An Independent Living Skills Training Program

Maureen E. Neistadt

The growing rehabilitation and consumer movement toward independent community living for disabled adults has placed new demands on the health care delivery system. Programs must be developed for the disabled adult that provide direct training in adaptive community skills, such as banking, budgeting, consumer advocacy, personal health care, and attendant management. An Independent Living Skills Training Program that uses a psychoeducational model is described. To date, 17 multiply handicapped adults, whose average length of institutionalization was 11.9 years, have participated in the program. Of these 17, 58.8% returned to community living and 23.5% are waiting for openings in accessible housing units.

Since World War II, striking advances in medical treatment and technology have significantly extended the life span of severely disabled individuals. However, it was not until the 1960s that the issue of quality of life for the severely disabled was raised by society. In the years since 1965, Congress has enacted the following to ensure the disabled access to adequate medical care, education, and vocational opportunities: Medicare and Medicaid, the Rehabilitation Act of 1973, the Education of All Handicapped Children Act, and the Rehabilitation Comprehensive Services and Developmental Disabilities Act of 1978. These legislative gains, coupled with a rise in consumer advocacy and political activism among disabled individuals and their families, have led to the mainstreaming of handicapped children, the deinstitutionalization of adult psychiatric patients, and the establishment of patients’ rights in health care facilities. In the past 6 years, a strong movement to deinstitutionalize the severely physically disabled has grown from these roots.

Two studies have reported independent living skills deficits among disabled persons living in the community. Burnett and Yerxa (1) found that the community disabled were significantly less confident in home skills and community mobility than both a disabled group, which attended college, and a nondisabled group. They found both disabled groups to be significantly less confident than the nondisabled group in the areas of cognitive problem solving, social/recreational skills, and school vocational skills. This lack of confidence can adversely affect functional performance.

Currie-Gross and Heimbach (2) found that those disabled living in the community who see their environment as controlling them through chance, fate, or other people in power report generally greater problems in mobility, self-care, employment, and independent living than those disabled individuals who see themselves as controlling their environment through their own actions and decisions. We suggest that those individuals who feel controlled by their environment can gain a greater sense of personal causation through counseling or behaviorally oriented courses that shape more assertive behavior.

Behaviorally oriented courses can provide disabled people with the opportunity to experience success directly in dealing with community issues. Without this direct experience, disabled people cannot be expected to develop either the skills or the confidence necessary to meet the demands of community living consistently.

Short-term rehabilitation programs tend to focus on direct success experiences with functional living skills such as self-care and homemaking to speed reentry into the community. Long-term reha-

Maureen E. Neistadt, MS, OTR, is Assistant Professor, Tufts University Boston School of Occupational Therapy, Medford, MA 02155; and Kim Marques, OTR, is a staff therapist, Occupational Therapy Department, Beverly Hospital, Beverly, MA 01915.
Treatment programs continue to emphasize these functional skills. However, when this functional focus is stretched by the long-term rehabilitation timeframe, it begins to lose its impact. After years of being cared for in a sheltered environment, a disabled individual may need to relearn community skills, such as banking and comparative shopping, and may need to learn new skills, such as employing and training personal care attendants. Practical community skills training for patients in long-term rehabilitation settings is an appropriate target for occupational therapy programs in those settings.

We will examine the life skills deficits of disabled individuals who have progressed through a long-term rehabilitation setting (Lenox Hill Nursing and Rehabilitation Care Facility, Lynn, MA) and describe a program designed to ameliorate those deficits.

Life Skills Deficits
Progress in community living for the disabled person is delimited by facility in dealing with the world and resistance to institutionally fostered dependency. These factors are a function of a) the severity of residual disability; b) the person's developmental stage at the onset of disability; and c) the length of time the person has been institutionalized for rehabilitative care. Severe cognitive deficits and organically based behavioral problems limit community living and vocational opportunities far more than physical impairments. No mechanical, functional aids can compensate for aggressive acting out behavior or lack of initiative. In the absence of cognitive and behavioral problems severe enough to preclude community reentry, the developmental stage at the onset of disability and length of institutionalization since then are major determinants of rehabilitative success. The patients on the 84-bed rehabilitation unit of the Lenox Hill Nursing and Rehabilitation Care Facility fall into the following three psychosocial groups, according to the onset of their disability: a) the "psychosocially deprived" group comprises individuals with severe congenital disabilities, such as cerebral palsy and spina bifida; b) the "psychosocially delayed" group consists of those under 25 years old who were disabled during their adolescent stage of psychosocial development; and c) the "psychosocially disrupted" group comprises those injured or disabled during their adult stage of development, after successful entry into adult roles.

The life skills deficits of each group are directly related to the psychosocial developmental tasks interrupted by their disabilities. These life skill deficits are compounded by specific, organically based perceptual and cognitive deficits, but the basic life coping strategies are derived from the individual's psychosocial development prior to injury or illness.

Individuals in the psychosocially deprived, congenitally disabled group have been institutionalized for all or most of their lives in custodial care settings. While growing up, these people had no consistent adult role models, and limited social and sensorimotor experience. This is detrimental as childhood is the normal time to master the basic cognitive skills: a) learning to read, write, and do arithmetic; b) learning to form concepts; c) learning to use language to describe social and physical reality; and d) learning basic social interaction skills (3). Custodial care settings do not foster the learning of these developmental tasks, which are prerequisites for adult abstraction, planning, and social interaction. Consequently, this group has the sparsest repertoire of community living skills. Their specific life skill deficits include inadequate basic problem-solving skills and immaturity in social interactions.

The psychosocially delayed group has a greater repertoire of community living behaviors. Developmental tasks of adolescence, the time of injury for those in this group, include achieving emotional independence from parents and other adults; preparing for a consistent, intimate relationship; developing socially responsible behavior; and beginning vocational exploration. Two specific life skills deficits of this group include difficulty in dealing with authority, which often leads to rebellious, self-destructive, acting-out behavior, and the reluctance to assume responsibility.

The psychosocially disrupted group had established families and careers prior to being disabled. Therefore, their community living skills repertoire is the largest of the three groups. Their specific life skill deficits relate to their feelings of loss and hopelessness. They find it difficult to redefine themselves after losing their careers and, in many cases, being abandoned by their families.

Individuals in the psychosocially delayed and disrupted groups are also at various stages of the grieving process over injury and loss of function (4). In contrast, those in the psychosocially deprived group seem to have a less well-defined sense of loss, perhaps because they have always been dis-
abled and have never experienced a sudden negative change in their abilities. People in the psychologically deprived group have a more diffuse sense of opportunities and experiences missed, and consequently have the greatest difficulty in defining personal needs and planning ways to fulfill them.

The life skills deficits of all three groups are exacerbated by the acquisition of institutional behaviors. These behaviors are antithetical to the independent, decision-making behaviors needed to function in the community. Among the learned characteristics of chronically institutionalized individuals are a sense of timelessness, an attitude of passive waiting and helplessness, a disregard for personal privacy, a display of bizarre behaviors such as hoarding belongings or gorging food, and poor interpersonal skills (5).

To address the life skills deficits of these three developmentally divergent groups, occupational therapists at Lenox Hill developed an Independent Living Skills Training Program based on psychoeducational tenets. Psychoeducationally based programs have been used in a variety of adult and young adult populations with psychosocial and/or physical disabilities (5-9). Behaviorally oriented educational programs have also been found to be effective in changing patients’ loci of control toward the internal, more independent end of the range (10).

Independent Living Skills Program

Overview. The program stresses “role-focused” and behaviorally or action-oriented groups within an essentially academic framework. Each member in the program participates in daily one-hour classes.

The following 12 module components divide these class periods into areas that encompass life skills: 1) Activities of Daily Living (adaptive equipment, body mechanics, personal appearance and hygiene, and diet and nutrition); 2) Personal Health Care Maintenance; 3) Basic Preventive and Emergency Medical Procedures; 4) Homemaking (cooking/shopping, laundry, basic home maintenance, general housekeeping, and home safety tips); 5) Financial Management; 6) Personal Care Attendant Management; 7) Housing and Building Accessibility; 8) Vocational and Educational Issues; 9) Social and Recreational Opportunities; 10) Transportation; 11) Sexuality; and 12) Life Planning/Advocacy. Specific goals for each of the modules stress either functional independence in the daily living skills or the ability to direct these skills.

The program goals and objectives also include improving problem-solving and decision-making abilities. These goals are essential, because the program participant’s ultimate goal is to live as independently and productively as possible. A summary of some specific module goals is found in Table 1.

The number of classes in each module ranges from 3 to 15 and varies with the difficulty and breadth of the life skill being covered. Staff members from the rehabilitation services, nursing, social service, dietary recreation, and housekeeping departments provide class lectures in their areas of expertise. A syllabus for each lecture provides an outline of objectives, goals, homework assignments, and means of obtaining further information for that subject. In addition to daily classes, participants attend biweekly cooking sessions, weekly community outings, and discussion groups. The program coordinator, who is a registered occupa-

<table>
<thead>
<tr>
<th>Table 1 Module Goals</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Adaptive equipment</strong></td>
</tr>
<tr>
<td><strong>Advocacy</strong></td>
</tr>
<tr>
<td><strong>Body Mechanics</strong></td>
</tr>
<tr>
<td><strong>Consumerism</strong></td>
</tr>
<tr>
<td><strong>Housing</strong></td>
</tr>
<tr>
<td><strong>Meal planning and preparation</strong></td>
</tr>
<tr>
<td><strong>Medications</strong></td>
</tr>
<tr>
<td><strong>Money management</strong></td>
</tr>
<tr>
<td><strong>PCA management</strong></td>
</tr>
<tr>
<td><strong>Personal health care</strong></td>
</tr>
<tr>
<td><strong>Recreation</strong></td>
</tr>
<tr>
<td><strong>Shopping</strong></td>
</tr>
<tr>
<td><strong>Transportation</strong></td>
</tr>
<tr>
<td><strong>Utilizing public human service agencies</strong></td>
</tr>
<tr>
<td><strong>Wheelchair maintenance</strong></td>
</tr>
</tbody>
</table>
| **PCA, personal care attendant.** | }
tional therapist, conducts the other groups and delivers all lectures not given by other staff members. In their free time, participants are expected to complete "homework" assignments, which include written exercises and reading, attend to or direct their activities of daily living (ADL), plan leisure time activities, and attend study sessions as needed.

Before starting the classes, participants sign a contract stating that they will attend each class session or report an absence prior to the scheduled class, complete all homework assignments, request tutoring if needed, and discuss any difficulties of the program with the program coordinator. The purpose of the contract is for the participant to state his or her responsibilities and to reaffirm his or her commitment to the program.

Pre- and postmodular quizzes, a mid-term, and a final examination provide a means of assessing achievement of classroom goals. Records are kept of attendance, classroom participation, and homework completion; this provides participants with feedback as to whether they have fulfilled their contracts. Participants regularly receive a numerical score based on the average of all written tests and assignments. Community outings and participation in both leisure time activities and task groups provide a further means of assessing social and emotional development. Toward the end of the program, participants are expected to plan leisure time activities independently and explore educational, vocational, and housing opportunities. They are also urged to get involved in other community organizations, such as support groups for the disabled, independent living centers, and political action groups. Each participant is actively involved in either planning his or her discharge or furthering independent living skills.

Recruitment. Recruitment occurs 30 days before the program begins. This includes notices on bulletin boards and verbal encouragement by all team members. Patients interested in the program are urged to obtain an application from their case manager or the program coordinator. The application forms include the candidate's personal data, current employment and therapy schedules, educational employment histories, and goals and objectives in independent living. The program coordinator receives the application, an appointment for an interview is made. With the assistance of the applicant, the program coordinator completes the physical and self-care sections of the American Association of Mental Deficiencies (AAMD) Behavioral Checklist (11). The program coordinator then obtains further clinical information to complete the AAMD Checklist from social and restorative services, nursing, and recreation during team meetings and informal contact. The medical chart is reviewed last. All this information helps the program coordinator decide whether an applicant meets the acceptance criteria and provides a comprehensive overview of the applicant's behavioral and learning styles. This information is later used to formulate educational strategies for each participant.

To be accepted, applicants must demonstrate 1) a potential for independence in or the ability to direct all levels of ADL, 2) an aptitude for community living, and 3) medical and psychiatric stability. The first criterion permits even severely physically limited patients to enter. Because our facility has established a strong alliance with community agencies that search for apartments and procure attendants, community placement is an achievable goal for all patients.

Applicants that are accepted receive written notice; those not accepted are notified verbally by the program coordinator. Rejected applicants are given suggestions for a preparatory rehabilitation program to improve their chances for program acceptance. This program may include ADL training, reading and math tutoring, or weekly sessions with the counselor to examine independent living goals carefully.

Outcome. Since January 1982, 17 individuals have graduated from two cycles of the Transitional Living Skills Training Program. One graduate had a diagnosis of juvenile arthritis, the other 16 had neurological disabilities. Table 2 gives the graduates' diagnoses, average ages, and average years institutionalized.

The first program cycle included 91.25 hours of instructive classes over a 3.5-month period. The average total time each par-
The second program cycle increased both a perceived change but also a perceived in- 

change in internal locus of control. The average total time each par-

cipant devoted to the program was 112 hours. This included time spent in the classroom, in cooking groups, on field trips, in study groups, and in individual tutoring. The second program cycle included 116 hours of instructive classes over a 6.5-month period. The average total time each participant devoted to the program was 131.5 hours. The second program was lengthened to include more material and to allow more learning and processing time.

Cognitive awareness of community living skills increased dramatically in all areas, as demonstrated by average pre- and posttest scores for each module (see Table 3). All differences were statistically significant \( p < 0.01 \), one-tailed \( t \) test. Moreover, the difference between the means of all pre- and posttests was statistically significant \( t = 7.18; df = 16; p < .001 \), one-tailed \( t \) test. Posttest scores increased by more than 40 points in body mechanics, personal care attendant management, and advocacy modules. The pre- and posttests were developed specifically for the program. Content validity was established through item review by Independent Living Center and rehabilitation professionals.

Subjective statements by graduates not only reflect a cognitive change but also a perceived increase in internal locus of control. One individual stated, "There is a fear of going out independently; anyone has it whether they want to admit it or not. The program has given me more knowledge, such as how to go about getting an apartment and a personal care attendant, and maintaining my wheelchair." Another student stated that, "It gave me more incentive to go out on my own. It was hard at first for me to talk in a group; now I feel more assertive" (12).

Behavioral changes resulting from the program are demonstrated by the discharge outcomes of the graduates—58.8% have already returned to the community; and 23.5% are waiting for places in accessible apartments or independent living centers (see Table 4).

Developmentally, nine of the graduates were psychosocially disrupted, two were psychosocially delayed, and six were psychosocially deprived. Of the disrupted group, 55.6% have been discharged to the community and 11.1% are waiting for housing. Of the delayed group, 100% have returned to the community. Of the deprived group, 16.6% have returned to the community and 50% are waiting for appropriate housing.

Discussion
The program has been successful in remotivating disabled adults to acquire independent living skills. The success of the program is due to its structure and also its demand for adult role behavior.

Specific class hours, homework assignments and deadlines, and frequent quizzes and exams helped participants plan their time in a directed and purposeful manner to achieve specified goals. This structure also introduced or reintroduced participants to the time pressure inherent in independent community living.

The program instructors expected all participants to meet the demands of the program by using adult role behaviors, such as responsibility and productivity. These expectations were communicated verbally and in the written contracts, and implied that all participants were capable of adult role behaviors. They seemed thrilled by the expectation of being capable to meet program demands. This was evident in the enthusiasm with which they participated in class, tackled assignments, and studied for exams.

Another important component to the success of the program was the constant positive reinforcement provided by the instructors through verbal stroking in class and written feedback on exams and assignments. Participants were visibly brightened by this reinforcement. Grades also appeared to be an important source of reinforcement; all participants kept assiduous track of their grade point averages throughout the course. The ongoing communication between team members was essential to reinforce participants' successes and help them work through frustrations.

Coordinated team effort was critical for the psychosocially de-
Table 4

<table>
<thead>
<tr>
<th>Discharge placements</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Own apartment without services</td>
<td>1</td>
<td>5.8</td>
</tr>
<tr>
<td>Own apartment with services (PCA homemaker)</td>
<td>4</td>
<td>23.5</td>
</tr>
<tr>
<td>Lateral transfer</td>
<td>1</td>
<td>5.8</td>
</tr>
<tr>
<td>More acute care facility</td>
<td>1</td>
<td>5.8</td>
</tr>
<tr>
<td>Independent living centers</td>
<td>5</td>
<td>29.4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Discharge plans</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Application to independent living</td>
<td>4</td>
<td>23.5</td>
</tr>
<tr>
<td>center program pending</td>
<td>1</td>
<td>5.8</td>
</tr>
</tbody>
</table>

Values are results from Transitional Living Skills participants obtained in Dec 1983.

In addition to the Skills Training Program and physical therapy and occupational therapy programs, this group needed intensive cognitive remediation and basic educational training. This group has the lowest community reentry rate (16.6%), indicating that discharge planning is a longer process, requiring more staff support than for the other two groups.

One need arising from the program is that of follow-up and continued group support for participants during the lengthy, often frustrating, process of applying for housing. A once-weekly advocacy group has been established to help graduates deal with their housing search and other discharge issues.

Finally, from an administrative view, the Skills Training Program was cost effective. One full-time registered occupational therapist was able to provide an average of 68 hours of treatment per week by using the classroom format combined with individual treatment sessions. In most rehabilitation settings, administrators expect no more than 26 hours of treatment time per week per therapist when time for meetings and documentation is taken into account. Given the format of this program, one OTR was able to produce the same treatment hours of 2.6 OTRs. This is a saving in staffing costs for the facility.

### Conclusion

Traditional long-term rehabilitation programs generally do not include an intensive period of academic instruction in community skills needed by the disabled for successful adaptation to an independent life style. Skill areas such as financial planning, advocacy, wheelchair maintenance, and interviewing need to be studied and practiced extensively by multiply handicapped individuals whose rehabilitation has imposed either a hiatus or a total lack of opportunity for daily use of these skills. Issues like sexuality, stress management, and self-health care also need to be addressed to improve the disabled person's self-confidence and ability to cope. To alleviate deficits and capitalize on strengths, a psychoeducational, modular approach has been found useful for disabled adults residing at long-term rehabilitation settings.

In addition to being cost effective, group instruction creates peer support, which contributes significantly to the cognitive and emotional growth of the class members. However, further research, exploration of material resources from related field, such as adult and special education, and creation of audiovisual aids specific to community-living skills instruction are still needed. Occupational therapists also need to become active in their community's political process so they can promote and support the creation of additional appropriate housing units and attendant services for the disabled. A community prepared to receive and assist the disabled must be considered the final stage of an effective rehabilitation system.

### REFERENCES

12. Deland S: Skills Training Program—Residents' Reflections. Top O' the Hill 2:1-4, 1982 (a publication of Lenox Hill Nursing and Rehabilitative Care Facility, Lynn, MA)