

"Paranoid Privacy v QOL"

People with any form of disability are frequently isolated from many aspects of society. Those with an intellectual disability are especially isolated. They are even more isolated by the overzealous use of privacy legislation.

Most of us in general society have an intellectual ability avenue which "reaches to the sky and is big as a city block". Our intellectual ability avenue is so huge, that we don't have the time in each day to use but a fraction of this.

In total contrast, the complete reverse is true for those in our society with any form of intellectual disability. They have a huge amount of time, a little ability to use but a fraction of this in a meaningful way.

They don't need restrictive and overzealous privacy silos to negatively impact on their already restricted ability avenue. They need a very open lifestyle which actively encourages meaningful relationships and involvement in as many aspects of life as possible.

Privacy laws in general, have little negative impact on the quality of life of the general community. Most people have the ability and opportunity to adjust their activities not to infringe reasonable privacy, or have privacy impact adversely on their lifestyle

In contrast, privacy laws, and the interpretation of these by bureaucrats and service providers can have a pronounced negative impact on the quality of life of people with an intellectual and multiple disability, and their families.

The Victorian Privacy Commissioner's Office says that many service providers and bureaucrats frequently overreact. They use privacy legislation, or their interpretation to negate other legislation and/or their responsibilities under care policies standards and values. The Commissioner's Office calls this "BOPA" ("Blame it on the Privacy Act"). They say the Department of Human Services is the worst offender!

Some of the practical effects of "paranoid privacy" are.....

- The residents of a group home cannot be told the name of a proposed new resident, until that resident has finally settled in.
- The records and communications diary of one resident must not mention the names of staff and/or other residents, i.e. a communications example would be, "John had a birthday party with a co-resident".
- Parents of an adult member with an intellectual disability are restricted from accessing, on behalf of their family member ("who is unable by reason of their disability to make reasonable judgements in respect to all or any matters concerning their personal circumstances and/or estate"), medical and health reports, and from managing their member's health fund.
- Parents are denied access to Day Centre and Group Home activity reports.

- Parents/Families are restricted from discussing their adult family member in Day Centre and Group Home peer groups, and similar situations where peer support and empowerment can help families and their family member.

In contrast, a group of regular guys living together in the community, would have few limits on what they would know about each other. We suggest, money and girlfriends would generally be the only reservations.

Where access to the records of a person unable by reason of their disability to make reasonable judgements in respect to all or any matters concerning their personal circumstances and/or estate is restricted to just the Service Provider, Community Visitors and State Trustees, there is little chance their overall quality of life care (QOL) will be questioned/monitored consistently.

Although we do not question the good intention of community visitors per se..... We have personal experience of group homes given good reports, but where the residents received little QOL care. Indeed, when we requested to meet with the community visitor/s, in this regard, the Office of the Public Advocate (OPA) categorically refused our request! The community visitor reports (copies) we have on file, show little indication of QOL activities or records being questioned or examined!

We recently received the following from the DHS.....

"Community Visitors used to record details of their visits in a book. The page(s) of the book were then ripped out and provided to direct care staff at the house they were visiting. I understand that line management would then record any actions necessary following the visit onto the back of the ripped out page(s), photocopy the page(s) for the Department's records and files and return the page(s) to the relevant Regional Convenor for the Community Visitors program.

There may have been occasion through this practice where staff may have mistakenly forgotten to photocopy the required pages, resulting in gaps in the information held by the Department about visits made by the Community Visitors program.

In response to this issue, NWMR and the Community Visitors program has developed a new system which would ensure more accurate record keeping and follow up of issues raised through visits by Community Visitors. This system is currently being implemented across the shared supported accommodation homes managed by DAS in NWMR.

A pre printed and bound record book will allow each visit by Community Visitors to be recorded in triplicate in the book. Community Visitors take the top copy for their records, the second copy is sent to the regional office and the third copy remains in the book which is kept at the house. If the Community Visitors identify any issues which require attention, a formal process is in place whereby the DAS Area Manager emails the relevant Regional Convenor advising of the actions that will be taken.

Domain Managers and House Supervisors are currently in the process of implementing this new system and I expect that it will be in place in every shared supported accommodation home managed by DAS, NWMR by the end of October 2008."

NOTE: Quality of life care for those living in supported accommodation group homes is defined within many papers. It is basically the provision of good basic care. plus that necessary to maintain, enhance and develop a person's life skills through interaction, developmental and social activities per se, and as defined within the "Active Support" concept.

In conclusion: Caring parents and families need the legal right to access and question that necessary for them to ensure their vulnerable adult family member is not receiving just minder care. Plenary Guardianship helps, but they should not have to fight bureaucracy bent on paranoid and unnecessary privacy for those with a lifestyle already severely restricted by their disability!

LISA Comment: As usual the DHS HO "shop window" sounds wonderful, but is not implemented at its regional, captive market, service points, which manoeuvre every which way to avoid accountability and transparency!

Check-it-out, folks - Then tell us if you ever see this in meaningful practice in "Disability Services"!

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LIFESTYLE IN SUPPORTED ACCOMMODATION (LISA) INC.

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