

# Lessons Learned

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by Charles Luce

## *My view of "Our Church" and mental retardation covers the last forty-two years.*

My view is extremely limited. For all 42 years I have been the father of a son, Steve, with Down Syndrome. For the last 15 years I have been privileged to view a broader part of the Church through service as a "professional," working to bring all people with mental retardation into full participation in our faith life. Let me share with you my thoughts and observations of those 42 years. I would like to keep focused on four words: service, social, education, and liturgy.

Some people long for a return to the "good old days." As far as our Church and people with mental retardation are concerned I think I do not wish to return to those days of yesterday. I say, "I think" because of my view of those days, a view that is certainly limited to my own experiences and what a very few others have reported to me. For other parents and their children with mental retardation the "good old days" may well have been the best. I leave it at that.

I have learned over time that a general statement such as "nothing is going on in my parish or diocese as far as people with mental retardation are

concerned" should not be made until you know for sure that nothing is going on. All too often "things are going on" that you do not know about; things that are being done quietly without fanfare. I have been guilty of making such an indictment, only to be pleasantly surprised, yet embarrassed when the truth was known.

**Lesson Learned: *There may be more happening than you realize. Search out the information.***

This is what I do know: that for the first 20 years of my son's life he was not involved in any appreciable way with "his Church." He was baptized into our faith and that was the extent of his participation. No religious education, no First Communion, no Confirmation. Why? Good question. The answer is that two parties must share the responsibility for this lack: his parents and his Church.

First, his parents. His mother is a lifelong Catholic, raised in an actively participating Catholic family and a product of Catholic schools through high school. I "converted" to our faith four years before my first son was born. I began service in the U.S. Army a year prior to his birth. For the next 20 years we moved very frequently, never staying in one place more than 18 months. Never long enough to establish roots within a parish, per-

haps not even trying because we knew we would be moving on. Five other children were born during this time. Our sixth child, Mark, was also born with Down syndrome; the other four were relatively "normal." My wife and I tried to remain faithful to the faith, attending Sunday liturgy, trying to raise the children in the faith by placing them in Catholic schools and/or parish religious education programs as available. All of our children except for our sons with mental retardation.

We wonder today why we did not "demand" that our two sons be served by our Church. Perhaps we thought that they could not benefit from instruction. After all, they had mental retardation. We do know that we were not strong advocates for them. We just tried to get along. Whatever the answer or answers, we did not push for them to be included.

**Lesson Learned: *Parents must be strong advocates for their children. If you do not advocate, who will?***

The other party, the Church, must also share the responsibility. Never once did anyone in any parish ever reach out to us as far as our oldest and youngest sons were concerned: no pastor, no religious sister or brother, no lay person. Not one person. We were members of each parish, participating in liturgies, giving money, and supporting our other children in reli-

gious education. Why did no one reach out?

Perhaps they felt, as I have heard a number of times from some very caring people, that our sons already were "little angels." That is a nice thought that may give comfort to some but we know through the teaching of our faith that they are not angels. Our sons are human, with all the needs and desires of every other human being.

Perhaps they did not know what to do. I would like to believe that this is the best answer in most cases. I am sure that all those people were not bad people; they were all Christians. But they just did not know what to say or what to do.

You see, it was during these years that great change took place. For many, many years people with mental retardation were separated from society "for their own good." They lived in segregated institutions. Those who were Catholic and lived in Catholic facilities participated as fully as possible in their faith. Devoted religious sisters cared for them, taught them of God's love and prayed for them. Priests were assigned to these facilities and cared for their flock through celebration of liturgy and the sacraments. Others living at home with their parents and families normally had little, if any, participation in the local parish. There were, of course, many exceptions to that statement, thanks to dedicated parents and religious leaders. But generally, the responsibility rested with the facilities.

When the de-institutionalization process began in the late 60s and early

70s, more and more Catholics with mental retardation stayed at home or returned home. The focus shifted from the facilities to the local parishes. It shifted from priests, religious brothers and sisters skilled in this ministry to folks with little or no experience with "different people." So it is not surprising that local parishes did not know what to do with our sons.

**Lesson Learned:  
*Parishes must reach out to all.***

Let me emphasize the four words to focus on: Service, Social, Education, and Liturgy.

Our sons with mental retardation did not have the opportunity to serve the Church or other people, not even by their presence, which I believe is an important method of service. They were not involved in any parish social activities. None. They did not participate in any parish education program. They did not attend Liturgy.

But, a change took place. After nearly 20 years of "wandering in the desert" of military life, we settled in one town and one parish. And we stayed for the next 26 years. A new phase of our life began to unfold.

Our typical children participated in this new parish life, attending religious education classes and going to Liturgy. We began to bring our two sons with mental retardation to Liturgy. We began to make new friends; to learn about this parish. But still no outreach for our sons.

For some reason, and I believe the Holy Spirit was working, my wife and I decided to try to form a group for special religious education. There were a few other children and young

adults with mental retardation in the parish. We publicized this new group effort and received no responses. Oh well, maybe something else will happen.

A few years later "people" began to change our lives. Ron, the parish DRE, inquired after a Sunday evening Liturgy why Steve did not go to Communion. Mark had died a year or two before. We explained that Steve had never received preparation. Ron then dedicated himself to begin a special religious education class. And he did. A second person, Julie, volunteered to be the teacher. She taught special education in the public schools. Another mom volunteered to be the helper and the class began with seven students. The following year Steve and the others received their First Holy Communion. You can imagine our happiness! Another year and Confirmation; this time as part of the typical group. Our son was now active in his faith life. And he was making friends!

Peggy and her daughter, Carrie sat near us each Sunday for Liturgy. Little Carrie became a good friend of Steve. She never failed to come over after Liturgy and give him a hug. Others talked with him and he began to really enjoy going to Church. No more long faces on Sunday evening getting ready to go.

After Steve finished those preparation classes he needed some other activity in Church. I asked Mary Jo and Ellison, the leaders of the new youth group, if our son could join them as a helper. He was welcomed with open arms. Then he began to

make friends with many youths in our parish. They all loved him.

A new youth leader, Jerry asked Steve to remain as a helper. His circle of friends grew and grew: Diane and Bob and Mike and Susan and Bridgett and Jim and Mary and John and Terry and Tawfig and Jackie and Theresa and Sister Mary and Father Bird and on and on. Soon most everyone in our parish knew him. And his life was changed. He was asked for a number of years to participate in the Holy Thursday washing of feet. He served as an usher from time to time. He was a greeter. And he helped us on many occasions to bring the gifts forward. He participated fully in parish life.

**Lesson Learned: *People make the difference. Just listen to the Holy Spirit.***

In 1985 I began as the executive director of NAPMR, now, of course, NAFIM. In this professional role I began to learn what was going on in other dioceses and parishes, and to learn what was not happening. For the next 9 years I worked daily with other very dedicated folks to increase awareness in the parishes and dioceses about the need to assist folks with mental retardation to participate more fully in their faith life.

I saw dioceses and parishes where folks with mental retardation participated fully. I saw dioceses and parishes where "nothing was going on." Once again, that statement should be used cautiously. I saw parishes and dioceses struggling to include people with mental retardation and other disabilities. I saw an apparent conflict develop between

separate services and inclusive services; a conflict also seen in the secular world of public education. I saw gifted writers produce religious educational materials geared toward the person with mental retardation. I saw priests modify their homilies to include, as best they could, persons with mental retardation. I saw the geographical similarities and differences. Many Northeastern and Midwestern dioceses have assisted people with mental retardation for years; much of the time through segregated programs. I saw Southern dioceses struggling to somehow include such people while worrying about just staying solvent. And I saw the vastness of the West present a real obstacle to the ministry with folks with mental retardation. I listened as people began to minister "with" our friends with mental retardation instead of "to" them. I witnessed the beginning of the great national movement toward inclusion in every phase of life: school, work, church, and recreation. And I have seen the tears caused by the closing of special programs; programs that served with dedication and distinction for years when nothing else was out there. Tears in the eyes of parents, tears in the eyes of their children, and tears in the eyes of the dedicated religious and lay workers who loved these children as children of God.

I shared the excitement of NAPMR Board of Directors when it began the "On the Move" project, an effort to use the expertise of the members of NAPMR to help others across the country. For the first time there

was an organized method of sharing information, assistance, and prayers. The basic assumption was that any problem related to people with mental retardation and the Church in any parish or diocese had already been solved by some other parish or diocese. The information just had to be shared. And today I witness the continuation of that project through NAFIM.

**Lesson Learned: *Nothing happens overnight.***

I also witnessed, and continue to witness today, the development of the "Culture of Death." This development includes a sharpening focus on people with disabilities particularly those with mental retardation. The aborting of "defective fetuses" is common place, even praised as a really outstanding cost saving methodology. How many families have denied themselves the joy, and sorrows, of raising a son like my son? So much emphasis on money: putting dollar signs on the care and treatment of persons with mental retardation; attempts to "ration" medical care; and the movement toward the early termination of life so that "someone" does not have to suffer. Why am I reminded of Nazi Germany?

**Lesson Learned: *There is a critical need for people with disabilities/mental retardation to join forces with Pro-Life advocates.***

And Pro-Life advocates should recognize that people with disabilities/mental retardation must be included in the advocacy effort.

Let me summarize the last twenty years for Steve. He finally was

## *Lessons Learned* ---

allowed to serve others and it changed his life dramatically. He was included in all social events and enjoyed all of them. He has learned the great lessons of life within the parish; that God loves him; that others love him; that he could love and serve God and others; that there is so much more to life than our intellects, our physical abilities and our material things. He attends Liturgy and participates fully with the parish. I might add here that he also serves to help priests to deter-

mine if their homilies are "good." He always sits right up front and if a priest is boring or goes on too long Steve closes his eyes and nods off, the signal to cut it off. But then I bet he's not the only one!

Recently we, the three of us, moved to a new town and a new and much smaller parish. Our son has been accepted from day one, no questions asked. He has met many new friends and enjoys parish activities. He continues to be a beacon to our

priest.