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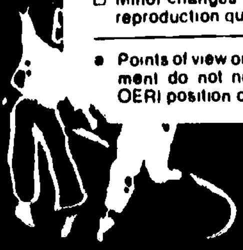
ABSTRACT

The book examines the place of leisure in the lives of disabled people and their families, in 18 articles by parents, counselors, recreation specialists, vocational counselors, researchers, and advocates. Stressed throughout is the potential of leisure when seen as a dimension of and vehicle for community living. Chapters are as follows: "Introduction: Finding the Way to Leisure, Laughter, and Love" (Deborah Gold); "Taking Part in the Dream" (Colette Savard); "Our Leisure Identity" (Judith McGill); "Leisure and Relationships: A New Identity" (Marilyn Ferrel); "Regenerating Community" (John McKnight); "Returning Home: A Parent's Story" (Rose Galati); "A Look Beyond Leisure Buddy Programs" (Deborah Gold); "A Unique Camping Trip to the Rockies" (Zana Lutfiyya and Nicola Schaefer); "The Politics of Leisure, Freedom, and Poverty" (Charles Sylvester); "The Impact of Integrated Employment on Leisure Lifestyles" (Judith Sandys and Diane Leaker); "You've Got a Friend" (Patrick Worth); "Creating Cooperative Play Environments as a Strategy for Integration" (Judith McGill); "David's Sport Involvement" (Christie Cass); "Recreation Is for Everyone: Getting What You Want" (Jule Hopkins); "Choices: Recreation Integration from a Parent's Perspective" (Heidi Prinz); "Ten Commonly Asked Questions about Recreation and Integration" (Deborah Gold); "Being Good Is Not Enough" (Margaret Brown); and "Conclusion: Connections" (Judith McGill). An appendix lists 12 additional resources. (DB)



THE PURSUIT OF

ENRICHING
THE LIVES
OF PEOPLE
WHO HAVE A
DISABILITY

REVISED
EDITION

THE PURSUIT OF
LEISURE

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Canada's National Institute for the Study of Public Policy Affecting Persons with an Intellectual Impairment

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Foreword

It has been about a year since *The Pursuit of Leisure* was first published. With a few small changes, it is now entering into its second printing. This fact alone suggests that an important need is being addressed.

But what is the need for a book like *The Pursuit of Leisure*? Over the years there have been several books that have discussed leisure activities and people who have a disability. These include a few guides that talk about how to establish activity programs. There are theoretical works that talk about recreational activities, but from fitness, motor coordination and learned behaviour perspectives. And there are other works that explore the social integration and normalization of people with a disability, while talking about training, vocational activities, "residential" services and recreational programs all in the same breath. These books have something concrete about them. They help us to think about leisure as a discrete "segment" of life, like other segments, and to think about that segment in terms of the many "activities" and "programs" that can be squeezed into it or out of it. In this sense, such books have been comforting: they help us to deal with leisure as something quite understandable and quite open to manipulation. They are full of answers.

Unlike *The Pursuit of Leisure*, however, these books generally do not talk about what leisure *means* to people who have a disability and their families. They do not focus on how leisure experiences can enrich lives and open new doors of meaning and enjoyment, while connecting people with disabilities more fully to their communities. Nor do most books on leisure and recreation for people with disabilities talk about what happens to individuals when opportunities to share meaningful experiences with others outside of school, work and home are lacking.

While *The Pursuit of Leisure* does explore these areas that have been left largely uncovered by other works, it is not a consoling book. It does not talk about leisure simplistically. The authors have not assumed that leisure is essentially an empty "segment" of life that those who have mastered the correct techniques can fill up like the other segments. They do not speak about leisure as something "optional," that people with disabilities should do when and if they get the time to master the necessary skills. Neither do they offer us the definitive "how to" book for those who want program tips. This work accepts squarely all the ambiguities, challenges and rich potential of leisure when it is seen as a dimension of and a vehicle for community living.

Taken as a whole, then, *The Pursuit of Leisure* speaks about leisure as something that moves fluidly across boundaries of work, school and home. At one moment it addresses in very practical terms what those attempting to enrich lives with people who have a disability can do, and probably should not do. At others it gives fresh insight into how leisure can be thought about on a more philosophical level. It accepts categorically that leisure options that include people with disabilities fully in their communities are not a distant ideal, but a necessity today and a long overdue right. To that end it is hoped that *The Pursuit of Leisure* will contribute to leisure programs and supports that will be sensitive yet courageous.

This edition includes some alterations to the first. The order of articles has been changed, as has the appearance of the typed word and the cover. These changes were thought advisable in the interests of bringing out the continuity between the book's themes and making the content more accessible. Deborah Gold's "Introduction" has been recrafted. Her "A Look at Leisure Buddy Programs" is now a look "Beyond" those programs and contains a few other small inclusions, as does her "Ten Commonly Asked Questions..." As well, some minor revisions were made to Patrick Worth's article, "You've Got a Friend" and to Judith McGill's "Conclusion." All of these revisions were made both for stylistic reasons and in the interests of including important ideas that did not appear in the first edition.

Cameron Crawford
Assistant Director
The G. Allan Roeher Institute

Introduction: Finding the Way to Leisure, Laughter, and Love

Deborah Gold

What does it mean to share a day at the park with a friend; to sip a few at the local pub; to entertain at home; to join a club; to enjoy an intimate dinner for two; to be asked, "can you come out to play?"; to dream about achieving, learning, and travelling? To many of us, it is these moments that make our lives most meaningful. As Judith McGill so aptly suggests in her article on identity, these times give us our most treasured memories. Many people with disabilities, however, are missing these moments and opportunities. Thus, their lives are impoverished, rather than rich and full. For example, Margaret Brown explains how her son Philip has missed out, even though he is very good at sports and physical activity. Colette Savard explains how her son misses out because he needs friends. He has been unable to make friends because of the constant presence of adults. This experience of being left out, of not belonging, of leading lonely and isolated lifestyles, is discussed in a number of the contributions to this book. John McKnight demonstrates how human service systems are not set up to help people to become included in communities: only communities can do that. Patrick Worth explains how services failed to meet his human needs, and simply perpetuated his isolation and exclusion.

Let us take a few minutes to reflect on *why* people with disabilities often experience such exclusion. Historically, persons with disabilities have been devalued in society, which means that, in a world where physical ability and intelligence are highly valued, people with a perceived lack of ability and/or presence of stigma are thought of in negative terms. This devaluation takes many forms, but its most prevalent consequence has been the exclusion of persons with disabilities from the mainstream of community life and from policy planning of all kinds. Since policy makers do not usually reflect all the needs of community members, rather than incorporating the needs of all citizens into basic, general services and service planning, they tend to create add-on, "special" services such as parallel transportation systems. Because of the inherent historical devaluation of citizens with disabilities, political will and social policy still do not reflect the ideology of inclusion. Thus, persons with perceived disabilities are often left with fewer rights and services than those who are valued by society: those with money, physical and mental ability, youth and health.

Typically barred from the mainstream of community life, persons with disabilities are consequently kept from knowing true leisure. What does this mean for them? It means that many still have few or no freely given relationships with non-labelled peers. It means that people continue to be "signed up" for structured programs with other labelled individuals, without their consent, and without understanding what alternatives they have. It means many children have few opportunities to spend time with their families because the support is not made available for them to live at home. It means, in the final analysis, that leisure, as described above and as many valued citizens know it, is not a part of the lives of large numbers of people with disabilities.

Throughout this book, leisure is discussed as a feeling, a state of mind, a sense of well-being. It is examined as a part of life that is deeply connected to relationships, intimacy, and love. Judith McGill and Marilyn Ferrel, in their articles, comment on the power of leisure to enhance skills, confidence, choices, relationships, and spontaneous moments. Most importantly, they each discuss the development of "leisure identities" as essential to the enrichment of lifestyles. In articles by Jule Hopkins, Heidi Prinz, and Christie Cass, the concept of choice is highlighted. Leisure is seen as all around us, and as an important part of community life. As we read, we see that leisure is there for the taking. We need only make the appropriate choices. This philosophy is questioned by Charles Sylvester, who asks whether leisure choices can be a reality for people who are poor. He discusses the "Politics of Leisure, Freedom, and Poverty." The readings in this book allow us to reflect on the need for, and the possibility of, taking part in leisure that is meaningful and enriching, in the face of many barriers such as poverty, labels, and institutions.

This book makes a contribution by encouraging us to think positively about change; how to truly help people lead more enriched lives. Both Margaret Brown and Colette Savard, for example, end their articles on a positive note, showing us the possibilities that emerge out of integration. In the piece entitled, "Ten Commonly Asked Questions about Recreation and Integration," I examine how integration happens and why it's important. One key reason why it is essential for us to concentrate on finding and providing integrated recreation and leisure is because it's fun. Reports from parents in this book and others, and ongoing discussions with individuals with disabilities, reveal that inclusion in the mainstream, with support, is usually more fun than a segregated experience.

What, then, is fun? It is, I think, linked to freedom, friends, spontaneity, and choice. Fun does not emerge automatically from a structured recreation program, or from a prescription by a "recreation therapist." And it is certainly not what people feel when they participate only in segregated sports and camps, or when they spend weekends wandering shopping malls all alone, or when all of the people they know are either service providers or other individuals who are handicapped. Fun and laughter are a part of having opportunities to decide what we enjoy, what we want to do, and who we want to do it with. They are an integral part of becoming ourselves, of relationships, of living. Joy is very definitely linked to community living and loving relationships, as expressed by Patrick Worth, Judith Sandys and Diane Leaker, Zana Lutfiyya and Nicola Schaefer, and Rose Galati.

Neighbourhoods, associations, clubs, and other groups help us to make these connections, and to have fun. Membership in groups, whether formal or informal, gives many of us our ability to meet people, learn new activities, develop skills, and make friends. These opportunities are difficult to get if people have never felt as if they belong. Relationships and leisure are inextricably linked together. We enjoy leisure with others; we develop relationships in leisure. Marilyn Ferrel elaborates on these links from her own experience. To provide leisure experiences without taking relationships into account is to reject the core meaning of a great deal of leisure. Such an exclusion overlooks the immense potential for change in this area of life for people who have been socially isolated.

Sometimes, people need support systems of many different kinds to make true leisure a reality. In the article on Leisure Buddy Programs, I examine this kind of support idea, its limitations and how we might think beyond support to friendship. Zana Lutfiyya and Nicola Schaefer follow this up with a practical account of how families, friends, volunteers, and workers can all provide support for leisure, fun, and laughter and in the process, make a seemingly impossible experience a reality. Leisure has the potential to connect people to their communities in a very real way. These connections can change people's lives. We must find ways to make living in the community meaningful and not a continuation of segregated and isolated lifestyles.

Here is a collection of reflections, ideas, strategies, and commentaries that demonstrate the complexity of the issues. Whether you are a parent of a younger or older child, a recreation worker, a support person, a volunteer, a teacher, an advocate, or friend, these writings call on us all to examine our attempts to create a sense of both leisure and belonging, not only for others but for ourselves as well.

Taking Part in the Dream

Colette Savard

My son Olivier is now seventeen years old. He attends a regular high school where he is no longer congregated or stigmatized by being with a large group of students with a mental handicap. Up until two years ago he was in a segregated class and had no real opportunities for getting to know his typical peers.

I feel that right now relationships are the most important thing to Olivier. When he is at school, Olivier has friends but when school is over, he only has his family. That is a lot and yet at the same time it is not much. It means that Olivier is very dependent on his family for his relationships. It has been hard for Olivier to make friends on his own — to make his own little place in a group. The reason for this is simply that he has been out of the group for so long. His new relationships are few and far between and not very consistent. When school is over, he is left to himself. We have tried to develop a circle of friends around Olivier at school that would extend beyond into his leisure time, but it hasn't happened. When he first joined the regular class, the teacher's aide took him around the school to try to help him meet other students. But this didn't help develop friendships.

Olivier is always accompanied by someone, whether it is a paid facilitator or a family member. At lunch he is accompanied by someone to go to the cafeteria to "hang out"; he is accompanied during classes and after school. I believe that this has become the major stumbling block to Olivier's making friends with his peers. Seventeen-year-olds do not want adults "hanging around" with them. It becomes a vicious circle. Until Olivier builds close relationships with his peers he will need to be accompanied by adults, but while he is being accompanied by adults he is not likely to build close relationships with his peers.

Since I have not found anyone who is skilled at helping Olivier develop friends, I sometimes feel that I must take full responsibility . But I often feel that I just don't have the energy it takes.

Fourteen to seventeen is a very difficult age for parents who are trying to get their sons and daughters involved in their communities. During the summer, the teenagers in our community are cycling, playing tennis, working at camps, or doing other jobs. I see them on the street walking and visiting informally with friends. Most of the things they do are spontaneous and informal and tend to be done with a few friends. Even formal leisure opportunities, where Olivier might meet teenagers his age, are not easy to find. They are often offered in the evening and not during the day. And municipal recreation departments don't offer much for teenagers.

This summer, Olivier surprised me by pushing me to find activities for him. Last week, he asked me to call two of the staff persons that work for the association and who support individuals to do recreational activities in the community. One of the staff members took him riding but he wouldn't go near the horse. He is now showing me what he does and does not like to do.

Once I find recreation programs to get Olivier involved in, they request that he be accompanied. This year I responded to an advertisement in the paper from a regular camp that was still accepting enrollment. I called and because I said that my son had a few special needs they said that they wouldn't accept him without someone accompanying him. They had not even met him.

Olivier likes to listen to music, his favourite music is hard rock including the Police and Men at Work. He also likes Claude Dubois and Beau Dommage. I would like to build on his interest in music by buying tickets to the Claude Dubois concert this month. I would also like to get him involved in playing the piano because he has always enjoyed playing my sister's piano. There is a conservatory down the street and

I think I would like to sign him up for classes one hour a week.

Olivier is fascinated by cars. When he meets someone with a car, the next time he sees that particular car he remembers the person. He gets so excited. It would be so nice if we could help him to develop this interest in a positive way. I have thought about getting him a subscription to Motor Trend Magazine, finding books on cars for him to read, getting him to attend car rallys, and watch races on television, getting him interested in building model cars, radio-controlled cars, and belonging to car clubs. Other young men his age are also interested in cars so that would give him something to talk to them about.

We have exposed him to a number of activities but he didn't stay interested in them long because he had no friends to do them with. We used to take him swimming but he never liked the water. We thought he might like the guitar. Both of his brothers have guitars. I remember setting out one of his brother's old guitars in a conspicuous place where he might find it and take an interest in it, but he would hide it on me. I got the message.

Olivier doesn't like physical activities because it is difficult for him to walk. He gets tired and asks to sit. He doesn't have the opportunity to do physical activities because our family is not involved in them. His leisure options follow pretty closely what the other members of his family do. We realize this is not good. If he had friends I think that it would be very different.

I see him more as an "intellectual" young man. There are all kinds of things that he could do with that type of disposition. He is very motivated by reading. He reads everything. He reads on T.V., on the street — he reads and spells all the time. He learned how to read one year ago. Everyone is so surprised that he can read and is always commenting on what a good reader he is.

Olivier also types, so I keep a typewriter at home and he has a new one at school. This summer I would like someone to come and tutor him in typing. He enjoys it. He can produce a whole page of work without a single mistake. I have never seen what he can do on a computer. I tried to find computer courses for Olivier. I have even found a volunteer who could accompany him to a class.

I was always told that Olivier lacked motivation and it appeared to be true until we put him in touch with something he liked and then the motivation came. It would be the same in leisure but he needs options in leisure.

I hope there will come a time in the near future that people will call for Olivier and he will have people to call and friends to go out with. I want him to have activities of his own, so that he doesn't always have to depend on his father, mother, or brothers. Part of my dream is for Olivier to have spontaneous leisure. I am not fond of group activities. If he is a person who likes to do things with one other person then that is fine with me, as long as his time is full and interesting.

I dream that soon I will not have to be there to prompt him every step of the way in his leisure. He will be the one taking over with someone there to help him or support him. So far it has been my responsibility to find volunteers. The dream is only now beginning to happen. Olivier is letting me know more and more what he does and doesn't like to do in his leisure time. This summer is a good example. Olivier has been telling me he needs more things to do — he is bored. This is a major step for him. He is becoming more involved in determining his own leisure life style and demanding new activities. As his mother, I am both excited and challenged by it and feel him taking part in the dream.

Our Leisure Identity*

Judith McGill

Remember jumping from the rafters of the barn with your cousins, taking a plate of freshly baked cookies to your favourite hiding place and sharing them with your best friend, building a sand castle with your dad, playing Monopoly with the rest of your family on a rainy day, piling leaves up in a heap and jumping into it over and over again, sleeping overnight in a lean-to with your neighbours, playing flag football at recess, going camping with friends on a long weekend with a case of beer and entertaining guests for the first time in your new apartment?

It would be difficult to argue that cherished memories like these can ever be replaced or even duplicated. All of these memories are leisure experiences and most of them involve relationships with other people. These common, everyday leisure experiences are often the ones that are missing in the lives of people with disabilities and yet these memories are at the crux of our understanding of the importance of leisure in our lives and in the lives of people labelled "mentally handicapped."

It is our leisure experiences that give richness to our lives, that break the monotony of habit and routine. It is through our leisure that we are able to experiment with life and with who we are as individuals.

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Leisure provides many people with an opportunity to find a unique identity apart from their work and family identities. Many of our friendships are either built or strengthened during our leisure time and through our leisure involvements.

Even though the connection between leisure and friendships is a very strong one, it is not yet widely recognized. For many of us, our most meaningful relationships outside our family centre around our leisure identities and leisure involvements. A lot of our time and energy apart from our work is spent enjoying our leisure time with people who have similar interests.

People with disabilities are often not helped to develop or strengthen their leisure identities. Instead, they are restricted to taking part in structured leisure activities. Too often, leisure for persons with disabilities is equated with supervised outings or segregated sport leagues. Spontanaeity and choice, two essential ingredients of leisure, are seen as not being practical or even possible. This is compounded by the fact that people with disabilities have had limited opportunities to make friends.

Friendships are often made through becoming a member of a community club or organization. Being a member of an organization helps to strengthen a person's leisure identity. For example, if you belong to the local YMCA and participate in the hiking club, you are more likely to meet other hikers and in turn learn about hiking. The hikers you meet may have other leisure interests that you would learn about. The friendships developed through the hiking club could "carry over" into other areas of your life. The more you perceive yourself as a member of the hiking club, the more eager you are to accept and become part of the unstated expectations and belief systems it values. This is perhaps more apparent in competitive clubs or high status clubs like private golf clubs. Nevertheless, it is a part of all groups and group memberships. By belonging to a hiking group, you are also more likely to learn the language people use when they refer to various trails and hiking methods and the subtle images that go along with the identity (i.e., style of dress and related lifestyle issues like nutrition). There are also other benefits that come from joining community clubs and organizations and that is the sense of community that a person can feel by being a contributing member to a group.

Being a member of a formal group is not, however, a prerequisite to having a leisure identity. Many people consider themselves as having a leisure identity without belonging to a group that shares a similar identity. They may consider themselves avid gardeners or fishermen without belonging to garden clubs and angling clubs. Leisure identities are supported in many different ways. People are supported in their identity as artists by the occasional compliment, while others are supported by day-to-day contact with other artists and the opportunities they have to take part in artistic pursuits. The more the people in our lives support us to be involved in the leisure pursuits that interest us and the more they perceive us in those identities, the easier it is for us to share that perception of ourselves.

A leisure identity is something that characterizes our leisure involvements. It has to do with how we describe ourselves and how others describe us in our leisure. Our leisure identities change as our priorities change. At any one time in our lives we may be able to define one or more leisure identities from music lover, to sportsperson, golfer, rummage saler, miniature collector, swimmer, gymnast, tree climber, listener, wrestling fan. .These identities go beyond mere participation in the activity and yet they are not necessarily things that we are good at, but things we enjoy. They describe who we are more than what we do, what we believe is important and what we value.

Victor loves model trains. In fact, Victor would not hesitate to describe himself as a "model train buff." At this time in Victor's life, his involvement in model trains has given him a unique leisure identity. His apartment is full of trains and train paraphernalia. His interest in model trains has become a big part of his life. Often on a weeknight, Victor and his friend James get together to plan out the major renovations and additions that need to be made to the model train set. A lot of Victor's leisure time and spare money are spent on his train set. Victor's friends and contacts are, for the most part, other people who enjoy model trains and consider themselves "model train buffs." He now belongs to two model train clubs, a provincial one, and one he established himself. The "Victor and Friends" model train club has a small membership of people who helped Victor build up his model railway. The members contribute to the club by typing newsletters, building model bridges, and ordering parts.

Victor has been supported in many ways and by many people to develop this leisure identity. Five years ago when he first moved out on his own, support workers suggested to him that he find something to do with his time. They encouraged him to buy a model train set to see if he liked the hobby. Once Victor began to take an interest, they introduced him to others who enjoy model trains and that formed the basis of his involvement. According to Victor, it did not take long for him to learn the language associated with model trains. The more involved he becomes, the more excited he gets about learning new things and meeting other people who share his interest. Model trains have opened up a lot of opportunities to Victor that weren't possible before.

Others have been supported by their parents and friends to find and develop leisure identities like Victor. David is a hockey player and a wrestling fan, Brandy is a Raffi fan, and Michael is a dart player. All of these individuals have strong leisure identities but they are the exception rather than the rule. Even though more people who have mental handicaps are living in the community, individuals still experience loneliness and boredom and have not found ways to use their leisure to give them a sense of meaning and uniqueness.

As concerned parents, advocates and human service providers we have not provided enough support to people with mental handicaps to develop strong leisure identities and become members of local community clubs and organizations. For the most part, it is a question of priorities. There is still an overpowering drive in our society to adhere to the traditional work ethic and to derive our sense of meaning from our work. It is still not widely recognized that leisure can play a vital role in expanding our friendships and relationships to provide us with a unique identity apart from work.

It is important that we find ways to recognize each person's leisure interests and support him or her to strengthen existing interests or develop new ones. This implies a radical shift from taking people to and from segregated dances and sporting events. It requires going beyond the mere activity and looking at all the aspects of a leisure identity. We must remember that building friendships is an important part of this process since it provides the ongoing supports. Friendships grow and develop out of our leisure experiences.

Leisure and Relationships: A New Identity

Marilyn Ferrel

Recreation has never been strongly emphasized in my life. Growing up as a person with a disability, most of my time was spent striving after the elusive goal of being "normal." The struggle to pursue this goal resulted in my lifestyle being abnormal. As a child I spent long hours learning to walk, dress, and feed myself. An hour a day was spent standing in braces and another half hour was spent doing a daily exercise routine. What were other children doing during that time?

In the 1950s, it was stressed that people who were different were to "be with their own kind." It was assumed that if I were in a segregated school I would have teachers and other specialists who were experts in teaching children with disabilities. Here, I experienced myself as a label rather than a person. I underwent painful exercises that were supposed to be good for people who are disabled. Physiotherapists punished me for my screams until eventually it dawned on them that they were dislocating my hips. It was hard for them to recognize that the exercise was good for some disabled people but not for others. I was only seen as a label, a machine, not as an individual.

The experience of being labelled in a segregated school had a devastating effect on my self-esteem and sense of identity. My whole identity was my disability. I saw myself as a disabled child, a disabled daughter, a disabled student, a disabled sister. In a school where all children have a devalued status, children who have a disability tend to devalue each other according to the severity of the disability. I was the "low person on the totem pole." One major activity for the girls in my class was to be a member of the choir. I was the only one to be rejected after singing for audition. Instead of spending noon hour with my girlfriends, who were in choir practice, I was to join the boys in the gym —despite the fact that I had no interest in floor hockey. Instead, I stole outside where I could be alone to cry. I didn't fit and there was no opportunity to explore my own contribution to the class.

Louise Bailey, principal of an integrated school, asked me how I eventually developed self-confidence, given that I had been in a segregated school for eighteen years. I had to think about that one. Then I realized how the church had always been an important part of my life. Here I had had some opportunity to interact with young people who would have been my peers if I had gone to the local school. At first the children just wanted to do things for me, but slowly I learned how to assert my independence. In confirmation class I began to ask questions, the way I did in school. Eventually I felt at ease with discussions and became active in Hi-C and Canadian Girls in Training (CGIT), youth groups in the United Church. Church enabled me to make contact with people in my local community. On Tuesdays, I went to CGIT. Nora was a girl who lived down the street. She and I would get together whenever there was a CGIT project, such as a mother and daughter tea, and we would cook or make things. Our friendship lasted for twelve years, until I graduated from university. Whenever my family couldn't find me, they knew I was down at Nora's. I spent the night with her when her father died.

Being in an integrated environment does not necessarily result in full integration. When I went to St. Clement's School, I thought that I had landed from Mars. I had had very little experience in being in an integrated environment on a day-to-day basis. I did not know how to react when the girls told jokes, talked about boys, and had fun the way teenagers do. I only knew how to work; that's all I ever had time for. The constant panic of keeping up, plus the lack of social skills, led me to escape by burying myself in my books. School became a nightmare. My only source of recreation was having a chat with my sister over a snack after school. Looking back, it would have been better if I had had the option of completing some of my academic work during the summer. One of the recreational activities that I would have enjoyed, and later discovered that I had some talent for, was public speaking. At the time I was too worried that my slight speech impediment would be a burden. Now, I realize the value of my participation to myself, and to other people, even though it would probably invite minor modifications to procedures.

Recently, I met one of the girls who was in my class at St. Clement's. We have become friends. I look back at St. Clement's and remember how she invited me to her house and was friendly towards me. We might have been friends all along but I had thought she was merely being kind and I didn't know how to reciprocate. When she took me to a class reunion I got to know the women better in one evening than in the three years I went to school with them. I had been too busy trying to be a "normal" student to learn the skills involved in relationships.

When I went to high school, I realized I didn't really need grade thirteen: the following spring I would be old enough to enter university as a mature student. For the first time, since the early grades of school, I had some free time to have some fun. I went to a public high school not expecting to make friends as I had heard that the students were all on drugs and I knew I was a bit of a square. Fortunately, there was a girl in my class whom I knew from CGIT. She took me under her wing the first day. One day a friend in a wheelchair introduced me to a boy with long hair named Richard. I was curious and, not expecting to talk to him again, I started to ask questions. That night my sister, who went to the same school, had her Young Life group at our house hoping I would meet some people. Richard happened to come with the group and we spent the night chatting. We became good friends. This was the first person, who wasn't handicapped or part of my family, with whom I had long intimate conversations. (Those chats with my sister had taught me good conversational skills.) My mother had a fit.

My relationship with Richard lasted three years. Before we stopped seeing eachother, he introduced me to another man who is now my husband. I could write a book about my relationship with Michael. It is through this relationship that I learned to trust another person enough to bond with him; how to be assertive without breaking up; and most of all, to let go of being possessive. It took me ten years before I was mature enough to enter into marriage.

I was fortunate to be more a part of the community than most people with my degree of disability. Still, opportunities for recreation were limited. The medical model forced me to develop extreme discipline in my life to keep up with the "normal" pace of school and work. It took me a long time to learn how to relax and relieve stress.

I enrolled in university part-time and was therefore isolated from the university community until I moved into residence. At the same time I broke up with Richard. Desperate for outside contact other than my family, I joined a writers' workshop. For the first time in my life, I discovered that I had a talent that was recognized by people who weren't labelled — writing poetry. This discovery was my first chance to have an identity that was not connected with being disabled. My poetry allowed me to express the depression of having to separate from Richard. It provided me with a medium to express my feelings and who I was. The workshop gave me an identity and a sense of being a valued person with something to contribute. Unfortunately, this new identity did not persist. To be a really good poet I would have to struggle with failure. This is still difficult to do, when I already have such a strong negative identity as a "disability."

The need to see myself other than as a disability hit home strongly when I recently attended a "Theatre of the Oppressed" Workshop with Lib Spry. Most of the participants already knew and accepted me fro work. When I got on my feet to do an exercise, the old tapes came back to me "You can't do it right," "You'll slow down the entire group," "you're a burden." Then it dawned on me: I was playing the tapes. Nobody else was playing them. I realized the labelling, the segregation, the devalued status had become internalized. The "cops in my head" persisted even when I was given the flexibility and freedom to explore my own identity as a person rather than a label. Lib came over to me while I was sitting on the sidelines. "I'm sure you can do this if you try it this way." Everybody else was encouraging me to participate, try new things. "Come on, Marilyn, stand on a chair, you can do it." They gave me permission not only to try new things but to change the exercises if I needed to. Participants were willing to be my partners and try a game in a new way.

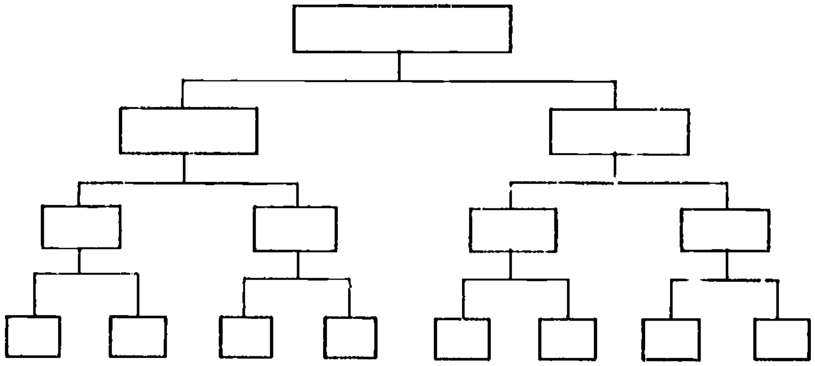
Regenerating Community*

John McKnight

Each of us has a map of the social world in our mind. The way we act, our plans, and opinions are the result of that map.

The people who make social policy also have social maps in their minds. They make plans and design programs based upon their map. Indeed, if you carefully examine their programs, you can detect the nature of their mental map.

Using this method, we have found that the most common social policy map has two locations: institutions and individual people. By institutions we mean large structures such as corporations, universities, and government mental health systems. These structures are best represented by the well-known diagram of their organizations:



This diagram describes the method used to organize a large

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*Reprinted with permission from the proceedings of the Annual Meeting of the Canadian Mental Health Association, 1985.

group of people so that a few of them will be able to control the rest of them. In this structure, there is ultimately room for only one leader. It is a structure initially created to produce goods such as steel and automobiles. In the last few decades, the structure has also been used to design human service systems. While these newly designed hierarchical managed service systems do not produce goods such as steel, they do produce needs assessments, service plans, protocols, and procedures. They are also thought, by some policy makers, to produce health, education, security, or justice.

If it is correct that these systems can produce these service commodities, then it is possible to imagine that there are consumers of their products. For example, we have all heard that there are now people called "health consumers." They are the individuals who are the other part of the social map created by most social policy makers. They make a complete economic world by acting as the user (consumer) of the products of managed institutional producers of such commodities as mental health, health, education, and justice. Thus, we can see that it was necessary to create health consumers once we had systems that could produce health. Otherwise, there would be no purpose for these large hierarchical managed systems.

Once we understand this social map of institutions and individuals, we can see why we have mental health providers and mental health consumers. We can also see how our developing service economy works.

Because the gross national product is the sum of the goods and services produced each year, many policy experts have come to believe that the well-being of our society significantly depends upon the amount of the commodities called services that are produced by institutions and used by consumers. For example, a person with a perilous and extended illness (a health consumer) contributes significantly to our economic growth by using large amounts of the commodities produced by the "health system." Indeed, a very ill person disabled for a considerable amount of time could cause production of much more medical dollar value through their illness than the value of their own production were they only a healthy florist.

This amazing development is possible, in part, because of the unusual two-place map used by many social policy makers in designing social services programs. Unfortunately, this map and the program designs that flow from it have recently encountered three major problems.

The first problem is that in spite of ever-growing inputs into institutionalized service systems, many individuals continue to reject roles as consumers. This is the problem of intractability that has resulted in an increasing focus upon the "compliance" issue. Especially in our big cities, many intractable young individuals continue to refuse to learn in spite of heightened resources and managerial inputs to the school system. This is commonly known as the educational problem.

Similarly, there are many other intractable individuals who refuse to behave in spite of our correctional institutions. This is a crime problem.

There is also the nutrition problem created by intractable people who refuse to eat the right food. And the chemical dependency problem created by intractable people who insist on smoking and drinking incorrectly. There is also the ever-growing number of intractable people who refuse to flourish in institutions created for labelled people, in spite of all the professional and managerial improvements designed by the system.

Indeed, there are so many intractable people refusing to consume institutional services that we are now designing new systems that surround these individuals with professionally administered services. Thus, one can now see individuals whose lives are bounded by institutions "targeting" their services at an intractable individual through teachers, doctors, trainers, social workers, family planners, psychologists, vocational counsellors, security officers, etc. This final solution is usually called a "comprehensive, multidisciplinary, coordinated, inter-agency service system." It is the equivalent of institutionalization without walls or the design of an environment to create a totally dependent service systems consumer.

The second problem with programs based upon the typical social policy map is that the sum of their costs can be greater than the wealth of the nation. In a recent white paper entitled "A Time to Serve" (Pergamon Press), a group of Swedish government planners described the escalating costs of their much-acclaimed social service system. They point out that at present rates of growth, the system could consume the entire nation's wealth within a few decades. Therefore, they propose that the government begin to "tax" people's time by requiring the Swedish people to contribute unpaid work to the maintenance and growth of their social service system.

While it is clearly the case that the United States is not in immediate danger of the Swedish economic dilemma, we are contributing substantial amounts to social service systems. A recent study by the Community Services Society of New York found that approximately $7,000 per capita of public and private money is specifically allocated to the low-income population of that city. Thus, a family of four would be eligible on a per capita basis for $28,000 which would place them in the moderate income category. However, only 37 percent of this money actually reaches low-income people. Nearly two-thirds is consumed by those who service the poor.

The third problem with the typical social policy map is that programs based upon its suppositions are increasingly ineffective and even counterproductive. For example, we now understand that our "correctional systems" consistently train people in crime. Studies demonstrate that a substantial number of people, while in hospitals, became sick or injured with maladies worse than those for which they were admitted. In many of our big city schools we see children whose relative achievement levels fall further behind each year. Thus, we have come to recognize the possibility that we can create crime-making corrections systems, sickness-making health systems, and stupid-making schools based upon a social model that conceives society as a place bounded by institutions and individuals.

It is obvious, upon the briefest reflection, that the typical social policy map is inaccurate because it excludes a major social domain — the community. By community, we mean the social place used by family, friends, neighbors, neighborhood associations, clubs, civic groups, local enterprises, churches, ethnic associations, temples, local unions, local government, local media, etc.

In addition to being called the community, this social environment is also described as the informal sector, the unmanaged environment and the associational sector

These associations of community represent unique social tools that are unlike the social tool represented by a managed institution. For example, the structure of institutions is a design established to create control of people. On the other hand, the structure of associations is the result of people acting through consent. It is critical that we distinguish between these two motive forces because there are many goals that can only be fulfilled through consent, and these are often goals that will be impossible to achieve through a production system designed to control.

There are many other unique characteristics of the community of associations. The associations in community are interdependent. To weaken one is to weaken all. If the local newspaper closes, the garden club and the township meeting will each diminish as they lose a voice. If the Legion disbands, several community fundraising events and the maintenance of the ballpark will stop. If the Baptist Church closes, several self-help groups that meet in the basement will be without a home and folks in the old people's home will lose their weekly visitors. The interdependence of associations and the dependence of community upon their work is the vital centre of an effective society.

The community environment is constructed around the recognition of fallibility rather than the ideal. Most institutions, on the other hand, are designed with a vision imagining a structure where things can be done right, a kind of orderly perfection achieved where the ablest dominate.

In contrast, community structures tend to proliferate until they create a place for everyone, no matter how fallible. They provide vehicles that give voice to diversity and assume that a consensual contribution is the primary value.

In the proliferation of community associations, there is room for many leaders and the development of leadership capacity among many. This democratic opportunity structure assumes that the best idea is the sum of the knowings of the collected fallible people who are citizens. Indeed, it is the marvel of the democratic ideal that people of every fallibility are citizens. Effective associational life incorporates all of those fallibilities and reveals that unique intelligence of community.

Associations have the capacity to respond quickly. They do not need to involve all of the institutional interests incorporated in a planning committee, budget office, administrative staff, etc.

A primary characteristic of people who need help is that their problem is created by the unexpected tragedy, the surprise development, the sudden change. While they will be able to stabilize over the long run, what they often need is immediate help. The rapid response capacity of associations, and their interconnectedness, allows for the possibility of immediate and comprehensive assistance without first initiating a person into a system from which they may never leave.

The proliferation and development of community associations allow for the flowering of creative solutions. Institutions tend to require creative ideas to follow channels. However, the non-hierarchical nature of the field of associations allows us to see all of the budding ideas and greatly increases our opportunities for the flowering of social innovation.

Because community associations are small, face-to-face groups, the relationships among members are very individualized. They also have the tradition of dealing with non-members as individuals.

Institutions, on the other hand, have great difficulty developing programs or activities that recognize the unique characteristics of each individual. Therefore, associations represent unusual tools for creating "hand-tailored" responses to those who may be in special need or have unique fallibilities.

Our institutions are constantly reforming and reorganizing themselves in an effort to create or allow relationships that can be characterized as "care." Nonetheless, their ministrations consistently commodify themselves and become a service. For many people with uncommon fallibilities, their need is for care rather than service. While a managed system organized as a structure of control can deliver a service, it cannot deliver care. Care is a special relationship characterized by consent rather than control. Therefore, its auspices are individual and associational. For those who need care, we must recognize the community as the appropriate social tool.

Finally, the community created by associations is the forum within which citizenship can be expressed. Institutions by their managed structure, are definitionally unable to act as forums for citizenship. Therefore, the vital centre of democracy is the community of associations. Any person without access to that forum is effectively denied citizenship. For those people with unique fallibilities who have been institutionalized, it isn't enough that they be "deinstitutionalized." In order to be a citizen, they must also have the opportunity for recommunalization.

In summary, the community of associations provides a social tool where consent is the primary motivation, interdependence creates holistic environments, people of all capacities and fallibilities are incorporated, quick responses are possible, creativity is multiplied rather than channeled, individualized responses are characteristic, care is able to replace service, and citizenship is possible. When all of these unique capacities of community are recognized, it is obvious why the social policy map that excludes community life has resulted in increasing failures. To exclude from our problem-solving capacities the social tool of community is to have removed our heart.

Why is it then that social policy maps so often ignore such an important continent as community? One reason is that there are many institutional leaders who simply do not believe in the capacities of communities. They often see communities as collections of parochial, inexpert, uninformed, and biased people. Indeed, there are many leaders of service systems who believe that they are in direct competition with communities for the power to correctly define problems, provide scientific solutions, and deliver professional services.

In this competitive understanding, the institutional leaders are correct. Whenever hierarchical systems become more powerful than the community, we see the flow of authority, resources, skills, dollars, legitimacy, and capacities away from communities to service systems. In fact, institutionalized systems grow at the expense of communities. As institutions gain power, communities lose their potency and the consent of community is replaced by the control of systems; the care of community is replaced by the service of systems; the citizens of community are replaced by the clients and consumers of institutional products.

Today, our society is the site of the struggle between community and institution for the capacities and loyalties of our people. This struggle is never carried out in the abstract. Instead, it occurs each day in the relations of people, the budget decisions of systems, and the public portraits of the media. As one observes this struggle, there appear to be three visions of society that dominate the discourse.

The first is the therapeutic vision. This prospect sees the well-being of individuals as growing from an environment composed of professionals and their services. It envisions a world where there is a professional to meet every need, and the fee to secure each professional service is a right. This vision is epigrammatically expressed by those who see the ultimate liberty as "the right to treatment."

The second prospect is the advocacy vision. This approach foresees a world in which labelled people will be in an environment protected by advocates and advocacy groups. It conceives an individual whose world is guarded by legal advocates, support people, self-help groups, job developers, and housing locaters. Unlike the therapeutic vision, the advocacy approach conceives a defensive wall of helpers to protect an individual against an alien community. It seeks to ensure a person's right to be a functioning individual.

The third approach is the community vision. It sees the goal as "recommunalization" of exiled and labelled individuals. It understands the community as the basic context for enabling people to contribute their gifts. It sees community associations as contexts to create and locate jobs, provide opportunities for recreation and multiple friendships, and to become the political defender of the right of labelled people to be free from exile.

Those who seek to institute the community vision believe that beyond therapy and advocacy is the constellation of community association — the church, the bowling league, the garden club, the town paper, the Legion, the hardware store, and the township board. They see a society where those who were once labelled, treated, counselled, advised, and protected are, instead, incorporated in a community where their contributions, capacities, gifts, and fallibilities will allow a network of relationships involving work, recreation, friendship, support, and the political power of being a citizen.

Because so many labelled people have been exiled to a world expressing the professional and advocacy vision of an appropriate life, the community vision has frequently been forgotten. How will people know when they are in community? Our studies suggest that this universe is distinctive and distinguished from the environment of systems and institutions. The community experience incorporates:

Capacity. We all remember the childhood question regarding how to describe a glass of water to its midpoint. Is it half full or half empty? Community associations are built upon the recognition of the fullness of each member because it is the sum of their capacities that represents the power of the group. The social policy map makers, on the other hand, build a world based upon the emptiness of each of us — a model based on deficiencies. Systems commodify deficiencies.

Collective Effort. It is obvious that the essence of community is people working together. One of the characteristics of this community work is shared responsibility that requires many talents. Thus, a person who has been labelled deficient can find a "hammock" of support in the collective capacities of a community that can shape itself to the unique character of each person. This collective process contrasts with the individualistic approach of the therapeutic professional and the rigidity of institutions that demand that people shape themselves to the needs of the systems.

Informality. Associational life in the community is a critical element of the informal economy. Here, transactions of value take place without money, advertising, or hype. Authentic relationships are possible and care emerges in place of its packaged imitation — service.

The informality of community is also expressed through relationships that are not managed. Communities viewed by those who only understand managed experiences and relationships appear to be disordered, messy, and inefficient. What these people fail to understand is that there is a hidden order to community groups that is determined by the need to incorporate capacity and fallibility.

While institutions and professionals war against human fallibility by trying to replace it, cure it, or disregard it, communities are proliferations of associations that multiply until they incorporate both the capacities and the fallibilities of citizens. It is for this reason that labelled people are not out of place in community because they all have capacities and only their fallibilities are unusual. However, because there are so many community associations, there are always some sets of associational relationships that can incorporate their fallibilities.

Stories. In universities, people learn and know through studies. In businesses and bureaucracies, people know from reports. In communities, people know from stories. Community stories allow people to reach back into their common history and their individual experience for knowledge about truth and direction for the future.

Professionals and institutions often threaten the stories of community by urging community people to count up things rather than communicate. Successful community associations resist efforts to impose the foreign language of studies and reports because it is a tongue that ignores their own capacities and insights. Whenever communities come to believe that their common knowledge is illegitimate, they lose their power and professionals and systems rapidly invade their social place.

Celebration. Community groups constantly incorporate celebrations, parties, and social events in their activities. The line between work and play is blurred and the human nature of everyday life become part of the way of work. You will know that you are in community if you often hear laughter and singing. You will know you are in an institution, corporation, or bureaucracy if you hear the silence of long halls and reasoned meetings. Associations in community celebrate because they work by consent and have the luxury of allowing joyfulness to join them in their endeavours.

Tragedy. The surest indication of the experience of community is the explicit common knowledge of tragedy, death, and suffering. The managed, ordered, technical vision embodied in professional and institutional systems leaves no space for tragedy. They are basically methods for production and have no room for tragedy. Indeed, they are designed to deny the central dilemmas of life and gladly give communities the real dilemmas of the human condition. There is no competition here. Therefore, to be in community is to be an active part of the consolation of associations and self-help groups. To be in community is to be a part of ritual, lamentation, and celebration of our fallibility.

Knowing community is not an abstract understanding. Rather, it is what we each know about all of us.

As we think about ourselves, our community and institutions, many of us recognize that we have been degraded because our roles as citizens and our communities have been traded in for the right to clienthood and consumer status. Many of us have come to recognize that as we exiled our fallible neighbours to the control of managers, therapists and technicians, we lost much of our power to be the vital centre of society. We forgot about the capacity of every single one of us to do good work, and instead, made some of us into the objects of good works — servants of those who serve.

As we think about our community life, we recognize that something has happened to many of us as institutions have grown in power; we have become too impotent to be called real citizens and too disconnected to be effective members of community.

There is a mistaken notion that our society has a problem in terms of effective human services. Our essential problem is weak communities. While we have reached the limits of institutional problem solving, we are only at the beginning of exploring the possibliltiy of a new vision for community. This is a vision of regeneration. It is a vision of reassociating the exiled. It is a vision of centring our lives in community.

We all know that community must be the centre of our life because it is only in community that we can be citizens. It is only in community that we can find care. It is only in community that we can hear people singing. And if you listen carefully, you can hear the words:

"I care for you because you are mine and I am yours."

AN ASSOCIATIONAL MAP*

John McKnight

ARTISTIC ORGANIZATIONS:	choral, theatrical, writing
BUSINESS ORGANIZATIONS:	Chamber of Commerce, neighbourhood associations, trade groups
CHARITABLE GROUPS AND DRIVES:	Red Cross, Cancer Society, United Way
CHURCH GROUPS:	service, prayer, maintenance, stewardship, acolytes, men's, women's, youth, seniors'
CIVIC EVENTS:	national holidays, art fairs, Hallowe'en
COLLECTORS' GROUPS:	stamp collectors, flower dryers, antiques
ELDERLY GROUPS:	Senior citizens' centres
ETHNIC ASSOCIATIONS:	Sons of Norway, Black Heritage Club, Hibernians
HEALTH AND FITNESS GROUPS:	bicycling, jogging, exercise
INTEREST CLUBS:	poodle owners, old car owners
LOCAL GOVERNMENT:	town, township, electoral units, fire department, emergency units
LOCAL MEDIA:	radio, newspaper, local access cable TV
MEN'S GROUPS:	cultural, political, social, educational, vocational

* ***Editor's Note:***
The map has not previously been published. For Canadian ideas, see below.

MUTUAL SUPPORT (SELF-HELP) GROUPS:	Alcoholics Anonymous, Epilepsy self-help, La Leche League
NEIGHBOURHOOD AND BLOCK CLUBS:	crime watch, beautification, Christmas decorations
OUTDOOR GROUPS:	garden clubs, Audubon Society, conservation clubs
POLITICAL ORGANIZATIONS:	political parties, caucuses
SCHOOL GROUPS:	printing club, PTA, child care
SERVICE CLUBS:	Zonta, Kiwanis, Rotary, Association of University Women
SOCIAL CAUSE GROUPS:	peace, rights, advocacy, service
SPORTS LEAGUES:	bowling, swimming, baseball, fishing, volleyball
STUDY GROUPS:	literary clubs, bible study groups
VETERANS GROUPS:	American Legion, Amvets, Veterans of Foreign Wars, their Auxiliaries
WOMEN'S GROUPS:	cultural, political, social, educational, vocational
YOUTH GROUPS:	4H, Future Farmers, Scouts, YMCA/YWCA

CANADIAN IDEAS

Deborah Gold

Acitivity clubs:
    sewing, quilting, bingo, folkdance, hiking, kayaking, pottery, knitting, stained glass, batik, woodworking, ceramics, climbing, skiing, swimming, remote-control cars, etc.
Community Centres
Canada Day
Ethnic: Jewish Community Centres, Ukrainian Club,
    Lithuanian Community Centre, etc.
Girl Guides/Boy Scouts
Liberal Party of Canada
New Democratic Party of Canada
Parade organizations
Progressive Conservative Party of Canada
Rhinoceros Party
Rotary Club; Variety Club
Seniors Centres
Volunteer Fire Department
YM/YWCA

Returning Home: a Parent's Story*

Rose Galati

Our family is typical and not so typical. My husband Dominic and I have two beautiful daughters. Maria, our youngest, is six years of age. She uses a wheelchair for getting around and during mealtimes. She is non-verbal at present although she makes many varied sounds to indicate her needs. She is also very socially aware and uses auditory cues to follow conversations. Felicia, our ten-year-old daughter, is able to get around on her own and uses tactile strategies to initiate activities and move about. She can communicate effectively using body language, facial expressions, and many sounds.

Both children have many strengths and a number of challenging needs. Dominic and I see our children as children first and we feel that all children have some needs that are more challenging than others.

Moving home

Three months ago my life changed. My husband Dominic, our ten-year-old daughter Felicia, and I welcomed back to our home the youngest member of our family, Maria. The circumstances under which Maria left our home are still not completely clear to us but the fact remains that Maria lived away from her family for just over four years. She left when she was only twenty-one months old.

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*Reprinted with permission from ***entourage***, Winter 1986, Vol. 1, no. 1.

I feel that Dominic and I have been able to draw many positives out of the events of the past four years. Some of these positives are direct results of the fact that Maria lived at Ceci's Homes for Children in downtown Toronto. Ceci's Homes structurally consists of four group homes that are connected and located in the market lane townhouse development at the foot of Jarvis Street in Toronto. The individual homes consist of fairly typical living space with several bedrooms, a laundry area, kitchen, dining room, and living room. The furnishings are above average, making the homes very appealing to the eye.

The children at Ceci's, approximately five per home, are all children with very challenging needs in many areas. I like to think that most of their needs, however, are the same as any other child's. The overriding philosophy at Ceci's involved community living to its fullest. So strong is this commitment that several years ago a pilot project was started at the two neighbourhood schools, St. Michael's Catholic School and Market Lane Public School. Maria, our daughter, was one of the few children who attended St. Michael's beginning with a regular junior kindergarten placement. Maria's movement into senior kindergarten with her friends — in fact, her whole school experience — led my husband and me to do some very serious thinking about education for both our children and ultimately proved to be the final piece of the puzzle that enabled us to realize our vision for our children.

The vision

For Maria, it meant coming home to live with her family again and for Felicia it meant leaving a segregated school setting and being placed in a regular classroom in the community. I should add that both Dominic and I are teachers with twenty-five years of experience between the two of us. It was a difficult decision to bring Maria home in that we would lose the opportunity of having her in such a positive school enviroment. The perceived commitment on the part of our home school board in Mississauga served to counter the loss of what St. Michael's had to offer. We are now in the process of negotiating and helping to develop an equally suitable placement for Maria within the regular school setting. Although it sometimes seems as if it is a long battle, we know that it is worthwhile.

When Maria first returned home, all of those incidental family experiences — company for supper, visiting an uncle or aunt, bridge on Friday night — became special times for a youngster who was missing these events when she lived away from us. Maria's special needs have become secondary to us and her status as our daughter — a whole daughter who needs her family — has become far more important.

Of course this does not mean that we ignore any of Maria's needs. I feel that we merely address these needs in a different way. There does not seem to be any negative behaviour or condition that weighs so greatly that Maria or Felicia would have to leave our home again. We have a mind set, however, that enables us to see the positives, the value of our daughters, so clearly that bed wetting, heaviness, and other challenges are just not important or strenuous enough that it should mean that they should live elsewhere. As a matter of fact, when Maria returned home and I developed an excruciating back pain, my husband and I proceeded to figure out what carrying and lifting techniques needed to be changed or what equipment we might need to adapt the environment for Maria and myself. There was no "It can't be done. Oh, well, we gave it a good try."

It has always been difficult for us to highlight the perceived negatives of our children's development. We see our girls as learners, growers, and most importantly as whole children who have some needs that must be addressed somewhat differently than typical children. Their present and future should not, under any circumstances, be considered solely on the basis of their "handicaps" but on their regularl needs too: the need to have community friends and experiences, the need to have a family, the need to risk, and the need to be seen as valuable contributing members.

Bringing it all together

When going out as a family means we need to negotiate entrances that are so obviously inaccessible and sometimes not so obviously inaccessible (when the door at the wheelchair entrance opens out), you begin to get discouraged. It takes a good deal of commitment and belief in the value of the struggle to go on.

Dominic and I believe that we are now that committed to making the community living model work for our children. We also have a network of supports ranging from government funding through the

Ontario Ministry of Community and Social Services to community involvement on a voluntary basis. Some of the best support comes from our children's friends who spend hours reading, listening to music, drawing, snacking, and being together with our girls.

We had for a long time been trying to build toward involving our children in shopping trips, ball games, and so on, but were hesitant and unsure of how our daughters would be accepted in the neighbourhood. It was quickly apparent that the community was more prepared than we thought. Now playgrounds, parties, even weddings, are not out of the question. Everything is possible.

Dominic and I made a very conscious and giant leap into realizing that all of the little activities we had been instructed to do with Felicia and Maria could be worked into all activities. What does it mean to practise frontal protective reflexes on a red rubber ball if Felicia can push a cart when she goes shopping? We have in fact found that, with little exception, repeated purposeful routines in appropriate settings have enabled Felicia to learn more quickly. We can see evidence of this in Maria's development as well. For a long time now we've been able to see more and more signs of Maria's awareness of her ability to manipulate her environment too. On many weekends before she moved home we would spend hours settling Maria to sleep. It occurs to us now that she was showing signs of insecurity. It's good to hear the happy sounds she makes at bedtime now and to know that she is getting a good night's rest. It's even better to know that she wakes up to the same voice and face every morning, too. I think Maria really likes that.

We feel that being together is certainly better. Our happiest times have been spent in our family room or in the backyard with our children. They have given us more than you can imagine and finally are beginning to reap the benefits of all that they have been able to teach us. Nothing is taken for granted in our home. All of our time is valuable and whether thoughtfully planned or entirely unplanned, it is neither a burden nor impossible. Felicia and Maria are our children.

We have, over the past two years, changed in many areas regarding the care and development of our children. Our vision for the future went from the desire to have a protected group setting for our children to the most integrated comunity setting possible, where networks of support and natural family experiences rank higher than low-risk, sheltered environments.

A Look Beyond Leisure Buddy Programs

Deborah Gold

What is a "Leisure Buddy Program"? What are its limitations? And how might we think beyond such a concept?

A Little History

In the mid-seventies, recreation services to people with disabilities were still substantially lacking in Canada. Advocacy by parents increased the need for integrated recreation opportunities. The publication of the book *Recreation Integration,* by Peggy Hutchison and John Lord, in 1979 again called for increased opportunities for people with disabilities and supported staff in agencies to attempt change within their organizations. Recreation departments across the country began to offer integrated opportunities to augment or replace the programs of the day: segregated, group programs for people with similar and/or differing labels.

Integration was quickly becoming the buzz-word of the seventies and eighties. Government departments on all three levels had developed a variety of initiatives to increase the participation of people with disabilities in society. And yet, it seemed that while opportunities were available to groups of people in a community setting, they were offered, for the most part, on a segregated basis. So, efforts towards meaningful social integration and interaction were minimal. It was at this time, in the early eighties, that the concept of "support" became popular in both the leisure and disability fields. A few communities had established one-to-one programs in the seventies. The book *Participation: Expanding Community and Leisure Opportunities for People with Severe Handicaps* by John Lord attempted to guide those who wanted Leisure Buddy programs. Published in 1981, it reads as a manual for providing support to individuals with very challenging needs on a "matched" one-to-one basis. The advent of this publication, and the seemingly obvious need of many service providers and parents, led to the establishment of "Leisure Buddy Programs" in various communities. In this article, I'd like to discuss not only the nature of these programs, but more broadly, the nature of the need that appears to have provided the rationale for their establishment: the need for friendships.

What exactly is a "Leisure Buddy Program"?

In simple terms, this kind of "program" works under the assumption that people with handicaps need a companion or "support person" in order to participate in fully integrative settings. That is, the presence of someone, assigned specifically to John Smith, will allow him the opportunity to be a part of the group. John needs some extra support while in the bathroom and while eating lunch. He is, let's say, ten years old. And the leaders of the program, let's say a day camp or playground program, are a little leery of accepting him. Their minds are put to rest when they hear he will be accompanied by a "buddy," someone who will hold ultimate responsibility for John, someone who has been trained, someone who is aware of John's needs and desires, someone who is John's friend. This, in effect, makes up the concept of a "Leisure Buddy Program." In actual fact, many such programs in Canada currently serve as many or more adults as children. In these situations, the "buddy" is seen as a companion or, as is often stated, a "friend" who accompanies the person with a disability to club meetings, movies, dinner, and other leisure activities in the community.

What are People's Real Needs?

Many people who have been devalued because of their handicaps end up with few choices and opportunities for personal expression in leisure. They often also end up with little to do except watch television alone. Their contacts, because of segregated lifestyles, are limited to paid staff and devalued people. They thus experience substantial relationship gaps in their lives. Those of us who latched on to the concept of "Leisure Buddy" programs in the early eighties saw this. We thought that these systems would get people involved in fulfilling leisure lifestyles in the community and would fill the deep void in people's lives the darkness and loneliness created by segregation and isolation. It's not that we expected such a program to be a cure-all; it is simply that we felt that if people only had a system of support, albeit artificial and arranged, they would be on their way to leading more fulfilling lives, lives with meaning and joy.

So, briefly, what are people's real needs? You would probably agree that they go something like this: love, friendship, companionship, fun, spontaneity, daily leisure, freedom and choices, vacations and so on.

How are these needs typically addressed?

It helps at this point to ask ourselves how our own needs are met in the larger culture. How do we meet our need to belong, for example? We start off in a family and, if we're lucky, there's some love, a little pain, opportunities for growth and development, and a real feeling that we belong. As we grow up, we find different settings in which we feel we belong. There's school, after-school clubs and teams, groups of friends, neighbourhood playmates, Brownies or Cubs and so on. And as we get older, we see our networks expanding and changing, depending on our circumstances.

How does our need for fun get met typically? This probably depends on who we are, what age we are, where we live, who lives with us, and much more. However, it can be said that there are certain valued and accepted ways of meeting the need for fun in our culture. People participate in recreational sports, attend spectator sports, go to concerts, share a bottle of beer at the cottage, take vacations, have dinner with family or friends, hold and attend parties, make and eat special dinners, go out for lunch, travel, join all kinds of clubs, get involved in activities associated with their religion, talk with the neighbours over tea, take drives in the country, read a good book...The list goes on and on. But the need is met, particularly for those of us who can express our needs, and who are supported to express them. For others, particularly those who have been socially isolated,these important needs are overlooked, while we provide people with basic assistance and with useless or meaningless activity. Even when we successfully meet the need for real fun, it is often either in a segregated context, or substantially limited in comparison to what we would expect in the larger culture. Why? It is not because we are bad people, or even bad service providers. It is simply because a service cannot meet these needs. It was not designed to do so.

The following story will illustrate. A friend of mine, a physiotherapist, knowing my interest in friendship, told me of a little girl she had been working with. The four-year-old told her that she didn't have any friends. Besides living in a rural community, this little girl is further isolated from interaction with her peers because of her daily schedule of physical exercises. Although her need for "treatment" was undoubtedly extremely important, it had superceded her need for friendships and relationships with other little children. This story is not an uncommon one. We need to take a very close look at people's basic human needs, as we attempt to meet their "special" ones, and to find a healthy balance. This is a very crucial challenge in the disability field.

Why a "Leisure Buddy Program"?

Professional Reasons

Agencies such as Parks and Recreation Departments and disability-related associations, see how they can provide integration and save money at the same time by the use of such a system. Most such programs utilize volunteers, rather than paid staff, and thus their benefits are seen to far outweigh their costs. Both professionals and parents have seen support as the key issue to integration; that is, if people only had a support person, then they could participate fully.

Parents' Reasons

Parents are very concerned about friendships for their children (Gold, 1986; Gold and Levy, 1988; Strully and Strully, 1984.) They are also interested in having their children go out and explore the community, venture far and wide, try new things. Parents find that they are often the ones to accompany their child(ren) with a handicap. It is with this in mind that they seek another companion — someone who is not related to their child, someone whom they can trust to be responsible, but whose only goal is to involve the individual in leisure activities. They also insist that it is a way for their child(ren) to make friends.

Direct Service Providers' Reasons

Many people work with a person with a mental handicap: paid support people; group home workers; teachers; teachers' aides; therapists of all kinds. These people, particularly paid "caregivers," also like the idea of a "Leisure Buddy Program." Their desire is to have someone other than themselves who can do things outside, or even inside, the home with a particular individual. This "companion" helps direct care staff to increase, even slightly, somebody's limited social networks, beyond paid staff.

The general appeal of such a program, for all three groups, also lies in what are seen to be the incredible advantages for the person who is labelled. The goals and objectives of many programs fall in line with these expectations. For example, one city explains that its labelled citizens will gain experience, knowledge, social skills, and friendships through their interactions with unpaid persons and especially peers who do not have disabilities (Grbac-Difrancescantonio and Fitzpatrick, 1981).

How a Leisure Buddy Program Works

Generally, such a program has a coordinator. This person takes requests from parents and individuals with disabilities who are looking for a companion in leisure. The coordinator also recruits volunteers and interviews them and the disabled individuals and a matching process is begun. A commitment of a certain amount of time is usually required of the volunteers. For more in-depth information about one model, refer to "One-to-one Support in Integrated Settings: The Leisure Buddy Program" (Gold, 1983).

In a recent workshop on friendship that brought together people who were concerned about leisure and friendship, the typical structure of a program was discussed. Across the board, these programs had certain common characteristics. The following are excerpts of statements made during the workshop that demonstrate how the programs work[1]:

- a coordinator for the program will have ongoing contact with volunteers;
- volunteers and others are matched on a one-to-one basis with devalued persons to do activities;
  the volunteers are chosen through a screening process; they sign confidentiality and liability forms; they are often asked to sign contracts;
- a time commitment is often asked of volunteers;
- an expectation is created that friendship will develop; programs are sometimes funded as respite care;
- volunteers are trained in the following areas: interacting, eating lunch, understanding physical handicap, wheelchair use and lifting, people's special needs, philosophy and goals of the department, agency, etc.;
- ongoing supervision, support, and evaluation are provided;
- volunteers' "contributions" are recognized through: pay, course credit, materials, references, transportation, bus passes, pins, souvenirs, barbecues, parties, training courses, manuals etc.;
- the status of the program is evaluated and funded on the basis of number of matches.

This list is by no means comprehensive. It does, however, outline quite simply how a program is coordinatred, and demonstrates how the professionals involved may often become dependent on the program yet not be fully happy with it. Very often, we cannot find enough volunteers for all the people on waiting lists. Because we have said that people need a support person in order to participate, many will not participate without one. This happens because once the program is created, the need for it becomes greater, and in fact we create needs this way. So, instead of saying, "this person needs friends," we say, "this person needs a Leisure Buddy."

Constraints of the Program Approach

What people are really in need of are friends: people they can count on in a crisis; people who feel they benefit from the relationship; people who like them for who they are. What people with handicaps often get in this kind of model is a volunteer — someone who is almost always the giver while the handicapped person is viewed as the taker, the one "for" whom things are done.

The relationship itself in these programs is unnatural. People are matched together who previously were complete strangers. Like Big Brothers and Big Sisters, there is little thought given in these programs to the strengthening of existing relationships in people's lives. Thus, professionals take control over what should be a very natural, or at least facilitated, process. This problem of "artificiality" is augmented by the fact that the volunteer often has to be a specialist of some sort, as shown by the amount of training he or she often receives. There is a direct contradiction between this concept and that of friendship. The latter usually more often begins because of a spark or magic between two people, having things in common, or simply liking eachother. It develops with support from both parties, and from outsiders, like parents and other friends.

We have also discussed the need for spontaneity and for some fulfilling leisure every day (or at least often enough to be meaningful). Because volunteers in these programs are required to make commitments to an agency, they are automatically kept from more spontaneous contact with the handicapped "participants." Also, volunteers are often monitored and judged or "evaluated" on their "performance." This job-like approach once again constrains the freedom and "give and take" that are normally a part of relationships. The need to pre-plan, and often to get approval for ideas, further restricts spontaneity. Also, sometimes volunteers are not permitted to venture out alone with a handicapped person. This would obviously strain the quality of the relationship.

Friendship is a difficult concept for us to define. We know what it is when we're in it, but it is impossible to plan for, or to "make happen." A "matched" relationship cannot take into consideration the "magic" of real affection. It might happen, but then again, it might not. And since often the motivations of the two people involved are different, the likelihood of this need being fulfilled is small. The obligation of the volunteer to the program and the client role in which the handicapped person is placed serve to heavily restrict the development of a real friendship based on mutual respect and love. Those of us who are involved in these types of programs must acknowledge willingly that there will always be limitations in what we do. It is not possible for a leisure buddy program to make friendship happen, but workers can set up the frameworks in which it can occur (Perske, 1988).

Opportunities in the Model

Despite the pitfalls, there are positive opportunities in "Leisure Buddy" programs. For one thing, in such programs, people with a handicap get the chance to meet and even to know typical citizens when otherwise they might not get that chance. Second, the volunteer could become a friend, although whether this happens or not is not usually due to the program itself. People with handicaps also get chances to try new things and to be involved in the community, even if these opportunities are somewhat limited. Thus, lives may be enriched. Also, typical citizens receive the opportunity to get to know someone with a handicap on a more intimate basis than if they were spending time in a program setting. The opportunity may be there for advocates to emerge from some of these relationships. Public education may take place as people are seen to value each other in public places. Finally, it is possible that, through these sorts of relationships, others may develop and people's networks could expand.

Suggested Future Directions

The critique of one system demands suggestions about replacements. The simplest way to go about answering the question, "okay, fine, so it has some problems in meeting people's real needs, but what would you suggest we do?" is to ask another question: "If we were to try to meet the needs for belonging, friendship, spontaneity, and leisure involvement, without designing a service, what would such a system look like?" The concept behind the following answer is a simple one, and yet, because we have become so dependent on services to meet people's needs, it can be difficult to put into practice. Many people with disabilities, particularly mental handicaps, have missed out on substantial opportunities to develop relationships with non-handicapped citizens. They have been literally disconnected from the mainstream. Thus, they often float around on the fringes or very much outside of community life. In fact, what we know as "lifestyle" is often completely alien to people with mental handicaps.

There have been attempts by parents and advocates in the field to develop lifestyles with meaning (see "Being Good is Not Enough" in this volume). These attempts have met with some success, although much of what occurs is simple trial and error. The idea that people need support rather than service, and support that is both directly geared to their strengths and needs and that takes a citizen rather than professionalized approach, is a new and pioneering one. It entails pulling three or four people who care about (or even simply know or once knew) the person around him or her to develop a lifestyle that is based on the person's needs.

It also involves gaining access to the natural networks that exist in our communities: clubs, associations, hang-outs, and centres where people naturally gather together in groups. This means that the decision-making power lies in the hands of the person with a handicap and his or her family and friends. It means that the volunteer, advocate, or other companion is not simply and only a friend or guardian of the handicapped person, but is required to be an "integrator" or facilitator of the person's access to natural networks and to other potential friends.

The person, in this model, becomes an interpreter of the person with a handicap to others. He or she is constantly aware of the need for the person to become "connected," and so chooses activities with the person that will enhance this process. He or she stays "on the look-out" for "magic" and "sparks" between the person and others in the world, and fosters this sense by making time for these people to be together — by inviting, by striking up conversations, by thinking creatively about how the person with a handicap could be more involved. A few facilitators very naturally introduce their friends with handicaps to people in their own networks, such as husbands and wives, parents and other family, friends or club acquaintances because it seems like the most simple and logical thing to do. In this way, involvement with the person is no longer a volunteer commitment, separate from other lifestyle components, but is now a natural, spontaneous connection.

In conclusion, we are called upon to understand the difference between companionship and friendship. Whether a companionship becomes a deeper friendship probably depends more on the individuals involved than anything else. A program can't offer what a friendship does. We feel responsible to create programs in which people can have friends. If we are not careful, soon we will have "friendship technicians," and we will be able to study this topic at college or university.

What must happen, instead, is a shift in the responsibility for relationship building back into the community, where it originated. Certainly, some "Leisure Buddy" programs can be the starting places for this to occur. But it can happen elsewhere as well. Parents, service providers, and volunteers can all have an influence in *facilitating* friendships between persons with handicaps and other citizens in the community. "Friendship" programs must rethink how they operate and *let go of people.* We must give up control of people's lives if we want connections to happen. With support, leisure can occur out of individual needs and personal interests rather than structured programs and arranged relationships.

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[1] This information was generated by program workers during a seminar on friendship hosted by The G. Allan Roeher Institute and facilitated by Judith McGill, February, 1988.

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A Unique Camping Trip to the Rockies*

Zana Lutfiyya

(with Foreword & Afterword by Nicola Schaefer)

Foreword

Every two years my sons and I fly to my native England for the month of August. It's a sanity-saving break for the entire family. My husband Ted can forget his immediate family responsibilities and concentrate on being a scientist, the boys can forget about school, and I can forget the existence of my telephone. And we're all much nicer to each other when we reassemble in the fall.

The only member of the family who hasn't in the past done very well out of this holiday is my twenty-two-year-old daughter Catherine. She is mentally handicapped with severe physical disabilities and has traditionally spent the time in an institution. This year, however, things would be different, because CAMR Manitoba (now the Association for Community Living - Manitoba) had a summer respite program for people with severe disabilities — for which Catherine incidentally had been the catalyst since I had some time ago decided she should remain in the community when I had to be away from home.

We have one community residence in Manitoba (in Steinbach, forty miles from Winnipeg) for people with really challenging needs. I've been connected with it peripherally since its inception three years ago and, apart from its having been forced by the Government to accommo-

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date too many people — six plus two "respite beds" — it ranks very high in many people's estimation, including mine. The people there kindly invited Cath to stay with them for the last two weeks of August. For the first two she would use the respite program. Zana, a good friend of Catherine's and mine, was in charge of the program and I was confident (I had to be. I was desperate to get away) that she would devise a way of caring for her. She did, though she was wise to tell me to sit down when she announcea her plan.

Summer respite trip, 1983

In charge of the Summer Respite Program, and having stayed with Cath in the past, I was committed to taking care of her for two weeks during the summer of 1983. I had staff, but no facility, so the main problem was where. We were staying in people's houses with their disabled family member to give the family a chance to get away for up to one month. However, Catherine's father was staying in Winnipeg, and it would be uncomfortable for him to have two or three respite staff in and out of the home while Nicola was away.

As I tried to convince Nicola that we would have no problem arranging something for Cath, I realized I had no idea how we were going to do it.

Then, one afternoon in the ACL-Manitoba office, Brian Law speculated that it was a shame that Cath couldn't go on a shopping trip to Minneapolis/St.Paul or something similar, as the Manitoba Recreation Council had made funds available to support individualized holidays for persons with handicaps. That was the thought that got us all started. Cath would need more than one person to assist her, but she could travel. A few hectic hours later we essentially had a trip organized. For two weeks, myself, my two staff and two other summer students could assist not just Catherine but two other persons with severe and/or multiple handicaps to go on a camping trip — to the Rockies, Banff, and Jasper. Why not? Not only would we meet three respite requests, it sounded as if it might be fun.

In addition to Cath — an engaging young woman who uses a wheelchair, communicates non-verbally and needs assistance for almost all her daily needs — Tracy, and John were to come on the trip. Tracy, twenty-two, is a classmate of Catherine's and, like Cath, has many attributes (including a radiant smile), uses a wheelchair, cannot talk and needs extensive assistance every day. John, nineteen, is a well-built young man who particularly enjoys such outdoor activities as cross-country skiing, camping, and swimming. He is described as being autistic/mentally handicapped, with some behaviour problems, and has difficulty communicating his requirements. With supervision and some prompting he can take care of his personal needs.

Staffing

We had five assistants; three women (including myself) and two men. All of us were university students who were studying a variety of subjects, among them education, psychology, chemistry, and theology. Three of us had experience working with persons with special needs. Four of us had camping experience. Two of us were certified in First Aid. And all of us had gotten to know Catherine, Tracy, and John and believed they would enjoy and benefit from a summer holiday. One of our strengths as staff was that we didn't know that persons labelled severely/multiply handicapped couldn't take such a trip!

Planning

After that initial afternoon, we spent much time planning the details of the trip, always mindful that an important element was flexibility. After checking with the Motor League, we planned our route, decided the camps we would use, and how far we would drive each day. We then arranged to have friends near each stop. These were people who knew about us and were prepared to help out in case of emergency or illness. They included relatives, the people at the YMCA just outside Banff, and the L'Arche Community in Calgary. Fortunately we never had to call upon any of these people.

Each of the assistants spent time with Tracy, John, and Cath before the trip. We became familiar with their personal routines, habits, medications, diets, and preferences. We did this not only to get to know them better but also so that they would feel comfortable with us. We set up menus, specially adapted to each person. We drew up medication charts and prepared first aid kits. We begged and borrowed all the camping equipment we needed; this included two tents, air mattresses, sunshades and umbrellas, cook stoves, sleeping bags, coolers, lanterns, a bicycle pump for the wheelchairs, and a Trivial Pursuit game.

Funding

Transportation: We used the Schaefers' van and a car belonging to one of the assistants. The van easily accommodated Tracy and Cath in their wheelchairs, two or three other people and a mass of camping equipment. The much smaller car, a Citation took the rest. The Manitoba Recreation Council provided us with a travel grant of $1,500.00. This covered all our travel costs: gas, insurance, oil, and mileage (which was paid to the vehicles' owners). For the trip, we significantly increased the liability insurance on the van and car and, since, the trip was sponsored by ACL-Manitoba, expanded the policy to the business category. These additional policies were cancelled at the end of the holiday, in the same month, and ended up costing $10.00 per vehicle.

Staff: The staff was made available through ACL-Manitoba. Three of us were paid by Canada Works summer student grant, one was paid jointly by ACL-Manitoba and a Federal Community Services grant, and the fifth person's salary was paid completely by ACL-Manitoba. The staff members were paid their regular wages during the trip, based on a forty-hour work week. The rest of our time was donated.

Fees: Though there was no charge to the families for the actual respite support, i.e., the staff, we did charge a fee for $200.00 to each camper. This covered the cost of food, supplies, camping fees at Provincial and Federal parks, one night in a hotel, laundry, and pocket money for activities and souvenirs. With the exception of the photo albums that were made at the end of the trip, we were under budget by about $50.00. Nor did we use the entire travel grant. However, we received several personal donations, including a two-bedroom apartment in Calgary for the duration of our stay there. Also, some of the food for the holiday was provided by the families and the assistants.

The trip

On August 3rd 1983, after several weeks of mounting excitement, we departed amid family send-offs and reassurances that it would be all right if we turned back at Brandon, Manitoba. The first two days were long, hot, boring drives across the prairies. Sheer enthusiasm surrounding the expedition kept us all in good spirits. It certainly wasn't the supper I cooked on the first night; bearing in mind the 33° C temperature, I had completely frozen all the food and it didn't have time to thaw before being cooked.

We were all pleased to reach Calgary and find my brother's apartment. There we showered, bathed, and got a good night's sleep. The next day the men went on to Banff to do some hiking and check out the good camping spots, while the women played tourist in Calgary. We shopped, visited the zoo and botanical gardens, went out to a classy pub and had a steak dinner in a posh restaurant. Friends and relatives in Calgary dropped by for visits.

Three days later we joined the guys up in Banff. We camped at Tunnel Mountain, a beautiful spot. We decided to cut Jasper out of the trip. spend more time in Banff and return home via Calgary. This allowed us to adopt a slower pace and see more of Banff, which is a lovely town. We strolled around, watching the other tourists and admiring the Rocky Mountains. We spent a full day at Lake Louise and managed to walk halfway around the lake before the path got too steep to manage Catherine's and Tracy's wheelchairs. A picnic with grapes at Coral Creek on a red and white checked tablecloth; a spaghetti dinner with homemade sauce and two bottles of wine; the gondola ride at Sulphur Mountain; shopping for souvenirs for ourselves and our families — these are our memories of the Rockies.

We drove to Calgary, down from the clean, crisp mountain air to the muggy prairies. Mounds of laundry and eight baths later, we all spruced up and went out to a highly recommended Chinese restaurant. We had a great time, with cocktails followed by lots of fine food. As had been the case throughout our trip, we received excellent and respectful service, with the waiters going out of their way to get to know John, Tracy, and Cath and what would please them. After dinner we took a stroll along a beautiful island park in the heart of Calgary and listened to performers at the Folk Festival. The city and park were all lit up and so were we.

The last two days saw us driving back to Winnipeg, with an overnight stop in Regina. The initial reaction of all the families was pleasure at seeing us home safely and surprise at how well we all looked.

All through the holiday we drew double takes and long looks. We welcomed them, especially from children. We would always smile (or smile back) and try to start a conversation. Children wanted to know why Tracy and Cath couldn't walk or talk, and then wanted to know what they could do. Adults were amazed that we were on holiday, all the way from Winnipeg. Fortunately they were so struck by this fact that they forgot to tell us all how wonderful we were for doing this. What we could probably never have explained to them was how much fun we had had on the trip ourselves.

Afterword

When I picked Cath up from the residence in Steinbach she looked marvellous and was on a high for several days — until she realized, I think, that life was back to boring normal. She brought with her a photo album of her jaunt to the Rockies with her friends and a diary kept by the assistants, so the rest of her family was able to enjoy her experiences vicariously.

Although I was intrigued by the idea of the trip when I first heard about it, I soon developed a daunting list of possible disasters. What if, for instance, despite the carefully planned menus that included loads of fresh fruit, vegetables, and bran, Cath's innards clogged up? What if she developed a chest infection that didn't respond to the antibiotic I'd sent along? What if a bear took a fancy to her? I decided that the concept "dignity of risk," of which I am a keen proponent, is all very well when applied to other people. However, although a few minor problems typical of any camping expedition cropped up, such as leaking tents, nothing went seriously wrong and eight friends thoroughly enjoyed a camping trip together.

One unsolicited comment, made to me by an assistant after the holiday, perhaps sums up the success of this extraordinary — or was it so extraordinary? — venture. "I had such a great time it didn't seem right that I was being paid!"

The Politics of Leisure, Freedom, and Poverty*

Charles D. Sylvester

New techniques are always needed for professionals to function successfully in an increasingly demanding society marked by change and complexity. Consequently, today's literature is rife with tools and strategies designed to enable them to meet their challenges by remaining on the "cutting edge."

This article, however, will not assist readers to reach or to remain on the cutting edge. In fact, I am simply making public a troubling conversation I have had with myself. In my conversation, I have found that the cutting edge, left unexamined, is a double-edged metaphor, at once cutting through for some people while cutting others off. With this in mind, I wish to share my thoughts on leisure, freedom, and poverty.

First, I need to explain what I mean by leisure, a once distinctive word deadened by the abuse of jargon. I am not referring to the popular free-time definiton. If that were the case there would be no rub between leisure, freedom, and poverty. Disproportionately represented among the unemployed, the poor would be leaders in leisure, having an abundance of non-worktime. For my purposes, *leisure is not free time; it is freedom's time.* I intend to argue, then, that the poor — though they

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*Reprinted from *Parks and Recreation*, January 1987, by special permission of the National Recreation and Park Association (U.S.)

have ample free time — have little effective freedom and, as a result, virtually no genuine leisure.

Freedom, of course, is an idea. Its application to our lives results in a variety of freedoms, including, for example, physical freedom, political freedom, religious freedom, and creative freedom. Each of these freedoms is a means for achieving a related end, such as spirituality or creativity. A point comes, however, where freedom transforms from a means into an end. This special realm is leisure, where freedom is expressed and relished for its own sake. In leisure we can sing, love, dance, write, converse, or perhaps reflect, delighting in the freedom that is native to self-expression. Leisure, in short, is the celebration of freedom at its crowning point in creative and self-determining activities enjoyed for their own sake.

Most people need an optimal level of freedom to attain leisure. In the face of starvation or imprisonment, leisure is difficult and rare. Leisure, therefore, requires a foundation built on the most fundamental forms of freedom — "freedom from" and "freedom to."

"Freedom to" suggests the ability to make choices and to act on them. Awareness of one's needs and desires, knowledge of available options, and possession of the resources necessary to act effectively on one's choices constitute its essence. More basic, however, is "freedom from."

"Freedom from" refers to the relative absence of social, physical, biological, and psychological constraints that impede free choice and action. Leisure presumes sufficient "freedom from" such chronic restrictions as disease, ignorance, and political oppression. In addition to these constraints, possibly the most pressing and pervasive barrier to freedom and leisure today is poverty. As philosopher J.L. Stocks observed, "Riches do not create leisure, but the struggle with poverty definitely excludes it."

Poverty defies ordinary experience and simple description. I can imagine the thrill of space travel, because I know the feeling of awe, wonder, and adventure. Having experienced the exhilarating struggle of athletic competition, I can dream of competing for an Olympic medal. And while I understand disappointment, even despair, I do not believe I have felt anything as severe as poverty. I sense that poverty, inflamed by hunger and unemployment, sucks the spirit and dignity from a person. Currently, then, it eludes my direct experience. Nevertheless, our capacity for empathy should allow us to confront poverty as a condition that involves everyone. Therefore, the following definition and numbers are merely intended to orient us to the scope of poverty. Once revealed, we may turn to its implications and, more importantly, our response.

Poverty is characterized by deprivation of the basic resources required for subsistence, typically including food, shelter, health care, and continuous employment. In 1983, the federal poverty level (American figures) was $10,178 for a family of four. During that year, 35.3 million people lived in poverty. This represented 15.2 percent of the population compared to 15 percent in 1982. By race, 35.7 percent of blacks, 28.4 percent of Hispanics, and 12.2 percent of whites were officially poor according to census statistics.[1]

Aided by a stronger economy and lower inflation, poverty figures declined in 1984. With the federal level at $10,609 for a family of four, 14.4 percent or approximately 33.7 million Americans lived in poverty. The rates for minorities remained high, with 33.8 percent of blacks and 28.4 percent of Hispanics mired in deprivation. Furthermore, 21.3 percent of all children, most living in households headed by a female, and 51.5 percent of black children under the age of six were officially poor in 1984.

Despite the overall reduction in poverty, census data showed a widening schism between rich and poor. In 1984, the richest 40 percent of the population received 67.3 percent of the national income. In 1980, they received 65.9 percent. Conversely, the poorest 40 percent of the population received 15.7 percent of the national income in 1984, compared with 16.7 percent in 1980. Thus, though poverty declined, a massive underclass caught in its chronic grip has formed.

Moreover, if poverty precludes the freedom necessary for leisure, we are compelled to admit that the enrichment that accompanies leisure and the impoverishment that festers in its absence is another difference separating the privileged and the poor. This prospect, however, becomes untenable if justice for the many is a necessary corollary of effective freedom and authentic leisure. Thus, the plight of 33 million poor is a severe injustice. It is hardly surprising, then, that Lerone Bennett Jr. protested abject poverty in supposedly free societies by asking, "In such a world, who has the effrontery — who has the gall — to praise the state of freedom?" We must be as boldly honest as we turn to the problem of leisure and poverty.

The fundamental problem of leisure and poverty raises many issues. Two, however, are particularly relevant. One pertains to the humanistic ethic espoused by many writers in the field. The other relates to the "Life. Be in it." public relations campaign.

While no single set of beliefs has been uniformly accepted or officially endorsed, humanism has been implied as a suitable ideology for the profession. Its central tenet or ethic is the supreme dignity and worth of humans. This means our efforts should be primarily aimed at improving and enriching the human condition. Yet applied to our profession, a humanistic ethic presents a disturbing irony.

Recognizing the interdependence of nature, we hold that all resources, human and non-human, should be protected and nurtured. On the one hand, engendered by a historical commitment to natural resources, the profession has championed environmental causes. Although certainly not spared from debate in its own right, this is a source of pride and accomplishment. Yet, on the other hand, a profound contradiction arises when 33 million members of nature's preeminent resource are eroded by poverty each day. Our response, however, has been negligible. Indeed, the profession has been quicker to defend the forests and the shorelines than families polluted by poverty. For those people who believe we can't be all things to all people, this situation may be tolerable. If, however, we sincerely advocate a humanistic ethic, we must accept all the implications, consequences, and responsibilities that flow from that choice. Chief among these would be the obligation of eliminating poverty.

This leads to the issue of "Life. Be in it." The "Life. Be in it." slogan is at one level irresistably attractive in its clever simplicity and jauntily positive tone. Only the most cynical could ignore its appealing invitation. On another level, however, its message demands serious doubt because of its naive simplicity — "life" is just not that easy "to be in" for many people especially if you happen to be poor. As it is grammatically constructed (Life. You be in it.), the slogan is a moral imperative that implies the only barrier preventing one from "being in it" is the understood You. On the basis of the message alone, one assumes that anyone not complying must possess a deficit of motivation or desire rather than the absence of opportunity. Once we surpass public relations and progress to the more substantial realm of human rights, however, the relevant issue is opportunity. A severe social handicap, poverty, excludes people from mainstream values and opportunities. Whether one elects to subscribe to "Life. Be in it" is a matter of personal choice. But access to life must be wide enough to include opportunity in that decision.

"So, fine," you may be saying. "I can buy into most of your argument. But my work involves play and leisure, not hunger and housing. How can I effectively respond to poverty?"

It is true that we are primarily concerned with leisure. And if we value freedom, as our rhetoric claims, then leisure as a special mode of freedom becomes very significant. Leisure — in all its myriad expressions — may in fact be one of the principal ends worthy of human desire. Our efforts, therefore, matter greatly. At the same time, our responsibilities increase, for in a democracy we are accountable for the conditions that make leisure a reasonable possibility for everyone. As David Gray and Sy Greben remarked, "Our concerns exceed the boundaries of parks and recreation to include matters affecting the total human experience."

Therefore, we cannot remain indifferent. John Kenneth Galbraith argued that one of the obligatory beliefs of our time "is that poverty is not an acceptable feature of our social life." He warned, though, of a "heartless society" where denial, indifference, and such rationalizations as post-industrial economics and Social Darwinism create a vacuous social conscience, permitting the unacceptable to become acceptable. I have argued that leisure has no moral foundation in the midst of poverty. Therefore, the protection and promotion of freedom is an ethical responsibility shared by all recreation professionals. Specifically, poverty may be met on two fronts.

First, by virtue of its concern for leisure, the National Recreation and Park Association (NRPA) is an advocate of freedom. One of its main responsibilities is to guard and nurture the conditions necessary for freedom and leisure to flourish. This can be partially achieved in alliance with other humanitarian groups devoted to eradicating poverty. For example, Hands Across America, last spring's fund and awareness raising event, presented an opportunity for the "Life. Be in it." cast to join hands in the collective grip on poverty. Projects of this sort serve largely to focus and maintain persistent attention on a pernicious problem that weakens the health and welfare of present and future generations. By sponsoring and cooperating with similar efforts, the recreation profession can become a leading lobbyist of the right to be "free from" poverty. As it does, the validity of "Life. Be in it." will improve substantially, enabling it to become a genuinely humane ethic.

Second, the responsibility rests with you and me. Will and commitment are paramount. Commitment, moreover, may take many forms from food and financial donations to teaching job skills to expressing your leisure through political activism. Once demonstrated, widespread commitment has a way of discovering, even demanding effective solutions.

But given our responsibility, what technique or approach should we use to subdue poverty? Surely there are ways to satisfy our will.

Effective strategies are, of course, important. But first I recommend we back away from our tools for a moment and consider the notion of mission. The recreation profession evolved from a vision held by such pioneers as Joseph Lee and Luther Gulick that play and recreation should be open to all. At the same time, leisure was becoming a sovereign right rather than a class privilege. Yet, observing contemporary trends, I am concerned we have neglected that vision and compromised our mission. Obviously, the issue is more complex than I can treat here. But I fear the marketplace ("bang for your buck") perspective and the perks of professionalism sometimes outweigh the primacy human needs and desires have traditionally assumed in our field. Even if my cynicism is unfounded, our efforts and accomplishments will be comparatively unimportant unless we maintain — or renew — the social awareness and commitment the recreation profession took root from.

I sincerely hope future scenarios are as promising as the one forecasted by the writer who predicted a "gradually extended distribution of economic goods and rewards so that almost all the population will have some financial resources to make leisure choice possible.' Yet each day people remain in the clutches of poverty, leisure will remain an unkept promise — always tomorrow — unjustly out of reach. In a democracy, that reach of freedom called leisure must be within everyone's grasp.

[1] Some Canadian Poverty Statistics

Deboroah Gold

The following information has been taken from two 1988 reports by the National Council of Welfare, "1988 Poverty Lines" and "Poverty Profile 1988," and *Income Insecurity: The Disability Income System in Canada,* published by The G. Allan Roeher Institute, 1988.

There is no single poverty line for all of Canada. To take into account two factors that affect living costs, Statistics Canada varies its low income cut-offs according to the size of the family and the place of residence. However, the National Council has been able to come up with some estimates that appear to be accurate since they take into account important factors such as cost of living increases and percent of income that is necessary for food, clothing, and shelter.

Just to give a brief idea of poverty lines, here are some examples of estimates for 1988. For a single person, living in a city of 500,000 or more, the low income line is $11,564; for a family of three living in a population centre of 30,000—99,999, the low income line is $18,078; for a family of five living in a large city, the poverty line is $27,408; figures decrease (the line is lower) with the decrease in population size of the centre and decrease in numbers in a family unit. Thus, a young couple living in a large urban centre must have a combined income of over $15,258 to be above the line while if they live in a rural situation, this income must be above $11,178.

In all of Canada, in 1986, the poverty rate for all persons was 14.9 percent, which represents 3,689,000 who were poor. In 1981, by comparison, the poverty rate in Canada for all persons was 14.7 percent. The family poverty rate ranges widely from a low of 8.7 percent in Ontario to a high of 21.2 percent in Newfoundland. The percentage of low-income unattached individuals varies from 28.3 percent in Ontario to 49.1 percent in Newfoundland.

Four in ten families headed by women are poor, compared to only one in ten led by men. The poverty gap between female-led and male-led families has not narrowed appreciably since 1980. In 1986, the rate of poverty for households headed by a female was 38.7 percent, while in male-led households it was 9.0 percent. Unattached women run a greater risk of poverty than unattached men, though the gap between them is not as wide as it is for families headed by women and by men.

Families with children experienced a substantial increase in poverty as a result of the recession, though the situation improved in 1985 and 1986. However, family poverty rates still have not returned to their pre-recession levels. More than half of single-parent families led by women — 56.0 percent or 233,000 — had incomes below the poverty line at last count.

The picture is brighter for elderly families. Their poverty rate declined markedly from 41.4 percent in 1969 to 14.2 percent in 1980 and just 9.5 percent in 1986. The elderly unattached still run a very high likelihood of being poor (42.7 percent in 1986), but their poverty rate was much worse (61.5 percent) in 1980.

Contrary to what many people believe, most poor families are headed by persons who work or are actively searching for a job. The risk of poverty is dramatically reduced for families with more than one earner. Women both make up a larger percentage of the poor and run a higher risk of poverty than men. However, the proportion of poor Canadians who are women has not increased during the eighties.

Among Canadians with a disability, poverty levels are very high. In 1986, 63 percent of people with a disability reported an annual income of less than $10,000. Only 5 percent had an annual income of more than $30,000.

The Impact of Integrated Employment On Leisure Lifestyles*

Judith Sandys and Diane Leaker

"Work" usually represents a major focus of our life as adults. In addition to enabling us to earn a living we look to our job to provide us with challenge and with an opportunity to do something worthwhile. Of perhaps equal importance is the social context of work: the fact that through our jobs we invariably come into contact with many different people. Often some of these relationships become significant ones that may extend far beyond the work place.

In January 1984, Community Living Mississauga initiated a project designed to provide for people with varying degrees of intellectual handicap the opportunity to work in the community (on a paid or unpaid basis) alongside non-handicapped people. Entitled "Community Vocational Alternatives," this project reflected our belief that everyone (regardless of the extent of their handicap) should have the right to be an active, participating member of their community. We had struggled for many years with the realization that sheltered workshops were inconsistent with our basic philosophy. We knew that congregating and segregating people did not facilitate community participation, indeed it served to inhibit it. Through Community Vocational Alternatives we set out to find people work in the community that was challenging, status-enhancing, consistent with their own interests,

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and that provided opportunities to interact and develop relationships with non-handicapped people.

This article will review briefly the impact of integrated work settings on people's leisure patterns, based on some of the workplace data we have collected as well as on individual "stories" of some of the people we are supporting. We will also discuss some of the factors that can impede or promote increased participation in leisure activities and the role of support workers in this regard.

Participants

At this moment, seventy people are being supported in individual work settings throughout Mississauga. We have always endeavoured to include a "cross section" of people rather than limiting participation to those perceived as most capable or most "ready" for competitive employment. Hence the participants in Community Vocational Alternatives vary greatly in the degree of their intellectual handicap and the extent to which they have other handicapping conditions (e.g., sensory impairments, epilepsy, psychiatric difficultes). In terms of past history, 75 percent are graduates from the local segregated school for people labelled "trainable mentally retarded" or have spent a major portion of their life in large institutions. Most attended segregated workshops operated by our association immediately prior to becoming involved in the program.

Changes in Leisure Lifestyle

When an individual first becomes part of Community Vocational Alternatives, and before a job search is carried out, we conduct a personal interview with that individual. This includes the collection of information about hobbies and use of leisure time as a source of clues to a possible career interest A list of activities and a record of social integration is maintained for each person supported by the program. This is part of the monitoring process to ensure that people are not isolated and that positive relationships with co-workers develop.

A comparison of the information accumulated in pre-placement interviews with data collected from integrated job placements, with few exceptions, reflects that in almost all cases, participants have developed a broader social base.

Briefly, people:

- eat more meals in public places
- spend more time doing activities aimed to improve personal appearance
- spend more time with non-handicapped people who are not paid staff
- travel further from home for social activities
- take part in a wider range of social activities such as golf and skiing, rather than limiting themselves to more traditional ones like bowling and swimming
- plan major activities (e.g., vacations) farther in advance to suit their own schedules
- attend many staff-related events including seasonal parties, dinner dances, showers
- often develop close personal relationships with one or two co-workers.

Paul's Story

Paul is thirty-one years old. He graduated from a segregated school and worked in a sheltered workshop for nine years. He, along with the friend with whom he shares an apartment, receives support from the residential services program operated by Community Living Mississauga. While attending the workshop Paul brought his lunch from home to eat with his co-workers in the small shop lunch room. He purchased snacks from the coffee truck. At Christmas, he enjoyed a special meal of Kentucky Fried Chicken brought into the shop from a local take-out. His after hours activities included a monthly People First meeting, a weekly baseball game on an association ball team, shopping with his residential counsellor, going to the movies or flea market with his girlfriend and weekend visits with his parents. His summer vacation was spent at a cottage with other handicapped people, often taken with little advance notice.

For the past year, Paul has been working in the community as an assistant grocery clerk. Most days he eats his lunch with co-workers in the grocery lunch room; every Friday he eats at a plaza restaurant with the bakery truck driver and "a couple of other guys." At Christmas he attended a formal party and was included in some informal house parties arranged by co-workers. Recently he was invited to a "men's night out" card party. As it was held out of town, Paul was asked to sleep over. Two weeks later Paul and his girlfriend were invited to a video night with two other couples.

Paul invited two co-workers over to his apartment last week to watch a video — he sent out for beer and pizza. His summer vacation this year is a trip on a houseboat with his residential counsellor, his roommate, and some other friends who are handicapped. Paul booked his time off two months in advance and is enjoying the anticipation of a planned holiday this year.

Paul's family have raised their expectations concerning what should be happening in his life. At first they reluctantly agreed to his participation in Community Vocational Alternatives, unsure that he would be able to do a valued job in the community. Now they have bought him cross country skis and are urging him to become more involved in integrated activities.

Michael's Story

Michael is thirty-three years old. He had lived most of his life in an institution and attended a workshop for ten years. His verbal skills are limited and in the workshop Michael was a loner, seldom initiating conversation. In December 1985, Michael moved from the institution to an apartment where he is supported by our residential services program. In April 1986, he left the workshop for a community job. He now travels to work independently on the public transit, meeting co-workers en route. As a dishwasher in a large hotel, he wears a uniform and works as part of a team. Michael's social life has changed substantially. He eats his meals in the staff cafeteria and is an integral part of the banter and camaraderie of a large department. At Christmas, he attended a formal dinner dance preceded by a cocktail party. For this occasion he picked up his date in a taxi. His vacations are pre-planned. (In the past, he took trips at a moment's notice with his Dad.) His family appears supportive of his community job.

Claudette's Story

Claudette is a twenty-six-year-old woman who has been employed in her position since March 1985. Claudette currently lives with a non-handicapped roommate in an apartment. Prior to this, Claudette resided in a townhouse with three handicapped women and before that she lived at home with her mother. Claudette is involved in a variety of leisure activities with her current roommate and has increased confidence in her ability to make more creative choices in her leisure pursuits since acquiring gainful employment.

Claudette has established strong supportive relationships with her co-workers and is viewed as a highly respected employee by her employers. Claudette is consistently involved with her co-workers during her workday and is considered a confidante by two in particular. Claudette has been involved in a variety of night school courses and is considering upgrading her education. She enjoys going to movies, dinner dates, bingo, and entertaining guests at home. She also likes working out in the exercise room in her apartment building as well as attending a fitness class. Claudette travels to work each morning with her roommate. This enables her to have breakfast and conversations with a friend prior to starting work. Claudette travels home from work each evening with a co-worker. Claudette now plans her leisure activities according to her finances and is more independent in budgeting since receiving her own pay cheque.

Issues in Integration

We do not wish to suggest that working in regular community settings invariably results in a great deal of community participation. Overall most Community Vocational Alternatives participants probably have fewer important relationships and participate in fewer leisure activities than does the average person. While there is always some socializing at work, this does not always extend past the work place. There are a number of factors involved. These include: the gap between parental and professional expectations, transportation, and income level. There is not space here to expand on these. Suffice it to state that these issues, combined with variations in personality and experience, are factors in the ongoing process of leisure integration.

There are also differences in the degree of sociability of work places. In some, people see a great deal of each other outside of work. In others, contacts outside the work place are rare or non-existent. We do make efforts to help people find jobs in situations that increase the likelihood of people developing relationships. This is one reason why we place people individually and never in groups. We avoid settings where people will be very isolated or where there is a great disparity in age between the individual and co-workers.

Finally, many people who have spent their entire life in congregated, segregated settings have not had the opportunity to learn all the factors involved in establishing and maintaining relationships. It is in this area that support staff can play a major role.

The Role of Support Staff

To the extent that we accept that a major goal of integrated work settings is to promote the development of relationships, we must consciously create the expectation that staff are expected to promote and facilitate the development of these relationships as an integral part of their job.

Staff in Community Vocational Alternatives do this in a variety of ways:

Modelling — An Example

Blair had some difficulty in the areas of communication. Due to a hearing impairment his speech was not always clear and he was reluctant to use full sentences. At the outset he did not talk with co-workers a great deal. His support worker made sure she was around during breaks and lunch. Often she suggested topics to talk about or assisted with clarification of details. As time passed Blair not only participated in conversations, but also began to initiate them. Blair's co-workers paid close attention to how the support worker encouraged his participation and soon adopted a style of their own to encourage further involvement.

Learning to Reciprocate

To be considered as social equals people often need support so that they are on the giving as well as on the receiving end of social exchanges. aul did not understand that having been invited to his co-workers' ouses several times, he was expected to reciprocate. His support worker encouraged him to invite his friends over to watch videos and helped him plan the refreshments (beer and pizza, of course!)

When Blair first hosted a barbeque at his home for his co-workers, he allowed his mother and his support worker (the only females in an all male group!) to prepare and serve dinner, and he left his co-workers to help themselves to refreshments. Afterwards he and his support worker talked at length about what it means to be a "host." Blair is currently planning a second barbeque for which he plans to take more responsibility.

Dealing with Family Resistance

In situations where families are reluctant to allow their son or daughter to participate in after-work social events, support workers may have to play a very active role. Driving someone to an event, organizing transportation, or attending an event with the individual are not unusual activities for support staff. In some instances, the process of facilitating such participation is a lengthy one.

Eddie who is thirty-one and who graduated from a "TMR" school is currently employed as a lobby attendant at a nationwide fast-food franchise. The employer holds monthly evening crew meetings at local banquet halls. The evening involves dinner, employee recognition, company updates, and social activity. Attendance is mandatory and reimbursed accordingly. Eddie's family was very resistant to him attending any function in the evening. They were only persuaded to agree to his attendance when they were told his job was on the line and his support worker would accompany him. After the first two meetings "an expectation" that Eddie would attend regularly was established. His support worker gradually transferred transportation arrangements to co-workers and Eddie has continued attending these meetings. The company also sponsors about six dances a year for all employees from franchises in a geographical area. Attendance is voluntary. His family continues to be resistant to his participation in social events and it is a constant struggle to engage him in more activities. The situation, however, is improving as Eddie becomes more vocal in advocating for himself. To date, he has attended three parties.

And What About Old Friends?

Our emphasis on helping people develop relationships with their non-handicapped co-workers has sometimes been incorrectly interpreted as wanting to discourage relationships between handicapped people. It is important to recognize the validity of any friendship. In our experience many of the people whom we support do not have very many important relationships in their lives nor are they generally involved in a wide variety of freely chosen activities. There is invariably ample room to maintain old relationships and develop new ones. Particularly in the early stages we feel it is important to encourage people to maintain contacts with old friends.

Conclusion

While there is a great deal of variety in the amount of "after hours" socializing that occurs in community jobs, in the majority of cases it is greater than in workshop situations. The opportunities to be invited to a wedding, shower, or house party, to leave the premises for lunch, to get a ride with a co-worker are practically non-existent in the workshop. It has often been said that the world defines us by what we do — perhaps we should add that the person with whom we do it is important too!

We suspect that most supported work programs do not focus specifically on the issue of relationship building. And indeed our own efforts in this regard have certainly not been as systematic or extensive as one might wish. Nevertheless, the results for some people have been substantial. It would appear to us that this is an area deserving of much closer attention. The challenge for all of us is to develop strategies that will help people with intellectual handicaps become valued members of any group of which they want to be a part. Our own experiences strongly suggest that such efforts can and do pay off!

You've Got a Friend*

Pat Worth

Last year, I helped Sean O'Sullivan when he prepared the advocacy report, "You've Got A Friend."[1] It gave me a unique experience to teach a paid government advocate about the ideal of friendship. What Sean O'Sullivan learned is that an advocate is not someone who will work with a person from nine to five, then go home and leave the person totally defenceless. What he learned is that the advocate never stops being a friend. You're not a friend from nine to five. Support and caring is what advocacy is all about.

Unfortunately, for a long time this was not the case for me. I went to a sheltered workshop and a very large community living group home for a number of years and the only people I had in my life were people who were paid to be there. My life wasn't my life; it was a service. The only thing I can say about service is that you can get it anywhere; you can get it at McDonalds and they will give you bad food with it.

It's important to know what advocacy is all about. An advocate is somebody who will help you in the community by introducing you to other people, by calling you by your name, not by a label. We are people first; we should be identified as people not as a label. The label is the real punishment. It stops you from getting jobs. it stops you from

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*Presentation made to the Ontario Association for Community Living on May 26, 1988.

coming out of institutions. It stops you from living in the community. Most of our People First members who are labelled have led lives in institutions for a very long time, have been segregated, have been punished. The real punishment is the label itself. It is demoralizing to see someone as a label, instead of as a person. I am a somebody. My name is Pat Worth. I am not retarded. I don't think anyone is. I think labels are very unnecessary.

An advocate must be a person who is willing to listen to individuals not because they are being paid or not even because they are volunteering their time, but because they're willing to listen. In my own life, I had people who were paid to be with me; people who would have me do jobs at the workshop for 50 cents an hour; people who would decide that I should live in a very large community living group home; it had thirty-five residents. I had no privacy, no kind of communication with others in the outside world, in the real community, the community that you all live in.

I wouldn't be standing here talking to you today if I were still living in the group home. For the Institutional Outreach project I now work on, I go into some of the institutions in Ontario and I look at the faces of the residents and I see the signs of giving up, the signs of being afraid, the signs of not knowing what is out there. They don't have true friends, they only have each other. They have people who are caught up in the same circumstances, who are very vulnerable to the system.

What do we have in place of advocacy in this province? We have cattle prods, we have institutionalization, we have labels, we have people who cannot speak for themselves. We make decisions for those who cannot speak for themselves. There are many who are not being heard because they are institutionalized. They are not out in the community because people in the community assume they cannot be supported. Well, they can't be supported if they don't have advocates; they're right about that.

When do the punishments stop, and when will people realize that we are people and we want to be treated like real people? You all have homes. You can all go home after work and lead a decent life. I am not saying you all make a lot of money, because I don't think that any one of us can say that. But you have a family life. You have family support. You have disagreements sometimes, but you still see each other. You can go outside and talk to your neighbour and not be afraid of your neighbour calling you some kind of dirty rotten name.

In the group home where I lived, I used to try to communicate with my neighbour. I went outside one time to talk to him because he would never come in, and he said to me, "I don't know your name, but you live over there, so you're retarded." He never identified me as Pat. He identified me as a label. That was my punishment. The punishment is when people assume that you can't do things or offer friendship to others because you are disabled.

The punishment is when we isolate someone or when we put someone in a place where we know that for even one day that person cannot survive. You would say, "No! I can't live there, I can't do this job, I can't live on this amount of money." Well, neither can we. We can't live like this, but we don't have people who will sit down and listen to us, or people who will take the time to listen to us.

I grew up in a segregated school until I was about sixteen. At the age of sixteen, I didn't even know how to write my own name. There are countless numbers of things that all people in the community can't do. But there is always something people can do. We have been thought of too much as a disability. We are not a disability. We are all People First. That is how we should be identified.

My life, before I got involved in People First, was a typical formula of boredom. What I had to look forward to in the residence, if I was lucky, was watching television, and the favourite program for Friday night was "Dallas." It is a very popular show. It's all about greed, about people in decision-making positions controlling and ruining other people's lives. Our lives will always be in ruins because people don't take the time to be our friends instead of making decisions that will segregate us, congregate us, and put us in places where our lives can become completely vulnerable. We can't live that way and you shouldn't expect us to live that way.

We all have the ability to listen. Sometimes we just don't use it. We just automatically think, "I know what is best for this person." But it is the person who knows what is best for him- or herself. It just takes time, and a willingness, a willingness to be a true advocate. That will save us from the punishment, because that will bring some light into our lives. Lots of People First members have a dark cloud over their heads because they don't have advocates in their lives.

A couple of years ago, People First participated in an inquest for a person who was labelled retarded, John Dimun. John unfortunately died in some very bad circumstances. He lived in a boarding home with fifty-five residents. His needs were not met because the place was overcrowded, because John could not speak for himself and all he had was a paid advocate for a friend. No one could give him the time without being paid to listen. John was very sick. He had a liver disease, but he could not say, "Help me. I'm sick." The day he died he weighed 44 kilos (he was 170 cm.) and no one realized he was sick.

Just recently, I was involved in another case myself. A friend of mine went away with me over the Christmas holidays last year. He was living in a group home. We were one day late getting back and we forgot to call and tell them. When he got back he was told that as a punishment he would be sent to his room for one week. He had also developed a relationship with a woman in the group home and for some reason that relationship was not acceptable to the staff. She was moved away against her will, and after she was moved they wouldn't tell him where she was. I stepped in as their advocate and their friend because this is morally wrong. There is no reason to interfere with the relationship; we should allow relationships to grow. This is when the friend becomes an advocate.

I didn't have any relationships when I lived in the group home or when I was in the service system — not real relationships. Of course I had friends who were vulnerable as I was, but I didn't have a true advocate. What I was able to do for my friend last year was to offer my friendship. He and his girlfriend are now back together and living in a place of their own. There is hope they will get jobs and they have a support circle made up of friends who gather around them and support them any way they can. They will not be left vulnerable.

Punishment has meant that we have been left vulnerable. People have decided to use punishment to control our behaviour, label us, institutionalize us, and take away our opportunities. A friend will listen to our rights and choices. A friend will listen to the people who cannot speak for themselves, because, even if they are unable to say it in words, they have something to say and they will definitely convey it in expressions.

We are people who have accepted punishments because the system has a way of breaking the spirit and getting us to believe that there is no other hope for us, that there will not be a true advocate. If you break the human spirit of a person, that person is nothing. At times I said to myself when things looked hopeless for me, "Sometimes I wish I were dead. It is better than leading a life of loneliness and having a dark cloud over you."

We need advocates to bring real life into the lives of people who are missing the real challenges, real rights and choices that you all have today. You have the right to go home to a home-cooked meal and talk to your husband or wife, your family and neighbours. You have the right to go to a regular school. You have the right to dream. I am sure you had a dream some time or other. Maybe it didn't come true, but you always had something to dream about when you were a kid. You all had dreams, you all had visions. We can't have visions without advocates. Advocates will help us accomplish these visions by allowing us to dream.

People say that dreams are wishful thinking, but dreams can be reality sometimes. They can become reality with a true advocate who will be a true friend. I have finally made it. Well, I haven't quite made it yet, but my life is a lot better now because I have had an advocate in my life. I have had support systems. I have had people who believed in me, who did not see me as a disability. I am not retarded. I am Pat Worth, member of People First, identified as a person first, not a label.

I don't know how many of you have seen *Cry Freedom*. It is a movie that was made about the suffering of blacks in South Africa. People there are segregated and isolated. They are identified by the colour of their skin and left vulnerable to the system of white rule, a system that doesn't believe in sharing the community with black people. Because of the colour of their skin, they are shot at in the streets. They don't carry firearms, so they are vulnerable.

In Canada, people with a mental handicap are left vulnerable to society. Society doesn't give us a fair chance. In a court of law, it is a judge or jury that decides the punishment for a person who has to be punished for crimes he or she committed. For people who are labelled "retarded," people in society stand in judgement, and our only crime is that we are disabled. If that is a crime, then it's everybody's crime.

Maybe our system doesn't shoot at us on the street, but it has done everything in its power to break the human spirit and make it impossible for us to survive. We need to survive with you or else we won't survive at all. We will just become vulnerable people wandering around wondering what is going to happen to us and afraid to think about what it means to live a real life. The community sounds like a scary place to us because all we have known is institutions, group homes, and workshops. When you don't know people in the community it becomes frightening because you don't know if you will have a friend there. If only someone like yourself would walk up and shake a person's hand and say, "I want to be your friend. I want to offer my support. Let's sit down and talk. I'll listen." Maybe it will take a little more time for you to understand our words and maybe we do have speech problems sometimes, but half the battle is to listen. Even if you don't understand you should still listen and some time maybe you will understand.

We all have to have people in our lives who support us. It is time to stop punishing us. Give us some friends. Reach out and be a friend.

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[1] "You've Got A Friend: A review of advocacy in Ontario," is a report published by the Ministry of the Attorney General of Ontario, 1987.

Creating Cooperative Play Environments as a Strategy for Integration*

Judith McGill

Why Cooperative Play?

Society as a whole has begun to question the traditional approaches used to meet the needs of persons with disabilities. Services to persons who have disabilities have been segregated and have effectively limited opportunities for participation in the community. There is now a widely accepted belief that persons with a disability have every right to participate in their communities as much as possible and with as much support as necessary. This belief is based on the premise that everyone is a developing human being and therefore should be treated with respect and dignity and given equal opportunities. As a result, there has been a general trend toward providing integrated services for disabled persons within the community that are based on individual needs and the principle of normalization.

Normalization has been described by Wolfensberger (1972) as both a process and goal. It involves all of what we do and say in our interaction with handicapped persons. The "process" relates to how we treat and work with handicapped persons. The "goal" is to enable handicapped people to live and appear in a way that distinguishes them as little as possible from the rest of society. Normalization implies

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selecting methods that are as close as possible to typical ways of doing things. It does not imply making the handicapped persons "normal," but rather giving them every opportunity to fit into society (Alberta Dept. of Recreation, 1982, p.25).

In recognition of this general trend, recreation service providers have begun to make programs and services available to everyone in the community. They have started to ensure that persons with disabilities have equal access to programs and that they are given the support they need in order to participate in these programs with their non-handicapped peers. This is all part of an attempt to help handicapped persons choose a more active leisure lifestyle and at the same time help them to be less dependent on segregated recreational services and be more a part of the community. By taking this approach to service delivery, recreation providers have started to respond to individuals and their needs rather than dealing only with groups of people.

While there is a steadily increasing movement toward providing integrated recreation services as opposed to segregated services, integrated services are still characterized by their developmental infancy and relative "newness." Our past experience in providing integrated recreation settings has been somewhat limited. We are only now beginning to understand what hampers and what enhances the process of integration.

As more and more people integrate play environments, we realize that the traditional approaches to providing structured play opportunities for children are less than ideal. In fact, we have some concern that settings that are traditionally competitive in nature may do more harm than good in nurturing the integration process.

It has been said that games are a reflection of the predominant values and practices of a society. If this is true, then our children's games reflect the same kind of "win at all costs" philosophy that pervades our post-industrialized society. What has happened to our games? They have become marred by destructive competition, destructive aggression, sadistic rivalry, dehumanization, fear of failure, feelings of rejection, cuts, drop-outs, wounded self-concepts, a lack of fun and a loss of love for activity. Our children have become casualties to our competitive insanity (Searle and Sutton, 1978).

Today, as adults who provide structured play opportunities for children, we reinforce this competitive attitude by providing only competitive structures and teaching only competitive games to our children. What this means to children is that only a few of them will be able to fully escape the feelings that accompany the fear of failure and the fear of not measuring up. A feeling of failure is built in to the game for at least a few of the participants.

> A basic structural problem exists in most present day games due to the fact that two or more people or teams are basing their feelings of success and adequacy upon something which only one can have — the scoreboard victory (Orlick, 1978 p. 145)

There are currently few if any real alternatives to competitive games in educational and recreational settings. This is unfortunate since more and more children are choosing not to play competitive games and therefore are left with few alternatives. By not providing alternatives we perpetuate the problem of inactivity and "spectatoritis."

"In North America it is not uncommon to lose from 80 to 90 percent of the registered organized sports participants by fifteen years of age or earlier" (Orlick, 1978, p. 129). The high level of drop-outs in sports and physical activity have promoted people to look for alternative play structures and opportunities for all children.

Terry Orlick, a professor at the University of Ottawa, has been doing research for some time on the benefits of teaching children how to play cooperative games as opposed to competitive games. While the philosophy of cooperative games is not entirely new and has been borrowed from more ancient cultures, the research he has done in this area is new. Orlick (1978 p. 133) believes that opportunities for cooperative social interaction must be "nurtured rather than destroyed." He says that for "fun to flourish, the imprisoning chains of the fear of failure need to be removed," and be replaced with feelings of acceptance, cooperation, mutual assistance, and positive interaction.

Terry Orlick has taken the fundamental philosophy behind cooperative games and developed games that can easily be adapted to today's society. As the leader of the Cooperative Games movement across Canada he has been instrumental in making cooperative games a viable alternative.

Cooperative Play and Integration

It is because cooperative play focuses on setting the tone for developing a positive sense of self and others that we feel it is appropriate for integrated recreation settings.

In a study done by Hutchison and Lord on the major barriers to integration, they cited inadequate leadership and inappropriate programs as major obstacles to integration. Their major criticisms of integrated programming was that it was "competitive, formal and skill oriented, instead of developmental and humanistic, allowing all persons to participate at their level" (Hutchison and Lord, 1979, p.23).

To facilitate integration, it is important that play providers be able to create an accepting and supportive environment where children feel free to interact and to play with one another. The environment should be one where all children, regardless of their skill level, are encouraged to participate to the best of their ability. It should be an environment that is fun and motivating and that permits each child to develop within his or her own growth and development patterns. The environment should not be one that puts undue stress on skill level or on negatively valued differences.

To create this kind of accepting play environment for children it is important that play providers know what they are capable of influencing in the environment. The play provider controls the environment by structuring games and activities and teaching what is appropriate and acceptable behaviour within the group. Due to the nature of competitive games, it is difficult to create an accepting, supportive environment because the play provider is always being put in the position of accentuating differences and producing winners and losers. By playing cooperative games and structuring cooperative activities, the play provider increases the mutual dependence and interaction between participants. This helps the integration process by increasing the level of social interaction and de-emphasizing individual differences. Both of these factors help to create an accepting and sharing environment.

Orlick believes that "cooperative games may be of particular significance to children who are shy or withdrawn, who lack self-confidence, who feel insecure, who don't feel liked, who have inadequate social skills, who have not learned to respond in a friendly manner, or who are reluctant to approach problems or people" (Orlick, 1978, p.142). While this may be especially pertinent to disabled children who have been deprived of past opportunities to learn appropriate social skills, it is just as relevant to other children.

Cooperative games enable play providers to facilitate positive social interaction by having children share common goals. They help children learn positive things about themselves and their playmates because the fear of failure has been removed and children feel freer to express themselves and to share in the fun.

Although most people will agree that play is important to a person's overall development, they rarely understand the devastating impact it has on children to be denied opportunities to play.

The Play and Development of Children with Disabilities

As play providers, we have felt in the past that the child who lives with a handicap has neither the time nor the skills to participate in structured play experiences. As justification for taking this position we cite their inability to engage in anything but solitary play. This puts us in a Catch-22 situation, since the longer we deprive children of structured play experiences the longer this will be true of their play behaviour. By not providing normal play opportunities to these children we are depriving them of the most enriching and growing experiences possible.

From what we know about play development, "it appears that the play of disabled children follows the same patterns as that of normal children" (Dartner, 1969). This would indicate that handicapped children do not learn to play any differently than their non-handicapped peers, but they do learn to play at a slower rate. This may be due to a number of factors, not the least of which is a lack of play opportunities. Nevertheless, it does point out the importance of providing structured play opportunities for handicapped children. Hutchison and Lord (1979, p.6) suggest that:

> For the child with a disability, play experiences are especially important in order to maximize the rate of physical, cognitive, and social development. A child who

> is blind learns to manipulate objects, explore the environment, and move in a coordinated fashion. A child who is mentally [handicapped] demonstrates confidence in playing and interacting with peers, due to early stimulation and play experiences with family and neighbourhood children. Unfortunately, many children with a developmental disability have few opportunities to play and interact with non-disabled children.

Integrated play provides a stimulating and highly motivating setting for children with disabilities. It provides a setting that gives handicapped children a chance to imitate and model the play behaviour of their non-handicapped peers. Likewise, integrated play environments teach non-handicapped children some very valuable lessons about their peers.

Research on integration has shown that there are numerous benefits when disabled and non-disabled persons have opportunities for **quality** interactions. Non-disabled persons learn by being teachers, improve their attitudes by becoming more accepting of individual differences, and learn that a disability need not be a handicap as first presumed (Hutchison, 1978, p.7).

Cooperative Games and Integrated Settings

In integrated settings where we are providing structured play opportunities, it is important that we have control over the game rather than vice versa. This is important so that we can use the game to our advantage and to make sure that everyone is involved and is having fun. The game should be flexible enough to meet the needs of the people in the group. The less control leaders have over the design of the game, the less able they are to facilitate the integration process.

Cooperative games have been designed so that they can easily be adapted to a specific group or a specific play environment. The rules are flexible enough that they can be changed to suit the needs of the group. These games are particularly suited for use in integrated settings because they reduce the unwanted anxiety that competitive games often produce. Cooperative games remove the fear of failure and rejection that often accompany games. By taking a non-traditional approach to teams, children with all levels of skills can feel a part of things and get involved. By using different approaches to scoring, children are given more chance for involvement, skill repetition, and accompanying feelings of success and achievement.

Cooperative games encourage children to work together as partners and to support each other. This makes it easier to incorporate a support person into the activity for children who may need it. The supportive environment helps to create a spirit of acceptance, which in turn enhances the integration process.

Cooperative games are taught mainly through demonstration and "doing." This makes it easier for children who have difficulty listening to a lot of instructions. For the most part, the equipment used in cooperative games has already been adapted to make it easier for everyone to handle (soft balls, large balls).

In cooperative games, children are given the choice to participate at the level they want or choose. Players are also given some responsibility for making sure everyone is involved.

To adapt the game to the needs of the group, it is important to understand which game variables can be manipulated.

Game Variables
(Questions to ask when adapting games)

1. **Players**: How are teams formed? Are teams evenly matched? Can you rotate players from team to team? Do you need to use teams? Can players be matched or paired up to play the game? Is the game suitable for the number of players? Can the players have some control or choice in the game or as to how the game is played?
2. **Goal or Objective**: Is the objective of the game challenging enough? Is the objective attainable? Have you started out by setting simple objectives and moved to more complex objectives when the group is ready? Does the objective match the skill level of the participants?
3. **Equipment**: Is the equipment threatening or is it easy to handle? How many balls or pucks are used to maximize involvement and activity? Is equipment used in novel or exciting ways?
4. **Type of Scoring**: How much skill is required to score a point? How must players interact before a point can be scored (i.e., co-ed

passing, position passing). Are points scored collectively? Are scores reversed? Are scorers rotated between sides? How many goals are there? What size are they? Do goals make it difficult to score?

5. **Type of Interaction**: How have you used different kinds of body linkages (i.e., link arms, walk back to back) to structure positive physical contact? Does the linkage suit the ability and the movement patterns of the players? Are you encouraging cooperative interaction and mutual dependence between players?
6. **Movement Patterns**: Have you experimented by suggesting different kinds of movement patterns in the games? Have players had a chance to suggest ways to move? Do you give "permission" for a range of movements to be acceptable?
7. **Limitations**: Have you set rules and boundaries to ensure safety? Are boundaries suitable for the level of activity?

By addressing the questions related to these game variables, cooperative games can be developed that provide a positive play experience for all children.

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David's Sport Involvement*

Christie Cass

I would like to submit this brief resume of my son David and his involvement in sports.

David was born thirteen years ago and shortly after his birth we were informed that he had Down Syndrome.

It was not long after David's birth that we were aware of the fact that new words were creeping into our vocabulary. Words like "normalization" and "integration" were becoming very familiar and meaningful to my husband and me. We were determined right from the beginning that we were going to do everything we could to give David the opportunities to live as "normal" a life as possible. This meant that David would be integrated in all his activities in his family, neighbourhood, church, school, etc. We were well aware that this would require varying degrees of support that would be provided initially by my husband and myself.

Both my husband and I are very athletically oriented and get a great deal of pleasure from sports and physical activities. We felt this would be a most enjoyable outlet for David and would be a life-long source of pleasure for him.

I learned from my early readings that children with Down Syndrome typically have poor muscle tone or "floppy muscles." This

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made me investigate ways in which I could help David develop strength, flexibility, and better muscle tone. At the age of three months, David began a program of physiotherapy. The therapist came to our house and worked with David, and I would carry out the program on a daily basis.

Swimming was the first "sport" that David was taught. We felt it would not only be good exercise for him and lots of fun, but also a "must to know" as we have a cottage on a lake with deep water at the shore line.

Teaching David to swim was a long and often stressful time as David had to overcome a fear of water before he was able to relax enough to attempt to swim. He now loves to swim and this love of swimming and the water has been great incentive for him to learn to water ski. He has been water skiing now for four years. He was determined to master a slalom ski this summer, but, due to a poor summer weather-wise, he did not have much opportunity to practise, so we have next summer to look forward to his doing that.

As a family, as well as swimming and water skiing, we enjoy bike riding and snow skiing. David's favourite sports, however, are team sports — hockey, baseball, soccer, football, and basketball. He will play "pick-up" games in these sports with anyone at any time. He does, however, play hockey, soccer, and baseball on organized teams in local neighbourhood leagues.

This type of integration gives him an outlet not only for physical activity, but a great opportunity to socialize with boys his own age.

It was rather humourous one day when the CBC (Canadian Broadcasting Company) was at his soccer game filming his team. When I enquired as to why they were there, they informed me that the "Journal" was doing a program on girls and boys integrated in sporting activities. They didn't even know just how integrated the team was!

David has experienced a great deal of success in these sporting events. Scoring a goal in hockey brings him praise and recognition from his team mates. He has been on championship teams in both hockey and soccer. But winning is not the important issue here, it's the fact that David's presence on the teams has by no means been a detriment to the team's success. In fact, one year he was awarded the ESSO hockey "most improved player" award for his team.

It really has been incredible watching the process David has gone through learning the skills in these games. Hockey especially has a lot of rules and position plays, etc. Not only does David have to know the various rules, he also has to know how to apply them to a game situation. This ability to learn rules and their application has had a great carry over into his academic studies.

The coaches in these leagues have been very understanding, helpful and supportive towards David. David, himself, has been a source of encouragement and hope to his last year's hockey coach, as he has a boy of four years who has Down Syndrome. Hopefully, he too will someday be able to be part of a team like David.

All in all, David's participation (integration) in team sports has been a very positive and rewarding experience for David, his family, his team mates, coaches, league organizers and other parents.

It is hard for me to imagine what life would be like for David if he did not feel able, confident (and welcome) to go to our local park and join in a game. Because of his participation in sports he is well known in his community by adults and kids alike, and for this reason he is accepted for who he is and not rejected as an "unknown" who is constantly being bused out of his neighbourhood for "special programs." Parents in the neighbourhood have often commented to me that knowing David as an individual person with his own strengths and weaknesses has been such a learning and rewarding experience for them and their children.

The benefits of his integration have been numerous and have given David a very positive outlook on life and he feels good about himself. He is a very sociable boy and his sports integration has also provided him with the foundation of very valuable physical, social, and emotional skills on which to build in order to prepare himself for a fulfilling, happy adult life.

I feel very strongly that David and all children with handicapping conditions should be given the opportunity to participate in community activities/sports (if they so choose) with appropriate supports if needed.

Recreation is for Everyone: Getting What You Want*

Jule Hopkins

The Surrey Parks and Recreation Commission in British Columbia provides programs and support services to everyone who wants to participate. This holds true for people who require supports because of a disability. These supports might take the form of: securing a volunteer; helping to choose a suitable program; helping with transportation and physical accessibility; and offering advice and assistance to the program instructor. The Commission's goal is that the recreation experience be a positive and growing one. The supports are provided so that people with disabilities are enabled to participate with their non-labelled peers.

What is Recreation Integration?

Recreation integration is laughing, playing, participating, learning, growing, and enjoying recreation activities with typical members of the community. Integration obviously has many benefits. A mother of a young child who is labelled "mentally handicapped" wrote to us and told us about a few of them:

> He really liked the sports program and we want you to know that for the very first time, he played outside with

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*Adapted with permission from the newsletter of British Columbians for Mentally Handicapped People, July, 1987 edition.

> his sister. They were playing soccer and he did very well. He kicked the ball correctly and was actually playing appropriately! This is a first for him and we attribute this directly to his integration in the sports program.

This parent felt excited and happy that her child not only learned and developed a skill, but also that he did it with his non-handicapped peers. It is every child's right to have this opportunity. It is the responsibility of a recreation department to provide it. Sometimes, however, parents and self-advocates need to know this is the case. Integration is a right, not a privilege. Many programs will accept people with disabilities but it is simply the fact that they have never been approached before that prevents them from doing so.

What Does Recreation Integration Mean?

From the perspective of a public recreation provider, it means one can choose from hundreds of recreation programs at any location that is convenient. It is the opposite of having to take the program that is "for" labelled people. It means trying anything we want; not accepting the limited choices designed or allowed **only** for people with disabilities. It means accepting the most convenient option; not driving many miles to get to a program; not sitting on a bus for two hours in transit.

When we join a public recreation program, we exercise a choice that is ours as full members of our communities. It is your right to make this choice. You do not have to settle for programs or opportunities that **others** tell you are for you because of a label. A parent of a child who is labelled "mentally handicapped" supported this concept in a speech she made to some program instructors:

> I never knew we could get our son into so many different things. He's now doing just as many things as his brother and he's so busy and happy.

How Can I Get Involved?

Because government agencies are typically more reactive than proactive, they work on the concept of response to need. Thus, many municipalities expect citizens to be the "starters." They want you to come to them, asking and telling them what supports you need to make involvement possible. To get involved in a public recreation program, a few procedural guidelines are outlined below.

1. Local recreation or community centres are the "hubs" of public recreation activity in rural areas, small towns, and districts of larger urban centres. This is where information is provided directly to citizens on a personal level, and where many programs are often provided. Here, you can obtain a community recreation brochure that outlines programs. It is often produced four times each year. Any program can be chosen on the basis of personal interest and convenience.
2. Approach the local Community Centre Recreation Office and explain that you want to participate in a program. Be prepared to share pertinent information. This will help with acceptance and understanding. When programmers and parents support each other, integration is often easier.
3. People with disabilities often require support in order to participate. If it is important or necessary to have a support person present during some or all activities, then ask the recreation department to help you find one. Recreation service providers should be willing to help all people get involved in their programs. If they are not, it is most likely because they do not understand the need. Once it is explained, they can use their resources and contacts to find volunteers and other kinds of supports. Often, support can be found from within the program, and parents have been successful in helping program leaders structure situations in which participants find out how they can support each other.
4. Cost should not be a barrier to participation. Most recreation departments have a policy in place to assist families financially. It is important to ask about such a policy.
5. It can be helpful to communicate closely with the leader of the program, so that activities can be followed up at home.

Unfortunately, the onus is often placed on parents and self-advocates to take the first step towards participation. But with support from recreation departments, friends, and neighbours, people who want to create change and get what they want are able to do so. One parent sums up the advantages:

Our son really looks forward to going to the integrated program and he is gaining confidence in his abilities like we've never seen before.

Choices: Recreation Integration from a Parent's Perspective

Heidi Prinz

Andreas is my son. He has just turned fourteen. He has a brother who is one-and-a-half years older who has been his greatest role model. The relationship of the children is quite typical. They are very close but they know how to get at each other to start a fight. Through the years, they have had really good times playing together and they still do. Besides his brother, Andreas lives with his parents, a dog, and two cats in a house with a rather big backyard, a treehouse, and a pool. We have been here for four-and-a-half years. Unfortunately, all our relatives live quite far away so Andreas misses out on having relationships with cousins and other relatives. Friends and peers are very important to him.

Andreas has a very friendly, out-going nature and will spontaneuously start a conversation with children or adults he has not met before. He is intelligent and has a great sense of humour. He can be charming and sometimes "full of beans." He loves musicals more than anything. He also adores magic, all kinds of music, drama, dance, swimming, books and stories being read to him, hiking, and biking. He is a TV, movie, and computer games freak. He adores all dogs and cats, and most like him in return. Andreas can be very persistent and stubborn if something is on his mind. He happens to have Down Syndrome.

For the past four years Andreas has attended our neighbourhood school in the regular grades and has developed some good friendships. In the beginning he would walk to school with his brother. Now he rides his bike with his friends. He would invite one or two children over for lunch (not more than once a week) and a lot of kids come to play (and swim) after school.

Since Andreas was not accepted at the neighbourhood school in Mississauga, where we lived the first nine years of his life, it was important for him to get out into the community, meet other childen his own age and become known to the community. I am aware of this now, I don't think I knew it then. It was just that my son was so very happy playing by himself, just watching his brother play, or doing nothing at all, I felt he needed all the stimulation the community could give him. And Andreas was not too keen on the existing recreation programs for handicapped children either. At segregated skating, for instance, he made a fuss every time we went. And he learned more the first time he went out with the neighbourhood school children than all the Saturdays I had dragged him to that program. In integrated recreation, you meet more children than adults, which is not always the case in segregated recreation.

Andreas and his brother were able to attend the second and third Summer-Get-Togethers started by Dr. Marsha Forest. Dr. Forest and her staff, as well as the parents of the other children, gave me the first real assurance that this was the way to go. Individual teachers in different recreational programs have also been really supportive and have given me confidence: for instance, the Trampoline teacher who approached me to find out whether I was going to register Andreas in her program; or the Theatre teacher at the Community College who gave me a letter of recommendation and the courage to register Andreas at a two-week theatre camp. Just lately I have had support from the recreation staff of our community school who advocated on Andreas's behalf, and from an integration advocate, who helped to get Andreas re-admitted to the summer theatre school he loves so much.

Andreas had his first swimming lessons when he was about one year old. He started integrated swim mainly because there was a private swim club in our neighbourhood that offered such a service. Andreas still takes lessons and just got his "blue" badge. Now his lessons are in public pools where he is just one of ten or so children. While we lived in Mississauga, the Parks and Recreation Department began to open some programs to integration. Other programs he attended were not "specially integrated." His integration was more natural.

By the time we moved to this area I realized that integration in recreation is absolutely necessary. Andreas started with the Cubs; he even went to a one-week overnight Cub camp. At the Olympium, the sports centre where he swam, he took part in the gym program for boys, as well as a March Break Day Camp. The community neighbourhood schools in this area offer a lot of programs, like Christmas, March Break, and summer day camps and would include Andreas if we wished. He has also tried jazz-dancing (I have never seen him work harder), but gave up one year later because there were no other boys in it. For the last three years he has attended a two- or three-week sumer camp with a theatre touring company for children.

His integration in the theatre camp has by no means been easy but has taken on-going monitoring and appears to depend on the attitudes of individual teachers and administrators for its success. As well, some community schools have a theatre program, and Andreas has made real friends there. And now that he is a teenager, there are the teenage "drop-in" programs, also run by our community school. They have proven to be a lot of fun, with self-made rock videos, movies and so on. Also in our neighbourhood is a computer club where children take lessons or, on Friday and Saturday afternoon, just drop in and play computer games. Since he needs some help with reading or computer skills, there is plenty of room to interact and kids seem pleased to help Andreas or to pair up for a game with him.

Getting started is not always easy. It's a dilemma for me. Do I say Andreas has a disability? When should I say this? I am still unsure about how to go about registration in formal programs. Most times I go and register Andreas for a program because that is what everybody else does. We were able to get Andreas into trampoline lessons because his brother was involved. Many times flyers come from our neighbourhood school; that is how we got into Cubs and the computer club. In both places Andreas found a lot of peers from school. Usually I would go and visit the community school in my neighbourhood to see which programs in their new brochures would suit Andreas best and discuss any problems that might arise. This year the staff also directed me to two programs I had not known about. One is a summer day camp with the city that had previously not been open to integration and the other one is a brand new teen camp. For the theatre and music programs, I asked around and even consulted college brochures, yellow pages, etc. I found a summer camp (residential) in a church bulletin. Any new place where I registered by mail, I would phone first.

I have had numerous and varied responses. Usually the kids in the different programs are fine, even in new programs. Sometimes it is the administrator, sometimes the teacher, who is afraid. Most places like to know that I will support them if problems arise; that they can phone me anytime. At least twice it happened that the gap between my phone call to find out whether and how I could register Andreas and the reality of the actual situation was too great. In one case — a radio workshop at a Community College that sounded like fun — Andreas actually got kicked out. My phone call never got to the proper authority. The teacher had never seen a child with Down Syndrome before. We dropped Cubs after two years because we found we could not change the attitudes of the leadership. On two different occasions, I had to hire an assistant to be with Andreas. In one case, a sponsor was found to pay an assistant. The need for an assistant turned out to be far more the program's need than Andreas's. Then again, there are programs where I only hear positive things and Andreas is accepted just as any other child.

My dream is to have Andreas accepted at anything he chooses to try. I would like Andreas to be allowed to be himself without having to be more perfect than the rest of the kids. I do not want to worry about whether the phone will ring with someone wanting to do something with Andreas.

I would advise parents to find out what the friends and peers of their children are interested in. I would say, see what your child likes and decide on a program. Don't automatically take "no" for an answer. Take another parent or someone from an agency you work with (an advocate) along. Urge your Parks and Recreation and other program staff to be creative in accommodating all children. Program staff have to think about the needs of all children as they plan. Let the community know what you would like to see in place for your child. Finally, I'd like to say that it would be impossible to do everything alone. You need help at every point. You need moral support. You need to know that what you're doing is right. Get support from agency staff, friends, neighbours, and other parents. We need to create change together. It is your child's right to be part of the community.

Ten Commonly Asked Questions About Recreation and Integration

Deborah Gold

Introduction

Over the past several years as direct programmer, researcher, teacher, and consultant, I have been asked many questions about the nature of integration in community recreation programs. Despite the amount of reading that is available on the general topic and the principles, it seems many people still have questions. These questions appear to fall into two distinct categories: those focused on the "practicals," and those that emerge from individuals who question the philosophy itself. This article is intended to deal with both types of queries, in no particular order. It was my hope that it would be helpful not only to those of us who have been posing these questions for quite some time now, but also to those who are just now beginning to ask questions. The intention is also to incite readers who haven't yet begun to ask.

1. How does recreation integration work?

This question is much like asking, "How does family life work?" Like living in a family, integration is a process. It is a process of trial and error, of people working together to come to common and creative solutions to problems and challenges. But the mere pressure of challenges and the fact of an uphill battle are not sufficient reasons to quit. The deepest and most significant comparison comes when we talk about philosophy and commitment. No matter how hard life gets in many families, people often pull together and find ways to "make it work" because of their commitment to the idea of being together in a healthy way. Often, when even one member of the family loses sight of the commitment, the process begins to fall apart. How does this compare to the process of integration? Where integration, in any field (recreation, education, employment, housing) has been successful, it has been largely due to the commitment of those involved in the process, on all levels. When administrative, supervisory, and leadership personnel are committed to the philosophy of integration, they often take the time to problem-solve with parents and advocates where others overlook this opportunity. The commitment to the philosophy is tied to an ability to see people with handicaps as people first, deserving of the same opportunities to participate as other people.

So, there is no particular way in which integrated recreation "works." There are, however, a few different approaches that have been found to be successful. People with mental handicaps are at risk of losing their integrated status in a particular activity at any time. Thus, success should be defined as probably temporary and possibly momentary. This is not because the people involved are bad people. It is not because people are not committed. It is often simply because people with mental handicaps have a less than valued social standing in our society. They are thought to be less capable, and thus they often get less in the quality and quantity of regular services we receive. So they are at risk. Thus, when I talk about success in this article, I am referring to a vague notion many of us have: when a person with a mental handicap is involved in the activity or program of his or her choice, when friendly and warm social interaction is taking place between the person and other participants, and when everybody appears to benefit from the experience, and feels it is worthwhile. Let's outline a few approaches that have worked in some places.

One technique, sometimes successful, is to designate one member of staff as responsible for providing recreation opportunities to people with handicaps or "special needs." This will only be useful if that staff person feels disposed towards integration rather than creating segregated recreation opportunities within the agency. In agencies (government, semi-private, or private) where this "special needs coordinator" can advocate for integration, and has a deep commitment to the concept, there are generally more integrated recreation opportunities for people.

Agencies and associations that provide volunteer support systems, or even paid assistants, are sometimes more able to integrate people with handicaps into their programs and community opportunities. More often than not, however, agencies that do not see integration as a priority will inform persons with disabilities, parents, and advocates that they must provide their own support person to accompany the participant. This increases the struggle and makes integration seem so much harder to achieve.

A third successful approach has been advocacy. Parents will get together with others having the same experience, and they will work together to gain acceptance into a program. Where parents and advocates appear to have the most success is in situations where they work together with the direct leadership of a program to help in the understanding of the needs and strengths of the person with a mental handicap. Parents will also ask resource people in the field to help them out—people with a commitment to the principle of community integration who are willing to help solve the problems creatively.

2. What are the typical challenges involved in integration?

Outlined below are several complex challenges in the field that may or may not be challenges for you or someone you know.

a) People with mental handicaps have often had very few or no opportunities to participate in regular recreation activities with nonhandicapped individuals.
b) People spend most of their leisure with either family or paid caregivers.
c) People with and without disabilities have traditionally been sheltered from each other, thus they often have to regain the ability to know each other as people first.
d) Because of this history of segregation, separation, and congregation with others with handicaps, many community members have the false notion that only people with "special" training and indefinable "special" skills can work with "these" people.
e) One person with a disability said that she was unsure for the longest

time about the contribution she would be able to make in an integrated setting. People with handicaps are often made to feel, in subtle or not-so-subtle ways, that they are useless, and that they have much more to benefit from integration than their non-handicapped peers might have In other words, it is a challenge to think about how those without handicaps might benefit from the integration, and about all that people with disabilities might have to offer.

f) The real challenge in integrated recreation is the facilitation of meaningful relationships between handicapped and non-handicapped participants. This is at the heart of successful integration. When people with handicaps have friendships with typical citizens, the goal of community living and involvement will have been reached. Thus, in recreation settings, the challenge is to **involve** people with each other; to **engage** them in activity and interaction together. It is a reflection of the **process** that is integration. It demonstrates that there are no endings in this field, just beginnings and ongoing searches for solutions. Simplistic and superficial solutions can not address complex problems.

3. How can I open up my recreation program to people with mental handicaps?

Although this question is seldom asked, it is included here to probe the thinking of those who have not yet welcomed people with mental handicaps into their recreation programs or who have had little "success" in supporting labelled people to participate fully. I have never been asked this question by a regular recreation service provider. Why? Most professionals who have never been asked to accept a person with a handicap into their programs or settings will avoid the issue until they are asked. There is often a fair amount of resistance to the idea, and so professionals will ask questions like, "Isn't there somewhere that would be more suitable for this person?" I have also been told, "This person does not belong here. We are not equipped to deal with her problem." The speed with which people feel capable of making judgements, ones that they would never make about non-handicapped individuals, always amazes me.

Sometimes, however, a camp director, a Girl Guides leader, or a tennis instructor will ask this third question. Then, we begin the process of solution-searching again. Those trying to open recreation programs to people with a mental handicap must keep the following in mind.

a) Make sure you are open to the concept of integration. Think about your values, and how deep your commitment really is. Are you prepared to accept the challenge? Ask yourself, "If I were in a car accident and became disabled, what would I want my life to look like?"

b) Check out your attitudes. Are you the type of person who knows what's best for the participants, or will you be working **with** all people to create situations that are geared to their individual needs, desires, and strengths? True leisure is often not sought in a program. How often do you go to a program to find leisure? Ask yourself how you can be a facilitator of individualized leisure pursuits in the community, rather than a program provider who only works with structured groups.

c) Ensure that the facilities and settings are accessible to people with disabilities, in design, ease of access through transportation, and with respect to the attitudes of the people who will be facilitating integration. Also, many people with handicaps have very little extra money for leisure pursuits. Events and opportunities should be made accessible financially as well.

d) Be prepared to advocate in an **ongoing** way for the rights of people with handicaps to participate with their non-handicapped peers. This can take a lot of courage, since people's values are often deeply challenged on these issues.

e) Many programs make themselves integrated, and then meet challenges once a labelled person becomes involved. This also takes creative thinking, but can be very rewarding because each solution is based on an actual situation. For example, at a day camp in one community, the swimming pool was inaccessible for someone using a wheelchair. When a young boy who used a wheelchair came to camp, the administrator brainstormed solutions with staff and parents. The answer they found was both practical and community based. They asked a family living in a neighbouring subdivision if they could lend the camp the use of their outdoor swimming pool during the times it would be needed by the youngster's group. The pool was within walking distance; the entire group went; it was outdoors, which was more fun than the camp's indoor pool; and they sent the camp's lifeguard along to cover the liability issues. The involvement of a neighbour was a wonderfully creative solution to this problem, and the young fellow was able to enjoy all activities with his group. This camp saw an apparent barrier as a chance to make things happen.

4. Who in my community might help my child become involved in integrated recreation?

Often, parents are not aware of where to turn for help as they attempt to find integrated recreation opportunities for their children, no matter what the age of the young person. There are a number of different avenues to try as parents seek support for their integration efforts. These are organizations that might have helpful information, resource people, or dollars. The following are a few ideas to answer the "who?" question.

a) If we think of community as it is discussed in John McKnight's article *Regenerating Community* in this book (see above), we can see that the essence of community is the presence of people — usually people who are involved with each other in some way. One family I know meets important people in their community through their involvement in their church. Church members, such as the Special Education superintendant of the school board, have proven to be helpful because they knew the family in a community-based, friendly context before their help was required in a professional sense. But we can get even more basic than this in describing who could be helpful to parents. Friends provide the support parents need when they want to discuss something important or private. Parents often seek out the advice or listening ear of another parent. Some are in a similar situation and can often help us sort out the big issues from the little ones or are simply able to say, "I've been there. I know what you're going through."

b) The Parks and Recreation Department or Commission in your community can often be helpful to you as you attempt to find integrated recreation opportunities. The important note here is that not all are very helpful and not all have dealt with the issue of integration as yet. Sometimes, in fact, it is easier simply to approach the director or leader of a specific opportunity or activity, and gain access that way. Every parent who is involving their child in anything wants to avoid red tape.

c) Talk to your friends, neighbours, your child's teachers, other parents, recreation practitioners, your doctor, grocer, dentist, colleagues at work, exercise buddies, club associates, etc. about the kinds of activities their children are involved in, and how they got involved. It is important to find out what all the different options are, and what the going "thing" in your community might be, whether it's hockey, piano, gymnastics, theatre, swimming, or baseball.

d) The most important resource is often the person with a handicap. This person will be able to express interests and desires, likes and dislikes, needs and strengths. Sometimes, these are not easily expressed until there has been an opportunity to try a new activity. And, sometimes, people have had so few opportunities simply to be with their peers doing fun things in their communities, that it might not matter what they do, as long as it is with peers and friends. I know one parent who got hold of a few government dollars targeted for "skill development at home," and hired a peer to accompany his sixteen-year-old son to sixteen-year-old type activities and experiences. They go out together with friends, and everybody pitches in to help. When they arrived last winter at the hockey arena, to find that it was impossible to get to the top row of bleachers in a wheelchair, all the young men helped carry Mark and his chair up the stands to where the teenagers hang out at the top.

This young man needed friends and opportunities to be a part of regular things, and his need was recognized. His involvement in community leisure will probably gain him some very important skills quite likely more relevant to his needs than if the money were used for an in-home "skill developer." At the same time, other parents and advocates find similar "facilitators" without any money to pay them. This is, in fact, more beneficial, since the support is not dependent on dollars to continue.

e) People who work with someone in other contexts can often be urged to think about facilitating leisure and friendships. For example, if your son or daughter lives in a group home setting, it is within the purview of a home service to provide opportunities for people to be involved in leisure and community. The challenge is really the situation itself. If there are four or five men and women with deep needs for involvements and relationships living in a place where most relationships are with paid staff who work on shifts, the challenge is to urge staff to think about people's real needs, and how these could best be met. For example, rather than attempting to be your child's only friend, a staff person's role might be to help him or her become a member of a club.

f) Often the most helpful people in a community are regular people who do regular things. Perhaps because they have had little exposure to the issues in the field, they often have not yet formed a "for or against" position. Thus, they are very seldom close-minded, and can be quite receptive to new ideas. They say things like, "It makes sense to me," and "well, that seems like it would be a basic human right." These "regular folk" are refreshing to talk to and often have good ideas when we run out because they have no vested interest in the issues.

5. Should adults with mental handicaps go to summer camp?

Summer camps and winter retreats for adults were started twenty to thirty years ago by parents who wanted their sons and daughters to have something to do and somewhere to go during the summer months. As the children got older, there seemed to be very little for them to do, and they were used to going to camp, which many of them enjoyed.

Today, we know that there are many problems with camps for adults with disabilities. If we begin by asking, "What are people's real needs when it comes to leisure?" we might see what an appropriate summer would look like for people. Everyone needs the opportunity to experience a vacation at least once a year, and sometimes twice. This vacation might be two to three weeks long during the summer, and might involve some travel with friends and companions. Adults in our society do not usually stop work for an entire summer unless they are planning travel in Europe, or something similar.

Many people rationalize summer camp experiences for adults with a mental handicap by saying that many non-handicapped adults go to Club Med and similar resorts for camp-like experiences. They neglect or forget to mention that Club Med type resorts are located in fabulous southern climes where very highly valued citizens gather together for all kinds of pleasure. The similarity to typical segregated camp experiences of many people with mental handicaps is non-existent. Furthermore, in camps, even if they are called lodges or resorts, people with mental handicaps are again segregated and congregated with others with like labels. This means that every single aspect of many labelled people's lives is lived with others labelled like themselves and with paid staff and volunteers. These camps are "institutions of summer" and although they are often fun, we therefore need to be thinking about some alternative experiences that go further to meeting people's real needs for age-appropriate leisure, valued social roles, acceptance into the community, fun, and friends.

6. What are some alternatives to summer camps and winter retreats with other labelled people?

Segregated summer camps for children aren't acceptable either. Children can be supported to attend regular camps where non-handicapped children go during the summer. Sometimes, there is a need for advocacy to gain entrance but, increasingly, parents are finding regular camps that will accept their handicapped child. This is an important alternative, since camp can be a place where children learn to live and play together and where they can experience the outdoors in a mutually cooperative atmosphere. In theory, camps should be easier to integrate than schools because leisure by its very nature is unstructured, social and fun.

In Ontario, there is an organization that provides support people for children who want to attend regular camp. To understand some of the advantages and problems associated with this concept, see above in this publication, "A Look Beyond Leisure Buddy Programs."

With people who have outgrown camp and similar "day programs," the alternatives should be creative and individualized. The best way to design a creative alternative is to look at how non-handicapped people take vacations and plan from there. One or two people with mental handicaps, with attendants, friends, and companions plan a vacation together based on the person's interests, needs, and desires. Some agencies and associations are beginning to do this kind of planning, and people can now have a regular vacation, with the required support. (See above in this publication, "A Unique Camping Trip to the Rockies.")

7. Which programs in my area are integrated?

All recreation opportunities for typical citizens should be open to every citizen. Unfortunately, this is not usually the case. Usually, I refer parents and human service workers to their local Parks and Recreation Department for more information. But I try to do this only if I know that there is an open attitude to people with handicaps within the department or a particular individual there who can be helpful. Certain municipalities are more progressive than others. But there are other recreation opportunities, provided by other agencies and groups in every community. I often spend time helping people to think about all the informal groups in which people gather to experience leisure and recreation (see above, "Regenerating Community"). Leisure does not often occur in a program as such, but with friends and associates in clubs, gangs, and gatherings. Sometimes, a club can be formed around the leisure interest of a particular individual with a handicap. We are contemplating this with a person who loves woodworking, but lives in a small town where there is no such club or activity group. He has few committed friendships at the moment, and he would like more opportunities to be with his peers and do woodworking at the same time (see above, "Our Leisure Identity").

For more information about the programs that may be available in your area or region, contact your local Association for Community Living, or one of the parent groups in your community. Just because a program is not officially "integrated" does not mean it is closed to you. Also, at the back of this book is a list of potentially helpful organizations that have branches across the country. All kinds of organizations run activities and programs year round. These include: YMCA/YWCA; YMHA/YWHA; Cultural Community Centres; Boy Scouts/Girl Guides of Canada; Boys and Girls Clubs of Canada; semi-private and private camps; and other organizations such as white water rafting and canoe camps and clubs; activity clubs; cultural clubs; political clubs; musical organizations; religious organizations; schools, and many more.

8. What alternatives could I find to Special Olympics?

It might first be important to ask why we would want to find alternatives to programs like Special Olympics. Segregated sports options are often the only options open to people with mental handicaps. The rationale for grouping people with mental handicaps together rather than integrating them into regular programs and activities stems from a deep belief that this is where they belong. These organizations were started because it was difficult for labelled people to participate in regular activities. In fact, statements such as "This is where they choose to be" and "They can develop sports skills here so they can then take part in integrated options" demonstrate resistance to the idea of integration. These rationales, however, are unsound. The fact is, we too rarely put integration to the test. I once had a discussion with a staff person from a special sports organization for people with mental handicaps. He insisted that people needed his organization to learn skills they might not otherwise learn. I explained that it seemed to me that many of us learn to do leisure and movement activities not from programs, but more often from family and friends.

Some people, by segregated sports professionals' standards, would probably never be "ready" for integration if that integration were to depend on the development of proficient sports skills. In fact, by that standard, neither would I, since I am not truly proficient at most sports. Also, what tends to happen in programs like Special Olympics is that even when a few very adept and able people are deemed "ready" to join regular leagues or groups, they resist doing so because they have been segregated for so long.

Thus, one alternative to segregated programs is to encourage the staff of these programs to work more actively on integrated activity. In fact, there is a philosophical commitment to integration in place in language, but in most locales, it is ignored in practice. Secondly, the parents I know who have been successful in discovering integrated recreation options for their children, no matter what their age or ability, have been the ones who have insisted on integrated options and staunchly refused to involve their son or daughter in segregated activities of any kind (or as few as possible). This usually takes quite a lot of repetitive statements such as "NO. I want integration." But it can be done. (For a sense of the options, see "Choices: Recreation Integration from a Parent's Perspective" and "David's Sport Involvement" above and "Being Good is Not Enough" below.)

People who work in segregated recreation programs believe that segregated recreation is the best option for most people with mental handicaps. My argument is not that these programs are of poor quality, but that people's deeper needs related to recreation, such as social, friend-making, and even physical activity opportunities, are not met. The latter is certainly true for people with more challenging needs who attend segregated "sport" programs but spend all or most of their time there being pushed around in their wheelchairs and thus experience little body movement. All three of the above experiences are often the real reasons (particularly the social opportunities) that people like to go to these programs. These needs could more easily and successfully be met in integrated community settings. As a final example to illustrate alternatives, one parent reports that her daughter (labelled multi-handicapped) is to participate in her school track meet in June 1989. The children are forming teams for a race. Each team will involve a child in a wheelchair and a pusher as teammate. They practice often and the daughter is absolutely thrilled. The other children are also enjoying every minute. The alternatives are all around us. Parents who support integration wish it was not such a struggle but they feel the rewards are worth the effort.

9. What kinds of activities could we get involved in?

Recreation can be as broadly defined and as widely varied for people with labels as it is for others. Activities for people with mental handicaps should be chosen, as they are for us, on the basis of five factors:

- interest
- ability and desire
- age
- friendship-making potential
- available resources, be they financial, contacts, or supports.

Recreation also covers many areas: physical activity, the arts, intellectual pursuits, family activities, hobbies, and cultural involvements.

10. What are the *how-to's* of recreation and leisure integration? This is probably the most commonly asked question in the field today. People will phone or write wanting quick-fix answers to very complex questions. People will say they "know all that" when we speak of philosophy and commitment. They'll say, "Thanks for the refresher course in values; now could you just get on with the practicals. How do we do it?"

There is no one way to "do it." The most interesting and challenging aspect of integration is the fact that it is a *process* not an end product (Hutchison and Lord, 1979). This means that it involves, although not exclusively, the following components:

a) People need a deep commitment to individuals who have been devalued and excluded. This requires that people involved in the process receive ongoing value-based training that will encourage them to think about the experience of social devaluation in a deep and meaningful way. Any training experience or interaction with people who have handicaps, which urges professionals to question and constantly upgrade and change their actions towards integration, will be beneficial. Parents also need opportunities to get together with other parents and listen to each other's stories. They need to gain strength from the experiences of other parents and to hear advocates and professionals speak about integration.

b) People need to *ally* themselves with people with labels, and truly listen to them, to hear about their real needs.

c) The process involves thinking about what would make sense and be right if the person did not have a label, and then applying those principles to the situation. For example, those who do not live with labels experience people moving in and out of their lives on a regular basis. They have friends, participate in a wide variety of activities, and change lifestyles depending on who they are and what life stage they are in. The lives of people with mental handicaps are often far more controlled than this. They have decisions made for them, and seldom have assistance in deciding for themselves. What they participate in, and with whom is not usually a matter of choice. And when people are invited to participate in the lives of people with mental handicaps, they are often paid in some way, whether with dollars or other rewards. Parents and professionals alike need to understand that people with labels have the same amounts of love and affection to give to a relationship as those without labels. There are many people in our communities who would and do respond positively to the idea of spending leisure with a labelled person. These people must be invited to be involved with the expectation that everybody, not just the handicapped person, will benefit from the relationship.

d) Once commitment and philosophy are in place, and are safeguarded through ongoing opportunities to reflect and think, the process is made stronger by planning that is geared towards the needs and strengths of each individual. This involves sitting down with people who are concerned about the situation of a person, and planning based on the wishes the person and his or her family have, the strengths and needs of the individual, and the input of each individual in the group. Whether we call this "lifestyle planning," "leisure planning," or "action planning," it is based on the concept that people often need supports to be a part of things. We so often search for services to meet needs, rather than seek the support from the natural networks around us. Natural networks can be used much more often to support people with handicaps so that segregated, expensive, and unnatural services do not have to be sought.

e) Every community in Canada that has responded to people with handicaps by providing integrated opportunities, has done so in a way unique to their community and region, and in response to the needs of the people involved. There are as many creative problem-solving techniques as there are people who are a part of the process. Sit down with others in your area who are concerned and, with the goal of integration in mind, think about creative approaches. Many citizens contact those living in other communities or contact The G. Allan Roeher Institute for information about what is happening elsewhere in the country, to get ideas or to ask for consultation services.

There are no quick-fix answers here. It has taken a very long time to get people with mental handicaps into the vicious circles that are the downward spirals into segregation and isolation. It will take initiative, creative and progressive thinking, and ongoing commitment to meet the challenge of making real social change in this field a reality — the challenge of turning these spirals upward.

Reference

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Being Good is Not Enough

Margaret E. Brown

It was clear from an early age that Philip was not exactly like "the average child" and that much of what he would accomplish in life depended largely upon the opportunities made available to him. As his parent, I soon realized that for this to happen, I would have to be knowledgeable and up-to-date on the current best practices. I would need to be willing to constantly seek out the existing options and/or create new ones as necessary.

At first, this seemed like a manageable task. After all, with three older children, I was not exactly inexperienced in addressing the medical, educational, social, and recreational needs of the family. However, attempts to provide experiences like his sisters', and to provide supports where necessary, led to fewer benefits for Philip than were initially anticipated. I consequently found myself questioning and analyzing not only what we were doing for Philip, but also what we had done and continued to do for our daughters.

What was it that helped our daughters' lives progress reasonably smoothly? They had family, neighbourhood, school, church, and recreation activities to help them grow and develop into relatively happy, healthy, participating young adults securely connected in our community. Philip had access to all those activities too, but a substantially different outcome soon became obvious.

Like most children in Nova Scotia, Philip started public school when he was five years old. Unlike most children, he was bused across town to a special education class designated for the "trainable mentally retarded." Knowing he would receive a public school education was reassuring at the time, but there were concerns too.

To counteract the negative impact of spending his entire school days with children who had mental handicaps, we sought ordinary, popular, extracurricular activities in the community for Philip. Many of these were family activities such as family swim sessions at the YM/YWCA, tobogganing on the nearby hill, or skating at the local arena. In those days, the family also spent part of the summers at the cottage on a lake, or went camping. Throughout the year, we would frequent children's concerts, museums, children's theatre and the like.

Philip had little difficulty learning the necessary skills to take part in the various activities. His apparent enjoyment in these was tempered by the fact that he had only his family members with whom to share the experiences. At the time, he had a severely limited, if not totally absent, ability to engage or be engaged by other children involved in the same activities.

In reflecting upon his sisters' experiences at the same age, it was clear they became involved with other children even during activities we did as a family. For example, during swimming or tobogganing, they played with other children whom they either knew from school or had just met. Why was this not happening with Philip?

Pondering this question, I thought perhaps he needed more opportunity to be involved with children on a regular basis. At home we began to work on useful play skills such as playing board games and card games. Perhaps this would open doors to more meaningful interactions with neighbourhood children. But it didn't.

Sunday school provided some continuity for being involved with a group of children from our neighbourhood. Perhaps this would help Philip connect with children. But it didn't.

When Philip was about eight years old, new opportunities presented themselves to assist in his growth and development. We moved into a community that had a mini-soccer league for children. Philip enrolled. Being a rapid learner of any ball skills, he quickly became technically very good. His knowledge of game rules was less well developed, but that was also true for most of the eight-year-olds on the teams. Surely being a member of a team in a league would lead to a friendship or two. But it didn't.

Why was it so difficult for Philip to gain a sense of belonging and to make friends? This had never been the case with his sisters. Perhaps the soccer season was just too short. Perhaps something that lasted throughout the year would help. The same year, Philip joined the Cubs in a neighbourhood church and continued in the group until we moved away about a year and a half later. The duration and continuity of his involvement in Cubs, and the "do our best" and "help one another" orientation seemed to set the right conditions for a friendship to bud and blossom. But it didn't.

At home, Philip learned to roller skate and to ride a bike. Believing these to be very highly valued accomplishments with young people, we thought neighbourhood friendships would naturally develop. Philip would have a shared interest, a shared value and a shared skill, and his connecting with other children would surely happen now. But it didn't.

Family activities such as swims, picnics, parades, cross-country skiing, concerts, restaurant meals, continued. Most often some other family or friends would go along with us. While his sisters had little difficulty in making friends with the children involved with these outings, Philip and the other children remained mere acquaintances and had difficulty getting beyond the politeness of a greeting.

When we moved to a new city, Philip was about ten years old. While school was still a "TMR" class across town, there were some attempts at integration with non-labelled students for a brief part of the day. Perhaps this was the missing link to building friendships. But it wasn't.

On most days after school, Philip travelled by public bus to the university to wait to drive home with me. While this denied him an opportunity to be in his own neighbourhood in after-school hours, we were not concerned, as years of experience had taught us that these were mainly lonely hours for Philip, without friends. As it happened, the time at the university proved to be great fun for Philip.

Typically each afternoon many of the students, mostly men, played a pick-up game of football in the courtyard. Philip's ability to quickly learn new ball skills earned him a chance to enter the games. More importantly, the students were willing to accommodate Philip's tremendous desire to participate with them. Philip was in ecstasy! He found himself in a group of dedicated football nuts. Not rain, nor hail, nor sleet, nor snow interfered with the game. They played every day without fail.

Philip's football skills improved remarkably. The young men continued to challenge him to learn more refined skills and to accurately follow the rules of the game. Philip continued to successfully meet these challenges. It was clear that Philip was becoming a very competent young athlete.

But an uneasiness kept creeping in on the joy of seeing Philip so happy and seemingly successful. Something was not quite right about this. What was it? He was wonderfully happy. He was learning and growing in a valued sport. He was well accepted by his teammates. Teammates! That was it! Philip's teammates were not his peers! These people were ten or more years older than Philip. He had little in common with them other than the love of the game. He was spending every afternoon with them.

As I thought about his sisters' experiences, I realized that I would have been very concerned had they spent much of their spare time with people ten years older. To be involved with people of varying age groups is definitely healthy and beneficial for all concerned. But Philip's involvement was unbalanced and excessive. I felt I would now have to redouble my efforts to have him engage in more meaningful contact with mates who would be closer to his own age.

After looking for community recreation programs that might fill the bill on Saturdays, I enquired about the advertised "Integrated Gym and Swim" programs. While the intent was to bring together children with and without disabilities in a recreational setting, children without disabilities almost never registered for these programs. This would amount to one more segregated environment for Philip and would defeat the purpose of building relationships with his non-labelled peers.

Next, we discovered the YMCA offered group instruction for youngsters in raquet ball. Philip was interested and subsequently enrolled. This proved to be less successful than other sports that he played. The wait time involved when teaching the game to a group led to boredom and a general lack of cooperation. I had thought that perhaps a sport played in pairs might facilitate the development of a friendship. But it didn't. That summer Philip became a stronger swimmer and was able to join the gang at the lake in swimming from one cottage to the next. Frisbee, baseball, tetherball, badminton, and soccer were enjoyed by all interested children of all ages. Philip finally seemed to connect with other children, with lots of carry-over from one activity to another and from day to day. At last Philip belonged, in much the same way as his sisters.

In pondering the reasons for this success, two factors appeared substantially different from those present during our previous efforts to facilitate relationships. First, the families who came to the lake in the summer came from all over. Very few of the families lived near each other during the remainder of the year. Consequently, all children arrived at the lake on an equal footing; none had a shared school or neighbourhood experience; all had to establish new relationships from scratch. Secondly, the relatively stable population of families at the lake throughout the summer, provided weeks in which a climate of acceptance and sense of community could develop.

I was dreading the end of this wonderful summer and a return to Philip's more usual life of separation and loneliness, but a surprise was in store. Philip's educational status was reclassified to "educable mentally handicapped" and he would be moving to a new special education class that happened to be located in our neighbourhood school. What a lucky coincidence! Not only that, but this school had a definite emphasis on sports, particularly basketball, with courts both indoors and outdoors. All the right ingredients for building friendships were in place. Surely the success of summer would lead to success in the school year. But it didn't.

The special education classes were located in a section of the school largely separated from the remainder of the school, with the nearest regular classes being for much younger students. The sports activities were not available to the special education students either during or after school hours. True, Philip did walk to and from school, but since none of his school day was shared with other students in the school, he was viewed as a stranger.

Early adolescence is complicated at the best of times. Philip's attempts to connect with young people in the school and neighbourhood were sincere but imperfect, and were almost always rebuffed. His attempts to engage with children younger than himself were largely thwarted, dictated by fear in the minds of parents and teachers who were operating on the basis of antiquated misinformation. Philip's frustration grew. He sent this message with his behaviour, and discipline difficulties began to appear at school.

I was perplexed as I thought about this sad turn of events. His sister had attended this school. Her years there had been relatively full and happy, with many friendships established and maintained. Even her mild interest in sports led her to play on the school volleyball team one year. Why was it so impossibly difficult for Philip?

The only possible rational explanation, despite my inability to always think about it rationally, was that the separation of classrooms and programs for the labelled students created insurmountable barriers to the normal growth and development of natural friendships. The implications of this thought were so enormous that I needed time to digest it.

In the meantime, the priority continued to be to provide Philip with opportunities to feel some sense of achievement and belonging. He enjoyed after-school classes in water polo at the community pool and mini-basketball at another school. While less optimistic than previously, I still hoped that perhaps one small step toward making a friend would occur. But it didn't.

The community ball field, tennis courts, and playground located across the street from our house afforded ample opportunities for various sports and games. As in the past, Philip found himself well accepted in neighbourhood games with the men who often played pick-up on the week-ends. Interactions with his peers, however, were strained unless mediated by a valued adult (real or imagined male "jocks" meet the criteria, mothers usually do not). These interactions ceased when the mediation ceased.

Sometimes Philip was allowed to invite himself to play with children his age in a game of baseball or soccer already in progress. He was allowed, I guess, because he was good; in fact he was often better than many of the young people already playing. But having the skills just did not seem to be enough to earn him an invitation from the others to play the next time.

Over the ensuing months I tried to make sense of what was happening to Philip. In early adolescence, he was a very accomplished athlete in a number of sports; he was social and gregarious, and loved to be involved with people. He had a winning smile and a great sense of humour; he was good at a number of card games and board games; he was a very accepting and forgiving person, always ready to give the other a second chance; and he always seemed ready to challenge himself to try again. Why could he not make meaningful contact with anyone?

In re-analyzing our past efforts on Philip's behalf, certain truths, not earlier apparent, began to emerge. First, in all the activities, whether Sunday School, basketball, Cubs, or swimming, the children rarely attended alone. They came in little groups of two or three or four. Second, the most likely and important explanation for his is that children typically show greater interest in doing things (or trying new things) with a friend. Finally, each small group usually included children of the same age, from the same neighbourhood, in the same class in school, engaging in several other activities together.

Again to compare Philip's experience with that of his sisters, the above pattern was true for them. Virtually all of the their activities were done with a couple of friends who were their classmates living in the neighbourhood. They joined any new, larger group with an already established sense of belonging. These young people had all sorts of shared experiences to talk about — for example: what happened in school today or yesterday; what will happen tomorrow; whose dog had puppies; who is going to be the disc jockey at the dance next week; and so on. There are many "important" topics of discussion in the locker rooms or in transit to and from activities. In many ways, the learning of a new skill or sport is almost incidental to the vital social learning that constantly takes place amongst friends.

This definitely had not been Philip's experience, nor could it be. The full meaning of the negative impact of segregated special education classes was becoming crystal clear. Philip was without membership in his own community. And all the created "integrated" opportunities served no purpose other than to allow him to develop some good skills. But good skills are of little use when you are always viewed by others as an outsider or a stranger.

Shortly after this revelation, circumstances allowed us to move to a town where all students were fully integrated in the neighbourhood school. A mixture of joy and fear filled my heart as Philip started off boldly to his new school. They said all children belong here but Philip had never known anything but segregated classes. Perhaps he would behave badly. Perhaps his needs would be too great. Perhaps starting in the junior high school would not be successful.

Some fears were realized, others were not. The first few weeks Philip did indeed behave very badly as he struggled to understand this new environment and his place in it. The school lived up to its belief that all children belong and worked hard to help Philip become a full member of the school community.

The school philosophy placed heavy emphasis on physical education and fitness for all students, as well as encouraging participation in the after-school sports and recreation programs. This seemed tailor-made for Philip's interests and abilities and in many ways helped smooth the transition into the real world for him.

Philip's growth and development became much more balanced. He increased his skill and strength in many sports and learned some new ones. But he also learned to be a real team member, to be a good sport, to share in the gossip, to participate in locker room humour, to do his homework, to help younger children, to be responsible for his own actions, and the list goes on.

During his three years there, Philip played one year on the school volleyball team, and two years on the school basketball team. Recreationally, he played soccer and badminton, and did cross-country running and track. In the neighbourhood, ping-pong, air-hockey, basketball, football, soccer, and street hockey continue to be the order of the day. Downhill skiing is his newest challenge.

Philip no longer struggles so hard to belong. He has a presence in his community. He has a place to use his skills and have them valued, and to learn new ones. He has friends, classmates, and teammates.

In June 1988, eighty-four students graduated from this junior high school. In September they enter the megacomplex of the regional high school. The shared experience of the last three years, and the true sense of belonging each of these students feels, provides the secure foundation for the next stage in their educational development. How different this is from the typical movement of students in segregated special education classes. How fortunate for Philip to be a part of that established group!

Philip has Down Syndrome, has a hearing impairment, and wears a hearing aid. He has a communication impairment, and a mild cardiac problem. These facts used to dominate his life. They now have very minor relevance.

Philip has been offered and has accepted full membership in his community. Without it, he has nothing. Without membership in a community, being good at sports or anything else simply is not enough.

Conclusion: Connections

Judith McGill

Leisure is powerful. It can provide a context for friends to do things together and to share common experiences. It can be the glue that keeps relationships together or the thing that brings people together for a first time. It can provide the context for being social, the context for belonging. For these reasons, leisure can make a lot of connections for people who have been labelled. For example, leisure can be the way in which they connect up to their co-workers or the way in which they share experiences with fellow students. It can be what opens the door to new experiences and networks of people. It can be one of the ways in which people who are devalued can relate to people who have taken on an advocacy role in their lives. Leisure can provide persons with a unique identity that can influence how they come to define themselves and how others define them. Leisure identities can help people to develop valued social roles by becoming members of a particular group.

All the articles in this book talk about these subtle and not so subtle connections. In the past, leisure has been viewed as something on its own, something that should be considered after everything else has been taken care of. Very few have appreciated the connections that exist between leisure and relationships in all areas of a person's life, including work and school. This book is about making those connections clearer.

Many of the articles written by parents focus on leisure as one of the vehicles for either establishing or maintaining friendships. Margaret Brown reminds us of the importance of paying attention to the way in which friendships form and how difficult it is to try to develop relationships in only one aspect of your life. She reinforces the fact that being good is not enough: relationships build over time and need to be nurtured. She challenges us to think about how often we expect strong long-term relationships to build when there is very little in the way of common experience or regular contact to sustain them.

Relationships are strengthened when they carry over from one setting to another — from the classroom to the playground to the climbing apparatus after school to the dance lessons on the weekend. They are strengthened when they involve common interests and are nurtured when individuals can make connections between leisure and the other areas of their lives.

Judith Sandys and Diane Leaker talk about the impact that working in the community has on a person's leisure. It is apparent that the relationship between work and leisure is a mutually reinforcing one. If there are conscious efforts made at developing social contacts at work, they are likely to spill over into a person's leisure.

Likewise, by working in the community, a person is more likely to become involved in valued leisure opportunities. This can happen for a number of reasons. In the community, the individual has access to more information about what's happening, what is available, and about what others are involved in. Through a real job in the community, a person is also more likely to have the income needed for these experiences.

Leisure is defined by Charles Sylvester as the freedom of self-expression, the freedom to choose self-determining activities for their own sake. To have leisure, it is necessary to have some level of freedom. This becomes problematic when we reflect on the extent to which people who have been labelled are controlled by the services in their lives and how by being kept out of the work force, they are kept poor. Sylvester draws the connections for us between poverty and leisure, poverty and social isolation, poverty and limited choices.

Rose Galati and Colette Savard call our attention to the connection between leisure and family life. In both articles, there is a sense that it was through their families' leisure time together that they began to see the dreams they held for their children forming and taking shape. The Galatis began to see that it was possible to take both daughters to family festivities and that, in fact, it wasn't the same without them. Olivier is now for the first time taking part in the dream that Colette has had for him and he has done this by taking more control of his leisure.

The community vision that John McKnight talks about draws on the wealth and richness of information organizations, many of which are leisure related. These organizations can enhance a person's connections with his or her community. Membership within these informal organizations or associations create opportunities for people to expand their personal networks and gain a sense of belonging. McKnight advocates that this vision be a collective vision shared by many people in the community, not just parents.

Patrick Worth urges us to understand that this vision of community will happen "if someone like yourself would walk up and shake a person's hand and say, 'I want to be your friend, I want to offer my support, let's sit down and talk. I'll listen.'"

If we think of one area of life that brings pleasure, where we are social or in solitude, where we are free and unobligated, that makes life worth living, we might call that area leisure. And if we are to assist people with disabilities to become connected in their communities, we might do well to look at this area as a prime connecting agent. It is often in leisure that all people make contacts, enrich their lives, get and stay healthy, and gain a sense of belonging. Since leisure is so much connected to relationships, education, work, and daily living, we must ask what its connecting power might be — particularly for those who are still lacking community involvement in these areas.

Leisure provides important opportunities for people to start listening. Only by listening will we enable people with handicaps to make connections and relationships in their lives and dare to dream about their futures in the community.

Appendix

Annotated Resource List

Adair, B., J. Gullick, and P. Hutchison, *Community Integration Game*, Leisurability Publications, Toronto, 1982.

Play with the process. A learning tool. Available from Leisurability Publications.

Canadian Parks and Recreation Association. *Reaching Out...Joining In.* ed., Nanci Langford, 1983.

Contains reports on programs for people with disabilities, from across the country. Many are not integrated, but more related to providing opportunities for participation of people with handicaps in segregated groups.

Canadian Parks and Recreation Association and Fitness Canada. *Curriculum Guidelines for Canadian Colleges and Universities: Leisure and Disabled Persons.* Government of Canada, 1983.

A report on a national study designed to better understand and change curriculum in Canadian colleges and universities.

Hutchison, P. and J. Lord, *Recreation Integration.* Toronto: Leisurability Publications, 1979.

This book has been a resource to many educators, students, and human service workers for the past ten years. Leisurability is in the process of producing a more current text to replace this one. Meanwhile, this is the only comprehensive book on the topic in North America, probably in the world. Available in English and French.

Journal of Leisurability. Toronto: Leisurability Publications, Inc., 36 Bessemer Court, Unit 3, Concord, Ont. L4K 2T1.

A Journal that has made a commitment to publishing Canadian articles on leisure, disability, community, advocacy, and social change.

Lord, J. *Participation: Expanding Community and Leisure Experiences for People with Severe Handicaps.* Toronto: The G. Allan Roehe Institute, 1981.

This resource outlines how to facilitate community participation through the use of one-to-one support persons. It is out of print but may be available through public or private librairies.

Manitoba Department of Culture, Heritage and Recreation. *Integrated Camping.*

Marlett, N J., R. Gall, and A. Wight-Felske, *Dialogue on Disability: A Canadian Perspective.* Calgary: University of Calgary Press, 1984.

Contains resources on disability. Topics include: early intervention, special education, community housing, employment advocacy, and recreation.

McClements, J. and J. Belyk, *Integration '84, Final Report.* College of Physical Education, University of Saskatchewan, 1984.

This book documents a cooperative integrated sport project for people with mental handicaps. Available from the above organization.

McGill, J., *Play for Play's Sake: Co-operative Games as a Strategy for Integration.* Toronto: The G. Allan Roeher Institute, 1984.

This book provides an alternative approach to structuring chidren's play environments in integrated settings by using cooperative games. It outlines the philosophy of cooperative games as a strategy for integration and describes how they can be used to integrate all children into regular play environments. Included are examples of games and lists of resources.

Victorian Advisory Council on Recreation for People with Disabilities, P.O. Box 120, Brighton, Victoria, Australia 3186. *Integration Notes.*

A resource book to which inserts are added every so often. Program ideas and integration strategies.

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$12.50.

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$6.00.

Leisure Connections: Helping people with a disability lead richer lives in the community, 1989.
$12.00.

The Language of Pain: Perspectives on Behaviour Management, 1988.
$14.95

Keith Edward's Different Day, Karin Melberg Schwier, 1988.
$6.00

Vulnerable: Sexual Abuse and People with an Intellectual Handicap, 1988.
$12.50

Service Brokerage: Individual Empowerment and Social Service Accountability, Brian Salisbury, Jo Dickey, Cameron Crawford, 1987.
$16.00

Community Living 2000 (Canadian Association for Community Living), 1987.
$3.50

The Family Book: For Parents who have learned their child has a mental handicap, 1986.
$8.00

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