

How Genuinely Supportive Persons, Agencies and Systems can enable People to have Real Homes of their own

Michael Kendrick is an international consultant, specializing in values-based leadership and social change in the disability and aged areas. The following analysis provides critique and insights that are relevant to those who seek to improve the service and system responses to the needs of people with disabilities.

Introduction

It is not always the case that what ordinary people may think of as a 'real' home agrees with what agencies and systems may think of as a 'real' home. This is because everyday people exist in the world of normative culture in which a home can mean much more than simply a place to live. A 'real' home is not solely one's dwelling place, but rather a key crucible in life that helps sustain and uphold much that is deeply personal, private and intimate about us. It reflects our deep identity, values and preferences for a good life.

Agencies and systems are not impervious to such concerns about home, but they may often come under the sway of other intentions and preoccupations that can distort how 'home' becomes interpreted in practice. What follows are some initial guidelines as to how supportive persons, agencies and systems can define their role in such a way that they can become a help rather than a hindrance to achievement in the lives of those who may require support in order to obtain a home of their own.

Supportive persons, agencies and systems should recognise that people should have sovereignty in regards to their homes and lives.

It is quite normal for people to want to be 'captains of their own ship' and to have the dignity of being master in their own lives. Often, when such persons require assistance in their lives, this dependence upon others can often act to undermine this autonomy, especially if the supporters act in ways that assert their dominance over the person's life and home. On the other hand, should such support persons, agencies or systems be deeply appreciative of the person's need to preserve and assert their personal sovereignty, then it would help create the 'right relationship' between such persons and those who seek to support them. In most instances, the ideal result is that one's home is one's castle.

Supportive persons, agencies and systems should 'idealise' what is a 'real' home and be guided by this.

It is unlikely that supportive persons, agencies and systems can properly uphold the fullest potential of what might be a 'real' home of one's own, without first taking the step of defining what ideals should guide the growth of people in their own homes and lives. Such ideals, if properly understood and appreciated, can then help guide their conduct, roles and perspectives relative to people and their lives. In this way, they may move from possibly undermining 'real' homes to becoming champions of this cause. Nonetheless, they will fail in this task if they do not first thoroughly clarify and sincerely embrace the ideals that best represent 'real' homes. Should this occur, then it becomes possible to help people to optimally obtain and sustain 'authentic homes of their own'.

Supportive persons, agencies and systems should recognise that one's home should be principally a private and personal setting rather than a public one.

There is much to be lost when one's home has become a public rather than a private space. For this reason, it is necessary that supportive persons, agencies and systems intentionally start from the premise that people's homes ought to be kept private and personal rather than be converted to places that are no longer private. 'Public spaces' are settings that are not controlled by the person but rather are dominated by impersonal entities operating in the public domain such as agencies and systems. This tendency may be further strengthened by laws, regulations and practices that assert more authority over what happens in one's home than the person whose home it is. This intention to keep the home principally that of the person does not mean that it cannot be supported by public funds. Rather, it simply means that having a home of one's own can also be the goal of public funding authorities.

Supportive persons, agencies and systems should recognise that designing, establishing and sustaining a home of one's own should be principally done by the person whose home it is. Though many individuals may require assistance to fully design, establish and sustain a home of one's own, this is no reason not to have them unambiguously central to this process. When a home becomes dominated by persons and entities other than the person whose home it is, it raises the quite legitimate question of whose home it actually is. The only way to know for sure is to eliminate any other possible rivals for dominance of the home and to entrench the person as the undisputed sovereign of their home and their lives. Further, such individuals should have the opportunity to explore and pursue all of the rich and diverse options for what home life can be, so that their eventual 'home' is as fully developed as it could be.

Supportive persons, agencies and systems should recognise that whenever a vulnerable person requires safeguarding or supervision, that this should be accomplished without subordinating or weakening the person's sovereignty in their home and life.

The tendency to 'take over' a person's life can readily be justified by many if the person's conduct is wanting or if the person is facing harm or damage. Though in moments of panic or anxiety on the part of supporters, it may not always appear this way, supporters can readily undermine people's sovereignty by refusing to approach personal supervision and safeguarding from the view point that this supervision and safeguarding need not come at the expense of their sovereignty over their homes and lives.

Supportive persons, agencies and systems should assist the person to individualise their home and lifestyle.

A person's home is an expression of who they are, and it is expected that this home should reflect the personality of that person. It should not be assumed that this personalising of home is always immediately possible, as with some individuals it may be harder to do. Such individuals may simply require more support in order to do as well as they can. Further, since each person is unique in their needs and requirements to succeed with making a home of their own, the type and extent of support should be adjusted to best address the person-by-person nature of 'home' and lifestyle.

Supportive persons, agencies and systems should not own and control people's homes.

The argument for a separation of housing from support has been made on many occasions and has much merit. However, simply separating these functions alone may not entirely resolve this issue. Even in exclusive support

roles, many persons and agencies could still exert control and dominance of the person and their lifestyle. The advantage of agencies not 'owning' the person's actual home is to emphasize the person as holding unambiguous home ownership or tenancy. It also narrows the question of whether the supportive person or agency undertakes its support duties within the proper framework of respect for the person, their home and lifestyle.

Supportive persons, agencies and systems should adopt approaches to management that shield people from unhelpful or invasive bureaucracy.

While not all bureaucracy is noxious and invasive, there are variants of bureaucracy that are. Increasingly, many conventional residential services are awash in bureaucracy of all kinds due to the requirements of the agencies that either support or fund such settings. This invasive bureaucracy can radically turn one's private home into a regulated site such that it begins to become the agency's home due to the agency's ability to impose its requirements on the home. Though many people may not realize it, much of this bureaucracy can be diverted from people's homes or otherwise minimized in terms of the amount, noxiousness and level of control that has an effect on the person and their home. To do so will require that the agency take intentional measures to bring this about since it is the principal vehicle for both the imposition of such bureaucracy as well as its withdrawal.

Supportive persons, agencies and systems should not compel nor coerce people to live together.

Though coercion of this kind is not a practice that agencies like to acknowledge, it is nonetheless quite widespread. This is in contrast to the occupants of homes largely deciding with whom they wish to live, including opting to live alone. These practices can be overcome by simply relinquishing sovereignty to people to decide with whom they wish to live. Put another way, it means that all relationships of home sharing must be entirely voluntary and the specific terms of these negotiated between the parties rather than household composition being imposed by other parties outside the home. This also applies to supporters that may either reside in the home or visit. These relationships should also be voluntary in nature and respect the shared and individual sovereignty of the persons who reside in a given home.

Supportive persons, agencies and systems should welcome, respect and cooperate with the person's relationships and personal networks.

Part of making a home of one's own is to integrate one's home life with one's web of relationships and one's lifestyle. This task will be thwarted if the supportive people or agencies in one's life lack suitable regard for the people in one's life. Relationships are an integral part of home life and personal lifestyle and it is important to uphold the relationships and networks that are important to a person. Relationships can also be very private and personal and therefore will need to be respected by supportive persons and agencies. It may also be true that some individuals would like to strengthen and expand their relationships and networks and may benefit from competent and thoughtful assistance.

Supportive persons, agencies and systems should utilize arms-length governance to enable people to have directive authority over shaping the supports they receive.

Many agencies are unaware that they can fashion ways to partner with people to ensure that such persons are placed in a directing role relative to the supports they use. Such empowered options can include various mechanisms such as hosting of service- user governed projects, providing administrative, financial and other

back up to self- directed or self-managed individual supports arrangements, and even cultivating new mini-agencies or projects. To do this would require agencies change their preference from authority resting only with those in elite agency positions to delegating decision-making about the design of services downward and outward to the service user and their allies. This would make agencies champions of the empowerment of people and extensively reduce their role as an obstacle to people directing their own supports, including those that come from unpaid sources.

Supportive persons, agencies and systems should avoid support arrangements that unduly commercialize relationships with supporters in home sharing arrangements.

The sharing of home with 'ordinary' people with whom one is compatible is clearly an option for many people. The voluntary nature of these relationships can become obscured whenever people are paid to live with a given person, such that the money becomes the rationale for home sharing. In many instances, where the amounts of money are sizable enough, the paid home sharing essentially becomes a job and the home a place of work. In extreme instances, the paid person quits their former employment because they can make comparable money 'home sharing'. While such homes may preserve much of what makes a home a home, it is nonetheless a return to homes being a part of agencies and systems.

Conclusion

Genuinely supportive persons, agencies, and systems can become welcome allies for people who want to have genuine homes and lives of their own. At the same time, they can also be an obstacle if they do not appreciate the many ways that they can get in the way of this goal. Becoming a useful ally of people does not happen by accident, and it is important that people, agencies and systems that want to be genuinely supportive, carefully study the differences between what helps and what hinders. In this way, they can make and uphold the decisions and principles that matter most.