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Find the conference's complete documentation [here](#)

## **Psychological Adaptation to Changing Respiratory Support**

Adolf Ratzka, Ph.D.

I got polio in 1961, and two days after the onset, I was put in an iron lung. Six weeks after that, I started to breathe on my own for about four minutes, and gradually increased that period by daily training, minute by minute. Three months after the onset of polio, I was able to leave the iron lung, and, as they say, graduate to the rocking bed which I used each night until 1966.

In 1966, I made the move to the cuirass. The cuirass I had for a long time. In 1978, I started experimenting with positive pressure through the nose via a face mask. The period of experimentation ended in May 1984. Since then I have not used the cuirass anymore and I use my face mask only. Moving from an iron lung at night to the rocking bed had definite advantages. People looked at me as more normal. I felt more normal, too. People could touch me. I was more independent and I could do more things for myself. Why did I exchange the rocking bed for the cuirass? I had received a scholarship and wanted to move from West Germany to the United States to attend college. There would have been no room for a rocking bed at the dormitory, so I had to give it up and try something else. I had not had much exposure to the cuirass before; nobody at the hospital in Munich had one, but it worked fine for a number of years.

What was the reason, then, for experimenting with positive pressure? The cuirass, I strongly believe, had reduced my chest capacity. As the years went by, I felt that my margins were getting smaller and smaller. With the cuirass, for example, eating late meals meant no sleep for several hours. After some years, I used to run the Monaghan 170C at maximum pressure all the time. A more powerful machine would not have presented a lasting solution either, because the "rib crushing" effect of the cuirass would have been even more powerful and would have accelerated my loss of vital capacity. It is difficult to travel when you have to haul a rocking bed along. A cuirass, on the other hand, is a marked improvement, especially when traveling by car. When it comes to air travel though, the delicate shell of the cuirass cannot be put with the other luggage.

By the time I was really getting into air travel, a positive pressure machine offered a lot more mobility. It is smaller, lighter, needs very little current, and can run on the wheelchair battery for many hours. Positive pressure presented a much more effective means of ventilation than the cuirass and it enables me to use respiratory support during the day. Having access to

respiratory support during the day has become more important for me as I get older and as my workload increases.

Positive pressure has even improved my social life. Have you noticed that those of us who have breathing problems are usually quiet when we eat? We have a hard enough time as it is getting our meal down, while everybody around us eats and talks. For many years I mistakenly thought that this silence of mine was just an expression of being a lousy dinner conversationalist until it occurred to me that I conserve my energy by concentrating on eating. It also helps in avoiding getting food down the wrong throat which can be a pretty scary experience for you and your company. The more I eat, the less air I have for speaking. For the rest of mankind, the opposite seems to be true: the more they eat - and especially - drink, the louder and merrier they get. Under these circumstances, talking - for me - is a very tiring effort, and I devote my energies to the essentials and enjoy my meal. Using mouth positive pressure after a heavy meal changed my image because when I fill my lungs with air, I can speak up, people listen, and I find myself a creative speaker. All my changes in respiratory support had for me a positive meaning. Unlike Dr. Newton-John, I do not feel that I lost something. In fact, in most of these changes I came ahead on two counts - I gained more mobility and a more efficient way of ventilation. How about changes where one of these conditions is missing, where the change would lead to reduced independence, like moving back into the iron lung? That will not happen to me because in Sweden there are no iron lungs anymore. If I get a bad case of pneumonia and my positive pressure equipment is not sufficient, I might have to consider a tracheostomy. I must admit that a large part of my motivation behind experimenting with face masks derives from the fact that I'm afraid of a tracheostomy. On the other hand, I also know that I want to live, and given the choice between dying or having a tracheostomy, I'd certainly opt for the latter. I know enough people who continue to live active lives despite a tracheostomy, or maybe I should say, because of a tracheostomy. Such positive role models may be the best help in overcoming one's resistance to any change. Whenever one is contemplating a new breathing method, one should seek out the people who make the best of it. It is also important here not to confuse cause and effect. For a lot of people the device or the new breathing method that they need takes on a symbolic value and they fight it as if it was the cause of their condition, whereas, in fact, it is an instrument to alleviate their condition. Our capacity to adjust to changing circumstances is enormous. What we have to keep in mind is that regardless of the equipment we use, we are still the same person. People around us will respect and love us for what we are, not for what type of machine we happen to use.

QUESTION: I am Sunny Weingarten. I know what Adolf Ratzka has gone through over the years. Psychological problems with respiratory users are a serious problem. I've used an iron lung for 35years, my portable fiberglass lung the last nine years. Polio people are very stubborn. I'm able to run a business from inside the iron lung, play the steel guitar, read four or five hours a day, and operate the TV and VCR. One person told me that I accomplish more in an eight-hour day in the iron lung than he does in his home. What is the best way to convince an individual that one can adapt, like I have, to the iron lung or portalung? What can we do to keep the psychological barrier down?

DR. RATZKA: What helped me to use the LP-3 was the 1981 conference in Chicago. Seeing so many people on respirators humming and puffing and sipping and sighing made me think, "Wow! If Sunny can give guitar lessons and fly the airplane with his partner, with his LP3, then I could do it too."

## **Workshop on Sleeping With a Face Mask by Adolf Ratzka, Ph.D.**

The face mask allows me to breathe through both mouth and nose. If I have my mouth closed during sleep which I usually do automatically, I get all the air through the nose. When I have a cold and my nose is plugged up, I use nose drops and an in-line Bennett Cascade humidifier.

One of the drawbacks of my mask is the fact that the seal is not perfect. In order to compensate for leaks, I have my LP-3 deliver 3 liters with each piston stroke. Three liters at a rate of 15 per minute for a period of eight hours makes the motor work harder than it was designed for. As a consequence, I have to have it frequently serviced. A solution would be to decrease the area of contact between mask and face, thereby decreasing the possibility of leaks.

At the conference in 1983, I demonstrated my extended mouthpiece of dental acrylic that was fitted on my teeth and has an opening between the teeth. The air comes through both teeth and mouth. Bruni Bung from Munich has continued along the same lines. With her mouthpiece, she can choose whether the air is to come through mouth or nose by connecting a small hose from the ventilator to either nose or mouth opening. She can do the switching herself, since she has good use of her hands.

A further improvement would be to design a valve that could be operated by the tongue and would allow the user to select a flow consisting of air through mouth only or through nose only or any combination in between.

One of the problems using mouth positive pressure is the drying of the mouth. If you hold a regular pipe-shaped mouthpiece between your teeth and try to sleep this way, the mouth will soon dry out. That can be quite painful and you'll wake up. Some people, I understand wake up frequently during the course of the night and sip ice water. Other users develop a hard mouth, as it is called, who claim that the tissue inside the mouth with time undergoes some changes and will take on the function of irrigating itself. Active humidification has its problems too. The hose from the humidifier up to the face should be as short as possible and vertically straight to avoid condensation. If the room temperature is too low, condensation will reduce the humidity of the air which reaches you. If you try to compensate for this by turning up the heat of the humidifier, it can happen that air humidity turns into sizeable water drops which squirt into your mouth and you hear gurgling sounds in the hose all night.

## **Independent Living: American Versus European Models**

### **SWEDEN by Adolf Ratzka, Ph.D.**

As the key person in the effort to import the independent living philosophy to Sweden, I am tired of all the criticisms of the rugged individualism that this model supposedly implies, and that it doesn't have a place in Sweden where we take care of each other. The attacks often come from the political left which hasn't grasped the idea yet that even if the great revolution comes, we still will need services and consumer control.

The independent living movement is trying to establish strong local and national organizations which can impact policy on all levels. In Sweden, organizations of disabled people are involved in planning decisions on all levels on a routine basis. On the national level, a powerful coalition influences national policy. When the government appoints a committee that is to deal with planning or social policy issues where the concerns of disabled people may be involved, the disability movement is asked to appoint representatives to this committee. In the United States, it is the President's office that would appoint the members. This is unacceptable in Sweden because representatives must be elected by this constituency in due democratic process.

In Sweden, disability organizations may often have a majority of the board consisting of disabled people, but seldom are disabled people working in the office and making the day-to-day decisions. As an example, the administrative head office of Disabled Peoples' International is located in Stockholm. None of the four people running the office is disabled. One of the explanations for this phenomenon might be that most Swedish disability organizations are organized along diagnostic lines. There is an organization for almost every disease group. This invites professionalism and may be one of the reasons why our organizations are so heavily controlled by professionals. In the U.S., on the other hand, most organizations have leaders with disabilities. Independent living programs associated with the National Council on Independent Living have to have a majority of disabled persons on board and staff.

The independent living movement works for services that enable disabled individuals to participate on an equal footing with the rest of society in all areas and at all levels. Sweden has had for many years a broadly supported public commitment to provide a relatively high level of such services, irrespective of income and often completely free of charge. Thus, there are extensive attendant care programs, free housing adaptation grants, and free assistive devices.

Independent living also implies that disabled individuals, the consumers, both as a group and as individuals, are in control of the provision of these services. In this area, there is still much to work for in Sweden. In attendant care, for example, most often the consumer does not have the right to decide who is to work for him or her.

The independent living movement employs the principles of peer counseling, peer support, and role modeling. In Sweden, peer counseling has not been used purposely. In fact, the term was introduced in 1983 at a seminar on independent living. The counseling that is available is provided mainly by non-disabled professionals. There is still a distinction in Sweden between

professionals on the one hand and disabled people on the other hand. In the United States, a new group of disabled professionals can provide powerful role models for their clients and bring about attitudinal changes in their colleagues.

In Sweden, very rarely are persons with visible disabilities in important positions. An exception is the recent appointment of a blind person as Minister of Social Affairs in charge of disability issues. The fact that he was blind was played down by the administration and his personal experience of disability was not recognized as a merit for his office.

In conclusion, the difference between the United States and Sweden in the living conditions of disabled people and the achievements of their movements is a reflection of the sociopolitical climate of our respective countries. In Sweden, people tend to see government as a kind of insurance where, ideally, each citizen contributes according to his or her ability by paying taxes, and each receives the services he or she needs. In the United States, the doctrine of "least government is best government" is currently in vogue. While most Swedes consider it natural that the state uses taxes to provide free social services, Americans, it seems, prefer to spend their taxes on free military services, not only for its own citizens but for people all over the world - whether they like it or not. Why don't more disabled people in the U.S. protest and demand that their tax money be used to alleviate and not proliferate disability? Given these basic differences, it is easier for disabled individuals in Sweden to get the consumer control needed than for disabled individuals in the United States to get the services needed.

### **Independent Living: Attendant Care by Adolf Ratzka, Ph.D.**

The terms "attendant" and "care" carry institutional connotations and project the image of passivity and dependence. I use the term "personal assistants" because disabled individuals need to view themselves as self-directed, independent people who are capable of managing their own lives. The way personal assistance is organized can either thwart consumers' potential for growth and self-direction or enable them to live as active and productive members of their community. Social policy is most often not made by the people whose lives are affected by it. If consumer groups succeed in lobbying for a reform, they rarely have the possibility of getting involved in the actual design of policy instruments. Because of an alleged lack of administrative experience or formal qualifications, it is common to leave this work up to administrators, social workers, medical doctors, and lawyers. There are a growing number of professionally trained people with disabilities whose expertise as consumers is underestimated. Since consumers have the most intimate experience of how personal assistance influences their lives, they have to formulate their needs and translate them into design criteria. If the design of personal assistance programs is left to government agencies, the system will conform to their needs but not necessarily to those of disabled individuals. Consumers must be decisively involved in designing the program.

Service delivery must encompass all needs. In order to live full and active lives, disabled individuals need personal assistance with a variety of activities, such as personal hygiene, dressing, household chores, driving, shopping, and sign language interpreting, in a variety of

situations. To break up these needs into several distinct programs for certain activities and certain situations, as practiced in some countries, can entail several funding sources and separate service delivery systems, each with its own eligibility requirements, administrative routines, and staff. As the number of different agencies involved increases, so does the consumer's vulnerability, since problems can arise at any link of the chain. The most far-reaching consequence is the sense of alienation and powerlessness that the division of responsibility for the programs breeds in consumers.

General solutions cannot satisfy individual needs. Government agencies, if left alone, tend to develop a single solution that is to satisfy all needs, because from an administrative point of view a single service delivery system is preferred. Yet disabled people are unique individuals with individual physical needs, personal resources, and life circumstances. For each individual, needs will vary over time as family situation, occupational status, interests, and health change. Personal assistance systems must adapt to needs, not the other way round. Choice is the key to independent living.

Programs must encourage consumers' productivity and gainful employment. In many countries, personal assistance programs are means-tested which leads to undesirable consequences. For one, coverage of the costs of assistance may be seen by the general population and consumers as a welfare payment which can have stigmatizing effects. Also, means-tested eligibility can act as an effective deterrent for gainful employment.

Consumers do not have the same possibilities of demanding competent, punctual, and courteous work from volunteers as from assistants who are paid competitive wages. One is likely to have more personal power and more independence when you function as an employer instead of an object of charity.

Funding must be as centralized as possible at the federal level. Single source funding at the federal level eliminates costly bureaucracy and regional inequalities that otherwise seriously impede disabled people's geographical and social mobility. Only at the national income tax level can all benefits from a personal assistance policy be internalized. Where personal assistance is financed by local governments and institutional care facilities by regional governments, local governments do not reap the financial benefits of de-institutionalization made possible by personal assistance. Personal assistance programs enable many citizens with disabilities to become gainfully employed thereby contributing to national income tax revenues. This is also true for family members who otherwise would often be forced to informally provide these services and whom such programs enable to pursue employment outside the home. The ideal single funding source is a federal tax-funded personal assistance insurance without means test.

Control over service delivery must be as decentralized as possible at the consumer level. Consumers are the best experts on their needs and must be able to decide what activities they need assistance with and how many different persons are to work. They have to have the right to recruit, hire, schedule, pay, and - if necessary - fire their staff. To rely on workers from an agency can involve high turnover which is inefficient.

Severely disabled individuals have specialized needs that differ from person to person. New workers have to be instructed and trained by the consumer in new work routines which takes time and effort. Having to depend on strangers can be humiliating since the work constitutes a close social relationship and consists of very personal and intimate activities. The assumption that any assistant can work for any person amounts to a denial of an individual's uniqueness as a human being.

Among the benefits of assuming responsibility for one's service system is the dignity of being able to make mistakes, the rewards of learning from them, and the acquisition of useful management skills. These experiences and social skills are useful for other areas of one's life, such as employment, and lead to increased self-confidence.

Administrators and trade unions often propagate more professionalism in the hope of upgrading assistants' status and improving the service. The criteria for professionalism (commonly healthcare-related formal qualifications and training) represent an obstacle to consumers' realization of their potential for self-direction if the attitude is conveyed that consumers are patients who need to be taken care of. Consumers who want to improve the quality of the service, and thereby the quality of their lives have to take more initiative and work with their assistants as a team where consumers instruct and direct. In order to support consumers in this role, independent living skills and peer counseling classes should be offered by organizations of disabled people.

Institutions do not have to consist of brick and mortar. If consumers cannot choose who is to work with them, if they have to accept service without alternatives, if they do not meet assistants as individuals on a one-to-one basis but deal with a hierarchically ordered organization, then they are facing an institution.

It is typical for institutions that as orders or rules are passed down from one echelon to the next, their interpretation automatically becomes narrower as employees voluntarily limit their own margins for decision making in order to avoid making a mistake. The individual consumer is powerless at the bottom of the pyramid. Institutional vestiges in service delivery must be identified before programs can be designed that truly support disabled people's emancipation.