



OFFICE OF THE PUBLIC ADVOCATE

Private Guardians Survey - FINAL REPORT

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Project #: 8236

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Addenda to this report:

1. Verbatim quotes – Ease of combining Carer & Guardian roles
2. Verbatim quotes – Comments about Specific Aspects of Support
3. Verbatim quotes – Final Comments and Suggestions



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INTRODUCTION:

Background

Objectives

Introduction

BACKGROUND

- The Office of the Public Advocate (OPA) sought to better understand the issues that face people in South Australia who have taken on the role of a private guardian. This exploration is driven, in part, by an increasing need for guardians due to changing demographics. The overall objective was to identify ways to adequately support and thereby encourage citizens to act as guardians for their spouse, family members or others. To achieve this aim, the OPA needed to better understand their needs for information and support. This was the basis on which the OPA applied for and was awarded a Law Foundation of South Australia grant to conduct a wide-ranging quantitative and qualitative survey of private guardians.
- While the population across Australia is ageing, South Australia is particularly vulnerable due to its existing age profile being notably older than other States or Territories. The need for guardianship is not limited to people becoming mentally incapacitated due to age. People of all ages may require guardians for a very wide variety of reasons and, consequently, guardians may also cover a very wide demographic range. The emphasis of the project was on people becoming guardians for spouses or other adult family members and the process involved when someone becomes mentally incapacitated.
- There are two types of private guardians:
 - ~ those appointed by the Guardianship Board, and
 - ~ those who have independently taken on an actual or potential guardianship role through an Enduring Power of Guardianship (EPG).
- The latter is akin to an Enduring Power of Attorney, which gives rights to make decisions about financial, property and related legal matters, but the EPG provides decision-making rights over medical and lifestyle matters. Where a private guardian cannot be found or, for example, there is conflict between family members which precludes the selection of any individual as guardian, the Public Advocate will be appointed as guardian, but this is not classed as private guardianship.

OBJECTIVES

- The aim of the project was to provide OPA with a comprehensive understanding of the experiences of private guardians. Issues covered included:
 - ~ their reasons for becoming guardians in the first place (the drivers).
 - ~ prior awareness of guardianship, EPGs, the Guardianship Board, OPA, etc.
 - ~ their experiences and the challenges they faced in becoming guardians, including those who proactively acted ahead of any need foreseen at the time and those appointed after a need became evident (the barriers).
 - ~ the decision processes and the sources of informational, material and human resources supports and barriers.
 - ~ their knowledge and understanding of their role, its scope and limitations.
 - ~ how they go about functioning in their role, with particular attention being paid to a sensitive exploration of how this matches with the principles of Section 5 of the *Guardianship and Administration Act 1993*, i.e. issues such as how the current or anticipated wishes of the protected person are taken into account in the guardian's decision-making.
 - ~ exploration of if and how the legal systems and processes could be improved.
 - ~ explorations of existing and desirable supports that currently or potentially might assist guardians to fulfil their roles, including the roles of government agencies, health professionals, legal professionals, community advocacy or support groups, etc.
 - ~ demographic, geographic and socio-graphic information about the guardians, to provide OPA with profiles of guardians in South Australia.

Methodologies

INITIAL ENQUIRY

- When there is insufficient previous research to guide you, conducting qualitative research as a first stage, to ensure the right questions are asked in the survey, can add significant value to a project. Similarly, a quantitative survey can often raise questions which need further exploration and subsequent qualitative explorations of these issues to allow deep probing to uncover the often-critical peripheral issues associated with the items being explored. Thus a multi-faceted approach was used for gathering information for the project.
- As relatively little was known about private guardians, particularly those with an EPG, the initial phase of the research project was to undertake exploratory research among guardians who agreed to participate in focus groups.
- It was initially thought that two focus groups could be conducted to provide insights and understanding in order to develop a focused and appropriately worded questionnaire for the main quantitative survey. The Public Advocate promoted the research project and invited private guardians to participate in this exploratory phase (promotion was undertaken via a radio interview). The response was considerably lower than anticipated and, as a result, only one focus group was conducted prior to developing the survey instrument. All aspects of this phase of the project, in particular the topic guide and the focus group recruitment process, underwent ethics approval from the HREC before it could commence.
- The outcomes from this initial discussion then provided background and insights to assist in the process of developing the primary phase of the research, two self-completion surveys.

PRIMARY QUANTITATIVE STUDY

- The quantitative study also needed to undergo ethics approval from the HREC, which entailed creating final versions of all promotional materials, questionnaires, introduction letters (which were attached to the paper versions of the survey) and full details of the methods to be used to gather the data. This process was quite protracted before approval to proceed was given, as a result of which the project timeframes had to be extended.
- The task was to undertake a quantitative study among the two types of guardians. This entailed two stages, as there was no easy way to identify people who have become guardians via an EPG. Both a paper copy survey and an online survey were used to gather the data from private guardians:
 - ~ The Guardianship Board provided the names and addresses of Board appointed private guardians, so the paper copy survey was posted to n=800 addresses enclosing an introduction letter from the Public Advocate, the questionnaire and a reply paid envelope. A total of n=143 were completed and returned, representing an 18% response rate.
 - ~ For the EPG survey, a range of promotional tactics were used to encourage EPG's to opt in to the survey and complete it online. The same survey instrument was used, so that the results were comparable and could also be merged to form a larger sample size. Radio advertisements, posters and letters of introduction, as well as personal emails from the Public Advocate directed to those who provide support services.

PRIMARY QUANTITATIVE STUDY

- Some of the organisations who assisted in promoting the online survey on behalf of the OPA and Harrison Research, to whom we offer our appreciation of assisting us in this difficult task, included (if your organisation is not listed but should be, we apologise for any omissions):
 - ~ JUSTICE-INFORMATION@LIST.SA.GOV.AU
 - ~ Carers Association SA
 - ~ Health Consumers Alliance
 - ~ COTA
 - ~ Respecting Patient Choices
 - ~ Alzheimer's Association
 - ~ Law firms known to OPA.
- The online survey was promoted as being available and linked to: the OPA website, Harrison Research website and also the Legal Services Commission website, so that potential EPG's had several opportunities to come in contact with survey. A sample of n=146 was achieved using this method.
- The two samples have been merged to make a sample of n=289, which has greater reliability than the individual samples ($\pm 5.68\%$ @ 95% confidence level for findings at the total sample level). The findings have also been cross-tabulated by the type of private guardian to make comparisons between Board appointed private guardians and Enduring Power of Guardianship private guardians across the whole survey.

FOLLOW UP QUALITATIVE INTERVIEWS

- The final phase of the research involved 20 in-depth interviews with a selection of Guardians, to delve more deeply into issues and barriers raised in the quantitative studies. They were selected from guardians (including both Board appointed and EPG's) who had taken part in the quantitative survey and who had indicated their willingness to participate in a further stage. One on one interviews, primarily by telephone but also offering the option for an in-home interview if that was more suitable, were conducted using a topic guide developed from the findings of the quantitative study.
- The following report represents key findings across all phases of the research project, incorporating:
 - ~ an Executive Summary and Recommendations,
 - ~ an outline of the findings from the exploratory focus group on which the survey instrument was developed,
 - ~ key findings across the quantitative research, and
 - ~ highlights of the follow-up, in-depth interviews.
- Appendices include the topic guide, the questionnaire used for both paper and online surveys, the follow-up topic guide and an explanation of margin of error and interpreting the statistical results.



EXECUTIVE ASSESSMENT

Executive Summary

- As mentioned in the introduction, the project included three phases; a qualitative exploratory phase (focus group), a quantitative phase (an online survey and a paper survey), and in-depth telephone surveys with Guardians who had agreed to participate in a follow-up interview. This summary covers the findings of all three of the project phases, followed by discussion on the implications of the findings and recommendations.
- A total of n=289 Guardians responded to the survey (margin of error of $\pm 5.67\%$ @ 95% confidence level). Almost half of the sample (47%) were current Board-appointed Guardians and a further 18% were former Board-appointed Guardians. Just over one in four (27%) were current EPG Guardians and 14% were former EPG's.
- Three in every four (75%) Guardians thought that the term "Protected Person" was an adequate description for the person for whom they are Guardian. Among the 12% who indicated that some other title would be better, there was no single title dominating their suggestions.
- Just over half (53%) of EPG Guardians indicated that they took on the role as a precaution. Conversely, three in every four (74%) current Board-appointed Guardians said there was a change in situation which prompted the action.
- For most (71% of all Guardians) there were no other choices or alternatives available to them. Just over half (53% of all Guardians) said it was an easy decision to become a Guardian. However, the decision was significantly easier for EPG Guardians than it was for Board-appointed Guardians, with 66% of EPG's stating the decision was easy to make versus 48% of Board-appointed Guardians saying the decision was easy. Despite this, Guardians overwhelmingly (88%) would make the same decision if faced with a similar situation.
- The top three sources of information about becoming a private Guardian were from; flyers / fact sheets from OPA (39%), advice from a medical professional (36%) and from a legal practitioner / agency (23%).
- One of the key aspects raised throughout the research was a perception that they lacked information, about aspects such as their legal responsibilities, decision-making, when and how to activate an EPG and so on. And more than one in ten (13%) private Guardians indicated they had no knowledge or information prior to making the decision to become a Guardian. Most interesting about this was the fact that there were no differences regarding prior information when analysed by whether Guardians were Board-appointed or EPG's.
- The value of the information they received was helpful in making an informed decision for most (58%) Guardians. However, nearly one in five (19%) Guardians indicated they needed more information, a further 2% said the information was not helpful, and 15% said they did not have any information prior to making the decision to become a Guardian. In their comments about this topic, several points were repeated many times throughout the study:
 - ~ Many would appreciate speaking to someone in person, not just receiving written information and applying the broad outline to their specific situation.
 - ~ Some raised the issue of a step-by-step guide or, at least, simplification of the processes they need to go through in both applying for Guardianship and making decisions on behalf of the protected person.
 - ~ Many wanted more detail around the legislative requirements and their legal responsibilities. This is somewhat balanced by those who said they received too much information and felt overwhelmed, in the early stages of the process at least. However, it was more common for guardians to indicate they felt ill-equipped for the role and wanted more practical advice / information about implementation and their rights and obligations as guardians.

Executive Summary

- ~ Guardians also expressed a strong desire to share information, advice and anecdotes with other Guardians as a means of providing support to each other, advocacy and sharing of resources. EPG's in particular expressed a sense of isolation in their role, as well as a desire not to have to continually "re-invent the wheel" in terms of finding resources, who to access for expert advice, and finding professionals who have proven to be perceptive and helpful.
- Two out of three (66%) Guardians undertake the role of financial administrator (or Power of Attorney) as well as Guardian. This was considerably more likely among EPG's than Board-appointed Guardians (86% versus 59% take on both roles).
- Those taking on this dual role of Guardian and administrator (n=219) were asked to indicate how easy or difficult it was for them to combine both roles. Nearly half (48%) said it was easy, 31% said it was neither easy nor difficult and 21% indicated it was difficult. When asked to provide further insights into why combining both roles was either easy or difficult, two key themes were noted:
 - ~ Undertaking both roles allows control and provides the means by which Guardians can effectively manage the affairs of the protected person.
 - ~ It is difficult for some because they lack the accounting knowledge to undertake the task without it being onerous. Some perceive that the need to justify expenditure is demeaning when they are acting on behalf of a loved one.
- All Guardians surveyed were asked to rate their satisfaction with aspects of support and advice to Guardians (0 to 10 scale, 0 = not at all satisfied, 10 = very satisfied). When they were read a series of statement (randomised) about support and advice, the aspects ranked highest were:
 - ~ *"How well you are listened to by the Board, if you have concerns"*, with a mean score of 7.2.
 - ~ *"How well other family / friends understood and supported you in your Guardian role"*, with a 7.0 mean score.
- And at the other end of the scale, the lowest ranked aspects were:
 - ~ *"How well you were assisted with legal advice on the process of Guardianship"*, mean score 5.5.
 - ~ *"The process of lodging annual expense accounts to the Public Trustee is comfortable"*, at a very low mean of 5.0.
- All other aspects in between rated between 6.9 and 6.2 mean scores. Whilst these scores represents 'satisfied', it is on the low end of satisfied and indicates some issues with the advice and support provided by both the Guardianship Board and the OPA. For example, the helpfulness of advice from the OPA was rated at 6.5, marginally behind the helpfulness of advice from the Board (6.8 mean score) but both of these suggest that the advice provided to Guardians is not as helpful as it could be and as Guardians would wish.
- Across all of these aspects of support and advice, Board-appointed Guardians were significantly more likely to indicate they are very satisfied compared with Guardians with an Enduring Power of Guardianship. Whilst this is not an unexpected finding, it does suggest that EPG's need a support organisation, an advocate for EPG's or a Helpline, to provide them with the confidence to make sound decisions based on the legal principles underpinning Guardianship.

Executive Summary

- Throughout the research, comments have been made by many Guardians to the effect that they feel they lack this legal framework to guide them in their Guardian role. Two in five (43%) of all Guardians indicated they were aware of the legislative principles which guide decision making, declining to 35% among current EPG's.
- When the four key Principles in the legislation were read to them, however, all Guardians rated these highly (between 7.8 and 8.6 mean scores out of a possible 10.0) and very few (around one in twenty) said the Principles did not influence their decisions at all. As mentioned previously regarding awareness of the Legislative Principles, however, EPG Guardians were significantly more likely to suggest they did not know how much the Principles in the Legislation influenced their decisions (between 1 in 2 and 7 out of 10 EPG's for each Principle).
- Having said this, 3 in every 4 (75%) EPG's have had no contact with either the Board or the OPA (versus 70% of Board-appointed Guardians having had contact with the Board and 35% having had contact with the OPA).
- Among those who have had contact with either of these bodies, the level of agreement among Guardians, across a number of performance indicators, were relatively high. The following statements and mean scores indicate that, when Guardians come in contact with the Board or the OPA, it is a relatively positive experience for them:
 - ~ The Board / OPA was professional in it's dealings with me – 8.4 mean (among those who had contact with Board) and 7.8 (among those who had contact with OPA)
 - ~ I was treated fairly – 8.3 (Board) and 8.0 (OPA)
 - ~ The Board / OPA was knowledgeable and competent – 8.1 mean (Board) and 7.7 (OPA)
 - ~ I was informed of everything I had to do to become and remain a Guardian – 7.8 mean (Board) and 7.5 (OPA)
 - ~ The Board / OPA went the extra mile to make sure I got what I needed – 7.2 mean (Board) and 7.0 (OPA)
- Given the apparent disconnect between EPG Guardians and the OPA and Guardianship Board (as highlighted throughout the research), the findings suggest that much of the decision making made by the majority of EPG 's (2 out of 3) is not guided by the legislation. This finding is further confirmed by comments made by many EPG's to the effect that they perceive they lack support, understanding, knowledge of the legal issues and responsibilities and status as Guardians at various levels. In particular they focused on support, status and understanding from: State government departments; service providers such as aged care facilities and medical professionals; and the general community.

Discussion

- The research has highlighted that guardians perceive many gaps in the services provided to them. To be fair, some of these gaps in service provision include aspects outside the purview of the OPA and Guardianship Board. These included aspects such as: lack of awareness and understanding about guardianship among medical and aged care service providers; difficulty in accessing some care services (e.g. palliative and high needs aged care); and the often raised onerous task of financial reporting to the Public Trustee were some of these key issues.
- The key issue raised across the whole study has been a **perceived lack of information**. Whilst this perception of insufficient information included aspects such as their legal responsibilities, mostly it was centred around practical implementation rather than the legal framework under which it operates. These included:
 - a clear understanding of what would occur during the Board hearing;
 - practical aspects of decision-making when there are no clearly articulated wishes in place or when there is family conflict over decisions;
 - when and how to activate an EPG;
 - where their responsibility as guardians begins and ends, clarity around the role and particularly its limitations;
 - framework to support ethical decision making.
- As mentioned earlier, one of the most common issues raised throughout the research concerned the **system of financial reporting to the Public Trustee**. This aspect was a source of frustration and concern for Board-appointed guardians, with many stating that they feel overwhelmed by the process. In particular, aspects such as: the complexity of the financial reporting requirements; the outdated process used; non-acceptance of financial package software and spreadsheet reporting; annual reports described as cumbersome and time-consuming, especially the requirement to provide month by month debit and credit details; and also the organisation being unhelpful and non-responsive to requests for information or responding to queries.
- EPG's also raised issues which were specific to their situation, particularly around the perceived need for a **support organisation**, an advocate for EPG's or a Helpline, to provide them with the confidence to make sound decisions based on the legal principles underpinning Guardianship. They are also wanting guidance and support in the moral and ethical questions around Advance Directives and other potentially serious issues which may have significant repercussions. Many feel the weight of responsibility in making this type of decision, particularly if there is family conflict around the best decision to reflect the wishes of the protected person.
- There were many comments throughout the research regarding **lack of recognition of the status and responsibility of guardians**, particularly among medical and aged care professionals and also banks. Some guardians indicated that other family members (who were not guardians) had greater influence over medical decisions than the guardian, whilst others indicated that medical professionals and banks have ignored the guardian's wishes and made decisions not in line with the stated wishes of the protected person. These incidences were not isolated but relatively common (among guardians of elderly dementia patients in particular), clearly indicating that the guardian role is not well understood among those people providing medical care / services and financial services for some protected persons.

Discussion

- Many guardians suggested that, rather than sending out flyers and fact sheets or leaving prospective or newly appointed (EPG) guardians to source information for themselves, that guardians should have a **one on one interview with an advocate** who could take them step by step through the process, related specifically to their situation and offering a range of support, special interest or advocacy groups as additional resources should they be required. Whilst this is most likely impractical in terms of the resourcing required to undertake this task, there is a clear message from EPG guardians that they feel isolated, with little or no information about other services available to support them and limited information about the legal framework for decision making (and some EPG guardians indicated they did not know when and how to activate the EPG).
- Along similar lines, some guardians suggested that having only **one agency** for accessing guardianship of all types could provide them with information about a wide range of services and support mechanisms, as well as advocacy, without the cost associated with seeking private legal advice but ensuring that all options were understood and formed the basis for well-informed decision-making.
- There was confusion surrounding the **differences** between a **Board-appointed** Guardian, an **EPG** and an **EPA**, what role each plays and the practical responsibilities and limitations of each. Whilst the fact sheets and flyers provided the legal and administrative facts, they are not a practical “how to” guide to guardianship. Guardians indicated they need clarity as to which form of guardianship is the most useful for which situations where guardianship may be needed. Some who visit a lawyer are provided with a Power of Attorney only to find later that they needed a Power of Guardianship. “If only we knew this earlier” was a relatively common statement made by guardians. This suggests that wider understanding of the differences between the various types of guardianship is required, both at the community level and also among aged care, medical and legal professionals.
- Among guardians who are also primary carers, the responsibilities of providing day to day care are often onerous and make sourcing information about guardianship and support mechanisms difficult as they lack the time to research information and resources. Whilst this does not come directly under the auspices of the OPA or the Board, it does demonstrate that many guardians are **time-poor**, perhaps also **isolated** and **under some degree of stress**.
- There is a need among guardians for **actionable advice** which will provide them with the mechanisms required to make well informed decisions on behalf of their protected person, whilst avoiding “reinventing the wheel” or using precious time to follow through on everything themselves.
- In many instances, Board-appointed guardians have indicated that they wished they had the **information about guardianship earlier** as it would have avoided delaying the decision, which in turn led to reduced choices / options available to them.

Recommendations

- The following recommendations encapsulate the thoughts of guardians in terms of the improvements they would like to see implemented. However, it should be noted that the previous pages also provide insights into changes which would improve the effectiveness of guardians and support the important work they undertake.
- Promotion of the role of guardian to service providers and the general public, to support the work of guardians. May include aspects such as:
 - how and when guardianship should be applied,
 - decisions which should be made by the guardian(s) alone,
 - when guardians should be consulted about medical or care decisions,
 - the responsibilities inherent in the role,
 - service providers' obligations to the guardian.
- A Helpline for Guardians and those contemplating taking on the role. May be partly funded by interested parties, such as the Law Society or Legal Services Commission, accounting firms, state government and so on. Information available through a Helpline for guardians might include:
 - advice which is easily understood and actionable, plain language not legalese;
 - access to support networks, including other guardians who have faced similar situations;
 - clear guidelines for a practical framework to support decision-making, action-oriented.
- New technologies offer a number of ways to achieve some of the information and networking goals, using online resources such as blogs. These can be used for a variety of objectives, such as:
 - engaging guardians in creating or revising policy and legislative frameworks (tapping in to the wealth of practical experience available among existing guardians);
 - engaging them on topical issues as they arise and using their input and experience to guide practice;
 - creating an interactive forum for them to ask questions of, or respond directly to, other guardians;
 - promoting up to date information and legislative changes to existing guardians.
- Create a video on the website which takes prospective guardians step-by-step through the process of obtaining guardianship, providing them with clear language explanations of the legislative requirements, offering advice and resources and, perhaps, showing some actual case studies demonstrating various actions which can be taken in common situations (with the guardians' permission and/or active involvement).
- The OPA website should also provide quick links to:
 - relevant support agencies, such as Carers SA,
 - experts in guardianship from the legal and medical fraternities who can provide guardians with the advice needed to support their decisions,
 - other guardians who are keen to share their experiences and their resources with newly appointed guardians.

Recommendations

- Not all guardians and prospective guardians will have access to the Internet, so promotion and education via other means will also be necessary. One idea worthy of consideration was to conduct a forum for guardians and those considering taking on the role (or other interested parties). The forum could include experts and professionals from:
 - the Guardianship Board and the OPA,
 - the legal profession and/or Legal Services Commission,
 - medical and palliative care services,
 - aged care providers,
 - disability services and so onwho could provide practical advice and answer questions for guardians who are either invited or who opt-in as a result of promotion. A professional facilitator would ensure that all participants were heard. The forum could be video recorded to form the basis of the online video for new guardians, suggested previously.
- Finally, it is well-documented that we are experiencing an ageing population and, since dementia prevalence is strongly age-related¹, many of the carers and families who are currently applying for guardianship are doing so on behalf of elderly parents. It can, therefore, be reasonably assumed that the number of guardians will continue to grow exponentially in the foreseeable future. As a result, it will become increasingly important to provide guardians and prospective guardians with a one-stop or one-portal source for advice, legal assistance, support mechanisms and guidelines for ethical decision-making, in addition to the current legislative principles and frameworks which currently formalise the process of becoming a guardian.

¹ AIHW, 2007, Dementia in Australia: National Data Analysis and Development, Canberra

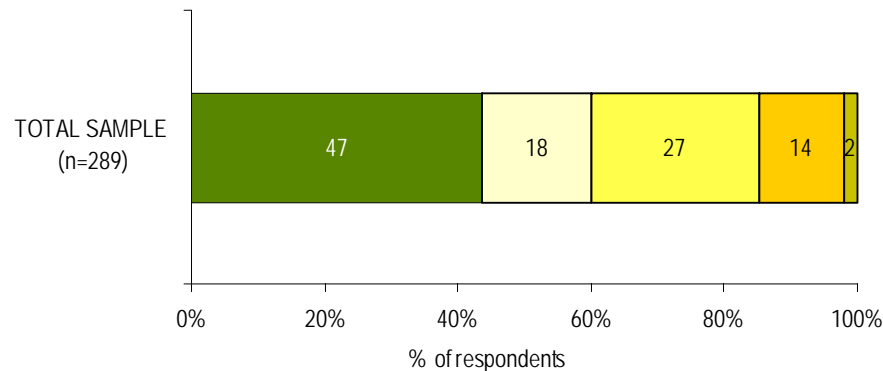


KEY FINDINGS: Profile of Respondents - Online & Paper Surveys

Profile of EPG & Board-appointed Guardians

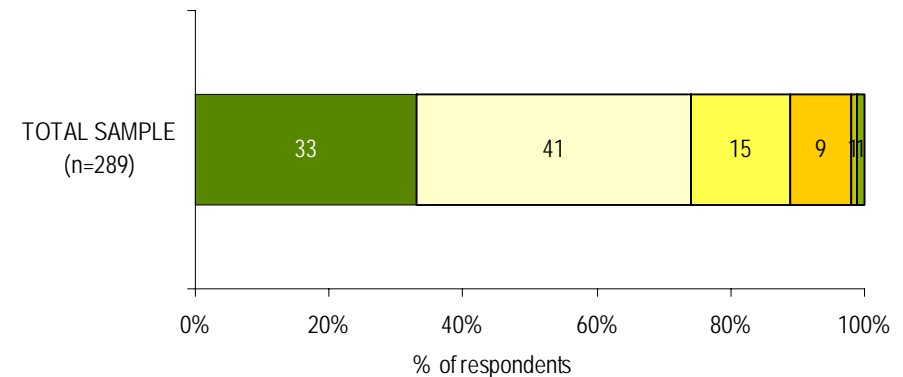
- The following section provides the key findings among guardians who completed either a paper survey (Board-appointed Guardians) or an online survey (EPG's).
- A total of n=289 private guardians responded to the paper survey (n=143) or the online survey (n=146). This sample size provides a margin of error of $\pm 5.67\%$ @ 95% confidence level. The calculation assumes that the combined 'population' of EPG's and Board appointed Guardians is 10,000 or more (EPG numbers are unknown).
- Nearly half (47%) of the sample were current Board appointed Guardians. A further quarter (27%) were current EPG's. Former guardians made up a further one third of the total sample (32%). This means that 8% of guardians surveyed undertake guardianship for more than one person / relative.
- Most private guardians surveyed have been in the role for less than 5 years (74%).

EPG OR BOARD APPOINTED GUARDIAN



■ Current Board appointed Guardian
 ■ Fomer Board appointed Guardian
 ■ Current EPG Guardian
 ■ Fomer EPG Guardian
 ■ Not stated / not sure

LENGTH OF TIME WERE/HAVE BEEN A GUARDIAN



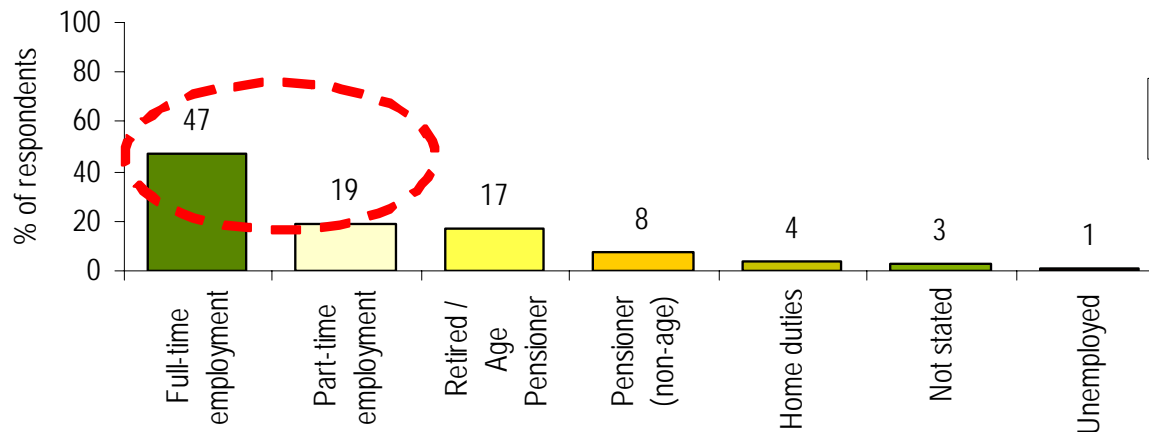
■ Less than 2 years
 ■ 2 to less than 5 years
 ■ 5 to less than 10 years
 ■ 10 to less than 20 years
 ■ More than 20 years
 ■ Not stated

- NOTE: In the following key findings, graphs showing red, dotted circles around specific responses denotes a statistically significant variation compared with the average and / or compared with other sub-groups.
- Variations which have not been circled in the graph means there is no statistically significant difference, even if the proportions appear very different.

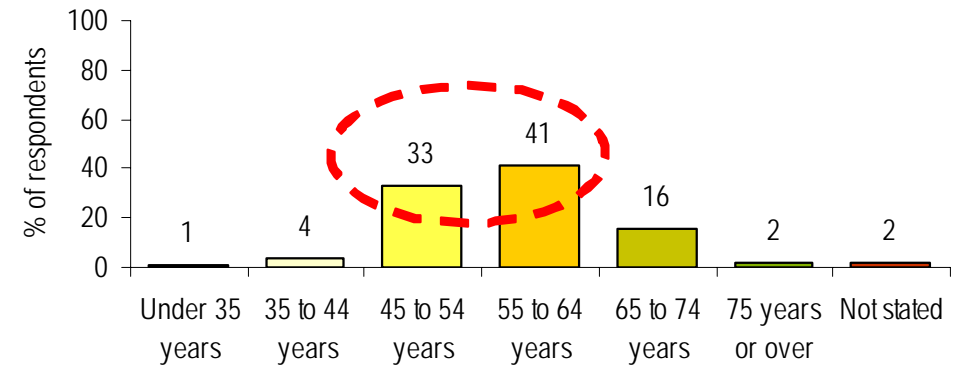
Profile of EPG & Board-appointed Guardians

- The most common age cohort, for 3 in every 4 respondents, was 45 to 64 years.
- This is logical as the sample incorporates those who are guardians for now adult children as well as those who are guardians for elderly parents.
- Household types represented in the total sample reflect the age profile:
 - ~ nearly a third (31%) of households are older couples, no children at home
 - ~ 18% were in lone person households
 - ~ 18% were couple/single parent with mainly adult children at home
 - ~ 12% were living in a group household (may or may not be related), and
 - ~ 9% were couple/single parent with mainly teenagers at home
- Two in every three guardians surveyed were employed, either full-time (47%) or part-time (19%).
- About one in six (17%) were retired / aged pensioners.
- This finding suggests that guardians tend not to be full-time carers for the protected person for whom they have guardianship, a factor supported by the finding that 13% are primary carers as well as Guardians and 10% share the carer role. The remaining three quarters are not carers for the protected person.

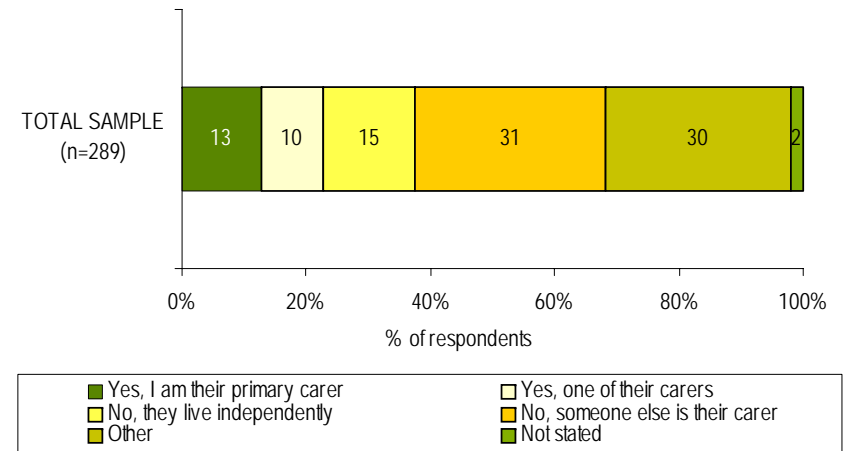
Q29 EMPLOYMENT STATUS OF GUARDIANS (BASE: n=289)



Q27 AGE OF GUARDIANS (BASE: n=289)



CARER AS WELL AS GUARDIAN





KEY FINDINGS: Background to Becoming Guardian

Title “Protected Person”

- Three in every four (75%) guardians (both Board appointed and EPG's) thought the title 'protected person' was an appropriate description.
- Among current Board appointed Guardians, the proportion favouring the title 'protected person' was significantly higher (86%). Conversely, EPG's were less inclined to perceive the title as appropriate, particularly former EPG's (55% said it was an adequate description, while a significant 25% indicated another title would be better).
- However, just over one in ten (12%) put forward another suggestion. Having said this, there was no single and clear title dominating the suggestions. Some of their comments regarding the title include the following quotes, which are typical of the feedback they provided.

“The description Protected Person implies that the person is already protected or that guardianship is assumed to be successful.

‘Person in Need’ would possibly suffice for me.”

“Person who needs assistance. Protected person sounds like a thing to be ordered about.”

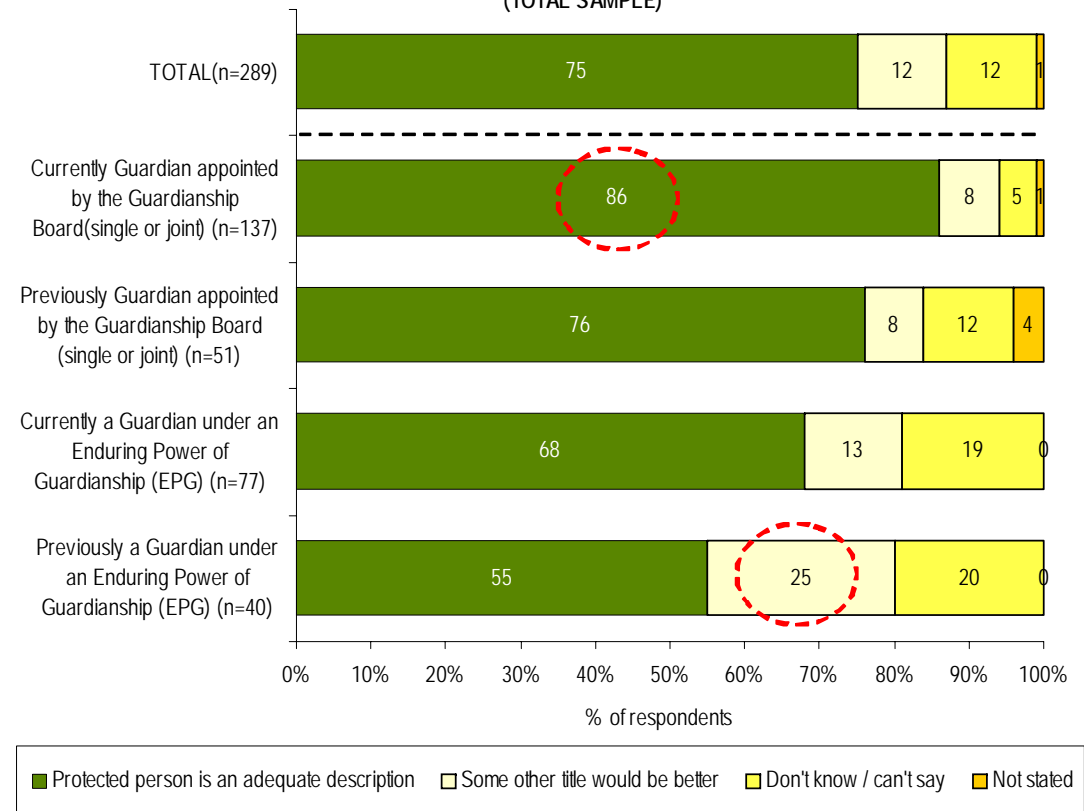
“Protected Person is an adequate description but it may not suit all guardianship situations ie: where a person has no need to be protected.”

“The term ‘protected’ implies that he needs to be protected by government from people who love and care for him, as I believe we are the ones who are protecting him from harm.”

“Unfortunately I don't have an alternative. Whilst I like it in a number of ways, I feel it may also remove some dignity from the person as well. So I guess I see it as adequate unless a better title could be used.”

“Cared for person.”

APPROPRIATENESS OF DESCRIPTION 'PROTECTED PERSON'
(TOTAL SAMPLE)



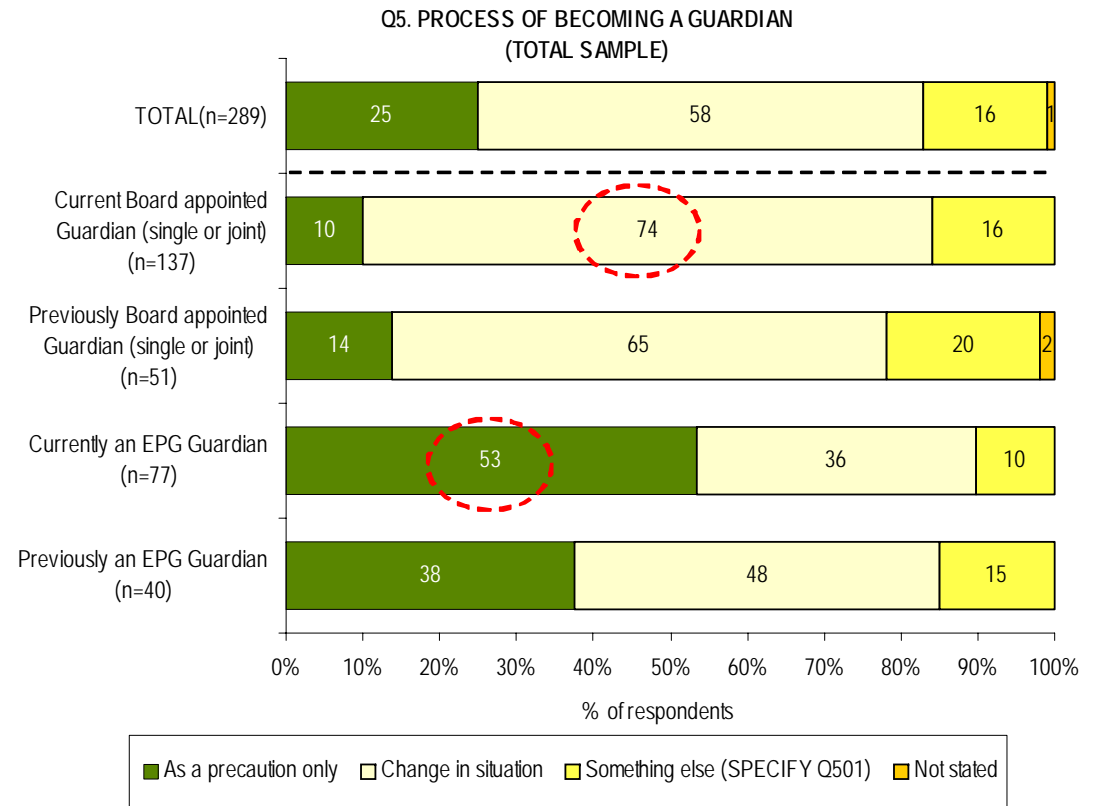
Precautionary or Need

- When asked if the decision to become a Guardian was as a precaution only or if it was a result of a change in situation (or something else), one in four (25%) indicated they took the step as a precaution only.
- The majority (58%) of these Guardians said a change in situation prompted them to apply for guardianship or for the Guardianship Board to become involved and appoint a Guardian.
- Not surprisingly, this was significantly higher (74%) among current Board-appointed Guardians. Conversely just over half (53%) of current EPG's said they took the step as a precaution.
- A further 16% of all Guardians surveyed indicated there was another reason for becoming a Guardian. Some of these indicated that the decision to become a Guardian was both precautionary and due to a change in situation.
- Given these findings, it can be assumed that in many cases the decision is delayed until there is little in the way of options or choices. Some of their comments to explain "something else" includes the following quotes, some of which seem to support this theory whilst other comments clearly indicate that the official action was taken to avoid conflict and provide protection for making decisions and for the care of the protected person.

"In hindsight there was a reluctance by her doctor, Domiciliary Care & RDNS to 'push' the situation when it was clear to all that my client was not coping and her safety was severely compromised. I think everyone hoped someone else would take the initiative."

"A nousey, overbearing social worker who did not accept my sisters unofficial instructions when she suffered a life threatening illness for which she has recovered enough to manage her life again."

"Conflict and differing opinions with another person who was also involved in the care of the person. The other person was out of touch with what everyone else thought was appropriate. Two people trying to make differing decisions just didn't work.."



"The fact that my son would not seek medical help, I sought a medical guardianship order where the PAO would be his guardian for a period of 6 months and after the 6 months I become his guardian."

"I am guardian of my 43 yr old son and have looked after him all his life. I have arranged for my daughter, his sister, to take over."

"My son was and continues to be a danger to himself."

"As a precaution only and change in situation. Young person had been under Guardianship of Minister as he was vulnerable. When he attained 18 years of age he was no longer under GOM."

Alternatives to Guardianship

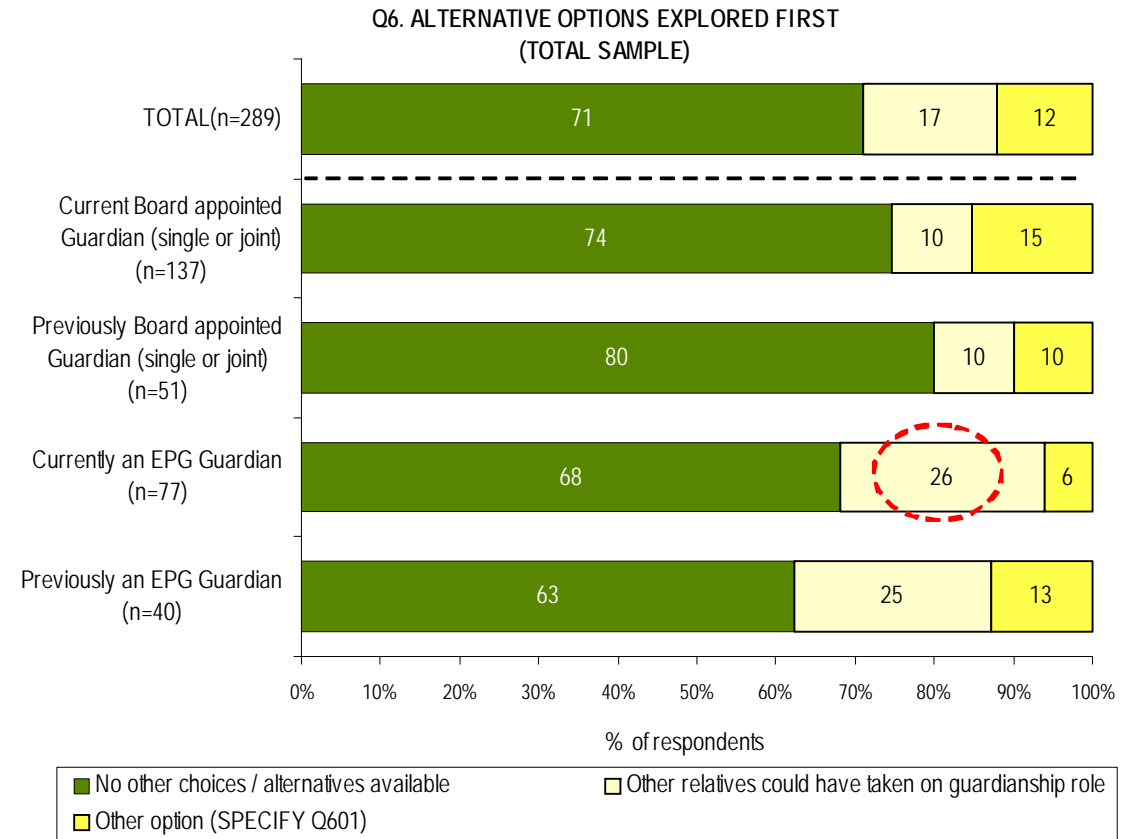
- Guardians were asked if there were alternatives to them becoming a private guardian for the protected person and, if so, what other options were explored first.
- The majority (71%) of all Guardians surveyed indicated there were no other choices or alternatives available.
- Around one in six (17%) Guardians indicated that other relatives could have taken on the guardianship role. The proportion of current EPG's indicating that others could have taken on the role was significantly higher (26%).
- Just over one in ten (12%) provided an other response. Whilst the comments varied slightly, the most common themes were:
 - ~ that the Public Advocate could have been appointed in their place or
 - ~ that the protected person made their own choice as to who they trusted to be guardian.

"The guardianship board could have taken total care, or I could have accepted joint care with the guardianship board, but I chose to become sole private guardian."

"Could have continued the informal arrangements but it was done to give the nursing home some security, I think."

"Other relatives could have but were not considered acceptable by the 'protected person'. It was a matter of choice and who the person trusted best."

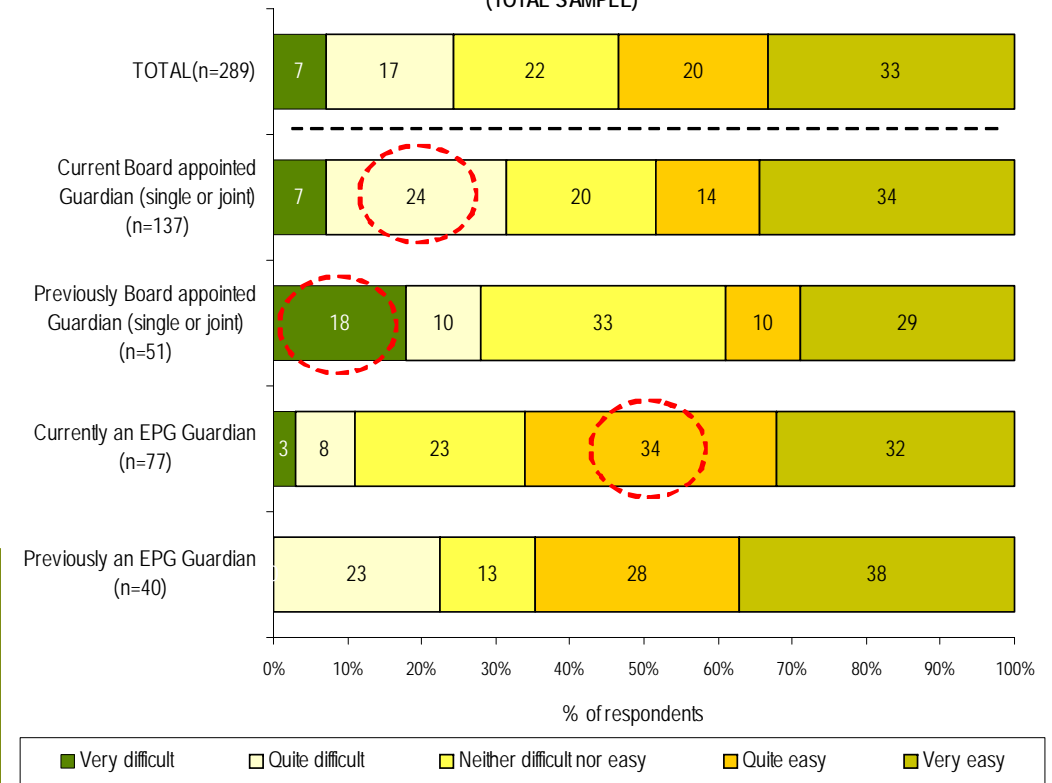
"There may have been one or two alternatives, but they were not considered by her and I believe not deemed suitable by others. It is likely that one at least would not have wanted the responsibility. At the time this happened, I was helping the protected person to sort out some major issues which had arisen. I am her goddaughter and was the person spending most time with her and doing numerous things for her, it seemed the obvious choice to her and to others, including the Public Trustee and the manager of the RACF. "



Difficulty of Decision to Become Private Guardian

- Respondents were asked to indicate the degree of difficulty they experienced in making the decision to become a private guardian. A 1 to 5 scale was used, with 1 representing very difficult and 5 representing very easy.
 - At the total sample level, just over half (53%) of respondents indicated that the decision was easy (33% of whom said very easy). This increased to two in every three (66%) current EPG's stating the decision was easy.
 - At the other end of the scale, almost one in four (24%) said the decision was difficult. Of note was the finding that Board-appointed Guardians, whether current or former, showed a higher incidence of stating the decision was difficult (24% of current said quite difficult and 18% of former said very difficult). This finding may suggest that the decision making process may be perceived as somewhat easier over time.
-
- When asked why it was difficult or easy to make the decision, the comments were very varied (as different as every family), but one theme came through strongly. The decision is a highly emotional one for most Guardians, either in a positive sense (as in, they wanted to become a Guardian as an act of love or a gift) or in a negative sense (such as, with situations where the protected person does not know what is happening to them but feels the Guardian is somehow at fault for creating the situation).
 - In some instances there was no choice and / or no other options available, so the decision was neither difficult nor easy but inevitable. Some 'protected persons' were able to make the decision in advance, which greatly assisted their Guardians in understanding the role, their needs and wishes and how to make decisions which were in the best interests of the 'protected person'.
 - Over the next few pages, the quotes provide some insights into this theme of doing what is required rather than making an active choice based on the availability of various options. Not all Guardians' experiences have been positive, however, as the quotes demonstrate.

Q7 DEGREE OF DIFFICULTY TO DECIDE BECOMING A PRIVATE GUARDIAN
(TOTAL SAMPLE)



- When asked, if faced with a similar situation in future, whether they would still take on the role of Guardian, almost nine out of ten (88%) said they would make the same decision.
- This is despite some of them expressing reservations and / or difficulties they associated with becoming a Guardian (as noted in the quotes over the next two pages).
- There were no statistically significant differences between EPG's and Board-appointed Guardians in terms of whether they would make the same decision.

Difficulty of Decision to Become Private Guardian

"Due to a change in my sisters situation there seemed no other alternative. There were no other family members available and to have her affairs cared for by an organization (all be it a well meaning one) didn't seem right." Board-appointed Guardian

"It was a normal bureaucratic process of form filling. A meeting was held to ensure we were aware of our obligations, it was a little daunting as we felt quite powerless. It was worrying that our love for our daughter may not have really counted for much." EPG Guardian

"In my circumstance it was taking away an independent right of my mother which I struggled with for years. It was an emotional journey." EPG Guardian

"My siblings and I were appointed joint guardians late 2011 for both our parents - mum because she became incapacitated and requested it and our father because he suddenly went from forgetful to having Alzheimer's. We had no choice and didn't want outsiders or a government agency being responsible for them." Board-appointed Guardian

"Brother has an intellectual disability. He would have been vulnerable to unscrupulous people, in regard to decision making. We currently work through options with him when issues arise, and try to assist him to make appropriate choices that will best suit him and his needs." EPG Guardian

"A few years before my father was diagnosed with dementia he ensured he had an updated Will, an appropriate guardian appointed, and a trusted person allocated to make medical decisions on his behalf. As his oldest daughter I was more than happy to take on this responsibility if that was what he wished at the time. I am relieved all these decisions were made prior to dad becoming ill." EPG Guardian

"I was conscious of the responsibility, but this was mitigated by the long term, ongoing decision-making partnership between us - the 2 Guardians and the protected person." Board-appointed Guardian

"I realised the importance of the role and the trust that my neighbours' had in my ability to protect them when they need assistance, also the honour being chosen over relatives or other friends. I took the role knowing what was required and I have faith in my ability to work on their behalf as they would wish to be treated. I have discussed with my neighbours their wishes and enjoy the role I have taken on." EPG Guardian

"It was my mother and between my husband and myself we were honoured to care for her including the role of guardian. It had its very stressful times but also very warm and wonderful memories." EPG Guardian

"The protected person was a parent and the responsibility was daunting and emotional but the decision inevitable." Board-appointed Guardian

"The situation arose with my mother in an aged care facility where a conflict of interest with a health care manager put her life at risk. Being naive, I trusted that these people would act in her best interests. This was not so, and there was no question about my becoming her guardian." EPG Guardian

"It is time consuming in going to a lawyer to get papers done and also needed to include Power of Attorney. Then there is the issue if something changes in the law and the current two documents are no longer adequate, so who and how are we told this?" EPG Guardian

"Requires commitment and ability to keep fighting other family members who have wrong intentions and don't have full understanding of requirements." Board-appointed Guardian

"Because it involves significant responsibility and quite a bit of preparation to appear before the Guardianship Board." Board-appointed Guardian

"It was difficult accepting that a guardian for my father was truly necessary. I felt that my opinions were not really listened to or respected." Board-appointed Guardian

Difficulty of Decision to Become Private Guardian ...cont.

- Some Guardians suggested that the decision was not made easy for them, for various reasons, including a lack of information about the process, limited ongoing support or a lack of understanding of what being a Guardian really means.

"We found out about hearing less than a week prior (by chance), nil communication from Modbury Hospital about hearing, We were therefore faced with instant decision at the hearing, Confronted with hearing our father had 'no mental capacity' to make any decisions for himself. This made the decision difficult. If we had information presented to us prior to hearing, we could have made an informed decision, which would have been easy." Board-appointed Guardian

"I wasn't exactly sure of the extent of the role." EPG Guardian

"I found the process of obtaining Guardianship over my aged mother somewhat bureaucratic and untrusting. I was my mother's only child, she had no surviving spouse or other relatives, and I had full Power of Attorney over her finances but I still had to jump through hoops." Board-appointed Guardian

"It was easier for me to be his guardian because I normally do every thing for him with regards to medical assistance. Not easy because I thought I would get much more assistance to help manage his medical situations. I received NO SUPPORT from the PAO. Actually the PAO was a hindrance to me." Board-appointed Guardian

"I was very happy to become a guardian for my grandmother. It was not a difficult decision to make. Caring for a family member comes first. What was difficult was the treatment of the Board. The bullying behaviour used by the panel was appalling." Board-appointed Guardian

"My husband was in hospital with an infection and very ill, he wanted me to take on this role just in case and it was not an issue for me, being the guardian actually makes things easier for me to manage. The issues I have are with government organisations eg Telstra, Medicare, Centrelink etc always having to produce the original documents. This is difficult when you live in the country and they are only in the capital cities and they are not helpful. Also having to pay stamp duty for documents that I sign as Power of Attorney e.g. sale of a home, I had to register the Power of Attorney document with another government organisation at a substantial cost. This makes it difficult. Also each time one contacts a government organisation you get a different story, there is no consistency and little understanding." EPG Guardian

"It was neither easy or difficult because it was hard to understand what it meant to be a guardian. The information available didn't provide any real sense of the long term implications of taking on the role, both for the 'protected person' and for myself as private guardian? This can be particularly difficult where guardianship involves a palliative care situation." EPG Guardian

"The responsibility attached to this position is burdensome, emotionally and physically." EPG Guardian

"From memory the application process was time consuming and it involved some decision-making such as who needed to be informed or would like to be informed even if they did not have a strong view on the outcome. One difficulty for me was that one of my brothers was mentally unstable at the time of the application and in that state he was a bit unpredictable. I doubt that the members at the hearing would have picked that up as he presented okay on the day even though both my other brother and I were aware that some of the information he presented was not accurate." Board-appointed Guardian

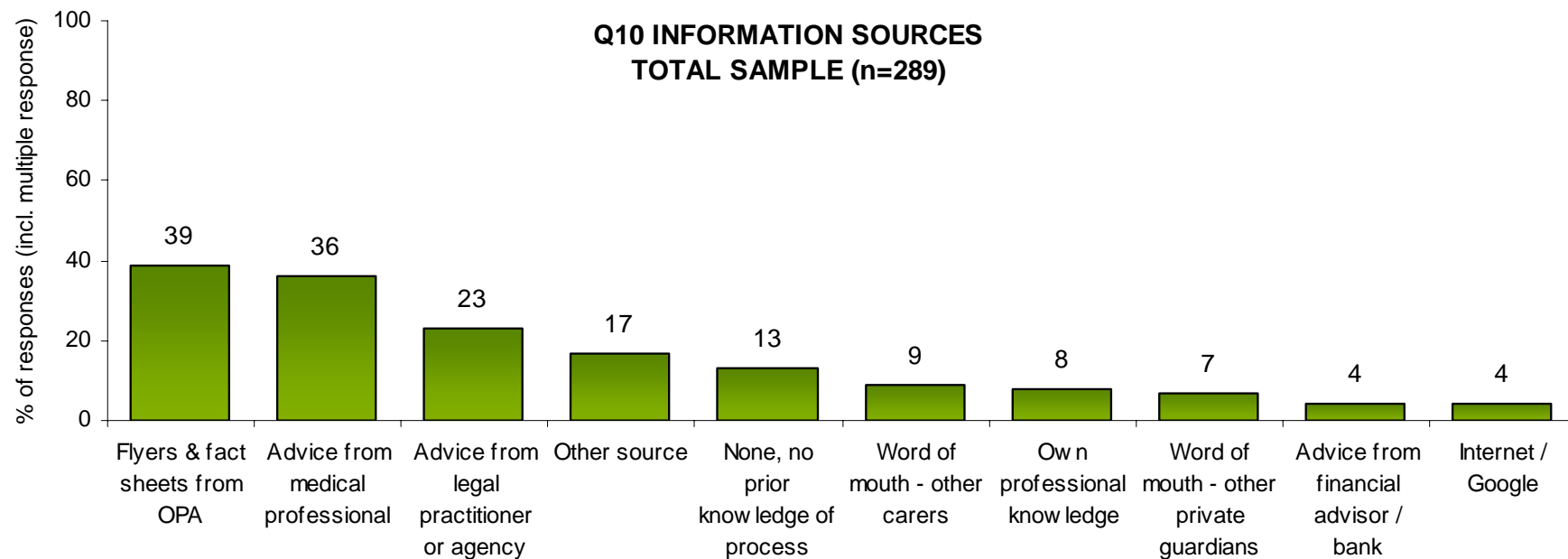
"Easy (in retrospect) that you do not know the implications of being a guardian when you take on that role, until you are doing it. And difficult because of how demanding it is and what it entails being administrator. As well as dealing with bureaucrats, solving problems that come up, plus very little help or support to assist you when needed." Board-appointed Guardian



KEY FINDINGS: Sources of Information about Guardianship

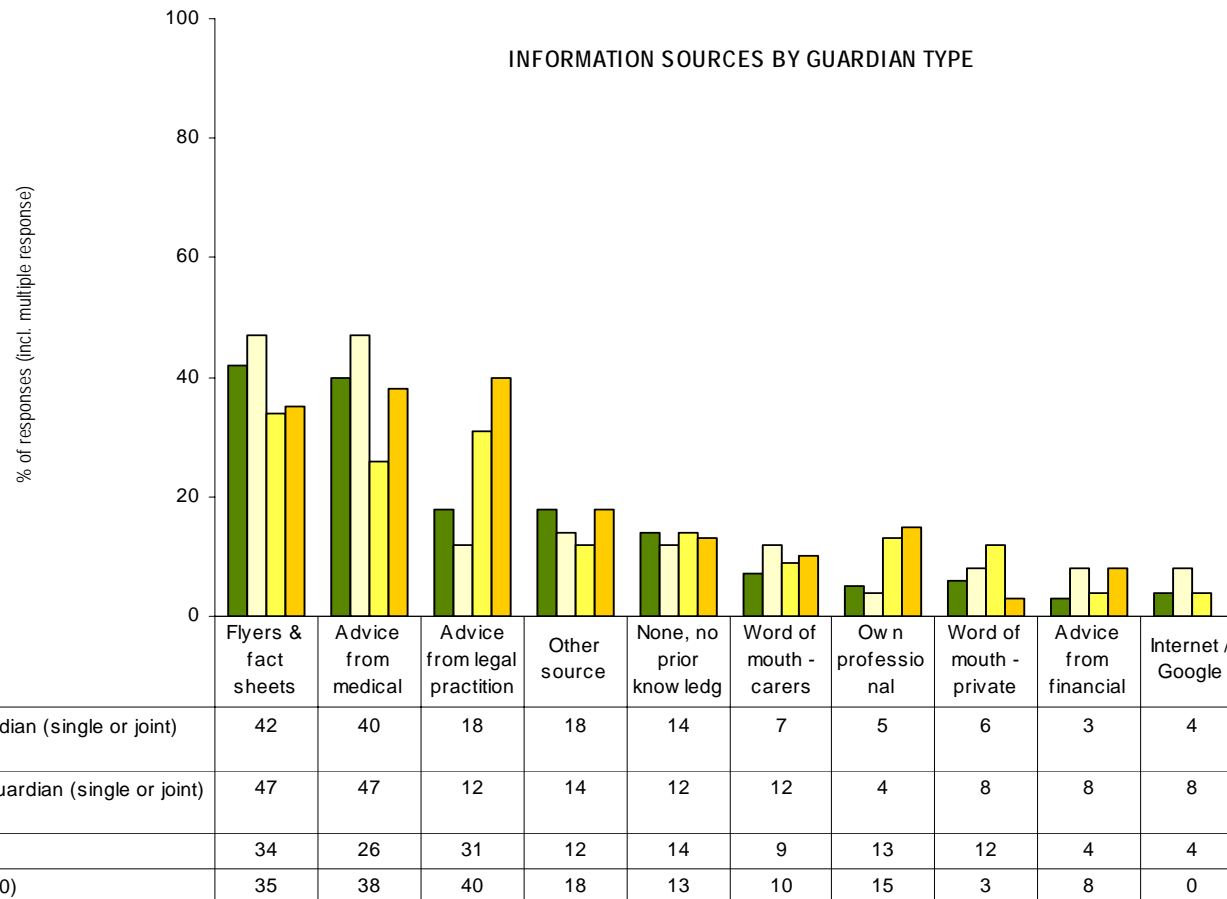
Information sources

- The most prominent sources of information about becoming and being a private guardian were from a flyer and/or fact sheet from OPA (39% of private guardians) and advice from a medical professional (36%). Legal practitioner / agency was the next most common (23%).
- More than one in ten (13%), however, said they had no information and no knowledge of the process of becoming a private guardian. This is in line with some of the verbatim comments made about the difficulty of making the decision to become a guardian (as raised in the previous section).



Information sources

- When the sources of information was analysed by the type of guardian, the results did not demonstrate any unusual patterns.
- As might be expected, Board appointed Guardians were more likely to have sourced information from medical professionals and the OPA, whereas EPG's were more likely to have been informed about the process through a legal practitioner.
- Of interest was the finding that there were no significant variations between the guardian types when it came to having no knowledge of the process of becoming a private guardian.



Value of Information

- Almost 6 out of 10 private guardians (58%) said the information was helpful. Having said this, nearly one in five (19%) said the information was helpful but they needed more.
- Whilst just 2% said the information was not helpful, a further 15% said they did not have any information prior to making the decision to become a private guardian.
- These findings provide a clear indication that access to sufficient information to make an informed decision is somewhat problematic for one in three private guardians.

- When asked to explain why the information was or was not helpful, most private guardians had something to say with regard to having sufficient information to make informed decisions. Their comments have been analysed by the type of Guardian.

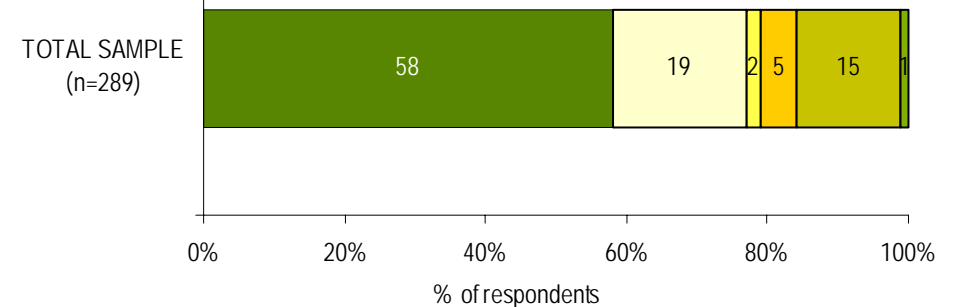
Board-appointed guardians:

- Among current Board-appointed guardians, a number of issues were raised regarding aspects such as:
 - ~ the amount of information and prior knowledge available / provided,
 - ~ the lack of one on one advice and support,
 - ~ more information about the degree of responsibility the guardian is taking on before they agree,
 - ~ when the decision is made due to a critical event, there is little time to deal with the complexity of the issues in a rational and thoughtful way, and
 - ~ some sources of information, such as hospital social workers, are not helpful or supportive.
- The following quotes, from Board-appointed guardians, are typical of the issues raised.

"ALL OF IT. There should be one single agency/ person who sits down with the family and goes through ALL options. Something like a Ward Clerk who has knowledge of what is out there and can help you gain access to the Departments you need."

"All the steps along the way, what would be involved, more help with financial statements, more explanation of exactly which areas I would be making decisions for him, and where he could still do it himself."

WAS INFO HELPFUL IN MAKING INFORMED DECISION
(TOTAL SAMPLE)



■ Yes, the information was helpful
 ■ Yes, but needed more information
 ■ No, it was not helpful
 ■ Can't recall / don't know
 ■ No, had no prior knowledge
 ■ Not stated

"Because I was requested to take over from another relative, I had no knowledge of the financial reporting method. I had enough info on responsibilities, which was good, but not enough guidance on the practical aspect of carrying out those obligations."

"Contact details of someone to talk to at the Office of the Public Advocate."

"Disability SA could have been more helpful. Staff were very negative and unsupportive to my decision and gave me no information that would assist me. Paperwork for application was not clear, for a lay person, on specific information required. Later accounting would have been easier if this was clear and some assistance in using the forms for accounting would have been helpful."

"Whilst written information is good, would have appreciated talking to someone in person."

"Simplification of process, too much information – confusing".

Value of Information

"Flyers / fact sheets needed. We were not prepared at all. We didn't know it was an option from interstate and none of protected person's carers (DOM Care, RMH social worker) discussed how it could work."

"For people with no experience it needs to be carefully laid out. I find the booklet from the public trustee helpful in looking at issues. My fellow guardian (her sister), when asked to do the financial statements she said she posted it back saying 'how was I supposed to know?'"

"Hospital social worker was against me doing what I did and I had to seek legal advice."

"I really didn't understand the process, and what it meant, it wasn't clearly explained to me exactly what my role would be. As I have never been in such a situation, I really didn't know what I didn't know, what to ask etc."

"The process of review every few years is stressful. It is as if they expect dementia to get better with time rather than the sad reality that it is stealing my father a bit at a time."

"More info from Guardianship Board / public trustee given before decision, not after."

"No information was provided about the process before it took place. I should have been informed as to exactly what would occur during the board hearing and as to what my responsibilities would be should I take on the role of guardian."

"We were bombarded with too much information from several agencies. It has been overwhelming and those agencies with the exception of the actual Guardianship Board and staff, just treat us like numbers. All documentation sent out is impersonal and general templates which don't take into account the specific issues of the individual. All we needed was someone to sit down and explain it in simple terms."

"The lawyer who helped us with the Enduring Power of Attorney should have at that time advised us of guardianship or Medical Attorney."

"Simplification of process, too much information was confusing."

"The main issues are trying to work with government agencies post-appointment and their lack of flexibility".

"More detail of what legislation requires and what is possible to get Offices' themselves to enforce SA legislation fully. Should not be the Guardians or 'Protected' Person's responsibility/cost/stress to ensure SA Offices' enforce their own legislation: even when breached by Offices under the Attorney-General Department. Shame on those in position that can help but look away."

"It is important to spell out any legal implications to an individual as a result of becoming a guardian. Also, provision of a hotline number to speak one on one with an informed person who can outline the role, including provision to ask questions for clarification."

"Would have liked something like a general information overview and opportunity to ask specific questions related to my situation. Even now I'm having difficulty getting my mother to understand and nominate someone for her own wellbeing. So maybe a 'face to face' forum when people get to a particular age to debunk some of the myths and enable people to understand the benefits but also the real things to be careful of rather than those very negative issues that are promoted through the media."

"The first application came as a great surprise and I felt I was under scrutiny and judged. I was very afraid and concerned."

- Not all Board appointed guardians perceived that the information was not sufficient to properly prepare them for the role they were taking on. Whilst these comments were in the minority, it should be borne in mind that 27% of all respondents said no further information was required (increasing to 43% of Board-appointed Guardians).

"Nothing else, we were overloaded with trauma and could not deal with anything else."

"None, we were well informed."

"The information provided to me at the time was adequate."

"The literature I received outlined my responsibilities quite clearly."

Value of Information

EPG guardians:

- Among current EPG guardians, whilst a number of issues were raised regarding aspects around becoming a guardian, there tended to be a softening to some extent of their perceptions of the situation.
- As many took out an EPG as a preventative measure, it seems that (at this point, at least) they were less likely to require additional information and tended to report that they found the early information relatively useful to their situation.
- Having said this, a few issues were raised about the following aspects:
 - ~ They would like to be able to share information, advice and anecdotes with other guardians as a way of becoming familiar with other situations and what can occur in the future.
 - ~ More information was needed about the legal implications of the EPG's role and decisions. Some were unsure of the extent of the role they were taking on, the level of responsibility and what this actually entailed.
- The following quotes, from EPG guardians, are typical of the issues raised by this guardian type.

"I simply signed a form which was duly witnessed. I did not understand the guardian's role or its limitations until I became involved in a dreadful Guardianship Board brawl with my sister and mother. By then I had familiarised myself with the documentation available on the G. Board's website. Potential guardians should be provided with documentation detailing their responsibilities, when guardianship comes into play, medical power of attorney, non-resuscitation orders. Similarly, Powers of Attorney should be made aware of their legal duties."

"Information as to exactly when to make decisions. Mum has dementia and it has been gradual, so taking responsibility for her has been a gradual process, especially when she lived independently. The hardest decision was to place her in residential care when I knew that she would not want this decision to be made."

"Probably just an information sheet explaining when it might be needed and steps to take if it is needed."

"Information about what help there is available once you've taken on the job, for the protected person and for the guardian."

"I am still rather vague about legal implications for me."

"Any information would've been helpful. However, understanding the impact to family, personal lifestyle and perhaps suggestion of support services would have been helpful both to me as the guardian and for my father who was going through huge life changes."

"More on the challenges a guardian will face with other non guardians, and the difficulty of assisting with choices such as medical directives."

"How to activate powers once a mental condition declines and where do I stand legally when protected person will not cooperate."

"I was satisfied with the information I had collected from various bodies to equip me with making the decision to take on the role. As a parent I believe taking on this role should be discussed with your family as there is a commitment required when things get busy with your guardian i.e. hospital stays, agency carers, RDNS etc."

"It is useful to be taken through various potential scenarios."

"Information about the process, responsibilities, capabilities or powers made available."

"Lack of anecdotal material."

"The possible difficulties which could have occurred since the documents have been activated. Such as medical confidence, dealing with Centrelink."

"Support and counselling processing information and possible implications. I now feel all is up to me and I want out! But I don't want the guilt that goes with it."

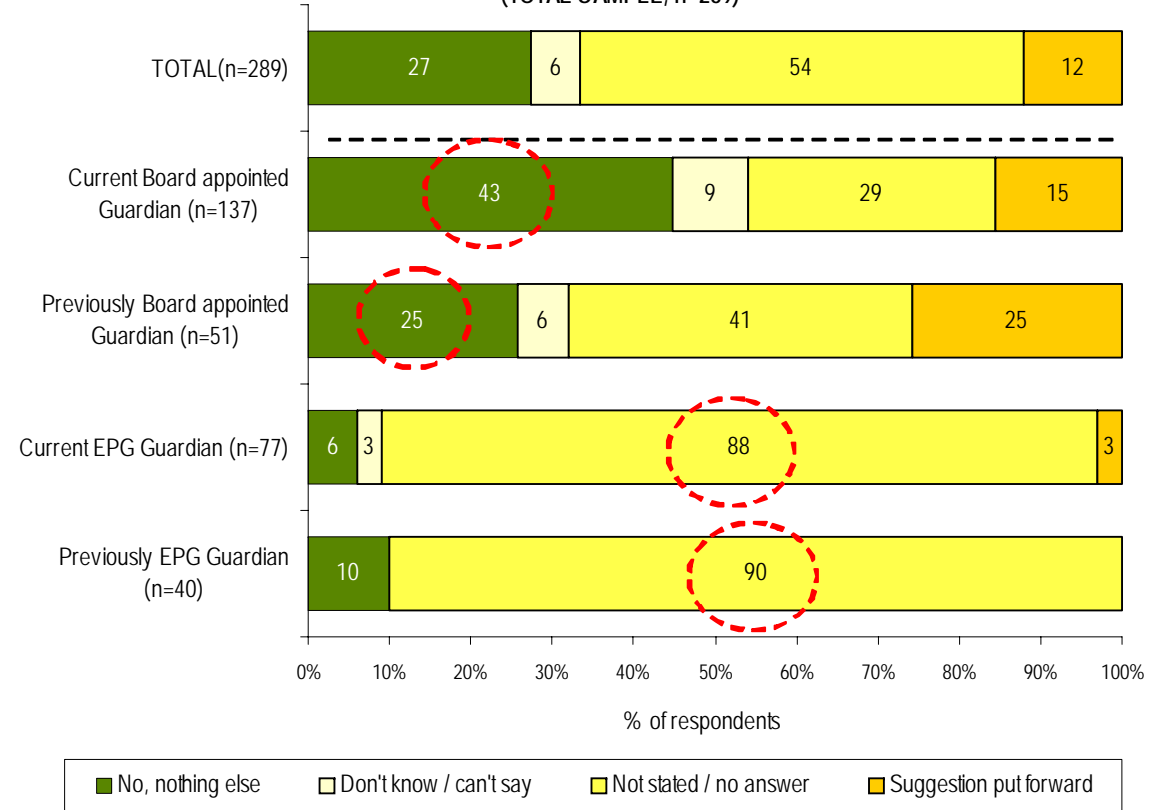
"It is time consuming in going to a lawyer to get papers done and also needed to include Power of Attorney. Then there is the issue if something changes in the law and the current two documents are no longer adequate, so who and how are we told this?"

"Until I actually had to put the guardianship into practice I did not have a full understanding of what it all meant."

Other Advice and Support

- When asked if they had any suggestion for other advice and support which would have assisted them in the process of applying for Guardianship, more than half (54%) did not respond to the question. As a self-completion survey, this does happen when respondents think that a question does not apply to them or that they have already responded (also, refer to verbatim quotes on the previous pages).
- Among current Board-appointed Guardians, a significantly high proportion (43%) indicated there was nothing else they needed by way of advice and support (versus just 6% of current EPG's). About one in seven (15%) of these guardians put forward a suggestion for advice and support which would have assisted them.
- Among EPG guardians, whether former or current, 9 out of 10 did not complete this question. Whilst there is no definitive evidence, this finding may suggest that they do not perceive themselves as part of the same process as Board appointed guardians and therefore the question did not apply to them.
- There were some significant suggestions put forward among the 12% of respondents who indicated other sources of advice and support to assist them. The following quotes attempt to do justice to the range and type of comments raised (continued on following page).

Q13 WHAT OTHER ADVICE AND SUPPORT WOULD HAVE ASSISTED THEM
(TOTAL SAMPLE, n=289)



"The thing that would assist is for services and government departments to listen to the families concerns and have a reporting line for elder abuse similar to child abuse report line. We found it exhausting running around trying to find the right service that could help. We were sent in quite a few directions by services. There is no straightforward information provided to us. We had no support during the process. And once an application to the Guardianship Board has been submitted, all funds for the person in the application should be frozen. My mother's second husband hired a lawyer to assist him and this was paid for from my mother's superannuation funds." Board-appointed Guardian

"A contact person that could give information and directions with any issues that arise or to explain process and accounting in more detail and explain the responsibilities of a guardian in relation to personal living etc. Where different services are able to help, what say / responsibilities they have in relation to a protected person and required communication with the guardian." Board-appointed Guardian

Other Advice and Support

"Briefing sessions on requirements, procedures, expectations etc. Perhaps in the format that WEA usually run would be good to attend." EPG Guardian

"Administration of finance is correct, if there is doubt on the carer, but it is also a hindrance / unnecessary inconvenience from a cultural point of view." EPG Guardian

"The hardest thing was having to attend the GB hearing with mum present. She had advanced dementia and no insight into her condition. Perhaps it could have been done with the family at the hearing and the Board speaking to 'protected person' separately." Board-appointed Guardian

"Social worker / Counsellor support when dealing with family issues." EPG Guardian

"Documentation in lay terms of what my responsibility actually is." EPG Guardian

"Flyers at the hospital and Aged Care facilities. ONE website with ALL of the information on it and links to the required agencies so we didn't have to track through a dozen different people to get it done." Board-appointed Guardian

"Some kind of service that can facilitate families, carers in supporting their request in nominating to undertake guardianship. Some people are not well enough to comprehend the benefits." EPG Guardian

"Clear information about where I could go for help - if only to discuss any problems that might be occurring." Board-appointed Guardian

"Perhaps doctors and lawyers need to introduce this and explain to families and clients the importance of discussion of these forms earlier rather than later in a persons life." EPG Guardian

"Being made aware that Guardianship existed as I thought POA gave the same rights as Guardianship. Information came at too late a stage." EPG Guardian

"We had to go looking for information, it was not easy to attain. Only when told you need this guardianship power, by looking it up on the internet, did we find out what it was about. Most people do not know that guardianship is also necessary, an Enduring Power of Attorney is not enough." Board-appointed Guardian

"Perhaps an information sheet on what to expect? what sort of decisions you could possibly be faced with making in the years to come. Also, what would happen if the appointed guardian became unable to make decisions?" EPG Guardian

"As a nurse I was presented the information in my work place. It would be good if this could be extended to all work places not just the medical arena. Too many families are left with crisis in emergency situations because they are unaware of legal issues around mental capacity. Could the OPA do in-services at workplaces whatever it may be. We are an ageing population and families need to know the legal issues around mental capacity." EPG Guardian

"Meeting with someone who knows the procedure of becoming a guardian and given material to read and consider it before undertaking being a guardian would have been much better than going in blind." Board-appointed Guardian

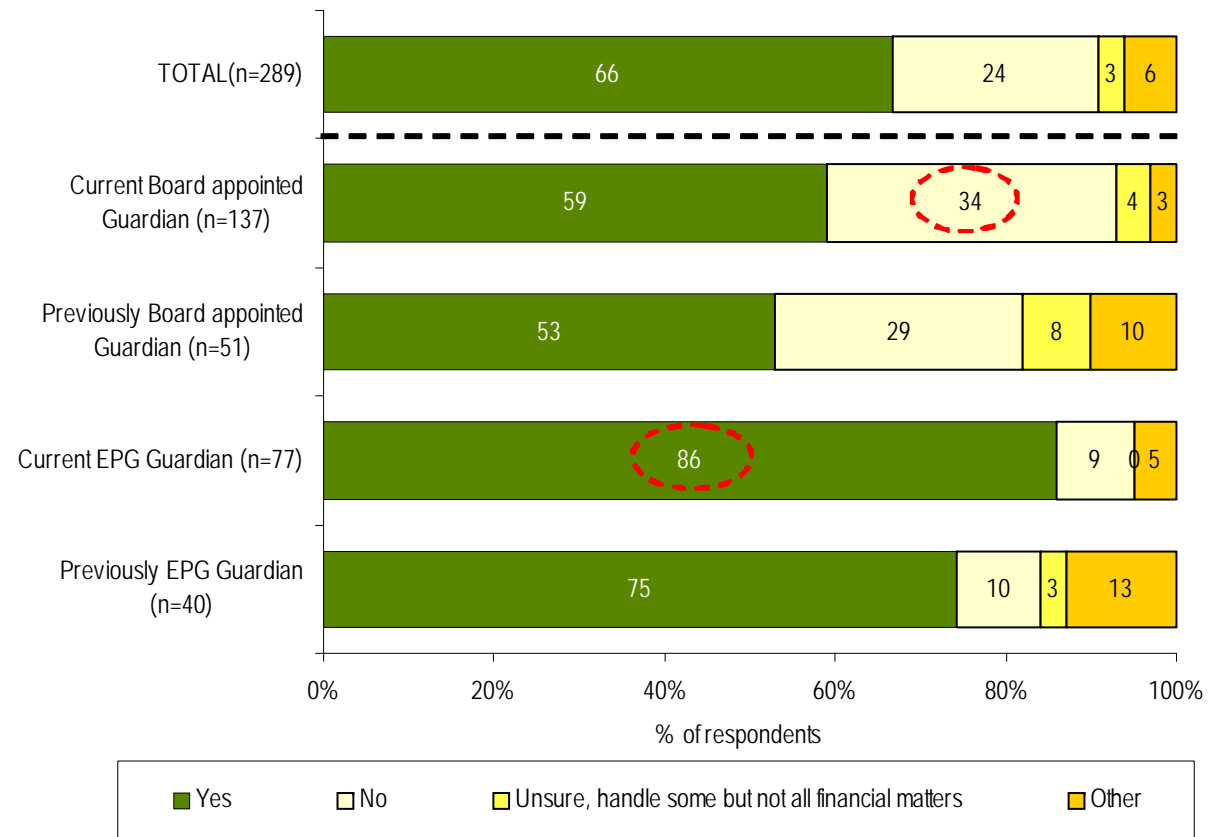
"Free or concessions on specialised legal advice regarding these matters." EPG Guardian

"More detailed information as to my rights to decision making, especially with the Public Trustees." EPG Guardian

Financial administrator / POA?

- All respondents (n=289) were asked if they were the financial administrator or Power of Attorney as well as the guardian for the 'protected person'.
- Two out of three (66%) said they take on both roles.
- There were notable differences in the incidence of being financial administrator / Power of Attorney as well as Guardian when analysed by whether the guardian was Board-appointed or an EPG.
- Among current Board-appointed Guardians, about a third (34%) said they do not take on both roles. At the other end of the scale, 9% of current EPG's stated they do not take on both roles whilst 86% said they are also the financial administrator and / or POA.
- Of note was the finding that, among guardians who are also the primary carer for the protected person, a relatively high proportion (82%) indicated they are also the Financial Administrator / POA as well as being guardian. This may reflect the lack of others available to provide at least some of these services. However, it also highlights that, for some guardians, the role is not just about making decisions but is very much focused on the day-to-day care of the protected person, as well as the ongoing Guardianship and administration of all of their affairs.

Q14 FINANCIAL ADMINISTRATOR / POWER OF ATTORNEY, AS WELL AS GUARDIAN? (TOTAL SAMPLE)

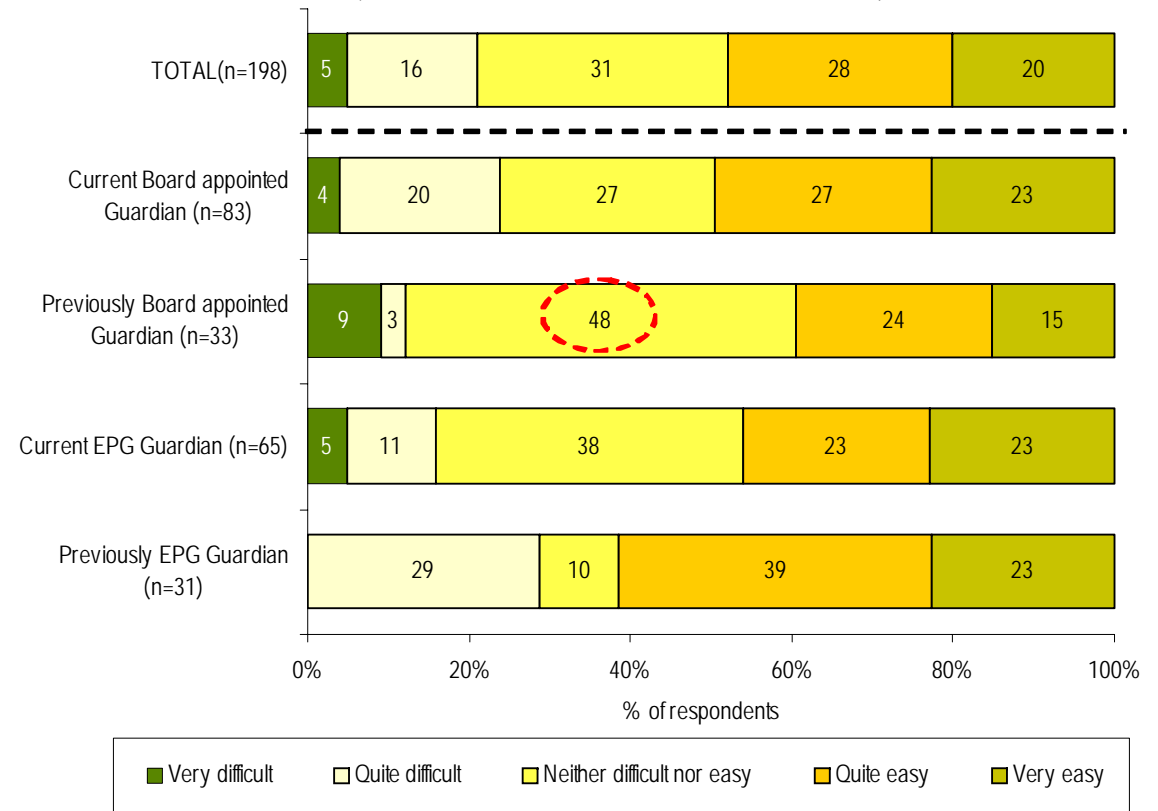


Ease of combining both roles

- Guardians who said they were the financial administrator / Power of Attorney as well as the guardian for the 'protected person' (n=219) were asked how easy or difficult it was for them to combine both roles. A 1 to 5 scale was used, where 1 is very difficult and 5 is very easy.
- A mean score of 3.4 / 5.0 was recorded, suggesting that guardians leant slightly towards easy rather than difficult but do not feel strongly in terms of the degree of ease. Proportionally, the findings were:
 - Nearly half of these guardians (48%) said the decision was easy (20% of whom said very easy)
 - Nearly a third (31%) said it was neither difficult nor easy
 - One in five (21%) said it was difficult.
- From their comments in earlier sections, this tends to suggest that the combined roles of guardian and administrator was less of a burden than combining the roles of guardian and primary carer (as noted in the quotes).
- Whilst there were some variations noted when analysed by type of Guardian, they were generally not statistically significant (exception noted by red circle) and did not provide additional insights into the knowledge gained about private guardians.
- When asked to provide further insights into why combining both the guardian and financial administrator roles was either easy or difficult, the key themes were:
 - It is easy because undertaking both roles allows control and provides the means by which guardians can effectively manage the affairs of the protected person.
 - It is difficult for some because they lack the accounting knowledge to undertake the task without it being onerous. Some perceive that the need to justify expenditure is demeaning when they are acting on behalf of a loved one.

Q15 EASE OF COMBINED ROLE OF GUARDIAN & FINANCIAL ADMINISTRATOR

(n=198, EXCLUDES DON'T KNOW & NOT ANSWERED)



- A separate attachment to this report provides all of the quotations in response to this question. The following quotes provide a taste of the type of comments which were typical of each key theme.

"It seems to me it is quite a simple process and it means that the person concerned is getting whole of life care from a person they trust and like, who has promised to care for them until death. It is non-negotiable love of a human being."

"A big responsibility for someone who has not had to handle someone else's affairs - and not a lot of information given on the financial side."

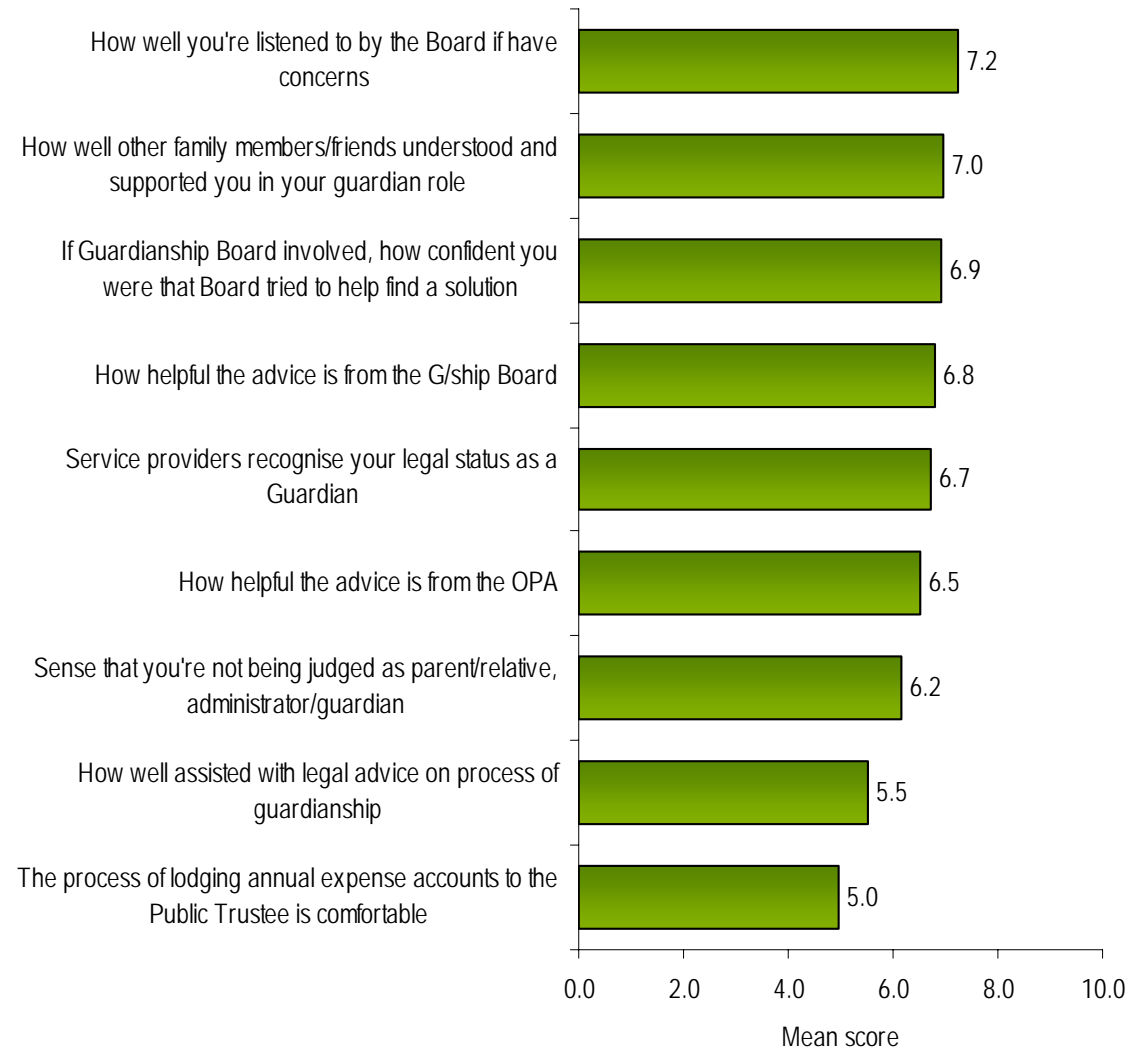


KEY FINDINGS: Satisfaction with Aspects of Support

Satisfaction scores – support and advice

- A series of statements, around aspects of support and advice, were put to respondents and they were asked to rate each statement using a 0 to 10 scale (0 = not at all satisfied, 10 = very satisfied). The questions were asked of all respondents (although, as noted previously, with self-completion there are always variations in the number of responses per statement).
- The mean scores reflect a varied customer base and experience. Further analysis by guardian type, on the following pages, provides greater insights into each of the scores and the level of satisfaction with the support mechanisms among Board-appointed versus EPG guardians.
- The top ranking aspect of support was for the statement *“How well you are / were listened to by the Guardianship Board if you have concerns”*, rating at a mean of 7.2.
- The lowest ranking aspect of support in terms of satisfaction, at a mean score of 5.0, was the statement *“The process of lodging annual expense account to the Public Trustee is / was comfortable”*. This finding ties in with one of the most often raised criticisms during the exploratory focus group, that is the sense of being overseen by the Public Trustee in terms of money spent on the protected person was not only onerous but also something that many (especially parents of an intellectually disabled child) found demeaning and an assumption of guilt.
- Another aspect which has also been raised throughout this survey is that many guardians perceive they lack the legal understanding to fully appreciate the process of guardianship and the basis on which they should make decisions. This is reflected in the relatively low score (5.5 mean) for the statement *“How well you were assisted with legal advice on the process of guardianship”*.

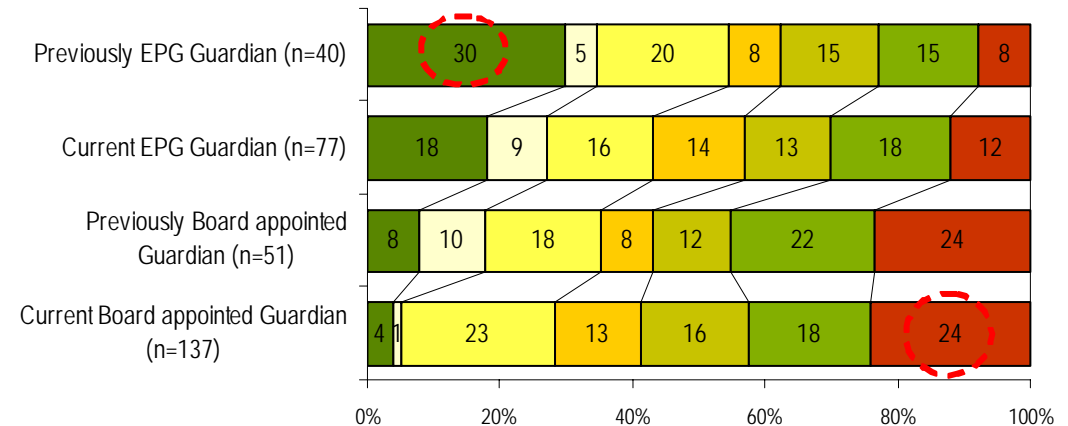
Q17 SATISFACTION WITH ASPECTS OF SUPPORT
(0-10 Scale) TOTAL SAMPLE, n=289



Satisfaction Scores by Guardian Type – Legal Advice

- When all respondents were asked *"How well you were assisted with legal advice on the process of guardianship"*, nearly one in four (24%) current Board-appointed Guardians indicated they were very satisfied (statistically significant @ 95% confidence level) and a further 18% said they were quite satisfied with this aspect. This was balanced somewhat by 36% of these respondents indicating they were not satisfied with this aspect.
- Among current EPG guardians, on the other hand, 30% were satisfied and 30% were dissatisfied with how well they were assisted with legal advice (versus 27% unable to rate and 13% neither satisfied nor dissatisfied).
- The mean scores for each were:
 - ~ Current Board-appointed Guardians – 5.6 mean
 - ~ Former Board-appointed Guardians – 6.1 mean
 - ~ Current EPG Guardians – 5.5 mean
 - ~ Former EPG Guardians – 4.7 mean

"How well you were assisted with legal advice on the process of guardianship"
(TOTAL SAMPLE, n=289)



	Current Board appointed Guardian	Previously Board appointed Guardian (n=51)	Current EPG Guardian (n=77)	Previously EPG Guardian (n=40)
Very satisfied (9-10)	24	24	12	8
Quite satisfied (7-8)	18	22	18	15
Neither satisfied nor dissatisfied (5-6)	16	12	13	15
Quite dissatisfied (3-4)	13	8	14	8
Very dissatisfied (0-2)	23	18	16	20
Not applicable	1	10	9	5
Don't know	4	8	18	30

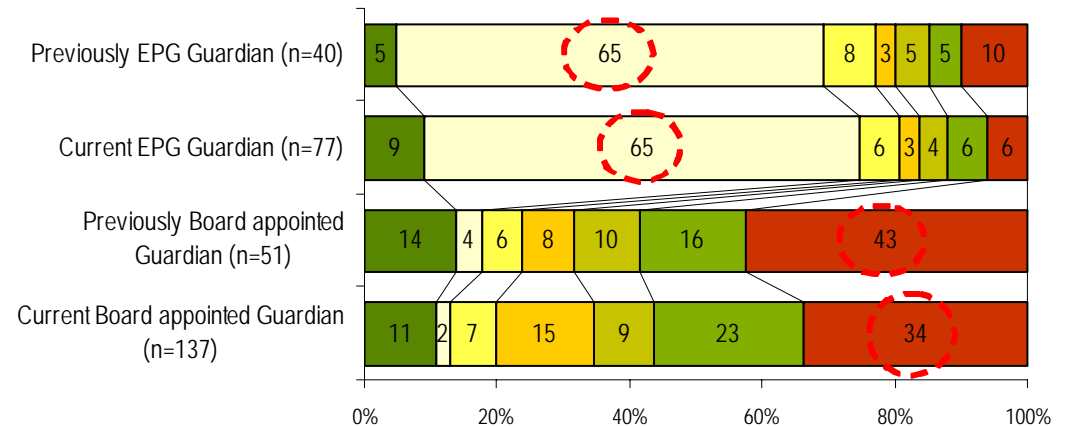
% of respondents

NOTE: Circles in red represent statistically significant differences at 95% confidence level.

Satisfaction Scores by Guardian Type – Guardianship Board Helpful

- All respondents were asked *"If the Guardianship Board was involved, how confident were you that the Guardianship Board tried to help you find a solution"*.
- One in three (34%) current Board-appointed Guardians indicated they were very satisfied (statistically significant @ 95% confidence level) and a further 23% said they were quite satisfied with this aspect (versus 22% indicating they were not satisfied that the Board tried to help find a solution). This pattern was similar among former Board-appointed Guardians (59% satisfied versus 14% dissatisfied).
- Among current EPG guardians, on the other hand, 65% indicated they had no involvement with the Board, versus 12% indicating they were satisfied with this aspect (versus 9% dissatisfied). Again, the pattern was similar among former EPG's.
- The mean scores for each were:
 - ~ Current Board-appointed Guardians – 7.0 mean
 - ~ Former Board-appointed Guardians – 7.5 mean
 - ~ Current EPG Guardians – 5.7 mean
 - ~ Former EPG Guardians – 6.1 mean

"If the Guardianship Board was involved, how confident you were that the Board tried to help find a solution." (TOTAL SAMPLE, n=289)



	Current Board appointed Guardian	Previously Board appointed Guardian (n=51)	Current EPG Guardian (n=77)	Previously EPG Guardian (n=40)
Very satisfied (9-10)	34	43	6	10
Quite satisfied (7-8)	23	16	6	5
Neither satisfied nor dissatisfied (5-6)	9	10	4	5
Quite dissatisfied (3-4)	15	8	3	3
Very dissatisfied (0-2)	7	6	6	8
Not applicable	2	4	65	65
Don't know	11	14	9	5

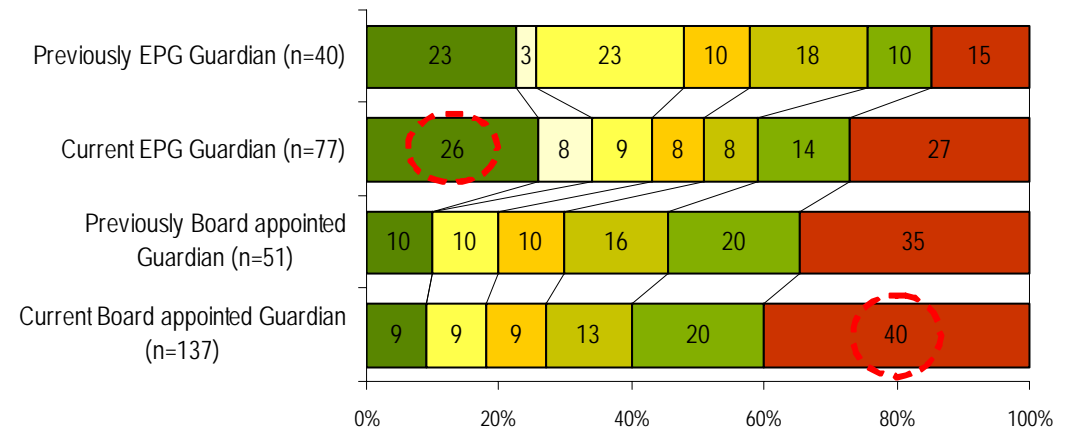
% of respondents

NOTE: Circles in red represent statistically significant differences at 95% confidence level.

Satisfaction Scores by Guardian Type – Service Providers

- Respondents were then asked to rate their satisfaction with the statement *"That service providers recognise your status as a Guardian"*.
- Two in five (40%) current Board-appointed Guardians indicated they were very satisfied (statistically significant @ 95% confidence level) and a further 20% said they were quite satisfied with this aspect. However, 18% indicated they were not satisfied that service providers recognise their status as a Guardian. Again, this pattern was similar among former Board-appointed Guardians (55% satisfied versus 20% dissatisfied).
- Among current EPG guardians the pattern was also similar, with 41% stating they were satisfied (combined very and quite satisfied) with this aspect and 17% stating they were dissatisfied. More than one in four (26%) said they did not know (perhaps indicating they had not tested this aspect among service providers).
- Showing the highest level of dissatisfaction with the recognition of the EPG's legal status were former EPG's (33% were dissatisfied versus 15% satisfied). This may indicate that improvements have occurred in recognition of legal status among service providers, although it was an aspect raised in the exploratory focus group, as well as commented upon in the responses to the survey (among EPG's in particular).
- The mean scores for each were:
 - ~ Current Board-appointed Guardians – 7.2 mean
 - ~ Former Board-appointed Guardians – 6.8 mean
 - ~ Current EPG Guardians – 6.8 mean
 - ~ Former EPG Guardians – 5.3 mean

"That service providers recognise your legal status as a Guardian"
(TOTAL SAMPLE, n=289)



	Current Board appointed Guardian	Previously Board appointed Guardian (n=51)	Current EPG Guardian (n=77)	Previously EPG Guardian (n=40)
Very satisfied (9-10)	40	35	27	15
Quite satisfied (7-8)	20	20	14	10
Neither satisfied nor dissatisfied (5-6)	13	16	8	18
Quite dissatisfied (3-4)	9	10	8	10
Very dissatisfied (0-2)	9	10	9	23
Not applicable			8	3
Don't know	9	10	26	23

% of respondents

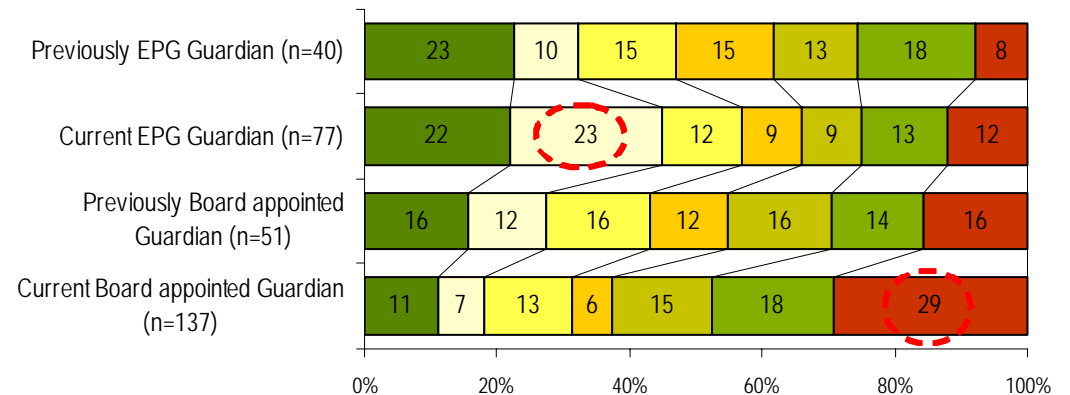
NOTE: Circles in red represent statistically significant differences at 95% confidence level.

Satisfaction Scores by Guardian Type – Not Being Judged

- Respondents were then asked to rate their satisfaction with the statement *"The sense that you are not being judged as a parent / relative, administrator or Guardian"*.
- Nearly half (47%) current Board-appointed Guardians said they were satisfied, 29% of whom said they were very satisfied (statistically significant @ 95% confidence level). On the other hand, 18% indicated they were not satisfied that they were not being judged. This pattern was less obvious among former Board-appointed Guardians (30% satisfied versus 28% dissatisfied).
- Among current EPG guardians the pattern was somewhat different, with 25% stating they were satisfied (combined very and quite satisfied) with this aspect and 21% stating they were dissatisfied. More than one in five (23%) said this aspect was not applicable to them.
- Showing the highest level of dissatisfaction with the sense of not being judged were former EPG's (30% were dissatisfied, similar to the proportion stating they were satisfied).
- The mean scores for each were:
 - ~ Current Board-appointed Guardians – 6.6 mean
 - ~ Former Board-appointed Guardians – 5.5 mean
 - ~ Current EPG Guardians – 5.8 mean
 - ~ Former EPG Guardians – 5.2 mean
- These findings seem to suggest that current Board-appointed Guardians perhaps enjoy a greater sense of confidence that they will be acknowledged in their Guardian role and not judged.

"The sense that you are not being judged as a parent/relative, administrator or guardian"

(TOTAL SAMPLE, n=289)



	Current Board appointed Guardian	Previously Board appointed Guardian (n=51)	Current EPG Guardian (n=77)	Previously EPG Guardian (n=40)
Very satisfied (9-10)	29	16	12	8
Quite satisfied (7-8)	18	14	13	18
Neither satisfied nor dissatisfied (5-6)	15	16	9	13
Quite dissatisfied (3-4)	6	12	9	15
Very dissatisfied (0-2)	13	16	12	15
Not applicable	7	12	23	10
Don't know	11	16	22	23

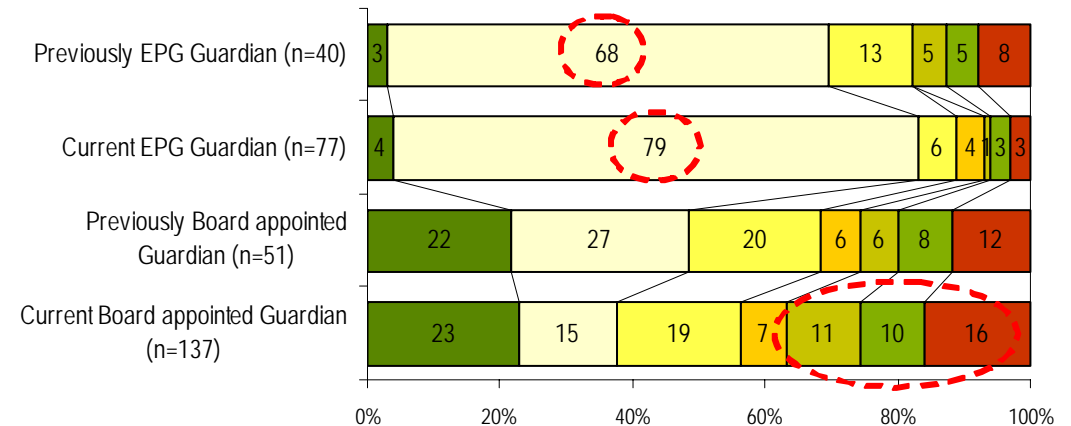
% of respondents

NOTE: Circles in red represent statistically significant differences at 95% confidence level.

Satisfaction Scores by Guardian Type – Public Trustee

- Respondents were then asked to rate their satisfaction with the statement *"The process of lodging annual accounts to the Public Trustee is comfortable"*.
- This aspect was the lowest rated for satisfaction and the graph alongside demonstrates that, higher proportions were dissatisfied with this aspect than were satisfied. This is despite the finding that high proportions of respondents could not answer or said this did not apply to them (especially among current and former EPG's).
- The proportional results and the mean scores for each were:
 - Current Board-appointed Guardians – 5.3 mean, 26% satisfied compared with 26% dissatisfied and 38% don't know or not applicable.
 - Former Board-appointed Guardians – 4.8 mean, 20% satisfied versus 26% dissatisfied and 49% don't know or not applicable.
 - Current EPG Guardians – 4.0 mean, 6% satisfied versus 10% dissatisfied and 83% don't know or not applicable.
 - Former EPG Guardians – 5.1 mean, 13% satisfied and 13% dissatisfied with the majority (71%) stating they don't know or this was not applicable to them.

"The process of lodging annual accounts to the Public Trustee is comfortable"
(TOTAL SAMPLE, n=289)



	Current Board appointed Guardian	Previously Board appointed Guardian (n=51)	Current EPG Guardian (n=77)	Previously EPG Guardian (n=40)
Very satisfied (9-10)	16	12	3	8
Quite satisfied (7-8)	10	8	3	5
Neither satisfied nor dissatisfied (5-6)	11	6	1	5
Quite dissatisfied (3-4)	7	6	4	
Very dissatisfied (0-2)	19	20	6	13
Not applicable	15	27	79	68
Don't know	23	22	4	3

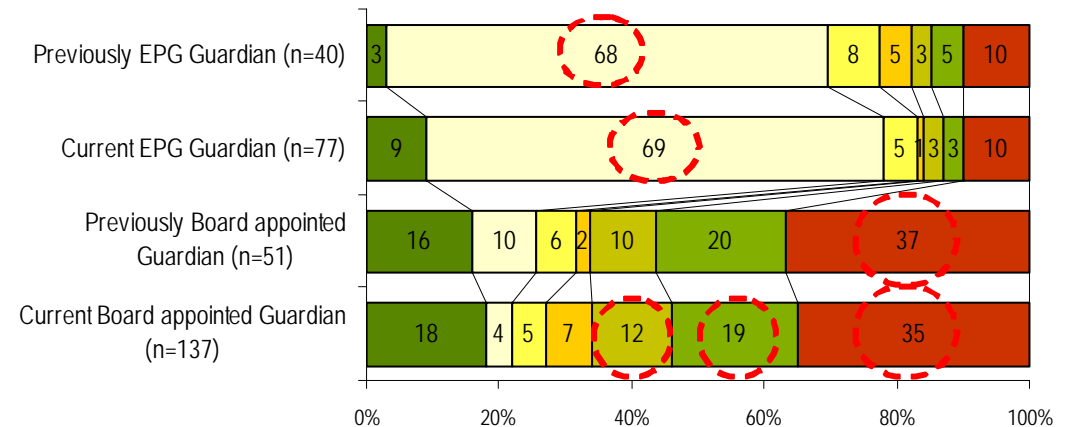
% of respondents

NOTE: Circles in red represent statistically significant differences at 95% confidence level.

Satisfaction Scores by Guardian Type – Listened to by G/ship Board

- All respondents were asked to rank the statement *"How well you are listened to by the Guardianship Board if you have concerns"*.
- Not surprisingly, Board-appointed Guardians were considerably more likely to indicate satisfaction with this aspect than EPG Guardians (two in every three of the EPG's surveyed said this was not applicable to them).
- Proportional ratings and the mean scores for each were:
 - ~ Current Board-appointed Guardians – 7.4 mean, 54% were satisfied (35% of whom were very satisfied) versus 12% dissatisfied that they were listened to by the Board.
 - ~ Former Board-appointed Guardians – 7.6 mean, 57% satisfied (37% very satisfied), versus 8% who were dissatisfied.
 - ~ Current EPG Guardians – 6.7 mean, 13% satisfied compared with 6% dissatisfied and most (78%) indicated this was not applicable to them or they did not know.
 - ~ Former EPG Guardians – 5.7 mean, with similar findings to those of current EPG's.

"How well you are listened to by the Guardianship Board if you have concerns"
(TOTAL SAMPLE, n=289)



	Current Board appointed Guardian	Previously Board appointed Guardian (n=51)	Current EPG Guardian (n=77)	Previously EPG Guardian (n=40)
Very satisfied (9-10)	35	37	10	10
Quite satisfied (7-8)	19	20	3	5
Neither satisfied nor dissatisfied (5-6)	12	10	3	3
Quite dissatisfied (3-4)	7	2	1	5
Very dissatisfied (0-2)	5	6	5	8
Not applicable	4	10	69	68
Don't know	18	16	9	3

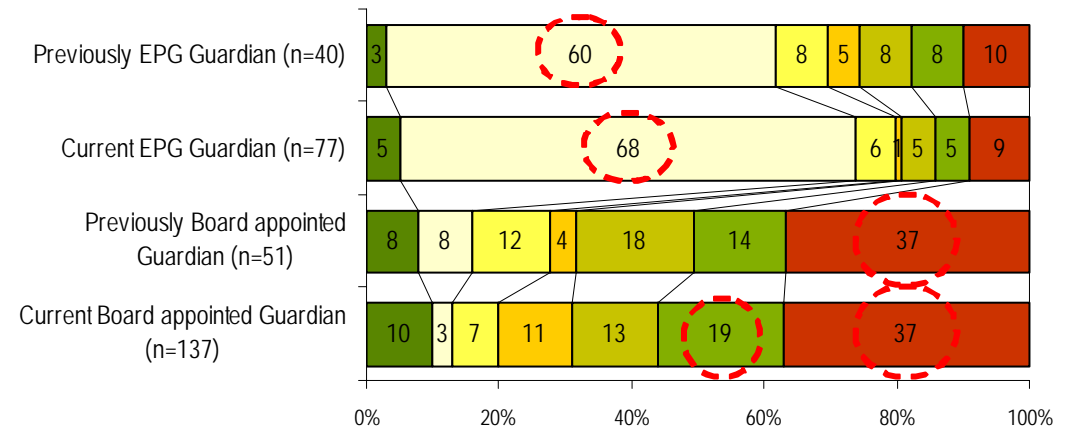
% of respondents

NOTE: Circles in red represent statistically significant differences at 95% confidence level.

Satisfaction Scores by Guardian Type – Board Advice Helpful

- All respondents were asked to rank the statement *"How helpful the advice is that you receive from the Guardianship Board"*.
- Again not unexpectedly, Board-appointed Guardians were considerably more likely to indicate satisfaction with this aspect than EPG Guardians. More than half (56%) of Board-appointed Guardians were satisfied with this aspect, whereas two in every three EPG's surveyed said this was not applicable to them.
- Having said this, nearly one in five (18%) Board-appointed Guardians were dissatisfied with this aspect. A similar pattern was noted about former Board-appointed Guardians.
- Proportional ratings and the mean scores for each were:
 - ~ Current Board-appointed Guardians – 7.1 mean, 56% were satisfied (37% of whom were very satisfied) versus 18% dissatisfied that the Board's advice was helpful.
 - ~ Former Board-appointed Guardians – 7.0 mean, 51% satisfied (37% very satisfied), versus 16% who were dissatisfied.
 - ~ Current EPG Guardians – 6.2 mean, 14% satisfied compared with 7% dissatisfied and most (73%) indicated this was not applicable to them or they did not know.
 - ~ Former EPG Guardians – 5.7 mean, with similar findings to those of current EPG's.

"How helpful the advice is from the Guardianship Board"
(TOTAL SAMPLE, n=289)



	Current Board appointed Guardian	Previously Board appointed Guardian (n=51)	Current EPG Guardian (n=77)	Previously EPG Guardian (n=40)
Very satisfied (9-10)	37	37	9	10
Quite satisfied (7-8)	19	14	5	8
Neither satisfied nor dissatisfied (5-6)	13	18	5	8
Quite dissatisfied (3-4)	11	4	1	5
Very dissatisfied (0-2)	7	12	6	8
Not applicable	3	8	68	60
Don't know	10	8	5	3

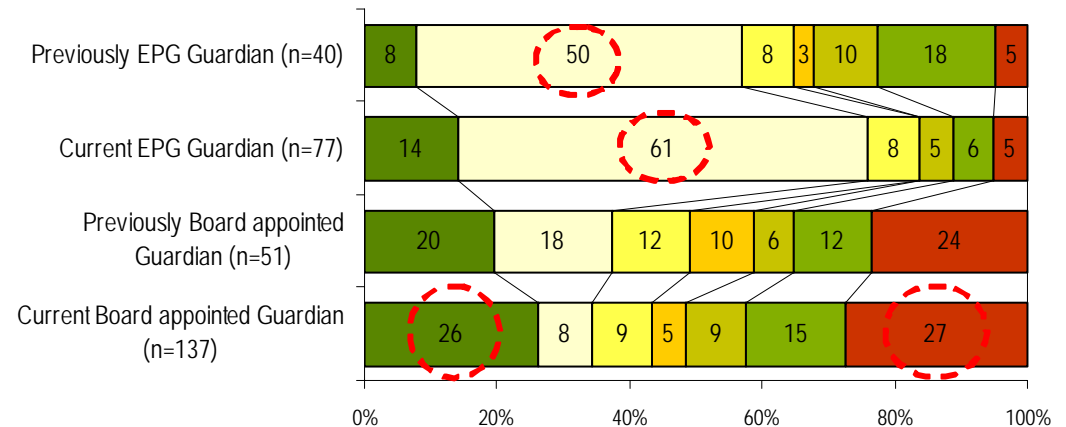
% of respondents

NOTE: Circles in red represent statistically significant differences at 95% confidence level.

Satisfaction Scores by Guardian Type – OPA Advice Helpful

- All respondents were asked to rank the statement *"How helpful the advice is that you receive from the Office of the Public Advocate"*.
- Proportional ratings and the mean scores for each were:
 - ~ Current Board-appointed Guardians – 6.9 mean, 42% were satisfied (27% of whom were very satisfied) versus 17% dissatisfied that the Board's advice was helpful.
 - ~ Former Board-appointed Guardians – 6.3 mean, 36% satisfied (24% very satisfied), versus 30% who were dissatisfied.
 - ~ Current EPG Guardians – 5.6 mean, 11% satisfied compared with 8% dissatisfied and most (75%) indicated this was not applicable to them or they did not know.
 - ~ Former EPG Guardians – 5.7 mean, with 23% satisfied and 11% dissatisfied, with the majority (58%) stating they did not know or this was not applicable to them.

"How helpful the advice is from the Office of the Public Advocate"
(TOTAL SAMPLE, n=289)



	Current Board appointed Guardian	Previously Board appointed Guardian (n=51)	Current EPG Guardian (n=77)	Previously EPG Guardian (n=40)
Very satisfied (9-10)	27	24	5	5
Quite satisfied (7-8)	15	12	6	18
Neither satisfied nor dissatisfied (5-6)	9	6	5	10
Quite dissatisfied (3-4)	5	10		3
Very dissatisfied (0-2)	9	12	8	8
Not applicable	8	18	61	50
Don't know	26	20	14	8

% of respondents

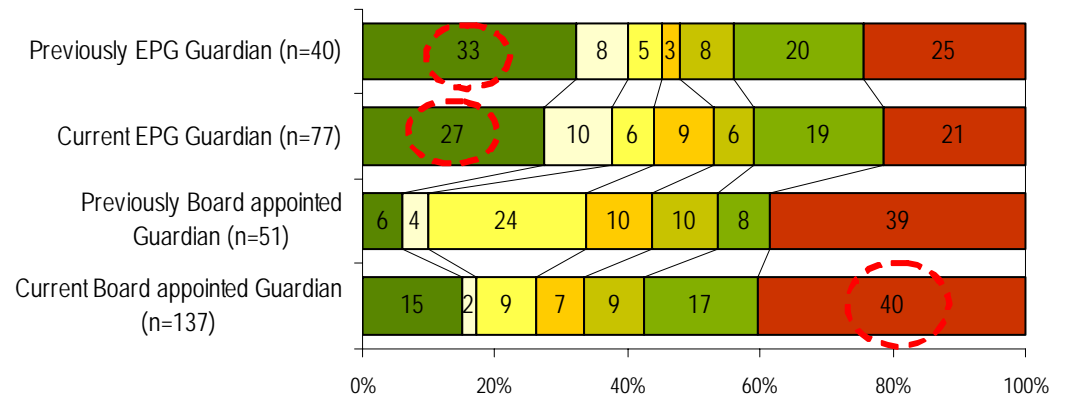
NOTE: Circles in red represent statistically significant differences at 95% confidence level.

Satisfaction Scores – Understanding / Support from Family

- And the final statement respondents were asked to rank was *"How well other family members and friends understood and supported you in your role as Guardian"*.
- As with all other statements, Board-appointed Guardians (current and former) were more likely to indicate they were satisfied with this aspect. On the other hand, EPG's were more likely to state that they do not know or that this aspect did not apply to them.
- Proportional ratings and the mean scores for each were:
 - ~ Current Board-appointed Guardians – 7.4 mean, 57% were satisfied (40% of whom were very satisfied) versus 16% dissatisfied that they received support and understanding from family / friends.
 - ~ Former Board-appointed Guardians – 6.1 mean, 47% satisfied (39% very satisfied), versus 34% who were dissatisfied.
 - ~ Current EPG Guardians – 6.9 mean, 40% satisfied compared with 15% dissatisfied and a third (37%) indicated this was not applicable to them or they did not know.
 - ~ Former EPG Guardians – 7.6 mean, with 45% satisfied and 8% dissatisfied, with two out of five (41%) stating they did not know or this was not applicable to them.

"How well other family members / friends understood and supported you in your role as Guardian"

(TOTAL SAMPLE, n=289)



	Current Board appointed Guardian	Previously Board appointed Guardian (n=51)	Current EPG Guardian (n=77)	Previously EPG Guardian (n=40)
Very satisfied (9-10)	40	39	21	25
Quite satisfied (7-8)	17	8	19	20
Neither satisfied nor dissatisfied (5-6)	9	10	6	8
Quite dissatisfied (3-4)	7	10	9	3
Very dissatisfied (0-2)	9	24	6	5
Not applicable	2	4	10	8
Don't know	15	6	27	33

% of respondents

NOTE: Circles in red represent statistically significant differences at 95% confidence level.

Comments about Specific Aspects of Support

- All respondents were asked if there was anything they would like to expand on, with regard to these aspects of support. As each comment is clearly very specific to their personal situation, coding these responses into themes did not do justice to them. Therefore, the verbatim comments made by respondents who chose to include additional comments, have been included as an Addendum to this report.
- The picture below shows the main comments (excluding the obvious ones, such as; Guardian, Board, Guardianship, person and Public), the themes of **family, mother, financial, care, protected, support, help, information** and **issues** demonstrate the key themes they felt should be raised to explain their ranking of the aspects of support. Many of these comments are emotive rather than practical comments and suggestions for process-oriented change to improve the system. This finding is in line with one of the key themes throughout this research, that support mechanisms and genuine advice for Guardians is not consistent and is often perceived as lacking.

NOTE: The Word Cloud uses size to denote the frequency with which a word is used and, therefore, it's relative importance to respondents.

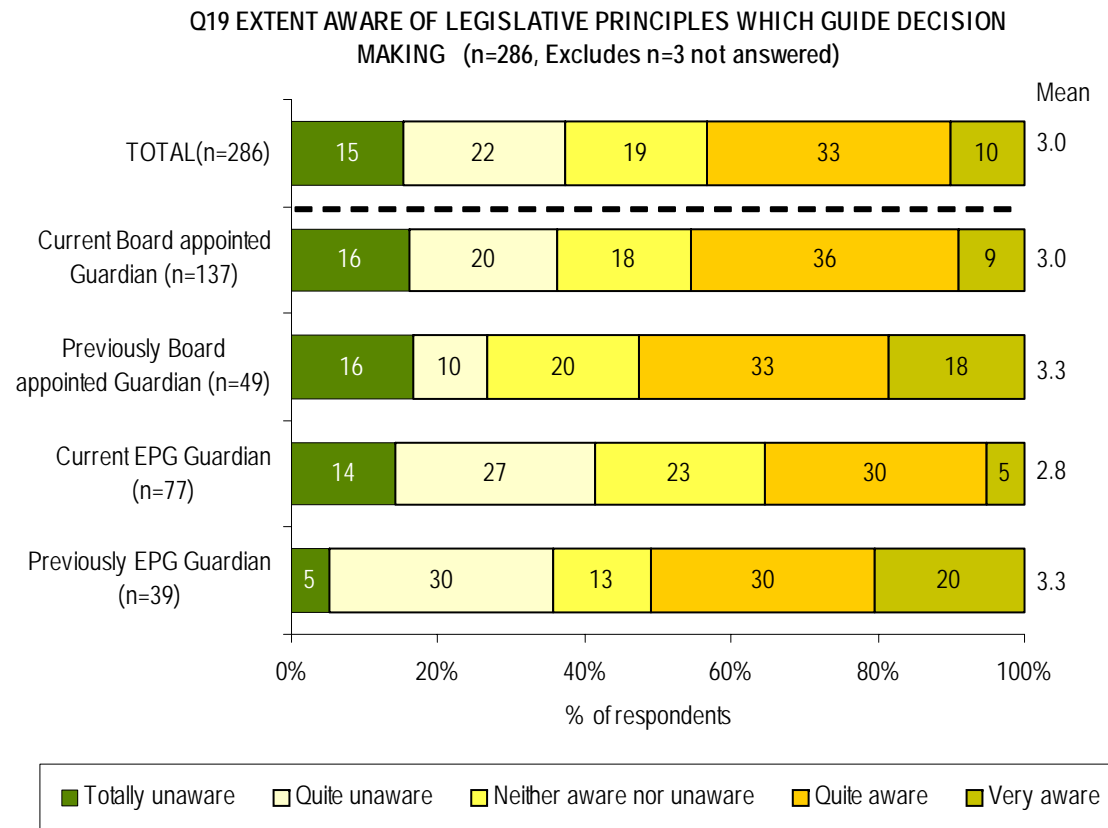




KEY FINDINGS: Legislative Principles

Awareness of Principles in the Legislation

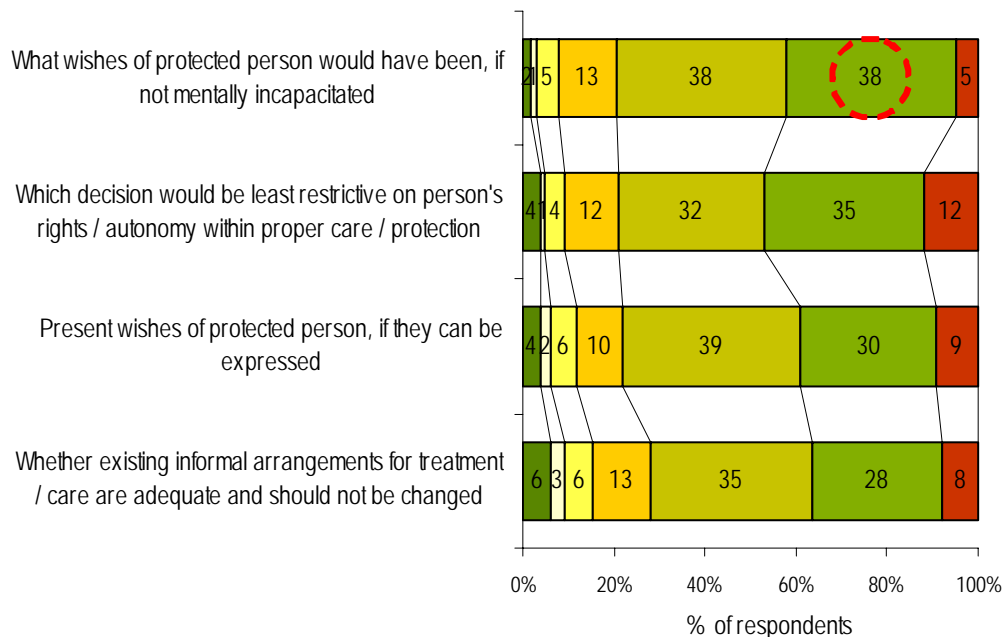
- Respondents were asked to indicate the extent they were aware of the principles in the legislation which guide decision making for persons with a mental incapacity. A 1 to 5 scale was used, where 1 is totally unaware and 5 is very aware.
- Less than half (44%) of all Guardians surveyed indicated they were aware of these principles guiding decision making. The mean score was 3.0 (or balanced between aware and unaware).
- Showing the lowest level of awareness of the principles guiding decision making were current EPG Guardians, with one in three stating they are aware (35%, 2.8 mean score).
- Given the apparent disconnect between guardians with an Enduring Power of Guardianship and the OPA and Guardianship Board (as highlighted throughout the research), this finding suggests that much of the decision making made by the majority of EPG guardians is not guided by the legislation. This finding is further confirmed by comments made by many EPG's to the effect that they perceive they lack support, understanding, knowledge of the legal issues and responsibilities and status as Guardians at various levels. In particular they focused on support, status and understanding from: State government departments; service providers such as aged care facilities and medical professionals; as well as the general community.



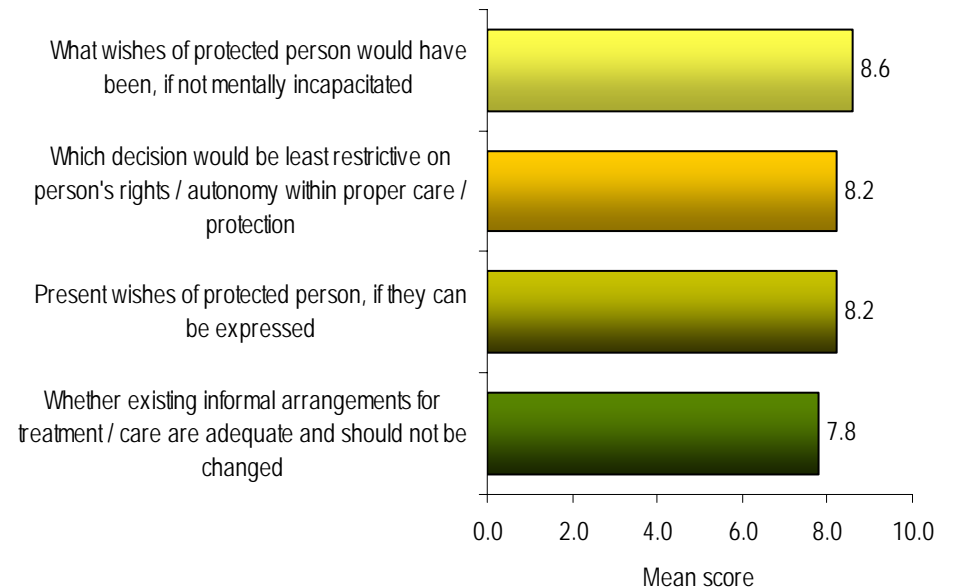
Influence of Principles in the Legislation

- Respondents were told *"The following are the primary principles in the legislation, mentioned in the previous question. Thinking about these principles, to what extent do they influence your decision making for the protected person for whom you are guardian? Use a 0 to 10 scale, where 0 is not at all influential and 10 is a very influential."*
- All four statements rated highly, between 7.8 mean score and 8.6 (as per graph alongside).

Q20 INFLUENCE OF LEGISLATIVE PRINCIPLES (n=289)
0-10 scale, 0=not at all influential and 10=very influential



Q20 INFLUENCE OF LEGISLATIVE PRINCIPLES (n=289)
0-10 scale, 0=not at all influential and 10=very influential

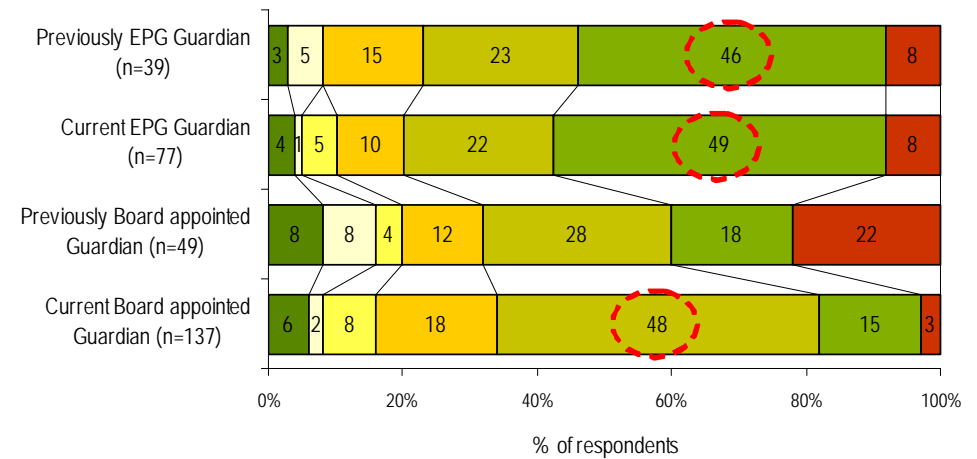


- When analysed by proportional rating, however, it was noted that, for each of these statements, about a third of all Guardians surveyed did not know the level of influence the legislative principles had on their decision making on behalf of the protected person. This tends to suggest that at least one in three Guardians does not take the legislative principles into account when making decisions for the protected person because they are unaware of them.
- A little over one in three Guardians indicated that the legislative principles were very influential in decisions about the protected person and a further one in ten said quite influential.
- Relatively small proportions (around one in twenty Guardians) said the principles in the legislation did not influence their decisions at all.

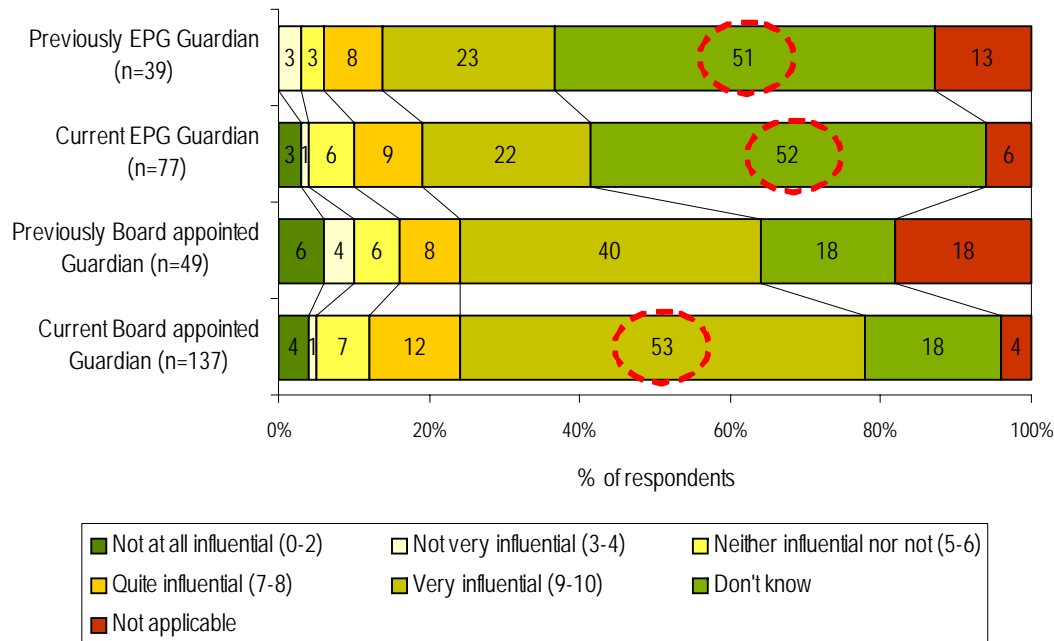
Influence of Principles in the Legislation

- *"Whether or not existing informal arrangements for the treatment and care of the person are adequate and should not be disturbed (changed)"*
- Almost half of EPG Guardians, regardless of whether they are current or former, indicated they did not know how much this principle in the legislation was influential in their decision making (49% current and 46% former). About a third of EPG's said this principle was influential (32% current and 38% former).
- In contrast, current Board-appointed Guardians were more likely to indicate that this principle concerning informal arrangements was influential (48% said very and 18% said quite influential) and less likely to indicate they did not know (15%).

Q20 "Whether or not existing informal arrangements for treatment and care of the person are adequate and should not be changed" (TOTAL SAMPLE, n=288)



Q20 "The present wishes of the protected person, if these can be expressed" (TOTAL SAMPLE, n=288)



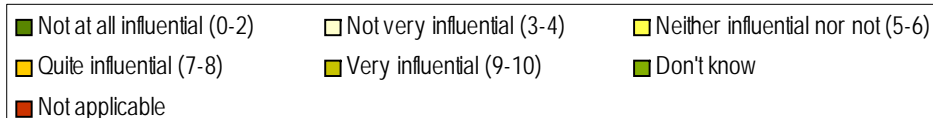
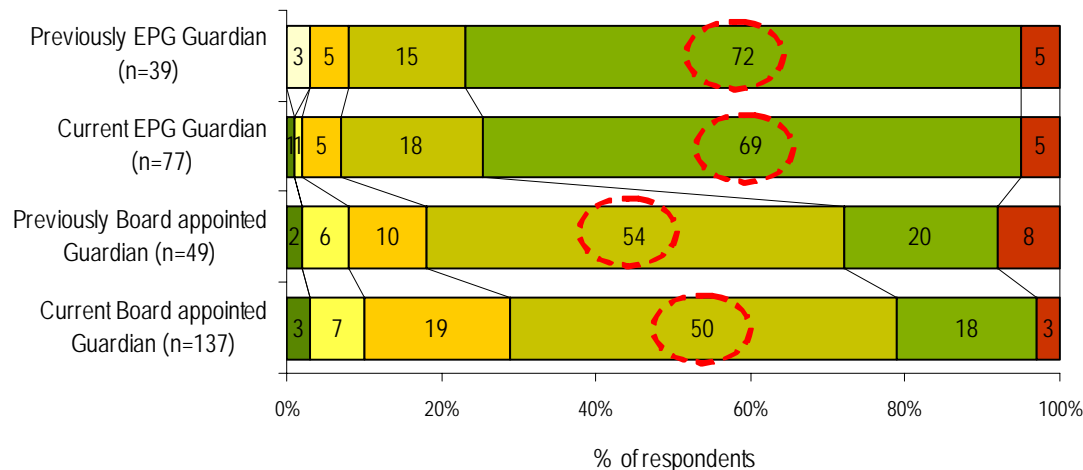
- *"The present wishes of the protected person, if these can be expressed."*
- A similar pattern was noted for this principle, with slightly more than half of EPG's indicating they did not know how much this principle in the legislation was influential in their decision making (52% current and 51% former). About one in three EPG's said this principle was influential (31% current and 31% former).
- In contrast, and following the same pattern, current Board-appointed Guardians were more likely to indicate that this principle concerning informal arrangements was influential (53% said very and 12% said quite influential) and less likely to indicate they did not know (18%).

NOTE: Circles in red represent statistically significant differences at 95% confidence level.

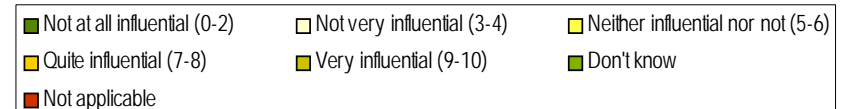
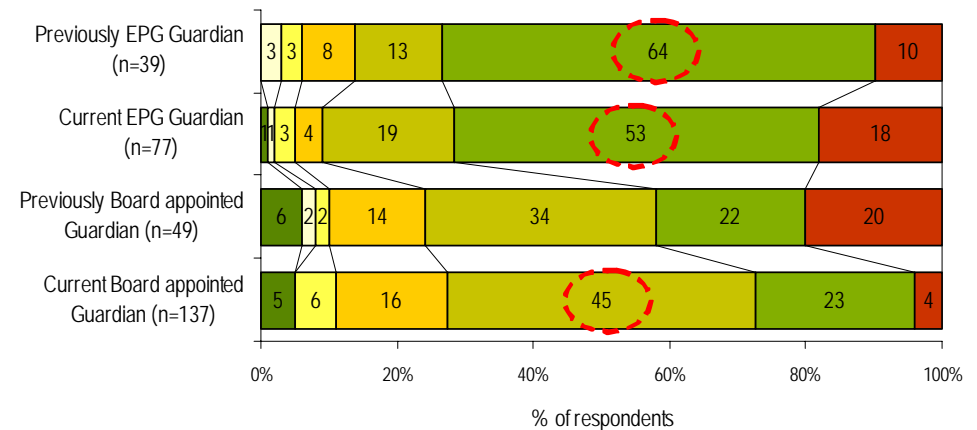
Influence of Principles in the Legislation

- *"Which decision would be least restrictive on the person's rights and personal autonomy while still ensuring his or her proper care and protection."*
- More than half of current EPG Guardians, and nearly two thirds of former EPG's, indicated they did not know how much this principle in the legislation was influential in their decision making (53% current and 64% former). About a fifth of EPG's said this principle was influential (23% current and 21% former).
- In contrast, current Board-appointed Guardians were considerably more likely to indicate that this principle was influential (45% said very and 16% said quite influential) and a little over a fifth indicating they did not know (23%).

Q20 "What the wishes of the person would have been if he or she had not become mentally incapacitated (where this can be determined)"
(TOTAL SAMPLE, n=288)



Q20 "Which decision would be least restrictive on person's rights / autonomy within proper care / protection"
(TOTAL SAMPLE, n=288)



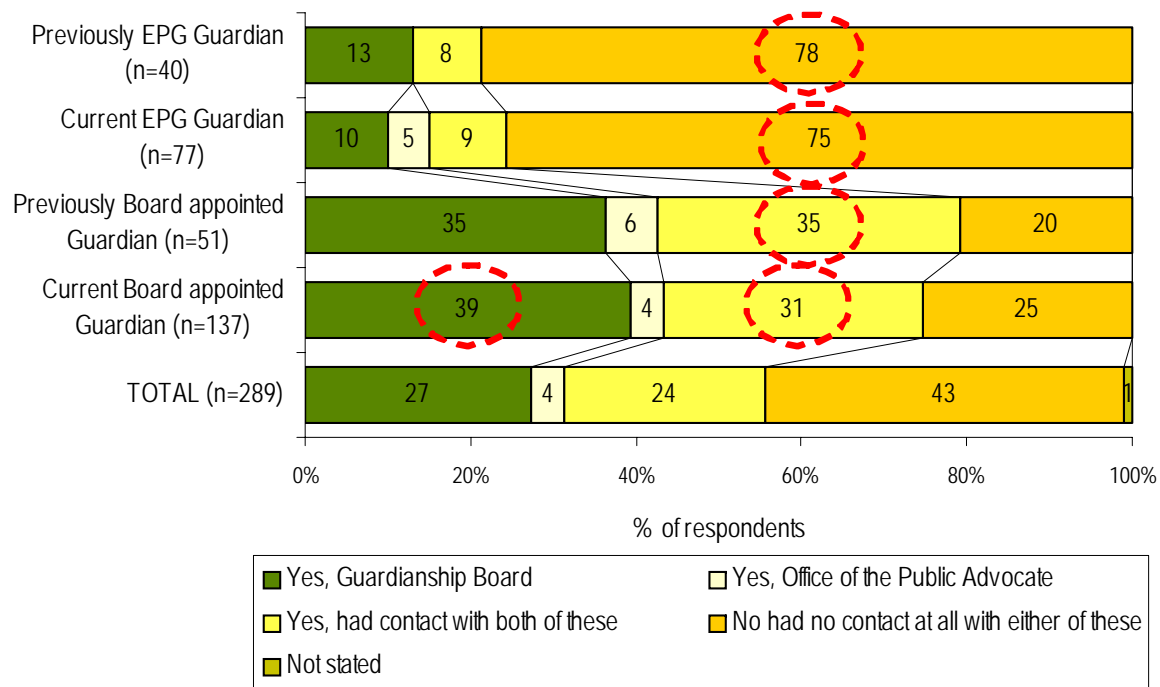
- *"What the wishes of the person would have been if he or she had not become incapacitated (where this can be determined)."*
- A similar pattern was noted for this principle in the legislation.
- Around 7 out of 10 EPG Guardians, indicated they did not know how much this principle was influential in their decision making (69% current and 72% former). About a fifth of EPG's said this principle was influential (23% current and 20% former).
- In contrast, about 7 out of 10 current Board-appointed Guardians said this principle was influential (50% said very and 19% said quite influential) versus 18% stating they did not know.

KEY FINDINGS: Contact with Board or OPA

Contact with G/ship Board or OPA

- When asked if, since becoming a guardian, they had any contact with either the Guardianship Board or the Office of the Public Advocate (or both), just over a quarter (27%) said they had contact with the Board. A further quarter (24%) indicated they have been in contact with both the Board and the OPA since becoming a Guardian. This means that half (51%) of all Guardians surveyed have had contact with the Board and 28% have had contact with the OPA.
- At the total sample level, 43% of all Guardians surveyed have had no contact at all with either the Board or the OPA.
- The pattern of having had interaction with either of these two bodies was significantly different when analysed by the type of Guardian. Not unexpectedly, among current and former Board-appointed Guardians, 70% have had contact with the Guardianship Board while around a third have had contact with the OPA (35% of current and 41% of former Board-appointed Guardians).

Q21 CONTACT WITH EITHER GUARDIANSHIP BOARD OR OPA
(TOTAL SAMPLE, n=289)

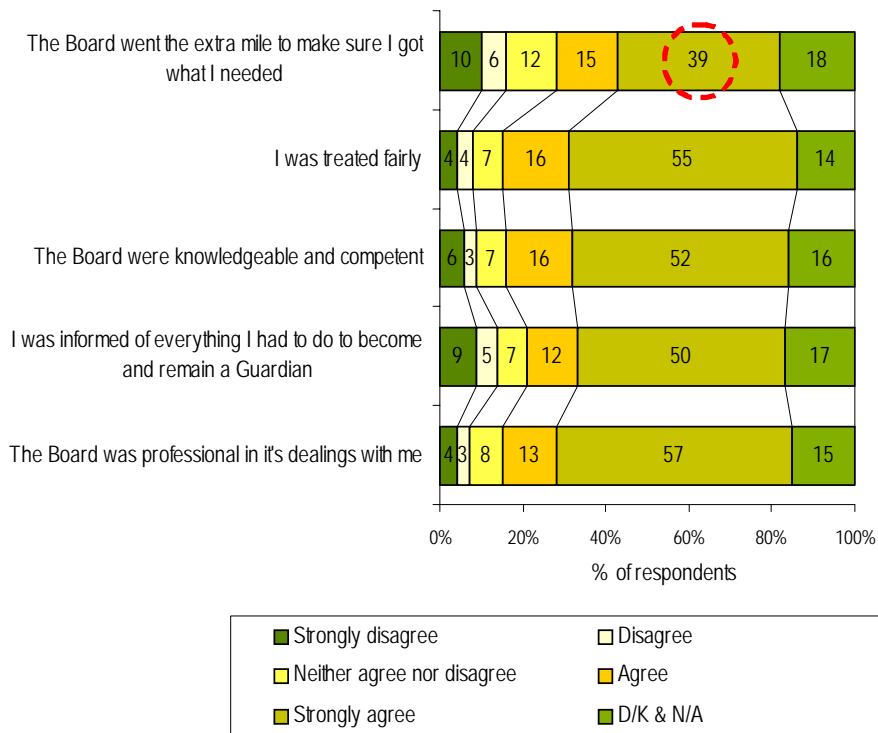


- Conversely, among Enduring Power of Guardianship guardians, this increased to three in four (75% of current and 78% of former EPG's) stating they have had no contact at all.
- The proportion of current EPG's who had made contact with either or both of these organisations were:
 - ~ 19% had been in contact with the Board, and
 - ~ 14% had been in contact with the OPA.
- Among former EPG's, the proportions were smaller.
- Across all Guardian types, there was a relatively low incidence of having made contact with only the OPA (4%).

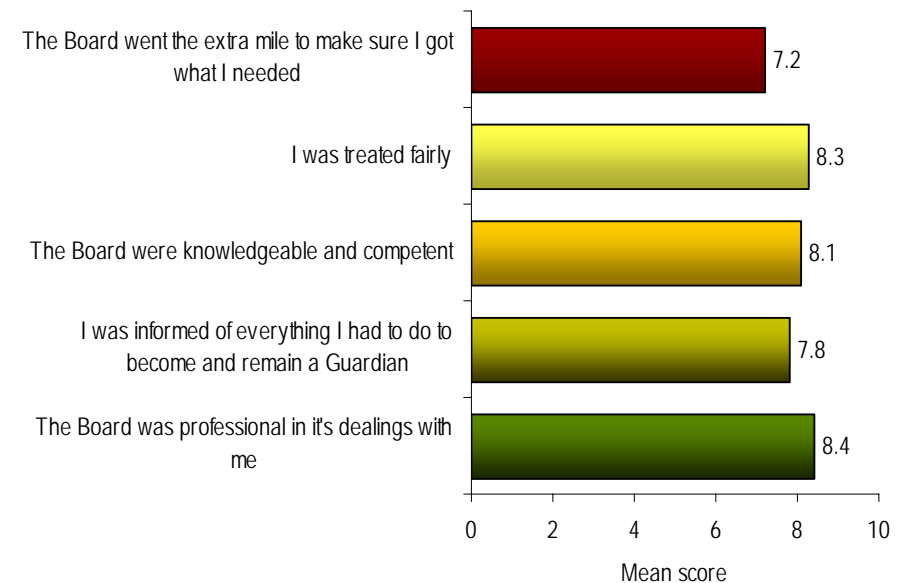
Contact with Guardianship Board

- Guardians who have had contact with the Guardianship Board (n=148, 51% of respondents) were asked to indicate their level of agreement with four statements relevant to their interactions with the Board.
- The highest ranking statement for agreement was for *"The Board was professional in it's dealings with me"* (8.4 mean score, falling between 'Agree' and 'Strongly Agree'). These respondents also showed a similar level of agreement for the statement *"I was treated fairly"* (at 8.3 mean).
- At the other end of the scale, the statement *"The Board went the extra mile to make sure I got what I needed"* showed the lowest level of agreement (7.2 mean score, at the lower end of 'Agree').

Q22 INTERACTIONS WITH GUARDIANSHIP BOARD
(0-10 SCALE, 0=STRONGLY DISAGREE AND 10=STRONGLY AGREE)



Q22 INTERACTIONS WITH GUARDIANSHIP BOARD
(0-10 SCALE, 0=STRONGLY DISAGREE AND 10=STRONGLY AGREE)

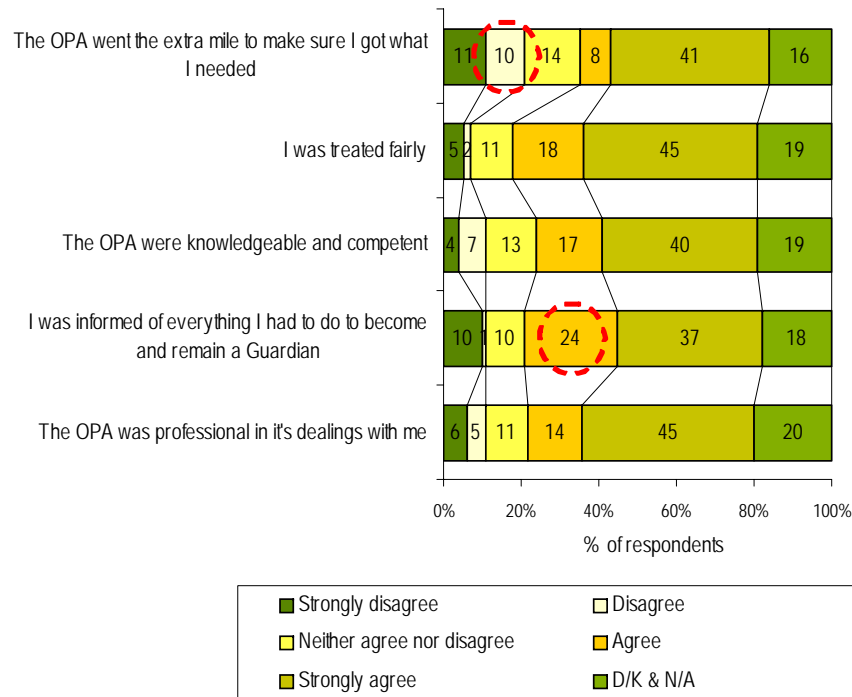


- When the same statements were examined by the proportions who agree compared with the proportion who disagree, the majority of the Guardians who came into contact with the Guardianship Board agree with each of these statements:
 - ~ *"The Board was professional in it's dealings with me"* – 70% agreed vs 7% disagreed
 - ~ *"I was informed of everything I had to do to become and remain a Guardian"* – 62% agreed vs 14% disagreed
 - ~ *"The Board were knowledgeable and competent"* – 68% agreed vs 9% disagreed
 - ~ *"I was treated fairly"* – 71% agreed vs 8% disagreed
 - ~ *"The Board went the extra mile to make sure I got what I needed"* – 54% agreed versus 16% disagreed.
- These findings demonstrate a good service culture, but also suggests that there may be room for improvement, particularly in making sure that Guardians get what they need.

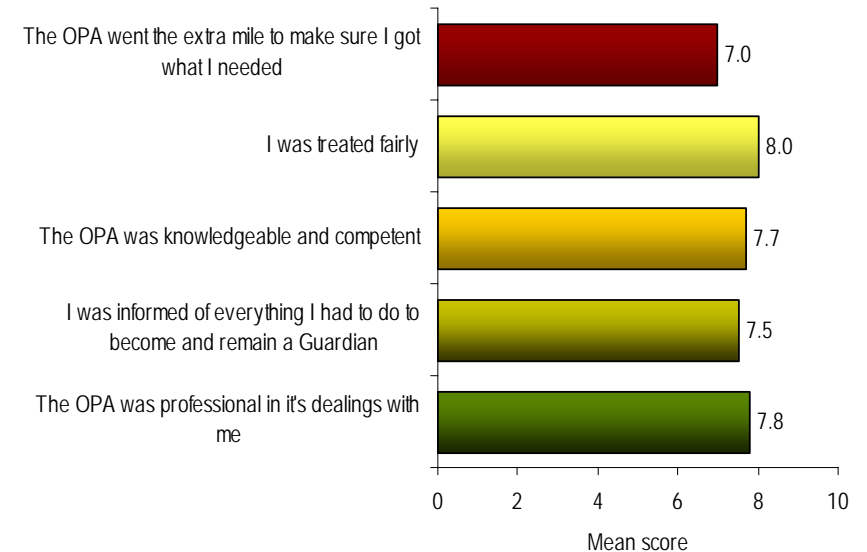
Contact with Office of the Public Advocate

- Guardians who have had contact with the OPA (n=83, 29% of respondents) were asked to indicate their level of agreement with four statements relevant to their interactions with the OPA (the same statements as for the Board).
- Each of these statements rated lower in terms of agreement compared with Guardians who have had contact with the Board. It should be noted, however, that these variations were not statistically significant at the 95% confidence level, due to the relatively small numbers (especially contact with OPA).
- The top ranking aspect of their interaction was for the statement *"I was treated fairly"*, 8.0 mean. As with those who had contacted the Board, the findings revealed that the lowest level of agreement was for the statement *"The OPA went the extra mile to make sure I got what I wanted"* (7.0 mean, just within 'Agree').

Q23 INTERACTIONS WITH OFFICE OF THE PUBLIC ADVOCATE
(0-10 SCALE, 0=STRONGLY DISAGREE AND 10=STRONGLY AGREE)



Q23 INTERACTIONS WITH OFFICE OF THE PUBLIC ADVOCATE
(0-10 SCALE, 0=STRONGLY DISAGREE AND 10=STRONGLY AGREE)



- When the same statements were examined by the proportions who agree compared with the proportions who disagree, Guardians who came into contact with the OPA showed higher proportions agreeing with each statement:
 - ~ *"The OPA was professional in its dealings with me"* – 59% agreed vs 11% disagreed
 - ~ *"I was informed of everything I had to do to become and remain a Guardian"* – 61% agreed vs 11% disagreed
 - ~ *"The OPA were knowledgeable and competent"* – 57% agreed vs 11% disagreed
 - ~ *"I was treated fairly"* – 63% agreed vs 7% disagreed
 - ~ *"The OPA went the extra mile to make sure I got what I needed"* – 49% agreed versus 21% disagreed.

Contact with G/ship Board or OPA, by Guardian Type

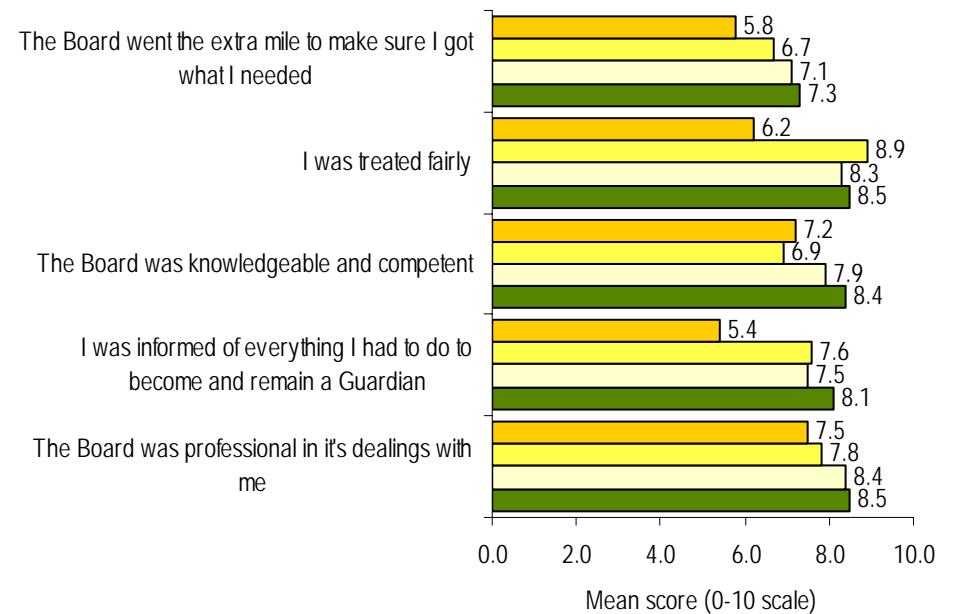
- When the same statements about contact with the Guardianship Board and the Office of the Public Advocate were analysed by Guardian Types, a pattern was observed of lower agreement with all statements among former EPG's compared with other Guardian types.
- However, the number of EPG's who have contacted either the Board or the OPA is too small to be statistically reliable. This factor, therefore, had little or no impact on the outcomes reported on the previous pages. Caution should be used if using this finding.

Q22 & Q23 INTERACTIONS WITH OFFICE OF THE PUBLIC ADVOCATE
BY GUARDIAN TYPE



■ Current Board appointed Guardian (n=49) ■ Previously Board appointed Guardian (n=21)
 ■ Current EPG Guardian (n=11) ■ Previously EPG Guardian (n=3)

Q22 & Q23 INTERACTIONS WITH GUARDIANSHIP BOARD
BY GUARDIAN TYPE



■ Current Board appointed Guardian (n=96) ■ Previously Board appointed Guardian (n=36)
 ■ Current EPG Guardian (n=15) ■ Previously EPG Guardian (n=8)



KEY FINDINGS: Final comments

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KEY FINDINGS: Exploratory focus group

Key issues raised by private guardians

- A mini focus group, with 4 participants, was held in late August 2011, after considerable preparation work in trying to locate and involve private guardians in participating in the research.
- The views of guardians were sought with the primary purpose of informing development of the survey instrument for the quantitative study. As very little work had been done in researching private guardians to date, there was a need to understand the issues from private guardians' perspective in order to develop a focused questionnaire which addressed the issues most relevant to private guardians and in a language with which they were sufficiently familiar to provide thoughtful and relevant responses. Note that the views expressed were from a very limited sample of private guardians and, as such, are indicative only and not representative of guardians in general.
- The key issues raised by these few guardians, under broad themes but not necessarily in priority order, included the following commentary and quotes.

Financial aspects

- There was a strong sense of frustration and embarrassment that they were in a position where legitimate expenses for their adult protected person (generally their child who was disabled either from birth or through acquired brain injury) had to be justified by the Public Trustee.

"If they were truly interested in helping people run accounts for other people, to be able to then take it into them, why can't they issue you with a little 'do it yourself' kit sort of thing."

"The point is the Trustees don't necessarily have an understanding of the people that we are dealing with."

"With us and the way we've got things set up, we don't have to put up with that, but I do hear stories from other people that the Public Trustee won't part with the money."

" They can't see the need if it's not what they consider to be 'normal' for a person to spend. Who can be the judge of that? We are not dealing with normal."

"We have to deal with Public Trustee all the time because we did the right thing."

- Whilst most indicated that providers of goods and services are relatively helpful and understanding, one mother whose son suffered acquired brain injury after a work-related accident explained how difficult it was to sort out her son's finances whilst he was in a coma. In her experience, the most difficult service providers were phone carriers, who refused to deal with her and would not accept that she had authority to manage her son's affairs. In the end, it was easier for her to simply continue the payment on his mobile plan, even though the mobile was rarely used.

"It was cheaper to keep the phone than it was to pay it out. Even now, he is on a plan but he can't talk because he lost his hearing, but he can text. Anything that goes wrong with the service, they keep calling him and saying they want to talk to him. I have shown them my guardianship papers once, how do I put it down the phone. But there should be some record though. To this day, you really have to be quite rude. You know, 'You're not listening to me, he cannot talk on a phone because he cannot hear'."

Key issues raised by private guardians

Support and Advice

- Whilst they acknowledged that dealing with either the Guardianship Board or the Office of the Public Advocate was always handled with care and understanding, other aspects of the protected person's care, such as how to get the right medical support, what sort of housing or supported accommodation should they be in and so on, they had to learn the hard way and almost invariably through informal networks.

"It was hard to get initially, because we had to organise things and no one was there with any advice about what to do about the situation."

"It is extremely diverse, because every disabled person is totally different to the next, so there is no one place for advice."

"People try to put them in packages, you know? Blind people are here, and deaf people are here and there is the rest. But those 'rest' are all so different and they all have different needs."

"We don't have to see the Guardianship Board. It probably would be nice to have more feedback from them. More feeling that you are doing something right. You are sent all this stuff and you never hear."

Making decisions

- Experiencing issues when making decisions on behalf of the protected person, and in particular medical decisions, was not uncommon among group participants. They cannot simply make a decision for the protected person, no matter how well intentioned they are, most reported going through the Guardianship Board and one had to go through the court system. The problem parents of intellectually disabled children who are now adults experience is that their child is never in a position to competently sign an Advance Directive.
- Likewise, those whose young adult children acquire a brain injury from an accident rarely have considered putting down on paper their wishes should something happen to them. When they are faced with authority, some indicated feeling quite intimidated whilst others felt that it was somewhat onerous for them when other parents of intellectually disabled children (known to them) do not go through legal channels and still manage the affairs of their adult child. A sense of being judged as parents / caregivers was another common theme, particularly in relation to the financial management of the protected person's affairs.

"When we were in dispute in front of the Guardianship Board, the people who were looking after my son were saying 'We are the professionals, we've got the training' and their attitude was 'These are parents. They have failed'. You know?"

"The first few times we met, the two or three of them, we were a bit overawed because we were hoping they were going to look favourably upon you as parents. The process was very good actually. They were very compassionate people."

"The thing I guess that is a bit strange, is that not everyone has to go through the Guardianship Board with children, or adults, like we've got. Several friends haven't got Guardianship and they are still running their finances."

"It was relatively easy to apply and the doctors all signed the form after my son's accident. They were all lovely people and I still maintained control over his finances. But I wasn't able to make decisions about his medical care, which I wanted at that time. I wasn't given that option, which I thought was confusing at the time. I understand now that we didn't have it in writing before his accident but what 20 year old boy thinks about a work accident changing his life?"

Key issues raised by private guardians

Motivation in becoming a Guardian

- All of these private guardians indicated they had no choice but to become guardian for their intellectually disabled child, generally once the child turned 18 years and / or a legal or financial matter could not be handled without an EPG or Board appointment in place. In one instance, an accident made it necessary to apply to the Guardianship Board, with assistance from the doctors at the hospital. None of these guardians would make a different choice, if in the same situation, although some mentioned how much easier it appeared to be for those who do not go through the Guardianship Board and Public Trustee processes.

Information

- In terms of finding resources, support services and other vital information to assist private guardians in their task of managing the affairs of a protected person (and, in many instances, caring for them physically, also), there was a clear message from private guardians that accessing information was a difficult path with no road maps. This was not just in terms of accessing support resources but also finding the right people to talk to who understand the situation guardians are in and who can inform them of what needs to be done for their specific situation. Because every intellectual disability is unique, they said that accessing relevant information was often by trial and error with few resources available to show them how to access information and from whom.
- Some saw the OPA and / or Guardianship Board as in a unique position to provide this information and resource support for guardians.

"The thing for me was I was going everywhere to get the information, but I'm not an expert, I didn't know who was telling me the truth and who didn't actually have that knowledge to impart to me."

"I was trusting people that I didn't really know and that's the hard thing. It takes a long time to accumulate the knowledge yourself, so you've got a background so you can then say, 'No, that's not right. This is what I want you to do'. It's hard to get to that point."

"There are not enough reviews. You have these obligations but don't have any feedback. But that's the only thing I think the Guardianship could be doing a bit more of."

- In terms of mechanisms in place to support guardians, either with information or with resources or advice, again they recognised that the Guardianship Board acted in good faith and was very supportive. There are, however, other forms of support they need to pursue the best care for their protected person. This was more common among those with children with an intellectual disability, rather than those whose elderly parents needed someone to manage their financial affairs but whose physical needs were taken care of in a nursing home or other supported care facility. Common interest groups and advocacy were key support mechanisms needed.

"Who is supposed to support you? I wouldn't have a clue where to get support from."

"There is a real learning curve in trying to manage these things and no one is going to come up to you and say, 'This is how you go about it'."

"Sometimes that's all it is, you meet somebody, you have a rapport with them and you know they will be able to help you, you just feel it and it's this wave of, not happiness, but 'Thank god, someone is listening to me'."

"The Guardianship Board have always been very supportive, though."

"There is not a great amount of support mechanisms. You get it by meeting people and someone says to you, 'Have you rung up this lady?' and that's where it all happens."

Key issues raised by private guardians

Disability sector in general

- Among private guardians, particularly those whose adult child has an intellectual disability since birth, the whole disability sector came under some criticism, particularly the fact that their protected person is always going to need additional care and resources and how resources for this sector are relatively low.

"It's a very underpaid sector of the community and I guess the government doesn't put much into it. They talk a lot about it, this new Medicare type thing, the disability insurance thing."

"They seem to go around in circles."

"But if you read the articles that come out, the discussion is more along the lines of accident acquired brain injury, it doesn't talk much about those who are born with it. There is a little bit."

"With an intellectual disability you get to a point where you don't really get better."

"For Centrelink, every year you have to fill out a form to say whether your daughter has changed. In case she comes out of it? I sent them a letter and said, 'She's not going to change. I wish she could but it's not going to happen.'"

Ideally ...

- It was difficult for these private guardians to suggest changes they would like to see or supports put in place. Some had been guardians / primary carers for 30 years or more and did not have any illusions or ideas about what an ideal service would look like. However, a key bugbear was a perception that the general community, and key institutions like the Public Trustee, lacked understanding about what guardians go through and some guardians perceived that they were being judged.

"What I would like to happen is I would like for people to be more understanding and not act like you're the criminal, because that's what happens."

"The accountancy fees, that would be a tax deduction. But what else can we claim in terms of what we spend on my daughter? One thing you don't get is a little booklet from the Trustee saying when you are doing your books, you can claim this for a deduction or that, like the money spent by you on accountants."

- These findings formed the basis for developing the survey instrument. The next section of the report deals with the key findings from the quantitative survey.

KEY FINDINGS: Follow-up Discussions

Overview of further insights

- As a final phase of the research, 20 guardians who had indicated they were interested in participating in a final stage of the research were contacted (usually by telephone) to provide further insights into the experiences of being a private guardian, with particular focus on their suggestions for improvement. They were selected on the basis that they had opted-in, but also they had made suggestions for change which were considered to reflect the focus of most guardians in terms of the aspects of guardianship they would like to see changed or improved. The topic guide forms part of this report (Appendix A5).
- The following provides a summary of the comments and suggestions made, paraphrased into categories to focus on the insights offered by guardians rather than their direct quotes:
 - One of the most common issues raised throughout the research concerned the **system of financial reporting to the Public Trustee**. This aspect was a source of frustration and concern for Board-appointed guardians, with many stating that they feel overwhelmed by the process. In particular, aspects such as: the complexity of the financial reporting requirements; the outdated process used; non-acceptance of financial package software and spreadsheet reporting; annual reports described as cumbersome and time-consuming, especially the requirement to provide month by month debit and credit details; and also unhelpful and non-responsive to requests for information or providing responses to queries. Almost none of the guardians surveyed had a positive perception of the Public Trustee.
 - There were many comments throughout the research regarding **lack of recognition of the status and responsibility of guardians**, particularly among medical and aged care professionals. Some guardians indicated that other family members (who were not guardians) had greater influence over medical decisions than the guardian, whilst others indicated that medical professionals ignored the guardian's wishes and made decisions not in line with the stated wishes of the protected person. These incidences were not isolated but relatively common (among guardians of elderly dementia patients in particular), clearly indicating that the guardian role is not well understood among those people providing medical care / services for some protected persons.
 - Many guardians suggested that, rather than sending out flyers and fact sheets or leaving prospective or newly appointed (EPG) guardians to source information for themselves, that guardians should have a **one on one interview with an advocate** who could take them step by step through the process, related specifically to their situation and offering a range of support, special interest or advocacy groups as additional resources should they be required. Whilst this is most likely impractical in terms of the resourcing required to undertake this task, there is a clear message from EPG guardians that they feel isolated and alone, with little or no information about other services available to support them and limited information about the legal framework for decision making (and some EPG guardians even indicated they did not know when and how to activate the EPG).
 - There was confusion surrounding the **differences** between a **Board-appointed** Guardian, an **EPG** and an **EPA**, what role each plays and the practical responsibilities and limitations of each. Whilst the fact sheets and flyers provided the legal and administrative facts, they are not a practical "how to" guide to guardianship. Guardians indicated they need clarity as to which form of guardianship is the most useful for which situations where guardianship may be needed. Some who visit a lawyer are provided with a Power of Attorney only to find later that they needed a Power of Guardianship. "If only we knew this earlier" was a relatively common statement made by guardians.
 - Along similar lines, some guardians suggested that having only **one agency** for accessing guardianship of all types could provide them with information about a wide range of services and support mechanisms, as well as advocacy, without the cost associated with seeking legal advice but ensuring that all options were understood and formed the basis for well-informed decision-making.

Overview of further insights

- Among guardians who are also primary carers, the responsibilities of providing day to day care are often onerous and make sourcing information about guardianship and support mechanisms difficult as they lack the time to research information and resources. Whilst this does not come directly under the purview of the OPA or the Board, it does demonstrate that many guardians are **time-poor**, perhaps also **isolated** and **under some degree of stress**.
- With this in mind, important aspects for guardians in general (and carers in particular) might include:
 - information which is easily understood and actionable;
 - access to support networks including other guardians who have faced similar situations;
 - access to a guardians' helpline; as well as
 - clear guidelines or a practical framework to support decision-making
- would provide them with the mechanisms required to make well informed decisions on behalf of their protected person, whilst avoiding having to "reinvent the wheel" or use precious time to follow through on everything themselves.
- The following dot points reflect the main themes and suggestions from the final qualitative interviews with selected guardians. They are not in any priority order but they have provided input into the Discussion and Recommendations section of this report.
 - Need someone to explain where process begins and ends, step by step and one to one not via fact sheets or over phone. Too much information early in the process, totally confusing and overwhelming. Took too long for me to understand what had to be done. Speak to a lawyer to clarify what is required of you as EPG.
 - Main problem was not knowing what to ask – you don't know what you need to know or how to ask in the correct manner to be clearly understood. Therefore, some "simple and easy" things turned difficult when my intention was misinterpreted. Blurring of roles between OPA and GB, lines not clear. Sometimes were bounced between the OPA and the Guardianship Board, with each saying that it was the other's department. A basic dot point list of what the Public Advocate does and what the Guardianship Board does and what they do together would have saved a lot of time and anxiety.
 - The demands of the method of bookkeeping required by Public Trustee. Presenting bank accounts, direct debits and other incidental receipts should be enough without having to present it how they require it. At the end of 12 months, all bank statements & fees should not need to be presented week by week. If fees have legal invoices, are paid by Direct Debit, the only things that need a little more scrutiny are clothes & incidentals. If balances are reasonable, the worksheets of the Public Trustee are too cumbersome.
 - It's bloody hard. Put it into place before the person's mental capacity goes. Need more information on legal side of personal funds, keep all types of paperwork, especially keep the simple things. All receipts to go into a folder, nothing to be left to question, clear direction, be precise. Good to have a layman to run things past.
 - Information much sooner. To work through the maze of treatments / options was such a frustratingly long time. Temporary guardianship should be offered way up there at the earliest opportunity. Otherwise, I cannot speak highly enough of the whole process, we just wish we had found out about it earlier.

Overview of further insights

- Having some sort of positive advocate who will be there for you all the way, providing feedback and helping work through the process. Looking after her finances is onerous, we are trying to find the right help. We sift through information on the internet, trying to help her lead an independent life.
- Legal fees are so expensive but getting good legal advice is important to make sure that the protected person's wishes are clearly stated. But make sure it is through Board or ARAS. Carers SA can provide certain number of sessions with psychologists or go through Seniors Information Service, they can direct to appropriate services. Main thing is to get good advice and make sure it is clearly spelt out.
- I still don't really understand the difference between a Board-appointed guardian, and an EPG or what the OPA does. Provide information in simple language and easily understood. Feel isolated from the "system". My advice to others is to accept all the support that you are offered, access any information you can, as well as support groups and Carers Association. I have great family who support me. Look after yourself because it's demanding. Access counselling, DomCare, RDNS. Reach out and accept whatever is on offer.
- The lawyer we went to was excellent and cost was reasonable. I would recommend others who are just starting out to get a good lawyer and also talk it over with family. Do it sooner rather than later. At the end, speak to practice nurse who specialises in the area of end of life.
- Whilst it's a job best done by family, you need a framework by which to make decisions. Also need an advisory service available and more transparency between Guardianship, EPG and EPOA. Would be nice to pick up the phone and speak to someone.
- Process is very complex. Dealt with Public Trustee, received support from Aged Care advocacy, but dealing with PT very unsatisfactory. They didn't trust me. I don't know where my boundaries are, I'm trying to work out where my responsibilities begin and end. I need to have someone to talk to, it would be wonderful to talk about similar issues. I feel so alone, I need clearer guidelines and perhaps talk to other guardians.
- We went through Guardianship process 20 years ago. Why aren't we automatically assumed as her guardians, after bringing her up since she was a baby and looking after her? We would like to feel validated as her guardians. They forget to ask and listen to us as her guardians, we are her voice and her needs are our needs. There is a lack of empathy in the system. Whenever we deal with an agency, we are always being invalidated. We have to conform to the agencies' thinking and framework. We don't have a say in framing individual rights in the broader community.
- There should be greater understanding of what is involved in becoming a guardian and there's a need to have information about how complex the procedure can be.
- I would advise others thinking about taking on the guardian role to do it very early and be very clear about what the role entails. Make sure there is an Advance Directive, a palliative care order and also a person to advocate on your behalf, it makes decisions so much simpler and clearer. There is no transparency or uniqueness any more. All guardians are treated as if protected persons were all the same, they are not. Every situation is unique. We had challenges to face all the way through. For difficult decisions it is very important to show a united front with other family members. Legal fees are very expensive and eat up funds if have to fight for rights.

Overview of further insights

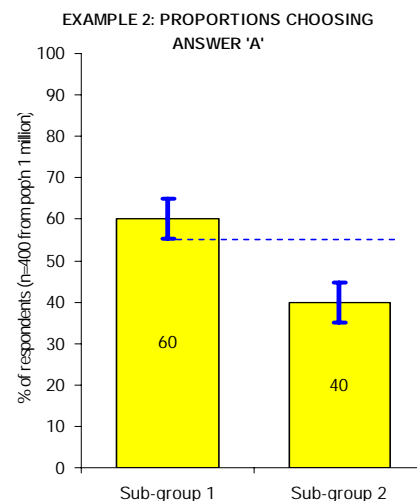
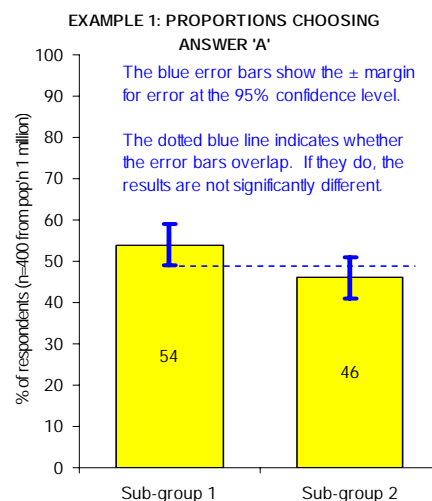
- Think long and hard before taking on guardian role as it's a lot of work and a lot of emotional stress, and difficult to make tough decisions. Can be a fall-out between friends and families. Read everything, all the fine print, and talk to a lawyer. Important to have everything clear and legal. I think there should be legislation to ensure that everyone has an Advance Directive before they become vulnerable, perhaps even at 18 or when they leave school.
- I hate the end of year financial summary, pages and pages of reconciliation. I feel like I'm stealing from him if I'm a couple of dollars short – need to sign a Stat. Dec. if the money is short.
- I went to a JP and he explained everything to Mum and we signed a Medical Attorney and Power of Attorney. I gave both Centrelink and the bank copies of my POA, but they overrode it and gave the monies to my brother and sister-in-law instead. Sister-in-law sold my mother's belongings. POA was useless, Centrelink would not speak to me. As a consequence, my brother and I have not spoken in years. Relatives need to be made aware of who is legally responsible. There is a strong emotional cost, I had to self-examine my motives and ask "am I making decisions based on my values or her values". All decisions I made were for her own safety and wellbeing.
- Firstly, consult with rest of family, it is a big responsibility and won't always go the way you want. Contact Carers organisation for phone counselling service and help with family conflicts and end of life decisions. Access to free legal advice would be good, as lawyers are so expensive. I feel that you don't get the authority you thought you would have with POA. There seems to be no consequences for anyone ignoring the POA unless you take them to court. The bank should be fined for ignoring POA and there should be legislation to cover us.
- Be aware, it pays to find out as much as you can. Our process was simple in the fact our only obligation was to find suitable accommodation for her care. Trying to find appropriate care was difficult. I believe there are now agents that you can consult who can do the work for you.
- There is no support if needed, I have mountains of paperwork that I find difficult to deal with. All the different bills, I've made mistakes paying money where I shouldn't and there is nothing to help with organising financial matters. The major problem is time, I don't have time to do anything. A Helpline would be useful, to find out what sort of services would be helpful and also, as I said, someone to handle mother's bills..

APPENDIX A1:

Margin for error & statistical significance

Explaining margin for error

- Because nearly all market and social research evaluates results based on population *samples*, rather than a census where everyone is consulted, there is an inherent degree of error in the results. However, if the sample obtained is a properly randomised section of the target population, there are statistical tests that will calculate the degree of accuracy for those results - known as the margin for error or Confidence Interval.
- Unfortunately for the layperson, there is no single figure that says, 'this is a statistically significant difference'. The factors that go into the calculation of statistical differences include:
 - ~ **population size** - the total number of people in the target audience, not in the whole population. For example, if an organisation were researching its casual staff's views on weekend work, the 'population' would be the total number of casual staff.
 - ~ **sample size** - the number of respondents, or people taking part in a survey.
 - ~ the **desired level of confidence** in the result - for example, a 95% confidence level simply means that, if we ran the identical survey and sampling methodology 100 times, you would expect to get a result within the calculated margin for error 95 times out of 100.
 - ~ the **proximity** of the result to the midpoint.
- This latter element (proximity to the midpoint) means that, regardless of sample or population size, a figure close to 50% is inherently less reliable than a figure close to 100%. As an example, if you wish to be 95% confident in the results for a population (N) of 1 million and a sample (n) of 400, a result of 50% would be subject to a $\pm 4.9\%$ maximum margin for error. In other words, you could be 95% confident that the real result would be somewhere between 45.1% and 54.9%. However, with the same population, sample and 95% Confidence Level, a result of 90% saying yes or no would be subject to a margin for error of only $\pm 2.94\%$, i.e. the real result would be between 87.06% and 92.94%.
- The following graphs may illustrate more clearly the way margin for error works. In each case, we have calculated the confidence interval for the results. If the intervals overlap, then the differences are not statistically significant; if there is no overlap, they are reliably different.



INTERPRETING RESULTS:

- Fortunately, researchers no longer have to check every result manually; our statistical analysis software packages tell us when figures are statistically different from one another and at what confidence level. However, the skill of the trained researcher is in *interpreting* the results and considering context, not just checking the numbers.
- For example, suppose that significantly more people aged 65-74 were aware of advertising for a sports store than people aged 75-84. It is significant, but is it relevant - in the context of the product and its major target audience of, say, active people aged 15-54? It is critical to good analysis that we judge relevance and highlight the key issues, not waste clients' time by just regurgitating numbers that the computer says are statistically different.



APPENDIX A2: Exploratory Topic Guide

- The focus group was held at Harrison Research's premises, in a room specifically designed to host such discussions. The moderator's guide was used to guide the discussion to ensure that all relevant topics were discussed .

To participants

- Explain the purpose of the focus group. Sample introduction: *"Our overall aim is to gain a comprehensive understanding of the experiences of private guardians. In this group, we'll be talking about your role and experiences as private guardians, how and why you became a private guardian, the issues you face and any problems or needs you might have, how you go about making decisions on behalf of the person you are caring for, your expectations of government, etc.."*

Warm up & Introduction (3 mins)

- Firstly, go around the table and get everyone to introduce themselves, e.g.
 - ~ first name only.
 - ~ how long they have been a guardian.
 - ~ whether they work outside the home.
- Technically, the person for whom they are a guardian is called a "protected person". How do they refer to them? Is there a better or more common term?

Current situations (10 minutes)

- Ask them to tell us a little about the protected person, e.g.:
 - ~ relationship to them.
 - ~ degree of care required.
 - ~ their role in that care - e.g. are they their carer as well as their guardian?
 - ~ ability to be involved in decision-making.
 - ~ how often are they making decisions on the other person's behalf?

Motivation to become a guardian (10 mins)

- For EPGs in particular: At what stage did they become a private guardian - before it was needed (i.e. precautionary) or when some illness or symptoms had begun?
- What motivated them to take on the role?
- Were they asked or did they volunteer? Were there any alternatives?
- What were their thought processes?
- How easy or hard was it to make the decision? Why / why not?

Process (10 mins)

- What process did they go through to becoming a private guardian?
- How clear was it - were they told what to expect? If so, by whom? How clear was the documentation involved? How could that have been improved?
- How long did it take? Were there any costs involved?
- Did they receive any support? From whom? How satisfactory was it? What else would have made a positive difference?
- What information did they get beforehand? What were the sources? How useful was it?
- What would they have like to have received and how?
- What should be improved in the process of becoming a private guardian?

Experiences as guardians (15 mins)

- What are some of the experiences and challenges they have had as a private guardian?
- How have they dealt with them?
- In retrospect, would they have preferred to do things differently? How? Why?
- Are they also the financial administrator for the protected person? If so, how do they find undertaking both roles? If not, who is the administrator and how do they work with them? What do they see as the advantages and disadvantages of being / not being the financial administrator too?

Decision-making and support mechanisms (25-30 mins)

- How do they go about making decisions on behalf of the protected person? What goes through their minds at those times?
- How much, if any, of their decision-making is based on prior discussions with the protected person before they became incapacitated? What are some of the limitations the guardians face while making decisions?
- Do their protected people have an Advanced Directive (explain if necessary)? Have they had occasion to test this with doctors / hospitals / nursing homes / family members? What issues or obstacles have been raised? How have the situations been resolved?
- Can the protected person take part in any decision-making about their lives? Why / why not? Are they able to make any decisions themselves? If not the final decisions, are they able to make their wishes known? How, if at all, are their preferences taken into account?
- How do they interact with the person they are protecting? Can they learn or anticipate what the protected person needs or wants?
- What would they describe as easy decisions and what are difficult decisions for them? Why is that?
- Do they have concerns while making decisions? How do they cope with such concerns?
- How often, if at all, do they consult with others before making a decision? Who / which organisations do they consult?

- How do they go about finding them?
- Have the services they provide been satisfactory? Clear and precise? Costly? Frustrating?
- In what circumstances might they seek a second opinion or supports? How useful have they found others' inputs? Why / why not? How could it be improved?
- How do they explain their situation and the specific decision they are asking advice about?
- Are there things they would like to do differently if other supports were available? What other things would they like to do and what would be required for that to happen?

Government agencies (5-10 mins)

- What government agencies are there that can help them in their roles as guardians (separate to their roles as carers if that applies)?
- Are they aware of OPA? What do they know about OPA? Are there any services they could provide that would help them in their roles as guardians?
- Thinking about their whole experience as guardians, how does the legal structure work for them? How easy, clear, costly, long etc.? What could be improved?

Wrap up and final messages (3 minutes)

- If they had their time over again, would they still become guardians? Why / why not?
- Is there anything that we haven't discussed that would help other people to take on guardianship?
- Any final message for the Office of the Public Advocate, which has commissioned Harrison Research to undertake this research?

THANK FOR PARTICIPATION AND CLOSE.

APPENDIX A3: Questionnaire

**8236 OPA - PRIVATE GUARDIANS SURVEY, NOVEMBER 2011

Q1. ROLE

"Q1 Which of the following applies to you personally? _(PLEASE NOTE: THIS CAN BE MORE THAN ONE)_"

MR

1. Currently Guardian appointed by the Guardianship Board (single or joint)
2. Previously Guardian appointed by the Guardianship Board (single or joint)
3. Currently a Guardian under an Enduring Power of Guardianship (EPG)
4. Previously a Guardian under an Enduring Power of Guardianship (EPG)

5. I ONLY have Power of Attorney for family / friend etc.

6. None of these

7. Not stated

IF 5-6 IN Q1 GO Q99

Q2. HOW LONG GUARDIAN

"Q2. For how long have you been, or were you, a guardian?"

1. Less than 2 years
2. 2 to less than 5 years
3. 5 to less than 10 years
4. 10 to less than 20 years
5. More than 20 years
6. Not stated

Q3. ROLE AS CARER

"Q3 Are you also a carer for the person for whom you are guardian?"

1. Yes, I am their primary carer
2. Yes, one of their carers
3. No, they live independently
4. No, someone else is their carer
5. Other (SPECIFY Q301)
6. Not stated

GO Q4

Q301 OTHER

Q4. TITLE

"Q4 Currently, the person whom you are a guardian is referred to in both legislation and this survey as the 'protected person'. Is this the best description, or is there a better title which would be more suitable?"

1. Protected person is an adequate description
2. Some other title would be better (SPECIFY Q401)
3. Don't know / can't say
4. Not stated

GO Q5

Q401 OTHER TITLE

Q5. PROCESS OF BECOMING A GUARDIAN

"Q5 Thinking back to when you first became a private guardian, can you recall whether it was as a precaution (that is, before it was needed) or as a result of a change in situation for the 'protected person'? _PLEASE NOTE: ACROSS ALL QUESTIONS IF YOU CHOOSE 'OTHER' YOU CAN TYPE UNLIMITED WORDS EVEN THOUGH THE BOX LOOKS SMALL_"

1. As a precaution only
2. Change in situation
3. Something else (SPECIFY Q501)
4. Can't remember
5. Not stated

GO Q6

Q501 SOMETHING ELSE

Q6. ALTERNATIVES

"Q6 Were there other alternatives to you becoming a private guardian to the protected person? If so, what other options were explored first?"

1. No other choices / alternatives available
2. Other relatives could have taken on guardianship role
3. Other option (SPECIFY Q601)
4. Not stated

GO Q7

Q601 OTHER

Q7. DEGREE OF DIFFICULTY IN DECISION MAKING

"Q7 How easy or difficult was it to make the decision to become a private guardian?"

1. Very difficult
2. Quite difficult
3. Neither difficult nor easy
4. Quite easy
5. Very easy
6. Not stated

Q8. WHY EASY OR DIFFICULT

"Q8 Why do you say the decision to become a private guardian was easy or difficult?"

Q9. CHOICES IN FUTURE

"Q9 If you were faced with a similar situation in the future, would you still take on the role of private guardian?"

1. Yes
2. No - why is that? (SPECIFY Q901)
3. Not stated
4. Not sure/depends (SPECIFY Q902)

GO Q10

Q901 REASON WOULDN'T TAKE ON ROLE

Q902 DEPENDS REASON WHY

Q10. INFORMATION SOURCES

"Q10 When first considering becoming a private guardian, what sources of information about the process did you use?"

MR

1. Flyers and fact sheets from the Office of the Public Advocate
2. Advice from medical professional
3. Advice from legal practitioner or agency
4. Advice from financial advisor / bank
5. Word of mouth from other private guardians
6. Word of mouth from other carers
7. Other source (SPECIFY Q1001)
8. Can't recall / don't know
9. None, had no knowledge of process to become a guardian
10. Not stated

GO Q11

Q1001 OTHER

Q11. HELPFULNESS OF INFORMATION

"Q11 Was the information you received helpful in providing sufficient information to make an informed decision about taking on the role of guardian?"

1. Yes, the information was helpful
2. Yes, but needed more information
3. No, it was not helpful
4. Can't recall / don't know
5. No, had no prior knowledge of the process to become a guardian
6. Not stated

Q12. ADDITIONAL INFORMATION

"Q12 What information, or other information, do you think should have been provided to you early in the process?"

BLANK

Q13. OTHER ADVICE AND SUPPORT

"Q13 And thinking about other types of support you may have needed as a person considering becoming a guardian, what else (if anything) would have assisted you with the process of applying to the Guardianship Board, or agreeing to be appointed under an Enduring Power of Guardianship?"

1. No, nothing
2. Suggestion (SPECIFY Q1301)
3. Don't know / can't say
4. Not stated

GO Q14

Q1301 SUGGESTION

Q14. EXPERIENCES AS GUARDIAN

"Q14 Are you also the financial administrator / holder of a power of attorney for the protected person?"

1. Yes
2. No] Q17G
3. Not sure, unofficially handle some but not all financial matters
4. Other (SPECIFY Q1401)
5. Not stated

GO Q15

Q1401 OTHER

Q15. COMBINING ROLES

"Q15 If you undertake both the financial affairs and the guardianship role, how easy is it to combine these two roles?"

1. Very difficult
2. Quite difficult
3. Neither difficult nor easy
4. Quite easy
5. Very easy
6. Do not combine both roles
7. Not stated

*USE 1-5 IF 1 IN Q14

Q16. WHY EASY OR DIFFICULT

"Q16 Why do you say combining both the financial administration and the guardianship role is easy or difficult?"

1. Don't know / can't say
2. Response (SPECIFY Q1601)
3. Do not combine both roles
4. Not stated

*USE 1-2 IF 1 IN Q14

GO Q17G

Q1601 RESPONSE

Q17G. SATISFACTION WITH ASPECTS OF SUPPORT

"Q17G Using a scale from 0 to 10 where 0 is not at all satisfied and 10 is extremely satisfied, how satisfied are you with each of the following aspects? _YOU CAN INDICATE YOU DON'T KNOW IF THAT IS MORE APPROPRIATE FOR YOUR SITUATION_"

1. How well you were assisted with legal advice on the process of guardianship
2. If the Guardianship Board was involved, how confident you were that the Guardianship Board tried to help you find a solution
3. That service providers recognise/d your legal status as a Guardian
4. The sense that you are/were not being judged as a parent/ relative, administrator or guardian
5. The process of lodging annual expense accounts to the Public Trustee is/ was comfortable
6. How well you are/were listened to by the Guardianship Board if you have concerns
7. How helpful the advice is/was that you receive from the Guardianship Board
8. How helpful the advice is/was that you receive from the Office of the Public Advocate
9. How well other family members and friends understood and supported you in your role as guardian

NUM 0-10, D=DK

Q18. COMMENTS ABOUT SPECIFIC ASPECTS

"Q18 Is there anything you would like to expand on with regard to any of these points?"

BLANK

Q19. AWARE OF LEGISLATIVE PRINCIPLES

"Q19 To what extent are you aware of the principles in the legislation which guide decision making for persons with a mental incapacity?"

1. Very unaware
2. Quite unaware
3. Neither aware nor unaware
4. Quite aware
5. Very aware
6. Not stated

Q20G. INFLUENCE OF LEGISLATIVE PRINCIPLES

"Q20G The following are the primary principles in the legislation, mentioned in the previous question. Thinking about these principles, to what extent do they influence your decision making for the protected person for whom you are guardian? Use a 0 to 10 scale, where 0 is not at all influential and 10 is a very influential"

1. What the wishes of the person would have been if he or she had not become mentally incapacitated (where this can be determined)
 2. The present wishes of the person, if these can be expressed
 3. Whether or not existing informal arrangements for the treatment and care of the person are adequate, and should not be disturbed (changed)
 4. Which decision would be the least restrictive of the person's rights and personal autonomy, whilst still ensuring his or her proper care and protection
- NUM 0-10,D

Q21. INTERACTIONS WITH GUARDIANSHIP BOARD OR OFFICE OF PUBLIC ADVOCATE

"Q21 Since becoming a guardian, have you had contact with either the Guardianship Board or the Office of the Public Advocate?"

1. Yes, Guardianship Board
2. Yes, Office of the Public Advocate] Q23G
3. Yes, had contact with both of these
4. No, had no contact at all with either of these] Q24
5. Not stated] Q24OTHER

Q22G. INTERACTIONS WITH GUARDIANSHIP BOARD

"Q22G In terms of interactions with the Guardianship Board, to what extent do you agree with the following statements in relation to your most recent contact with the Board? Use a 0 to 10 scale, where 0 is strongly disagree and 10 is strongly agree and DK if you Don't Know"

1. I was treated fairly
2. I was informed of everything I had to do to become and remain a guardian
3. The Board were knowledgeable and competent
4. The Board went the extra mile to make sure I got what I needed
5. The Board was professional in its dealings with me

FOR EACH

NUM 0-10,D

IF 1 IN Q21 GO Q24

Q23G. INTERACTIONS WITH OFFICE OF PUBLIC ADVOCATE

"Q23G In terms of interactions with the Office of the Public Advocate (OPA), to what extent do you agree with the following statements in relation to your most recent contact? Use a 0 to 10 scale, where 0 is strongly disagree and 10 is strongly agree and DK if you Don't Know"

1. I was treated fairly
2. I was informed of everything I had to do to become and remain a guardian
3. The OPA were knowledgeable and competent
4. The OPA went the extra mile to make sure I got what I needed
5. The OPA was professional in its dealings with me

FOR EACH

NUM 0-10,D

Q24. IMPROVEMENTS TO SERVICE

"Q24 Do you have any suggestions you would like to put forward to improve the services provided by the Public Advocate?"

BLANK

Q25. INTEREST IN IN-DEPTH DISCUSSIONS

"Q25 To make sure we gain the most from this research, we will be running some in-depth interviews in the next few months, which will look more closely at the experiences of private guardians. This would provide you with an opportunity to expand on any issues or concerns you may have. Would you be interested in participating in a final stage of the research through either a telephone call or a face to face interview (whichever is most convenient to you)?"

PLEASE NOTE - THIS IS ENTIRELY VOLUNTARY, YOU DO NOT HAVE TO AGREE TO FURTHER DISCUSSIONS IF THAT IS YOUR PREFERENCE."

1. Yes

2. No

IF 2 IN Q25 GO Q27JP

Q25A DETAILS

"Q25A Please provide contact details below. Someone from Harrison Research will contact you by phone to arrange a suitable time for interview."

MR

1. Contact name* (SPECIFY Q25A01)

2. Best contact number* (SPECIFY Q25A02)

3. Best time to call (SPECIFY Q25A03)

GO Q26JP

Q25A01 NAME

Q25A02 CONTACT NO.

Q25A03 BEST TIME TO CALL

Q26. GENDER.

"Q26 What is your gender?"

1. Male

2. Female

3. Not stated

Q27. AGE

"Q27 Which age bracket are you in?"

1. Under 35 years

2. 35-44

3. 45-54

4. 55-64

5. 65-74

6. Over 74 years

7. Not stated

Q28. HOUSEHOLD

"Q28 Which of these best describes your household?"

1. Lone person household
2. Group household of related or unrelated adults
3. Young couple, no children
4. Older couple, no children at home
5. Couple or single parent with mainly pre-school children
6. Couple or single parent with mainly primary-school children
7. Couple or single parent with mainly teenage children
8. Couple or single parent with mainly adult children still living at home
9. Not stated

Q29. EMPLOYMENT STATUS

"Q29 What is your employment status?"

1. Part-time employment
2. Full-time employment
3. Unemployed
4. Home duties
5. Pensioner (non-age pension)
6. Retired / age pensioner
7. Student
8. Not stated

IF 3-7 IN Q29 GO Q31

Q30. OCCUPATION

"Q30 Which of these best describes your occupation?"

1. Manager / administrator
2. Professional
3. Associate professional
4. Tradesperson / related worker
5. Advanced clerical, sales & service worker
6. Intermediate clerical, sales & service worker
7. Intermediate production and transport worker
8. Elementary clerical, sales & service worker
9. Labourer / related worker
10. Not stated

Q31. POSTCODE

"Q31 What is your postcode? _IF DON'T KNOW PLEASE TYPE 9999_"

NUM

That concludes the survey. On behalf of the Office of the Public Advocate and the Guardianship Board, as well as Harrison Research, thank you again for your valuable input.



APPENDIX A4: INTRODUCTION LETTER

Telephone
8342 8200

Reference: OPA 4693

9 January 2012

Dear Guardian,

I am writing to invite you to be part of a survey about being the guardian of an adult. The Office of the Public Advocate wants to better understand the issues and problems involved in being a guardian. We'd like to hear from you about your experiences, and your ideas about the services and supports that could assist guardians.

The Office of the Public Advocate obtained names and contact details of 800 guardians with the consent of the Guardianship Board. The Board agreed we could write to guardians the Board has appointed under a Guardianship Order, to invite you to be part of this research. Please be assured your name and details will not be released to anyone else, or used for any other purpose, and you can participate in the survey anonymously.

Harrison Research has been commissioned to undertake the research. It is, as far as we know, the first survey asking guardians about their views and experiences and we are keen to hear from as many guardians as possible. Responses will be anonymous and will be collated and analysed by Harrison Research, who will provide a report to the Office of the Public Advocate. We will publicise the outcomes of the survey on our website and in our Annual Report. The findings will inform our services and recommendations for future information and support for guardians.

Please note that a guardian is someone who makes decisions about health care, accommodation and personal circumstances on behalf of someone else who cannot make those decisions for themselves. Guardians can be appointed in two ways: by the person who they will make decisions for (under an Enduring Power of Guardianship), or, by the Guardianship Board, under a Guardianship Order.

If this applies to you, then we would like to hear from you. Enclosed with this letter is a survey form and a reply paid envelope. You can either:

1. complete this form and post it to Harrison Research,

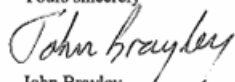
or, if you prefer,

2. complete the survey on-line. You will find a link to the on-line survey on the Office of the Public Advocate website www.opasa.sa.gov.au or on the Harrison Research website : www.harrisonresearch.com.au

We are very keen to hear your views and encourage you to be part of this study. Please return the completed form before 30 January 2012, or complete the on-line survey.

If you have any questions about this research you can contact the Office of the Public Advocate on 8342 8200, or Harrison Research on 8490 4200.

Yours sincerely



John Brayley
Public Advocate



PUBLIC ADVOCATE

■ 7th Floor ABC Building
85 North East Road
Collinswood SA 5081

■ PO Box 213
Prospect SA 5082

■ Email:
opasa@opa.sa.gov.au
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■ Ph (08) 8342 8200
Country Callers:
1800 056 969 Toll Free
Fax: (08) 8342 8250

The letter alongside was attached to the paper-copy questionnaire when posted to the list of Board-appointed Guardians.

The online survey was promoted via a poster sent to support organisations. The same information (except condensed) was provided on the poster as is shown here in the letter.



APPENDIX A5: IN-DEPTH TOPIC GUIDE

8236 OPA – TOPIC GUIDE FOR FOLLOW-UP IN-DEPTH INTERVIEWS

Process involved in becoming a guardian (10 mins)

- Briefly, what process did they go through to become a private guardian? (i.e. through a lawyer, medical professional, Guardianship Board etc.)
- How clear was the process? Were they told what to expect? If so, by whom? How clear was the documentation involved? How could that have been improved?
- Were there any costs involved? Were these reasonable?
- Did they receive any support? From whom? How satisfactory was it? What else would have made a positive difference?
- What information did they get beforehand? What were the sources? How useful was it?
- What should be improved in the process of becoming a private guardian?

Experiences as guardians (10 mins)

- Briefly, what are some of the experiences and challenges they have had as a private guardian?
- How have they dealt with them?
- In retrospect, would they have preferred to do things differently? How? Why?

Decision-making and support mechanisms (15 mins)

- How do they go about making decisions on behalf of the protected person? What goes through their minds at those times?
- (DO NOT ASK IF YOU ARE TALKING TO A GUARDIAN OF AN ADULT CHILD WITH INTELLECTUAL DISABILITIES) How much, if any, of their decision-making is based on prior discussions with the protected person before they became incapacitated?
- What are some of the limitations / difficulties they face while making decisions?
- (DO NOT ASK IF YOU ARE TALKING TO A GUARDIAN OF AN ADULT CHILD WITH INTELLECTUAL DISABILITIES) Does their protected person have an Advance Directive (explain if necessary)? Have they had occasion to test this with doctors / hospitals / nursing homes / family members? What issues or obstacles have been raised? How have the situations been resolved?
- Can the protected person take part in any decision-making about their lives? Why / why not? Are they able to make any decisions themselves? If not the final decisions, are they able to make their wishes known? How, if at all, are their preferences taken into account?
- How do they interact with the person they are protecting? Can they learn or anticipate what the protected person needs or wants?
- Do they have concerns while making decisions? How do they cope with such concerns?

Legislative framework for decisions (10 mins)

1. How often, if at all, do they consult with others before making a decision? Who / which organisations do they consult?
2. How do they go about finding them?
3. Do they use legal advice to assist them in making decisions? Which decisions?
4. Are they aware of the legislative framework to guide their decisions on behalf of the protected person? To what extent are they guided by this framework?

Support mechanisms (10 mins)

1. What advice would they give to anyone who asks them about becoming a Guardian?
2. What types of support would they suggest they access, to provide them with information and a framework for being a guardian? PROBE FOR DVD OF PROCESSES, ONLINE RESOURCES, PLAIN ENGLISH EXPLANATIONS, OTHER LANGUAGES, ETC.
3. What external advice or sources of information have they accessed? What else would have been helpful? How should this information be provided to them?
4. Which, if any, support groups or special interest groups are they associated with? How helpful are these in providing advice and support for Guardians?
5. What other supports would help them to make decisions for their protected person?
6. Would a "Guardians Support Group" or Advocacy Group help? What other ideas for providing Guardians with support can they suggest? PROBE FOR NEWSLETTERS OR REGULAR CORRESPONDENCE FROM THE OPA OR BOARD, DATABASE OF EPG'S TO KEEP THEM INFORMED OF LEGISLATIVE AND OTHER CHANGES, HELPLINE FOR GUARDIANS TO ASSIST AND GUIDE THEM IN DECISION-MAKING. ANYTHING ELSE?

That concludes the interview. On behalf of the Office of the Public Advocate and the Guardianship Board, as well as Harrison Research, thank you again for your valuable input.