



Enabling Self-Determination

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Section I: Introduction and Background

The Centers for Disease Control (CDC) estimated that 462,792 persons were living with HIV/AIDS in the U.S at the end of 2004. The prevalence of AIDS in our communities is increasing due to the number of incident cases annually (41,350 per 100,000 in the population) and decreases in mortality (1). The proportion of women among incident cases has tripled in just over a decade, from 7% to 23%, and people living with AIDS are increasingly of minority status (1). Additionally, an increasing proportion of those infected also struggle with the effects of mental illness, substance abuse and homelessness (2).

These statistics point toward the reality that AIDS is a fast growing and changing phenomenon, requiring services that can offer flexibility in how they address the diverse needs of people living with AIDS. While medical interventions have been effective in altering the prognosis of AIDS, the disabling circumstances that affect the majority of people with AIDS have not been addressed. This is because: a) few AIDS-related services focus on self-determination (i.e., being able to live on one's own and attain/maintain employment), and b) the multiple conditions and identities that characterize under-served, multi-problem individuals with AIDS mean that they do not readily fit into and cannot readily access existing services that support employment and independence. There is no clear model of service to support this emergent disability group.

In early 2000, the authors of this program initiated a Rehabilitation Services Administration project, entitled Employment Options, that offered employment-focused services to Chicago-area residents with AIDS. Results indicate that approximately 67% of the 92 clients who completed the program became successfully employed. However, nearly a third of the clients that were initially enrolled dropped out of the program within the first 8 weeks. Since many of the clients who ended their participation lived in supportive living settings, their situations were examined more closely by conducting key informant interviews with facility staff and by surveying 58 residents in the five facilities in Chicago whose mission is to offer supportive living to persons with AIDS.

Data from the survey highlight that the residents of supportive living facilities (who constitute the research target group) closely resemble the nationally emerging population of people with AIDS, in terms of gender and ethnicity. Also, our survey indicates that many are aware that they will eventually be required to

move beyond supportive living. Though they express sincere wishes to do so, their confidence for living on their own and finding and maintaining employment is severely shaken. For these individuals, their AIDS diagnosis carries uncertainty, threat, and social stigma.

Like other people with chronic illness (3,4), residents of these supportive facilities often lose their previous roles and commitments and become consumed with the routines of managing their own illness(es). Many express concern about overcoming the inertia of habitual inactivity and the challenges of instituting a daily life routine to support community living and working. Most residents lack meaningful roles for community participation or productivity. Additionally, they often have lived chaotic lives characterized by unstable living situations or homelessness, chronic unemployment, hospitalization, domestic violence and incarceration. Typical roles with which these individuals identify are often those of marginalized individuals, and, consequently, they carry a significant amount of stigma (i.e. homeless person, drug addict, prisoner, or patient). Thus, members of this population tend to lack social support and a network of peers who model community participation and integration.

Most residents also face a variety of physical, cognitive and emotional challenges that impact their functional capacity. Most (over 60%) are recovering from addiction, and over 50% have a documented mental illness. Half (50%) of the residents report serious symptoms and/or medication side effects that complicate and interfere with performing daily tasks. Most lack at least some of the basic skills that are required for independent living and employment.

Environmental factors - such as limited access to Social Security entitlements, lack of affordable housing, and attitudes towards HIV - complicate these issues. While some resources exist in the community to aid persons with disabilities to manage entitlements, find housing, and obtain employment, few residents know about or take advantage of them. Residents must navigate a jungle of poorly coordinated systems and service agencies that sometimes function with redundant purposes. Accessing these systems requires organization, determination, and self-advocacy that is often beyond their personal capacities. Moreover, facility staff, such as case managers and other AIDS service organizations' staff, is often unfamiliar with the broader array

of services available to people with disabilities, regardless of HIV status.

Nationally, programs accustomed to serving clients with a terminal prognosis are struggling to make the transition to the implementing of a rehabilitation model (2,5). Supportive living facilities for people with AIDS have now been organized to provide care to meet sustenance needs such as housing, nutrition and basic case management. Because of this transition, these facilities often lack the knowledge, skills and organizational structures for offering services to support self-determination (6).

Due to the dearth of available programs addressing the above-mentioned needs, the project “Enabling Self-Determination for Persons Living AIDS” (ESD) was proposed. This project received funding from the National Institute on Disability and Rehabilitation Research (Grant H133G020217) and was developed in a partnership between the Department of Occupational Therapy at the University of Illinois at Chicago and five supportive living facilities in Chicago. The focus of this project was to implement and rigorously study an innovative model program of services for people with AIDS. This multi-faceted, intensive, personalized, and coordinated program of services emphasizes a balance of personal development and environmental supports in an effort to empower clients to access resources and services that support their self-determination. Project staff - including peer counselors and staff at the supportive living facilities - and clients were actively involved as partners in the research process. They collaborated in the development and implementation of this programming that supports independent living, community integration, and employment.



Section 2: Guiding Framework:

An Introduction to the Model of Human
Occupation and
Application to Program Design

The Enabling Self-Determination for People Living with AIDS (ESD) project was based on two guiding frameworks. The first framework is the Social Model of Disability (7,8,9,10), which views disability as the result of interactions between the person and the environment. It underscores how: a) problems at the community or societal level, such as lack of housing and societal stereotypes, can impose disability on the individual (7,8,10,11), and b) eliminating social and physical barriers and creating proactive policies can reduce disability (9,10,12). This framework was considered in developing and implementing this client-centered program, both in decisions about content and in the promotion of self-advocacy within the client's environment. Additionally, all services were provided at the supportive living facilities to lessen possible difficulty in traveling off-site to access services.

Complementing the Social Model of Disability, the Model of Human Occupation also emphasizes person-environment interaction (13,14). The Model of Human Occupation is an occupational therapy conceptual practice model that describes the occupational nature of human beings, articulates the nature of occupational function and dysfunction, and provides for numerous technologies for application (e.g. assessments). In this instance, "occupation" does not exclusively refer to employment, but refers to the ways people spend time and energy to fulfill their life roles. While the Model of Human Occupation is explicitly meant to guide the practice of occupational therapists, many of the concepts included in the model are drawn from multiple disciplines of scientific inquiry. For this reason, a brief introduction to the model is provided here, followed by a description of how the model was used to shape program design. (Individuals who wish to learn more about the Model of Human Occupation, its assessments, or its application to people with HIV/AIDS or other disabilities are encouraged to access the resources provided in the references section).

According to the Model of Human Occupation (14), four main factors influence occupational behavior. The first three are volition, habituation and performance. Volition refers to the process by which a person experiences, interprets, anticipates and chooses occupational behaviors. Volition is a collection of thoughts and feelings pertaining to one's abilities and effectiveness, enjoyment and satisfaction, and what is

important and meaningful. Volition is made of three components: a) personal causation, which refers to one's sense of capacity and efficacy, b) interests, which refers to what one is attracted to and prefers to do, and c) values, which refers to one's world view and what is important within this world view. One's sense of self as an occupational being is represented in personal causation, values and interests. These components, in turn, influence what one chooses to do and how one chooses to behave.

Habituation refers to the processes that allow a person to maintain patterns and regularity in everyday life. Two components of habituation, internalized roles and habits, give this regularity to occupational behavior. Internalized roles reflect one's positions in the social realm (e.g., being a parent, worker, friend, sibling, etc.) Roles provide both identity and expectations for behavior. Habits evolve from repeated behavior in a particular kind of environment. They enable behavior to be automatic and to fit environmental conditions. One's daily routine (e.g., brushing teeth before going to bed) and one's manner of doing familiar occupations (e.g., brushing top teeth before bottom teeth) are both examples of habits.

Performance refers to the innate capacities that are the foundation for skilled performance. Impairments, which restrict performance, may prevent or alter how persons engage in occupational behaviors. One example of a skills impairment is short-term memory loss. This deficit can affect the way a person engages in occupational behaviors, such as, for example, paying bills and advocacy groups.

The fourth factor influencing occupational behavior is the environment. The environment is thought of as having both social and physical dimensions. The physical dimension of the environment includes spaces and objects. The social dimension includes the types of occupations that people perform, as well as social groups.

This model emphasizes that occupational behavior is always a result of the interaction of these four elements (volition, habituation, performance, and environment). Ordinarily, a single factor alone does not sufficiently account for failure or success. Consequently, the key to understanding how any person performs and experiences his or her life occupations is to examine the intersection of his or her volition, habituation, and performance abilities with the physical and social environment. Using work as an example occupation,

volitional characteristics such as world view, likes and dislikes, and beliefs about personal capacity interact with environmental opportunities and constraints to shape one's choices about the kind of work one does and the level of satisfaction one finds in his or her work. Similarly, one's performance capacities and learned work habits interact with the demands of doing a particular job in a particular work environment to affect one's work performance. Such explanations of work behavior and experience could offer a holistic and effective means of understanding a worker and developing appropriate services.



The Model of Human Occupation and Enabling Self-Determination for People Living with AIDS

Each factor described in the model is addressed throughout the ESD program. An examination of the four factors of volition, habituation, performance, and environment and their interaction helps to form this comprehensive program.

Volition

The ESD program addresses participants' values, interests, and personal causation in multiple ways. First, the structure of the program allows for the expression of interests and values through participant choice. This program was developed as a semi-structured intervention with plans for group content and service delivery. However, the program participants were allowed to influence the ordering of the groups and specific content areas. For example, at one of the supportive living facilities, approximately every four months, group participants were asked to reflect on the content they had received and what type of group content they would like to see in the future.

Participants also directed the intensity of their services, collaborating with their occupational therapist and case manager to determine how often they would access individual sessions. In these individual sessions, participants worked with the occupational therapist to explore interests, set goals and problem-solve barriers to success.

Additionally, the content of the programming, both group and individual, stressed the importance of ongoing self-assessment; thus helping to shape an individual's personal causation. Participants engaged in activities asking them to evaluate their own strengths and needs in specific areas. By practicing these techniques, participants were able to develop a more established sense of self and improve their abilities to set achievable goals. The flexibility and client-centered nature of this intervention enabled participants to draw their own conclusions about what they wanted to do in life and how they were going to achieve their goals. The intervention informed and validated participants' choices, supporting their self-determined success.

Habituation

Participation in the ESD program also challenged participants to incorporate aspects of the programming into their individual daily routines. With the start of this program, it became evident that many of the residents had difficulties creating and maintaining daily routines. Interestingly, different program intervention sites had different requirements of its residents, some mandating attendance at multiple on-site and off-site groups and others without participation requirements. Some of the facilities changed their participation requirements during the duration of this program, asking residents to maintain a schedule of productive activities. Still, attending the ESD program's group and individual sessions added some structure to the day of a resident, and intervention content directly addressed issues of routine. Additionally, participants often worked individually with the occupational therapists to discuss the following topics that promote the construction of a routine: opportunities for volunteering and education; availability of vocational programs to gain skills; strategies for regaining a healthy routine and developing positive habits.

Performance

Many participants faced challenges that affected their abilities to go back to work and/or attain independent housing: limited formal education and skills, for example: low self-esteem; fatigue; as well as decreased cognition, strength, and endurance. Occupational therapists provided participants with an objective assessment of their abilities and also helped the participant to develop skills in self-assessment. Program

staff provided opportunities for the participants to learn about and test their physical and mental skills in a number of ways. For example, therapists referred participants to outside agencies for help in obtaining a GED; learning new skills, such as word processing and food sanitation; and attaining placement in paid employment. Participants were also given opportunities to practice skills, such as public speaking, through speakers' bureaus that educate about HIV/AIDS and through formally contributing to the leadership of the program's groups. The intervention also addressed specific pre-vocational skills, such as interpersonal communication, hygiene, and time management.

Environment

Implementing the intervention where the participants lived was an essential part of the ESD program. Participants were able to problem-solve with the therapist in their own physical and social environments. The onsite delivery also allowed the therapists to address problems occurring at the residences in a timely manner. Group and individual sessions often focused on the stresses of community living and aimed to build skills that could benefit participants in their home and other environments. The intervention also included discussions that centered around potential social and physical barriers, such as managing public entitlements, addressing a poor credit history, building interview skills, and accessing community resources. In these ways, the intervention was able to help ameliorate some of the difficulties and barriers that the residents faced both in and outside their housing environment.



Section 3: Program Development

Braveman (15) presents a process to guide occupational therapists with development of clinical programs that includes the following four steps:

- Needs Assessment
- Program Planning
- Program Implementation
- Program Evaluation

Each of these steps will be described as they relate to the ESD program.

Needs Assessment

Needs assessment includes:

- Gathering data and problem identification
- Describing your target population
- Identifying resources to meet needs

For the development of the ESD program, we already had an idea about the structure and type of programming that might work best for this population from our previous project, Employment Options. We knew we specifically wanted to target people living in supportive facilities for adults with HIV/AIDS, as these individuals constituted a large portion of the people who dropped out of the Employment Options program before its completion. The ESD program was based on the following information and experience:

- In our previous program for people with AIDS, we used Participatory Action Research (PAR) to identify if and how client needs were met and to develop and refine services (16,17,18). Clients shared their perspectives and experiences in the program and their ideas about what constitutes useful services. This information shaped our proposed program.
- We surveyed residents with AIDS in five supportive living facilities to gather information on their programming needs and desires. We also surveyed and conducted focus groups with staff concerning their views of client needs and gaps in current service provision.
- We collaborated with two supportive living facilities to pilot and refine new services.

- Another source of influence on the program was our previous experiences implementing similar services with other groups of people with disabilities and our research related to service delivery with people in urban contexts (19,20,21).

In the first two months of the project, we worked with staff from the three facilities where the ESD program was initially implemented, in order to refine the program and develop logistics for program implementation. Additionally, we conducted separate focus groups with the residents and staff at each of the partnering facilities to identify service needs and to tailor the educational programming. Based on the information obtained in these groups, we identified the informational needs and priorities at each site.

The needs of both participants and facility staff were monitored throughout the program so that the program could be adapted to changing priorities. Participants would take part in meetings where they were asked to reflect on the program thus far and offer ideas for future groups. Formally at meetings or informally during the work day, staff would often suggest group topics that reflected the needs of the clients, as well as the needs of the housing community.

Program Planning

Program planning includes five elements to be discussed below:

- Defining a focus
- Adopting a conceptual model (theory) to guide intervention
- Establishing goals and objectives
- Establishing methods to integrate the program
- Developing referrals

Based on the results of our needs assessment, we decided to focus our program development on services that promote self-determination (i.e., being able to live on one's own and attain employment). Our ongoing research into factors that influence independence and employment success among people with disabilities (including those with AIDS) indicated that self-determination involves transition through the following processes: 1) having the capacity for self-management, 2) identifying future goals and managing routines,

3) developing competence and vision and 4) achieving success and satisfaction in everyday living and working (21,22,18,23,24,25).

As discussed in Section 2, we used the Model of Human Occupation to guide the intervention development and implementation. The Model of Human Occupation has been used successfully for two decades to design rehabilitation programs that focus on supporting success in community living and employment. These programs have involved groups that share characteristics with our target population (e.g., people experiencing AIDS, homelessness, mental illness, and imprisonment) (26,27,28,21,29,30,31,32,33,34,16,35,36,37,4,25).

This conceptual model was also used to guide the development of goals for the program. In general, goals set during the process of program planning should: 1) be problem oriented, 2) be described in measurable behavioral terms, and 3) clearly describe what participants should be able to do once they complete the program (15). Programs can have long-term, overarching goals, while specific interventions may have shorter-term goals with a narrower scope. The intervention goals (short-term goals) should support the program goals (long-term goals). Additionally, when developing programming and program goals, it is necessary to develop a plan for how to evaluate the program, analyzing how successfully the goals were achieved. In order to do this, one needs to determine how to decide if a goal is achieved (outcome indicator) and how this achievement will be measured (outcome measure). This same process should be implemented when developing a specific intervention. For example, in an intervention consisting of four occupational therapy groups, each individual group needs to have goals, outcome indicators, and outcome measures (e.g., test, demonstration, verbal review). These do not have to be complicated, but they do need to be articulated in order to have an efficient and effective intervention. Table I includes sample goals, outcome indicators, and outcome measures developed for ESD at the program and intervention levels.

Goals and objectives must be developed through a collaborative process involving all key stakeholders in the program. In this case, project staff from the Department of Occupational Therapy at the University of

Table 1: Sample Program and Intervention Goals

Program Goal	Outcome Indicator	Outcome Measure
Supportive housing facility residents will move to more autonomous housing after participating in the program.	Percentage of persons residing in more autonomous housing (i.e., subsidized housing, supported housing, independent apartment)	Statistic or percentage
Intervention Goal	Outcome Indicator	Outcome Measure
Participants will be able to identify at least one solution for each of three barriers to getting information about housing over the phone.	Number of solutions participant identifies	Verbal demonstration in group

Illinois at Chicago (UIC), facility and administrative staff from the intervention sites and program participants all contributed to the development of ESD goals and objectives. Members of your target population can and should be involved in identifying and validating planned goals and objectives. To formalize this process, participants can be included on a planning committee or a participant advisory panel.

Integration of the program proved to be a challenge, as, in the case of the ESD program, services needed to be integrated into the supportive living facilities' physical space and schedule. We learned from our previous project, Employment Options, that residents in supportive living facilities routinely lack the personal and environmental resources needed to sustain attendance at a program that is held off-site. Providing services where the residents live promotes their increased participation and allows residents to explore the many challenges related to becoming self-sufficient, including returning to work and living in the community, within the safety of the supportive living facility. At the same time, integrating new services into an existing pattern of service delivery can create numerous challenges. During this phase of program planning, it is important to pay particular attention to the establishment of timelines; the definition of roles, responsibilities, and areas of collaboration with other staff in the environment; the identification of potential obstacles to the implementation of the program; and key resources that are necessary for success. It is also vital to be very familiar with the services that the site already offers. Not only will this help to avoid duplication of services,

but it will also foster a mutually beneficial relationship that supports collaboration in service provision for clients.

ESD was developed through a collaborative effort of the UIC Department of Occupational Therapy and five supportive housing facilities for adults with HIV/AIDS in the city of Chicago. The expertise and the wide range of knowledge and skills available to us from these organizations was a particular advantage. However, managing varied models of service delivery, different short- and long-term goals, and dissimilar measures of success in program evaluation proved to be challenging. All stakeholders were committed to developing and delivering an effective clinical program, but many shared concerns as well. The intervention sites had articulated concerns regarding the reporting of outcomes for budget allocation and internal reorganization. At the same time, the UIC occupational therapists were concerned with the research agenda of the project and meeting the commitments made to the funding agency. Open and direct communication about how to reach each organization's objectives, without compromising the objectives of the other involved parties or of the ESD program itself, was the key to successfully moving forward and integrating ESD into existing services.

Because the intervention was implemented at the supportive living facilities, services offered through ESD were open to all residents who sought to attain independent living and/or employment. As participants could work on one or both of these goals, individuals who considered themselves to be underemployed were also allowed to participate in the programming. Formal referrals from site staff were not necessary for an individual's participation, so many staff, especially case managers, would ask the therapists if they could work with specific residents on particular goals. It was originally planned that clients would complete their participation in ESD programming after nine months of involvement, but because the groups offered remained open to all residents and because the programming became incorporated into the services offered by the intervention sites, most participants were not considered discharged from the ESD program until they were discharged from their housing facility.

In order to aid in this discharge process, referrals to outside agencies became a critical part of this intervention. With this project population, the greatest barriers for self-determination were in the areas of

access to affordable housing, community integration, and employment. The project therapists helped inform consumers and site staff about community agencies and businesses that can provide clients with information and access to services and resources that specifically address these barriers. These included:

- Agencies providing services related to independent living, housing and community participation (e.g., Center for Independent Living)
- Community resources for full participation (e.g., leisure, peer support groups, AIDS service organizations that provide opportunities for socialization and networking)
- Agencies providing vocational preparation services (e.g. specific job training, computer skills, job coaching and mentoring)
- Employers willing to provide training internships and employment opportunities

Program Implementation

We carefully designed and implemented a four-phase continuum of services corresponding to the factors that influence independence and employment success among people with disabilities, using the Model of Human Occupation as a guide. At each phase we focused on supporting the development of personal confidence, habits, and skills. Equally important were the environmental interventions and supports. People with disabilities, in general, face severe gaps in housing, education, transportation, jobs and participation in many areas of life; they often are met with discrimination and negative attitudinal barriers regarding disability as well (39,40,41,7). The four phases of the ESD program are outlined in Table 2.

Phase I: Capacity for Self-maintenance. The first phase of the program includes comprehensive individually tailored assessment and assists clients to establish basic habits for self-management and health maintenance. Assessments are used to determine the participants' baseline capacities, and clients and project staff utilize these results to establish individual goals. Clients participate in individual and group sessions that focus on issues of importance to them, for example: basic nutrition and exercise and their specific relationship to AIDS and good health; strategies for managing medication side effects; maximizing medication adherence; and stress management groups address relaxation techniques and ways to improve attitudes and lifestyles.

Phase 2: Identifying Future Goals and Managing Routine. During phase 2, clients continue to establish supportive habits and develop more complex daily routines. Clients are individually assessed in self-care and independent living tasks, as needed, and appropriate interventions are provided to improve skills in interpersonal communication and in basic or instrumental activities of daily living (e.g. meal preparation, laundry, budgeting). Clients have the opportunity to participate in one of two productive placements:

a) household responsibilities that contribute to the function of the residence and prepare clients for responsibilities of independent living (e.g. care of common areas) and b) part-time “jobs.” These placements are limited in time and responsibility, but they do provide opportunities for the client to explore and practice work-relevant skills and develop self-confidence in his or her ability to engage in productive pursuits. Clients explore involvement in leisure and community activities in groups, assuming increased responsibility for planning and organizing trips or house activities. Financial skills training, such as opening a checking account and following a monthly budget, occurs in groups and individual sessions. Clients who receive social security benefits (e.g. SSI/SSDI) learn how the work incentives of these programs apply to them. Finally, individual and group sessions support clients to identify long-term goals related to independent self-manager and worker roles. During this phase the clients develop more specific plans for a transition to community living, employment (if appropriate), or engagement in another productive activity (i.e., school, volunteering). Toward the end of this phase, clients begin to take steps toward implementing these plans. This involves, for example, exploring alternatives for housing or identifying and enrolling in an educational or work-related training program. Here, clients are supported to begin making connections to community agencies and resources.

Phase 3: Developing Competence and Vision. The key feature of this phase is to help each client move toward community living and employment, if appropriate. Each client is supported in the additional planning and achievement of steps related to these goals. During this phase clients are involved in one or more of the following: a) planning for relocation to a more independent living situation, b) participating in employment internships or vocational training, and c) participating in specific jobs. Each client's program develops from his or her independent living and career/educational goals established in Phases 1 and 2. Some examples of what

clients participate in at this phase include: searching for a new living situation; taking English as Second Language (ESL), GED, or continuing education classes; engaging in specific job skills training; or completing an internship. Each client's sequence and configuration of involvement depends on personal desires and capabilities.

Group and individual sessions provide the information and skills necessary to prepare for obtaining community housing. Individualized sessions may include home visits for clients who have moved outside the facility, onsite job coaching, and other services tailored to support success in employment, volunteering or school. Workplace education, as needed, at sites where clients are placed may also be provided. Peer mentors are valuable in this phase, as they can assist in forming a realistic vision of the future as well as offer practical knowledge to participants.

Table 2: Overview of Project Phases & Services

Phase 1: Capacity for self-maintenance	Phase 2: Developing future goals and managing routine	Phase 3: Developing competence and vision	Phase 4: Achieving community living and work success and satisfaction
<ul style="list-style-type: none"> •Individual assessment and goal setting •Medication adherence •Nutrition & exercise program •Stress management •Orientation to local community •Development of positive support systems •Support groups led by peer mentors 	<ul style="list-style-type: none"> •Home management/ IADL •Grooming & personal appearance •Interpersonal communication skills •Developing health interests & leisure pursuits •Household responsibilities •Facility-based jobs •Financial management skills •Support groups led by peer mentors 	<ul style="list-style-type: none"> •Participation in volunteer positions or internships •Referral to the Office of Rehabilitation Services and One-Stop Centers •Referrals to related training programs or schools •Job search preparation •Support groups led by peer mentors •Planning for transition to community living 	<ul style="list-style-type: none"> •Job participation •Job coaching and peer mentoring •Managing benefits •Self-advocacy training •Obtaining community housing •Home visits and support in establishing and maintaining the home •Support groups led by peer mentors

Phase 4: Community and Work Participation & Achievement. Phase 4 consists of: a) supporting client efforts to make/sustain a transition to community living and b) participation in a paid internship or competitive employment, or supporting the client in a job search until he or she is employed. It is also recognized that some clients will be unable to achieve competitive employment and will, instead, participate in other productive activities, such as volunteering. Many clients will wish to gradually transition to community living,

employment, or other productive activities. For most, the transition is likely to involve employment first, since many clients require the financial resources to obtain their own housing and often prefer to begin employment while within the supportive living context. Plans for these transitions will have been made in the previous phase, so the sequence and timing will depend on client circumstances and preferences.

Groups continue at this phase and focus on independent living issues and problem solving, community involvement, managing benefits, health insurance, the Americans with Disabilities Act (ADA), and making decisions around disclosing one's illness as clients encounter real-life choices that come with obtaining paid employment, housing, and a more active routine. Services address the common difficulties clients have handling the dual stress of achieving employment and housing independence. Individually, staff works with clients to create their goals and budgets, assist with filling out applications, and searching for housing, furniture and other items.

Though these phases are planned to be ordered, residents often enter or exit the program at any time, so topics from the different phases can be presented as needed. This system continues to allow for group content to build and more completely address the wide array of needs of the population. Groups, then, cater to a variety of needs on a weekly basis, as opposed to addressing the interests of some in larger blocks of time.

Program Evaluation

Program evaluation consists of measuring the effects of a program compared to the goals it is designed to accomplish, in order to determine whether or not your program is successful. If it is not as effective as would be expected, steps must be taken to identify factors that are limiting participant outcomes in order to improve the program. Program evaluation guides the decision making process by providing data that will help determine if programs should continue, be discontinued or changed.

Program evaluation can include both qualitative (what people say about the program) and quantitative (statistics) study of outcomes (14). Formal and informal strategies to collect and analyze data can be used to guide decisions about how to improve the program. For example, in ESD, the qualitative component of data

collection took place within the framework of participatory action research (PAR), a strategy for conducting research that involves study participants in all phases of the research that affects them (41). Data collection for this type of information ranged from more formal focus groups with site staff and residents to informal conversations about the program during the work day. Formal methods, such as tracking participant outcomes, assisted in measuring the effectiveness of the ESD program using numbers and statistics. The outcomes measures used to evaluate program success included the number of participants who were living more independently in the community, employed part-time or full-time, and engaged in other productive activities, such as school or volunteering, after involvement in the intervention.

Through the process of ongoing program evaluation, changes and improvements were constantly being made to the ESD program to deliver a more effective intervention to the participants. Intervention protocols continued to be improved using a participatory action approach in collaboration with facility staff as part of the capacity building efforts through the completion of the project. Staff from each of the facilities assisted with evaluation of the intervention efforts for both individual clients and group interventions, and these improvements and recommendations were incorporated in the program.

Program Outcomes

When we discuss program outcomes, we are talking specifically about the actual impact a program has on participants. These outcomes can be intended or unintended, positive or negative, relevant or irrelevant.

Program outcomes must be well defined in order to be measured. For example, in ESD, one of the program aims was to increase the likelihood a participant would move to independent living in the community. In order to measure this goal, we had to define what we meant by “independent living.” Creating this definition generated many questions. Should financially subsidized housing be included in the definition? What about other housing programs that require a lesser degree of participation than the supportive housing programs? Should moving from a supportive living program to an independent living program be counted the

same as moving to an apartment without any supportive services? When pondering these dilemmas, we decided to look at specific case examples. For some program participants, moving to an unsubsidized apartment without any supportive services attached would have put them at risk for relapse in the management of a mental illness and/or substance abuse. The tasks of paid employment and managing completely independent housing would be overwhelming and could additionally result in symptom exacerbation of their HIV/AIDS diagnosis. In these circumstances, moving into more autonomous housing, even if it was not completely independent, would be a positive outcome. Additionally, although these participants would continue to utilize public benefits, they would also be at decreased risk for hospitalization and homelessness. Thus, we defined our program outcome in terms of achieving more autonomous housing versus financially independent housing without supportive services.

For ESD, the following program outcomes were identified:

- 65 people participated in this study.
- 52 people participated in post-intervention follow-up assessment, 31 of whom participated in the ESD program and 21 of whom received a standard program of psychoeducational groups related to return to work.
- ESD program participants were between 1.3 and 2.1 times as likely to be employed in the year after the end of treatment than were standard program participants.
- ESD program participants were between 3.6 and 5.8 times as likely to be engaged in other productive activities (such as attending school) in the year after the end of treatment than were standard program participants.
- For people over 44 years old, participation in other productive activity is far higher for those in the model program (67%) than it is for those in the standard program (0%).
- None of the demographic factors, such as age, gender, level of education, recent work history, current work status, history of mental illness, history of substance abuse, and level of impairment appeared to relate to engagement in paid employment or other productive activity or the other out-

comes.

- The nature of an individual's life history narrative slope (e.g. positive, stable or regressive), as measured through the initial Occupational Performance History Interview-II assessment (42), did relate to engagement in paid employment or other productive activity or the other outcomes. For example, having a positive narrative slope appeared to have an additive effect to program conditions so that such subjects were more likely to benefit from the services (43).



Section 4: Program Specifics: Staff, Promotion and Format

Program Staff

The ESD program had a project director, project co-director, two full time occupational therapists, two peer mentors, a research specialist and a research assistant. The occupational therapists and two part time peer mentors were responsible for clinical services.

ESD Staff and Their Roles

Project Director

The project director was ultimately responsible for oversight of the total project, all service activities, and program evaluation.

The Project Co-Director

This person supervised three service personnel, oversaw the implementation of the model program and control service condition, and supervised data collection and financial management of the project.

Occupational Therapists

Two full-time occupational therapists assisted with program development, provided services directly to clients, and were in charge of recruitment tasks.

Peer Mentors

Two peer mentors assisted with delivery of education and support groups and elements of individual interventions.

When making staffing considerations for this type of program, having at least one professional clinician on staff (occupational therapist, licensed and certified social worker, therapist, etc.) is important because of the complex physical and emotional issues involved with people who are living with HIV/AIDS. This program views the individual holistically and addresses a wide array of issues from basic nutrition to preparing for job interviews. Because of the diversity both of program content and of participants, it becomes important to have a staff member who is able to quickly understand new content and grade group activities to allow for a range of abilities. Though the aims of the program are to help individuals attain independent housing and employment, helping participants find the kind of housing and productive activity that best fits their physical, emotional, and cognitive abilities must remain central.

Having a peer mentor on staff can increase the effectiveness of services (44,45,46,47). Peer mentors can be strong bridges to professional services (48) and can increase client motivation to work towards goals (49,50,51,52). For these reasons, a model of peer teaching, mentoring and support was integrated into the program. These peer mentors, who previously resided in supportive living facilities, helped facilitate support

and discussion groups on various topics and provided individual guidance and support.

Successful peer mentoring requires clear objectives, workable practices for matching, supporting and ending peer relationships, training of peer mentors, regular supervision and ongoing social and emotional support (48). When using peer mentors, we suggest: 1) providing a manual outlining program objectives and information to the mentors, 2) providing a structured training program for the peer mentors, 3) providing formal supervision within a safe and supportive emotional context, and 4) conducting observations of peer-mentor/client interactions and group facilitation to evaluate the quality of their services.

Staff Training/Education

In addition to training in universal precautions for infectious diseases, staff must acquire a basic HIV education, including:

1. History of the disease
2. Pathology of the virus
3. How the disease affects the immune system
4. Transmission of the virus
5. Medications and side effects
6. Cultural and societal issues

Staff also needs to be trained in information about federal public entitlements, as well as assistance programs that are pertinent to your own location. The staff should have basic knowledge of federal legislation such as the Americans with Disabilities Act (ADA), Health Insurance Portability and Accountability Act (HIPAA), and the Family Medical Leave Act (FMLA). Additionally, staff members should be familiar enough with computers to teach clients basic computer skills and assist with searching for volunteer positions, jobs, and education opportunities on the internet.

In our program, the peer mentors received additional training in how to be a peer mentor, group facilitation, and active listening skills, both through readings and through feedback from the occupational therapist. Peer mentoring for people with HIV/AIDS training programs were accessed in the community through

local organizations and branches of the Red Cross. The peer mentors also were required to attend group programming and process the groups with the occupational therapist. With the help of the occupational therapist, the peer mentors were then prepared to co-lead a group and received feedback on the facilitation.

Program Promotion

Though we did not need to advertise our program through brochures or advertisements, we did need to educate facility staff and residents about what our program entailed. Since we were providing services at the facilities, we needed to make sure to respect the culture of the facility and let staff know we were not encroaching on the services they already offered. At the beginning of the program, we attended staff meetings to explain our program and to gather feedback and suggestions from staff. We worked with staff of the three facilities where the ESD program was initially tested to refine the program and develop logistics for program implementation. This process of inclusion encouraged staff investment in the project.

We also attended house meetings to promote our intervention to the residents, and peer mentors became important in promoting the intervention at facilities where house meeting attendance was low. Our most powerful promotion, however, was through casual contact and our extended presence at the agencies. Residents and staff started to recognize who we were and became curious about what we were doing. Once our programming became part of the agency culture, the intervention began to promote itself.

Program Format

Clients participated in group and individual interventions to build their capacity for activities of daily living and preparation for living independently in the community. These direct intervention strategies were designed to support the creation of positive routines and habits and to increase the motivation of participants to engage in occupations that support the attainment of their personal goals. Intensity of program participation varied for each individual. The program also consisted of individual follow up sessions to offer on-going support.

Group Intervention

- Efficient way of educating clients on materials relevant to most

- Some of the facilities required group participation and incorporated our intervention into their own programming
- Clients' feedback on groups included feelings of increased support and decreased isolation
- Clients learn from each other's experiences

A group format was chosen as an efficient way of educating clients about commonly relevant topics and to encourage clients to learn from each other's experiences. Groups consisted of three to eighteen participants, depending on the intervention site, and were generally one hour in duration. Topics covered included physical health (e.g., HIV medication management, sexual health education), mental health (e.g., managing change, stress management), independent living skills (e.g., personal hygiene, food safety), pre-vocational skills (e.g., time management, communication skills), and vocational skills (e.g., job search strategies, interview preparation.) Information more specific to the population being served, such as management of Social Security entitlements, disclosure of HIV status to employers, and legal rights under the American with Disabilities Act were also presented. Groups also addressed themes relevant to people in recovery, both from substance abuse and mental illness. These groups dealt with more abstract concepts, such as trust, honesty, and shame. Program staff and site staff implemented most of the group materials. Groups were offered at least once a week over the course of the project, and two of the facilities offered groups daily.

Individual Intervention

- Allows for establishing individual goals and treatment plans
- Used to assess someone's physical, cognitive, and emotional status
- Supports recognition that each client's ability to learn is different, and some clients may need more assistance than others

Individual sessions were used as a means for ongoing assessment and also to work with clients to establish individual goals and treatment plans. All participants were required to meet with an occupational therapist at least one time for initial assessment. The therapists were then available to the participants, as needed, at least one day a week. There was no requirement to engage in individual sessions. The occupa-

tional therapists found that keeping “office hours” was more successful in attracting participants to engage in individual sessions than scheduling sessions on a weekly basis. Individual sessions could range in length from fifteen minutes to over an hour. Topics discussed during these sessions included follow-up on information presented in group sessions, interpersonal communication problems, stress of community living, and lack of routine. Participants engaged in a variety of activities with the occupational therapists, including trips into the community to access the local park district, practice in reading medical test results and credit reports, and training in how to access the internet. Assertiveness training also became a major subject of individual sessions as the occupational therapists would coach clients in their communications with vocational and medical service providers, banks, and housemates.

Peer Mentors

- Can inform content and format of services offered
- Can increase credibility of intervention
- Can increase client motivation to work towards goals

The two peer mentors actively participated with other project staff in refining the program. Since they had an HIV/AIDS diagnosis, were of minority status, were in recovery from substance abuse and had resided in supportive living facilities, they had a personal understanding of the kinds of challenges faced by our clients. Additionally, some of the peer mentors were managing a mental illness, further connecting them to participants. During the ESD program, it was found that trust and honesty in the relationship between peer mentors and program participants were major determinants of whether or not the peer mentors were accessed and how they were used. The peer mentors in this program achieved varying degrees of success in gaining the trust of different clients. For some participants, the peer mentors served as role models for advocacy and goal achievement. For others, concerns about a peer mentor’s level of education, knowledge of specific topics, and ability to maintain confidentiality limited their involvement with the peer mentors. Generally, however, participants in the ESD program appreciated the peer mentors’ availability, familiarity and guidance.

Through sharing their own stories, successes and failures, the peer mentors helped participants to form realistic visions of the future. Individually, they assisted participants in searching for services, volunteering opportunities, and continuing education programs on the internet. They also taught participants how to create a resume on the computer and post the resume on internet job search sites (e.g., monster.com). Through informal conversations, participants learned about local community support services and discussed strategies for accessing those services to ensure success when moving to more independent housing. Peer mentors also co-lead groups on topics such as general HIV education, exercise and money management.

Program Intensity

- Increased sense of control among participants
- Intervention tailored to individual needs

Participation in these direct interventions varied in intensity for each individual. Though two of the facilities had some requirements for group participation, residents were allowed to choose from a variety of groups addressing different topics. Participants could also choose to participate in additional groups beyond the requirement and engage in individual sessions with their occupational therapist. This flexibility in intensity of service utilization allowed clients to have a greater sense of participation in their treatment plans, to choose the services most relevant to their needs, and to control the formats through which those services were delivered. One participant became very interested in learning how to search for volunteer positions, and later employment, on the internet. She used a series of groups on the topic to gather information and to discuss her own difficulties in searching for jobs. She chose to utilize individual occupational therapy sessions infrequently and only to ask specific questions related to accessing and utilizing specific websites and search engines. These individual sessions lasted only between five and twenty minutes in length. Another participant attended groups at least twice a week to explore different interests and to gain information about various topics. He then attended weekly, hour-long individual sessions to process the information acquired in the groups and to formulate goals around learned information that seemed particularly relevant to his situation.

Post-Intervention Follow Up

- Clients need ongoing support, encouragement, and contact to manage the difficulties of maintaining change

The different sites we worked with had varying degrees of continued support after a client was discharged from their facility. We began working with agency staff to develop alumni programs for former residents who left the facility on good terms. Though these alumni programs did not come to complete fruition during the time this project was funded, one of the facilities did develop a monthly program for former residents, and all of the facilities offered employment or volunteer opportunities to former residents.

Employer HIV Education

Another aspect of our follow up was to provide employer HIV/AIDS education. Though we were not requested to use these skills during the time this project was funded, we were trained facilitators of the Positive Workplace: Managing HIV at Work, a Structured Videotaped-Driven Training Program produced by the Workplace Resource Center of the National AIDS Fund. The offering of this service is necessary because HIV is not like other disabilities/illnesses. Stigma and discrimination is associated with the diagnosis, and ignorance of the mechanisms of the condition and its transmission generally fuel these negative attitudes.



Section 5: Referral, Assessment and Documentation

Screening Criteria

The criteria for participating in Enabling Self-Determination for People Living AIDS were:

- Must be a resident of supportive living facility where service is being provided
- Must have a desire to attain employment and/or independent housing

Each facility uses strict criteria for granting residency (e.g. willingness to submit to random drug screens and adhere to recommended psychiatric treatment) so that no additional exclusion criteria were needed.

Assessment

If the participant was appropriate for the program, we would meet with him or her individually and begin the assessment process. This initial one-on-one meeting with the participant became essential in gaining a detailed life history, establishing rapport, and getting a general idea of the client's goals.

We used many assessment tools that captured multiple aspects of a person's behaviors (habits, routines), motivations (values, goals), abilities (physical, cognitive, psychological), and environment (home, family, community). This holistic approach is important because all of these factors affect how successful someone may be in building a positive and productive future. We realize that the following assessment tools are mostly used by occupational therapists (see Table 3), however, assessments from other professions that address similar areas can be used in substitution. We continue to recommend a holistic approach with whatever assessments you use.

In addition to these evaluation tools, it is important to recognize other challenges participants may face. Many participants deal with substance abuse, psychological and emotional problems unrelated to HIV (schizophrenia, bipolar disorder), domestic violence, other medical diagnoses (hepatitis, stroke, back injury), and homelessness. Participants often see many other health care professionals. It is a good idea to be a part of this team in order to provide the best treatment possible. You will need to have the participants sign a release of information form in order to discuss anything about them with other professionals.

Assessment is an ongoing process, as people's circumstances can often change. Periodically re-administering appropriate assessments or selecting newly relevant assessments is important for effective

Table 3: Primary Assessments Used in ESD

Assessment	Use
Worker Role Interview (50)	Used to gather information on the psychosocial/environmental components during an initial assessment process in conjunction with observations made during physical capacity evaluations or observation of performance of occupations.
Occupational Performance History Interview-II (42)	Used as an initial assessment to gain narrative information on the participant's occupational performance and history including the participant's roles and physical and social environments.
Occupational Self-Assessment (53)	Used as part of an initial assessment battery and as part of a goal setting process to assess the participants level of satisfaction with his/her occupational competence and environment.
Assessment of Communication and Interaction Skills (54)	Used to assess the impact of disease/illness on communication and interaction skills.
Model of Human Occupation Screening Tool (55)	Used as a screening tool to assess occupational performance through the concepts of motivation, habits, skills, and environment.
HIV Impairment Checklist (56)	A self report checklist used to understand the number of impairments due to AIDS or AIDS treatment and the client's perception of severity.

treatment. It is also helpful to gather information from clients to ensure your program continues to fit their needs. Programming must match the changing concerns of the participants in order to remain effective.

Documentation

Having a well-organized documentation system is vital for tracking client progress and outcomes, as well as for recording the contributions and successes of your program. When developing a documentation system, issues of confidentiality are important to consider, especially for people with conditions associated with stigma like HIV/AIDS and mental illness. In the records for our program, we used participants' first names and last initials on most documents. Each participant had his or her own folder where documentation for individual sessions was kept. For each session (minimally of 15 minutes), we would write a short paragraph detailing the session. These records became important in helping the client look back on previous sessions and reflect on his or her progress.

We documented participant attendance in groups on a separate group participation record. Since our program was a research project, we also developed codes for participant identification. Facility staff recorded

group notes according to the documentation system of their particular site. You will need to consider the best way to ensure client confidentiality in your documentation system and train staff to be consistent in the recording of sensitive information.

Documenting a participant's functional abilities is not only important for your own program's purposes, but it may help the participant obtain and maintain Social Security entitlements. Continuing Disability Reviews (CDRs) are performed by the Social Security Administration to determine whether or not beneficiaries are still disabled. You may need to write a letter of support and/or provide assessments on the behalf of participants who have a CDR or who may be in the process of applying for entitlements.



Section 6: Group Outlines

Groups were generally one hour each with no break. At the beginning of each group, we would review the agenda for the session. Group topics were varied and reflected the needs of the participants at the time of their presentation. Multiple groups on most topics were developed to present different focuses. For example, we presented two groups on public entitlements: one focusing on how to manage your benefits and interactions with the Social Security Administration, and one to discuss how paid employment can affect entitlements.

Groups were designed to include education, discussion, opportunities for self-assessment and practice of new skills. For example, in a group discussing communication skills, participants were asked to brainstorm the qualities of aggressive, assertive, passive and passive-aggressive communication styles, discuss the pros and cons of each style, and role play situations incorporating each style into their interaction. Choosing to implement groups with topics that are relevant to what is happening at the moment; challenging the participants to learn; offering them the forum to share their knowledge, thoughts and feelings; and providing ample opportunity for “doing” during the group sessions all contributed to the acceptance and success of the services provided. Please refer to Appendix A for an example of a group overview and activity.

The following is a list of group topics used in ESD programming.

Group Topic	Sub-Topics Addressed
American with Disabilities Act	<ul style="list-style-type: none"> • Issues of disclosure in employment
Budgeting	<ul style="list-style-type: none"> • Creating a budget • Tips for saving • Setting financial goals
Change	<ul style="list-style-type: none"> • Stages of change • Barriers to change • Coping with change
Cold and flu management	<ul style="list-style-type: none"> • Cold/Flu prevention
Community resources	<ul style="list-style-type: none"> • Accessing community resources
Cultural sensitivity	<ul style="list-style-type: none"> • Stereotypes • Culturally specific communication • Sharing my culture
Disclosure of HIV/AIDS status	<ul style="list-style-type: none"> • Family • Intimate relationships • Legal responsibilities • Work

Group Topic	Sub-Topics Addressed
Employment	<ul style="list-style-type: none"> • Job search strategies • Interview strategies • Work skill self-assessment
Exercise	<ul style="list-style-type: none"> • Benefits of exercise • Exercise and HIV
Fear	<ul style="list-style-type: none"> • What is fear? • Overcoming fear
Financial credit	<ul style="list-style-type: none"> • What is credit? • Obtaining and reading your credit report • Reestablishing good credit • Bankruptcy • Credit cards • Fraud/Identity theft
Goals	<ul style="list-style-type: none"> • Elements of a goal • Personal goal setting
Health insurance	<ul style="list-style-type: none"> • Exclusions to insurance coverage • Types of health insurance plans
HIV/AIDS	<ul style="list-style-type: none"> • HIV basics • HIV medications
Honesty	N/A
Housing	<ul style="list-style-type: none"> • Housing assistance programs (AIDS specific and general) • Utility assistance programs • Realistic housing goals • How much money do I need?
Hygiene	<ul style="list-style-type: none"> • Personal care • Safe food handling • Using cleaning products safely and effectively • Universal precautions
Interpersonal communication skills	<ul style="list-style-type: none"> • Communication styles • Body language • Dealing with confrontation • Communicating over the phone/in writing
Leisure	<ul style="list-style-type: none"> • Activity interests • Accessing low cost/free leisure activities • Importance of having fun
Making mistakes	<ul style="list-style-type: none"> • Forgiveness of others • Forgiveness of self
Medication adherence	N/A
Nutrition	<ul style="list-style-type: none"> • Nutrition basics • My food pyramid • The “bad guys” of food • The “good guys” of food • Eating on a budget • Weight management • Health and Food

Group Topic	Sub-Topics Addressed
Personal boundaries	<ul style="list-style-type: none"> • Defining personal boundaries • Expanding personal boundaries
Public entitlements (SSI, SSDI)	<ul style="list-style-type: none"> • Basics of SSI/SSDI • How working affects entitlements • How savings affect entitlements • Managing paperwork • Effective communication with the Social Security Administration
Relaxation/Meditation	N/A
Resilience	<ul style="list-style-type: none"> • What is resilience? • How to develop resilience
Self-assessment	<ul style="list-style-type: none"> • Strategies for self assessment (e.g., journaling) • Process of self-assessment
Self-esteem	<ul style="list-style-type: none"> • Causes of low self-esteem • Identifying personal achievements
Sexually transmitted diseases	<ul style="list-style-type: none"> • Chlamydia • Herpes • Gonorrhea • Trichomonas • Human papillomavirus (HPV) • Safer sex
Stress and stress management	<ul style="list-style-type: none"> • Physical and mental effects of stress • Coping with stress by changing behavior, thinking and lifestyle
Stress of community living	<ul style="list-style-type: none"> • Gossip • Managing attitudes • Discussion of current house issues
Thankfulness	N/A
Time management	<ul style="list-style-type: none"> • Developing a schedule • The value of time
Trustworthiness	<ul style="list-style-type: none"> • Being trustworthy • Trusting others
Values	<ul style="list-style-type: none"> • What are values and why are they important? • Clarifying personal values



Section 7: Individual Occupational Therapy Intervention

After initial assessment, individual occupational therapy intervention usually begins with establishing the participant's long-term and short-term goals and developing an action plan. At this time in the program, participants may have already attended a number of group sessions.

The frequency of treatment can vary tremendously, depending on the participant's needs. In our program, some participants wanted to meet every week to discuss time management, while others only wanted to check in once every month to monitor their long-term goals. There were some participants who never engaged in a formal individual session but instead accessed the occupational therapist for fifteen minutes in a hallway, for example, to ask for help completing a specific activity (e.g., filling out a credit report request form). Also, the therapists were usually available for individual sessions only one day per week. Though they attempted to schedule regular individual sessions with participants, they found that holding consistent "office hours" at the facilities and allowing clients to "drop-in" was more successful.

The focus of occupational therapy intervention can vary widely. We will present some examples here as they relate to the Model of Human Occupation (refer to Section 2).

Volition

Some participants need to start with the basics: What would they like to achieve during their time at the facility? What are their interests and priorities? Oftentimes, residents have never been asked these questions before, and they may have difficulty identifying what they would like to do with their time at the facility. For those who have spent the most recent period of their lives obtaining and using substances, questions like these can be particularly daunting. For the first time in their recent past, participants have stable housing for an extended period of time, consistent access to food, and are in recovery (as required by program sites). For these participants, you may need to assist them in **clarifying their values**. In other words, what is important to them? Where do they want their lives to go from here?

Other participants may feel that they are not qualified or do not deserve to improve their own lives. For example, a participant who had worked as a prostitute since she was a fifteen years old and had a history of substance dependence could not name a single time in her life when things were going well. She could not

believe that her life would ever improve. For her, treatment began with **building her self-confidence** and helping her believe that she did deserve a future better than her past and could succeed. Designing opportunities for her to experience success, offering the just-right challenge, and helping her explore interests became essential parts of her treatment.

Other participants may have an inflated sense of their abilities and be unaware of or unaccepting of their limitations. They may have unrealistic goals and require reality testing. Some ways to **test limitations** in a safe environment would be to identify with the participant an ambitious and challenging task associated with one of the client's goals. After the completion or attempted completion of the task, you can together evaluate the client's performance, identifying strengths and weaknesses that were exhibited during the activity. Another strategy is to offer opportunities for responsibility, such as answering phones at the facility or providing a short presentation as part of a group. You can then assist the participant in a self-evaluation of his or her performance.

A primary goal of some participants may be to **develop or identify interests**. This can be harder than it sounds. You can begin this process by asking questions about how the person spends his or her "free" time. Some participants may have difficulty identifying specific activities, and you may need to probe further: Do you ever go to the movies? Is shopping fun for you? Do you like animals? You could also use an interest checklist assessment if individuals find the task overwhelming or too challenging (57). Once the participant identifies an interest, a treatment goal can be created. For example, a participant states that he has always loved animals. Together you can brainstorm places he could work or volunteer that have animals, like a pet store or the local rescue shelter. If the client is unable to brainstorm ideas, you can educate him on resources to find these types of opportunities, for example the internet, and help him practice using these new resources.

Participants come into the program with co-morbidities such as substance abuse, mental illness, family issues, and physical limitations in addition to HIV/AIDS. An important first step for these participants is to **establish priorities for setting goals**. Throughout the program, we encourage participants to make

health and well being their number one priority. For example, in order to avoid stress and anxiety that would put her at risk for relapse, one participant decided not to explore returning to paid employment until she reached one year of sobriety.

Habituation

At the beginning of the individual treatment sessions, it is important to get a clear idea of how participants spend their day. One way is to have participants identify their **daily routine** using a written time sheet or a weekly calendar. Oftentimes participants do not have full daily routines. This lack of activity can result in general malaise or becoming overwhelmed when they do have an event they have to attend at a certain time, like a doctor's appointment. Encouraging participants to engage in and offering clients information about leisure activities, exercise, volunteering, or participating in an education program can help them to build a more satisfying daily routine.

For many participants, **managing their medications** is a big part of their daily routine. If a participant is having difficulty maintaining his or her regimen, individual treatment could focus on developing compensation strategies; for example, keeping a chart or checklist of medications and adherence schedules or teaching the participant to use a pillbox that has the days of the week on it.

This issue of **time management** is crucial for participants to think about in order to balance new activities in their lives, such as work, volunteering or school. For example, one participant said that he goes to the doctor twice a month on Monday mornings, and feels that he would not be able to return to a "9 to 5" job because of that. He and the therapist were able to problem solve solutions that would allow him to integrate a work activity into his schedule without sacrificing his health. The participant asked his doctor's office if they have Saturday hours and was able to reschedule his appointments for that weekend day. Though the solution seems simple, the participant had never before thought to ask about scheduling on a Saturday. Often times a treatment session on time management consists of brainstorming immediate solutions, creating task lists, and coming up with alternatives to prevent future problems. Chronic lateness also can be addressed individually by giving participants feedback on their attendance in groups. If a participant is consis-

tently late to group, you and the client can set a treatment goal for him to be on time to the next two groups. If the participant does not meet that goal, it is important to talk about factors that made him late and to discuss how his tardiness might affect his long-term goal achievement (e.g. maintaining employment). It is also important to acknowledge and praise the participant if the attendance goal is accomplished.

Money management is another skill area in which participants may need to develop good habits. For those receiving public entitlements and considering return to work, they need to determine how paid employment can affect their benefits. For others, they may need to correct the habit of spending money first on material objects before paying bills or attaining food. Oftentimes in the ESD program, participants had never thought about how they were spending their money. Now that they were in stable housing and required to pay some rent, they needed to think about budgeting for the first time. A treatment session focusing on money management goals could involve a participant writing down his total income and total expenses and seeing how they match, evaluating a spending diary, or practicing how to say “no” when others ask for money. Participants may then progress to using individual sessions to open a checking or savings account or access debt consolidation services.

Performance

There are many aspects of a person’s performance that need to be evaluated when attempting to build a routine and engage in productive activity, like work or school. For people living with HIV, major areas to consider are fatigue, endurance, neuropathy, side effects from medication, cognition and perception. If a participant has deficits in any of these areas, treatment can focus on the **remediation of deficits** (exercise, strength training) and/or **utilization of compensation techniques** (energy conservation, work simplification). Working with the client to identify productive activities that match performance skills also is important.

Participants may need to **develop new skills or update their old skills** in order to be productive. This is something that they can work on during the individual treatment sessions. Many of our participants wanted to gain or update **computer skills** and learn how to use the internet. We were able to help them by teaching them the basics and referring them to off-site computer classes or websites that offer tutorials

(see Appendix B for a list of Chicago resources).

Example of Compensatory Techniques

A participant with significant memory impairments was having difficulty remembering to pay his monthly bills and often sent his payments to the wrong vendors. Intervention included using a checklist of all the bills he needed to pay for each month and who they should be sent to, setting a date for paying his bills (e.g., the first of the month), and printing address labels he could put on the envelopes instead of writing each out by hand. These materials were kept in a 3-ring binder. This helped him to pay his bills on time and greatly reduced his anxiety surrounding his memory problems and his fears of missing payments.

Some participants may need to improve their **communication and conflict resolution skills**.

Through role-playing and feedback sessions, you can address many issues that involve inappropriate communication. For example, a participant often appeared menacing to other residents, though he insisted he was not trying to be threatening. The therapist gave him feedback on his nonverbal communication skills and suggested strategies he could use to monitor his body language.

Example of Communication Skills Intervention

The therapist noticed that the participant was consistently monopolizing group time with personal problems. This was addressed in an individual session by giving the participant constructive feedback and reviewing model interaction skills.

Skill development can also be addressed in individual sessions through working towards attaining **employment, volunteer or internship positions**. Participants can role play job interviews, create or update their resume, learn how to search for jobs on the internet and access job placement agencies during individual sessions. You can also educate participants with special situations, such as those with criminal records, about specific agencies that can offer important information and/or assistance in finding employment. Volunteer and internship roles can help participants learn new skills and test their tolerance for returning to work

or school. Also, they can practice good workplace behaviors such as communicating assertively, arriving on time, and dressing appropriately. They may also practice completing an application, as is required for many volunteer positions. Internships and volunteer positions offer participants a comfortable, non-threatening environment where they can practice their skills without worrying about a paycheck. For those who plan to seek employment in the future, volunteering and internships are good ways to have something recent on a resume.

Environment

In individual treatment sessions a therapist may have to address environmental issues. The **participant's home environment** can greatly affect his or her ability to move forward with goals. Participants are living in a communal residence with shared space and responsibilities. The stressors of this environment can contribute to relapse and exacerbation of mental or physical illness. Creating a plan with the participants for how they can protect themselves from these stressors can help avoid distraction from their purpose.

Example of Intervention to Help Participant Manage Environment

A participant who had been sober for nine months became very upset when she saw a resident outside of the facility using drugs. She thought that he often came to groups high and felt that if he wasn't kicked out of the house, she may as well start using again, too. The therapist worked with her to identify how her life is different now than when she was actively using to illustrate her progress towards her goals. She and the therapist also discussed how she could assertively communicate her concerns to housing staff.

Issues related to a **participant's social group** may be addressed individually as well. For example, some clients may have family members who “show up” when the participant receives his/her monthly social security check. These clients often give up the majority of their check, preventing them from paying their own bills or fulfilling their own needs. This may go hand in hand with a money management goal where a participant has their check deposited directly into an account, so they cannot “give up” their cash.



Section 8: Skills Preparation and Vocational Rehabilitation Referrals

Collaboration with Agencies

Outside agencies sometimes may be better equipped to offer resources focused on specific goal attainment, such as educational and vocational goals. In order to have a successful referral, the participant should be able to articulate these goals. Sometimes the goal is a means to an end, such as taking an English as a Second Language (ESL) course, completing an HIV/AIDS education course, or training or working on computer skills. It is important to have a working relationship with agencies to aid in the referral process. Here are some suggestions:

- Research organizations in the community that offer job placement assistance programs that may match well with your participants.
- Attend networking events hosted by different organizations and gather information.
- Join a government leadership team that advocates for people with disabilities. These types of groups can keep you up to date about the law and changes that could affect participants.
- Work with the coordinator of a training program to organize a smooth referral process for the participant.
- Designate a contact person for each agency and do a site visit. At the site visit be prepared to ask questions about their programs and services. Other good questions to ask may be:
 - ◆ What are the requirements for acceptance into your program?
 - ◆ Do you do follow-up? For how long?
 - ◆ What are the demographics of your clientele?

Non-profit organizations and government agencies are able to assist participants reach career and employment goals.

- Training and job placement assistance programs can help participants update or gain new skills in such areas as computers, hospitality, skilled trades, retail, health services, etc.

- Refer participants to programs that offer services distinct from those at your institution or agency, such as:
 - ◆ career aptitude tests
 - ◆ certification to become an HIV/AIDS educator
 - ◆ intensive career counseling
 - ◆ direct job placement
 - ◆ literacy programs
 - ◆ GED classes
 - ◆ ESL classes
 - ◆ supported work or Job Coach

Confidentiality

If a participant is directly referred to another organization, confidentiality issues need to be discussed with the participant.

- Participants may not want to disclose their status to anyone, even from agency to agency.
- Sometimes the agency you work for could be known as an HIV/AIDS organization simply by the name. Be aware that directly referring a participant could disclose a participant's HIV/AIDS status simply by stating where you work.
- You can take the following steps to respect your clients' decisions about disclosure:
 - ◆ Ask the participant how he or she feels about disclosure to the contact person at the other agency.
 - ◆ If the participant agrees to be directly referred and does not have any issues with disclosure, create a written agreement or "release of information" with the client's signature giving you permission to discuss their case at another agency.
 - ◆ If the participant does not want to disclose, it may be possible for the participant to self-refer, or he or she can ask another care provider that is not HIV/AIDS specific to refer them.

Internships and Volunteering

Internships and volunteer positions are steps to paid employment that allow participants to build skills and test tolerance for full or part-time work. Collaborating with other agencies is an excellent way to de-

velop internship and volunteer opportunities for participants. Volunteering is often scheduled on an as-needed basis and loosely structured. Internships are more structured than volunteer positions but more flexible than paid work.

- Volunteering and internships are great resume builders, especially when a participant has significant gaps in employment or a history of frequent job terminations.
- Internships and volunteer positions are opportunities for participants to learn “on the job”.
- A participant can “test the waters,” build self-confidence and see how tolerant they are of a work-type routine without worrying about getting fired.
- Internships and volunteer positions are usually much more flexible than paid work.
- Internships and volunteer positions are opportunities for participants to learn about their own capabilities and skills.
- Internships and volunteer positions can lead to paid work within the organization.

Participants as well as the provider can develop internships and volunteer positions in the following ways:

- Call non-profit organizations and inquire about a volunteer program or internship opportunities. Many agencies have volunteer coordinators to assist participants with placement in an appropriate position.
- Attend networking events sponsored by organizations of interest.
- Use the internet as a key resource for searching on college and non-profit web sites that post listings of available positions.
- College campuses and local business bulletin boards may also have listings posted.
- Contact local businesses and ask if they could arrange for an internship opportunity. (If the provider is making the contact, keep in mind confidentiality and disclosure issues).
 - ◆ Discuss the length of time and schedule available for an internship or volunteer position.
 - ◆ Discuss the possibility of the position turning into paid work.

- ◆ Create an internship contract for the participant and the business.

Job Search Strategies

When a participant is ready to start looking for paid work, one of the first steps is to have the participant brainstorm ideas about the type of environment and schedule they prefer. Participants should also understand how employment can affect their entitlements and decide what salary range will work best for them. After these elements are explored, the participant may begin the job search process. The following is a guide to help participants in their job search.

Where to look for jobs

- The internet. This is an excellent resource for newspapers and on-line job sites.
- Paper classified ads.
- Word of mouth. Participants should tell people they know they are looking for a job and ask friends if they know of any openings.
- College bulletin boards.
- Placement agencies for temporary to permanent jobs.
- Job and career fairs.

Participants should research the employer

- Acknowledge the environment and size of the company or organization. Is the company large enough that they have a human resources department or is it just one person?
- Look at the employer's web page.
- Walk by the building when people leave work or have lunch and notice the workers (i.e. casual, wearing suits, do people look happy?).
- If possible, call and request information about the employer.

How to reply to ads

- Fax, mail or post a resume with a cover letter for jobs that are of interest.

- Participants should keep a file of when they responded to a job notice and the contact person for the position.
- If a phone number is available, the participant should follow up on the position a week after sending a resume.
- Be aware if the ad says “no calls.”
- If a person’s name is given, or if you can get the name of the specific person the resume is going to, address the cover letter accordingly.

Forming Relationships with Employers

Working with employers builds support for the future of people with HIV/AIDS in the workplace. It is suggested that employer relationships be built first upon support for the agency, and then progress to negotiate job placement options. Forming relationships with employers requires time and patience. Do not expect employers who do not know the agency or you to respond to phone calls.

There are several ways to network with employers, gain program support and develop jobs. Some tips are listed below:

- Attend job fairs and introduce yourself to employers.
- Set up a site visit with the employer to gather information and observe the work environment.
- Look for local job developer groups (mostly from non-profits) that share employer information.
- Attend local HIV/AIDS organizations’ functions to network with employers or with people who know employers.
- Look on employer web sites and investigate if they have any charity awards. If so, call the employer and find out more information.
- If you know of any employers that have a reputation for working with community-based organizations or on different projects with non-profits contact them and tell them about your program.
- If at all possible, try not to “cold call.” Often times, employers are not responsive and it does not give you a chance to explain the program. Options more effective than cold calling are going door-to-door

to network with employers or sending a mailing that informs employers about a potential partnership. This mailing should include information about your organization, for example an informational brochure.

When relationships with employers are formed:

- Maintain the relationship by sending a newsletter, short update letter, or any other information that may be of interest.
- Offer to do quarterly HIV/AIDS in the Workplace training.
- Ask to be sent any new job listings monthly and always thank the employer through a quick e-mail or phone call.

The Formal Interview

Participants are often frightened about job interviews because of their HIV status and/or the length of time since their last interview. It is important participants are informed of their rights in disclosing their health status to employers, and you can strategize with participants about how to explain gaps in their resumes without revealing this personal information.

The basics on interviewing:

- Participants should schedule the interview for a time of day in which they feel their best. For example, a participant that has medication side effects mostly in the morning should schedule the interview for the afternoon.
- If a participant needs to take medication during the interview, they should excuse themselves to the restroom. A participant should not miss a dose of medication because of an interview.
- Participants should bring a pen, paper, resume, references and a snack to the interview.
- If a participant has medication that requires it be taken with food, he or she needs to know before the interview how long the process will last and/or if they are allowed to take breaks.
- Participants should be prepared to fill out an application and sign for a permission for taking a drug test.

Issues not to discuss on the first interview:

- If a participant wants to disclose HIV status to the employer, it best to wait until hired. This way, if the participant does not get the job, the participant knows he or she was not discriminated against because of HIV status. **Remember, a participant never has to disclose HIV status.**
- The first interview is not a place to discuss an accommodation. It is possible to discuss this issue if the participant is closer to being hired or on the second or third interview. However, it may be best to request an accommodation after being hired.
- Discussions about insurance, vacation time, and compensation are better left for the second interview.

Participants need to be prepared to answer interview questions about work history and health:

- Even if the participant did not leave his last job on good terms, he or she should not be negative towards the job or their former employer.

Interviewer: Why did you leave your last job?

Participant: I felt it was time to move on and to get more experience in retail sales.

- Some participants fear that employers want to know about illnesses or want a “good” reason for a large gap in work history. An interview is not the place for disclosure of personal information or confessions. The participant should explain the situation briefly and focus on the positives of present time.

I was sick for quite some time, but now I feel good and have been volunteering for a few months. I am excited to return to a regular work routine.

I became disabled and had to take some time off to take care of myself. It was a difficult time, but I am feeling better than ever and cannot wait to learn more about computers. I am excited to put the classes I took to use.

- If the participant has a criminal background, he or she should never lie. They must tell the employer the truth. The participant should be brief and positive.

I did some things in my past that were not the smartest. I realize that. Although I know I cannot change the past, I look forward to working on my career goals for the future.

Closing the interview

- Participants should be prepared to ask questions that are creative and that do not repeat information already discussed during the interview. For example:
 - ♦ What do you like about your job?
 - ♦ What caught your interest about this industry?
- Ask what the next steps are. Should the participant call the employer? Should the participant wait for the employer to call?
- The participant should remind the employer of their interest in the position.
- The participant should send a thank-you note directly following the interview, regardless of how they think the interview went.

Job Acceptance and Negotiation

Participants need to understand that they should not just take any job. They need to explore how their entitlements (SSI, SSDI, Medicare, Medicaid, etc.) will change when they go back to work. They also need to research exactly how their prospective company's health benefits work and have an understanding of their rights under the Health Insurance Portability and Accountability Act (HIPAA).

Participants should examine the types of insurance offered before accepting a job

- Investigate the pros and cons of each job offer and benefits package.
- Will the participant have to wait for coverage due to a pre-existing condition?

Package and pay negotiation should be researched and well thought out:

- The internet is an excellent resource for looking up average salary ranges in different careers.

- Participants should take into account if insurance is offered. Insurance should be evaluated as part of the salary.

Job Offer 1: A participant is offered a job and the pay is \$35, 000 without any medical benefits and no vacation.

Job Offer 2: A participant is offered a job and the pay is \$27, 000 with excellent benefits including dental and vision and 2-weeks of vacation.

The participant would be receiving a better overall package by taking the second job offer.

- The participant should evaluate how many personal and vacation days are available. A person with HIV/AIDS may need more personal or sick days compared to someone without a chronic illness and should consider how much paid and unpaid time off is available.
- The participant should ask about any other benefits such as short and long term disability coverage.



Section 9: Capacity Building and Benefits of the ESD Program

An important element of the ESD project was building the capacity of the three supportive living facilities to deliver the model program after the completion of the demonstration project. The literature recognizes that building capacity requires a genuine engagement of staff at the target facilities in planning and problem solving all program elements (51,52,53,54). Our approach drew from similar principles and strategies taken from two models of community capacity building (55,56). The principles and strategies are shown in Table 4.

Table 4: Capacity Building Principles and Strategies

Capacity Building Principle	Related Project Strategies /Supports
Establish a shared sense of community and responsibility.	<ul style="list-style-type: none"> • Continue volunteer membership on agency committees, Board of Directors, and Advisory Committees.
Build capacity for problem solving, improve the skills and knowledge of agency staff, and impact the effectiveness of the organization.	<ul style="list-style-type: none"> • Collaborate with facility staff on planning, implementation and problem solving model program implementation. • Involve facility personnel on project Advisory Council. • Identify linkages of program to overall mission and agency services.
Establish effective systems through programmatic and procedural approaches.	<ul style="list-style-type: none"> • Training activities for facility staff will include: <ul style="list-style-type: none"> • Manual will be developed for implementation of all program elements. • Facility staff will observe project staff implement all aspects. • Observation/feedback to facility staff by project staff. • Developing formal and informal mechanisms for feedback from facility staff to project staff on an ongoing basis.
Attend to environmental circumstances that facilitate or inhibit capacity building efforts.	<ul style="list-style-type: none"> • Participation of facility staff/leadership on the project Advisory Council. • Staff involvement in project planning, implementation and evaluation activities.
Work with multi-agency/multi-sectoral partners to establish effective relationships at a community network level to sustain built capacity and outcomes.	<ul style="list-style-type: none"> • Inclusion of facility staff alongside representatives of key state and local service agencies on the project Advisory Council. • Development of a project resource manual documenting contact information, methods of referral and service information for all agencies to assure information is maintained even in the case of facility staff turnover.

Staff of the three facilities was involved in planning, implementing and evaluating the ESD program from its inception. In this way, staff members were able to become familiar with the program features and details of its implementation. Based on our discussions with the facilities before implementation of the project, it was realized that sustaining the program would require some combination of retooling existing staff, adding personnel, and working to take advantage of existing services in the local area. The occupational

therapists on the ESD project were available to act as consultants to help the facilities problem-solve in these areas. For example, the occupational therapists helped the facilities more clearly define the roles and responsibilities of different staff members to better utilize the time of existing staff and avoid unnecessary overlap. Additionally, during the tenure of the program, one of the facilities hired a part-time occupational therapist and a peer mentor trained through the ESD program.

The occupational therapists also consulted with the facilities to integrate the ESD program at a programs level. For example, the existing mandatory services at one of the facilities were not well coordinated. Two of the groups that were meant to have distinct goals often overlapped in content and format or provided such disparate information that residents were having difficulty recognizing the “take away message” of the services. Through the ESD program, the occupational therapists were able to work with staff to create more complementary content and formats for different groups. In this way, residents were able to learn information from a variety of angles and practice positive behaviors within the safety of the group.

With this more curricular approach to programming, staff was encouraged to use group topics to help clients set and work on individual goals. Individual goals could mirror group content, or group content could help an individual reach his or her goals. For example, in the process of learning how to access his credit report in a group session, one client decided he wanted to clear up an unpaid student loan in order to go back to school. He was able to set the long-term goal of returning to college with his case manager and use group content to help him reach short-term goals, like learning strategies for reestablishing good credit.

ESD project staff engaged the three facilities in a collaborative effort to identify the best approach for sustainability. This approach allowed the formation of a partnership that helped empower facility staff to take ownership of the ESD program. Before the final implementation, we identified within each facility the staff members who would have responsibilities for program components and made sure they received direct, one-to-one training in those areas. These staff members observed the occupational therapists plan, implement and process group experiences. Then, the staff would plan, implement and process group experiences under the supervision of the occupational therapist.

This process began approximately four months before the completion of the project. The occupational therapists would first ask the staff persons to observe the group, and then the occupational therapists and staff would process the group together asking, for example, the following questions: What went well? What did not go well? What were the dynamics like in the group? How were difficult clients handled? Was the content appropriate/relevant to the clients?

Through this system of processing the experiences of planning and implementing groups, a “peer evaluation form” (Appendix C) was adopted to allow site staff to systematically and consistently critique each other’s group facilitations. Group planning was then discussed, and the occupational therapists were able to offer constructive feedback to staff on how they accessed, organized and designed group content. The staff then co-planned and co-lead multiple groups with the occupational therapists, always continuing the practice of processing group experiences. After approximately four sessions of co-planning and co-leading groups, staff members were charged with planning and implementing their own group under the supervision of the occupational therapists.

During this time, staff received feedback from the occupational therapists and from each other. This process helped to develop a culture of constructive criticism among staff that would endure after the occupational therapists were no longer working with the facilities. In this way, the facilities were able to sustain the group portion of the ESD program after the termination of the project.

In addition to this one-to-one skills training, the occupational therapists were able to offer staff in-services in skills such as public speaking and establishing good boundaries with clients. They were also able to offer information and connections to resources that had not been previously accessed by staff at the facilities. For example, the occupational therapists were educated on local vocational rehabilitation and job placement services that, in some instances, case managers were unaware of.

A significant event beyond the original plan of the project related to capacity building was a one day conference titled "With Knowledge Comes Hope." This event was sponsored by the three parent organizations of the supportive living facilities and co-sponsored by the University of Illinois at Chicago Department of Occupational Therapy. The event featured nine concurrent educational and discussion sessions and a keynote speaker, as well as information tables and light entertainment. The conference was planned by staff of the facilities and four residents who acted as consumer members of the planning team. Project staff helped to coordinate the event which had seventy-two attendees.

Benefits of the ESD Program

Through focus groups with staff at the facilities, we learned that inclusion of occupational therapy in programming can result in a number of benefits to the staff and those who are recipients of services. Occupational therapy impacts the programming positively by focusing on issues holistically, being process oriented and strength-based, and providing opportunities to practice skills.

Reflecting on their experiences with the ESD program, staff members felt that occupational therapy services can have a significant impact on changing the culture of programming in their settings. Staff recognized a shift from viewing clients in a purely negative and illness oriented manner to one that is able to recognize that each human has strengths and potential. This helps the staff to refocus the way they provide services and to begin to understand the need to focus on each client's strengths rather than their failures.

ESD was also found to benefit the facilities in that services focus on learning practical skills rather than creating an environment that has a heavy emphasis on discussion sessions. The programming provides an opportunity to put into practice skills that are necessary for clients to achieve their goals. For example, opportunities to practice resume writing, filling out applications, interacting with a supervisor, and time management were offered in order to help clients obtain future employment. The staff felt this "doing" part of the intervention is vital to the success of clients.

Staff also stated that the ESD program helped them to focus and restructure their own programming. With this model, they were able to develop programming that is structured and provides a systematic proc-

ess for clients to move through the program. This helps the clients and the staff to have a clear understanding of what is expected in order to progress.

Overall, ESD was perceived as having positive effects on programming. The benefits allow staff to begin to see the strengths of clients, focus on practical skill acquisition, and provide a chance to progress through programming that is structured and allows a common understanding of what is necessary to succeed.



Section 10: Suggestions for Program Improvement

As a result of our ongoing assessment for program improvement as well as feedback from participants, the following suggestions can be taken into consideration when developing a new program.

Further inclusion of peer educators and mentors

- Participants find it helpful to have role models and other people who know what it is like to have HIV/AIDS and transition to independent living and work or school.
- We began to incorporate peer mentors into project planning and implementation, but a program could benefit from a more fully integrated system of peer mentor support.

Consideration of staffing (cultural diversity, language)

- Due to the changing HIV/AIDS population (more women, African-Americans, and Latinos) it is helpful to have staff members from these backgrounds.
- It is likely that participants will feel more comfortable with staff from their own background, especially in cultures where HIV/AIDS is still heavily stigmatized.
- Language can also sometimes be a barrier to participation, so having a bi- or multi-lingual staff member would have the potential to increase client involvement.

Problems with contacting participants

- Since our participants were living in transitional housing facilities or in substance abuse programs, they did not have access to a personal phone. Contacting these participants was sometimes difficult. There may be free voice mail access that your participants may be eligible for in your area. It is worth looking into not only for staff to be able to contact the participant, but also for potential employers.

Positive Workplace Training (National AIDS Fund)

- It is suggested that members of your staff get the training to become facilitators for the “Positive Workplace” (see Appendix B). If that is not possible, we suggest having someone who is a facilitator come and present the workshop to your group. This content would familiarize participants with the workshop and show how it can be used with employers. Also, many participants may not know the basic issues explained in the presentation and may learn something themselves.



Section II: Challenges to Program Implementation

Over the course of ESD we found multiple barriers to providing participants services. The following six items are potential pitfalls in delivering services to supportive housing agencies.

Participant no shows

One of the biggest frustrations with program implementation was when participants did not show up to groups and scheduled individual sessions. Many times, participants did not notify staff of an absence. Since there were no direct consequences for missing a group or individual session (except for missed content), it was challenging to convince participants of the importance of letting staff know when they were unable to make appointments.

We incorporated these issues as group topics, discussing respectful and disrespectful behaviors in terms of accessing services, employment, etc. We also changed our expectations of participation. By the end of the program, instead of scheduled weekly meetings, clients were engaged in more informal sessions and allowed to “drop in” for a session during our “office hours.” Participants still had the option to schedule an appointment, if desired.

Lack of agency support in participation

Contributing to participant no shows were the varying participation policies of the intervention sites. At one site, we had consistent group participation because the site gave us reign over an established group that was mandatory for clients in the program. We saw an increase in participation at another facility that changed its participation requirements during our tenure, becoming a more structured program with more specific programming requirements. A third facility did not require any participation in programming, with the exception of guidelines for alcohol/substance abuse recovery. After initial difficulties with participation at this site, we found that the peer mentor role model was successful at engaging residents in the program. With the peer mentor and the occupational therapist, the residents at this facility seemed more apt to engage in one-on-one or semi-private sessions versus attending larger group sessions.

Peer mentor hiring, training and retention

A third challenge was hiring, training and retaining peer mentors. Our first challenge of hiring was in advertising the positions. We mostly used the facilities where the intervention was taking place and word of mouth to publicize the positions. This led to the dilemma of whether or not we should hire a peer mentor who currently lived at one of the supportive facilities. We initially decided that this housing situation would not be a conflict but later found that some participants viewed these peer mentors as less knowledgeable, since they had not yet transitioned to independent living. We also observed that the bump in income to the peer mentor seemed more difficult for those living at the facilities to manage compared to those who already lived independently in the community. The salary increase created issues related to the amount of rent to be paid and mandatory savings plans at the facilities, and the readiness of the peer mentor to manage that larger amount of money.

We also learned that we needed to develop more realistic hiring criteria. We aimed to hire individuals who had at least a GED and good computer skills, as well as people who could manage a twenty-hour-a-week job. We found that there were some people who would have been excellent peer mentors who did not have or were in the process of obtaining their GED. We also discovered that our expectations for fluency in a variety of computer programs were unrealistic. The people we hired had basic computer skills, but required a large amount of training and supervision around using programs such as Microsoft Word. Lastly, many of the people we interviewed did not have an active recent work history. Asking them to transition to work twenty hours a week proved overwhelming for some. We were able to modify this hiring criterion and offer a quarter time position. This solution seemed to alleviate the stress of the peer mentors we hired.

Training of the peer mentors also proved to be challenging. We needed to develop a very clear plan of what we wanted the peer mentors to learn and how we wanted them to learn it. Initially, we handed over materials to the peer mentors, including video tapes about HIV in the workplace and literature on developing active listening skills, and asked the peer mentors to review the materials autonomously. We would then briefly go over the materials with the peer mentors to ensure adequate understanding. The peer mentors

seemed to find this system overwhelming. Taking a more active approach of discussing topics, practicing skills and processing experiences seemed to be a more effective way for the peer mentors to learn the skills they would need to co-lead groups and offer individual support to clients. This method of training, however, required the occupational therapists to spend a significant amount of their time with the peer mentors, which often interfered with other responsibilities. Future planning of including peer mentor support in a program such as this would benefit from a more concrete system of training and a more realistic appraisal of the time commitment to adequately train and supervise peer mentors.

Lastly, retention became an issue around including peer mentors in the ESD program. We hired a total of five peer mentors throughout the project because of turnover. Termination of employment was due to relapse from substance abuse and/or exacerbation of mental illness and concerns about health and stress management. We found that more intense supervision was needed around skills such as time management, computer competence, and stress management. We also initially underestimated the need for training in communications technology (i.e., email) and the complexities of supervising staff who worked as little as ten hours per week but needed to move between two facilities. Some of the peer mentors required education around professional behaviors, such as showing up on time for work, returning phone calls, asking for supervision when problems arise and giving notice if the decision is made to terminate employment.

These difficulties in retention lead us to question our hiring process. Future programs might benefit from developing an interview process that can screen for potential problems without violating discrimination rules in hiring. We began to think about how we might be able to do this in our hiring practice, but did not develop an actual interview protocol.

Substance abuse backgrounds

Some participants relapse during their time in programming. Others may quickly leave the facility after they arrive due to relapse, community living stressors, or poor fit. In these circumstances, we found it very helpful to keep in good communication with a participant's case manager and/or substance abuse counselor to help ensure future contact and follow-up with the participant.

Keeping group on topic

This was a challenge for a number of reasons, including difficult client personalities, chaos at the residence and medication side effects. The occupational therapists employed group leadership strategies to manage these difficulties and keep participants focused on the topic at hand.

Death of participants

Unfortunately, due to the nature of HIV/AIDS and other related illnesses, some of our participants passed away while enrolled in our program. We established close relationships with most participants, and this was difficult to deal with. Being able to process issues of grief with supervisors and/or work colleagues became important in managing our own attitudes and emotions.



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Appendix A: Group Example



Overview

Stress: Focus on How Stress Affects Your Body and Mind

Total time for session: 1 hour

Place: Room with enough chairs for all participants as well as a writing surface. There should be either a black/whiteboard or flip-chart in the room. The space should be private, so as to avoid outside distractions and to encourage discussion.

Intended Audience: This group is intended to be conducted with people with HIV/AIDS who are living in supportive facilities or who require support in this area. The size of the group can be 4-16 people, though an ideal group size is 5-8. Participants must have at least an average level of cognitive ability to participate in this group. This session can be easily adapted for individuals with physical limitations.

Learning Objectives:

- To establish/maintain rapport with and between participants
- To discuss and ensure confidentiality
- To establish group norms
- To identify what happens to the body during a stress response
- To identify positive effects of stress
- To recognize that stress can affect physical and emotional health
- To recognize that stress can have negative effects on the immune system
- To identify how stress can affect decision making
- To identify “first steps” towards maintaining personal optimal stress levels

Agenda:

Activity 1.0	Ice Breaker and Group Contract (optional)	5 minutes
Activity 1.1	Introduction	3 minutes
Activity 1.2	What Happens to Your Body When You’re Stressed?*	10 minutes
Activity 1.3	Positive Side of Stress*	15 minutes
Activity 1.4	Health Effects of Stress*	10 minutes
Activity 1.5	Decision Making Under Stress*	12 minutes
Activity 1.6	Wrap-up	5-10 minutes

What you’ll need:

- Pens or pencils
- Clock or watch (to monitor time of activities)
- Dry erase board or flip chart with markers
- Copies of handouts for everyone:
 - *Handout 1.2 - What Happens to Your Body When You’re Stressed?
 - *Handout 1.3 - Positive Side of Stress
 - *Handout 1.4 - Health Effects of Stress
 - *Handout 1.5 - Decision Making Under Stress

Facilitator Key**Activity 1.2:** What Happens to Your Body When You're Stressed?**Time:** 15 minutes**Setup:** A visual aide to record participant suggestions

Instructions: Ask participants what changes they notice in their bodies when they are feeling stressed. Probe, when necessary, and encourage participants to be specific in their descriptions. For example, if someone says "I feel bad when I get stressed," ask them, "What in your body feels bad? What part?" This becomes important when later identifying personal signs of stress (found in the group *Stress: Vulnerability to and Indicators of.*) Remind participants, as necessary, that you are asking what happens *in their bodies* when they feel stressed – not how they feel emotionally. Record participant's suggestions on the visual aide. See sample.

When suggestions fade, distribute and review the handout, especially the information about the fight-or-flight response. Also emphasize the idea that feeling this way for long of periods time or frequently can be harmful to your body.

Learning Objective(s) Met:

To identify what happens to the body during a stress response

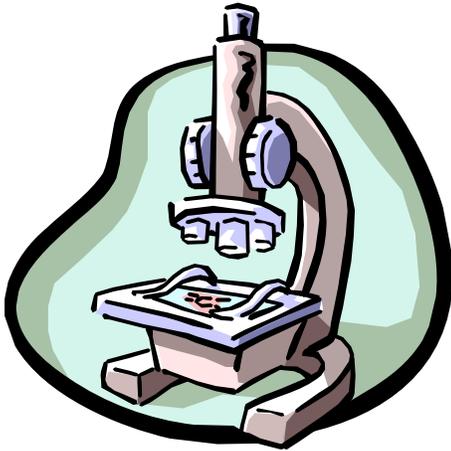
Handout(s) for participants: 1.2 – *Biology Lesson: What Happens to Your Body When You're Stressed?***References for Handout:**The stress response. http://www.mbmi.org/pages/mbb_1.asp (22 Sept. 2003).Spurlock, J. (2000). How stress affects the body. <http://www.amwa-doc.org/publications/WCHHealthbook/stressamwa-ch09.html> (22 Sept. 2003).**Supplies Needed:** Markers for visual aide**Sample**

Participant states: "I just feel really tense when I get stressed."

Facilitator probe: "What specifically in your body feels tense?" "Do your muscles feel tense?" "Do you feel tension in your head?"

Participant states: "When I'm stressed I'm really sensitive to everything."

Facilitator probe: "What kinds of things? Noises? Being around people?" "How are you sensitive?" "Do you jump at noises?" "Do you feel unsafe around others?"



Biology lesson: What happens to your body when you are stressed?

- When you feel like you are in danger – physically or emotionally, in reality or in your imagination – a small area in the center of your brain causes hormones to go through your bloodstream and excite your body systems.
- When released into the body, these hormones cause the “fight-or-flight” response. The following changes occur during this response:
 - Pupils (the black part of your eye) widen to let in more light
 - More adrenaline and other hormones pump into your bloodstream
 - Alertness increases because there are more chemicals in your brain
 - Heart races
 - Blood pressure rises
 - Muscles tense
 - Digestion slows
 - Sweat production increases
 - Hair may feel prickly and stand on end

Your body is getting ready to defend itself!

- Having these body responses for long periods of time or a lot of times can be harmful.



Appendix B: Resources

Chicago Area Resources

Employment and Training

Calor

3220 W. Armitage Ave. Chicago
773-235-3161

Job placement assistance and HIV case management and several other programs that target/serve the Latino HIV impacted community

Chicago Women's AIDS Project

5249 N. Kenmore Chicago
773-271-2242

Women's support services, working support groups, buddy program, massage and referrals

Chicago Women in Trades

1657 W. Adams Street Suite 401, Chicago
312-942-144

Training Program for women interested in obtaining and apprenticeship in the trades

El Valor

1924 W. 21st Street Chicago
312-997-2030

Job training and placement assistance for lower level clients who may need supportive work or who have developmental disabilities

Enterprising Kitchens

4545 N. Broadway Chicago
773-506-3880

Job preparation program that hires women to make soap and learn self-sufficiency strategies

Greater West Town Community Development Project

2045 W. Fulton Chicago
312-563-9028

Job training and placement in woodworking, trades

Health Works Theatre

3171 N. Halsted St. Chicago
773-929-4260

Volunteer Opportunities for a theatre troop that educated youth about HIV

IAM CARES

3333 W. Arthington
Suite 139 Chicago
773-265-3302

Offers job training programs and placement for people with disabilities. Must have a documented disability (have an ORS case manager, be on SSI or SSDI) to qualify for services

Appendix B

Illinois Employment and Training Centers

Several different sites across the city –

Northwest Center (at the old Wright College campus) 773-736-5627

Pilsen Center – 312-243-5100

Westside Center 773-227-7117

Mid-South Center 773-538-5627

Southwest Center 773-8847000

Excellent resource for resume writing (has a computer lab) and job search. Open to the public. More intensive job training services are available if needed and client must qualify

Inspiration Café

4554 N. Broadway Chicago

773-878-0981x205

Excellent resource for volunteer placement and food training program, in which clients receive food and sanitation certificate. Case management services and educational seminars also available

Jane Adams Resource Corporation

4452 N. Ravenswood Chicago

773-728-9769

Job training and placement in drafting (clients receive free computer classes with this) and the trades. Also offers computer training classes (i.e. Microsoft, excel) at prices cheaper than Community College

Jewish Vocational Services

2020 W. Devon Ave. Chicago

773-761-9000

Evaluate skills and prep clients for placement with different skills training

Jolt

773-265-3300

Contact IAMCARES for details

Chicago area job developer's meeting to create networking opportunities and resources among social service workers

Mayor's Office for People with Disabilities

2102 W. Ogden Ave. Chicago

312-746-5743

Good resource for job links and training programs. Client must qualify

New City YMCA LEED Council

735 W. Division Street Chicago

312-266-5400

Job placement and training for the retail (Crate and Barrel, Walgreen's) and the trade industries

Prologue Adult Learning Center

1105 W. Lawrence Chicago

773-728-8120

Excellent resource for GED program, ESL and tutoring. Also, excellent resource for volunteer opportunities staff are very open and willing to train volunteers

Appendix B

Spanish Coalition for Jobs

2011 W. Pershing Road Chicago

773-247-0707

Employment network links and school

Women Employed

111 N. Wabash Ave. Suite 1300 Chicago

Job training programs for displaced homemakers (women). Individual career consulting available as well as access to a job bank. Membership organization – so a fee of about \$20 to join

City Colleges of Chicago

Richard J. Daley College

7500 S. Pulaski Road

773-838-7500

Kennedy King College

6800 S. Wentworth Ave.

773-602-5000

Malcolm X College

1900 W. Van Buren St.

312-850-7000

Olive Harvey College

10001 S. Woodlawn Ave.

773-2916100

Harry S. Truman College

1145 W. Wilson Ave

773-878-1700

Harold Washington College

30 E. Lake St.

312-553-5600

Wilbur Wright College

4300 N. Narragansett Ave.

773-777-7900

AIDS Legal Resources

Legal Assistance Foundation of Chicago, HIV AIDS Project

312-347-8309

Legal assistance for low income, HIV positive Chicago residents

AIDS Legal Council of Chicago

312-427-8990

Legal issues assistance and work topics that affect people with HIV

SSI Coalition

312-223-9600

www.ssic.org

A non-profit organization that assists people with SSI and SSDI issues and court representation

Public Benefits

Illinois Department of Human Services

1-800-720-4166

Call to contact the closest office to report income, process Medicaid applications and appeal

Internet Resources

www.aidslegal.com

AIDS Foundation of Chicago

Learn about how to get a case manager or general AIDS info

312-922-2322

www.npo.net

An excellent resource of non-profits throughout Chicago; volunteer opportunities and job postings

www.state.il.us/ins/healthinsurance/HIPAApre-ex.htm

IL department of Insurance-HIPPA

National Resources

Job Search Internet Sites

www.monster.com

www.hotjobs.com

www.usajobs.opm.gov/index

www.career.yahoo.com

www.headhunter.net

www.socialservice.com

www.nmac.org/about/jobs/jobbank.asp

www.careercity.jobcontrolcenter.com/search

AIDS Related Internet Sites

www.aidsfund.org.

Essential resource for HIV/AIDS back to work information. Especially good on topics of interviewing, and explaining the gap in resumes

www.thebody.com/pos_work/ADA

Americans With Disabilities Act

www.medscape.com/Home/Topics/AIDS.html

Medical HIV/AIDS Information

www.ama-assn.org/special/hiv/hivhome

Journal of the American Medical Association (JAMA) HIV/AIDS Resource Center

www.niaid.nih.gov

National Institutes of Health

School or Training Resources

www.fafsa.ed.gov/entfafsa.htm

Apply for undergraduate financial aid

www.lgta.org

Land Grant Training Alliance – on line computer lessons

Mavis Beacon – typing tutorial

Public Benefits

Social Security Administration

1-800-772-1213

Call to contact the closest office to report work, obtain application and make appeals

HIV/AIDS Training

Work Positive, Inc. (The Positive Workplace)

930 N. Palm Ave., Suite 235

West Hollywood, CA 90069

Phone: 310-657-6898

Fax: 310-657-6888

Email: info@workplace.com

Appendix B

Job Search Resource Books

Job Search Secrets by D. Lussier and T. Noteman

The Only Job Hunting Guide You'll Ever Need by Kathryn and Ross Petras

Job Interviews Made Easy by Marler/Mattia

Computer Resources Books

“For Dummies” Series for Access, Excel and Word



Appendix C: Peer Evaluation for Group Facilitation

Peer Evaluation for Group Facilitation

Did You:		Comments
Ensure a good, functional work environment (space, light, equipment, etc.)?	<u>Y</u> <u>N</u>	
Give opportunity for people to introduce selves, if applicable?	<u>Y</u> <u>N</u>	
Provide an agenda/purpose/goal and time-frame of group/topics?	<u>Y</u> <u>N</u>	
Use a variety of strategies to convey/ summarize information (visual aides, handouts, repetition, anecdotes, etc.)?	<u>Y</u> <u>N</u>	
Keep personal opinions to a minimum, instead directing questions back to the group?	<u>Y</u> <u>N</u>	
Observe social interaction between group members and intervene when appropriate?	<u>Y</u> <u>N</u>	
Allow group members to solve differences, when appropriate?	<u>Y</u> <u>N</u>	
Remind members of proper group behavior, when appropriate?	<u>Y</u> <u>N</u>	
Encourage quieter members to participate and limit more talkative participants?	<u>Y</u> <u>N</u>	
Keep group members on subject?	<u>Y</u> <u>N</u>	
Give a summary of points raised/learned at the end of the session?	<u>Y</u> <u>N</u>	
If used, were handouts:		
Easy to read and understand (language, use of bullets, white space, etc.)?	<u>Y</u> <u>N</u>	
Free of typos and formatting inconsistencies?	<u>Y</u> <u>N</u>	
Clear in emphasizing a few main points?	<u>Y</u> <u>N</u>	