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Action by the unimpaired on behalf of the impaired

One major facet of the normalization principle is to create conditions through which a handicapped person experiences the normal respect to which any human being is entitled. Thus the choices, wishes, desires, and aspirations of a handicapped person have to be taken into consideration as much as possible in actions affecting him. To assert oneself with one’s family, friends, neighbors, co-workers, other people, or vis-à-vis an agency is difficult for many persons. It is especially difficult for someone who has a disability or is otherwise perceived as devalued. But in the end, even the impaired person has to manage as a distinct individual, and thus has his identity defined to himself and to others through the circumstances and conditions of his existence. Thus, the road to self-determination is indeed both difficult and all-important for a person who is impaired.

In society, one common and accepted way to assert oneself and the endeavors one feels identified with is through cooperation within social bodies of common interests and goals, such as political parties, labor unions, teatotaler clubs, social and recreational organizations, etc. Through these bodies, common feelings and needs can be shared and expressed, and common demands formulated. If bodies suitable to one’s own important goals do not already exist, they may be created as needed.

Overt and especially collective expression of thoughts and feelings is not only a traditional therapeutic device to relieve tension, but is also the way of cultural exchange and politics. It provides modes of identification with one’s self, helps define a ‘cause’, and serves as a medium for establishing meaningful and functional social relationships.

While voicing one’s striving for self-determination and recognition through deliberations within a peer group – however small – might be the accepted way in society, it has taken a long time for certain handicapped, disadvantaged, and devalued groups to gain an adequate voice and representation in society, and to be recognized in their demands to participate in decisions involving their interests. Thus, we have seen the formation of self-help action groups not merely in behalf of, but also by, the blind, the deaf, the physically handicapped, the poor, etc.

Regardless of how much encouragement and understanding the handicapped might have received during their youth and their training periods as adolescents, it is to be expected that as adults, their weak ego-images and their feelings of insecurity in their relations to their social environment will

Special thanks and inspiration are acknowledged to Ann and Mogens Bakk without whom the subject matter of this chapter would have remained but a vision.
express themselves through descriptive statements of feelings of dependence and degradation, inferiority and injustice, humiliation and aggression. Such statements are never comfortable to hear, and therefore one must anticipate that various bodies in society will react with equal discomfort when confronted with very normal expressions of and demands for a very normal self-determination on the part of persons who have previously been viewed paternalistically, and as incapable of and unentitled to speaking for themselves.

**Self-assertion by the impaired**

Let us assume for the moment that we were dealing with a self-interest organization of handicapped (young) persons. From such a group, one would fear, expect, or welcome platform statements such as the following.

‘We want to chose our vocations ourselves and have influence over our education.’

‘We demand that our capacity for work should not be underestimated.’

‘We demand more information about our handicap and our job prospects.’

‘We want to have leisure time together with other (young) adults of the same age.’

‘We wish to have an apartment of our own, and not be infantilized.’

‘We think that we should be present when our situation is discussed by doctors, teachers, welfare workers, foremen, etc.’

To gain a voice and a power presence when one is blind, deaf, physically handicapped, poor, of a despised minority group, etc. is difficult enough. But when it comes to the mentally retarded – where part of the basic handicap is an impairment in clear expression, and in adjusting to social demands and realities – such aspirations are not yet commonly accepted as feasible or even desired. This is why the interests of the retarded to date have been represented primarily by their parents who have taken steps to unite in bodies capable of formulating common policy and expressing strong demands. While this is taken for granted in North America, an even more radical step has been taken in Denmark and Sweden where the parents of the retarded succeeded in having laws and regulations enacted which prescribe that the responsible authorities must have regular contact and discussions with the associations for the retarded.

If this path toward assertion could be trod also by the mentally retarded themselves who, by the very nature of their handicap, are less capable of speaking on their own behalf, and who are thus among the most handicapped of the handicapped, then a much-neglected facet of the normalization principle would be implemented. Not only the involved professionals, the retarded, and their parents would be affected by such developments, but many other groups in society as well, because this enhancement of the voice of the most voiceless of all would point the way to the strengthening of the voice of other devalued and impaired groups.

Much as the voice of the parents of the retarded has an almost unique force given to it in Denmark and Sweden by legal mandate, so have similar steps been taken to break new ground in strengthening the voice of the retarded themselves. As a matter of fact, the self-assertive platform statements listed a few paragraphs back as expectable from handicapped young adults.
were not hypothetical in nature, but were actual outcomes of an historic first move by the retarded to gain meaningful control over their own destinies.

Statements such as those listed were made in Malmö, Sweden, during May of 1970, by 50 adult retarded delegates to a three-day conference representing 24 of the 25 counties of Sweden, and two Danish guests.² The participants were moderately and mildly retarded men and women, 20 to 35 years old, who had in their backgrounds the experiences from classes for the retarded, vocational schools, institutional boarding schools, small institutions, hostels, independent apartments, adult education courses, unemployment, sheltered workshops, independent employment, club activities, earlier and smaller conferences, etc. By means of committee work at the conference, they could not only experience that they had a role to play and to fill, but they were also able to redefine by and through themselves their roles as mentally retarded persons. By giving a voice to their common experiences, aspirations, and right to self-determination, they appear to have made the first organized attempts to break through our communication barrier, thus reaching toward a more direct relationship between themselves and the mainstream of society.

In an earlier chapter of this book it was pointed out that normalization is both a goal and a process, both a means and an end. The conference of the retarded in Sweden thus points to the formation of self-interest groups of the handicapped as a major normalizing measure, and the desirability of teaching group processes to the handicapped by which such self-interest groups can be attained and made effective. The formation of self-governing social bodies consisting of student councils, independent clubs for handicapped youths or adults, committees on various levels for various programs, and smaller or larger conferences where their experiences, desires, and recommendations could be identified, surveyed, expressed and summarized, could serve both as a means and an end of normalizing their conditions of life.

In Denmark and Sweden, much of this has already been accomplished in the field of mental retardation where national authorities in 1969 and 1970 recommended that whenever possible, councils of the retarded should be established within institutions, special schools, vocational schools, residential centers, group homes, boarding homes, sheltered workshops, etc. For instance, a few years ago, the student council of the vocational school for the mentally retarded in Stockholm was unhappy with some of the regulations of the school. They held a meeting where they wrote their own suggestions, and most of these were later implemented by the school authorities. To prepare pupils for such tasks should be looked upon as part of the social training component of the curriculum, so that in the future, handicapped graduates will have had more experiences of this kind as part of their background than most of the handicapped young adults of today.

**Social training for self-assertion**

A major means of enhancing the capability for self-determination is through various forms of social training, in some cases through means which are different from or more vigorous than those employed in the past. In the fol-

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² See the appendix to this chapter for a full rendition of the demands formulated by the conference delegates.
lowing, I will outline various prerequisites and numerous steps that can be taken in this direction.

While still in childhood, many of the handicapped will receive some form of special (but hopefully not always segregated) education. The goal of such special education or of the training component of a residential facility is to provide an education that enables the student to become a socially competent and adjusted adult, and to make him as personally independent as possible.

Growth to adulthood is difficult for anyone, and adaptive social interactions and communications are necessary means for such growth. When young people leave the schools and go out into the labor market, or into higher studies, new relationships are formed to support the orientation in the new contexts and conditions. New friends or new ‘career models’ are sought or discovered to assist in finding the direction for the development to independence in the adult world. This process is both frustrating and exciting, but generally also rewarding.

For a handicapped (especially retarded) adolescent, growth into adulthood is an even more difficult and uncertain process. He is very much aware of and sensitive in regard to his handicap, and lacks confidence in dealing with social situations in an adult way. His longings to have friends and to share the common experiences of his peer group are not easily satisfied. Thus, the loneliness of the handicapped is often vast even though most of them live in so-called integrated circumstances.

In order to build up self-confidence, facilitate a handicapped person’s growth into adulthood, and combat alienation from life and his nonhandicapped peer group, social training programs which provide varied and repeated constructive experiences in authentic situations in the community are indispensable. In Scandinavia, one of the major means emphasized with the retarded are various forms of adult education which draw from the simple insight that being treated in as adult a fashion as possible is even more important to a maturing handicapped person than to a nonhandicapped one.

If, after having left special education, a handicapped young adult either has no work, or after work has no meaningful leisure activities and contacts, he will tend to ‘shrink’ and regress, thus increasing the fears of his parents in regard to his future. Natural tendencies to overprotection will reinforce the vicious circle originally created by societal prejudice towards the handicapped person’s differentness. The risks for family breakdown in such a situation are not to be ignored, and the handicapped person is usually well aware of these implications and his role in them. Programs which provide the positive experience of feeling that he is meeting the same situations as are other adults, that he is being recognized as an adult, and that he is accorded attitudes that are the same as those expressed towards other adults – with the same expectations, demands, liberties, and responsibilities – assist not only in the development of his maturity, but are also critically important to his parents. Through the results of these programs, they can gain new insights into the extent of independence that their son or daughter can achieve. As normal as it is for children to grow up within their families, so it is just as normal for adults to become emancipated from their family. Ultimately, all families dissolve, but in a relationship between parents and their impaired adult child, the process of dissolution is especially difficult.
Swedish experience has shown, however, that when a retarded adult son or daughter has taken part in adult education programs, in club activities which provide more advanced social training, and in representative work in councils or committees for the retarded, families can gradually redefine their parent-child relationship in such a way that their relations are closer to the normal patterns of development, emancipation, and change in the relationships between parents and unimpaired adult children.

In their previous schooling, the handicapped have been used to the vertical teacher-pupil relationship where the teacher, however encouraging, almost invariably has related in no other way than that of a teacher talking down to the pupil. In adult education, this approach is not feasible with adults generally, is damaging if used with handicapped adults, and can be particularly damaging to retarded adults. In their self-concept and their growing awareness of being adult, they have to be fortified by being treated and met and talked to as adults, and on the level of adults in a horizontal relationship. Thus, the nonimpaired dealing with retarded adults have to play a double role: while having to be aware of the specific demands of the handicap of retardation, they should avoid showing those concerns openly, but must fortify the retarded by meeting them as regular adults.

Major means in Sweden and Denmark to transmit adult education have been the sheltered workshop, programs of independence training in hostels and boarding homes, and specific adult educational programs which have included advanced forms of social training. To experience a normal rhythm of the week (which for most people consists of having one place to live, another place to work, and having leisure time at a variety of places) provides the handicapped adult with the range of conditions and experiences of life that will support his self-confidence and feeling of adulthood. Being able to work in the open market or at least the sheltered workshop, and making some money, strengthen motivations for further learning. Living in hostels and apartments adds motivations for adult education in budgeting, cooking, sex education, etc. In boarding homes and sheltered workshops, the residents are confronted with the necessity of reaching agreements on rules, regulations, and cooperation, and on the means of establishing such rules.

The subjects of the adult education courses do not only include further work in reading and arithmetic, but also in foreign languages, contemporary society, and political elections and how to take part in them. The trainees have also had increasing practical training in how to handle themselves when out in town: how to use cafeterias, restaurants, movies, theaters, libraries, concert halls, amusement parks, public transit, taxis, sports centers and swimming pools, etc. In order to be able to freely choose among and utilize such facilities for cultural and leisure time activities in their communities, the trainees have to acquire self-confidence by experiencing themselves as capable of passing over various thresholds of challenge and growth. From lack of social experiences and previous practical training, they have often acquired handicaps on top of the original impairment, but generally, they are highly responsive to encouragement to pass successive thresholds. One of the major motivations is being able to do what the peer group of the same age is doing.
SOCIAL TRAINING FOR EQUALITY THROUGH SPECIAL COMMUNITY EXPERIENCE COURSES

One type of social training for the retarded developed in Sweden has sometimes been structured as a three-day course given on a weekend, with the aim of teaching the retarded to overcome various barriers or thresholds in their social functioning which had previously increased their feelings of being alienated, and of not being able to take part fully in the social and leisure time of their community. The result of this alienation is a feeling of being a tourist in one's own city, without the pleasure associated with tourist experiences. Therefore, these courses have had the theme of 'being a tourist in a new city'.

The retarded and the nonretarded volunteers travel from their home communities to meet in a first-class hotel of a larger city. The nonretarded often arrive with the thought that they are to be the teachers, and the retarded will be their pupils. However, soon after arrival, all participants discover that they are taking part in a course common for all. As tourists, they are all going to learn and be enriched through new experiences and meeting new people. All are given the same amount of money for budgeting their weekend needs and activities, such as meals, shopping, sightseeing, and entertainment. When they are exploring the city in small mixed groups of three or four persons (which are changed at certain intervals), they gradually learn not only about the life and the assets of this new city, but they also learn from being together. They find out about public transit, price levels of various restaurants, the amusement possibilities for their Saturday night, and the interesting sightseeing places for the Sunday morning walk.

Through these experiences, occasional lectures, and comparative reports and discussions, the nonretarded gradually learn more and more about the proper ways of being together with the mentally retarded, as well as vice versa; and when they later listen to the report from the retarded, and to their reactions to the attitudes of the nonretarded they have met, the nonretarded commonly experience that they were the pupils and the retarded the teachers. They have also learned about the loneliness of the retarded; their hunger for age-typical experiences; and something about the methodology which enables them to assist in program developments whereby the wishes and desires of the retarded and their self-determination can be strengthened, encouraged, and respected. The retarded have found that they can express and expect respect for their wishes for more social activities of the same kind that they have just experienced and in which they can participate in their own home town. Returning home to their cities, both the retarded and the nonretarded have higher incentives and motivations for carrying on leisure time programs, involving more and more people – retarded as well as nonretarded – all working together with a definite attitude of 'here we are all adults', and of respect for the wishes and desires of the retarded.

SOCIAL TRAINING FOR INDEPENDENCE THROUGH SOCIAL CLUBS

The term 'leisure time activities' refers to things done at one's own leisure, initiative, and according to one's own personal rhythm, interests, and wishes, free from external pressures. It is a time for relaxing or for expression of other parts of one's self than are being expressed or used at work. It is a period of freedom, of privacy or communication with others. For very many
handicapped adults, however, leisure time is grey, monotonous, and confined, without much sense of freedom. Actually, they are often relegated to themselves with a feeling of being outsiders, having their handicap awareness increased. Thus, they have strong motivations for participating in different types of leisure time activities. In recent years, this has been increasingly provided for them, but often without freedom to choose alternatives. Rarely have handicapped adults had much influence over the direction of these programs, their carrying out, or the introduction of different types of programs. They have had little influence on their own leisure time situation and options, or opportunity to relate to nonhandicapped persons of the same age with a feeling of peer group relationships, or an expression of peer group independence.

In contrast, participants in the above-mentioned social training courses have mostly gone ahead and formed clubs consisting of not more than 30-40 members. These clubs have carried on leisure time activities which provide more varied social experiences and exposure to different types of cultural resources in their communities. Even if mentally retarded, members have formed part of the executive body of the clubs, such as president, secretary, treasurer, etc., with the nonretarded assisting as vice-president, etc., and gradually withdrawing. Generally, the retarded have been over 18 years of age, and the nonretarded volunteers over 22 or 23, as it was imperative that the nonretarded have enough maturity and experience at being adult to be able to provide fortifying ‘career models’, and to have the ability to deal with confidential problems.

Through the meetings, the retarded were not only assisted in influencing their leisure time, but even planning it was, itself, part of leisure. Through the clubs, they also had the opportunity to meet new peers and form friendships. In this way, they gradually gained the confidence in themselves and others to dare express themselves about their own problems on the job, in the home, or when venturing about the city. Their nonretarded friends could give support and sometimes also quietly intervene as advocates.

In time, different clubs began to arrange visits to each other as part of their programs, thus widening their options and increasing and deepening friendships. Growing confidence was one of the results of the practical experiences gained. Also, the realization that they were sharing problems and interests with others helped the members in redefining to themselves their situation as retarded, as well as experiencing their awareness of being retarded in a new and dignified way. Through these clubs, the retarded were able to contact other organizations, other groups of young adults, and key social bodies dealing with leisure time activities in the community. They were also able to express and make known publicly their problems and endeavours, in newspapers and on television.

SOCIAL TRAINING THROUGH PARLIAMENTARY PROCEDURES

The growing number of clubs created a demand for courses in parliamentary techniques. Through weekend courses, the retarded were provided orientation to the procedures of decision-making, the basic rules of discussions and vote-taking, the functions of a committee, election of a board, the roles of the board members, and means of financing and budgetary control. The main element of the course was most practical: the participants elected a
chairman and a board, then formed the necessary committees to decide upon a full program for social evenings, and to carry it out after having presented the budgetary requests. The social evenings resulting from these decisions, the work and preparations in which the nonretarded were only observers, were always highly successful. Afterwards, the participants realized that they had done everything by themselves, taking on both the responsibilities and the consequences. The final part of the course was devoted to technical advice regarding club affairs, and to discussions of general club issues. Increasingly, the specific problems of the retarded in the community were aired as they realized that others in other places were sharing the same experiences and problems.

These experiences suggest that in order to provide realistic steps to higher and more secure platforms of social interaction, and for the formation of clubs, committees, conferences, etc., schools should increasingly utilize parliamentary procedure and decision-making as a training device. Discussions and vote-taking are not only good pedagogic tools, but they also assist in building up motivation. Class conferences can be held as proper preparations for taking part in the school's student council where rules and regulations, leisure time programs, and other matters are discussed.

An historic step toward self-determination: the Malmö congress of the retarded

With the increase in adult education and leisure time programs for the retarded, the growing number of clubs run by retarded adults, the more frequent contacts through weekend courses, exchange visits between clubs, and regional conferences, there developed a need in Sweden for a national conference of retarded adults. In 1968, the first one was held, with 20 participants, in order to discuss leisure time activities. The second one, in 1970, was a full-scale three-day conference attended by two elected representatives from all but one of Sweden's 25 counties, with two Danish guests attending as observers. This conference was called in order to discuss problems within the areas of leisure time activities, residential living, vocational training, and work. Work was carried on through small committees of 6-8 persons, and when each problem area had been discussed, the groups reported their points of view to the whole conference. The nonretarded observers were not allowed to influence the deliberations of the committees, other than occasionally moving discussion from one issue to the next, and making supporting notes.

The group reports were sent to the conference as a whole, and the resulting comments and reactions established a consensus on the main points. These were then immediately edited into a final report by a joint committee of the retarded with some nonretarded observers, and presented by three representatives elected by the group to the national conference of the Swedish parents' organization which was taking place at the same time, each representative reading part of the report. The full report is given as an appendix to this chapter, and the reader is advised to study it before proceeding further.

As mentioned in the introduction to this chapter, when a handicapped person expresses himself, one should expect certain demands and statements of frustration. However, the retarded delegates expressed some things which
not only may come as a surprise to most people, but which can give us new insight into appropriate behavior toward and programs for the handicapped in general. I will selectively discuss some of these expressions found in the appendix.

Wanting to be in small groups during leisure time activities, and not to be seen in large groups in public, reflects the retarded persons’ wish for individuality, and for not being unnecessarily stigmatized. They are objecting to the mass management procedures to which they have so often been exposed in programs arranged especially for them and/or in public. Experiences of this kind have increased their already high frustrations and their awareness of their handicap.

The desire to have more opportunities to relate to persons of their own age in their leisure time expresses their need to be brought out of their isolation and loneliness, and their need to establish real friendships and ties with model peer groups. It is also a demand for recognition.

The strong opinions held by the retarded on their right to take part in decisions regarding their own leisure time activities reflect their dissatisfaction with situations they have so often experienced when things have been arranged for them and not with them, thus increasing their feeling of dependency, and depriving them of a part of the pleasure of motivation.

The extremely negative sentiments expressed toward summer camps have their explanation in the fact that the retarded are typically sent to camps with retarded children. This makes the adults feel that they are being equated with children, segregated as a special group, and excluded from activities with and enjoyed by their age peers. This kind of experience is inimical to their growth into adulthood. Summer programs for handicapped young adults should be structured in such a fashion as to meet recreational needs in a manner that is as culturally comparable as possible to summer activities and recreational endeavors of nonhandicapped (young) adults. Also, the handicapped adults should be included in the planning and the carrying out of these programs.

With regard to the points of view on residential circumstances, the drive towards more independent living is obvious. There is awareness of the need for a continuum of residences and programs providing an evolution toward decreased dependence. Demands for respect of privacy are reflected not only in the descriptions of humiliating routines, but also with regard to an age-appropriate sharing of privacy with a member of the opposite sex. This has also to be understood in terms of the insights of the delegates that in a partnership with another person, they are more able to have a competent social and independent life.

With regard to vocational training and work, increased demands for more varied and demanding jobs are to be expected from the participants. Compared to other issues, the stereotypical underestimation which is so frequently experienced by the retarded elicited the strongest emotions and reactions.

If some of the work-related expressions were relatively expectable, others might come as a greater surprise. When asked why they wanted their fellow workers to be informed of their handicap, the delegates’ reaction was ‘They are not stupid; sooner or later they will find out.’ It had been their experience that it was better to deal with this problem straightforwardly. Their handicap is no secret to themselves, and they are often far less hypocritical about it
than other persons. This same insight and stamina was also reflected in their
demand to have more information about their own handicap and their op-
portunities in the open market. It was realistic that they wanted to know how
their impairment reflects on their opportunities, and thus how to handle their
limitations. They wanted to be dealt with honestly and on the level. This
same concern was also expressed when they described their feelings of
humiliation when other people meet in team conferences, etc. to deal with
their situation and prospects. Since those deliberations and decisions are con-
cerned with their existence and their future, they have a strong feeling of
their right to take part in a nonhumiliating way.3

Are self-directing groups of the handicapped segregating?
The question might be raised whether the formation of self-directing groups
consisting entirely or substantially of the handicapped will not tend to set
them apart and encourage segregation. There is no doubt that segregation is
a danger, but this danger must be balanced against the important functions
these groups perform.

First of all, such groups can provide an opportunity for social interaction
and self-expression which otherwise may not be available in the same quan-
tity or quality. For instance, it could be that some handicapped young adults
will find it easier to mix with the nonhandicapped, but that the older handi-
capped will have much greater difficulties in meeting their social needs in an
integrated fashion. Many of them may wish to join a self-directed group in
order to state this hunger.

Secondly, these groups can serve as essential media for bringing about
greater integration, by providing occasions of sharing in the social life of the
community. By being more experienced, and having increased their compet-
cencies, the handicapped have multiplied their options to join other organiza-
tions, clubs, and social groups.

Thirdly, to persons who previously had no alternatives available, these
groups open yet another option. Here, it is important to realize that a person
may participate in the group even as he simultaneously engages in other
totally integrated or even yet more segregated activities elsewhere. Some
handicapped persons will have no need for special groups, and should not
belong to them. Yet others can benefit from short-term membership. Perhaps
most important is the fact that the group does provide a new option, and that
the handicapped person gains the freedom to determine for himself whether
and how much to utilize it.

Finally, there will be handicapped persons who will want to belong only to
a self-directed group which has a highly specific goal. For example, many
persons may wish to belong to a body that provides them with an opportunity
to speak for their own interests and to exercise power on behalf of these, but
not to a body concerned with leisure time activities.

Various frameworks for self-directing groups of the handicapped
Questions may also be raised concerning the frameworks within which
creation of self-directing groups of the handicapped could or should take

3 Informal discussions, not recorded in the conference report, revealed that while the
retarded wanted to be present in the deliberation of their case, they did not want to be
confronted with a large team, but a small group of two or three others.
place. Here, three major options can be defined. One is for groups of the handicapped to function as a part of the groups for the handicapped, such as parent organizations working for the interests of the retarded. However, it would be essential for parents to have confidence in the development of groups of handicapped adults, and to be able to support these developments even as they become increasingly aware that their relationship with their adult children is gradually undergoing a change. As an organization advocating the interests of the impaired, they will also learn realistically about the actual and changing needs of the handicapped adults, and thus will be better able to provide supportive social action.

As a second option, organized bodies of residents and clients might also be established, in order to exercise self-determination within the framework of institutions and agencies. Developments of this kind have taken place not only in Denmark and Sweden, but also in other parts of the world, e.g. Canada and the United States.

Finally, it is also possible that the growth of groups and clubs and local organizations for handicapped adults might be developed independently in special organizations, cooperating with other handicapped groups or other social bodies.

Self-determination for the retarded as a test case for other devalued groups

In concluding, it is important to confront a major issue often raised specifically in regard to the mentally retarded. Thus, it is sometimes argued that the described techniques of giving the retarded support on their road to participation in decisions concerning their own situation are feasible and desirable; that they can provide social enrichment in a satisfactory way; that these steps allow for a more positive way of dealing with the stigmatization and the retarded persons' awareness thereof; and that they might give them a social role commensurate with their abilities. However, the argument might go, this still does not mean that they are really able to render meaningful judgment about the things they are dealing with, and that consequently their expressions should not be taken seriously or as having real social validity.

It might be argued that training in parliamentary procedures, learning how to make decisions and carry them out, taking the consequences, and learning from the experience is merely a good pedagogic and social training tool. It is useful in many situations, and leads to desired behavior modifications, an increased social realism on the part of the retarded, and thus in a nice way offers them a confrontation with their limitations — but that is all there is to it. When the retarded start dealing with all but minor decisions, they are out of their own realm.

There is, however, more to it than this.

It might also be argued that all these programs for enabling the retarded to express themselves, to express their own wishes to participate in the forming of their leisure time, to express themselves concerning rules and regulations in institutions where they are living, and even to express themselves as a political body is a very good therapeutic device. These devices enable the retarded to give vent to their frustrations, and to readjust to their situation in a more satisfied frame of mind. And that is all there is to it. The expressions of their frustrations and their hopes can not be taken seriously as to their specific content, and as to the actions that consequently should
be taken, as this would not assist the retarded to adjust to their real situation and limitations.

There is, however, more to it than this.

It might even be argued that these procedures are more than pedagogic, behavioral, and therapeutic devices, and that the content of what the retarded say is interesting and worth listening to, but that it still only confirms that they are retarded. The arguments presented, and the wishes, anger, and dissatisfaction that the retarded adults express, are only to be seen as a delayed youth revolt, which means that after all, as adults, they still remain children. Therefore, in an adult society, what they have to say should only be expected to be received with the relative respect shown to enterprising young people who may some day be adult and mature enough to adjust their demands and expectations. And that is all there is to it.

There is, however, more to it than this.

There are admittedly some pedagogic and behavior-modifying values in the programs described, even in the experiences of the councils and conferences. In the same way, all people benefit from good pedagogic methods, from learning by experience, and from taking part in conferences of the nature described. There are also admittedly important therapeutic values to be gained from participatory experiences in decision-making, and in the public expression of personal or shared experiences. These participatory experiences are the same self-supporting instrumentalities used by many people when they gain more satisfaction in their lives by taking part in minor or major social activities which fulfill needs for expression, which support feelings of importance, and which provide recognition of the respect due to a regular citizen. Experiences of this kind serve to reconcile all people with the terms of their existence, and to derive identity from the role they are playing. Thus, the therapeutic values experienced by the retarded in these matters are the same as those experienced by others in comparable contexts — nothing less, nothing more.

There is, however, as said repeatedly above, more to the issue of self-determination than pedagogic and therapeutic benefits. And this is the realistic content of what is being said. That is what counts, in the same way as it does for others. The persons affected most intimately — the mentally retarded themselves — have added the voices of their real experiences.

Admittedly, in the expressions quoted from a conference such as at Malmö, and in the trend of the views there presented, there are elements mindful of experiences of youth. This is to be expected, since the process of growth into adulthood takes a longer time for retarded adults. They are, however, in their daily lives dealing with experiences and attitudes of those who are delaying their adjustment as adults; and as they have a need to identify themselves as adults, these real frustrations have to be expressed and recognized.

Also, retarded adults such as those who attended the Malmö conference are not only talking out of this kind of real experience, but are also able to describe in detail conditions of life with which they are familiar, and in which they have deep-going concerns and interests. Their experiences have not only a sufficient personal experience base, but are also shared by many others whom they know. They can express not only their own concerns, but those of their retarded friends who are less capable, and perhaps even in-
capable, of expressing themselves. They know what they are talking about, and they know that they are describing the realities of their existence. They realize as well that they have or should have the right to express those concerns. They are acting as citizens with the same right to be respected as others.

If this right is not acknowledged and respected, if the retarded are not treated and met on that level, then the procedures described might become harmful and dangerous. If the problems and the aspirations presented by the retarded adults are not dealt with realistically and with respect, but manipulated and essentially disregarded, then the persons treated this way will become injured and will experience the rejection and devaluation they have so often confronted. If, however, their representation and aspirations are dealt with in regular democratic ways, leading to whatever decisions and actions, then the procedures remain meaningful, strengthening, and are able to lead to further developments.

Whatever the organizational framework in which the right to self-determination of the retarded is being expressed, this respect has to be shown openly. If only lip-service to the benefits of the right to self-determination is given by the parent associations, the institutions, the agency bodies, or by other organizations, then damage will be done, developments will be frustrated, and the role of the retarded will diminish. If the right to self-determination is not respected, it is not there.

And here follows a point which I consider to be among the most important ones of this chapter: by resolving the issue of self-determination with the retarded who are among the most voiceless and devalued of those considered deviant by society, then we can reach new heights in achieving a meaningful and culturally common self-determination for other devalued and impaired groups, thus normalizing their conditions of life and increasing its quality. But if the right of self-determination is not taken seriously for the retarded, it will not be taken seriously for many other groups.

Where and how far the self-determining developments with retarded adults will lead, only local enterprise and initiatives will completely reveal. But when mentally retarded adults express their right to self-determination in public and in action, and thus gain and experience due citizen respect, they also have something to teach, not only to other and obviously more capable minority groups, but also to society in general; something about the deeper importance of democratic opportunities, the respect due to everyone in a democratic society – and that otherwise, democracy is not complete.

APPENDIX

Summary of the proceedings of the national conference of retarded young adults in Malmö, Sweden, May 8-10, 1970

Below follow the translated and slightly edited conclusions and demands formulated by 50 retarded delegates who attended what appears to have been the first national conference in the world of retarded young adults. Explanatory comments are included in brackets.
Leisure time activities

We found that:
We want to be together in small groups during our leisure time.
Dance evenings ought not to be for more than 14-16 persons.
Under no circumstances do we want to walk in large groups in town.
There should be more evening courses in, among other things, alcohol
and narcotics.
The counties and the communities should give more money and assist in
getting locations for leisure time activities.
We want to have leisure time together with other youngsters of the same
ages.
We think, further, that the financial situation of the handicapped today is
such that he cannot afford the leisure time activities or organizations he
wants to take part in.
To have better contact with leisure time leaders, we think they should be
of the same age as we.
We all agree that we want more rights to participate in decisions, especially
in planning and carrying out our leisure time activities.

Vacations

We all think one should decide oneself what to do during vacations.
We think travel abroad is good, but one should travel with other non-
retarded young adults of the same age.
Travel should be prepared with courses in the language, manners, and
habits of the countries we visit.
We have all agreed that summer camps for adults should be banished.
(This refers to segregated camps for both retarded adults and children).

Living conditions

We found that:
We wish to have an apartment of our own and not be coddled by personnel;
therefore we want courses in cooking, budgeting, etc.
We want to have a right to our own apartment but without priority in the
waiting list. (In Sweden, one may have to sign up for an apartment well in
advance).
We want the right to move together with members of the opposite sex
when we feel ready for it, and we also want the right to marry when we our-
selves find the time is right.

We who live in institutions and boarding homes have found that:
The homes should be small.
We want to choose our own furniture, and have our own furniture in the
room.
We will absolutely not have specific hours to follow in terms of going out,
returning, etc.
We want to have more personal freedom, and not as it is now in certain institutions and boarding homes where you have to ask for permission to shop for fruit, newspapers, tobacco, etc.

We want the right to invite other youngsters to our hostels.

One should not have food coupons in institutions and hostels, even if it has practical advantages; but we want to pay with our own money.

When we are living in institutions, we want social training so as to be able to move out into society and manage on our own.

Even in institutions, we want to be able to go steady and live together with members of the opposite sex without having the personnel meddle in our private lives.

*We who live at home have found that:*

It is largely good, but one ought to move out when the time is right to a sheltered apartment or small hostel, because one cannot for one's whole life be dependent on one's parents.

We want, however, to have our own key when we live at home.

**Education**

*Separate (special) schooling*

We think ten years of separate (special) schooling is good enough, but there should be more courses in languages, math, contemporary events, social orientation, handwriting, social training, etc.

We think that the name 'separate school' is degrading. (The objection here was to the term 'separate school', which specifically connotes mental retardation in Sweden, and not to 'special school' which refers to special education more broadly).

There should be student councils which can take part in decisions about the curriculum, the choice of books, leisure time activities in school, etc. The same goes, of course, for vocational schools.

*Vocational schools*

We think that one should attend the vocational school for three years, but that the possibility for an extra year should be available. (This was already available according to Swedish law).

We demand more training in a wider range of vocational fields so that we can have a larger freedom of choice in determining our vocations.

We want to choose our vocations ourselves, and have influence over our education.

We demand that longer periods of real work experience than at present should be provided to vocational students, and that higher salaries be given during these practicum periods. At the same time, we want to have study grants (stipends) during our vocational education.

*Adult education*

We ask for adult education in the daytime, either in study circles a few days a week, or during a longer continuous period.

To compensate the salary one loses during the study period, we ask for study grants (stipends).
Work

We demand more interesting jobs.
We do not want to be used (exploited) on our jobs by being given the worst and the most boring tasks, as at present.
We demand that our capacity for work should not be underestimated.
We want that when we are working in the open job market, our fellow workers should be informed about our handicap.
We want employee councils at our place of work (sheltered workshops).
We think that we should be present when our situation is discussed by doctors, teachers, welfare workers, foremen, etc. Now it feels as if they talk behind our backs.
We demand to have more information about our handicap, and the possibilities we have of entering the open market.

To have a better atmosphere in the work setting, we demand the following:
A smoking room, with machines for pop and coffee; toilets with doors that lock; doctors and sick rooms available; our own closets with locks; and a lesser number of study group visits.
We demand a salary high enough so that we do not need to depend on the pension which we think is denigrating when one is so young. (Most pensions are given to the aged).
At the same time, we think that savings accounts should be voluntary (instead of mandatory).
We think that piecework pay is tiring and stressful, and instead we want higher pay per hour or per month.

Last day of the conference

Today we have talked about what to do to improve the bad conditions we have found during the discussions Friday and Saturday.
We demand that continuous information about the prevailing bad conditions should be given to the counties and communities, schools, sheltered workshops, and other institutions for our handicapped group.
We demand also that much stronger information be given to people in general through newspapers, radio, and television.
We have today elected a committee of six members and two alternates with the following tasks:
The committee shall continuously receive reports about the decisions of the National Board of the (Swedish) Association for Retarded Children.
The committee shall work for the general public and pressure the authorities.
At the same time, the youth conference demands that the committee shall participate in decision-making when the national board of the ARC is dealing with youth questions.
We think it fair that the National Association pays the cost in connection with work with the committee.
The conference today elected the following: Bo Carlsson, Uppsala; Lars-Rune Larsson, Stockholm; Lena Ljungkvist, Borås; Göran Ivarsson, Östersund; Anders Lindström, Eskilstuna; Lars Thomsen, Göteborg. Alternates: Maj Ahlkvist, Uppsala; Jörgen Jonsson, Uppsala.
We think it fair of the National Board to take the demands we have presented into consideration, and through the support of the National Association we hope for a rapid change of the unsatisfactory conditions that exist today.