

NEW DIRECTIONS FOR PARENTS, FAMILIES AND
PROFESSIONALS

SELECTIONS FROM THE WRITINGS OF

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These articles are from the following books by Robert Perske:

New directions for parents of persons who are retarded. Nashville: Abingdon, 1981

Hope for the families. Nashville: Abingdon, 1981

Mental Retardation: the leading edge. Washington: United States Department of Health Education and Welfare, 1979

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RISK AND COURAGE

“Of Human Courage and Dignity” was the title of an article by Wolf Wolfensberger that appeared in the *Omaha World-Herald*. In it, he told about the courageous actions of a young man who was mentally retarded.

The director of a local sheltered workshop had just received a letter from a mother whose two sons had perished in a fire, which had destroyed their home. One of the sons, already a young adult, had been a worker in the workshop because he had Downs Syndrome and was severely retarded. The letter, with spelling errors and exactly as written, follows:

“Dear Mike & all I was in North Platte on a Monday but the shop was closed. I wanted to thank all of you for every thing you had done for Robert. He was so proud of his job and the ability to do things on his own.

I am very proud of him as he went to the back room to save his brother. He had Donald from the head of the bed to the foot if he had only a few more minutes he would have had Donald out - even though we know Donald was dead at the time.

I am sending his one check back as they say it would not go through the machine, put the money in your fund so your books will balance.

Today was my first day back at work. It was a long day but I know I have to keep busy. My two boys were my whole life so now I have to start over. My husband is very understanding – was hurt very bad also.

If I can be of any help at any time please feel free to let me know. I feel I proved to the world that a retarded child has a place in the world and can be a useful person.

Many thanks for everything,

(Signature and town of residence)

The boy had carried the check the mother enclosed; it was burned at the edges, and that was the reason it would not go through the magnetic check-reading machine.

Robert's mother had a different image of her retarded son than that traditionally held by society. For example, traditionally the term “mental retardation” triggered such action words as “protect”, “comfort”, “keep safe”, “take care” and “watch him closely.” When a man like Robert takes a heroic risk, he forces one to ask a most important question: *Why did it seldom occur to people that a man or woman who was retarded could develop into a courageous person?* What kept one from expecting such noble traits in them? The answer may be that some people were so over-concerned with protecting the mentally retarded that they failed to recognize the courage with which they could face life.

The Indignity of Overprotection

Acting on the impulse to protect at the right time can be kind. But it is not kind to so overprotect a person that he is emotionally smothered. It diminishes his dignity as a human and keeps him from experiencing the risks in life necessary for normal human growth and development.

It is tempting to build virtually total avoidance of risk into the lives of persons who are mentally retarded by limiting their sphere of behavior and interaction in the community, jobs, recreation, relationships with the opposite sex, and so forth. This is especially true in institutions where overpopulation and understaffing is a problem. Even buildings, constructed supposedly for the benefit of the retarded, were designed to help the residents avoid risk. Fortunately, there is a growing awareness that persons who are retarded must assume their fair and prudent share of risk, commensurate with their level of functioning.

Important Expectations

The urge to overprotect invariably squeezes the life out of any good expectations one might have for a person who is retarded. And when expectations for a person are low, his feelings of being no good are reinforced, while his urge to make his life count for something good can slowly be diminished.

I learned this in a forceful way some years ago when a ten-year-old severely retarded boy named Billy wandered away from the Midwest institution where he lived and became lost in the woods that skirted the institution grounds. The temperature was below freezing. All off-duty personnel were called back to the institution to form emergency parties to search for the boy. Two moderately retarded teenage boys, Ray and Elmer, asked a staff member if they could search for Billy, too. The staff member “moved through channels” and, after some time, received approval for the boys to join in the search, and they found the lost boy! At a later

program, the superintendent gave Ray and Elmer special recognition and letters of commendation. By this time, many of the staff were haunted by the fact that there were thirty-five adolescent boys and forty girls in the institution who functioned every bit as well as Elmer and Ray. Since this particular wooded area is not terribly large, they might have been mobilised more efficiently and quickly than the staff. The tremendous urge to be good protectors blinded everyone's eyes to the things these retarded persons might have achieved if they were allowed to take the risk.

Some Courageous Human Acts by Retarded Persons in Germany

One of the touching proofs that some mentally retarded persons can rise to an occasion now comes out of the days of Nazi Germany. In a book recently published in German, Wilhelm Teufel describes some courageous human responses of retarded children and adults in the 700-place institution at Stetten, Germany, when Adolf Hitler began his euthanasia program. In 1940, two grey buses with windows painted grey arrived periodically. They were loaded with residents who were "transferred" to a castle some miles away where they were gassed and cremated.

Teufel points out that it didn't take long for some of these retarded persons to sense what was taking place. Then he described some amazing happenings. Some of the ambulatory persons became deeply concerned for the non-ambulatory, knowing they had little chance to fend for themselves. Many used their best wits to scout and plan special hiding places to which they fled every time they saw the Nazi buses coming up the road. One boy instinctively ran to his hiding place when the critical time came. He then returned after the buses were gone, saying, "They didn't catch me. I'm smarter than they." Karl fought with the driver and ran away shouting, "I'll hang myself before I'll die like that." Richard, who suffered from some spasticity, knew he did not have a chance. With calm and purpose he gave his pocket money and watch to his closest friend. He discussed the situation with his housefather. They even prayed together as he made himself ready to die like a man with dignity, "Cool" Emily calmly got into line on the day her name was called and walked to the bus. But as she came near the door of the bus, she calmly walked right on by and nobody even noticed. Later, when the bus was gone, she returned to the institution and busied herself with her assigned task of scrubbing steps. All this points up how persons who are retarded can, will, and should respond to risk with full human dignity and courage.

Alternatives for Action

All of the above is high-sounding. Good. We need to say high-sounding things about persons who take risks and rise to an occasion. (I'm haunted by what I might do if my brother was dying in a fire or if I was faced with the grim experience of dying in a Nazi gas chamber. My responses might not have been as courageous as these mentally retarded persons might.) But these true stories do drive home the fact that the world in which we live is not always safe, secure, and predictable. It does not always say "please" or "excuse me." Everyday there is a possibility of being thrown against a situation where we may have to risk everything, even our lives. This is the *real* world you parents have to face. But it's the same world your retarded child must learn to face as well! You have the opportunity to make practical applications of this theory. Prudent risk can be programmed into the daily living of your child. The following are some practical alternatives:

1. You, the
parents and other brothers and sisters, can get together and agree when your retarded child should be allowed to sink or swim. Then the family works as a team in knowing when a child should be left to cry alone; when he should be left in the living room alone; when he is allowed to move out of his own yard; when he can walk alone to his friend's house in the next block. This type of risk could progress to such things as buying groceries, taking a bus, and so forth. Bear in mind that each decision for each child at each specific instance must always be a new and fresh decision. What counts is that the family team agrees on where they will protect and where they will allow the child to take the risk himself.

2. In some
instances of failure, *restitution* work - not necessarily punishment - is helpful. One set of parents, after taking a course in precision teaching, decided that when their child wet his pants or had a bowel movement in his jeans, he should be firmly but kindly taught to clean up his own mess. He cleaned the floor; put his soiled clothes in the washer and dryer; he put on clean clothes. Later, he had to get the once - soiled clothes, fold them, and put them away. This was work. But it was good restitution work. He learned to pay the price for his failure. All of a sudden it dawned on him that it was better to put that stuff in the toilet where it belonged. This child was ready for such a risky program. This differs in degree from the heroism described earlier. But in these parents' minds, their young man is very much a hero, too.

3. In Sweden,
Bengt Nirje attempted to build a program of "hidden social training" into the many youth clubs scattered

throughout Stockholm. These small twenty-member clubs composed of half mentally retarded and half-normal teenagers had a rule never to do for a person what he could learn to do for himself. For example, a group travelled to a special program in a part of the city where they had never been before. When the program was over, each member was left to find his own way home alone, even though this involved the struggle of asking questions of strangers, getting one's own directions, finding the right bus or subway, and so forth. At another time, a day's outing at a particular amusement area was planned, and then some of the members were "called away," leaving the retarded persons to entertain themselves.

Your family could develop your own hidden social training situations, which could be tailor made for the retarded person in your midst.

Again, you as parents can be thankful that your child was born in this period of time. Society is beginning to see the need to prepare the persons who are retarded for facing real risk in a real world. Where many have worked overtime in past years to find clever ways of building avoidance of risk into the lives of the mentally retarded, now one has the opportunity to work equally hard to help find the proper amount of normal risk for every retarded person. There can be healthy development in risk taking. And there can be crippling indignity in safety!

2.The Need to Give

Margaret Ramirez and her eight-year old son Jim walked out of the examining room at Denver's Children's Hospital. Her face was drawn and there was a quiet sadness in her eyes. Sensing that it was hard for her to speak, I suggested we get some coffee at the snack shop before making the drive back to her home in Sterling. We purchased our coffee - Jim wanted a bag of salted peanuts - and we sat down at a table. For awhile we sat in silence; even Jim sat quietly. Then it came.

"How much more does my kid have to take?" she said. "Hasn't he had enough?" She alluded to Jim's Down's Syndrome and the unbelievable number of crises he had weathered. There had been bouts with pneumonia, some painful incidents with neighbourhood children, and a Logan County social worker's efforts to separate Jim from his mother and send him to an institution in Wheatridge.

Margaret told me what she had learned that morning: Jim's heart contained a hole between two chambers, causing him to experience periodic shortness of breath, headaches, and chest pains. The physicians had said he needed corrective surgery.

The mother poured it all out right in front of Jim. After all, it was 1956 and the principle of normalization had yet to arrive on the scene; we failed to be as considerate of his feelings as we would learn to be in later years.

During the conversation, we ignored what Jim was doing - that is, until we had to acknowledge what was taking place. This sharp, likeable young man, fully aware of the trouble centering around him, had twisted up his usually smiling face into a serious frown. He had emptied the bag of peanuts on the table, and with determination, he had divided them, peanut by peanut, into three equal piles - one for his mother, one for me, and one for himself. Then with gracious sweeping movements, like a priest giving Communion, he placed our piles neatly beside our coffee cups.

Soon after, Jim did have his surgery, his uncomfortable symptoms ceased, and he grew to manhood in his own home.

Over the years, I lost contact with that mother and son. Now my most vivid memory of that day in Denver focuses on the way Jim - in the middle of *his* crisis - consciously chose to offer something to his mother and to me, as his attempt to alter the painful situation.

We always believed it was more blessed to give than to receive... as long as you were not handicapped. Then your giving became downright embarrassing to others. After all, because of your handicap, everybody should have been giving to you - or so we thought. This warped belief condemned hundreds with handicaps to be perpetually typecast as the suffering man lying beside the road never as the Samaritan who came by, stopped, and gave help. Today, we know better. Healthy living requires a high degree of giving, and those deprived of this option can become hopelessly crippled. Evidence to support this way of thinking is on the rise.

ITEM: Benny Savidis, a man with a thirty-two-year history of institutionalisation, now grows beautiful tomatoes on a patch of ground behind his group home in Chicago. He produces enough for the home and gives the surplus away to six families on the block. Four other families have refused to accept his gifts, and Mr. Savidis has expressed sadness about this.

ITEM: Upon leaving a position in a Midwest institution, a seventeen-year-old resident a long-time acquaintance - withdrew an item from his cigar-box treasure trove and handed it to me. It was a metal belt buckle bearing the national emblem of the Philippine Islands.

My first reaction was not to accept it. But I did, and it remains in my possession today.

Society usually sees children as receivers, and rightly so. Their survival depends upon it. Adults are more typically thought of as givers. Small wonder, then, that past views of persons with handicaps portrayed them as *eternal children*. The English journalist/advocate, Ann Shearer, cast additional light on this predicament a few years ago: "Mentally retarded persons are all too often caught in a half-world between childhood and adulthood, fitting into neither, frozen into a continuous state of becoming prepared to enter adult life, yet not enabled to reach it."

It is possible that some persons with handicaps have not traversed this valley between childhood and adulthood because we have not permitted them to give to others and to the world as much as they are able to give.

Consider These Options

•Become tough-minded about not doing for your children with handicaps what they can do for themselves.

•Become even tougher-minded about being an unembarrassed but sensible receiver.

•Find regular, gracious, and natural ways to recognize and *reinforce* such acts of giving. Learn verbal and non-verbal ways to express appreciation: That was a thoughtful thing you did for me, son ... What you did makes me love you all the more, daughter... You make me glad you are in our family.

•Do not overdo your reinforcements. There can be times when our Good girl! and Good boy! can be so phoney and loud we almost send our children sliding out of their chairs. Proper reinforcement is so important that some professionals study for doctorates, just to learn the right way to do it.

3. HEALTHY LAUNCHING PADS

If the modern family is a fluid, always changing system, then children are close members of the system *during their early developmental years*. Later they are "launched" from that system.

This is a far cry from the earlier rural American "extended kin" system where children could grow up, do their own fair share of the chores, do their part to add to the large family economy, and stay at home as long as they liked. Even uncles, aunts, and grandparents could move in and be a productive part of the system. The socio-economic situation of today pressures us to "have them, raise them, and launch them."

You, as parents, will need to decide whether someday you expect your retarded child to move out on his own or to be with you for life. If you choose the latter, you will be faced with the question "What will happen to him when we are gone?" If you decide that this child should be launched like the rest of your sons and daughters, you will be less prone to overprotect him. You will allow him to take his fair and prudent share of risk. His successes and failures will be his responsibility.

It must be granted that you could lose in your expectation that he will become an independent member of society. But even so, it is better than making him so extremely dependent on you that when your life ends; your retarded son or daughter is forced to make an abrupt and unplanned separation. More and more, the parents of children who are retarded dare to expect that their child will progress apart from them after, the approximate age of twenty-one.

Some years ago the cry, "What will happen to my retarded child when I am gone?" was a painful one, and the answer usually was obvious. The son or daughter was placed in Endsville State Hospital and School, a large institution that gave only custodial care. The institution's name was even deceptive, for it was a "hospital" with very little treatment, and it was a "school" with very few educational opportunities.

But that's changing now. At this very moment parents of the retarded, professionals, and volunteer citizens are locking arms and fighting for complete systems of community-based services for mentally retarded persons of all ages and functioning. What a wonderful time to be working in the field of mental retardation! Populations in institutions for the retarded are decreasing. This means that the very nature of institutions will change from being custodial to becoming short-term resource centres for those who have special needs. Every professional, whether he works in the institution or the community, and every parent, whether his child is at the institution or in the community, has waited a long time for this revolution in the care and treatment of mentally retarded persons.

Although this will be discussed later in the book, you have the right to launch your child into a life that is independent, semi-independent, or sheltered small group living apart from you. It's normal for your other children. It should be normal for your retarded child.

Alternatives for Action

1. While it is early you have the right to plan the “trajectory” or direction of your child's life. This means visiting with others and finding out what services are being offered as well as those being planned in your own area. This knowledge could be invaluable as you plan.

2. Your other children will sooner or later leave the nest - or be booted out. Where once they were totally dependent, on you, they emancipate themselves. Later, they contract for other interdependent relationships (friends, bosses, landlords, creditors, and spouses).

This dependency-emancipation-interdependency movement should be looked at realistically in relationship to your retarded child. He may not move as far as the others may, but he is more than likely capable of movement.

3. As you become aware of the myriads of alternatives to the old idea of custodial institutionalisation, you as a citizen have the right to join with others in fighting for revolutionary new services. Then it may dawn on you for the first time that you are not just fighting for your own child, but you are advocating for *all* those in your community who are retarded. That's good. It means you are growing!

4. Community Residences

THE RESIDENTIAL CLUSTERS OF EASTERN NEBRASKA

Not long ago the delivery of residential services to mentally retarded citizens was organised by states in a very simple way. All resources were channelled to “total” institutions. Every dollar and every service activity was administered by a single agency, which was responsible for all the needs of the handicapped resident.

It will never be that simple again. Indeed, the delivery of residential services to retarded persons in their own neighbourhood will be an extremely complicated task, requiring more agencies, people and funding than ever before. Although many regions in the nation have begun to build such systems of residential services, no one has as yet completed the task, and no one knows what final shape such organizations will take.

Eastern Nebraska Community Office of Retardation Omaha, Nebraska

On July 1, 1968, the Greater Omaha Association for Retarded Citizens presented the Douglas County Board with a plan which (1) described all components needed in a system of community based services for mentally retarded persons and (2) called for the return of all handicapped persons from the county who resided in Beatrice State Home, 90 miles away. The plan was approved. A few months later, neighbouring Cass, Dodge, Sarpy and Washington Counties joined to make it a five-county effort, and one of the nation's most ambitious deinstitutionalization programs was underway.

The five-county program took place simultaneously with a larger state effort. In 1967, the governor appointed a Citizen's Study Committee on Mental Retardation, authorising the committee members to survey and report on the human situations of retarded citizens throughout the state. That report was submitted to the governor on the same day that the Omaha group presented its plan to the Douglas County Board.

The state report documented that Nebraska was one of the least progressive states in the nation with regard to planning and funding for mental retardation services. Conditions at Beatrice State Home, the state's single large institution for mentally retarded persons, were grim. It was located in a remote, rural section of the state, it contained 2300 handicapped citizens who were forced to live in deplorable, overcrowded conditions; and the cost per resident was a mere \$3.58 per day. At the same time, there were virtually no community services for mentally retarded persons in the state. This report received massive publicity, which reached almost everyone from the citizen on the street to the governor himself.

By 1969, a total of 14 state laws were passed with mandates ranging from the organisation of the state into six powerful community based service regions, to the repeal of a law ordering institutionalised females to be sterilised before moving back into the community.

It was with this added impetus that the five counties in Eastern Nebraska, comprising one-third of the state's 1.5 million population, were formed into Region VI, the Eastern Nebraska Community Office of Retardation (ENCOR). ENCOR began immediately to develop community service thrusts. The following is a description of the residential component of this regional service system as it exists today.

•*Support the Home First* Through the years ENCOR's policy has been to do everything possible to help the mentally retarded persons live at home before offering them residential care in the community. All ENCOR divisions join with many generic agencies to provide services which support mentally retarded persons in their own home. For adults, "home" means their natural setting in the community; and for children, it is with their family

•*Residential Clusters* Today, handicapped clients who have come from the institution or who can no longer be supported in their own home, live in one of 17 clustered subsystems of residences, where they are being helped to move through less and less restrictive settings and to take on more and more personal responsibilities as they develop. As clients become more responsible, they have increasingly less need for ENCOR services. To carry out this developmental process, each cluster is organized with one core residence and from 12 to 15 alternative living units (ALU's) around it.

•*Core Residences* A core residence is a group home of not more than six recently admitted handicapped clients who live there for an average of from three to six months in order to "settle in." Here, the first individualized program plan (IPP) is developed by an interdisciplinary team consisting of the necessary ENCOR staff and other agency consultants, as well as the client and a family member or guardian. This first IPP is launched shortly after the client enters the core residence; it provides the initial data on an individual's growth pattern.

The recent admission of Mary Ann, a 43-year-old former resident of the institution, provides an example of ENCOR's initial program planning. She is learning to travel into the surrounding community, to use the telephone, to speak more clearly (teeth and jaw formation are being evaluated for possible surgical corrections simultaneously with initial speech training), to work daily in an industrial training center, to achieve a series of beginning industrial skills and to take part in various recreational opportunities. Also, Mary Ann is learning to maintain her own bedroom, carry out other specific housekeeping tasks and adopt acceptable behavior patterns.

As these initial tasks are accomplished, Mary Ann's personal growth pattern will become more apparent and predictable and an alternative living unit, fitting her needs will be sought. Central to this developmental pattern is the core residence the supervising "mother house" for the ALU's it develops.

• *Alternative Living Units* It is the responsibility of the staff assigned to Mary Ann's core residence to find an ALU in the community that meets her developmental needs and to change the ALU when her continued progress warrants it.

The numerous ALU's that now operate in the ENCOR system are, of course, as individual as the clients serviced by the system. An ALU can house from one to four handicapped clients, be in a city, a small town or on a farm, require 24 hours of intensive supervision or only three hours a week for assistance with shopping and chequebook balancing. Some clients live with a family in the community; others live alone in an apartment. Some may require only short-term crisis assistance, while others need long-term intensive training. As one ENCOR spokesman put it, An ALU is any residence a particular person needs. All of the details are determined by the ever-changing IPP.

Many changes have taken place since the day the state report and county plan were submitted. Beatrice State home has been renamed Beatrice State Developmental Center and its population has been reduced from 2300 to 850. All but 250 of original 780-institutionalized citizens from Region VI have returned to the community-to independent living, their family homes, nursing homes or ENCOR residential settings (where 250 persons are accommodated in the 17 core residences or 105 ALU's throughout the five-county region). It has been estimated that more than 350 mentally retarded citizens in the region have been helped to stay in their homes instead of being sent to the institution, as would have been the case ten years ago.

Despite the many changes all persons interviewed regarding the regions' residential services still hold to the original, unifying goal of the 1968 Douglas County report ...all will be returned to the county (now five counties) for care, education and training. As the effort continues, ENCOR's attempting to solve the following problems:

•*Severity of Handicap* Of the 250 persons still at the institution, 60 percent are severely and profoundly handicapped. As a result, the agency must develop a more intensified technology than ever before.

•*Nursing Home Problems* There are 95 persons in the area now living in nursing homes who need ENCOR residential services.

•*Community Client Needs* Although much of the emphasis is on client institutionalisation, there are many mentally retarded persons already living in the community who someday will need residential care. Services for these persons must be planned and also carried out.

•*Ideological Standards* The service system began with a small number of persons who believed unwaveringly in the value, dignity and rights of mentally retarded persons. Their high ideological standards gave them added enthusiasm, energised their efforts and inspired their creativity. As new personnel are employed, extra effort will be needed to keep the ideology rich.

•*Limited Unstable Funding* Through the years, the funding from federal, state and county sources has always been in a state of flux - and always short. There have been some increases, but there have also been cuts that have crippled or killed vital components of the service. There have never been sufficient funds to accomplish the goal of the Douglas County plan, and there has *never* been a single, stable source of funding from any level of government, which is earmarked specifically for community residential services for retarded citizens.

•*Security for Parents* In the past when parents placed their child in an institution, the government informally guaranteed that the child would be cared for after they died. No such guarantee has been made for parents placing their child in this community service. This lack of security has led some parents to attack ENCOR when they are forced to choose between it and the institution.

•*Largeness* As ENCOR becomes larger, there is increasing danger that central management will be forced to develop common denominator policies that enhance one client's life while diminishing another's; or rules that can correct an inefficient staff member's behavior while snuffing out a valuable worker's freedom to create. The organisation of the 17 clusters was a defence against such creeping institutionalisation. Now, as even they get larger, ENCOR must continue planning to keep each small unit alive, personal and at top efficiency.

The parents, professionals and citizens of eastern Nebraska have invested a massive amount of time, energy and emotion in an effort to provide continuums of residences for the handicapped persons in their midst. In doing so, they have had to deal one by one, with hundreds of bureaucratic and prejudicial obstacles that have appeared in their way. They have learned that society does not take kindly to those who attempt to correct or change the practices and beliefs it has been institutionalising for hundreds of years. Nevertheless, these people have not wavered from their goal.

5. NORMALISATION

Since 1950, success has built on success for the organised parents of mentally retarded persons. The early turbulent period gave birth to the beginning of the human dignity movement. The early human dignity movement opened the eyes of parents to the beauty of seeing their children as developmental human beings, as all of us are. As the process continued, persons who are retarded were increasingly recognized as members of the human race. And while American parents continued to move through these initial historical phases, the same thing was happening in Sweden.

By 1967, Swedish parents of mentally retarded persons had placed pressure on their lawmakers to develop human legislation on their children's behalf. The Swedish Parliament, pressured by the parents, went into committee to develop a law benefiting the retarded. But they failed to include any consulting parents of the retarded in the writing of the law. Then Bengt Nirje, the executive secretary of Sweden's association for the retarded, reported an amazing thing. The parents of the retarded began meeting in a building near the Swedish Parliament. They worked long hours and produced a "Law of Normalization" all by themselves. They petitioned Parliament to take a look at it. The Normalization Law, passed by Parliament in 1968, with only a few minor exceptions, was the one the parents wrote.

Bengt Nirje has given an excellent outline of what the early principle of normalization aimed to do. The following rights were to be accorded retarded citizens of Sweden as soon as they were honestly able to receive them:

The right to a normal rhythm of day.

The right to a normal routine of life.

The right to a normal rhythm of year.

The right to a normal developmental experience of the life cycle.

The right to decide and choose for oneself.

The right to live and experience in a bisexual world.

The right to normal economic standards.

The rights to live, work, and play in what is deemed normal and humane for that society.

A Normal Rhythm of Day

These means persons who are mentally retarded have the right to get out of bed and get dressed when others normally do this. They have the right to eat their meals at the normal time in a normal family-like atmosphere that is relaxed, harmonious, and satisfying. They even have a right to certain other personal rhythms: times when it is normal for one to break away and do his own thing.

For years America's eminent psychiatrists have attempted to tell us that the most meaningful human interchanges can - or should - take place around the dinner table. In our Christian and Jewish religious traditions, many of the most meaningful encounters take place at times when we "break bread together." Our children who are retarded have a right to these important human encounters, too.

A Normal Routine of Life

Normal people live in one place. They go to school or work at another place. They participate in leisure time activities at other places. All of these places are normally kept segregated and separate. That seems simple. A tremendous part of the learning and experiencing of life takes place on the road, rubbing elbows with all kinds of persons and seeing many new things. This is a part of normal living. The child who is retarded has a right to this normal routine.

A Normal Rhythm of Year

This means that everyone has the right to find times to change his or her life situations. It means everyone is entitled to observe holidays and special days in a normal family-like way. It means everyone is entitled to a vacation! A chance to --getaway from it all" is a right that must be available to persons who are retarded.

Normal Developmental Experiences of the life Cycle

Every person should have the chance to experience a full childhood, which is rich in warmth of atmosphere and sensory stimulation. Childhood should be spent in a family-like setting where adults insure the security that every child needs in his early developmental years. When he reaches school age, a child needs an education, regardless of his level of functioning.

During the adult years, it is normal to expect persons to do productive work. They are expected to make "their bread" with their hands.

In old age, persons usually tend to be in the community close to the place where they spent the adult years of their lives.

Parents of a child who is retarded must anticipate that their child will also move through these stages.

The Right to Make Decisions and Choices for Oneself

Every human being needs to learn what is right or wrong, what he should or should not do. When he is immature, his choices may be in small things. As he is given opportunities for decision-making, he will become better able to choose. Your retarded child has this right also.

The Right to live and Experience in a Bisexual World

Normal human beings live in a society made up of both males and females who are expected to relate together according to their mental and social development. Persons who are retarded must be given guidance and opportunity to relate to persons of the opposite sex as a child, youth, or adult, as their level of development dictates.

The Right to Normal Economic Standards

A person is entitled to make a living if he can. If for some reason he is honestly unable to do so, he is entitled to a financial standard of life that is considered normal. I recall the joy of a retarded friend who “made it” in the economic world. He made his own money and lived in his own room under minimal supervision. But his greatest joy came from owning his own savings account book! Every person has the right to live within normal economic standards.

The Right to live, Work, and Play in. What Is Deemed Normal and Humane for That Society

This means a family-like atmosphere from birth to twenty-one and normal living arrangements conducive to good adult relationships later. This means, in Sweden, that persons who are mentally retarded are dispersed throughout society. Apartment buildings include a small number of units for persons who are mentally retarded.

Everything is geared to help them live as normally and as independently as they can.

Americanising the law

Since 1968, American parents, professionals, and now lawmakers have been pondering, arguing, stretching, bending, and compressing the Swedish law so it is applicable to the American culture.

The United Nation's Declaration on the Rights of Mentally Retarded Persons (adopted December 20, 1971) bases its statement on the principle of normalization.

Highly scientific definitions are being given, such as the one the Accreditation Council for Facilities for the Mentally Retarded now utilises as the keystone of their standards: “The principle of normalization shall be defined as the use of means that are as culturally normative as possible to elicit and maintain behavior that is as culturally normative as possible, taking into account local and subcultural differences.” The following is another version:

Let a retarded person live as normal a life as he possibly can in as normal a setting as possible.

That person is more prone to live up to this normal environment and those normal expectations. . . . Meanwhile society has a chance to closely observe and catch the spark of this human being's struggle to win his place in normal society and will be more prone to open its heart and widen its tolerance for those who were often seen as “different.”

The point I'm trying to make is that as the retarded person stretches to better achieve, society can stretch to better accept.

Alternatives for Action

Here's one for you to ponder:

You should struggle to give your child every chance to achieve as normal and as full a life as possible. At the same time, do it for yourself as well. Sometimes the two struggles will clash. This means you have a conflict to ponder and some rough choices to make. That's OK; both of you can be stronger from such decision-making.

At other times your child's chances and your chances will move hand in hand. Strength comes from this as well.

In other words...

work for your child

but

work for yourself as well!

6. Parent/Professional Relationships

In the past, parents did not always feel comfortable with professionals. Gail Stigen, a professional, and the parent of a child with developmental disabilities wrote an extremely humorous book, *Heartaches and Handicaps* (Palo Alto, Cal.: Science & Behavior Press, 1976) which focused on this issue. Among her many hilarious descriptions of parent/professional encounters was this sketch of her first session with a social worker.

Suddenly, I became aware of this person standing next to me... I got up to look into the face of this elegantly turned-out person who was watching us with no expression. What I had at first perceived to be a store dummy finally asked if I was her nine o'clock appointment. I quickly checked my driver's license to remember my name, which I blurted out before I forgot it. It was conveyed to me that I should follow this humanoid...

There followed a scene only an over-trained professional can stage-manage. When we entered her office (with me trailing as due my inferior role), the door was firmly closed and my Social Worker sat down behind her desk in her Executive Swivel Chair. At first I thought I had been forgotten. What seemed like hours went by as she perused an impressive file, while I stood there like a lump, my shoes pointed inward, and I fought an overwhelming urge to whistle or hum...

The office was shoebox shaped and not much bigger. My razor-sharp mind told me that there was no chair for me and I realised immediately that we were going to have quite an informal session, with me either on the floor (as in Girl Scouts) or perched on her desk (as at the office Xmas party).

At last this deity seemed to decide that my hulking, looming mass was distracting her from her homework, and she motioned me to an area to the left of her desk, where I obediently stood. Finally, she told me I could sit down. I thought that was very thoughtful of her, but I couldn't find anything to set my considerable bulk on without courting disaster (by then I had discovered what appeared to be a doll chair next to her desk). But yes, by God, yes. The "doll chair" was MY chair. You've all seen those *National Geographic* photographs showing (members of a primitive tribe) squatting with their knees under their chins, staring blankly ahead. You now have the picture of my posture.... It was going to be a long fifty minutes.

Stigen makes us laugh at professionals, all right. But she is also uncanny at expressing the unsettling discomfort many parents used to feel in the presence of such trained people. On the other hand, professionals did not always feel comfortable with parents. And the more prim and perfect those highly trained ones appeared, the more they may have been putting up a false front to hide their own feelings of inadequacy.

I recall a psychologist who was deathly afraid of non-professional encounters with the parents of his clients. On one occasion, he left a shopping cart full of groceries in the aisle of a supermarket and quietly walked out when he spied a parent shopping in the same store. These discomforts extend to other professions, as well. I was once invited to a Hooray-It's-Over-Again party, held by schoolteachers who were celebrating the end of their semester parent-teacher conferences. Imagine that! After all those years of attending uncomfortable sessions and trying to avoid slips like, "Hello, Ms. Prim, I'm Robert Failure. Tell me where I am a flop as a father this time." After all those years of gosh-I-must-be-a-lousy-parent feelings, suddenly and a little too late, I learned that teachers felt just as incompetent around me! But that was then.

Today, when you observe boys and girls with handicaps performing skills that, a couple of decades ago, none of us thought they could accomplish take a closer look.

More often than not, you will find parents and professionals working together as team-mates, in such ways as... parents in classrooms from time to time teachers in homes learning from each other continuous two-way communication (notes, telephone calls, meetings) developing individual education plans together discussing divisions of labour (what tasks in home, classroom, neighbourhood-and for how long) emergency meetings happy communications (guess-what-Jim-did-today messages) evaluating progress sometimes laughing for joy after an achievement other times, feeling whipped patting each other on the back respecting each other knowing how much they need each other.

What happened to the discomfort? I guess nobody had time for it. Too much attention and energy was being expended on pinpointing a child's specific developmental delay and on determining what each person could do about it. When a this-kid-needs-us-all-so-let's-go-to-work attitude becomes uppermost in everyone's mind, parents and professionals often become close-knit comrades with a common cause. Without their planning it - or even thinking about it - it happens. When partnerships like these really click, it often carries over into other areas. For example, in Nebraska, from 1967 through 1975, some parents and professionals worked so closely together that they developed a common human-service philosophy and specific goals for achieving it. Then they became active with the governor and state lawmakers in a massive overhauling of legislation for persons with developmental disabilities. They developed state plans, county plans, attitude-change programs, regionalised community-based service systems, and funding to operate the programs.

Parents and professionals had come as partners to the state capitol at Lincoln from places like Norfolk, Hastings, Scottsbluff, Ogallala, and Omaha. They had delivered a "double whammy" to state government. Parents spoke in hearings and approached legislators in the foyer. They spoke clearly about the problem people with handicaps faced in Nebraska. And, of course, legislators being used to such people - knew how to listen respectfully, thank them for coming, and quietly shrug it all off a few minutes later. But no sooner did the parents finish than their sidekicks - the professionals - took over, providing the lawmakers with detailed statistics.

It was obvious to everyone that neither the parents nor the professionals alone could have influenced the government so powerfully. It was their well-planned, carefully detailed teamwork that did it. Many senators expressed amazement at the effectiveness of that. Said one, reminiscing at a later date, "You people were too

much. If we could have kept you apart, we would have been OK. But when you came at us together... well, you were too much.”

Later, when professionals in other, larger, more powerful states began to wonder how such a conservative state as Nebraska could have increased the quality of living for persons with mental retardation in such a short time, two of the movement's leaders explained.

We are now convinced that failure of parent and professional to co-operate *truly* and *genuinely*, rather than merely working alongside each other, must have accounted for the failure of many a planning effort, and for some of the confrontational clashes in certain large states. And in our opinion, those professionals who believe that substantial sustained progress can be achieved at the agency level alone, without regard to the consumer or to cultural concurrence, will be doomed to eventual failure in their enterprises.¹

Strong words. They remind us never to underestimate the power that can be developed when parents and professional's pull together to help a child with a handicap.

Consider These Options

- Stop feeling insignificant in the presence of professionals.
 - Look for professionals willing to team up with you.
 - Know that you and only you possess and can provide crucial information about your child with a handicap.
 - Never think you must apologise for asking professionals to join with you in developing training programs for your son or daughter.
 - Do not feel you always must be so patient. A biological developmental time clock is ticking away inside your child. He or she is already behind schedule on some things. Do everything you can to see that neither you nor a professional wastes your child's time.
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7. Candid Consumers

The only consumer service that can regulate itself successfully is that of the parachute packers - they must test their own products. Other services cannot renew themselves without feedback from their customers.

In the field of developmental disabilities, good interaction between consumers and hands-on workers definitely is needed, but that is not enough. Leaders who operate above such side-by-side relationships also need clear communication from those who receive the services. After all, agency directors, school principals, and bureau chiefs control the planning, the use of funds, and the delivery of the services, which ultimately shape the destinies of persons with handicaps. Therefore, these shapers need shaping, too. Here are some specifics.

Serving persons with handicaps has become big business, and no business can remain efficient unless it hears from those it serves.

Listening to feedback only from those the agency chooses to hear is not enough. Such behavior often leads to the rubber-stamping of agency decisions and plans.

Complaints will improve a service more quickly than commendations.

Salaries of workers need scrutiny. Service efficiency diminishes when some workers receive high salaries for doing little, while others almost kill themselves for the minimum wage.

Technically, persons with handicaps are the true consumers. Nevertheless, parents and other family members usually are the communicating consumers.

Parents and other family members possess an invaluable perspective. Because they live with the persons who are receiving the services, they are in an excellent position to know that person's specific needs and whether they are satisfied. No other worker can fully duplicate this perspective.

Bureaucrats and parents do not always agree as to whether a program works well. For example, a writer can interview a program director that - with the use of charts, graphs, and timelines - convinces the journalist that these programs are “the best in the nation.” (The number of bureaucrats who believe their programs rank on top is awesome.) But when parents describe the same program, the interviewer gets a completely different story.

¹ W. Wolfensberger and F. Menolascino, “Reflections on Recent Mental Retardation Developments in Nebraska,” *Mental Retardation* (December 1970)

Somehow, the *rhetoric* delivered by some bureaucrats fails to match the *performance* observed by the parents. Persons with handicaps in mixed-signal programs such as these can suffer irreparable harm.

Thorough program planning must include both service-agency leaders and consumers. Of course, if parents do nothing, insensitive bureaucrats are happy to go along without consumer input. They can build do-nothing programs, place elaborate public relations facade's around them, and get paid... as long as consumers sit back and let them. Eric Toffler warns that this turn of events in countries such as Canada and the United States now reaches frightening proportions. Such one-sided planning "takes on an elitist character that removes decisions from the ordinary citizen and hands them over to remote experts and bureaucrats" (*The Eco-Spasm Report*

[New York: Bantam Books, 1975]). Toffler claims that grassroots people-such as parents-are needed "to help (and watch) the planners."

So you have decided to be a candid consumer, a fearless-feedback-giver-to-the-top when things go wrong with the services delivered to your son or daughter. That sounds simple. You plan to go to bureau chiefs, just as Nathan went to King David and convinced the monarch he was wrong for messing around with Bathsheba and for having her husband put out of the way. (Nathan made it look easy - he forced David to fall to his knees in remorse and blubber a plan of restitution.) Or you decide to go, like strong but kind Marshal Dillon, who calmly placed his hand on his holstered gun and, with no-nonsense timber in his voice, said, "I'm tellin' you, Dirk, you cannot do what yer doin' any longer." (It was a piece of cake when Matt did it. Dirk, being no fool, stopped doin' what he was doin', thanked the marshal for the advice, and shaped up.)

But when you go to the director, principal, or bureau chief with your feedback, he or she may not respond as did David or Dirk. Some bureaucrats possess an uncanny number of responses to give you the impression they think you are an ingrate, a troublemaker, or a weird person. It can set your head spinning. Such leaders preach their own brand of tell-us-where-we-are-wrong-because-we-need-to-know sermon. But when you really tell them, they make you feel as though you were a deviant.

Why? Anthropologist Laura Nader, who recently finished a massive study of consumer-complaint failures throughout North America, gave an interesting explanation in an article titled "Complainer Beware" (*Psychology Today* [December 1979]).

The imbalance of power gives producers a psychological, as well as an economic advantage over consumers. One and a half centuries ago, de Toqueville observed that as a people, Americans are intolerant of deviant or eccentric behavior. A prime technique in handling complainers is to *make them feel like deviants* [author's emphasis], to communicate to the complainer that he or she, is out of line, or at least that the complainer's experience is aberrant.

Therefore, you need to improve the power balance between yourself and the bureaucrats in order for your pleas on behalf of your son or daughter to be taken seriously. You must build your own little power generators and crank them up when needed.

See power for what it is. Some persons try to put the idea into your head that power is bad, but power need not be bad. It is neutral. It can be used for good or evil. Good power is beautiful to behold. Your son or daughter needs the products of good power.

Trust your own senses. Consider this real situation, a few years ago.

What do you do when you are the parent of a mentally retarded eight-year-old who lives in an institution? You admitted Jamie because you couldn't keep him at home; and nobody else in town had any better suggestions. And when you visit your son, you try to believe that he is better off in the institution... that the ward attendants are more sensitive to Jamie's needs... that the quality of professional care is higher. You force yourself to believe this even on the Saturday when you find your son has a large bruise on his right arm and the ward nurse informs you that he has a broken tooth. (Nobody seems to know how it happened). Then you wonder about the boy's "developmental program" they told you about. He's not hyperactive any more, but he's too quiet and unresponsive.

You want to ask all kinds of questions about Jamie's care. In fact you want to ask so many questions of so many people that someone might think you were doing detective work. But nobody else is asking anything. And you don't want to sound like an upsetter or a troublemaker. So you mindlessly nod... and don't say anything at all.²

You too will be caught in darned -if-you-do-and-darned-if-you-don't situations such as that one - uncomfortable positions. Even so, practice the refusal to deny what your senses tell you. In time, power can result.

Know that you are not a deviant. Understand that some bureaucrats make you feel that way to weaken you - to get you to "cave in."

² Perske, "Speaking for One's Own Child" *Listen Please* (Downsview, Ontario: Canadian Association for the Mentally Retarded, 1978).

Get your facts straight. Real facts, simply stated, lined up one after another can be powerful. Without clear, clean facts, you can go off half - cocked and accomplish nothing.

Write out your facts. Do not try to write them as a professional would. Do it “in your own voice.” In other words, sound like yourself. Make a simple list of the points you want to make. Then draw simple conclusions from that list. Remember your ABCs - Accuracy, Brevity, and Clarity.

State your facts calmly. Speak without excitement or hysterics. Practice in front of the bathroom mirror. (I do.) When you are sure of yourself, you will feel calmer.

Make your points in letters. Spoken words can be forgotten or denied. Words on a page are harder to ignore. By the way, do everything you can to get your points on a single page. Bureaucrats do not read as much as they would like you to believe. The top page usually receives the most attention.

Send copies to other powers. Bureaucrats pay more attention to your letter when governors, legislators, advocates, newspapers, TV and radio stations, and other agency heads receive copies. Of course, the audience you muster will judge you according to the facts you raise. Fine. That is, if you know what you are talking about.

Organise with others. In a sense, every voluntary organisation for persons with handicaps began in order to correct some sort of power imbalance. Think about the power you can achieve from developing the first eight generators. Then think about the power that could be martialed if, say, eight people came together and carried out the tasks in resonance!

Do not feel the organisation must be large. Some six-man bomber teams have made greater impact than thousand-member battleship crews. An alert, committed, well-focused organisation of eight competent persons may do more for persons with handicaps than an aimless organisation of one hundred.

Support one another in the organisation. Learn from the Flying Tigers. When their small squadrons of P-40 fighter planes encountered overwhelming opposition, they flew in a tight circle, each plane staying on another's tail. Then when a “bandit” dived on a plane, the comrade behind took out the bandit. Tremendous power can be generated when small groups of people “cover one another's tails,” care for one another, root for one another, and protect one another.

Keep your organisation morally honest. Unselfish integrity and a proper moral vision are the only qualities that will keep you from becoming a Mafia. Those people are organised, too. In *War and Peace*, Tolstoy suggested repeatedly that organizations are in continual danger of becoming evil. In fact, he believed that evil groups had an easier time. Reinhold Niebuhr explained why this is so in *Moral Man and Immoral Society*. He describes the way persons with high personal morals, when they become members of an association, agency, or bureau, can lie, cheat, steal, and even murder with hardly a twinge of conscience. Nevertheless, consider the challenge of Leo Tolstoy: “If evil men can work together to achieve their evil ends, then good men can organise for their causes, too

Organise coalitions. Many small organizations can come together to solve a single crucial problem. The Right to Education for All Handicapped Act (U.S. Public Law 94-142) is the product of such coalitions. Remember, however, that coalitions can work only when all members struggle with the same unifying issue.

Utilise existing due-process laws. For example, when a child’s evaluation, placement, or individual education plan is not working, the parents have a legal right to utilise a series of steps, taking as many as necessary to correct the situation. The parent can... discuss the situation with the child's teacher, request to see the child's records, discuss the situation with the principal, request the school district to review the evaluation, program, or placement, request the state board to mediate the disagreement call for an informal hearing from an impartial

Consider These Options

When things are cool and no problem exists, ask to read your son or daughter's records. If there are statements in the records you do not understand, ask someone to explain them. You have the right, and the responsibility, to have this information.

Before they happen, think about what you will do when you get caught in “double binds” (those darned-if-you-do-and-darned-if-you-don't situations). They will happen. So start thinking about how you will be true to your own senses then.

Conquer the fear that if you speak out on behalf of your son or daughter, you and your child will surely suffer reprisals. More often than not, the opposite happens. Your son or daughter is usually better off because you had the courage to speak.

If you become successful at generating power on behalf of your son or daughter, do not hide your story under a bushel. Be unabashed about sharing the steps you took with parents who are still standing at the bottom of the well of powerlessness.

panel, at which witnesses and legal advocates can appear to help state the case.

Know the law and utilise it to generate power in your favour.

Get a lawyer. Bear in mind that all powerful principals, directors, and bureaucrats have lawyers ready to move at a moment's notice. Why not you? Journalist Lynn Isbell put it this way.

One snowy morning, a young mother of a retarded boy went to visit the principal of the school her son attended.

“Why,” she asked, “does my son have to ride the bus for two hours a day? Why is there no library in this school? Why does this school start later and end earlier than all the other schools in the district?”

The principal was shocked at her ingratitude. Didn't she feel lucky that her son could go to school at all? Did she have to ask for *quality* too? “It's the responsibility of the people higher up,” he said.

So she went “higher up” and talked to some administrators who said that the problem was that the district couldn't afford anything better and that, anyway, the decisions were made higher up.

This particular mother had an unfortunate and inconvenient dread of heights and was beginning to feel somewhat dizzy. So she decided to get some company for the climb ahead. It seemed like a lawyer would be good company so she called a lawyer who had no fear of heights at all.

It's amazing how much easier it became to solve some of these problems at less dizzying altitudes after the meeting with the people “higher up” during which the lawyer took copious notes.

This is a true story... It doesn't have a happy ending yet, but boy, are things looking up for all the kids in that particular district. You, too, can overcome your fear of heights. (Dougan et al., *We Have Been There*)

Go to court. Powerful people - millionaires, bankers, bureaucrats, institution superintendents, corporation heads, school district leaders, and public officials, ranking professionals - go to court at the drop of a hat.

J.P. Morgan became famous for ending unsatisfactory negotiations by, saying, “I'll get my lawyer, and you get yours, and let us go to court.” But when an ordinary citizen or group of citizens decides to sue, the bureaucrats anguish, wail, and cry foul, as did the mayor of Santo Vittorio.

Why? Because courts are the greatest equalisers of power imbalance that an ordinary citizen can have. Without them, minority groups of all kinds would never have a chance for justice. One of the things that makes our country great is that both bankers and bums can have their cases heard before a no-nonsense judge who calmly listens to rational evidence on both sides of a question and then makes an impartial decision. I am a firm believer in the court system of our land. And I believe it will be a bad day if we ever lose our faith in the courts as our fair and final protectors.

And so, gentle parents, ordinary citizen, keep your kind manner. At the same time, however, remember that you can generate an awesome power, a force that can help your son or daughter with a handicap be accepted, helped, and treated as the rest of this continent's citizens are treated. That is “*kind*” power. For only the strong can be truly kind - the others fake it out of fright.

Powerlessness is a horrible state. It is like standing at the bottom of a well and trying to climb out on a trick ladder – every time one puts a foot on a rung, it slips down. Do not let anyone render you powerless in that way.

A standard statement in a powerful corporation where I once worked was Power Creates Its Own Opportunities. And it certainly does. In thousands of different ways, power can be used to gain more power.

Power is used to move Amtrak's train 61 from Montreal to Washington, or Air Canada's flight 823 from New York to Vancouver. And power can be used to move people, too.

Use the power you generate as honestly and as fairly as you can. You may not feel the need to generate it for your own sake, but you do need to generate it for the sake of your son or daughter with a handicap.