Research has demonstrated that stable housing contributes not only to the physical and emotional health of people with AIDS but also to societal goals of providing effective health care in an efficient and cost-effective manner. A stable home environment also makes it easier for people with AIDS to address mental health or substance abuse issues. Yet, publicly supported housing for poor people with AIDS has been criticized as singling out one special population for extra government attention. People with AIDS experience extreme difficulties obtaining and retaining appropriate housing, and this, along with the compelling public health benefits of stable housing, justifies government efforts. This article provides a brief overview of housing needs and programs for poor people with AIDS in the United States as well as an explanation of how the changes in the epidemic over the last five years have influenced AIDS housing provision.

**The AIDS Housing Challenge**

In 1989, the U.S. Citizens Commission on AIDS identified HIV disease as a primary cause for homelessness in the nation, especially in urban areas. One reason for this was discrimination. People with HIV were often evicted from their apartments or suffered the loss of employment or income. Additionally, mothers with HIV were often forced to place their children in foster care because they were too sick to care for them. This resulted in the loss of many of their welfare benefits, decreasing monthly income and increasing homelessness.

The 1989 finding that HIV is a primary cause of homelessness remains true today. One national study estimates that one-third to one-half of people with AIDS are homeless or in danger of becoming homeless.\(^1\) Of special populations with AIDS (elderly, youth, drug users, and others) surveyed in New York state, 64 percent had slept in non-permanent housing such as the street, a shelter, emergency housing, a transit station, a tent, or a car over the previous 12 months.\(^2\) A similar national survey found that 47 percent of clients of AIDS housing providers had lived in a hospital, jail, shelter, tent, or car, or on the street immediately before coming to the housing agency.\(^3\)

Once homeless, the problems for people with HIV are just beginning. The lack of an address and telephone number makes it difficult for a person to access health and support services. Homeless people with HIV fear violence and discrimination—despite the explicit inclusion of HIV status into federal non-discrimination laws for those with disabilities—both from their peers and from the social service system if their disease status is disclosed. People with HIV, especially those in the later stages of disease, need shelter 24 hours a day. However, homeless shelters are often open only at night. Shelter residents are susceptible to infectious diseases—for example, tuberculosis and Norwegian scabies—which spread easily and quickly when people are in close proximity to one another. When homeless people with AIDS become ill as a result of opportunistic infections, inadequate housing often lengthens the amount of time it takes for them to get well, even after entering a hospital. In addition, homeless shelters rarely provide the necessities, including safe storage and refrigeration, for medications that may be crucial for HIV antiviral treatment.

People who are homeless often delay treatment until their conditions are acute. This results in a higher number of emergency room visits among unstably housed people with HIV and a longer than average hospital stay once admitted. HIV-positive people who are unstably housed are less likely than those who are stably housed to see a physician regularly and have a
For most of us, housing is about finding a place we can afford and turning it into a home where we want to stay. For planners who develop housing alternatives for low-income people with HIV, affordability remains a key challenge, particularly in cities such as New York and San Francisco. But, according to Benjamin McCloskey in this issue of FOCUS, the ultimate challenge is to create a housing system that offers both stability—a place people want to and can stay—and flexibility.

People with HIV are no longer moving only from independent living to hospice care as they did when HIV antiviral treatment was limited to AZT, ddI, and ddT. Rather, the responses of individuals to treatment—with ups and downs, successes and setbacks—demand a varied menu of housing options and a fluid process of movement from housing with greater to lesser levels of support and back again.

At least, that’s the ideal. McCloskey describes the range of housing alternatives for low-income HIV-positive people, the challenges facing housing providers, and some potential solutions to these dilemmas. He also discusses the value of supportive services, including mental health care, in maximizing the efficacy and cost-effectiveness of housing.

Glenn Motola offers some examples of both the trials and triumphs of running a housing program that attempts to respond to the psychosocial and medical requirements—ranging from poverty to psychiatric disorders to substance use—of its residents. In particular, he describes the challenge of congregate housing and the tension between meeting the needs of individual residents and sustaining a cohesive housing community that serves the needs of all residents.

For many mental health providers working on the front lines of the epidemic, treating clients who face complex psychosocial issues is not unusual. But in the context of housing, these issues are pieces in a larger puzzle that require providers not only to manage multiple diagnoses but also to respond to the interpersonal complications that arise in people with HIV, some of whom may be in recovery while others are actively using drugs or living with depression or bipolar disorder, or experiencing cognitive impairment.

McCloskey suggests that the combination of flexibility and supportive care can improve this situation and reduce costs. Flexibility ensures the ability of providers to place people whose health is improving in more independent, and less expensive, housing facilities, and back again if health fails. Supportive care, for example, mental health and substance abuse treatment, both increases the likelihood that residents will be able to continue to make transitions to the most effective and efficient care and ensures that housing facilities successfully meet both individual and group needs.

For society, the difficult truth remains that services such as low-income housing options and mental health treatment for people with HIV are intimately related to effective medical care. Not only do such services protect life, they also improve the quality of living and ultimately save society money.

Creating a Continuum of Care

The benefits of stable housing for people with HIV is clear. Housing alone, however, is not sufficient, especially for those who are leaving homelessness or who have psychiatric or substance abuse disorders in addition to HIV. In order for clients to successfully remain in housing, they must have a range of supportive services that are paired with their housing. Among these services are: housing search assistance, landlord/tenant mediation, legal assistance, case management, vocational training, mental health care, detoxification services, transportation assistance, medication management, and nursing care.

A client’s need for supportive services depends not only on his or her personal history, but also on his or her current health situation. HIV disease affects people in a wide variety of ways and disease manifestation may go back and forth over time, enabling some people to continue their work, school, and home lives unimpeded, but leaving others partially or fully disabled and still others in need of constant nursing supervision. Many AIDS care residences serve people whose needs lie somewhere in the middle of this range. The continuum of care necessary to respond to this situation requires a variety of housing options.

There are five main AIDS housing options:

- **Emergency housing** consists of homeless shelters, hotel vouchers, or short-stay apartments.
- Transitional housing often serves as a place for clients waiting for more permanent housing, including those coming from emergency housing or mental health or drug treatment programs.
- Rental assistance, in the form of federal government-paid vouchers or individual or shared apartments designated for people with AIDS, allows clients who are largely independent, but who require financial assistance, to choose their own living situations with a private landlord.
- Independent living residences are facilities that provide residents with individual apartments or rooms—offering them privacy—plus supportive services such as case management or in-home health care for those times when they may be especially ill.
- Medically supported housing, for people who are either very ill or at great risk for becoming ill in the near future, provides assisted living (such as daily food service), skilled nursing (including medication management), or terminal care (for those in the last six months of life), or all three of these functions.

As of early 2000, there were more than 900 providers of AIDS housing in the United States, one-quarter of which are in California or New York. The majority of these providers are located in urban areas. Almost 90 percent of providers are non-profit organizations that receive funding from various federal, state, local, and private sources. About 1,000 buildings with dedicated AIDS housing units are in operation, representing 10,800 units of housing. Rental assistance in various forms is available to around 17,000 households throughout the country.6

The continuum of care in San Francisco illustrates many of these types of housing assistance. Some clients, many of whom are attempting to return to work or school after recovering from extended illness, receive partial rental subsidies at a flat rate. They require less than $300 each month to support their living expenses in a private apartment. Supportive services for these clients include housing search assistance, vocational training, and money management. Clients who are too ill to work, but too healthy for nursing care pay 30 percent of their monthly income to a private landlord, with the remainder of the rent (up to a pre-determined ceiling) paid for by the program. Supportive services available for these clients include case management, transportation assistance, and landlord/tenant mediation. Those clients who are most ill live in licensed care facilities providing 24-hour nursing and medication management.

Changes and Challenges for AIDS Housing

Although the array of housing options available to people with AIDS is referred to as a housing continuum, in reality, most cities employ a few discrete types of housing, which often results in an inadequate response to changes in the epidemic. The limited options for housing may result in client placement in housing that provides an inappropriate level of supportive services.

For example, waiting lists or residency requirements may make it difficult for an extremely ill client to move from a 24-hour nursing care facility to a more independent living situation if and when she regains her health. This difficulty exists primarily because the AIDS housing system was designed at the beginning of the epidemic when long-term survival was unlikely. What used to be a one-way street toward increasing illness is now filled with detours, loops, and parking spots.

Part of the challenge to adapt to these changes is financial. Housing is expensive, but with additional funds, AIDS housing providers could build or acquire a greater number of housing units. More units would give providers more options to design various levels of care for a larger number of clients. Ultimately, this would create a more fluid care system in which clients would be able to move to appropriate facilities as their health changes. Somewhat paradoxically, spending money to create new housing with several levels of supportive service is the only way to ensure that public and private funds are spent wisely. For example, a client who no longer needs 24-hour nursing care would be happier and better served in a facility that provided fewer services at a lower cost, resulting in the optimal use of public funds. This fluid continuum is consistent with current trends of assisting people with HIV to move from severe illness through appropriate levels of care toward health and the eventual return to productive work. Investments in fluidity may also pay off by building into the system greater responsiveness to future changes in the epidemic.

Acquiring dedicated housing units or subsidizing housing for people with AIDS is doubly challenging in cities such as San Francisco.
Francisco, Boston, Los Angeles, and New York. These cities have high residential real estate costs that translate into higher costs for both dedicated AIDS facilities and rental subsidy programs. They are also subject to large changes in real estate costs over short periods of time, events that are beyond the control of AIDS housing providers but must nonetheless be anticipated.

Establishing Fluidity

How can municipalities and health care providers create a more fluid continuum of housing at a time of funding cuts and the increasing devolution of expenses and responsibilities to local governments? For several reasons, the temptation is to eliminate or drastically reduce supportive services in order to preserve actual housing units. First, supportive services may be available at other agencies unconnected to housing. Second, staffing of supportive services is more flexible—that is, it can be more easily increased or decreased—than is the number of housing units or residences. Finally, the nature of the housing market requires long-term financial commitments with relatively fixed expenses. Without supportive services, however, there is a greater likelihood that clients will be evicted or otherwise involuntarily exit programs. It is important to note that even if supportive services are available at other agencies unconnected to housing, the demand for such services is usually so great that service providers must triage clients. Those clients who are currently housed are of low priority and often do not receive sufficient services from agencies unconnected to housing.

The example of “Mary” illustrates the importance of supportive services. Mary qualifies to receive a housing subsidy for a private apartment but has both substance abuse and psychiatric disorders in addition to HIV disease. The housing specialist assigned to Mary’s case ensures that Mary has the proper connections with substance abuse and mental health treatment providers in the area. This care enables Mary to remain in rental housing, which is less expensive than the hospital care she might otherwise be in. Or take the example of “Tom.” Tom receives a housing subsidy and lives in a private apartment. Tom’s landlord sees that Tom is not taking good care of the unit, which has become dangerously messy, and threatens to evict. A case manager can help Tom learn proper housekeeping skills which he can demonstrate to the landlord, avoiding the eviction.

Rather than eliminating supportive services, cities and organizations must look for creative ways to save money or locate other funds. One possibility would be to restructure rental subsidy programs to reduce or limit the per-unit cost of providing housing subsidies. This may be done by requiring some clients to pay a greater share of their income for rent or by offering incentives such as lower rents to clients who move to less expensive apartments or housing situations. Other cost-saving opportunities may arise from adjusting staffing for supportive services, housing inspections, billing, or client eligibility confirmation, possibly consolidating these services to create staffing efficiency or outsourcing them to groups doing similar work in more efficient ways.

Conclusion

The AIDS housing continuum should be designed—or re-designed—to accommodate people whose health status may change dramatically and whose need for supportive services may also vary. Without this fluidity, people are likely to be “over-housed” in facilities that limit their independence or “under-housed” in situations that compromise their health. While flexibility is difficult to achieve in areas with tight rental markets and high demand for services, the lack of fluidity not only compromises the quality and quantity of client care, it also increases per capita public health costs.
It is someone’s home, a triage center, a 24-hour sub-acute care center. It is a refuge to those who have no one in their lives, to those who cannot remember which room is theirs, to those with decimated CD4 cell counts. It is a complex community.

Supportive care communities, also known as “congregate living settings,” are residential facilities that provide comprehensive care to those living with disabling HIV. In these settings, residents are constantly observed and monitored, prompted to take complicated medication regimens regularly, fed nutritious meals, and kept in regular contact with staff who coordinate their care. They can participate in activities and meet others struggling with similar challenges. They live in a safe environment, possibly for the first time in years. For some, the environment is one in which to regain dignity and rebuild life. For others, it is a place to end life with dignity, in the company of others.

Today, residents in HIV supportive care are living longer than they once did. With this vigor has come not only hope but also a host of challenges that arise when people live together, particularly when many of these people have weathered homelessness, untreated mental illnesses, untreated HIV, and substance use. This article reviews the experience of San Francisco’s congregate facilities and the challenges of operating these communities successfully.

Eligibility for Care
In the 1990s, San Francisco opened five state-licensed HIV residential care facilities for the chronically ill, funded by local, state, and federal agencies. Each serves individuals who have physician-documented disabling HIV and incomes of less than $35,650, although most have incomes of between $12,000 and $20,000. At time of admission, individuals must require 24-hour care. The communities are staffed by nurses, nursing assistants, social workers, activities coordinators, and cooks.

Prospective residents access these communities in several ways, but primarily through a city-monitored waiting list for people with HIV. In addition, a limited number of beds—currently 10 beds at one of the facilities—are reserved for people who are acutely ill and completely unable to live in an unmonitored setting and who are referred by hospital discharge planners, medical practitioners in city clinics, and social workers in the community. In addition, another facility has 15 beds primarily for people who are acutely ill or at the end of life.

Sustaining Community under Stress
In most congregate communities, each resident has his or her own room and shares common areas for dining and living. Because eligibility criteria focus only on disease severity and income and not on the capacity to live with others, this arrangement can be particularly challenging for individuals who have limited social and interpersonal skills, have never lived in congregate settings, or have psychiatric or substance abuse disorders. In addition, these settings are likely to attract residents who are physically fragile.

The most important goal in this context is protecting the safety of residents, in particular, the most vulnerable residents, while accommodating as many individual behaviors as possible. The most difficult behaviors to accommodate are those that arise from substance use and psychiatric disorders. The standard that must be applied here is not what might be tolerable for an individual under the care of a substance abuse or men-


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See also references cited in articles in this issue.
Each program applies a risk reduction model when working with the substance use issues of their residents. This model, which does not stress abstinence, can create difficult situations in the community for both staff and residents especially those residents who are working in active recovery programs. Most facilities have adopted a policy banning the possession or use of drugs, including medical marijuana, on the premises. This protects residents in recovery from having to experience active use in their homes and other residents from the social hazards of disruptive behaviors that may accompany substance use, including everything from theft to noise. Again, some of these behaviors—for example, yelling in the middle of the night—might be acceptable if residents lived alone or could have ongoing, individualized staff attention. But, in congregate care, particularly with physically debilitated residents, such behaviors can seriously compromise the integrity and functioning of the communal living situation. On the other hand, staff encourage residents who are struggling with substance use to approach them for support.

The congregate setting may also have difficulty both meeting the needs of clients with serious psychiatric disorders—especially psychotic, suicidal, or homicidal clients—and sustaining community safety and cohesion in their presence. Unfortunately, even when clients are deemed by community-based psychiatric providers as requiring mental health hospitalization, public mental health treatment facilities may perceive congregate settings as being sufficient for the care of such clients, even though residences usually do not have staff to provide appropriate care.

Lessons Learned

Over the past few years, San Francisco programs have developed approaches to overcome these challenges. First, it is useful to establish relationships with the residents’ primary care providers. Ideally, one provider will care for a majority of the residents in a facility and can make site visits. Although San Francisco programs have achieved this ideal relationship with a few providers, most providers are stationed at centralized clinic sites. It is critical for program staff to initiate frequent and clear communication with providers and to ensure that clients’ medical and psychiatric needs are met.

Second, clients may have multiple case managers at different social service agencies. To achieve the best outcomes, all providers must work together, preferably with one case manager taking a lead role.

Third, it is essential that mental health providers work with residential facility staff in managing the clients with psychiatric conditions and that intervention be prompt. Further, residence staff should obtain releases from clients allowing staff to communicate with clients’ mental health providers.

Fourth, it is crucial for staff to have well-defined boundaries with residents. To avoid sending clients mixed messages, staff should establish and consistently adhere to written, resident-specific care plans.

Finally, nurturing a sense of community can establish a culture built upon caring and support that will ultimately ease day-to-day management challenges. For example, encourage residents to hold forums where they can address community issues and respond to members who are compromising the milieu. Skilled clinical staff can structure these meetings so that they are therapeutic and productive. To discourage destructive behaviors and reinforce positive ones, some programs have implemented “token economy systems,” whereby items—such as shampoo or chewing gum—funded by management are awarded by residents to residents who are publicly acknowledged in community meetings for positive behaviors.

Conclusion

Congregate living is a crucial component of the HIV care system, providing the most basic needs of living—food and shelter—to disabled, low-income people with HIV. The beauty of these communities is that they provide not only these fundamentals, but also the companionship of a community that can stave off the isolation that is so much a part of serious illness. The challenge in sustaining a community is for providers to constantly balance the psychological and physical needs of individuals with the equally important needs of community cohesion and personal safety.

Authors

Glenn Motola, PsyD is the Director of HIV Services for Catholic Charities CYO in San Francisco, San Mateo, and Marin counties. He was the Clinical Coordinator and then Program Director at Leland House, the largest HIV care community in San Francisco. HIV Services runs the 45-bed Leland House, the 32-bed Peter Claver Community, and works in collaboration with Dolores Street Services which operates the 10-bed Cohen residence, with Larkin Street Youth Services, which operates a 6-bed HIV community for youth, and Maitri, which operates a 15-bed hospice/acute care community.

Comments and Submissions

We invite readers to send letters responding to articles published in FOCUS or dealing with current AIDS research and counseling issues. We also encourage readers to submit article proposals. Send correspondence to rmarks@itsa.ucsf.edu or to Editor, FOCUS, UCSF AIDS Health Project, Box 0884, San Francisco, CA 94143-0884.
**Effect of Housing on Health Care Behavior**


Unstably housed people with HIV on Medicaid may be receiving less adequate health care than stably housed people with HIV, according to a large New York state study. Unstably housed participants had higher rates of hospital and emergency room care, however, there was no significant difference in the use of HIV antiviral therapy by housing status.

To understand the effect of housing status on health, researchers controlled for health insurance status by surveying only individuals on Medicaid, since there is the perception that uninsured and unstably housed people with HIV misuse health care services. Researchers interviewed 1,445 individuals face-to-face for 45 minutes, paying participants $10.00 for their time. The interview consisted of closed- and open-ended questions concerning the participants’ sociodemographics, health status, health risk factors, quality of life, and health care access and utilization.

Participants fell into three groups—homeless, doubled-up, and stably housed—based on their housing status at the initial interview. “Homeless” participants were living on the streets or in a temporary housing facility, “doubled-up” participants were living in someone else’s house or apartment, and “stable” participants were currently living in a place of their own.

Eighty-one percent of participants lived in the New York City region, and 19 percent were from upstate counties. Among stably housed participants—whose mean age was 40—70 percent were male, 10 percent were White, 30 percent were Latino, and 60 percent were African American. Homeless participants were more likely than others to be male and less educated. In addition, they tended to have higher levels of what were defined as health risk-related behaviors, including sex with injection drug users or HIV-positive partners, than did the stably housed and doubled-up participants. Homeless participants also had significantly more outpatient visits in the three months prior to the interview and were less likely to be taking *Pneumocystis carinii* pneumonia prophylaxis than those in stable housing.

Compared to those with stable housing, doubled-up participants regularly saw physicians for HIV treatment and monitoring six months less often and homeless participants regularly saw physicians for treatment and monitoring 12 months less often.

**Developing Housing for People with HIV**

Stajduhar KI, Lindsey E. Home away from home: Essential elements in developing housing options for people living with HIV/AIDS. *AIDS Patient Care and STDs*. 1999; 13(8): 481–491. (University of British Columbia, Vancouver.)

Supported living/respite care homes for people living with HIV should replicate a home environment and represent a collaborative effort among the range of stakeholders, according to survey of people with HIV in British Columbia. In addition, people living with HIV should be involved in the planning of supported living/respite care homes. Typically people living with HIV desire to remain in their own homes while also recognizing the need and demand for assisted living arrangements.

Researchers applied a model of participatory action research—a method founded on the principles of social activism, critical social theory, and feminism—to give the community of people with HIV in Victoria an active role in the design and implementation of the survey. The researchers divided the sample of 78 individuals into two groups, including research participants and research respondents. The “research participants” were 18 people chosen from the community, including researchers, staff from AIDS organizations, and people living with HIV. These participants became a part of the research team and influenced the design and analysis of the survey.

The “research respondents” were people living with HIV, people living on the

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**Homeless participants had significantly more outpatient visits and were less likely to be taking PCP prophylaxis than those in stable housing.**
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street, staff from AIDS service and community-based organizations, health care providers, and nonprofessional caregivers. The respondents participated in focus groups and in-depth interviews on the housing needs of people with HIV. Researchers evaluated both focus groups and individual interviews. Using qualitative coding and analysis, they coded the transcripts into themes and patterns.

The main desire of respondents was that the home be a “normal,” aesthetically pleasing living environment where care could take place. The home should have an ambiance of warmth and safety while still respecting residents’ rights to privacy. Respondents also emphasized that the type and level of care should be ongoing and palliative, instead of currently available institutional care that appears sterile, inflexible, and overburdened.

Respondents defined three main issues that would need to be addressed in creating of a home: coordination of round-the-clock services from the local care providers in a speedy and efficient manner; sensitivity to the special needs of people living with HIV; and the existence of a strong support network for caregivers to reduce the onset of burnout. In general, since the course of HIV disease is unpredictable, it is important to create housing services that are flexible: enable people to stay in their own homes for as long as possible; are consistent and coordinated with existing community resources; are owned by the community; and are designed primarily by people with HIV. A supportive care/respite home should be a collaborative effort between the public, community-based organizations, traditional hospital-based health care systems, the government, and most importantly, the communities directly affected by the epidemic: people living with HIV.

HIV and Comparisons of Nursing Home Care
Shin JK, Newmann LS, Gebbie KM, et al.

Quality of care measurement in nursing home AIDS care:
A pilot study. Journal of the Association of Nurses in AIDS Care. 2002; 13(2): 70–76. (Columbia University; and Village Care, New York.)

HIV-positive patients in New York State nursing homes differ from other long-term care patients in terms of demographics, diagnosis, and approach to care, according to a pilot study of a “quality of care” measure specific to HIV-related issues. In response, it would be beneficial to develop long-term care facilities specific to HIV and apply different monitoring standards to HIV-related care.

Researchers analyzed the Minimum Data Set, a standard assessment of long-term care used to monitor the quality, effectiveness, and efficiency of all New York nursing homes for the year 1997, the first full year that reflects post-triple combination treatment experiences. The analysis included two parts: a comparison of all the HIV-positive patients versus all other admissions; and a comparison of nursing homes that had more than 100 HIV-positive admissions, fewer than 100 HIV-positive admissions, and no HIV-positive admissions. Of a total of 665 nursing homes with 180,095 individual admissions, eight had high rates of HIV-positive admissions, 107 had low rates of HIV-positive admissions, and 550 had no HIV-positive admissions.

HIV-positive patients were significantly different from HIV-negative patients. HIV-positive patients tended to be 40 years old to 59 years old and male, and were more likely to be Black or Hispanic than White. HIV-negative patients tended to be more than 60 years old, White, and female. HIV-positive patients were primarily covered by Medicaid, and HIV-negative patients were primarily covered by Medicare. HIV-positive patients in both low and high HIV-positive rate of admission homes had a higher prevalence of occasional or frequent bladder or bowel incontinence, weight loss, antipsychotic drug use, and anti-anxiety/hypnotic drug use. In the high HIV-positive rate of admission homes, HIV-positive patients also had significantly higher rates of depression.

Next Month

Rising rates of sexually transmitted diseases such as gonorrhea and syphilis are correlated with rising rates of unprotected sex, particularly among men who have sex with men. But the relationship between HIV and other STDs extends far beyond the role of STDs as an indicator: STD infection increases the chances of contracting and transmitting HIV and HIV infection increases the chances of contracting and transmitting other STDs. In the October issue of FOCUS, Paul Gibson, MS, MPH, Director of the STD Community Interventions Program for the California Department of Health Services, reviews the relationship between HIV and other STDs through the lens of risk perception. He also provides an overview of the eight major STDs.
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