

Organisation and Insecurities - A Risk to the Good Life

Security is mostly a superstition. It does not exist in nature, nor do the children of men as a whole experience it. Avoiding danger is no safer in the long run than outright exposure. – Helen Keller

I last attended a FEDVOL event in 2007. As a family we are now **three years closer** to some sort of deeper relationship with either one or a number of service providers.

Like any other parent we want to be happy watching our children grow into adulthood. We want them to have a happy life; we want our children to be fulfilled and to achieve their potential; we want them to enjoy their passions; we want them to find love. We all want what's best for our family members. *The first danger I see is the risk that I will be witness to a family member not living a good life while I am alive.*

Like any other person we want to die with the comfort that those we leave behind will live out a happy and secure life. The life expectancy of people with an intellectual disability continues to improve. *The second danger I see is the risk is that I will die haunted by the fear that our family member will be institutionalized.*

Whatever type of services will be availed of this person will remain at the heart of the family. That is a fact no matter how service delivery is configured or reconfigured, no matter what budget cuts there are, no matter who amalgamates with who, no matter what accreditation a service receives, and no matter what CEO, social worker, PA, or driver is employed or retires. I don't know who those organisations or people will be in 10, 20, 30 years. I don't know what our relationships with them will be like. I don't know what type of equality will be accorded to our family in exercising our 'right to care'.

The fear of the unknown and a desire for control and uniformity is embedded in the genetic code of 'risk management'. When risk aversion becomes the dominant value in our lives the anxiety it spawns creates a demand for consistency in what people delivering services do and a narrowing expectation or conformity in what people with a disability are assumed to want. Risk aversion as the dominant value starts with safe generalized assumptions and delivers a contained set of safe options. Risk aversion as a dominant value in our lives is a key driver of institutionalization and an inability to adapt quickly to the needs of a person. Risk aversion is a problem not because it becomes a dominant value just in organizations but because it has become a dominant value in the way we families think about what our family member is entitled to, what they might be able to do, and what opportunities they could be afforded to experience a normal messy life. I see your challenge as not being just to handle 'risk' and the 'duty of care' in your own organization but to work with the attitudes around the management of 'risk' and the 'duty of care' in my family and my community.

For me working with an institution is 'Risky Business'; budget cuts reducing options; generalized assumptions used to manage a 'population' of 'service users'; overly cautious options based on fantasy '*what ifs*' and unlikely legal actions; committees procrastinating around decisions - all pose a risk to the quality of life of a member of my family. The way you work in the future, the way your employer operates, the type of services you provide, and the relationships you have with us as consumers are all part of what for us is 'Risky Business'. For our family it will be our business for at least the next 30 years.

Decommissioning the 'Duty of Care' in a Messy Life

Taking on the role of sole owner of the 'duty of care' diminishes the responsibility of others to play a full role in the messy life of a person they share time with. At a discussion after a session on Social Roles at a seminar early this year a manager in a large progressive service described how they supported a man (lets just call him John) take on a valuable role as part of the management team of a local GAA team. This 'initiative' ticked all the boxes until the staff member and the GAA team manager for one reason or another were no longer available to John. The senior manager wondered what to do –

- Should John stay on with the GAA club?
- Could they allow a person from the club to pick John up from the residential service to continue his participation with the GAA team?
- Should they provide training to the club members on what to do with John in certain situations?
- What would the procedure be if something went wrong?
- What if he wasn't being taken care of and he disappeared?
- Was there a protocol around John being 'readmitted' back to the service?
- Who should be Garda vetted?
- She summarized the conundrum the service found itself in by asking 'How far our duty of care extended?' and 'To what extent would it be liable if something went wrong?'

On hearing this presentation of seemingly insurmountable difficulties I felt bamboozled. For some reason the 'problem' as it was presented triggered an anger in me. I just about succeeded in containing my feelings to a single heckle; "It is time that you and the service got off the bus!"

I have to admit I really didn't know what I was saying or what my rationale was at the time. Here's my reading of the scenario now (with apologies to the manager concerned for not being able to explain what I meant at the time):

- Firstly the notion of an 'extended duty of care' is way too elastic – In real life we let go our control over others so that they can learn to take control of their own life and live with friends, neighbors and the people who share their passions in the community.

- Secondly, when you stack up all the ‘*what if’s*’ and ‘*how to’s*’ the institution creates an excuse to avoid or postpone a decision on what to do. In real life postponing decisions either frustrates us or teaches us that we have no control and perpetuates institutional dependency and a persons learned helplessness
- Thirdly, dithering with an important aspect of a persons life creates a heightened perception of ‘risk’ among the community stakeholder. In real life people in the community look for cues on how they should act from institutions and people in authority.
- Fourthly, an organizations failure to build the principle of ‘*institutional redundancy*’ into ‘Person Centered Planning’ perpetuates a notion that nobody else has the capacity to exercise care when dealing with a person who is part of their team. In real life people look out for each other.

Much ‘duty of care’ considerations in the risk management of messy lives has been about;

- A need to avoid something that might go wrong in a future where there is some anxiety that the organization would be held ‘accountable’.
- A compulsion to exert more and more control over something that the organization has been assumed to have a ‘duty of care’ over.

The risk management of a life in an institution (either in it’s ‘lite or ‘full’ form) can be attractive what with it’s SOPs and training programs, formats, protocols, standards and whatnot. It is ordered, predictable, based on set assumptions, and illuminated by the clean lines of defined but limited options. But, a lived life is messy. Still those clean lines do look attractive. They look particularly attractive to a family cast into the often conflicted role of carer for a person labeled with ‘complex’ needs. How comforting the prospect of a life being managed by the assertion of a simple idea like the institution’s ‘duty of care’. But, a lived life is messy. People in a family using services live in a real world, a world of chaos, a real world of surprises and unpredictability, a world of pain and constraint. It’s messy; sometimes a little messier than what would be considered normal. Sometimes we want to escape that. Sometimes the trappings of the institution with it’s clean lines, ‘duty of care’ and risk management offer the prospect of comfort and escape.

I wonder are the family lives of anyone, not least the risk management zealots, so controlled, predictable, ordered and dictated by forms and risk assessments and protocols? Not likely, because that’s not a lived life. A lived life is messy. People who work in organisations are normal people with the normal unpredictable scripts of a lived life. Maybe sometimes at work people try to engineer a degree of control and predictability that cannot be achieved in their own life. A lived life is messy. This type of engineering and conformance management might be acceptable if we were working to produce a widget in a factory, or code for software that is sold in Shanghai or Stuttgart. However this ‘control’ driven behavior masquerading as ‘risk management’ is not acceptable when dealing with the

lives of the people in any family. A lived life is messy. A lived life is one that takes many turns, some struggles, some failure and a celebration of the odd hard won success. A lived life is messy.

In order to decommission the sacred cow that is the 'Duty of Care' the bull of 'sole responsibility' needs to be taken by the horns. More responsibility and control needs to be shifted to the person, their 'natural supports', and the community if they are to live a good life now;

1. Don't confuse your organizations insecurities around control with the idea that others don't have the capacity to care effectively
2. Stop making duty of care so elastic, let go and learn to live with the small failures of others
3. Give people some basic ideas on who (*you think*) a person is, (*your*) ideas of their capabilities, and what (*your perception*) of the 'non negotiables' in their lives. Then hope your ideas turn out to be wrong when a person is trusted to live a life that is less dependent on the institution
4. Don't insult a neighbor by making them sign anything when they are being neighborly
5. Build into PCP an exit strategy for the organization to encourage a person and the people in their life to avail of the opportunity to take risks and learn to control what is their own.
6. Lose the fear of 'liability' and 'accountability', - they are part of a future fantasy that are likely never to happen
7. Do you best for what is happening now and communicate the same expectations to others, - that's part of a present reality that's definitely happening now

Staring at the Sun

People are never so important that they cannot die. Systems, operating procedures and organisations can also die or at least lose their usefulness. This is especially the case when your business is the business of a persons messy life. A rolling continuous redundancy is to be expected when what you are dealing with is so diverse, so changeable, unpredictable and so messy as a lived life. Organisations generally don't do messy well. Death is the ultimate in messy. Organisations don't do death well.

For families deeply involved with the care of their adult members death is a very present but much ignored certainty. When the family member is a baby we spend time figuring out the mechanics of wills and how to negotiate discretionary trusts. We have this silly idea that money will keep them safe. After that we plough energy into a negotiation with the educational system. After that it's a focus on training, or work or activation or whatever you call it. And then it stops. We ignore the future and the inevitable it brings. We flirt with the notion of 'living in the moment' but can't commit to it because to 'live in the moment' requires an absence of fear, an absence of anxiety, and a confidence in some sort of happy future certainty. Our death tomorrow, or the next day, or whenever is the only real

certainty in our messy lives. The buried anxiety we carry around the care of our family member after we have passed on contains the germ of a very uncomfortable death. We don't do death well.

In his book 'Staring at the Sun' Irving Yalom says that people are hardwired for the dread of death. That's natural. It's a huge (but inevitable) prospect. We dread our own deaths not because of the uncertainty of what we go to but because of the uncertainty of what we leave behind. It literally does not bear thinking about. This dread drives us towards an inability to contemplate what life would be like without us. Yalom says that if we are to lead a full life now we have to confront the dread of what is going to happen when we die. He says that by not facing this fear we are inhibited from letting ourselves or the people around us live a good life.

Some people do death well.

- My friend Patricia uses a progressive Dublin service. She has talked about her relationship with her boyfriend and the special time they spent together during his final illness, the respect that his family accorded her at the funeral proceedings, her role tending his grave, her bereavement counseling, and now her struggle over whether or not it's time to move on and have another relationship.
- A person in their 50's using services in the West won't acknowledge the doctors advice on the impact that cigarettes have on their health. The same person is very clear about what the funeral will look like and how their life will be celebrated.
- I am indebted to a mature student taking the social studies degree in GMIT who talked to people about the impact that health service delivery had on their ability to live an independent life. One respondent, Michael, a young man with DS in his mid 20's had this to say:
" I am conscious that being on drugs for my health causes problems. Can't do nothing, Aware! Yeah! But my family never speak of people dying in my presence."

On the other hand some don't do death so well

- A person who has lived in a residential service for very many years with what is regarded as a severe learning disability has had only minimal involvement in the deaths of his family members. The person is significantly changed since they briefly attended the funeral of their last remaining family member a number of years ago. Some staff close to the person think that the death of that final family member still carries a great weight for that person.
- A person living in a small residential home in south Dublin passed away in St. Vincents after quite a long illness. Staff members who sat with her for those final weeks are still deeply effected by what they saw as the insensitivity of hospital staff when it came to the particular needs of that person while she was dying

- During the Galway Film Fleadh the FEDVOL hosted a documentary and open forum called 'Monica and David'. The program tracked a year in the life of a young couple (Monica and David) and their parents. The focus of the drama was on Monica and David getting married. There were other major life events featured as well like moving to a completely new neighborhood, moving in with Monica's parents, and the parents retiring. All those stressors in one year and the only row that featured was about the way the new husband made the bed! The young couple had many supports and quite a few challenges;
 - They had moved to a part of Florida where there were very few young people
 - They had no work after they left their old neighborhood
 - They were now living with their retired parents who were much more involved in their lives than previously

As you might imagine the documentary captured many emotional moments. For me the scene with the most impact was where both sets of parents confessed in a rather distressed state that they could not begin to contemplate what would happen in the lives of Monica and David after they died.

All or any one of Monica and David's challenges had the makings of a scary scenario. However the fact that the parents of two young adults who live with an intellectual disability are not able to think beyond their own death is both the scariest and at the same time the least surprising. The scenario represents the most real and stark type of 'risk assessment' that parents have to contemplate – what happens when we are gone? And you know what – we don't dare go there. Talk to many parents about what their thoughts around death are and I guarantee that many will include in that fantasy a picture of themselves standing at the grave side of their own son or daughter.

This twisted fantasy that we occasionally tip into is however just that – a fantasy. People with intellectual disabilities live longer. In 1981 the proportion of people with moderate, severe or profound intellectual disabilities who were over 35 years of age was only 26%. In 2008 that figure is at 48%. The majority of adults with an intellectual disability continue to live with their families. As they age these care givers increasingly need to be supported in that role. And that is where the real risk is for a parent and their adult family members with an intellectual disability. They are moving towards a death that is either full of fear or the meager comfort and dulled expectations of what institutionalization has to offer to support a lived life.

I dread my own death not because of the uncertainty of what I go to but because of the uncertainty of what I leave behind. This dread drives people into either an inability to contemplate what a person's life would be like without us or the acceptance of the clean lines and safe contained life that is bounded by an institution. This dread has at its core a lack of confidence in community and an inability to visualize our family members living a full messy life. This inability to contemplate our own death as parents inhibits us from letting go control over the lives of our children while they are alive.

This type of 'risk management' inhibits the possibility of people being able to forge some degree of independence or carve out a valued social role in the place where they have lived and the communities where they belong. It stops us from supporting our children in taking the risks, enduring the knocks, and living the normal life of a chaotic, unplanned, free and precarious existence that is the 'Good Life'..

By the way, the failure of an organization to consider it's own 'death' has very real impacts on the quality of life of the people who it purportedly serves. Where the organization cannot contemplate it's own redundancy or the redundancy of it's systems, procedures and operating paradigms and unwilling to change the way it deals with people the resulting tension impacts on the most vulnerable people that make up it's domain. Those people are most likely to be unrepresented front line staff and the people who use the service. Here's just four examples;

1. A residential service in the West responds to budget restrictions by closing down two of it's bungalows which already have too many adults living in them and distributing the 'residents' around the other bungalows in the complex.
2. A service provider seen as progressive takes two years to address the fully acknowledged problem of a person who lives in abject fear because they live in the same house as another person who regularly terrorizes them
3. Staff in a day centre do not report self harm incidents because the committee dealing with this issue only meet monthly, cases are investigated over a subsequent month and recommendations aren't issued for another month
4. Psychotropic medication given to people for years on the basis of an open ended prescription without a stated psychiatric diagnosis continue to be given to people along with a bucket full of other medication that counteract theside effects

In this era of uncertainty and budget cuts it is irresponsible for service providers and families to hide heads in the sand and fail to address the risk, the possibility, the chance that the time for sole dependency and costly institutionalized care has run out. There is an idea going round that organizations have the advantage over humans that they can morph into something else. You work in organizations not far removed from institutional monoliths that can only respond to a suggestion for change with the slow torture of endless discussion. The situation becomes hopeless when it is 'informed' by legal advice that is poisoned by a pathological distrust of anything that is not mummified in the institutional trappings of risk management and the 'duty of care'.

We all know that the right thing to do is to support people living their own unique messy lives. We all know that we cannot depend on this pathological future fantasy of 'what ifs' and unlikely liability. The right thing to do now is to support people in living a 'HAPPY LIFE', in a community 'WHERE THEY BELONG', with opportunities to 'SHARE LOVE AT HOME', and empowered by the availability of 'QUALITY CHOICES'.

So when we talk about the risk of institutionalization, when we talk about our concern that a family member will be supported in living a good life, and when we talk of a concern around contained options a very sensitive vein is being tapped into. The last thing we need is risk aversion as a dominant value in our lives and the anxiety it brings with it. We need people delivering services to be consistent not in relation to standards and SOPs but to the twists and tweeks of the persons own particular individualized program. We need a broadening of expectations around what people with a disability are assumed to want starting with what the basic things that any of us want from life. We need to accept that it's normal that people will conform first a foremost to their own individual sense of self.

Your work decommissioning the 'duty of care' and dismantling the trappings of risk management removes some limitations to living a good life. Of course at the same time it exposes people to the natural real time risk of a normal messy life. Families need help living with those risky ideas. What you are doing to promote the messy reality of 'community living', 'natural networks of support', and 'strong, positive social roles' for people living with an intellectual disability has a very important place at the deathbeds and funerals of each of their parents and any of their siblings.

In the business of supporting people to live with the usual dangers, discomforts and risks that make up their wonderful messy lives we as family and you as organizations need to be making sure that there are good deaths as much as there are happy lives. The NFVB Vision Statement has been able to encapsulate what the future for our family member could be like in their relationship with a service provider. That vision carries in it the death of many of the negative aspects of institutionalization as we have known it.

My wish for you who work in this business is that when you retire you have no regrets about running the risk of unpopularity because you pushed families to see beyond the meager comfort and safe options of institutionalization. My wish for you is that when you say goodbye to the people you have provided a service to they will not grieve unduly because they have strong relationships with people outside of the institution. My wish is that when your organization is having it's resource life squeezed out of it you won't have to experience panic and fear because there is nobody in the family or community to share the 'duty of care' with. My wish for you is that people with intellectual disabilities will appear at your deathbed saying to you; 'It's all right. You've done a good job. You did what you knew was right. We have our own messy life now. You can rest in peace'.