

# Ganzheitliche Pflegestrukturen für ältere LGBTQIA+ Menschen

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Das Alter rückt näher und in der Tat auch ein gewisses Nachdenken, wie es dann für mich als trans Person weitergeht. Die Hauptangst, die ich habe, wenn ich in ein Heim (oder auch häusliche Pflege) käme, ist, wie mit dem Trans-Sein umgegangen wird. Sprich: Was weiss die pflegende Person, hat sie Vorbehalte gegen trans Menschen, werde ich richtig wahrgenommen? Die Angst auch, dass mir mein Mannsein aufgrund meiner Genitalien abgesprochen wird bzw. das Geschlecht nur auf die Geschlechtsteile reduziert wird. In einem Heim wäre mir die Diskretion wichtig, dass ich nicht zwangsgeoutet werde und es dann unter Pflegekräften wie Bewohner\_innen die Runde macht, ich sei gar kein "richtiger" Mann. Da wünsche ich mir also mehr Aufklärung, am besten schon in der Ausbildung, und vorurteilslose Akzeptanz und Verständnis.

(Henry, Transmann, im Gespräch 2019)



(Ich wünsche mir), dass sämtlich Alterstrukturen ein Wissen haben (oder wissen, wo sie sich informieren könnten), wenn es um ältere oder gebrechliche trans Menschen geht.

Wichtig ist, dass sie (die Pfleger\_Innen – DM & PAS) wissen, dass Geschlecht ein Kontinuum ist und dass alle, auch demente Menschen ein Recht darauf haben, entsprechend ihrer eigenen Identität angesprochen zu werden. Das Geschlecht darf nicht an den Geschlechtsteilen, an operiert oder nicht operiert, an Hormonen oder keine Hormone festgemacht werden, sondern muss die von der Person gewünschte Geschlechtsidentität reflektieren. Bei einigen trans Menschen kommen eventuell noch bestimmte medizinische und praktische Faktoren hinzu, die sich von jenen der cis Frauen oder Männer unterscheiden. So kann z.B. ein trans Mann ohne Genital-OP mit einer Urinflasche nicht viel anfangen.

(Henry, Transmann, im Gespräch 2019)



Die sozialwissenschaftliche Forschung und quantitative Umfragen aus dem Kontext der LGBTQIA+ Selbsthilfe unterstreichen, dass diese Themenfelder wichtig sind.

Die Forschung hat aber auch blinde Flecken!



## **Sozialwissenschaftliche und gerontologische Forschung zu LGBTQIA+ und Altern entwickelt sich in den frühen 2000er Jahren:**

- Folge der Awareness durch ActUP, der HIV-Krise, und der Bürgerrechtsbewegungen in den 1970er und 1980er Jahren
- “Pioniergeneration” dieser Zeit beginnt zu altern
- Fokus auf die Lebenswelten von Individuen (Mikroebene) und statistische Erhebung von Populationen (Makroebene)

### **Bias:**

- Auslassung der Mesoebene auf der Communities agieren
- Akademische Expert\_Innen erforschen LGBTQIA+ und erobern (anders als in den 1980er Jahren) Deutungshoheit
- Sozialwissenschaftliche Studien mehrheitlich deskriptiv und weniger Lösungsorientiert...



## Internationale Stimmen aus der Forschung



“LGBT people are significantly **more likely to age alone** without a spouse or partner or children to support them. They are in greater need of formal caregivers such as home health workers and visiting nurses or assisted living communities. They have valid **fears about experiencing discrimination based on their sexual orientation or gender identity and expression and some even feel the need to go back into the closet.**”  
(Alpert 2015)

## Internationale Stimmen aus der Forschung



“LGBT older adults are much **more likely** than the general population to **experience disability and physical and mental illness while they age**. They are more reliant than the general population on services such as senior housing, transportation, support groups, legal services, and assistance from caregivers with their activities of daily living. Yet older LGBT adults also **report widespread experience with discrimination by caregivers and service providers** that range from refusing to provide care to physical abuse and harassment.”

(Witten 2014)



## Internationale Stimmen aus der Forschung



“Plans for **concealing gender identities, suicide** and **euthanasia** are one way for older TGNC adults to cope with the fears of entering long-term care (Bockting & Coleman, 2007; Ippolito & Witten, 2014). The National Senior Citizens Law Center (2011) reports that TGNC older adults, **regardless of the degree of gender transitioning, are at risk for abuse, mistreatment, or violence in institutionalized settings**, especially those needing assistance with activities of daily living such as showering, dressing, and toileting.”  
(Porter et al. 2016)

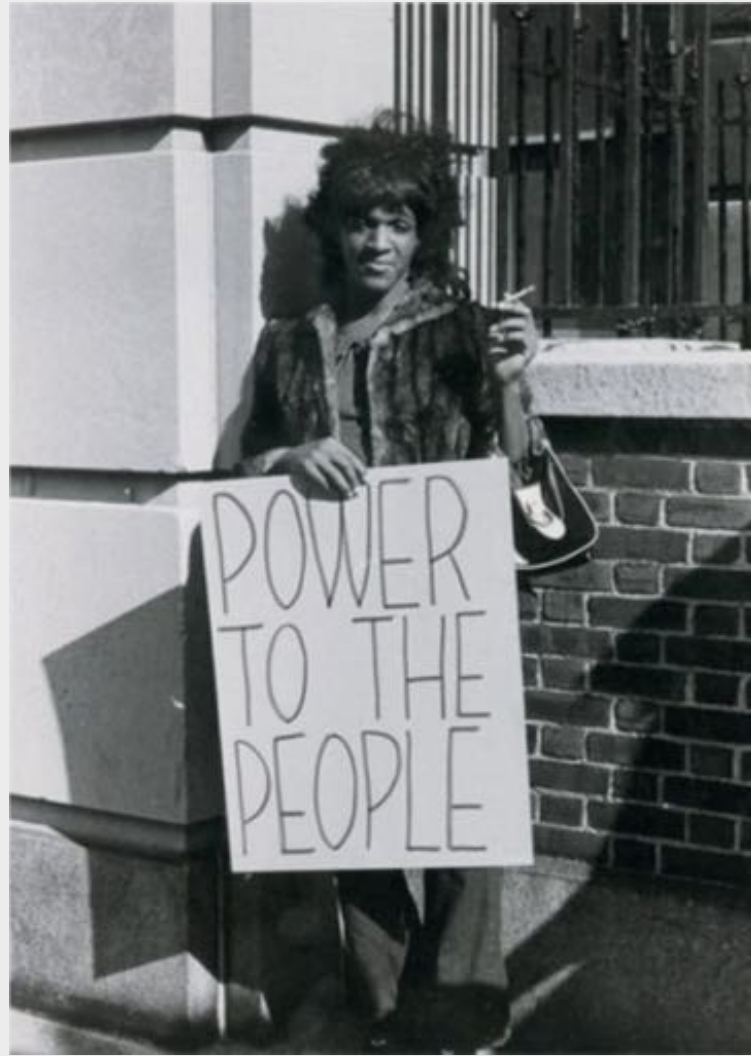
## Internationale Stimmen aus der Forschung



“Knowledge is improving as trans(gender) / gender diverse people age but there are still unanswered questions about what later life and health will be like for trans(gender) / gender diverse people (...). We are only now seeing the first generation of trans(gender) / **gender diverse people in their 60s and over who have taken hormone therapy for 30 years or more, many whom are living with gender reassignment surgeries performed using the very different techniques of the 1960s and 70s.**”

(Age UK 2017, zitiert nach: Westwood 2019)













LGBT AGING  
PROJECT

## Welcome to the LGBT Aging Project

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The LGBT Aging Project is a non-profit organization dedicated to ensuring that lesbian, gay, bisexual and transgender older adults have equal access to the life-prolonging benefits, protections, services and institutions that their heterosexual neighbors take for granted.

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### **Our Mission & History**

The LGBT Aging Project was founded in 2001 by a group of advocates from both the aging service network and the LGBT community who recognized that lesbian, gay, bisexual and transgender elders are invisible to mainstream elder service providers and that older LGBTs are often invisible within the LGBT community as well. In 2013, the LGBT Aging Project became part of The Fenway Institute at Fenway Health, helping to strengthen training, outreach and educational efforts for LGBT older adults at both organizations.

The LGBT Aging Project hosted a LGBT Aging Summit with over 100 agencies and activists which resulted in a written action plan that outlined the goals of our work, ranging from training of mainstream elder care providers to civil marriage rights and expanded social activities for LGBT elders themselves.

In most cases our aim was to facilitate change in existing systems, not provide direct services ourselves. We projected completion of most of our work plan within three years. However we have exceeded this timeline due to tremendous culture change and receptivity to LGBT issues over the past few years.

**National  
Resource  
Center**



## **ON LGBT AGING**

The National Resource Center on LGBT Aging is the country's first and only technical assistance resource center aimed at improving the quality of services and supports offered to lesbian, gay, bisexual and/or transgender older adults. Established in 2010 through a federal grant from the U.S. Department of Health and Human Services, the National Resource Center on LGBT Aging provides training, technical assistance and educational resources to aging providers, LGBT organizations and LGBT older adults. The center is led by Services & Advocacy for GLBT Elders (SAGE) in partnership with 14 leading organizations from around the country: the American Society on Aging (ASA), CenterLink, FORGE Transgender Aging Network, GRIOT Circle, Hunter College, the LGBT Aging Project, the National Asian Pacific Center on Aging (NAPCA), the National Association of Area Agencies on Aging (n4a), National Caucus & Center on Black Aged, Inc. (NCBA), the National Council on Aging's National Institute of Senior Centers (NISC), National Hispanic Council on Aging (NHCOA), Openhouse, PHI, and the Southeast Asia Resource Action Center (SEARAC).

[lgbtagingcenter.org](http://lgbtagingcenter.org)  
[facebook.com/lgbtagingcenter](https://facebook.com/lgbtagingcenter)



SAGE (Services and Advocacy for GLBT Elders) is the country's largest and oldest organization dedicated to improving the lives of lesbian, gay, bisexual and transgender (LGBT) older adults. Founded in 1978 and headquartered in New York City, SAGE is a national organization that offers supportive services and consumer resources to LGBT older adults and their caregivers, advocates for public policy changes that address the needs of LGBT older people, and provides training for aging providers and LGBT organizations through its National Resource Center on LGBT Aging. With offices in New York City, Washington, DC and Chicago, SAGE coordinates a growing network of 21 local SAGE affiliates in 15 states and the District of Columbia.

[sageusa.org](http://sageusa.org)  
[facebook.com/sageusa](https://facebook.com/sageusa)  
[twitter.com/sageusa](https://twitter.com/sageusa)  
[youtube.com/sageusa](https://youtube.com/sageusa)



# Inclusive Services for LGBT Older Adults

A Practical Guide To Creating  
Welcoming Agencies



**National Resource Center ON LGBT AGING**

Aging service providers should be aware that the effects of a lifetime of stigma, discrimination, rejection and ridicule puts LGBT older adults at greater risk for physical and mental illnesses, and other issues including:

- social isolation
- depression and anxiety
- poverty
- chronic illnesses
- delayed care-seeking
- poor nutrition
- premature mortality



## Checklist for Intakes and Forms

- ❑ Staff should ask all clients about their sexual orientations and gender identities. This prevents staff from only asking those who they “think” are LGBT or singling out any one client.
- ❑ Forms should be updated to include relationship options such as “partner” or “significant other.”
- ❑ Create an opening for LGBT clients to talk about any family members of choice by asking them open-ended questions such as, “Who do you consider family?” or “Who in your life is especially important?”
- ❑ Encourage clients to write in their own gender designations by inserting a blank line in addition to “male and female.” Having this additional fill-in-the-blank welcomes people to define their own gender.
- ❑ If you are ever unsure about how to address an individual, **let the person guide you.** Don’t be embarrassed to ask, “Am I using the term or pronoun you prefer?” or “How do you self-identify?” Clients will appreciate when staff members take the time to learn more about them, as well as when staff can demonstrate the agency’s commitment to respect and safety.

## Checklist for Confidentiality

- ❑ Have a clearly stated confidentiality policy written on all forms and ask staff to read the policy aloud before beginning the intake process.
- ❑ Explain how a client's personal information, such as name, gender identity, sexual orientation, health conditions, and other potentially sensitive information may be used by the agency. Let your clients know who may or may not be able to access that information, or how it may be made available for certain urgent situations, such as looking up a phone number for an emergency contact.
- ❑ Reassure clients that their medical and health information must remain private and is federally protected against intrusion and unlawful sharing. If possible, hand out materials on the federal Privacy Rule and how medical and health information is kept private. For more information, visit [www.hhs.gov/ocr/privacy/](http://www.hhs.gov/ocr/privacy/).
- ❑ Emphasize that your agency will not discuss a client's sexual orientation or gender identity with the client's family or friends without his/her specific permission.
- ❑ After the intake, be sure to ask clients if there is any information in particular that they expect to be kept confidential, or if they wish certain information, such as their preferred gender pronoun, to be known and used by other older adults and staff members.
- ❑ If a client wishes to have certain areas of the intake form left blank, such as sexual orientation or gender identity, do not force them to give an answer. Remember, clients may "come out" over time in different stages—and when they are comfortable and ready, they will disclose.
- ❑ Offer your clients the option to answer questions in private.

*Let clients disclose information about sexual orientation and gender identity at their own time and pace.*

## Checklist for First Impressions

- Hang images of LGBT older adults in your welcome area or other high traffic common areas. Be sure to include representation from multiple racial and ethnic groups, aging generations, sexual orientations, and gender identities. Make certain that embracing and highlighting people of color and LGBT people becomes the norm, not the exception.
- Hang rainbow flags, rainbow-colored items, or Safe Zone signs around the agency to signify LGBT solidarity and acceptance.
- Prominently post your agency's non-discrimination policy on your website, all paper or print materials, and in the lobby of your agency. The policy should specifically state your agency's commitment to inclusion and protection of all people, as well as their caregivers, family members, and friends, regardless of sexual orientation and gender identity. The policy should also be readily available in print form for your current employees as well as any prospective employees or staff members. **This should be done regardless of whether your state specifically protects against sexual orientation and/or gender identity discrimination.**
- If your agency has a patient's bill of rights, post this in high traffic areas so that clients and staff members can see your commitment to equitable care.
- If possible, have single-stall, gender-neutral bathrooms available for staff members and clients. For clients who are transgender or gender non-conforming, this can signal a deepened understanding of gender diversity. **However, all clients, including those who are transgender and gender non-conforming, should be allowed to use the restroom they feel most aligns with their gender.**
- Display copies of LGBT-relevant magazines, publications, and information about local LGBT resources in your welcome area. If your agency has bookshelves, include books with LGBT content, characters, and authors.
- Highlight or display your partnerships with, or outreach to, the LGBT community. For example, if your agency regularly hosts LGBT programming or works with your local LGBT community center, hang banners or advertisements displaying these events and partnerships.



## Checklist for Working Toward LGBT Programming

- Decide if current programming can be modified for LGBT clients. For example, when bringing in volunteer attorneys or financial advisors to help clients, be sure that they are using inclusive language and presenting information about particular issues that arise out of legal inequalities, such as different tax implications for same-sex couples, or the latest information on the tax deductibility of transgender-related surgery.
  - Make your agency's meeting space available for diverse groups within the LGBT community to meet or hold their events. This can help your agency foster new partnerships within the LGBT community.
  - Co-sponsor LGBT events or programs with local LGBT groups.
  - Volunteer to speak at LGBT community center events or programs.
  - Consider creating groups for LGBT clients. Some examples include:
    - An intergenerational group between your LGBT clients and younger LGBT people. Many of the societal problems faced by LGBT youth such as bullying, loneliness, and isolation are issues LGBT older adults face as well, and your clients might welcome the opportunity to provide support to LGBT youth.
    - LGBT-specific support groups such as an LGBT bereavement group, a "Coming Out Later in Life" group, an LGBT caregivers group, or an Older Lesbians' or Gay Men or Transgender discussion group, among others.
- If you are unsure what programs may be useful at your agency, disseminate a survey to your clients to find out their concerns or needs. (See section addressing Data Collection.)*

### Checklist for Highlighting LGBT-Specific Programs

- Advertise your LGBT-specific programs and services on your agency's website and calendar.
- Publicize your LGBT services and other diverse programming in your local LGBT community's newspaper or through your LGBT community center's notifications lists.
- When hiring new staff, place job postings in LGBT newspapers, magazines, websites and community forums.

*If you already offer LGBT-specific and other diverse programming, make sure everyone knows about it!*



### Checklist for Transgender Inclusion

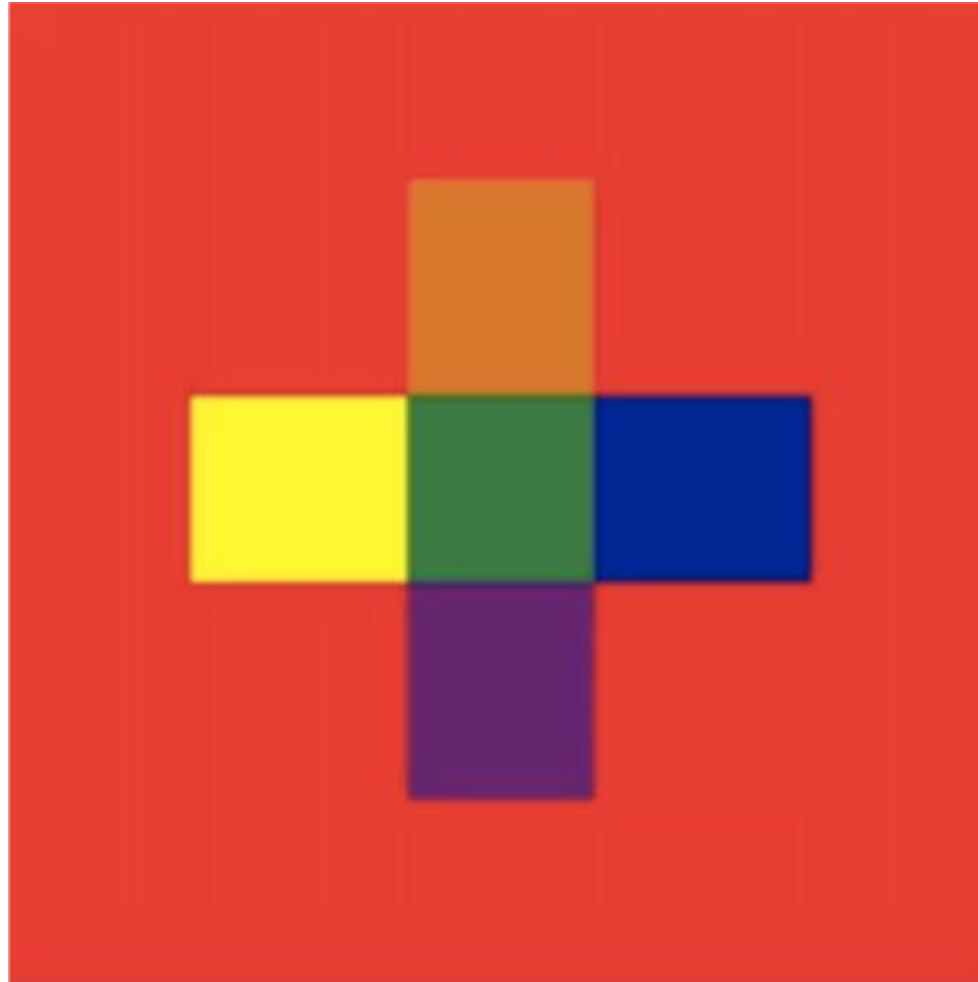
- ❑ Staff should always know and use the pronoun that their clients prefer, even when the client is not within earshot.
- ❑ Where services (including shared rooms) are segregated by sex, assignments should be made based on the client's gender identity, not his/her sex assigned at birth.
- ❑ If your staff administers or prescribes medication, it is appropriate to identify the various medications that a client is taking, including whether he/she is taking hormone medications. This will ensure there are no conditions or factors that serve as a reason to withhold a certain medical treatment. If you do not handle medications, you most likely don't need to know whether a person is using hormones.
- ❑ If your staff is responsible for administering or arranging for certain sex-linked preventive care such as mammograms or pap smears, it may be necessary to know what surgeries a transgender person has had to ensure he/she receives care appropriate for his/her body. If you are not responsible for such medical care, your agency staff most likely do not need to know what surgeries (if any) a transgender person has undergone.
- ❑ If assistance with bathing or other personal care is offered, all staff should have received training on providing professional care to all clients, including working with clients whose physical bodies are different from their outward gender expression or their inner gender identity.
- ❑ When billing health insurance companies, you may need to know if your client has insurance under a different name and/or gender. It is never appropriate to ask, "What is your real name?" Instead, if you need the data, ask the person, "Can I make a copy of your insurance card?" and possibly an additional question to confirm that the name on the insurance card should be used for billing purposes.
- ❑ If your staff arranges clients' appointments with other health professionals, discuss with transgender clients what personal information they are comfortable disclosing. It is not necessary to "warn" professionals that a client is transgender; that information is often unnecessary for appropriate treatment. Further, sharing it without your client's permission is a breach of privacy and may violate HIPAA regulations.
- ❑ Staff should remember that transgender clients, just like everyone else, should be able to use whichever restroom aligns with their gender identities.
- ❑ Staff should always model proper behaviors such as calling someone by his/her preferred name and not engaging in gossip about clients. This sets the tone for other staff and clients.

## Checklist for Policies and Procedures

- Review your visitation policies and make sure that it includes the client's right to receive visitors that the client has designated, such as a partner, domestic partner, spouse, or friend. Policies for accepting visitors should be the same for both same-sex and opposite-sex partners.
- Review your policies and definitions for "family" and make sure that they include a client's "family of choice"—friends, partners, and other people close to the individual—as well as "family of origin"—biological family members or those related by marriage or kinship.
- Consider selecting at least one person to be responsible for ensuring that your agency is continually improving services and care geared toward LGBT and other diverse older adults. This individual could also serve as a direct liaison between clients, their friends, partners, and families to receive input and suggestions about improving care for LGBT clients.
- Highlight or honor those staff members who have demonstrated exceptional care or a commitment to serving LGBT older adults and their families. Use these exemplary staff members as possible mentors or guides for other staff members who may have hesitations or are unfamiliar with engaging LGBT clients.
- Ensure that your agency or organization's board and leadership reflect diversity and inclusion of LGBT older people by race, ethnicity, gender and socio-economic status, among other characteristics.
- Create ongoing monitoring mechanisms for clients to report and address biased behavior from fellow clients or staff and for staff to report discriminatory or biased behavior. This process should be presented to clients and staff and also posted in high-traffic areas.
- Have a designated staff person, preferably a Human Resources manager, handle complaints quickly and speak confidentially with each affected party to address the incident as well as any underlying patterns of discrimination or disrespect. Avoid creating a confrontational environment or situation that places one person's account against the other person's account.

## Checklist for Assessments

- Have conversations with LGBT clients about how well they feel the agency is doing.
- Speak with members within the LGBT community who are experienced in working with LGBT older adults to understand what they recommend for effectively engaging this population.
- Form a group of agency staff and clients who can provide internal and ongoing feedback on how the agency is serving LGBT and other diverse older adults.
- Create and distribute informal or formal surveys, or online or paper forms, to capture data about the needs, interests and experiences within your agency.
- Create and distribute workforce surveys for the agency's staff to understand how prepared they are to serve LGBT older adults, as well as the types of resources they need to work with diverse LGBT aging clients.
- Ask the family members or other support networks of your clients about the efficacy of your agency's services.





# Sensibilität für LGBTI im Alter



(KEYSTONE/Caetan Bally)



Sind Alters- und Pflegestrukturen in der Schweiz auf die Betreuung von LGBTI- oder HIV+/aidskranke Menschen vorbereitet? Dies ist die Kernfrage der Studie, die PINK CROSS und LOS in Zusammenarbeit mit TGNS (Transgender Network Schweiz) und der Aidshilfe St. Gallen in Auftrag gegeben haben.

Mit den Schlussberichten der Fachhochschulen gibt es darauf in der Schweiz jetzt erstmals eine Antwort.

# Die wichtigsten Ergebnisse

## Alters- und Pflegeeinrichtungen

Schweizweit wurden in einer nicht-repräsentativen Online-Befragung 1327 stationäre Alters- und Pflegeeinrichtungen per Email erreicht, davon haben 353 teilgenommen, was einer Teilnahmequote von 27 Prozent entspricht.

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Wissen zur Thematik



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Erfahrungen mit LGBTI- und/oder HIV+/aidskranken Klient\*innen



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Verankerung von LGBTI-Themen in der Institution



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Wahrgenommene Einstellungen und Reaktionen des Personals



- Die Lücken im Wissen insbesondere über den Umgang mit und die Bedürfnisse von LGBTI-Klient\*innen;
  - Die Themenbereiche LGBTI und/oder HIV+/Aids sind kaum in den Leitbildern der Einrichtungen verankert;
  - Wegleitungen zu Diversität sind in den Einrichtungen nur wenig bis mäßig bekannt;
  - nur wenige Einrichtungen verfügen über verbindliche Verhaltenskodizes für den Umgang mit LGBTI- und/oder HIV+/aidskranken Klient\*innen.
  - die Einrichtungen ergreifen selten bis wenige Massnahmen zum Umgang mit den interessierenden Klient\*innengruppen;
  - die Einrichtungen stellen selten Unterstützungsangebote für Betroffene zur Verfügung.
-

# Familien in der Schweiz

Statistischer Bericht 2017



Schweizerische Eidgenossenschaft  
Confédération suisse  
Confederazione Svizzera  
Confederaziun svizra

Eidgenössisches Departement des Innern EDI  
**Bundesamt für Statistik BFS**

Neuchâtel 2017



20 000 Haushalte werden von homosexuellen Paaren gebildet. Davon haben rund 500, das heisst knapp 3%, ein oder mehrere Kinder unter 25 Jahren<sup>3</sup>. Im Jahr 2013 gab es 6 087 homosexuelle Paare, die in einer registrierten Partnerschaft lebten.

Der Anteil Kinder und Jugendliche unter 25 Jahren, die mit beiden Elternteilen zusammenleben, sinkt von 95% bei den unter 4-Jährigen auf 63% bei den 18- bis 24-Jährigen (siehe Grafik 2.4). Der Anteil jener, die nur mit ihrer Mutter oder mit einem der beiden Elternteile und der Partnerin oder dem Partner dieses Elternteils zusammenwohnen, erhöht sich mit dem Alter und erreicht den höchsten Wert bei den 13- bis 17-Jährigen mit 13% bei den Erstgenannten und mit 4,8% bei den Zweitgenannten. Bei den 18- bis 24-Jährigen gehen die entsprechenden Anteile zurück, vor allem, weil 20% von ihnen nicht mehr bei ihren Eltern oder bei

einem Elternteil leben<sup>4</sup>. Nur sehr wenige Kinder wohnen alleine mit ihrem Vater. Mit 2,7% kommt dies bei den 18- bis 24-Jährigen am meisten vor.

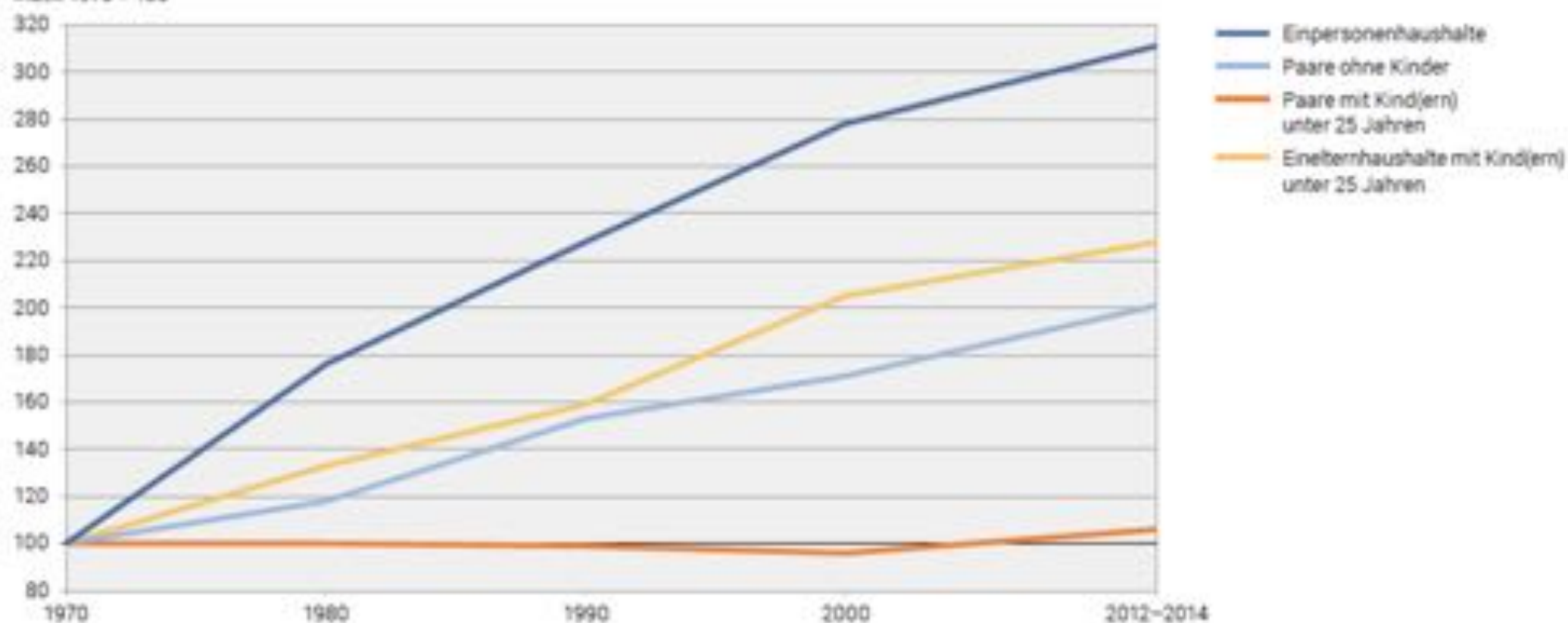
## 2.2 Entwicklung seit 1970

Von 1970 bis heute ist die Anzahl Haushalte schneller gewachsen als die Bevölkerung (siehe Grafik 2.5). Allerdings verliefen die Entwicklungen je nach Haushaltstyp sehr unterschiedlich: So nahm die Anzahl Haushalte mit Kindern unter 25 Jahren nur halb so stark zu wie die Bevölkerung (15% gegenüber 31%), während sich die Haushalte ohne Kinder mehr als verdoppelt haben (Erhöhung um 122%).

## Häufigste Haushaltstypen, Entwicklung von 1970 bis 2012–2014

G 2.6

Index 1970 = 100



Quelle: BFS – Strukturerhebung (SE) 2012–2014 kumuliert, eidgenössische Volkszählung (VZ) 1970–2000

© BFS 2017

## Beobachtungen aus der Forschungsliteratur:

Mithilfe von **qualitativen Forschungsmethoden** (meist Interviewstudien) wurden die Sorgen und Positionen von LGBTQIA+ Individuen erforscht.

Ethisch-normative Fragen beschäftigten sich mit dem unmittelbaren Umfeld der Pflegeempfänger\_Innen, also z.B. dem Verhältnis zu Pfleger\_Innen und den damit verbundenen Herausforderungen.

Es erscheint mir, dass die Forschung lange Zeit nicht an **Community- und Netzwerkaspekten** von alternden LGBTQIA+ Menschen und dem Wissen, welches durch diese generiert wird, interessiert (**Mesoebene**) war. Daher vielleicht auch die Idee, dass LGBTQIA+ Menschen im Alter seltener pflegende Angehörige haben. (Anmerkung: Basiert dies vielleicht auf einem veralteten Familienbild?)

## Beobachtungen aus der Forschungsliteratur:

**Quantitative Studien** sind noch relativ selten und auch weniger aussagekräftig, da die Pioniergeneration der sichtbaren LGBTQIA+ Bevölkerung in Europa erst jetzt in das Pflegealter eintritt.

Auch belastbare **epidemiologische Studien zur Intersektion von Alter und der LGBTQIA+ Bevölkerung** (z. B. zu den „Langzeitfolgen“/„Ergebnissen“ von Hormontherapien für Trans\* Menschen) liegen daher noch nicht vor.

Die statistische Situation in der Schweiz ist schwierig, insbesondere seitens des BAG und anderer öffentlicher Institutionen liegen kaum aktuelle Daten vor.

**Pionierarbeit wird aus der Community selbst geleistet**, beispielsweise mit der nicht repräsentativen Studie „Sensibilität für LGBTI im Alter“ von Pink Cross. (Institutionelles Wissen und Einstellungen des Personals)

**Die kulturelle und spirituelle Situation von LGBTQIA+ Populationen im Alter im Zusammenhang mit der Bevölkerungsentwicklung wird nicht beleuchtet.**

In den USA ist die qualitative und quantitative Forschung multiperspektivischer, eng mit (bundes-)staatlichen Akteuren sowie Pflegeeinrichtungen verbunden. Sie setzt an den Pflegeinstitutionen an.

Allerdings dominieren auch in den USA die aus dem ActUP Aktivismus resultierenden Non-Profit Strukturen.





Professionalisierung, Kontextualisierung  
und Personalisierung der Pflege für ältere  
LGBTQIA+ Menschen...

Eine Einladung Forschung neu zu denken!

## The Construction of Lay Expertise: AIDS Activism and the Forging of Credibility in the Reform of Clinical Trials

Steven Epstein

University of California, San Diego



*In an unusual instance of lay participation in biomedical research, U.S. AIDS treatment activists have constituted themselves as credible participants in the process of knowledge construction, thereby bringing about changes in the epistemic practices of biomedical research. This article examines the mechanisms or tactics by which these lay activists have constructed their credibility in the eyes of AIDS researchers and government officials. It considers the implications of such interventions for the conduct of medical research; examines some of the ironies, tensions, and limitations in the process; and argues for the importance of studying social movements that engage with expert knowledge.*

One of the most striking aspects of the conduct of AIDS research in the United States is the diversity of the players who have participated in the construction of credible knowledge. Inside of a large and often floodlit arena with a diffuse and porous perimeter, an eclectic assortment of actors have all sought to assert and assess claims. The arena of fact making encompasses not just immunologists, virologists, molecular biologists, epidemiologists,

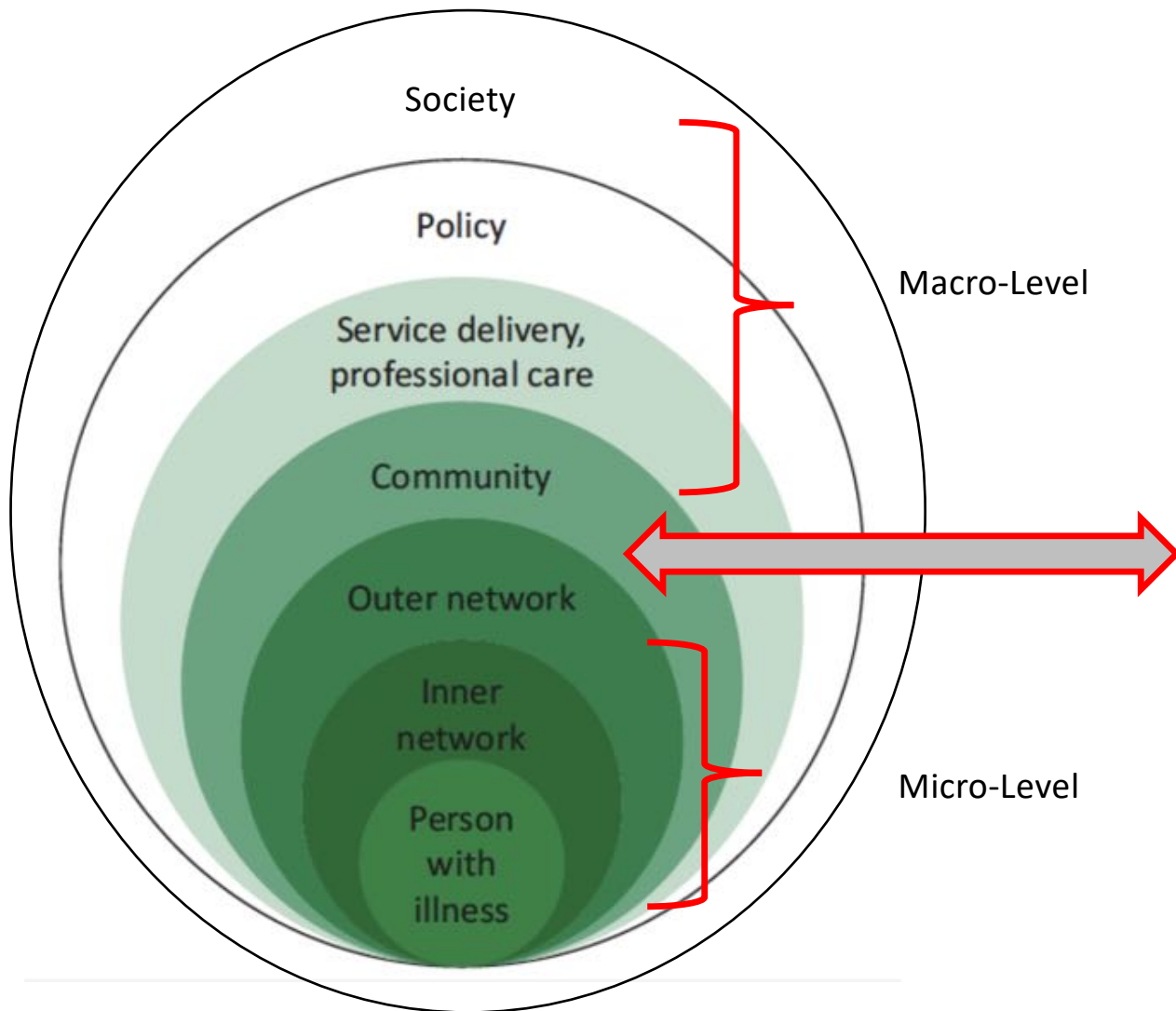
**AUTHOR'S NOTE:** This work was supported by a postdoctoral fellowship in the Science Studies Program at the University of California, San Diego, and a research grant from the Academic Senate at UCSD. An earlier version was presented at the 1993 annual meeting of the Society for Social Studies of Science at Purdue University, West Lafayette, Indiana, November, 19-21, 1993 where the audience provided helpful comments. I am grateful to Marc Berg and Monica Casper for extensive editorial suggestions and for their efforts in organizing this issue of the journal. Thanks also to Olga Amsterdamska and the anonymous reviewers and to Michael Burawoy, Héctor Carrillo, Susan Cozzens, Troy Duster, Andrew Feenberg, Tom Gieryn, Jerry Karabel, David Kirp, Harry Marks, Brian Martin, Mary-Rose Mueller, Evelleen Richards, David Rier, Leslie Salzinger, Steven Shapin, Leigh Star, Yuval Yunay, and audiences at the University of Pennsylvania and the University of California, San Diego, for useful criticism and suggestions.

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Siehe auch: Abel 2018

## Erfahrungswissen als epistemische Ressource

Nicht nur „Vernunft“, sondern auch:	körperliche Wahrnehmung
Nicht nur „objektive“ Tatsachen, sondern auch:	subjektive Empfindungen
Nicht nur „quantifizierbares“ erheben, sondern auch:	individuelles Erleben
Nicht nur top-down Expertise, sondern auch:	Community based and koproduiertes Wissen

## Ganzheitliche Forschungs- und Implementierungsstrategie

### 1. Bedürfnisse, Erfordernisse, etc. community-basiert erfassen

- Citizen Science (partizipativ, Universitäten, Community, Heime, politische Akteure etc.)
- Community based Action Research (**Erfahrungswissen**)
- Transdisziplinäre Forschung (z. B. zum Thema **Spiritualität, interkulturelle Kompetenz und LGBTQIA+** etc.)

### 2. Partizipativ auswerten und gesellschaftlich kontextualisieren (z. B. **vor dem Hintergrund des demographischen Wandels** in der Schweiz)

### 3. Informieren

- Akademisch publizieren ohne auszuschliessen (**open access**, vereinfachte Sprache)
- Websites, Twitter, Blogs, Medien, „blaue Seiten“ etc.
- Schulbesuche, Infoabende, Praktika etc.

### 4. Implementieren

- Guidelines (**mehrsprachig**, z. B. auch die Sprachen von zugewanderten Care-Givern berücksichtigen)
- politische Lobbyarbeit
- **Partizipative Evaluation**
- Schaffung von Pflegestrukturen und Kulturen, Pfleger\_Innen Ausbildung, Trainings, etc.



In unserer Arbeit mit jungen Erwachsenen aus der LGBTQIA+ Community in Genf ist uns immer wieder ein tiefes Bedürfnis nach Spiritualität begegnet.

Wir glauben, dass dieses Bedürfnis auch an den Schnittstellen von Alter/Pflege/LGBTQIA+ für viele Menschen eine Rolle spielt.

Dabei sind aber einige Hürden zu bewältigen: Negative Erfahrungen mit Glaubensinstitutionen in der individuellen Lebensgeschichte, Vorurteile von religiösen Personen etc.

Spiritualität in der Pflege (Spiritual Care) muss aber nicht notwendig religiös konnotiert sein.

**Spiritualität und LGBTQIA+ im Alter ist sowohl in der praktischen Pflege als auch in der Forschung ein großes Desiderat!**



Wie jeder andere Mensch stellen sich auch LGBTQIA+ Personen im Alter fragen nach dem Sinn des eigenen Lebens.

### **Spirituelle Bedürfnisse**

sind u. a.:

- Unterstützung bei dem Umgang mit Verlust zu bekommen,
- Umstände zu transzendieren,
- zu Vergeben und Vergebung zu erfahren,
- Bedeutung, Bestimmung und Hoffnung
- zu lieben und Liebe zu erfahren,
- persönliche Würde und die Erfahrung der Wertschätzung der eigenen Person,
- Ärger und Zweifel auszudrücken,
- sich auf den eigenen Tod und das Sterben vorzubereiten

Spiritual Care ist u. E. personenzentriert, beschäftigt sich mit der menschlichen Würde und Mitgefühl.

**Spirituelle Begleiter\_Innen für LGBTQIA+ Personen in Pflegekontexten sollten:**

- zuhören ohne zu urteilen,
- Authentizität repräsentieren,
- offene Fragen stellen...,
- spirituelle Kränkungen der fragenden Menschen akzeptieren,
- Zeit mit den fragenden Menschen verbringen und entsprechende Angebote machen

## **Angebote können u. a. die folgenden sein:**

- Spezialisierte und sich wiederholende inklusive Rituale,
- Gesangsangebote,
- ethnische und kulturelle Veranstaltungen,
- Lenscape (Beispiel Emmanuel Church Genf)
- uvm.



## **Embracing spirituality (als ein Aspekt von Caring Communities)**

- Acknowledging care receivers as spiritual beings – e. g. in grief and end-of-life situations
- Sensibility towards negative experiences with institutions of faith
- Openness towards individual and / or alternative expressions of spirituality / faith
- Developing methods for talking about grief and end-of-life situations in a affirmative atmosphere
- Integration of “spirituality” experts



## **Abschliessende Gedanken:**

Caring communities are laboratories for the recognition and inclusion of LGBTQIA+ needs and culture in care contexts and therefore strengthen individual care networks.

We all will become ambassadors/pioneers for LGBTQIA+ needs and culture when we might become care receivers ourselves.

Care Institutions may become (in close collaboration with caring communities) spaces of real life experimentation and implementation of LGBTQIA+ research in care and medicine.



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