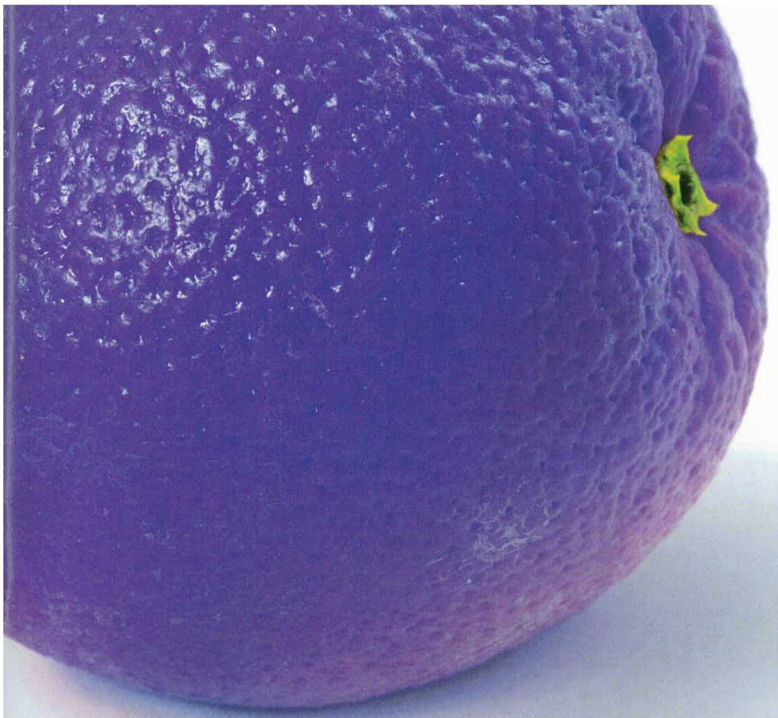

julia farr association

The experiences of people living with disability accessing primary healthcare - Challenges and Considerations

Research Report

THE EXPERIENCES OF PEOPLE LIVING WITH DISABILITY ACCESSING PRIMARY HEALTHCARE – CHALLENGES AND CONSIDERATIONS

RESEARCH REPORT

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TABLE OF CONTENTS

1.0 SUMMARY 2

2.0 INTRODUCTION 2

3.0 RESEARCH METHODOLOGY 3

4.0 SURVEY RESULTS 4

4.1 GP Clinic Accessibility **4**

4.1.1 Access to the building and reception area where GP works 4

4.1.2 Access to consulting room 5

4.1.3 Ability to get onto examination tables 6

4.1.4 Access to and use of bathroom facilities 7

4.2 Relationship with GP **8**

4.2.1 Level of knowledge GPs have about a person's disability and how this relates to overall health 8

4.2.2 Extent that GPs are confident and relaxed when supporting a person living with disability 9

4.2.3 Time taken by GPs to explain 9

4.2.4 Quality of service provided by GPs 10

4.3 Choice of GP **12**

4.4 Future Use of GP Services **13**

5.0 DISCUSSION 14

5.1 GP Clinic Accessibility,. **14**

5.2 Relationship with GP **15**

5.3 GP of Choice **15**

6.0 CONSIDERATIONS 16

6.1 Strengthening GP understanding of accessible facilities **16**

6.2 Strengthening GP communication with people living with disability **18**

6.3 Strengthening GP knowledge about people's experiences living with disability **18**

6.4 Reducing barriers to making a choice of GP **19**

7.0 CONCLUSION and RECOMMENDATIONS 20

8.0 DISCLAIMER 21

9.0 REFERENCES 22

1.0 SUMMARY

General Practitioners (GPs) perform a crucial function in the provision of primary healthcare to people living with disability in our community, with reliance on this support continuing to grow.

A survey exploring the experiences of people living with disability accessing their local GP service was distributed via South Australian disability community networks in May 2009. Based on the 52 responses, the results highlighted that in general people living with disability were satisfied with GP services. However, a range of concerns and issues were raised about the challenges people faced when visiting their GP, highlighting the need for further work to improve access to GPs.

This report discusses the survey findings in terms of how GPs can enhance the quality of service they provide to people living with disability. The key considerations focused on:

- improving GP clinic awareness about physical access obligations;
- increasing GP knowledge and experience about disability and how to effectively communicate with people living with disability;
- finding out more about the barriers that prevent people from accessing their GP of choice.

These considerations are a useful focus for further work in the area.

2.0 INTRODUCTION

GPs play a very important part in the provision of primary healthcare to our community. They provide the first point of contact for people seeking medical assistance as they have "the skills and experience to provide whole person, comprehensive, coordinated and continuing medical care" (Western Australian General Practice Network 2009, p.1). The valued role of GPs is reinforced by the fact that on average over 80 percent of the Australian population see their GP each year (Western Australian General Practice Network 2009).

The role GPs play in supporting people living with disability has grown significantly over the past couple of decades, due to more people moving out of institutions into community housing arrangements, and the increasing numbers of people living with disability due to Australia's ageing population (Australian Institute of Health and Welfare 2009; Fidock & Williams 2009). This growing reliance on GPs responding to the health needs of people living with disability has highlighted some of the difficulties people have experienced when accessing their local GP. The difficulties

include people not being able to physically access clinic facilities, GPs not having sufficient knowledge about a person's disability to respond to his or her individual health needs, and communication barriers (Senate Community Affairs Committee Secretariat 2007).

To identify ways that access to GPs can be further improved, the Julia Farr Association developed a survey to seek feedback from people living with disability about their experiences and views on the ease of access to, and quality of service from, their local GP.

3.0 RESEARCH METHODOLOGY

The questions for the survey focused on gathering feedback from respondents about their experiences in two key areas:

- GP clinic accessibility;
- Relationship with their GP.

The questions on GP clinic accessibility focused on:

- the ease of access people had getting into the GP clinic and its facilities including the reception area, consulting rooms and bathroom;
- whether people were able to get onto examination tables when required.

The questions on the relationships people had with their GP focused on whether the GP:

- provided a good service;
- had good knowledge about the survey respondent's disability;
- was relaxed and confident when supporting the individual;
- took time to explain things to make it easier for the individual to understand.

Survey respondents were also asked if they chose their local GP and whether they would go to see their GP more often to help them to stay well if their GP had better knowledge and interest in the nature of their disability.

For each survey question, respondents were asked to circle their response on a Likert scale[1] which best reflected their experiences. The Likert scale used for this survey included five response levels: *strongly disagree, somewhat disagree, neither*

[1] A Likert scale is designed to measure the extent that people agree or disagree with a statement (Encarta World English Dictionary 2009).

agree nor disagree, somewhat agree and *strongly agree*. The survey also provided respondents with the opportunity to comment on the responses they provided.

The survey was distributed through disability community networks via the Julia Farr Association website and email distribution list, and through its inclusion in the Community Support Incorporated newsletter *Networx*. Surveys were collected during the month of May 2009. The nature of the methodology meant that participants were self-selected.

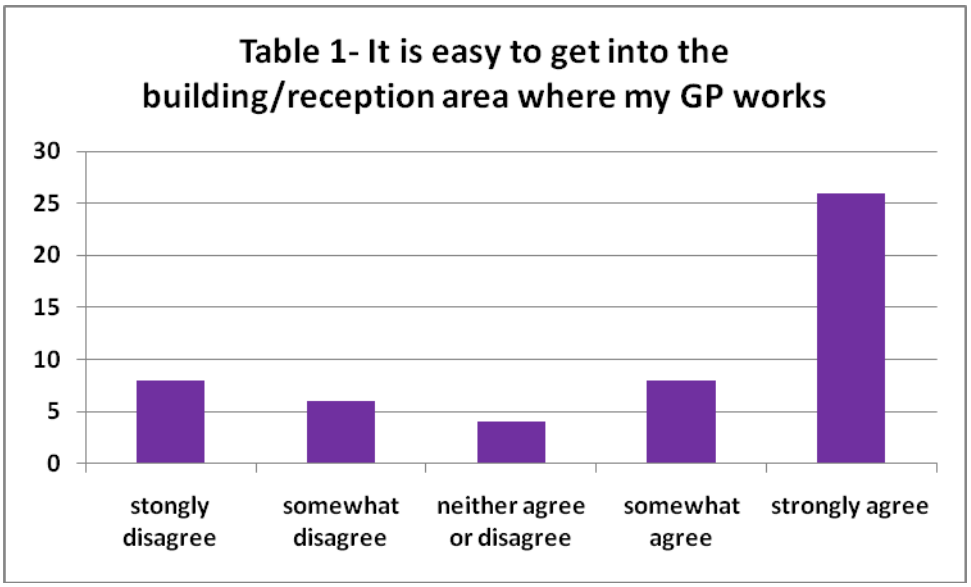
4.0 SURVEY RESULTS

A total of 52 surveys were returned. Below is a summary of the experiences and views expressed by survey respondents. Note that the survey tool did not require the respondent to divulge the type of disability they live with.

4.1 GP CLINIC ACCESSIBILITY

4.1.1 ACCESS TO THE BUILDING AND RECEPTION AREA WHERE GP WORKS

Over 65% of survey respondents agreed with the statement that it was easy for them to access the building/reception area where their GP works (26 *strongly agreed* and eight *somewhat agreed*).



The comments provided by those who felt that they had good access to their GP's building and reception area highlighted that respondents were happy with the design of the facilities such as the presence of automated doors, ramps, wide entrances and open spaces. However, some

concerns were raised, for example about entry doors being too heavy and difficult to open, ramps being hard to coordinate and car parks being hard to move across because of a gravel surface.

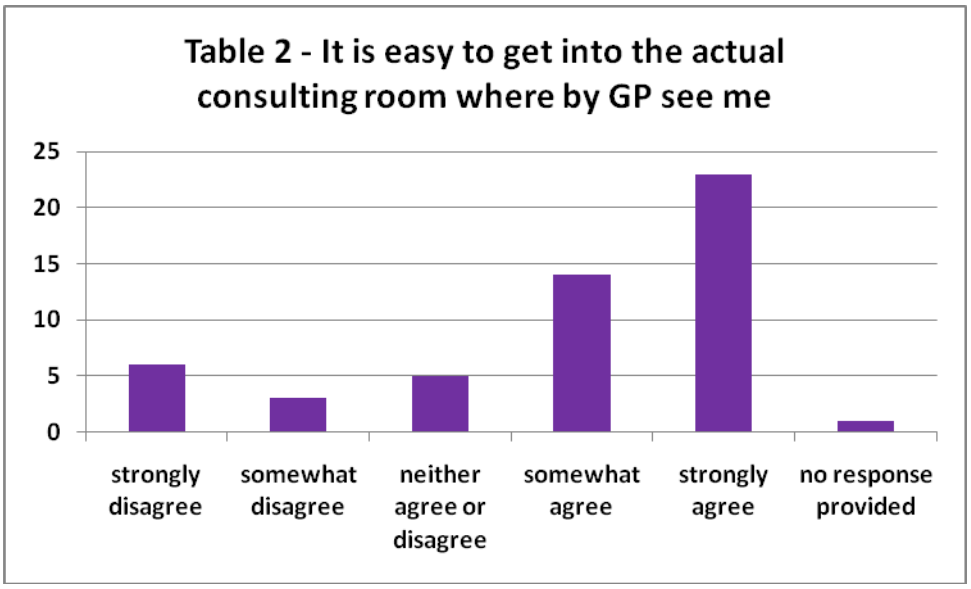
A smaller number of respondents identified having difficulty accessing the building and reception area of their GP's clinic, with eight *strongly disagreeing,* and six *somewhat disagreeing,* that they had ease of access to these areas.

Respondents identified a number of barriers that prevented them from having appropriate access to their GP's clinic. These included:

- the reception counter was not accessible;
- doorways were too narrow;
- there was only a single manual door entrance;
- no accommodations were made for people who have low or no vision.

4.1.2 Access to consulting room

Over 71% of survey respondents agreed with the statement that it was easy for them to access their GP's consulting room (23 *strongly agreed* and 14 *somewhat agreed*).



The comments made by those who *somewhat agreed* highlighted some barriers to access. These included:

- corridors being poorly lit and not being wide enough to accommodate people using a wheelchair or walker;
- access to consulting rooms being obstructed by equipment;
- doors being difficult to open and manoeuvre through;

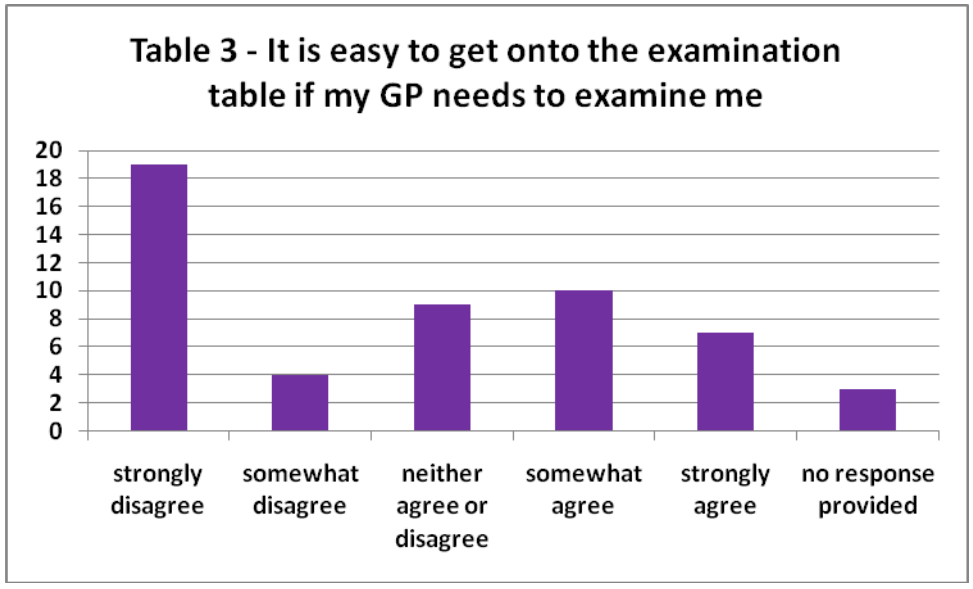
- consulting rooms not being large enough for people who use a wheelchair.

The remaining 14 respondents either disagreed (nine people) or *neither agreed nor disagreed* with the statement about ease of access to their GP's consulting room. The main challenges they identified were narrow corridors, the rooms not being big enough to accommodate people who use wheelchairs, and no provisions made for people who are blind or have low vision.

4.1.3 Ability to get onto examination tables

Over 44% of the survey respondents disagreed with the statement that it was easy for them to get onto their GP's examination table (19 *strongly disagreed* and four *somewhat disagreed*).

Over 32% agreed it was easy for them to transfer to their GP's examination table with seven strongly agreeing, and 10 somewhat agreeing. The remaining 9 respondents (over 23%) neither agreed nor disagreed with the statement.

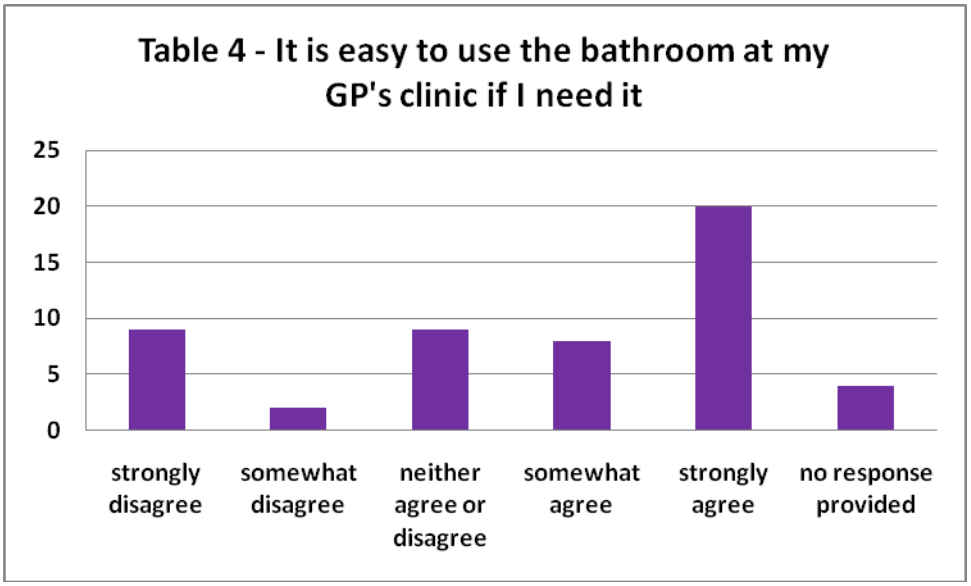


The key barriers that prevented respondents from using examination tables were that they were too high and not adjustable. Many highlighted the only way they could get onto the examination table was by using steps or being assisted by others or by a lifter to get onto the table. This assistance was not always available or suitable, making transferring to the examination table difficult for a number of respondents. In one situation a respondent had to be transferred onto the examination table using a

height adjustable plinth as no lifting supports were available to access the table. This made the individual feel insecure and vulnerable.

4.1.4 Access to and use of bathroom facilities

Nearly 54% of survey respondents agreed with the statement that it was easy for them to use the bathroom at their GP's clinic (20 *strongly agreed* and eight *somewhat agreed)*. In comparison, over 21% disagreed (nine *strongly disagreed* and two *somewhat disagreed)*. A further 9 respondents *neither agreed nor disagreed*.



The comment made by those who *neither agreed nor disagreed* was that they had not used the bathroom facilities.

Those respondents happy with the access they had to the bathroom facilities stated that they were clean, had grab rails and were easy to get into. However, some highlighted that although their GP practice had attempted to make the toilet more accessible, it was still too small for a person using a wheelchair.

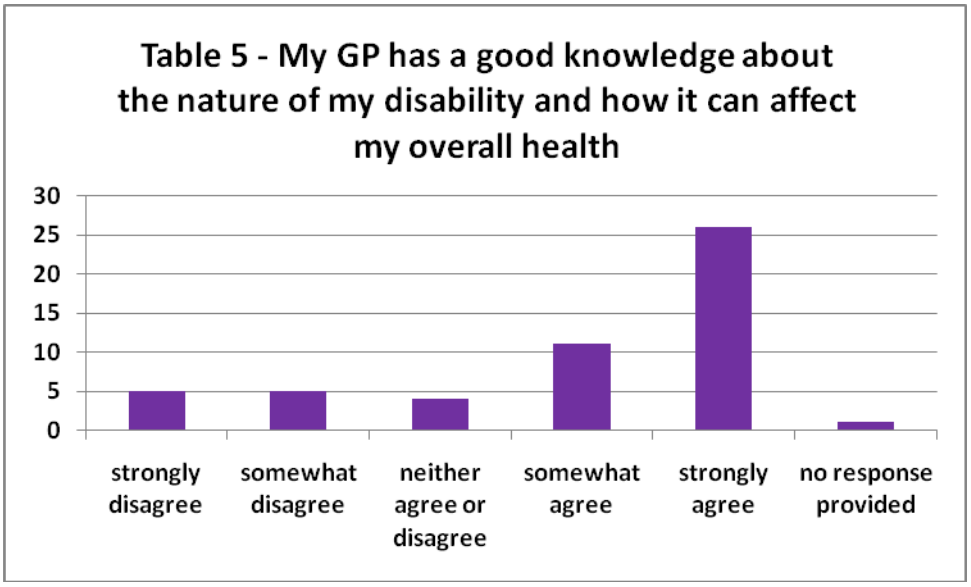
Other barriers identified by survey respondents were:

- toilet doors opening inwards which made it difficult to access;
- toilets being used to store equipment;
- not being able to physically enter the toilet facility;
- only having one toilet available for use.

4.2 RELATIONSHIP WITH GP

4.2.1 LEVEL OF KNOWLEDGE GPS HAVE ABOUT A PERSON'S DISABILITY AND HOW THIS RELATES TO OVERALL HEALTH

Half of the survey respondents (26 people) stated that they *strongly agreed* with the statement that their GP had good knowledge about the nature of their disability and how it can affect their overall health. A further 21% (11 respondents) stated that they *somewhat agreed*. In comparison, just over 19% (10 respondents) disagreed with this statement and four *neither agreed nor disagreed*.



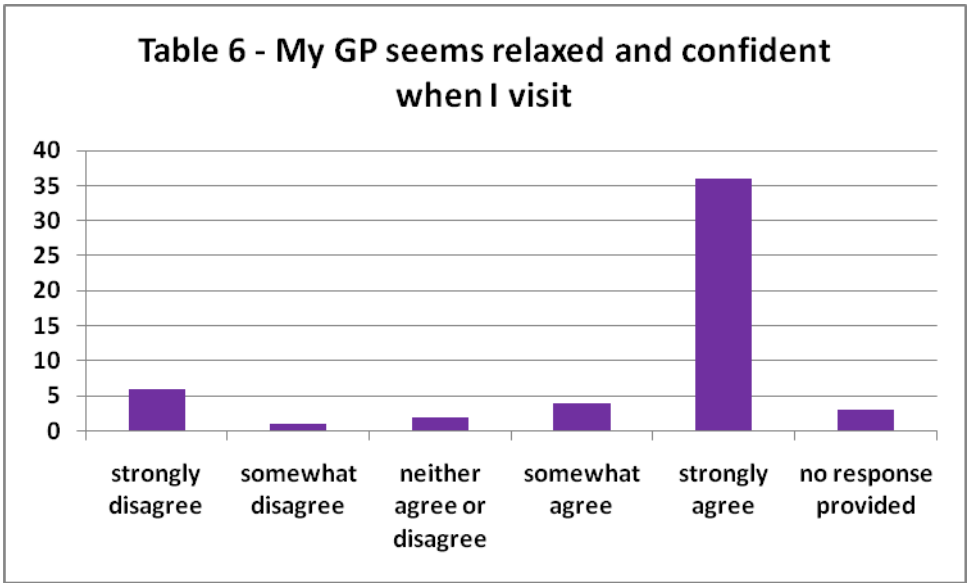
The key reasons why respondents felt that their GP had a good knowledge about their disability were:

- their GP understood their health issues or was willing to learn more about their disability to stay on top of complicated health issues and medication management;
- there was good communication and rapport.

The main explanation given by those who disagreed was that their GP lacked sufficient knowledge about their disability and their personal health needs. Some respondents reported feeling annoyed and distrustful because of this.

4.2.2 EXTENT THAT GPS ARE CONFIDENT AND RELAXED WHEN SUPPORTING A PERSON LIVING WITH DISABILITY

Over 69% of respondents (36 people) *strongly agreed* and four *somewhat agreed* with the statement that their GP seemed relaxed and confident when they visited. A minority of respondents (seven people) disagreed.



One of the reasons why respondents felt that their GP was very confident and relaxed when supporting them was because they had known their GP for a number of years and developed a good relationship over this time.

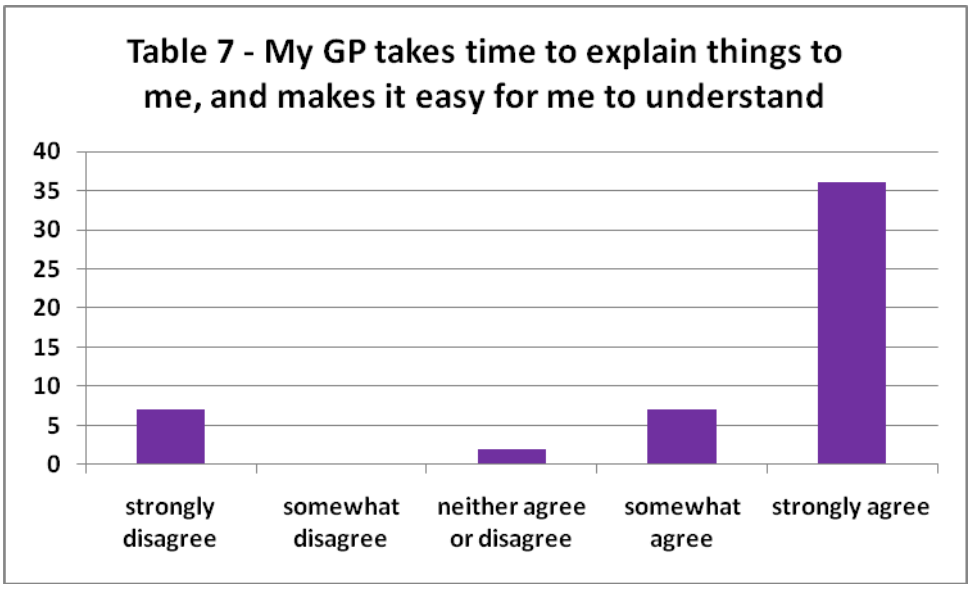
In contrast, those who felt their GP lacked confidence supporting them stated that their GP:

- demonstrated a lack of knowledge about their support needs;
- did not communicate effectively;
- seemed uncomfortable at times.

One respondent commented that many GPs are not very good at supporting family members either.

4.2.3 TIME TAKEN BY GPS TO EXPLAIN

Over 82% of survey respondents agreed with the statement that their GP took time to explain and made things easy to understand (36 *strongly agreed* and seven *somewhat agreed)*. Seven people *strongly disagreed* and two *neither agreed nor disagreed*.



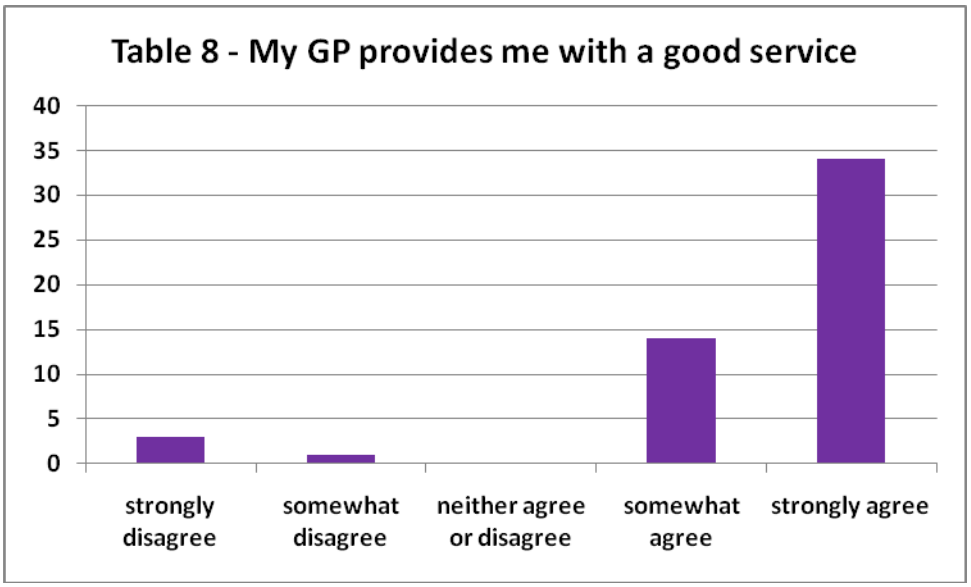
Some respondents reported that their GP took the necessary time to thoroughly explain things and was prepared to answer questions to help clarify. In the case of one respondent the GP was willing to examine referenced material during consultations and discuss this openly. However, some respondents highlighted that despite these efforts they still had difficulty, at times, understanding what their GP was saying.

The respondents who felt their GP did not take time to clearly explain reported that their GP:

- only explained what he or she wanted to explain;
- treated the respondent as if he or she did not understand;
- spoke to the respondent's support person, not the respondent;
- did not treat the respondent with dignity and respect.

4.2.4 Quality of service provided by GPs

Over 92% of survey respondents agreed with the statement that their GP provided them with a good service (34 *strongly agreed* and 14 *somewhat agreed*). Three respondents *strongly disagreed* with this statement with one *somewhat disagreeing*.



Survey respondents who *strongly agreed* that their GP provided a good service commented that they felt comfortable talking to their GP about issues, expressed confidence that their GP would provide the right advice and highlighted their GP's willingness to take time out after hours to respond to their health issues.

Survey respondents not happy with the service said their GP:

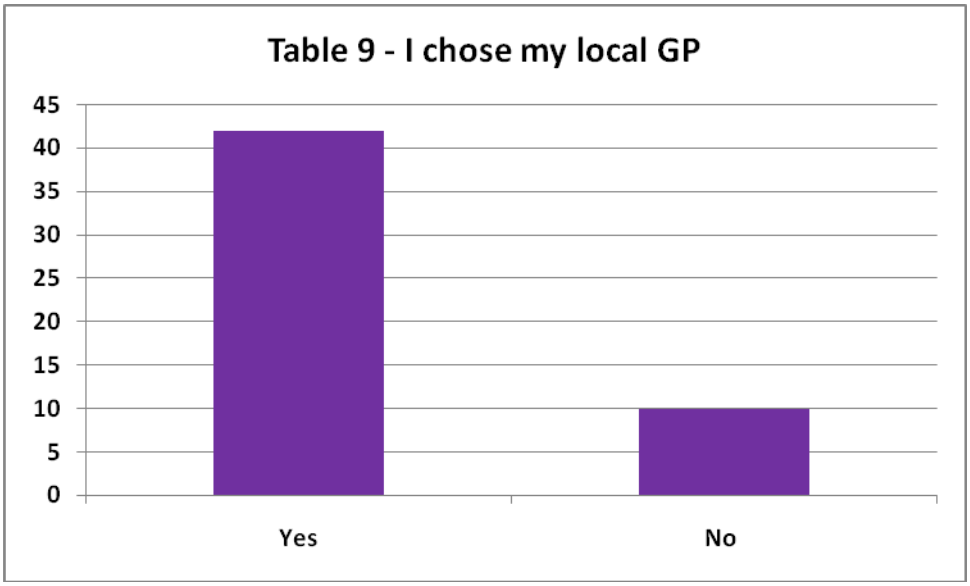
- lacked sufficient knowledge about their disability;
- was not always available;
- did not provide extra support when required;
- did not explain why medication was required;
- required them to visit for repeat prescriptions even though extra time and resources were needed to do so.

One respondent also highlighted the view that GPs lacked knowledge about the Medicare incentives available to assist GPs to support people living with disability, or were not willing to use these initiatives. For example:

> *"I have been effectively teaching my GP about new medicare initiatives. Lots of people in my network of disabilities say their GPs are ill-informed about medicare initiatives or are not keen to fill out forms for them to access the initiatives."*

4.3 CHOICE OF GP

A total of 42 survey respondents (over 80%) stated that they chose their local GP.



Those respondents that did not choose their local GP reported that either their accommodation service chose their GP or they were unable to access the clinic and had to rely on a locum service to visit them at home.

Out of the 42 respondents who chose their GP, a high percentage expressed satisfaction with the service provided by their GP agreeing that their GP:

- had good knowledge about their disability and how it can affect their overall health (over 78%);
- was confident and relaxed during consultations (over 85%);
- took time to explain things (over 90%);
- provided a good service (over 97%)

In comparison, the 10 respondents who did not choose their GP reported dissatisfaction with the service they received with:

- half stating that their GP did not have good knowledge about their disability;
- 40% stating their GP was not relaxed or confident when providing them with support;
- 30% highlighting that their GP did not take time to explain things;
- one fifth believing that their GP did not provide a good service.

4.4 Future Use of GP Services

Over 21% of survey respondents stated that they agreed with the statement that they would go to see their GP more to help them stay well if their GP had better knowledge about their disability (seven *strongly agreed* and four *somewhat agreed*).

Although respondents indicated they would visit their GP more regularly if their GP had increased knowledge about their disability, some identified barriers to doing this such as GP visits costing too much and their GP not being readily available.

Twice as many respondents (over 42%) disagreed with the statement that they would see their GP more if they had better knowledge about their disability (15 *strongly disagreed* and 7 *somewhat disagreed*).

Respondents who disagreed highlighted they did not need to see their GP more as they only went when required and they were satisfied with their GP's knowledge about their disability and the quality of service provided.

Over 30% of survey respondents (16 people) stated that they *neither agreed nor disagreed* with the statement.

Respondents who *neither agreed nor disagreed* highlighted that they already visited their GP on a regular basis and that their GP had sufficient knowledge and interest in their disability. However, a couple of respondents did suggest that GPs should have greater knowledge about support services available in

the community to ensure that people had access to the necessary information and supports they required. It was also suggested by one respondent that a 'one-stop' website or resource tool be established to advise GPs about community supports, therapy and Medicare incentives available.

5.0 DISCUSSION

52 surveys were returned by members of the South Australian disability community. While this cannot be declared a representative sample, the experiences and views expressed by respondents mirror findings from a range of research studies and inquiries in Australia and overseas on the experiences of people living with disability accessing their local GP. The survey findings also illustrate a range of issues that warrant further consideration and examination.

5.1 GP CLINIC ACCESSIBILITY

Over 65% of survey respondents agreed with the statement that it was easy for them to access the building/reception area where their GP works and over 71% agreed that it was easy for them to access their GP's consulting room.

These results are promising as they suggest at least some GP practices have worked to make their facilities more accessible through installing aids such as automated doors and ramps.

It appears that more work is required in this area with respondents identifying a range of barriers to physically accessing their GP clinic. These include not being able to access the reception counter, not having enough space available for people to manoeuvre their wheelchair, and no accommodation being made for people who have a vision impairment.

This need for improved accessibility is further supported by the finding that over one in five respondents expressed difficulty accessing and using bathroom facilities at their GP clinic.

23 respondents (over 44%) were also unable to get onto examination tables due to tables not being adjustable or being too high. It is surprising that this statistic was not higher, as research undertaken in 2003, which focused on the extent to which people living with disability had access to adjustable height examination tables in GP clinics across Australia, identified that in South Australia only 85 out of 1,812 (or under 5%) of examination tables were adjustable (King 2003).

5.2 RELATIONSHIP WITH GP

A very high percentage of survey respondents felt that their GP provided a good service (over 92% people), with an average of around three quarters expressing agreement that their GP had good knowledge about their disability and associated health needs, was confident and relaxed when providing support, and took sufficient time to give full explanations. A number of reasons for this level of satisfaction were provided by respondents including GPs having a good rapport with respondents, GPs demonstrating a willingness to learn about a person's disability, and GPs allocating additional time to explain issues and answer questions.

These experiences suggest at least some GPs in the South Australian community are taking measures to ensure they provide a quality service to people living with disability. However, the survey findings show that some people are still experiencing situations where they are not receiving such a service. The findings highlight that an average of one out of five respondents felt their GP did not provide a quality service due to factors such as their GP not communicating effectively, not taking time to explain, and lacking sufficient understanding about their needs.

5.3 GP OF CHOICE

Having choice about the GP you visit can have a significant impact on the quality of service you receive, as evidenced by the survey findings, where those who had the option to choose their GP were more satisfied with their GP service in all areas surveyed. In comparison, those who did not make this choice felt disrespected and frustrated that their needs were not being met. Such occurrences are reinforced by findings elsewhere, reporting that having lack of choice and control is likely to result in people feeling discouraged and disempowered and "contribute to people living with disability not receiving the support they require" (Fidock & Williams 2009, p. 10).

6.0 CONSIDERATIONS

The following considerations are offered with the recognition that GPs typically have heavy workloads, and are expected to carry a critical level of knowledge on a wide range of healthcare topics. It is clear from the survey feedback that in general people value their GP's service, and it is important that the following considerations be approached in a way that is not overly burdensome for GPs and their support staff.

6.1 STRENGTHENING GP UNDERSTANDING OF ACCESSIBLE FACILITIES

The survey findings highlight a need to look at ways to provide more information to GP clinics about what is legally required to make their facilities accessible for people living with disability and how they can go about achieving this.

The Royal Australian College of General Practitioners, the largest representative body in Australia for GPs (Royal Australian College of General Practitioners 2008), has developed Standards for General Practices which "provide guidance and direction in safe, comprehensive and quality health care in the Australian general practice setting" (Royal Australian College of General Practitioners 2007a, p. 1). Criterion 5.1.3 of these standards focuses on the need to provide GP premises and services that are physically accessible for people living with disability (Royal Australian College of General Practitioners 2007b). This criterion provides information about what GP clinics need to consider in regards to improving physical accessibility including the provision of height-adjustable examination tables. It also recommends that GP clinics refer to the Australian Standards[2] that relate to the access of people living with disability to buildings. Brief reference is also made to complying with the Commonwealth Disability Discrimination Act 1992 and the rights of people living with disability to access general practices (Royal Australian College of General Practitioners 2007a). However, as GPs are not mandated or required to undertake formal accreditation against these standards, instead having the option to self-assess whether they have achieved these standards (Royal Australian College of General Practitioners 2007a; n.d.), there is no guarantee that GP clinics will adopt these measures or have adequate information to identify whether their facilities are appropriately accessible.

Not being able to physically access GP clinics and facilities can potentially impact on the quality of health support that people living with disability receive from their GP. In the case of examination tables, evidence suggests that approximately one in ten people are not examined by their GP due to being unable to get onto a

[2] More information Australian Standard AS 1428, which provides design requirements for buildings encompassing the specific needs of people living with disability, can be found at: http://infostore.saiglobal.com/store/Details.aspx?ProductID=1380768

fixed height examination table. This creates “the potential for misdiagnosis or non-detection of serious medical conditions” (Physical Disability Council of NSW 2009, p. 5).

It is important that GP clinics have greater awareness of their international and national obligations to provide equity of access to their facilities and services for people living with disability. The United Nations Convention on the Rights of Persons with Disabilities, ratified by Australia in July 2008, highlights that people living with disability “have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability” (United Nations n.d., p. 18). An inability to physically access GP clinics and services can directly impact on this right.

The importance of providing equitable access is further strengthened by the Commonwealth Disability Discrimination Act 1992 which “provides protection for everyone in Australia against discrimination based on disability” (Australian Human Rights Commissioner n.d., p. 1) by making it against the law for public premises to be inaccessible. The Act refers not only to buildings, car parks and pathways but “also covers issues such as fit out design (for example, the height of service counters) and the way premises are maintained and managed (for example, ensuring accessible toilets are not used as storage spaces or overhanging branches do not result in a barrier on a path of travel)” (Small 2003, p. 1).

Currently there exists a range of detailed regulations and standards across different levels of government, including the Building Code of Australia and Australian Standard 1428[2], all of which apply to the accessibility of the built environment.

To assist in ensuring compliance with the Commonwealth of Australia Disability Discrimination Act 1992, and address any gaps, draft Disability (Access to Premises – Buildings) Standards have been developed “to give certainty to building certifiers, building developers and building managers that, if access to buildings is provided in accordance with these Standards, the provision of access, to the extent covered by these Standards, will not be unlawful under the Act” (*Draft Disability (Access to Premises – Buildings) Standards 2009, p. 2*). These standards[3] were tabled in federal parliament on 15 March 2010 and will commence operation on 1 May 2011, to “allow States and Territories time to

[3] More information on the Disability (Access to Premises - Buildings) Standards 2010 can be found at: http://www.comlaw.gov.au/ComLaw/legislation/LegislativeInstrument1.nsf/0/F1E48F0BD27FFCF4CA2576E2008071DD?OpenDocument

adopt the Premise Standards within their building law frameworks" (Attorney-General's Department 2010, p. 1).

If GP clinics had ready access to information about providing equity of access to people living with disability, they would be better equipped to improve facilities and services.

6.2 Strengthening GP communication with people living with disability

There is a strong link between the provision of quality primary healthcare to people living with disability and the presence of effective communication (Cook & Lennox 2000; Ziviani et al. 2004). If good communication is not present it can result in people living with disability feeling frustrated and potentially impacts on the capacity of GPs to diagnose health concerns and prescribe appropriate treatments (Ziviani et al. 2004).

Research has identified that some of the key factors that contribute to ineffective communication between GPs and people living with disability are:

- GPs minimising the interactions they have with people through reduced eye and physical contact;
- GPs not speaking directly to individuals;
- GPs not using alternative means of communication to assist (Ziviani et al. 2004).

In order to improve the communication that exists between GPs and people living with disability, GPs may need to access more information about how they can effectively communicate with people living with disability. This can include, for example, GPs encouraging people living with disability to actively contribute to consultations, and employing "alternative methods for seeking information or transmitting information" (Ziviani et al. 2004, p. 222) such as using photographs, diagrams or models of the body to discuss health issues and treatments.

6.3 Strengthening GP knowledge about people's experiences living with disability

The survey findings indicate the need for greater GP awareness of a person's specific disability and the supports available.

Evidence suggests that GPs with insufficient knowledge about a person's disability are less likely to provide a quality service (Cook & Lennox 2000). This lack of understanding can lead to people living with disability not having their health needs met due to misdiagnosis or 'diagnostic overshadowing' (Disability Rights Commission n.d.) which occurs "when a person's symptoms or conditions is wrongly attributed to their disability rather than a separate medical condition" (Senate Community Affairs Committee Secretariat 2007, p. 119).

To increase the knowledge and awareness of GPs about living with disability, it has been suggested, as a result of research conducted by the Disability Rights Commission in England and Wales on the physical health inequalities experiences by people living with disability, that there needs to be a strong focus on involving people living with disability in the design and delivery of training (Disability Rights Commission n.d.).

Another suggestion put forth by a survey respondent was to establish a web-based 'one stop' resource site that provides ease of access to information for GPs about the types of community services that are available to assist people living with disability, and the Medicare incentives they can access to enhance the support they provide.

A focus on increasing the knowledge of GPs in these areas will not only benefit people living with disability but also the wider community. This is supported by the Centre for Developmental Disability Health Victoria (n.d., p.2), who state that such a focus will ensure "health professionals will acquire valuable attitudes, knowledge and skills applicable to many other people in their practice populations. These populations include those with communication or cognitive difficulties; those with complex chronic medical and social issues; ... and those whose disadvantage and/or vulnerability requires health professionals to provide proactive healthcare and advocacy".

6.4 REDUCING BARRIERS TO MAKING A CHOICE OF GP

The experiences of survey respondents suggest that a range of factors can influence the extent of choice of GP including:

- Physical constraints, such as having reliance on locum services due to not being able to physically access the GP clinic;
- Personal circumstances where others make the decision about which GP to see;
- The financial cost to visit the GP;
- Lack of ready availability of GPs with good knowledge about disability.

As demonstrated by the survey findings, people living with disability who chose their GP are more likely to have their health needs met. If more is known about the barriers that prevent people from having this choice, then removing these barriers should increase the quality of service provided by GPs.

7.0 CONCLUSION AND RECOMMENDATIONS

The purpose of this survey was to identify ways to improve access to quality primary healthcare for people living with disability.

The survey findings highlighted that, in general, respondents were satisfied with the quality of service provided by their local GP and the accessibility of their clinic.

However, more can be done. Demand for GP services will increase as Australia's population grows and ages, and there needs to be sufficient capacity for people living with disability to consistently access good service from their GP of choice. This can occur through:

1. Raising GP clinic awareness about how to make GP clinics and facilities accessible, highlighting the relevance of the United Nations Convention on the Rights of Persons with Disabilities and national legislation and standards;
2. Raising GP knowledge about effectively communicating with people living with disability;
3. Raising GP knowledge about the experience of living with disability, the supports available, and how to best respond to health needs;
4. Raising the awareness among disability/health policy makers to ensure that people living with disability have a genuine informed choice about which GP they see.

Therefore we recommend:

a) That there be a non-negotiable component of medical graduate GP training on 'providing primary healthcare services to people living with disability', and that this be led by trainers who live with disability;
b) That the Royal Australian College of General Practitioners (RACGP), together with local GP Divisions, provide a regularly updated resource giving clear guidelines to GPs on how to best meet their obligation to provide fully accessible premises and services.

8.0 DISCLAIMER

This paper is for information purposes only and is not intended to be relied on by readers as advice in any particular matter.

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