

A Discussion Paper;

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Concerning:

**“Self Direction” In Services and the Emerging
Safeguarding and Advocacy Challenges That May
Arise**

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Table of Contents

A Rationale for Examining Self-Directed Options as Potentially Posing Some Concerns in Regards to Vulnerabilities, Safeguards and Advocacy

- Possible Areas Where Specific Advocacy And Safeguarding Energies May Need To Be Directed
- Discerning Vulnerability; The Presence Of Unappreciated Or Unforeseen Risks Or Difficulties
- The Actual Adequacy Of Supports
- The Reliance On Standardized “Broad Brush” Safeguards And Supports Rather Than Specifically Targeted Safeguards
- The Ability To Contend With Unusual And Rare Developments Versus More Commonly Occurring Ones
- The Challenge Of “Imagining Better”; Addressing The True Potential Of People

Resolving the Many Concerns about Safeguarding and Support In Self-Directed Arrangements

- Discerning Needs And Vulnerability More Accurately
- Recognizing The Limits, Fragility And Possible Dysfunctionalities Of Existing Safeguards And Supports
- Redesign How “Self-Direction” Ought To Be Offered
- Managing The Implementation Of “Self-Direction” Better
- Conclusion
- Some Key Questions For Discussion

A Rationale for Examining Self-Directed Options as Potentially Posing Some Concerns in Regards to Vulnerabilities, Safeguards and Advocacy

In recent years we have seen a growing number of examples of service and support options that place the service user in the role of guiding or directing the services that they receive. These options are often broadly called “self directed” services, but this term can be quite misleading as there are, in reality, quite a variety of distinctive ways that these might be implemented in practice, and there are often important differences in how these varying options may function. Nonetheless, such options are likely to constitute a growing component of many community service systems and should now be given closer scrutiny in regards to the varying balances of their relative advantages and disadvantages, irrespective of which model of self-direction is being employed.

The reason to study these options more carefully goes beyond the fact that they are increasingly popular, and will start to shape the lives of ever more numerous people. The history of human service models of varying kinds contains an abundance of examples of how it is possible to herald the new model while looking back with disfavor at the models these replace. A good example of this from recent times would be that of group homes. At one point, they were the preferred means of providing people with a chance to leave institutions and take up a lifestyle in the community. In regards to these purposes, they were normally quite successful. Yet, with the passage of time, it has become clearer to many that group home models have within them features that may actually inhibit both fuller participation in community life and the realization of personal potential. Few people who championed these models initially would have guessed that several decades later such group home models would be called “mini-institutions”.

For advocates, service reformers and many current residents of group homes, it is now possible to imagine and obtain a lifestyle that is considerably more autonomous, socially inclusive and person centered than what is presently available to people in group homes, quite apart from nursing homes and institutions. While many might deny it to be true, these newer socially inclusive “person centered options” can quite readily support people who live with significant impairments of all kinds, providing that the supports they receive are appropriately relevant to their precise needs and requirements. It is also quite practical for such persons to play a part in “self-directing” the design and implementation of such supports, again providing that any needed supports are in place. The fact that many people may still have difficulty believing that these things can be done, does not alter the fact that plentiful examples of these already exist and are believed to live up to the claims made about them.

Nonetheless, the same conditions applied when group homes were beginning to establish themselves as a key part of the present community service systems. Group

homes were then argued as being feasible, even for persons thought to be severely impaired, and abundant success stories were offered as evidence that the various misgivings people might have had about such options were misguided or overstated. The intensity of the attestation that the models were largely trustworthy was particularly prominent when the alternative was to let people remain in institutions.

As we now know from examining any number of complaints lodged annually, by advocates in many jurisdictions, group homes have not always been implemented in optimal ways, and many shortcomings have emerged that were minimized as being likely by the original advocates for them. This is not meant to suggest that the original advocates were fundamentally incorrect in their assertions, but rather that many valid options may not, in reality, be implemented in ideal terms in regards to quality and sound practice, thus opening the door to shortcomings, vulnerabilities and perversities. Obviously, something of the same process of the gradual emergence of some unexpected “downsides” can be anticipated in regards to “self-directed” options even if, as a general matter, they deliver on most of the crucial benefits attributed to them by proponents.

Knowing now that self-directed options may bring with them their own specific challenges in terms of quality, it is sensible to both begin looking more closely at these and evaluate whether proactively preparing strategies and safeguards that might minimize or avoid negative consequences would be helpful. In this regard, by adding the presence of thoughtful safeguards of various kinds well in advance of their use only once something has gone wrong, it may well be that such intentional safeguards will actually increase the likelihood of success; they might actually enrich the potential viability and vitality that may be present in such arrangements.

Possible Areas Where Specific Advocacy And Safeguarding Energies May Need To Be Directed

Discerning Vulnerability; The Presence Of Unappreciated Or Unforeseen Risks Or Difficulties

Much as can be seen in the history of the development of group homes, it is often very difficult to safeguard people from difficulties that are not foreseen. Today, it is obvious to many people that segregated group living arrangements can act to keep people apart from their communities. Even so, it is also true that people in highly individualized and personalized living arrangements in the community may find themselves very lonely and isolated, albeit they have more autonomy and individualization. It is also true that people can be neglected “one person at a time”, so the presumption that self directed options are free of their own vulnerabilities would be quite unjustified. In fact, group home residents may have some potential advantages that are not always normatively available to people in sparsely funded and supported personalized community living arrangements, such as the comparatively prompt availability of staff, the companionship of other service users, some monitoring of people’s well being and so on.

There are indeed realities that may intrude on self directed situations as much as they might in other service or support arrangements. These could include a lack of adequate resources, the non-availability of good quality staffing options, various self-destructive patterns of conduct of the service user, poor staff performance, the absence of natural supports as well as the perverse conduct by natural supporters or other community members, damaging attitudes, a lack of support for "lifestyle building", social isolation, poverty and deprivation and so on. If features such as these are properly appreciated and attended to they may not prove to be quite as troublesome as when they are unrecognized, denied or ignored. Yet, as has been seen in other service models, it is quite easy for people to not get these matters properly in focus and address them effectively.

The Actual Adequacy Of Supports

Many models of self-direction rely quite extensively on the person acting as a direct administrator of their own supports including being the employer of record, their own accounts record keeper, staff supervisor, scheduler, planner and whatnot. In some instances, select elements of the "business" side of the arrangement may be supported by purchasing payroll and other supports from "fiscal intermediaries". In other instances, such as with "microboards" assistance of various kinds is provided to the person by their "support circle", if one exists.

In the case of consumer/family governed individual supports cooperatives, a variety of supports are made available to members on an as needed basis, including having the cooperative manage most supports if this is seen as desirable. In the case of systems which designate elements of their system to provide assistance and support, this can take the form of independent planners, case managers, service coordinators, brokers, social workers, key workers or any number of other such roles. In the instance of many centers for independent living, additional support may be asked for and received on a person by person basis. If it is not specifically requested, the support may be only minimal, such as providing persons with a (not vetted) list of available persons that may be looking for work as attendant care providers.

It would not be surprising that the difficulties some individuals may face in self-directed options may go unrecognized or unappreciated due to incorrect perceptions or assumptions about the individual's precise abilities or capacities. In such instances, it would follow that the needed supports for the person are therefore not built in, as the presumption is that such supports are not required. This may apply not only to their ability to specifically manage the self-directed aspects of the implementation of supports, it may also apply to other aspects of the person's functioning that relate more to their overall well-being and the vulnerabilities of their life circumstances. For instance, if a given person lacked the personal confidence and authority to appropriately direct and oversee staff, it is conceivable that the staff might be able to exploit or poorly serve this person. The person may be quite competent financially, but lack the inner strength or experience to be able to

adequately act as a supervisor and employer. In such instances support to the person in these roles would be quite useful.

Even where support may be available, it is also conceivable that those assigned by many systems to support individuals in these situations may not be able to intervene unless requested, or they may be limited in the time they have to provide support, or perhaps they may only superficially know the people, thereby being at some risk of not properly understanding the support that might be needed. Equally, they may be persons that specific service users do not relate well to, or they may create difficulties in how they conduct themselves, thereby making it less likely that the service user would want their involvement.

For these preceding reasons, and perhaps many others, it would not be prudent to assume that the mere presence of formal or informal supports, either embedded around the person, or supplied from external sources, means that these supports are actually effective in practice. A more prudent assumption would be that no matter what supports are nominally available, how they work in practice will be subject to any number of limitations coming including their actual relevance to what the person needs, their actual and timely availability and responsiveness, their dependability and integrity, their skillfulness and competence, their ability to adapt and learn, their values base and attitude, the quality and nature of their relationship with people and so forth. In this regard, it would not be unusual that existing supports may, on occasion, be absent, irrelevant to what is needed, perform poorly or any number of other deficiencies that could lead to consequences for the person that are negative. This could be true even if some of the supports are admirable, as one "weak link", even as an anomaly, may be enough to place the person at risk if the matter is a crucial one.

The Reliance On Weak Safeguards As If They Were Strong

It is quite common for systems to list the presence of many formal and informal safeguards as being indicative that these safeguards are active and potent simply because they exist. The reality may be more equivocal, particularly if the safeguards are naively trusted or given greater credence than deserved. For instance, many systems rely quite heavily on external monitoring of vulnerable people through case managers, service coordinators and others on the assumption that these persons can and are able to be in touch with people on a regular enough basis to be effective, that they will perform adequately, that such case managers are comparable to each other and that the presence of case management, even in the advanced form of assertive community treatment teams, will be sufficient or even optimal in supporting people. The reality may be that such expectations of case management systems are much too overstated in their singular ability to support a wide array of people in complex lifestyles in the community.

The same might be said for other commonly instituted safeguards such as the presence of person centered plans, the existence of some version of support circles,

the (theoretical) accessibility of formal or informal advocates, the availability of generous amounts of paid staff, contact or involvement with day programs, prescriptive regulations of the kind that require a lot of documentation, quality assurance systems involving licensing, accreditation and incident reporting, the presence of written policy that “says the right things”, training/credentialing of staff, the involvement of families and friends, self-advocacy membership, rights training, routine monitoring, compulsory reporting requirements and so on. All of these undoubtedly can provide something of benefit, but even this is not automatically the case, and the very presence of such safeguards may actually serve to relax some people’s vigilance.

Obviously, not all abuse will be reported, even by highly trusted people, including families, particularly if the abuser is a family member or family friend, not all people can effectively advocate for themselves, it is conceivable that person centered plans may be inadequate or “pro forma”, support circles can fail to deliver on expectations, written policy may not be adhered to, “qualified” staff may be otherwise unsuitable, scandals routinely occur in already licensed settings and so on. Systems of all kinds can and do fail, and communities and natural supporters frequently are ineffectual in heading off tragedies. None of these shortcomings invalidate the possibility of drawing some safeguarding benefit from any of these safeguarding measures, but it does indicate the need for more careful discernment of what is effectively safeguarding people versus what we hope is effective.

The Reliance On Standardized “Broad Brush” Safeguards And Supports Rather Than Specifically Targeted Safeguards

In most instances, it would be incorrect to typify the participants in self directed arrangements as if they were more or less alike, since self directed options are now being used with all sorts of people. Consequently, the needs and vulnerabilities of people are quite as varied as their lifestyles within community. It is also true that vulnerabilities can develop and change with great rapidity in even one person’s life, so a certain amount of dynamism needs to be considered as being normative irrespective of the fact these varying support arrangements are rather simply classified under the “self-directed” heading.

Notwithstanding the intended individualization of these arrangements, there is a temptation to assign features to “self-directed” support arrangements that are of an “across-the-board” or standardized character such as can be seen when everyone more-or-less gets the same safeguards and supports. This can be seen in such things as person centered plans, the mandatory imposition of planners or case managers, the routinized surveillance or scrutiny of people’s lives on a scheduled basis and so on. Though the needs of people may vary considerably, there is implied in such practices the faith that such standardized safeguards and supports will “work” rather uniformly, even though what one person may urgently need at a given moment may be entirely irrelevant to another.

Were safeguards and supports to evolve and be negotiated on an individual basis, it would be possible give greater priority to crucial safeguards and supports, and to minimize investments in those which offer little value, given the person's actual fundamental needs and requirements. This would reframe the safeguarding and vulnerability question as being subject to person-by-person determinations of what is actually needed, and imply a balancing of considerations unique to each person. While such discretion would undoubtedly bring its own paradoxes to the development of supports, it would nonetheless be a methodology that would be more consistent with the intended aims of individualization, autonomy and negotiated rather than imposed solutions.

The Ability To Contend With Unusual And Rare Developments Versus More Commonly Occurring Ones

Though it is rarer than not for persons with disabilities to be assaulted, murdered or raped by the staff that they have personally hired or similarly victimized by acquaintances they have made in the community, such events do occur at a rate which is at least twice that which is expected for the general community. In this regard, safeguards and supports must deal effectively both with events which are infrequent, as well as events that are more routine. The average community member must manage similar questions, but with lessened vulnerability overall to such events occurring in their lives. If the presumption is that the presence of self-direction models or partial individualization somehow inoculates the persons taking advantage of them from such concerns, then it is easy to see how people might be very unready to cope adaptively with such possibilities.

Even if people do see the limits of what self direction actually delivers in terms of insulation from the many conceivable hazards within community life, it is not at all easy to develop support and safeguards given that the dangers to be protected against involve persons who will conceal their true intentions and conduct both before and after the fact. Nonetheless, it is more likely that people will make measurable progress on these issues if they are first taken seriously and pursued with a conscionable amount of vigilance. For instance, if people who are seeking to hire staff can be supported in the vetting and supervision of staff, persons whose conduct is ultimately sociopathic will be easier to detect, whereas such malevolent persons will likely find circumventing detection by unsupported service users to be comparatively easier. This difference would be accentuated the more isolated the service user is from the various resources that might make them less vulnerable.

Even with the address of more commonly and regularly occurring vulnerabilities faced by service users such as knowing who to trust, managing dominating, aggressive and exploitive people, protecting one's possessions from theft, avoiding being drawn into fraudulent propositions, being sexually or emotionally exploited, even in legally consensual relationships, being poorly served by service agencies and so on, all pose challenges for safeguarding even when the service user is exceptionally competent and self-possessed. If the service user is not up to these challenges due to impaired

ability, weakness, inexperience, anxiety, lack of confidence or any number of other normal limitations, then highly autonomous and unsupported lifestyles might well exacerbate the person's vulnerability by immersing them in situations that exceed their ability to manage well, at least at a given moment.

The Challenge Of "Imagining Better"; Addressing The True Potential Of People

There may exist for some people the assumption that "self direction" is about helping people be in greater control *of the lives they now have*. This is understandable, but it may unduly emphasize the present opportunities in a person's life rather than those which have not yet even been considered. Much of the true potential in the lives of many people, particularly those whose development and life experiences have been distorted by oppression and deprivation, might not appear in the person's present life circumstances. This does not mean that this could not exist, but it most certainly will mean that these possibilities will never exist unless some nurturance is provided first for their consideration as "dreams", and their eventual realization as practical initiatives.

This suggests that "self-direction" might need to encompass investments in "dreaming", much as has been repeatedly suggested by people involved in person centered work. Such dreaming is not equivalent to idle fantasy, as it grows out of the sustained exploration of potential ways of meeting one's needs in novel forms, and may, at times, result in some quite stunning changes of direction in life. A "self-direction" strategy that leaves people trapped in lives that do not represent their true potential will end up being a kind of self directed lesser life than might otherwise have been possible. This is not meant to suggest that all "dreams" can or should always come true, but rather that dreaming can help visualize future directions in life that better express a given person's most crucial wants and needs, and legitimate actions taken to realize this potential.

Resolving The Many Concerns About Safeguarding And Support In "Self-Directed" Arrangements

These sorts of concerns have long been present in other supported living arrangements in the community, so it makes them all the more likely to surface again in self-directed options. The remedy is clearly not to avoid "self-direction" itself, but rather to examine the fuller context through which it is offered. In reality, given that "self direction" could conceivably be embedded in better and worse overall conditions of support for the vulnerabilities of people, it argues for a closer examination not of self-direction "per se" but rather, the merits of the ways it is being offered given both the normative support and exceptional safeguarding needs that may be present for specific service users.

Fortunately, it is quite feasible to couple together a multi-path approach to safeguarding and supporting self-directed options that promises to improve the prospects for "self-direction" measurably. These pathways are evident from the

earlier discussion, and can be distilled into the following distinct measures, all of which can be taken up together as a combined strategy. These include efforts to discern vulnerability and needs more accurately, recognizing the limits and fragilities of existing supports and safeguards, redesigning the overall context of how “self-direction” is offered so as to strengthen, add on or reconfigure features that will ensure greater success on a prolonged basis, strengthening existing safeguards and adding ones where there are crucial gaps and managing the implementation of “self-direction” better.

Discerning Needs And Vulnerability More Accurately

It is unlikely that the wide range of needs and vulnerability of the people involved in self-directed options can be managed properly if the presumption is that such concerns should not exist, or are adequately in hand. Rather, a safeguarding mentality should be adopted that emphasizes that it is precisely by asking about needs and vulnerabilities that what is true for a given individual can be properly understood both in the specific context of their lives, and in a more general sense in regards to aggregate factors that affect large numbers such as poverty, access to supports and opportunities to name and decide key issues that shape their lives.

In relation to the individualized nature of needs and vulnerabilities, it would be sensible for people to have a hand in contributing their own sense of the relative priority of needs and concerns in their own lives, and play active and defining roles in designing and testing of safeguarding and support strategies that may conceivably help them. The presumption that remote experts ought to assess such deeply personal matters and have the sole authority to prescribe remedies simply re-institutionalizes the very same paternalism that brought about the need for “self direction” in the first place. This does not presume that such persons can do this unassisted, or without difficulty; it simply argues for them to be agents in their own lives, including the defining of what supports they may need.

At the same time as the personal autonomy of people in the service user role can be upheld, it is simultaneously possible to address the fact that other parties to the “self direction” equation - family members, friends, advocates, clinicians, staff, managers of services and others - may indeed be misunderstanding service users, and may have to be assisted to do better. Clinical evaluations and functional assessments, while useful to a degree, do not usually deal with the person’s more existential and social needs, nor do the conventional and often bureaucratized methods of external assessment lend themselves to the intimacy of highly personal discussions about needs, goals, vulnerabilities and fears. So, while a clearer understanding of the person is pivotal, how it is achieved may also be very consequential in arriving at answers that leave the person’s dignity and self-respect intact.

Recognizing The Limits, Fragility And Possible Dysfunctionalities Of Existing Safeguards And Supports

It is likely going to be the ability to be constructively conscious and critical of the inherent shortcomings of the present patterns of support and safeguards that will eventually enable interested people to improve them. Rather than wait for these to perform poorly, with all the attendant negative consequences for the person, it would have great preventive advantages to test and evaluate safeguards and supports long before they are actually utilized. This can be done by subjecting them to any of the many scenarios that might occur, such that it becomes possible to see if there is anything that is lacking or unpersuasive.

Naturally, if the attitude is that “if it is not broke, don’t fix it”, then people would have to wait until safeguards and supports fail before they are evolved and modified to attend to shortcomings that have become apparent. This is clearly not a useful strategy as it is predicated on solving problems only when forced to. A better approach would be to become pre-emptive of such failings by first seeking to know what might be absent or dysfunctional in a given pattern of supports and safeguards and trying to imagine and install measures that would correct for these. Even if it was not immediately possible to remedy such concerns, it would still be better to have developed a clear and precise sense of what can and cannot be counted on.

Redesign How “Self-Direction” Ought To Be Offered

It will undoubtedly prove to be true that some approaches to providing “self-direction” will contain a much better array of supports and safeguards that make it more likely a person will both meet their needs and reach their life potential and goals than might others. Given that much of what people may actually need is normally quite modest and achievable, it is useful to begin to note the features of “self-directing” models that work better than others and to subsequently evolve what might be thought of as the next generation of self direction. This will likely mean an examination of many factors that contribute to success that are not always highlighted in many self-direction initiatives such as conceivably the role of values and assumptions, the place of commitment and fidelity to people, the willingness to experiment, the value of persistence and so on.

In any case, it will be useful to devise advice as to what are the crucial supports that tend to enliven self-direction, add to the likelihood that people will get precisely what they need, and gradually embed self direction in the most viable approach to safeguarding the vulnerabilities that arise when people try to take charge of their lives. Rather than presume that the answers rest in strengthening existing models alone, it may well be that the better answers are in jettisoning some of what we do in favor of approaches we have yet to try. As such, “self-direction” in a few years time may well prove to be quite different from our original conception of it, given what we have learned since then.

Strengthening Safeguards And Adding Novel Ones

It is fair to say that it should not surprise us that many people who are participating in current self directed arrangements might require either strengthened or improved safeguards than what is currently provided to them under the existing arrangements for “self-direction”. If this problem is looked at developmentally, then making adjustments as we learn is a tried and true facet of trial and error, whereas an absence of these actions may indicate a failure to learn from experience and stagnation in the evolutionary process of the testing of new ideas in order to make progress.

The logical alternative would be a situation where there is ongoing experimentation with a variety of approaches to “self-direction” rather than a premature “fast freezing” of approaches into an undeserved orthodoxy, particularly in light of how juvenile the efforts at “self-direction” are likely to prove to be, given their comparatively short lineage in historical terms. This would mean a willingness to overturn any number of aspects of how “self-direction” is presently packaged if that is what the facts warrant. Even this would not be enough, as there would still be a need to see if any progress actually resulted from trying other ways. In specific terms this might well mean both the introduction of strengthened safeguards as well as the pioneering of new safeguards and supports. Nonetheless, it would be helpful to know one way or the other whether varying the approach produced better outcomes.

Managing The Implementation Of “Self-Direction” Better

It is not always the case that valid concepts alone can make the difference if their implementation is flawed. Conceivably, many people may mistake the goal of self-direction with its actualization, even though these can be quite different aspects of the process. For instance, it is quite possible that while the goal of helping people control their lives may be present, the actual “how” that is used to implement this goal may be misguided such as one might see in instances where the person is supported to make self-destructive choices in the name of absolute autonomy and freedom. Particularly when there may have existed feasible ways to curtail the tendency towards self-injury, a failure to pursue them needs to be seen as negligent of the person in the “best interests” sense. Many of the judgment calls implied in such scenarios may rely heavily on whether the person is being sensibly supported, or whether their (effective) self-immolation is being facilitated in the name of “choice”.

Thus, it would be unwise to come to believe that the matter of quality of eventual results is resolvable at the level of goals, unless such goals are linked to a particularly clear sense of excellence in outcomes. Thus, it is sensible to also look closely at how concepts may change due to the thinking process at work in how they are implemented. This “operationalization” of self-direction may or may not remain faithful to the ultimate aims of valid “self- direction”, but there may be no way of knowing this unless there is clarity both as to goals and the merit of what is done to effectuate them.

Conclusion

This is a discussion paper, and its usefulness will not come from the paper settling the many matters involved, but rather that the paper may act as a catalyst in engaging people to consider what may or may not be at stake in the rise of “self-directed” support options in the present community service system. This paper is intended to call into doubt the wisdom of current practice, not out of some malicious intent, but rather to encourage the reader to begin to question conventional wisdom or practice in the hope that we might collectively rethink such matters should this be necessary. As such, the reader is cautioned to not consider this paper to be the final word on these issues, but rather see it as a stepping stone to ongoing evolution of our thinking on this subject.

Some Key Questions For Discussion

- Are there any reasons to be concerned about what might possibly happen to people in self-directed situations?
- What are the precise vulnerabilities that may be present in self-directed situations?
- Are there any risks, vulnerabilities or concerns about self-directed situations that are not presently receiving the attention they deserve?
- Are there key supports that people in self directed situations ought to routinely have available to them?
- Is the availability and the quality of the supports presently available to people in self directed situations adequate?
- Is there an over reliance on standardized safeguards and a neglect of the use of safeguards that are specifically tailored to the precise requirements of a given person in self-directed arrangements?
- Are there risks or vulnerabilities present for people in self-directed arrangements that are rare but nonetheless will affect at least some people?
- Are we making sufficient investments in people’s capacities in self directed arrangements to use their expanded self directed powers to imagine and pursue improved lives for themselves or are we simply letting the matter go unaddressed?
- What would help us be better able to perceive, understand and manage the risks and vulnerabilities in self directed arrangements?

- What would help us better appreciate the limits, shortcomings and dysfunctional aspects of the safeguards we are now relying on, or which we might some day come to rely on?
- Are there ways that self direction delivery models could be better redesigned with safeguarding and vulnerability issues in mind?
- Once self directed arrangement programs are in place are there ways that they could be managed better in light of safeguarding and vulnerability concerns?
- Who should be acting on the safeguarding and vulnerability questions?