

COMMUNITY ACTIVITIES OF YOUTHS AND ADULTS WITH DOWN SYNDROME

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To date, few studies have examined the daily activities of youths and adults with Down syndrome who live in community environments. This information gap may be explained, in part, by the orientation of past research on Down syndrome. Until recently, research has focused on infant and child development, which is not surprising given that prior to advances in medicine (e.g. the use of antibiotics, nutritional improvements, and the introduction of modern cardiovascular surgery), persons with Down syndrome usually had relatively short life spans and often died before reaching adulthood. Most of the existing systematic behavioural research on youths and adults focused on mental development (IQ) (Connolly, 1978; Berry et al, 1984) and adaptive behaviour (Greenspan & Delany, 1983; Silverstein et al, 1985). Moreover, these and similar investigations of behaviour most often employed samples of persons who reside in institutions rather than in community residences. Because the type of residence (e.g., public versus community residential facilities) influences community participation and adaptation (Hill & Bruininks, 1981; Bruininks et al, 1981), it seems critical that we assess the activities of persons living in the community as well as those in institutions because they are likely to differ.

The study reported here was undertaken to assess the degree of community participation of youths and adults with Down syndrome. Using a sample of youths and adults with Down syndrome from the State of Rhode Island in the United States, a survey was undertaken to describe their vocational and social/leisure activities. The results of this survey build upon and augment a small number of previous studies.

Lane (n.d.) is one of the few researchers who has studied the vocational pursuits of adults with Down syndrome. He identified seventy-six adults from Cannonville, Utah, England (population of half a million) described as having Down syndrome and through a survey obtained information on their daily activities and jobs. Results revealed a striking level of unemployment, showing that of those surveyed, only one was competitively employed, one was an unpaid employee at a residential community, three were living at home engaged in household activities, five were residents at a residential facility for mentally handicapped persons and forty-seven were enrolled at an Adult Training Center. Interviews with specialist career officers concerned with job placement indicated a pervasive attitude that adults with Down syndrome were unemployable.

The survey also suggested that overprotective parents and problems in using the transportation system were obstacles to employment. In Lane's opinion, the stigma associated with the Down syndrome label leads to lowered expectations, which, in turn, affects opportunities for meaningful employment. While we suspect this situation may be generally applicable, statistics on the rate of employment of persons with Down syndrome in the United States and Great Britain remain currently unavailable.

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In spite of these negative factors, individuals with Down syndrome have demonstrated competence in vocational pursuits as evidenced in case studies and anecdotal reports. Indeed, they have been employed successfully in various capacities. Examples of such jobs include the following: librarian (Nelson, 1978), operator of office machines (Dybwad & Dybwad, 1977), maintenance worker in a business firm (Wieck, 1979), and grounds maintenance worker in horticulture (Lewis, 1979). However, we cannot specify if these vocations are typical or atypical, since normative data remain unavailable.

An investigation of the employment and residential status of 246 mentally retarded youths who had exited high school in Vermont from 1981–1983 (Hasazi et al, 1985) indicated that 46% were working in paid jobs. Of the "paid" employed, virtually all were employed in non-subsidized jobs (93%) and a small percent worked in sheltered workshops (4.4%) or subsidized jobs (2.2%). Forty-seven percent of those labeled educable mentally retarded were employed and only 14% of those labeled trainable mentally retarded held a job. The majority of youths employed were in service occupations.

Interestingly, the findings of Hasazi et al (1985) indicated that the majority of employed youths found their jobs through their self-family-friend network rather than through other institutional services, the military, or school related personnel. Thus this study provides dramatic evidence of the importance of on-going social networks for individuals with mental handicaps, but again, we cannot clearly differentiate between the employability of those persons with Down syndrome and those with other handicaps.

With respect to community social/leisure activity participation, few, if any, studies have focused specifically on youths or adults with Down syndrome. A general review of the literature on the social/leisure participation of developmentally disabled citizens undertaken by Putnam et al (1985) indicates that individuals generally spend the majority of their leisure time in rather passive, non-goal oriented activities, such as watching television or staring into space.

Crapps et al (1985) investigated the degree of community participation of 15 mentally retarded adults (etiology not identified) residing in community settings and found that the majority of subjects' time was spent in their homes. When the subjects were in the community, they participated in a very limited range of activities. Another such study, undertaken in Manchester, England (Cheseldine & Jeffree, 1981) surveyed leisure activities of mentally handicapped teenagers in 214 families. Spare time activities most frequently mentioned by parents or guardians included: 1) listening to records or tapes; 2) watching TV; 3) shopping (alone or with family); 4) trips in the car with the family; and 5) helping in the house – all activities that are essentially passive or family oriented. Cheseldine and Jeffree (1981) cited three major barriers to full leisure participation: 1) the attitudes of parents who are unaware of leisure activity needs; 2) the lack of local friendships outside the school environment; and 3) the lack of basic leisure skills.

Methods

To obtain information on community activity participation, the parents of seventy-one youths and young men and women with Down syndrome (Trisomy 21) between the ages of 15 and 31 (mean age = 21.2 years) were surveyed during the period of June, 1984 through August, 1984. These persons with Down syndrome (subjects) are followed in the Child Development Center of Rhode Island Hospital, a University Affiliated Program, which provides comprehensive services to persons with developmental disabilities. Since the Child Development Center is the only

such facility in the southeast portion of New England and provides care for nearly all persons with Down syndrome in Rhode Island, there was nearly complete ascertainment and no selection bias existed. Of the 104 questionnaires mailed, 15 were returned because the letters were not deliverable as addressed and it is assumed that these families had moved. Seventy-one (79.8%) of the remaining 89 questionnaires mailed to parents of young men (N = 46) and women (N = 43) were completed and returned.

Survey Questionnaire

A survey questionnaire was designed to obtain demographic information on the subjects, including date of birth, current residence type and locations, number of siblings, and present and previous educational placement. One section determined type of employment (e.g. competitive, sheltered workshop), salary, hours employed per week, years employed, and reasons for unemployment. The questionnaire also assessed general abilities in skills of independent living. Social/leisure activity participation was assessed by presenting a list of twenty activities and asking respondents to indicate the frequency with which the subject participated in each and if the subject was not involved in a particular activity, the reasons for non-participation or less than desired participation.

Results

The findings on residence type indicate that most of the individuals with Down syndrome lived with their parents (83%) at the time of the survey. The rest lived with relatives or friends (3%), in small group homes with one to eight residents (11%), or in foster homes (3%). None of them lived alone, in institutions, in large group homes, or in nursing homes. Locations of residences were fairly evenly distributed among urban (29%), suburban (24%), small town (17%) and rural (30%) settings.

With respect to education, most subjects under age 22 attended regular (63%), as opposed to special schools (24%), and none attended residential schools. Only three individuals were placed in a combination regular education – special education situation (i.e., partially mainstreamed), and most were in special education classes in regular schools. The majority of those persons 22 years of age and over (beyond school age) were receiving training in sheltered workshops (80%). Those not in sheltered workshops were either still in special education classes, day activity centers, or in on-the-job training.

Regarding employment, of the sample of 30 individuals beyond school age, only one individual with Down syndrome was reported to be competitively employed (for the last 5 years). He was working as a janitor and disassembling electrical parts. Seventy-eight percent of the subjects attended sheltered workshops, 15% were unemployed and the rest participated in other types of vocational training. For those receiving salaries, wages averaged \$.69 per hour, and hours worked per week ranged from 6 to 40 (mean = 31.4). Reasons cited for unemployment in rank order include: 1) ability level too low; 2) communication problems; and 3) no job opportunities. Interestingly, respondents did not check behaviour problems as a reason for unemployment.

Table 1 indicates the subjects' social/leisure activity participation. Activities which occurred with relatively high frequency were watching TV, listening to the radio or records, playing with toys or games, spending time with one's family. Active leisure pursuits, such as engaging in sports, were less common. The more community-based activities, such as spectator sports, clubs or organisations and

Special Olympics tended to be enjoyed by fewer subjects and were more episodic, occurring only several times a year. However, religious activities, going shopping, and going to movies, concerts or plays were community activities which took place more frequently. Very few individuals went out on dates (15.5%), and only did so about once or several times a year. Three major reasons for non-participation or less than desired participation in social/leisure activities were: 1) no one to accompany the individual (31%); 2) lack of leisure activity skill (29%); and 3) lack of available leisure activities (27%). Few respondents felt that transportation problems, behaviour problems, lack of communication, or community acceptance were impediments to involvement in social/leisure activities.

Table 1
Participation in Social/Leisure Activities

	N = 71	Daily %	Weekly %	Several Times Per Year %	Once per year %	Does not Participate %
TV, radio, records	68	88	10	0	2	0
Short auto trips	67	34	49	6	9	2
Spends leisure time with family	66	61	13	8	12	6
Visiting family or friends	63	13	49	19	16	3
Vacations	58	0	1	5	47	47
Shopping or errands	58	5	47	35	10	3
Movies, concerts, plays	54	0	6	26	50	18
Toys, games	53	68	24	2	6	0
Religious activities	52	8	61	10	11	10
Parties, dances	50	0	6	30	40	24
Reading, writing	46	57	26	2	7	8
Walking, jogging	44	34	23	27	11	5
Special Olympics	43	2	2	0	45	51
Spends leisure time with non-handicapped friends	43	33	28	9	25	5
Entertaining	40	8	35	10	25	22
Spectator sports	40	2	18	20	45	15
Participating in sports	39	10	31	18	23	18
Hobbies, projects	36	14	36	22	25	3
Club or organisation meetings	35	0	31	34	29	6
Going on dates	11	0	0	18	46	26

The list of independent living skills shown in Table 2 indicates the number and percentage of subjects that performed the various activities near independently or independently. As can be seen, most subjects possessed the basic self help skills associated with eating, toileting and dressing. Similarly, individuals were able to entertain themselves during leisure time. However, very few subjects were able to read books, make purchases, and plan and prepare meals.

Table 2
Skills of Independent Living Performed Completely or Mostly Independently
(N = 71)

	N	%
Feeds self	71	100
Toilets self	66	93
Dresses self	63	89
Maintains neat and clean appearance	59	87
Entertains self during leisure time	55	80
Reads safety and other functional signs	33	47
Arrives on time for appointments and other activities	25	40
Attends social events with friends	21	31
Cleans home	16	23
Reads books, newspapers and magazines	11	16
Travels safely within the community	11	16
Purchases food and other items	5	7
Plans and prepares meals	3	4

Discussion

The results of this study suggest that these youths and adults with Down syndrome are not fully participating in community vocational and social/leisure activities. Our findings on employment of adults age 22 and over are consistent with Lane's (n.d.) results – that is, individuals are chronically underemployed. It is *disturbing that of those employed only one individual was competitively employed* and others primarily worked in sheltered workshops (80%). The percentage employed in non-subsidized work was extremely low relative to the employment rate (46%) of a sample of persons labeled mentally retarded in Vermont (Hasazi et al, 1985). Even those described as trainable mentally handicapped in the Vermont sample had a much higher employment rate, in that 14% were employed in non-subsidized work. The average salary reported also was strikingly low (\$.68), and the average number of hours worked per week was about 30. These results indicate that there may be much to do in terms of obtaining employment in integrated community environments for individuals with Down syndrome, particularly with respect to providing community-based vocational training, communication skills training, and provision of job opportunities.

The data on social/leisure activities show that subjects participated in a preponderance of passive and non-community based leisure activities. These findings are consistent with the research on leisure participation of developmentally disabled citizens in general (Putnam et al, 1985). Even when community-based leisure activities were enjoyed by a large percent of the sample, the frequency of participation often was negligible. For example, participation in Special Olympics typically occurred only once or several times a year. Although a worthwhile activity in many respects, Special Olympics tends to involve individuals on an episodic basis. Preferred social/leisure activities are those which engage disabled and non-disabled individuals on an ongoing basis. The inclusion of handicapped persons in community-based recreation activities (e.g., 4-H Club, daily walking, dances, community swim) is more likely to have greater long-term value for them and is more consistent with the principle of normalization.

Many of the parents who participated in this investigation contributed written comments indicating a general frustration with the lack of social/leisure activity options for their sons or daughters. For example, one parent wrote that: "For years (her son) has had regular children to play with. Yet for the past six months or so his friends have reached the age where they are working and leaving the neighbourhood. So, after many years of activities and family and friends, he is in the house watching TV."

Survey results indicate that efforts to improve social/leisure activity participation should address three areas. First, there is a need to find community companions who can accompany these individuals to social and leisure events. Second, training in leisure skills should be offered during and after the school years. And third, a variety of leisure activity options should be made available in community settings.

Our assessment of independent living skills indicates that, in general, skill levels of subjects warranted a greater degree of participation in community vocational and social/leisure activities. Interestingly, very few subjects possessed skills in the domestic areas of house cleaning and meal preparation or in purchasing food or other items (even though 47% of the subjects go shopping on a weekly basis). We suspect that this finding is more of an indictment of our education and training programs than it is an indication of the capacities of these individuals with Down syndrome. It has been demonstrated that even severely mentally handicapped persons can acquire such skills when systematically trained in community settings (Nietupski et al, 1976).

It is noteworthy that all subjects of this study lived in community residences, and many of school age were being educated in regular schools. In the U.S.A., there have been dramatic increases in the numbers of persons with mental handicaps who are integrated into public schools (Reynolds & Birch, 1982) and community residences (Lakin & Bruininks, 1985) during the last two decades. Whether or not persons with mental handicaps, particularly those with Down syndrome, are experiencing a similar degree of integration in community vocational and social/leisure activities remains questionable, however, based upon the results of our survey. Further research on this topic is warranted and should include consideration of a variety of variables as they relate to community participation (e.g., adaptive behaviour levels, IQ levels, educational history and social service utilization.).

It is further recommended that a greater variety of activity options should be provided, for instance, community recreation and cultural activities, continuing education courses, or various jobs. Fortunately, promising programs now exist for this purpose, some of which can be put into place with community volunteers and relatively little funding. For example, Salzberg and Langford's (1981) "companionship model" pairs disabled and non-disabled adults for community leisure activities and community "Rec Clubs" provide skill training while promoting integrated community recreational opportunities (Schloss et al, 1986). Adult education programs can be offered to persons with disabilities at colleges and universities (Corcoran, 1979), and community-based competitive employment programs can be developed (Wehman, 1981). It is essential to provide these types of opportunities for meaningful involvement in community activities. In addition, an expansion of the scope of research and development in the area of community participation of persons with Down syndrome and other disabilities clearly is warranted.

In sum, much remains to be done to foster the more complete integration of individuals with Down syndrome into community structures. Increased participation

by such individuals in vocational and social/leisure activities will enrich their lives and give them the opportunities which they deserve.

Summary

A survey regarding the vocational and social/leisure activities of youths and adults with Down syndrome in Rhode Island, USA, was administered to parents. Results indicated that only one individual with Down syndrome was competitively employed in the community and that most persons attended sheltered workshops. Leisure activity participation included activities that were more passive and solitary than active and community based. Major reasons cited for non-participation in social/leisure activities were lack of companions to accompany the individual, lack of leisure activity skill and lack of leisure activities.

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