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THE POWERFUL PROCESS OF NORMALIZATION
WITH THE
MENTALLY RETARDED: PAST AND FUTURE

by

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"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."

(Standards For Residential Facilities
For The Mentally Retarded 1.1.1.1.)

That seems like a statement some egghead would make. All the words are hum-drum and usual. But these words, stacked together the way they are, could force us all to make a social somersault. They could catapult us into a whole new age of toleration among God's human family who live on the face of this earth! It's like what that man Einstein did. He took three simple components: energy, mass, and the speed of light. He stacked them together in a most creative way and all of us have been catapulted into the nuclear age. Normalization could be like that.

This is a critical time in history. As we stand at this point in time, with the new principle of normalization in our hands, we need to look back and we need to look forward. First, let's look back to see how we came to develop the principle. Then, let's look forward and predict what this principle can do for the associations who are advocates for the mentally retarded.

The history is grim when it comes to telling how people saw the mentally retarded. It has been documented that they have been seen in at least nine different ways. They have been seen as:

subhuman organisms
objects of pity
objects of charity
objects of ridicule
unspeakable objects of dread
holy innocents
eternal children
sick people
a menace to society.

(The parents were seen in some weird ways, too.)

All of these ways in which people saw the mentally retarded persons tended to develop attitudes toward them, and structures around them, that belittled them and made them less than human.

By 1950, a group of parents of the mentally retarded banded together because they didn't know what else to do. They were at their wit's end. They had received many "mixed signals" about what to do with their retarded child. They became fed up with the way society and professionals in the society had been viewing and treating their retarded sons and daughters. So, they formed the NARC movement, an intense but respectful backlash movement against doctors, psychiatrists, neighbors, teachers, policemen, clergymen, and society in general. The turbulence they caused when they met together continues to this very day, and has increased in its intensity.

By 1964, this stirring had opened their eyes so that they could see a new principle, get their hands on it and use it in a most powerful manner. It was the principle of human dignity. It began when the man, David Vail, held a series of workshops in various institutions within the state of Minnesota, in which he attempted to sharply define all the things that belittled prisoners, inmates, patients and residents, making them to be less than human. At a climactic point, he let everyone in the workshops give simple descriptions of dehumanization in their own words. Here are only a few from that longer list:

"Dehumanization is..."

- Taking everything from the patient on arrival (such as a ring with sentiment).
- Being brought to the hospital handcuffed to a sherriff or policeman.
- Toeing the line for someone's convenience.
- Having a haircut like the rest of the bunch.
- Not being able to go "Trick or Treating" on Halloween.
- Not having clothes that are becoming.
- Tailoring clothes with safety pins.
- Patients being transferred to another institution without knowing why, where, or when.
- No space for privacy.
- An extraction with no dentures.
- Not being able to have a cigarette when you awaken at 3:00 a.m.

But the man, David Vail, helped people to make another list that he entitled "Human Dignity".

"Human Dignity is..."

- Selecting one's own clothing and accessories.
- Being able to have a cool drink without having to ask for it.
- Having your own dresser for your own personal belongings, even one drawer.
- Having clothes to wear that are becoming.
- A penny in the pocket.
- When one who is ill is treated like a patient and

not like a person to be punished.
Providing a patient with as much freedom and
decision...as his condition allows.
Being allowed to be yourself.
Being appreciated for what one is worth.
Having funds to pay for eyeglass repair and false
teeth.
(These are only a few of the longer list.)

All this was published in a book aimed for changing the attitudes of professionals in all kinds of institutions and prisons. During that period, most professionals in such places were't even aware of the lists. But the uncanny thing was that parents of the retarded saw the lists and they began to make up their own.

Work with the human dignity principle tended to open the eyes of parents of the retarded to another principle: the developmental principle. Now they were free to see the mentally retarded as developing human beings like all of us are developing human beings. It seemed to come as quite a thrill to parents, that as every person has his own developmental roadmap and rate of growth that is different from everybody else, so the mentally retarded have theirs as well. This developmental model came like a breath of fresh air to many, because it allowed everyone to live, experience and achieve, according to his own roadmap and rate of growth to the best of his ability.

By 1968, the human dignity principle and the developmental model further opened the eyes of parents--and certain professionals who now were in a resonance with them--to a strange new Law of Normalization that was passed in Sweden. The first detailed explanation appeared as eight poetic planks:

1. A normal rhythm of day meant that normal eating, sleeping, and daily habits were a human right.
2. A normal routine of life meant that the retarded should move as much as they were able through the community to school, recreation, and work.
3. A normal rhythm of year opened the way to enjoyment of holidays and season changes instead of a regular, hum-drum day-after-day existence.
4. Normal developmental experiences of the life cycle gave them the right to a family-like atmosphere when they were young and to have the normal developmental experiences of youth, adulthood and old age.
5. The normal chance to make one's own choices could put a stop to smothering overprotection. It allowed the retarded to experience the risk of making their own decisions.
6. The right to live bisexually showed how fiercely serious the Swedes were in allowing the retarded to have any experience that a normal person could have in their culture.
7. The right to normal economic standards became a new possibility either by earning it or by pension.
8. The right to live, work, play, in what is deemed normal and humane for their society meant that the retarded should

be given a chance to make a good life in the community instead of being put away in isolated groups of buildings with acres of beds in one room and acres of tables in another, and a regimented existence in between.

And so, the stirring that began in 1950 led to the human dignity movement; which led to seeing the retarded as developmental. That, in turn, made us alert to Sweden's law. All these principles seem to function like a fuse moving toward unleashing the catapulting power of the Americanized version of the Normalization Principle as we know it today.

Now, with the Normalization Principle within our grasp, what can we in the ARC movement expect in the future? Allow me to make some predictions:

1. We Will Start Some Fights.

(One could expect that a guy from the land of Wolfensberger, Menolascino and Clark would say something like this!) But, this fight is not one of blind rage. It is not sending aimless barrages into a smokescreen. It is a fight with eyes that are now wide open and focused. It is a fight based on solid principles and laws that are on the books of our land. Normalization has helped us to see so many things that heretofore we were unable to see.

Within the past year, it has been clearly documented that many rights guaranteed by the Constitution of the United States have been denied the mentally retarded. In some cases, the first, fourth, fifth, sixth, eighth, ninth, thirteenth, and fourteenth amendments have been denied United States citizens, human beings who happen to be mentally retarded. Normalization has helped us to see that many human and legal rights have been heretofore denied mentally retarded persons who could have enjoyed them. If the parents of the retarded, the volunteer citizens, and the volunteer professionals in the ARC movement don't fight for these rights who will?! So, with what normalization has helped us to see, we will start some fights.

2. We Will See Through The Facade of Certain Institutional Systems.

In the fairy tale, The King's New Clothes, we laugh when we read about the tailor's conspiracy to convince the king and the whole town that the king's new clothes were the most beautiful, most wonderful duds that a monarch ever had. And it would have been pulled off if only one little kid watching the parade hadn't blown it by shouting "He's naked!"

We are intrigued when we read how Catherine the Great in the late 1700's built a grandiose governmental camouflage around the terrible conditions of suffering and isolation which she dealt to peasants of Russia. And all those who dared to see through the camouflage and write about it, were banished to Siberia.

We neither laugh, nor are we intrigued when we read how people in the town of Dachau "played dumb" and "remained ignorant" to what was going on in the concentration camp on the very outskirts

of their town.

But now, what will we do if the principle of normalization is understood and it helps us to see the crippling, warping, limiting things that living in certain institutions can do to once developing human life? What will we do if we can no longer be impressed by the titles and degrees of certain department heads, their noble fatherly and maternal attitudes, their public relations statements, the elaborate facades that some of them build? What will we do when our understanding of normalization helps us to see clearly and definitely what is actually going on in the wards--and especially the back wards? It won't be easy to laugh it off, be intrigued by it, or to claim ignorance.

Learning can be a frightening thing. When one learns a new concept, it can be painful and produce anxiety. It can demand new actions and responsibilities. It can force one to slap the flanks of many institutional "sacred cows". Learning about normalization is like that. For example, anyone who has read, learned from, and taken seriously NARC's Policy Statements On Residential Care, will begin to see some painful things they didn't heretofore see. Normalization can help one see through the facades of certain institutional systems.

3. We Will Learn Some New Things About Education.

After learning the principle of normalization, it will become increasingly hard to merely accept the forever closing doors of the classroom on mentally retarded persons. Expulsion because a retarded person will never do reading, writing and arithmetic, or because he is non-ambulatory, non-toilet trained, non-disciplinable, or "non-feasible" (whatever that means) will not be as easily accepted.

Any child who has his own roadmap of growth, his own rate of growth, and the God-given right to achieve it, has the right to be placed in an educational process that will help him to develop to the best of his ability and to live as normal a life as he possibly can. Any force, governmental or otherwise, that seeks to set limits on such a vital human development, or to deny it, will now be seen as a prejudicial, belittling and dehumanizing force.

One who reads, learns from, and takes seriously NARC's Policy Statements on the Education of the Mentally Retarded cannot help but get caught up in something so fresh and genuinely futuristic, that when one attempts to tell others about it, people at first will think he's gone off the deep end. It's not easy to tell educators:

- That severely and profoundly retarded persons are subjects for education;
- That compulsory education means just that;
- That education for the retarded should be the responsibility of the state educational agency;
- That disruptive behavior could be the fault of the teacher;
- That maximum possible integration should take place between the mentally retarded students and so-called normal students;
- That specific achievement outcomes should be spelled out;

And that public educational services should start with the mentally retarded at age 2!

These are only a few of NARC's policy statements. But that's what normalization does. It forces us to learn some new things about education.

4. The Courtroom Will Be A Familiar Place.

The Pennsylvania Case dealt with the right to education. The Alabama Case fought for the right to treatment. The Tennessee Case fought for the right to not have to work for little or nothing. The Willowbrook Case is fighting for the right to not be treated like an animal--so it seems. Other cases will spring up. It can be expected that there will be a case fighting for the retarded person's right to live in a community setting. There may even be a case fighting for his right to normalization. Each case seems to be setting a precedent that other cases can build on. Each case has brought tremendous teaching and learning to society in general.

But, one can learn that when the ARC wins a case, that doesn't end it all. The opposition doesn't roll over and play dead. The fight for funds to back up the court ruling must continue. So, the battle goes on. But the amazing thing is that members of ARC's are getting over their self-conscious jitters about "taking something to court". They are beginning to see that courts are there for this purpose; that it is the judge's rightful duty to sit on the bench, to listen to all the facts and make an honest judgment. In short, the ARC's are beginning to believe in the court systems and to use the courts is a normal and natural way of democratic life. The ARC's surely ought to believe in the courts of our land. They haven't lost a major case. But that's what learning about normalization does. Because of it, the courts are becoming a familiar place.

5. Public Attitudinal Change Toward The Retarded Will Take Place. ARC's are becoming less and less interested in mere public relations. They are seeing the need for public attitudinal change. With what they know now, they are more prone to raise holy hell when false information is given verbally, in print, or on radio and television about the mentally retarded. One disk jockey in our town learned this fact after making belittling statements about "retards" in his in-between-the-record banter. Another normally warm and gentle man in our town has become violently angry by statements about retardation in basic high school psychology texts. Committees are being formed that will monitor statements about retardation in newspapers, radio and T.V. They will respond firmly and honestly to negative statements. They will respond warmly and graciously when helpful statements are made.

Make no mistake, this public attitudinal change will not come easily. We've known the comfort of talking about mental retardation on radio and T.V. That's "nice". It's acceptable. When the ARC's start knocking on doors attempting to get approval for a community service agency to purchase a home for six small mentally retarded children in a certain block, they will face many homeowners who

would be thrilled to have the home on their block. But, they will face a few who will exhibit naked prejudice and hostility. However, with what one can know about mental retardation at this point in time, these few prejudiced ones no longer seem so fearful. One can see them as a challenge. One can now see their attitudes as very sick and very much in need of a healthy change.

Much of this has come about because of what the normalizing principle has helped us to see. In fact, some ARC's are feeling a stronger urge to teach normalization to mayors, county commissioners, governors, senators, professionals, clergymen, neighbors and friends. If we really believe what the principle of normalization teaches us, public attitudinal change toward the retarded will take place.

6. Community Delivery Systems Will Spring Up.

We are learning that life in an institution is at best an artificial life. It is normal to live in the community inasmuch as possible. And one never learns to live in the community by living at Endsville, an institution a hundred miles away. One learns to live in a particular community by living in that community. He learns to live on that block that has those houses, those people, the grumpy man two doors down, the nice lady next door, the dog that bites, the dog that doesn't, the people who laugh at him, and his friends, the people who don't. He learns to find his way to that store, across that street, and to put mail in that mailbox on the corner. He knows the danger of getting lost. He learns to live in West Omaha by living in West Omaha. If he moves to North Omaha, he learns to live in North Omaha by living there.

A mentally retarded person, whether mildly or profoundly retarded, has the right to live as much in his own community as he possibly can, even if the retarded child's family-like atmosphere is carried out in a home where professional parents are trained to meet his special needs. For this reason, there is the growing need for community delivery systems that will help a retarded person to "make it" in his own community inasmuch as he possibly can. As society sees this, developmental centers, public school classes, vocational services, small group residential homes for all levels of functioning, guidance services and advocacy systems will come alive.

That's what the normalization principle has helped us to see. If one can really believe what normalization teaches, community delivery systems will spring up.

7. The Role and Function of the Local ARC Will Change.

The turbulent beginnings which led to human dignity movements, which led to the developmental principle, which led to normalization, now will force the ARC 's to make some radical shifts.

They will become thorough-going volunteer advocacy operations. Programs of advocacy will be instituted on many levels. For example: There will be Pilot Parents--veteran parents who will be volunteer advocates to newly identified parents of retarded children. There will be citizen advocates--individual citizens who will be screened, trained and helped to develop a close supportive relationship with a

retarded person who is trying to make it in the community. There will be consumer and group advocates who will not rest until they have pressured or inspired their government to provide every community service a retarded person needs in order to have the fullest life possible in the community. Then they will monitor the programs that government has provided. The ARC's educational programs, their public attitudinal change programs, their governmental and legislative affairs, their youth programs, their emergency task forces, will all carry a sharp and clear-cut advocacy focus. In short, the local ARC will pledge itself to fight for the rights and dignity of every mentally retarded person who lives in that particular community. And in being such thorough-going individual and group advocates, the role and function of the ARC will change.

Conclusion

And so, with our knowledge of the normalization principle, what can one expect in the ARC movement of the future? We will start some fights. We will see through the facade of certain institutional systems. We will learn new things about education. The courtroom will be a familiar place. Public attitudinal change toward the retarded will take place. Community delivery systems will spring up. The role and function of the local ARC will change.

There's more. Feel free to add your own, or make your own list of predictions.

Many parents of the mentally retarded, interested citizens, and volunteer professionals who hold membership in a local association for the retarded seem to have a vision of care, treatment and attitudes toward the retarded that is something greater, more efficient, more healthy, more human, more inexpensive (cost/benefit wise), and more dignified than many government officials, professionals, citizens and neighbors ever dreamed.

The principle of normalization has helped one to see this vision. With it, the mentally retarded can be given the chance to live as normal a life as they possibly can. Limits fall away and they can know the thrill of developing to the best of their ability. Dehumanization diminishes and they are accepted and loved as fellow human beings. Sick myths about the mentally retarded are crashed; then society, sensing this development, is more prone to open its heart. A new toleration can be achieved. It is quite possible that the application of the normalization principle could catapult us into a new age of toleration among God's human family on the face of this earth!