have no intellectual understanding of what constitutes consubstantiation or transubstantiation. Finally, I decided to let the Holy Spirit take care of the theology.

Many people with MR are capable of memorizing the Lord’s Prayer, and they practice every Sunday. In fact, the two most important elements of our worship are the times for prayer requests and special music. Residents follow our models of vertical to horizontal, that is, God to human and human to human. They almost always pray for their parents first, followed by other family members.

They ensure staff members attending services hear their names in prayer requests, and they often express awareness of war as they pray for military service members. The special music time gives a resident the opportunity to sing a solo with the coveted microphone and to dedicate the song to a staff member or a romantic interest. Over the years, it has been gratifying to see the improvement in individuals who focus on music.

Memorial services for residents at state schools not only assist people through the grieving process, they also support weekday staff who normally would not be present for Sunday worship. In larger state schools, memorial services may be scheduled on a quarterly basis to honor more than one deceased resident. At our smaller campus, services are held at the home in which the resident lived. Those with a higher level of MR may experience great anxiety at a friend’s death and may self-actuate this anxiety through end-of-life questions. Direct-care staff who may have worked with the deceased individual for years often have emotional and spiritual ties. Though this sometimes requires pastoral counseling, many memorial services celebrate not only the life of the resident but the vocations of caring to which staff members are called.

Debbie’s parents moved from Brooklyn, New York to San Antonio to be closer to their other daughter. Debbie had lived in a nursing home specializing in cerebral palsy, and her sister recommended the state school to their mother with the assurance Debbie would receive good therapy here. Debbie, who is now thirty-three years of age, was delivered at full term by
caesarian section due to placenta previa. Pronounced developmental delays were noted after only a few months, and she was diagnosed with profound MR. Her adaptive behavior composite age equivalent is assessed at seven months. Her best modes of expression are facial/gestural, and she is known to occasionally cry or scream for no apparent reason although she calms with music. She also was diagnosed with spastic quadriplegia, athetosis and thoracic kyphosis with severe lordosis of lumbar spine. Debbie receives physical management and positioning, and communication therapy. Her mom visits frequently.

Debbie lives in a home on campus where all forty residents are nonambulatory. Some are more expressive than others and can self-navigate their wheelchairs. Debbie is completely dependent upon others and has a feeding tube. Yet, those who work with her daily know her likes and dislikes and are well aware of her unique personality and soul.

Worship services conducted at this home have the same musical emphasis as the other services. A few residents can sing or mouth the words, and a few can express prayer requests either verbally or through gestures. Debbie can do neither. Her soft gaze reveals nothing, yet we know music is beneficial for her. So much of conventional ministry depends upon transference from those ministered to, but in this environment, love cannot be expressed in conventional terms.

The future of chaplaincy in state schools pivots on future models of ICF-MR programs. Some states have already closed all of their state schools in favor of group homes or private institutions. The philosophical battle lines drawn for treatment methodologies traditionally pit organizations against one another. For example, the ARC favors closing state schools while the Voices of the Retarded (VOR) seeks to give residents and families a choice whether to live in a group home or a larger state school.

State legislatures faced with budget shortfalls attempt to balance the books with draconian solutions: consolidate resources by closing some facilities and uprooting residents to other cities, a move welcomed neither by residents nor their families; privatize large facilities by turning management over to private companies, a solution welcomed neither by state employees, families, nor by organizations that seek to close state schools. The chaplain’s presence is not a given. Last year, the Texas Department of Criminal Justice (TDCJ), which runs a privatized prison system, eliminated approximately one-third of the prison chaplaincy positions—this despite the rhetoric of “faith based initiatives” from the Bush administration. Nevertheless, professional chaplaincy tends to survive even in the most hostile political environments.

The good news is that because of improvements in medicine, technology and basic ethical and philosophical changes in treatment, a child born with MR in 2004 has a life expectancy of sixty-six years, compared with nineteen years in the 1930s. More importantly, the quality of life for these people has improved. One of our songbooks at the school includes these words to “Help Us Accept Each Other” penned by John Beck:

| Help us accept each other as Christ accepted us; Teach us as sister, brother, Each person to embrace. |

Be present, Lord, among us and bring us to believe We are ourselves accepted and meant to love and live.

Teach us O Lord, your lessons, as in our daily life
We struggle to be human
And search for hope and faith.
Teach us to care for people, for all, not for just some,
To love them as we find them, or as they may become.  

References
2. Ibid., 39-40.