Vulnerability in Adult Home Sharing Situations for Persons with Disabilities

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Introduction

This paper central purpose is to highlight some of the more likely vulnerabilities that may be present for the people who find themselves resident in supported adult home sharing living situations. It does not directly define or address the conceivable safeguards that may be crafted to offset these vulnerabilities, though it may assist with these by giving some prominence and clarity to the varieties of common vulnerabilities that may be present in supported adult home sharing situations. What is meant by "(supported) adult home sharing situations" is described within the paper.

The Nature Of Human Vulnerability

The origins of the word vulnerability in Latin come from the word "vulnus" which means wound. The verb "vulnerare" means "to wound or injure" so the English word "vulnerable" essentially means "being susceptible to being hurt or wounded". Though many use the term "vulnerable people" to describe a certain sub-group of people they believe to be notably vulnerable, it is misleading insofar as it seems to suggest that there are people who are vulnerable and presumably those who are not. In reality, all human beings can be hurt and this can occur in multiple ways, including hurts that are seemingly abstract but that may have real consequences for people such as damage to their reputation, loss of respect, rejection, vilifications and so on. Consequently, there are no invulnerable people as much as many would be tempted to hope that this could be achieved. What may be true is that there are people whose life circumstances make them comparatively more vulnerable than others. In essence, they experience "heightened vulnerability" (Wolfensberger, 1991). For instance, few would argue that the lives of the very poor are full of much more hardship, deprivation and stress than those who are more affluent.

This recognition of differential degrees of vulnerability underlines the importance of context as a predisposing factor in creating vulnerability. This is in contrast to the idea that vulnerability is innate in people and therefore unaffected by the circumstances of life. Few would argue that environmental factors are irrelevant to the shaping of life conditions that then would result in altered states of vulnerability. Obviously, being present in a war zone would undeniably heighten one's vulnerability to the various hazards of war and being homeless would greatly aggravate health and other vulnerabilities. Similarly, a similar contrast could be expected if a very dependent person with a disability was abandoned by family rather than being supported by them. Hence, vulnerability is not normally a "stand alone" state that is inherent in a person, but is rather the result of the circumstances of

one's life and their effect on either shielding a person from harm and hurt or accentuating these very same factors.

It is also notable that people can be "made" more vulnerable if the circumstances they are placed in give rise to a greater likelihood that they will be hurt through neglect or active forms of injury to the person. Similarly, the net vulnerability of people can be circumstantially reduced through intentional measures intended to reduce or offset vulnerability. This can be seen in the precautionary measures taken to protect oneself from exposure to the elements. Hence one reduces vulnerability by how one dresses, by limiting exposure to adverse weather and by other similar protective measures.

A Proposed Definition of Intentional Safeguards

"Intentional safeguards" can be thought of as consciously designed measures that can variably be Added on, built in or strengthened in order to preserve or enhance something of value in a situation and thereby better manage the vulnerabilities of people and situations. (Kendrick 2008)

These intentional measures employed to reduce and offset vulnerability are proactive safeguards and these can have measurably beneficial effects if they are well designed and used quite mindfully in combination with other safeguards. Intentional safeguards do not eliminate or transcend vulnerability, but they can serve to manage it adaptively such that people will experience much less vulnerability. As has often been said, seat belts do actually save lives and such an outcome is clearly meaningful and consequential. Hence, while seatbelts are not a panacea, it is clear that they can be an effective intentional safeguard insofar as they can be of clear benefit in reducing, to a degree, the vulnerabilities inherent in the use of automobiles.

Some of the Components of Varying Adult Home Sharing Situations

The creation and use of home sharing arrangements is widespread by governments and agencies in many countries and has constituted a key component of the mix of supports to adults for many decades, particularly in the form of adult boarding homes. In the current period, these adult home sharing arrangements exist under a wide range of names including adult family homes, family care homes, home sharing, shared living, home care, adult fostering, care home, life sharing, domiciliary homes, specialized home care, personal care homes, intentional community households and so on. The living circumstances existing within these various arrangements can vary considerably in many important details including such features as;

The types of people living in such arrangements e.g. persons who are elderly, developmentally disabled, homeless, mentally ill etc. and their specific identities including such elements as;

- Their degree of impairment, disability or health status
- Their ages and gender

- Their personal histories
- Their specific support needs
- Their economic, educational and social backgrounds
- Their legal status
- Their personal competencies
- Their cultural and linguistic identities
- Their abilities to communicate
- Their specific personal (heightened) vulnerabilities
- These living situations also vary as to the variety of contextual factors that may shape these living arrangements such as;
- The numbers and mix of persons congregated in one setting
- The types of persons sought and utilized in both support roles and home sharing roles
- The extent of family, personal network and advocacy presence in how such homes operate
- The views held by key parties as to the value, competencies and social prospects of the persons believed to need support
- The balance between custodial and developmental priorities in the lifestyles of the people being supported
- The way such arrangements are financed
- The operating philosophies and attitudes of key parties
- The presence or absence of adaptive intentional safeguards
- The physical settings and locations
- The type of personal supports needed and available
- These arrangements can also vary in relation to the systemic contexts within which they operate. This may include dimensions such as;
- The legislative basis for their existence.
- Their comparative costs relative to other forms of support.
- Their ability to enrich or benefit other parties.
- Their cultural value and priority placed on the lives of the people being supported.
- The types of organizations that fund, monitor, certify and assist such arrangements.
- The presence of legal and other advocates and champions.
- The degree of accountability of the involved parties.
- The presence of philosophies that buttress the deep well-being and interests of the people supported.
- The integrity, competence and commitment of key parties with oversight responsibilities.
- The consciousness of what makes people vulnerable and the presence of a vision for better practices, options and values.

The nature of these arrangements can be much more complex than their names may at first suggest, since they are subject to influences of all kinds, including highly personal factors

and variability. Consequently, it is important to sufficiently allow for considerable variation even in models of adult home sharing that would initially seem to be relatively comparable. Like with all human creations it would be tempting to over generalize in the interests of simplicity and this may lead to many unhelpful distortions.

Some Positive Potentials That May Be Present In Some Home Sharing Arrangements

Typically people will make choices not simply based upon the intrinsic advantages of a given option, but how these might compare to the pluses and minuses of other options. Consequently, many may look to home sharing not solely because there are some advantages, but that the other alternatives are far less attractive. Similarly, while home share arrangements, may have some apparent drawbacks of one kind or another, some people may be attracted to their apparent potentials even if there is no assurance that these will always eventuate in practice. So, the appeal of home sharing may be relative to what is on offer elsewhere. Of course, it may not be the person who sees or decides upon these potentials as the decision to use a home sharing option may be imposed upon them by others, be this for laudable reasons or not. Nevertheless, there may be conceivable comparative advantages in some home sharing arrangements and it is good to appreciate what these might be.

For instance, some specific home sharing arrangements may be preferable because they might conceivably;

Offer the person a highly individualized living situation that is in notable contrast to group or congregate care settings.

Allow them to live in a home of their own with people of their own choosing.

Permit them to have a lifestyle where they are no longer seen or treated primarily as being a "client", but rather are seen principally as a person.

No longer be in a segregated setting that has limited opportunities for social inclusion and be able to replace this with a living and lifestyle arrangement that has better prospects for belonging as a member in community groups, chances to step into valued social roles and to develop relationships and personal networks.

Offer greater opportunities for expanding one's lifestyle opportunities in ways that might appeal deeply to the person i.e. to get a life that is more interesting and personally satisfying.

Grant the person more respect, value and standing and thereby escape what they may believe to be a more socially devalued identity.

Create opportunities to have their personal needs better understood, appreciated and addressed such that they are spared the distress of unmet needs.

Have access to people who could be potential allies, advocates or champions in terms of their loyalty, commitment and personal presence.

Some Illustrative Examples of Common Types Of Vulnerabilities That May Be Present In Home Sharing Arrangements

It is conceivable that people in home sharing situations may be subject to any number of vulnerabilities. What follows are some important sources of potential worrisome vulnerabilities that can arise in adult home sharing arrangements. Given that numerous vulnerabilities may be present for given individuals, it is important to recognize that some vulnerabilities may be of greater significance for one person rather than another

The Home May Not Actually Be The (Vulnerable) Person's Home Or A "Real Home Of Their Own"

Though the term "home sharing" may seem to suggest that the home is somehow equally shared, this may be misleading. Typically, it is "your" home if you have effective sovereignty over it (Kendrick 1993, 1994, 2008) and this may not always be the case. For instance, you may be expected to move into a home already owned or rented by the home sharer or an agency and if the arrangement does not work out, you may have to move rather than the other person thereby underlining whose home it actually was. Even in instances where you may be the legal owner of the home, the home sharer may come to dominate you such that you are no longer in control in your own home. Given that this domination may be subtle and not easily apparent to others, it may have effect even if unnoticed.

It is typical for one's home to be an expression of the people who live in it. A dwelling is not necessarily a "real home" since it is possible to be housed but lack many of the distinct qualities of what most people may want in their home. In fact, if one moves into an already established household of the home sharer(s), it is not uncommon that the newly arrived person will be expected to fit into that household rather than be permitted to leave their own mark on the home. In other words, they are simply a guest in someone else's home. In some instances, the new arrival may be seen largely as a boarder that principally needs caring for rather than a person who needs a "real home of their own". In such instances, helping the person obtain a "real home" is not a central purpose, so being housed becomes the default purpose that takes precedence.

Neglect: Many Of The Person's Needs May Not Be Properly Understood, Valued Or Addressed

Though it may seem odd, it is not unheard for people in home sharing roles to define their support roles relative to their home sharing companion in ways that are at considerable variance to what might be optimal for that given person. For instance, many may feel that all that they need to do is to make the sure that the person remains fed, clothed, safe and somewhat occupied. In other words, they would have a largely custodial emphasis in how they see and carry out their role. Though a given person may benefit from this kind of

support, they might have also benefitted from developing new interests, joining in on many interesting new engagements in the broader community, obtaining a job, making new friends, expanding their horizons and so on. It is also possible that the home sharer may not particularly appreciate that these are important unmet needs and feel that they are expected to do something about them. As a consequence, the person may have quite important needs neglected with whatever results such deprivation engenders. If the alternative to home sharing is seen as continued homelessness, then the failure of a given home share situation to meet needs may be rationalized as not desirable but better than a worse option (Jean 2000).

A great deal would rest upon the expectations set for the home sharer in regards to their specific obligations relative to meeting the person's needs. In the instance of a home sharing situation where the arrangement was embedded in an intentional community with a philosophical emphasis towards building relationships, community and enriched opportunities for lifestyle development, one could expect a quite different result than might occur if the person entering the home sharing situation was seen largely as a supplemental source of income for the receiving family in a family care type arrangement. Thus the aims and expectations of the home sharing arrangement, whether these originate with a sponsoring organization, a funder or the home sharer themselves or possibly other sources, may be less important than that they exist and have some manner of useful existential impact for the person concerned. In the case of the Oregon Department of Human Services one of their key safeguards is a training program for caregivers that emphasizes understanding and responding to a wide range of likely needs of residents in their adult foster home system (2009).

Becoming Entrenched In the Client Role

The client role is normally entered into when the person is seen as being the object of care and supervision and this may be conveyed through funders, agencies, staff and other similar sources who define themselves as being principally caregivers relative to the person, even if they are not paid or remunerated in other ways. It has already been indicated that this view of the person can result in them having, to some degree at least, a largely custodial existence. However, it should also be appreciated that it also defines the role of interveners of various kinds as being part of a formal process of "service" such that they are principally rendering some element of service i.e. they are service providers and the person is therefore principally a client for identity purposes. Many housemates who are paid for their presence may easily slip into staff like roles since it is similar to support worker or staff roles. Notably, the same thing may also occur with unpaid housemates if they largely relate to the person from the vantage point that they are in staff like supervisory or custodial role.

The creation of this client-hood identity as being "life defining" may have quite significant consequences for the person because the client role may obscure, eliminate or undermine other more positive and beneficial roles for the person as well as their status and roles within community. For instance, in intentional "life sharing" home sharing arrangements

where the people are together solely because they want to share their lives together, then the client role would not normally arise because the defining role is that of friends. Similarly, in situations where the people do not have any contact with agencies, funders, staff and whatnot, then the home and their personal relationship is far removed from the world of services and its resultant client-hood. When a home situation is actually dictated more by the roles arising from services than from the people in the home, there is always the risk that services may become not only unhelpfully invasive and dominant, they may also fail to support people in more "natural" roles in life that allow people to simply be ordinary people rather than "clients".

The Placement of The Person Into Devalued Social Roles

Many people may have had some exposure to the nature of devalued social roles (Cocks, 2001; Goffman, 1968; Osburn, 1998) and their impact on people and how they are perceived and treated by others. Examples of such social roles (Wolfensberger, 1972) would be that the person is seen predominantly as a danger to others i.e. a menace, a child or child-like, an object of pity, subhuman, burden etc. Though many people may associate such roles with prior eras in history, these roles are still very much a factor in our culture and still have real effects on people's lives including people whose lives are lived in home sharing arrangements. For instance, some adult home sharing situations involving families taking someone into their home may function in many ways like adult foster homes in which the person being fostered is seen and treated as a child as the family assumes the adult/parent role. Persons in other home sharing arrangements may be seen and placed in the role of "menace" should their behavior be interpreted as threatening to others. Should the person be seen as sub-human there may be a tendency to overlook their normal needs and wishes on the premise that these do not apply to the person being supported.

These and other instances of people being seen and placed in negative and devaluing social roles may act to trap them in identities that greatly distort who they really are. It may also have the effect of preventing the person from taking on valued social roles with all of the benefits that might come with them. For instance, if a person in a home sharing arrangement is treated as if he or she could not possibly be interested in a romantic or intimate relationship, yet he/she finds themselves attracted to and possibly in love with another person and this is not seen as real or important by others in the household, this may well be a form of dehumanization in that the person's humanity is denied and dismissed as being of any importance. In contrast, if the person is credited with having the same feelings, needs and interests as most people might have in their life, this elevates the person to being seen as being like others and sharing their humanity. Though the valued social role of being "a person just like everyone else" may seem fitting, it is important to also recognize that it is also a role that may be denied to many people.

Violence, Abuse, Mistreatment Or Exploitation Of People

Anyone familiar with systems that support home sharing arrangements will be well familiar with the kinds of instances where a person in a home share arrangement is harmed by another person in the setting. Sometimes these violations are comparatively minor, such as prodding or poking a person who is slow or occasionally shouting at a person in a humiliating way. However, in other instances it may involve theft, brutal beatings, rape and even torture (Sobsey, 1994). Though such settings may be comparatively better than other settings in terms of overall statistics on the mistreatment of people, it does not mean that such abuse of people does not occur or cannot occur. This abuse may vary from small harms to persistent sexual abuse Andrews et al (1993). It is also more likely to go unnoticed if the presumption is that such conduct is unthinkable. In some instances, such home care providers have been convicted of theft from vulnerable residents and their estates (Oregon Department of Justice, 2008).The reality is that people are vulnerable in at least home sharing arrangements and it is important to start from this premise if such vulnerability is to be managed more optimally.

The Person Is Seen Largely as an Income Source

Financial interests can often be a factor in why people may do what they do. Some home sharing arrangements do provide such an opportunity for some people to obtain an income or other financial benefits. Though it is not always the case that such interests and motives can dominate how a person is regarded and treated, they may nonetheless still be a factor even if mixed in with other factors. This could express itself in many ways. For instance, a person may feel that they want to leave a home sharing arrangement, but the person who is obtaining a livelihood from it may resist this desire for fear that they would lose this income. This may serve to hold back the person from advancing in their life. Similarly, a person who offers their home for home sharing purposes may, in some systems, be able to double, triple or otherwise enlarge their income simply by taking in more people whether this is in the interest of those people or not. Similarly, if the person whose livelihood is being generated from the home sharing situation is more interested in the money rather than the supported person's benefit, the lifestyle of the home may be significantly slanted to the preferences and convenience of the person who is profiting to some degree from the arrangement.

The Person Is In A Home Sharing Arrangement Because It Is Cheaper Or More Expedient For The Funder Or Beneficial Principally To Other Parties

Though many systems or agencies may deny that financial incentives, expedience or accommodating other interests or similar motives may be a factor in how some people could get placed into home sharing arrangements. Greed has long been noted for its distortion of even global financial systems (Korten, 2010), so its potentials to distort human service agendas is also a concern. The comparative overall poverty of persons with disabilities makes them very vulnerable to service system decision-making because of their dependence on such systems (She and Livermore, 2006).While there may be many good reasons, deriving from concerns around the best interests of a given individual that could lead to a preference by the authorities for a given home sharing arrangement, it is also true

that a person could conceivably be provided to a home in order to keep that home in business. In other instances, a person could be placed in a home, not because it is best for them, but is cheaper than providing them another option that suits them better. Further, it is also possible that a person may be placed in a home sharing situation simply because there is a vacancy there and it is quicker and easier to go with that option than making the effort to find an arrangement that is more optimal for the person.

The Person May Be Forced To Live With People They Are Not Compatible With

The practice of placing people with other people that are a poor match for them in terms of compatibility and other similar considerations is actually quite common in the history of residential services. Not surprisingly, it is an ever present danger in home sharing situations because there are no guarantees that a good choice of home sharing partners can or always will be made given how challenging it can be to predict compatibility well. As a consequence, this frailty in regards to human judgment will mean that all people considered for home sharing situations will be exposed to this vulnerability. Further, even where it is discovered that the match has been a poor one, it should not automatically be assumed that this miscalculation will be promptly remedied, as there is also a long history of examples of people being left in unsuitable situations.

The Person May Be Dominated, Deprived Of Autonomy And Discouraged From Exercising Normative Self-Determination And Rights

Though we are currently in an era where there is a welcome emphasis on self-determination, it is also true that this has arisen principally because of the disempowerment of countless people relative to the service system. This systemic vulnerability to being discriminated against may not be noticed for what it is and its resultant negative impact on people's lives (Satz, 2008). Even in what should be relatively empowering self-directed support arrangements, the person ostensibly directing the service may find themselves overwhelmed by the disempowering conduct of their own staff. Not everyone is gifted at being sufficiently assertive and this leaves them vulnerable to others who might want to dominate them. (Alberti, R., & Emmons, M. 2001).

This loss of autonomy may for some individuals be very problematic if such experiences had previously occurred in their life and had produced traumatic impacts. In many instances, people have tried to correct this through various training efforts to help a given person become more assertive and able to protect themselves, but this by itself may not be able to overcome the selection of home sharing partners who are disempowering and dominating in temperament by other involved parties who lack appreciation for the consequences of such decisions (Kendrick, 2002). It is obviously not always the case that such an issue would be present in given home sharing arrangement, but it is enough to know that it might arise often enough to be a concern.

Potentially Damaging Attitudes, Values and Stereotypes In Home Sharing Partners Or Involved Agency Or System Officials

It has been well known for some time that attitudes can have a profound effect on people lives and particularly so if the person is already been made vulnerable and dependent (Zola, 1982, Kessler Foundation, 2010, European Commission, 2001). It is also very difficult to prescribe and compel positive and helpful attitudes for those involved with the care and support of persons involved in home sharing situations. Though positive values and aims may be communicated by officials in leading roles, it cannot be assumed that these will be of any significance as a practical preventive influence on daily conduct. Obviously, screening for the selection of potential supporters based upon positive attitudes and values is often seen as a useful safeguard as would be special trainings and supervision directed to shaping attitude. Nonetheless, beliefs, attitudes and stereotypes are difficult to manage as they are not necessarily conscious or easily recognized at the level of daily interactions (Nelson, 2009). Consequently, it should be assumed that home sharing situations will also have their share of potentially serious attitudinal challenges if nothing else than a probable predictable continuation of a long history of problematic attitudes towards persons with disabilities.

Conclusion

There are obviously many conceivable vulnerabilities that may be present or accentuated in supported adult home sharing living situations. For instance, there is the vulnerability of the discontinuities imposed upon individuals who are moved involuntarily through multiple homes, the vulnerability of people who are forced to live with people who are unfamiliar with their language and culture or people who needs and vulnerabilities overwhelm the persons sharing the home. The intention is not to comprehensively identify all known vulnerabilities but rather to establish first that people are and will be made vulnerable simply by being in such situations. Secondly, this recognition also should bring with it the further recognition that these vulnerabilities may not always be managed well such that they are offset adaptively. Thirdly, it invites a further discussion of what safeguards might need to be consciously introduced to improve such living arrangements in the interests of the person being supported. This paper does not take a position on whether these options should or could be used well as one element among many of personalized support options.

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