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Briefing

Family members causing harm to their loved ones living with disability

PURPOSE

The purpose of this briefing paper is to help inform people about the issues that may be relevant to situations where family members harm, or consider causing harm to, a family member living with disability.

Our hope is that this briefing can raise awareness and so help reduce such occurrences from happening in the future.

Note that this briefing is in no way designed to excuse the act of intentionally harming a loved one. The Julia Farr Association (JFA) does not condone unlawful acts. JFA recognises that many families are under pressure because of some of the issues identified in this briefing paper, and yet do not resort to harming their loved ones.

SUMMARY

This briefing paper explores some of the challenges and issues families face in regards to providing support for loved ones living with disability. The paper highlights some of the possible reasons why family members are driven to extreme measures, such as harming their loved one. Some possible underlying factors are identified through researching specific cases where family members have caused harm to their loved one or have thought about doing so. Some key themes are raised for consideration to encourage further examination into why such events occur and to think about ways families and their loved ones living with disability can receive greater support.

BACKGROUND

In a recent court case in Adelaide, a court heard allegations that an elderly father shot his son living with disability so no one else would have to bear the burden of his care (Edwards 2009; McGregor 2009; Fewster 2008). This case, however resolved, raises the serious social issue of family members harming their loved ones living with disability. No comment or implication is made or intended with respect to the circumstances of any particular case.

JFA felt it was important to explore some of the possible reasons why family members would consider causing harm to their loved ones. We examined the available information on a number of cases involving family members harming or threatening to harm their son or daughter living with disability. Using both Australian and New Zealand media and literature sources we identified six cases that have occurred over the past ten years.

In so doing, JFA identified some possible key factors which we felt needed to be highlighted and considered.

KEY FACTORS

In examining the available reports, there appears to be a number of possible factors that placed families in a position where they thought about causing harm to their loved ones.

1. *Families attempting for years to get the support they needed, but with little success.*

- In one case a family had been turned down by eight organisations due to the complex needs of their daughter (Dekker 1998). In another case a family could only secure three hours out of the recommended 20 hours support they required (*The Sydney Morning Herald* 2004).

2. *Ageing parents being concerned about the future their loved one will have when they are gone (Elliott 1999).*

- It is estimated that approximately 55,600 people living with disability and aged over 30 are living at home with their parents who are aged over 70 (National Carers Coalition 2005).

3. *Families not being given sufficient support upon learning that their child had a disability.*

- A baby was killed by her father in a case where the family was not given immediate support after their baby's 'diagnosis' but were instead sent home in a taxi (*One News* 2004).

4. Families being concerned about the lack of appropriate accommodation available for their loved ones.

- In one case parents aged over 65 had been waiting more than three years for suitable permanent accommodation for their son (Elliott 1999). In another case a loved one was in supported accommodation and had frequently been verbally and physically abused by staff and residents (Jacobsen 2007).

In the cases we looked at, where family members have caused harm to their loved ones and have gone through court proceedings, it was deemed that the family member had diminished responsibility due to the pressures and suffering they were experiencing resulting in receiving a reduced sentence (Jacobsen 2007; *One News* 2004).

Although the factors mentioned above are based on specific situations, they do highlight some of the pressures family members are placed under within the community. With increasing numbers of ageing parents supporting their loved one living with disability in Australia, services and communities need to have regard for these factors.

Below are some themes to consider, to help reduce the likelihood of such occurrences in the future.

THEMES FOR CONSIDERATION

1. Families accessing sufficient resources to get through their daily lives

- JFA believes that there will always be some limits on the amount of public resources available for people living with disability. Part of the reason for this is that there will always be competing demands for the public dollar. Another part of the reason is that money cannot buy everything in life, for example a genuine sense of belonging within the community, intimate and loving relationships, a fulfilling job, and so on.
- If it is accepted that resources are and always will be finite, then it is important that the available funds are used well.

Questions to Ask

1) What can Government and local services do to grow the capacity of communities to be inclusive of people living with disability? This is about being 'good neighbours', and there needs to be thought about how this is initiated because it may not happen spontaneously if local people are under-informed or mis-informed about people who happen to live with disability.

2) Can Government demonstrate that it is spending public funds in ways that are delivering genuine outcomes for people (ie effective) and in ways that are not wasteful (ie efficient)? This will help ensure that the available resources have maximum impact.

3) If we accept that people living with disability and family members are the best experts in understanding their own needs and aspirations, is Government giving them the opportunity to buy their own services? 'Individual Funding' is increasingly being adopted elsewhere eg the United Kingdom, and significant gains are being reported. More information on Individual Funding can be obtained from the following link - http://www.juliafarr.org.au/individualised_funding.asp.

2. Families accessing information about the support that is available

- JFA believes that it is likely, for a variety of reasons, that not all people living with disability and their families have access to information about the support that is available.

Questions to Ask

4) Can Government and local services demonstrate that it is as easy as possible for people to access the information they need? This can include online material and printed material, in a variety of formats including visual, audio and touch formats, and at a variety of community locations.

5) Have Government and local services successfully built networks with, and supplied information to, other people who may be involved with people living with disability and family members? Such people could include GPs, other primary healthcare practitioners, and local community leaders.

3. Families growing their capacity to be successful as families

- JFA firmly believes that successful families come in all shapes and sizes, and of course includes families where there is a family member living with disability. It is not helpful to assume that a family must struggle simply because a family member lives with disability.
- All families learn together and grow together. Families that include a person living with disability may at times need assistance on that journey, such as through information and planning support.

Questions to Ask

6) How are Government and local services helping families to link up with other families in similar situations?

7) Is Government offering planning support to every family that may need it?

4. Family members being supported to see a future for their loved one after they have gone

- JFA recognises that some family members may struggle to see a future for their loved one when they have gone, perhaps because they have had difficulty seeking or getting assistance in the past, and cannot envisage anyone else taking on the primary support role once they are gone.
- JFA believes that families should be assisted to plan for the future with hope. There are a number of different methodologies available, but of paramount importance is ensuring that families can see a positive, attainable and sustainable future for their loved one.
- Person-centred planning is one approach that focuses on people living with disability and their families being in control of making decisions about what they want to do and what support is required. Person-centred planning 'helps build the person's place in the community and helps the community to welcome them. It is not just about services, and reflects what is possible, not just what is available' (Sanderson & Routledge n.d., p. 6). More information on person-centred planning can be obtained from the following link - <http://www.helensandersonassociates.co.uk/PDFs/WHAT%20IS%20PERSON%20CENTRED%20PLANNING.pdf>.

Questions to Ask

9) Do Government and local services assist families to undertake authentic person-centred planning? This can help families to plan a decent life for their family member living with disability, and which also assists the family to be successful.

5. Increasing numbers of family members ageing who are caring for a loved one living with disability in the family home

- It is possible that there are increasing numbers of family members in Australia who are aged over 70 supporting their loved ones living with disability at home who are aged over 30. Their increasing demands on services can be predicted in line with the ageing of the primary support person.
- It is also possible that Government and local services are not adequately attending to this, because of more pressing demands on resources from people who are in more immediately fragile situations or in crisis.
- As a result, it is possible that many of these ageing families are not known, or not being adequately planned for, by Government.

Questions to Ask

9) How good is the information that Government has about those ageing family members who are providing primary support to a person living with disability?

10) How are Government and local services setting aside time and resources to pro-actively plan for the future needs of these families and the person living with disability?

CONCLUDING REMARKS

As a society, we must do everything we can to help ensure that our communities are inclusive and supportive, where people can see a positive future for themselves and their loved ones.

We hope that the contents of this paper, and the questions raised, will help people who are under pressure to reclaim hope in their lives.

DISCLAIMER

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