The Ship of Fools: A Fictional Reality

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"The probability of the decision element at the top correctly measuring the system state decreases exponentially with the depth of the hierarchy. Each level adds noise to the information as it passes through. Thus the measurement signal is very noisy in a large bureaucracy."[1]

Agitated, fingers strumming on the table, he looks nervous. There is a bead of sweat on his brow, he straightens up; he doesn't need to rise to the bait. What was it he learned at college again, how to deal with conflict, that's it, how to listen and diffuse.

"Are you listening to me, I need help."

"Don't talk to me like that."

"But I'm at the end of my tether, are you going to do ANYTHING for me?"

"Don't speak to me so aggressively."

"I'm getting desperate, you take her. I've been doing this for too long, I need help, you take her..."

"I'm leaving. I can't take this abusive behaviour any more."

He attaches his pen to his clipboard and stands up to leave. He hears a sob. He touches the woman's arm and says, "Phone me, you can talk to me any time you want."

"But I only ever get your answer machine."

He gets into his four wheel drive and turns the key in the ignition, sighs, another job well done.

She finds herself part of an ongoing and surreal experience; of people working within a system so random they have no control over it, where policy decided by some distant committee dictates what happens in the lives of people dependant on others for their care. Where those who provide care try, and fail, to interpret these policies in relation to the reality of people's lives, dictated by limited finances and limited support.

Those with severe mental health problems, long term illness or learning disabilities are being further handicapped, their lives limited by pointless levels of bureaucracy which cause unimaginable stress to them, their families and care workers. To illustrate: Care in the Community and Inclusion in an ideal world means that everyone is entitled to live in the community and access community activities, such as vocational education, as and when they need them. However, overall, there is little flexibility or creativity in the narrow menu of services and support available to people with learning disabilities, their families and carers.[2] The reality for many people is that a new form of day service is in place. With limited community resources and funding, town centres, bowling alleys and parks are full of people with learning disabilities; turning cheap or free public spaces into unofficial day centres/hospital wards.[3] If we could work together, look at quality, sustainability, invest time and energy into getting it right, then perhaps we could create something which actively supports the individual from opportunity to opportunity—giving them some form of quality of life.

By breaking up the way care is provided, with responsibilities divided across different departments and funding bodies, it has become infinitely more difficult to find one person within local authority who is accountable for service provision. As a practical outcome, for the individual receiving the care, to challenge the service becomes almost an anathema, as you can't actually locate who is responsible for it. A subsequent problem begins to emerge: through splitting up care and making accountability harder to identify, it becomes virtually impossible to detect carelessness and indifference, thereby victimising those who the policies were established to protect in the first place.

Don't Let The Bastards Get You Down

She sits holding her clip file. Self important, she lords it over an emotional wreck of a woman. The woman's getting agitated, she can give her what she wants or she can let her wait. She will let her wait, leave her in limbo. It must feel so good, all that power: she can make decisions which will change her insignificant little life. She can decide whether she deserves it, and she doesn't think that she does. Does she?

As her brother, he thought he knew a thing or two about learning disability but after his father died he had his eyes opened wide. This new found sight was affording him a glimpse of another world, a world of petty bureaucracy, mediocre service and burnt out carers. Emphasis changed for him. It became all important to get a house for his sister, to help his mother. Countless meetings, emails, telephone calls and letters, a campaign to local MSPs and councillors, meetings with social work managers and still things aren't going anywhere. At first he is told it is because there was no house available; then it is because there wasn't the finance; then it was because they have too many other people to deal with. He feels tense: his mother wont stop crying and his sister is confused; nipping, scratching and biting anyone who comes near her. The situation is starting to get desperate.

The more desperate you are, the more emotional you become, and the less likely you are to get the help you require. The irony being, the more desperate you become the more help you require. You end up passed from person to person, lost within a system controlled by trivial protocols. The people working within it have to spend so much of their time filling in forms, counting pennies and covering their backs, it leaves little time to deal with people face to face.

Agencies established to support people with learning disabilities and their carers can find themselves in a no win situation. These agencies are dependent on their funding from local authorities. Problem being, as a result they are unable to speak out against inequalities, because if they do they may lose their funding or not have their contracts renewed.

On a wider point, the new Independent Mental Capacity Act[4] allows for an Independent Consultee to advocate for those people who have no family or friends to speak on their behalf. The problem remains: if that independent consultee is funded by the local authority, how can they speak out on behalf of an individual if what they are saying goes against/contradicts the policies of the people who sign their paycheque? Is it a case of split loyalty?

Burn Out A Series of Disjointed Vignettes

She picks up the phone, dials.

"Yes," says a tired voice at the other end of the phone.

"I want to talk to you about how you are getting on sorting out care/housing/respite/funding for your son/daughter?"

"I'm very tired, I can't do much, it's still the same, there's not much I can say to you, it just goes on."

She sighs and puts the phone down.

Her friend found a house for her daughter who has a learning disability, three years ago. Her daughter shares with another man, and a private care agency provides her care. She says the care workers aren't trained[5] and in fact are frightened by her daughter's behaviour. House staff no longer want to work with her and added to that her house mate doesn't want to share the house with her any more. The fighting can get physical and her daughters behaviour is getting worse. The mother describes the situation as a time bomb. Until recently, she was receiving phone calls from care staff at all hours of the night, demanding she calm her daughter down. She says if she goes over to the house and sees her in such a state of anxiety she will have to move her back to her home. After all, she is her mother. She has been told that if she removes her daughter from the house, she will have to stay with her permanently and she will lose all her care. So she has to watch from a distance as her daughter gets increasingly depressed and more and more likely to lash out. She has a bright idea. To try and ensure her daughter's well being, she has offered to move out of her council house, so that her daughter can move in, have her house, and the mother will arrange to live elsewhere. All she needs is the funding for her carers. Her social worker is very helpful. She describes her as 'salt of the earth', but it's not up to her. It's her managers who are holding things up: they say they can't find the money.

He looks at her. "Its about giving your son choice and person centred planning[6], about listening to what you all need."

She looks blank.

He leaves her house and gets into his car.

She looks out the window, watches him drive off, picks up the phone and calls her daughter. "I have no idea what he just said to me," she tells her.

Back in the office he listens to the messages on his answer machine. He skips the more irate messages. Sits down, flicks through his paperwork: another training programme to attend on Choice, Empowerment and Vulnerability. The phone rings. He leans over and switches his answer machine back on.

She's on the phone again. This time to a mother in her early sixties; her husband left years ago. Her son has a profound learning disability; he's in his mid-thirties. The mother is one of these women who won't complain, doesn't want to trouble people. She can hear from her voice that a life time of caring has taken its toll. Her son doesn't sleep well at night, so his mother sleeps lightly, listening out for footsteps on the floor in case her son falls down the stairs. Her son attends a Day Centre five days a week for six hours a day. On top of that, she gets home help for about seven hours a week. So every morning she gets up, washes her son and gets him dressed, feeds him breakfast and gets him ready to go. Every afternoon her son comes home about 3pm. She feeds him, they sit and watch telly, she washes him, gets him undressed and puts him to bed. She has done this more or less every day for the last thirty-five years, except on a Saturday and Sunday when they get to be with each other all day with the exception of three hours, when she gets to go to the shops on her own. She loves her son and is scared of what will happen to him when she is gone. She doesn't particularly trust anyone else to look after him, but now she is willing to let go. For the past five years she's been trying to sort out housing for her son, but she is not a fighter. She has offered to give up her own home, in order that her son and his carers can have somewhere to live. She, in turn, will move to sheltered housing. The social work department say that they don't have all the money for his care — as having staff that would need to be awake all night would be too expensive. So in the meantime she waits and they both get older and more vulnerable. Perhaps if she collapses they will listen to her.[7]

"Look, all you have to do is ask them to put you on the housing list and get a doctor to describe your sons disability accurately. Make sure that the social work department psychiatrist gets that information along with a number of letters of support. That will give him all the points he needs to get to the top of the housing list. I have compiled a catalogue of meetings and broken promises they have made with your family since 1990. It was 1990 when you first requested a house, wasn't it?"

"Yes," they look at her hopefully.

"I have to stay out of this, you say you put all this together, I cant be seen to be involved in this in any way. All I can say is that they are treating you badly and that the catalogue I've put together will embarrass them into doing something for you."

"They took away my respite,"[9] she says through tears. She's seventy years old; her daughter still stays at home. Her daughter has profound learning disabilities and severe physical disabilities. She needs round the clock personal care. "They told me the respite home isn't properly equipped for people with such extensive physical disabilities", she says, "but I told them she's been staying there for six years and there has never been a problem, but they wouldn't listen. They said its policy."[9]

For six months they have been in a state of extreme distress: mentally preparing for their daughter to move home, guilty about moving their daughter into someone else's care, stressed by the constant worry for their daughter's personal safety, let alone the practicalities of getting her house ready. On top of that, they still don't know if their daughter is actually going to be able to move in as they have not heard anything from Social Work in months.

They have the best carers in the world for their daughter; real honest people who know and like their daughter, and they know their daughter likes them. Things are starting to happen. People are starting to talk to each other; it looks like the move may just happen. Trouble is, the care costs are too high. They have been told if it goes beyond a certain cost then the Social Work department will have to ask other companies to tender for the contract. That means their daughter will be cared for by people who don't know her. They are told that the costs need to be kept lower. There are a few days to go, a decision has to be made, but they are still wrangling over the costs. They are both tense, guilty, desperate. They get a phone call: the care organisation and social work department have managed to agree on a price. Their daughter moves in. But what about the actual care? Have all eventualities been planned for? In amongst negotiating costs they try to remember if they were ever asked about their daughters medical needs. A niggling doubt eats away at them, "What if… ?"

She is sitting in her living room. She has an opened letter in her hand. It is from the Social Work department. She skims its contents and sees the word funding. Her chest tightens, she finds it hard to breathe, but she needs to talk to someone. She's in a state of panic: what if they don't have the money and her daughter has to move back in with her. How would she cope? She picks up the phone, her hands are shaking. She dials and the phone rings out.

"Hello, I'm not at my desk at the moment if you would like to leave a message after the tone I will get back to you as soon as I can."

In Conclusion

Learning disability care has become a business, with individuals and their carers transformed into facts and figures to be overseen by social workers who now have to act like accountants. Pretending that these complicated situations don't exist doesn't make them go away, and not planning for them properly has real long term implications. In fact, lack of clear understanding of the day-to-day reality of the situations people find themselves in is exacerbated further by disjointed support and misunderstood policy, as much as it is by limited funding. I am concerned that the policies we are creating to protect those we view as vulnerable inhibits the levels of care they receive. We are actually limiting what they can do, how they do it, where they do it and how we describe how they do it — becoming so protective that we compromise their well being. In relation to the quality of the services and their appropriateness to the individual, listening to the individual and their carers, rather than counting pennies, will result in services which will cost less in the long term, both financially and emotionally.

Maybe one day the people who make the decisions will realise that they should come and see what is actually happening on the ground, experience it from the lower end of the hierarchy, and then perhaps they will create a service which actually provides for the people who really need it.

Notes

1. Moore's *Laws of Bureaucracy*.
2. *Independence, well-being and choice*, 28th July, 2005. Keith Smith, Chief Executive, BILD.
3. "The Scottish Commission on the Regulation of Care should be given the resources needed to monitor, audit and guide the service providers on standards and best practice in community care services." The Scottish Parliament, Research Note RN 01/23, 14 February 2001.
4. The Mental Capacity Act 2005 provides a statutory framework to empower and protect vulnerable people who are not able to make their own decisions. It makes it clear who can take decisions, in which situations, and how they should go about this. It enables people to plan ahead for a time when they may lose capacity.
5. "Staff at all levels should have access to, and be encouraged to participate in, appropriate training on multidisciplinary working and team building. This should include opportunities for cross agency placement." The Scottish Parliament, Research Note RN 01/23, 14 February 2001, *Delivery of Community Care in Scotland*.
6. "We suggest that this takes the form of a new personal life plan. This plan would be for everyone who has a learning disability and wants a life plan. The plan should describe how the person, his or her family and professionals, will work together to help that person lead a fuller life." *The same as you? A review of services for people with learning disabilities*, The Scottish Executive.
7. "Local authorities, by working with health boards and the voluntary sector, should make sure that they look at the extra needs of those with profound and multiple disabilities and those of their carers. The centre for learning disability should set up a national network of support to local providers offering advice and training on the extra needs of people with profound and multiple disabilities." http://www.scotland.gov.uk/ldsr/docs/tsay-08.asp 'Recommendation 29', *The same as you? A review of services for people with learning disabilities*, The Scottish Executive.
8. Care given as an alternate care arrangement with the primary purpose of giving the carer or a resident a short term break from their usual care arrangement.

   www.health.gov.au/internet/wcms/publishing.nsf/Content/ageing-manuals-rcm-contents-glossar3.htm
9. "The issue of reasonable risk-taking is closely related to choice and is of great importance, if people with learning disabilities are to lead full lives in the community. However, literature in this area shows discrepancies in the ways in which risk is perceived. People with learning disabilities have been viewed as keen to take risks, while their family carers have been perceived as being protective and seeing risks as hazardous. Professionals, it has been suggested, have a more balanced view." The Foundation for People with Learning Disabilities

This is a work of fiction. All characters and events are the product of the author's imagination. Any resemblance to real persons, living or dead, is entirely coincidental.