

MUSLIM CARERS' PROJECT

A Joint Project between the Ethnic Disability Advocacy Centre (EDAC)
and the Muslim Women's Support Centre of WA (Inc) (MWSC)

Supported by Carers WA



FINAL REPORT

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1. INTRODUCTION

1.1 Project Background

The Ethnic Disabilities Advocacy Centre (EDAC) and the Muslim Women's Support Centre of WA (MWSC) initiated the Muslim Carers Project to study and report on the relevant factors that should be considered when providing care for a Muslim client.

Due mainly to migration, there has been an increase in the number of Muslims residing in Perth, in the last few years. As a result of this increase in size of the Muslim community there has been a greater need for service providers to be aware of Muslim religious practices and be sensitive to the needs of people with disabilities and their families/carers from Muslim communities. Furthermore, many of these arrivals have emigrated from countries that do not have disability facilities or services and are, therefore, not familiar with or of aware of their availability. Muslim family carers needed to be informed of the facilities and services available to assist them as well as providing opportunities to increase skills in the physical, emotional and financial aspects of self-care.

This report makes several recommendations, which are relevant to the work of all service providers working with people with disabilities and their families/carers from Muslim communities as well as family carers themselves.

1.2 Project Objectives

The main objectives of project were:

- To develop a training module for service providers on Islamic practices and perspectives of caring for people with disabilities.
- To develop a training module, in consultation with Carers WA, for family carers on how to take care of themselves
- To develop and implement a community campaign to recruit potential carers who can be trained to provide appropriate respite for Muslim families caring a person with a disability; and
- To pave the way for the formation of a Muslim carers group.

1.3. Methodology

The objectives of the project were met through a series of tasks that were carried out by an appointed Project Officer overseen by a steering committee.

The Project Officer was recruited on the basis of her familiarity with disability issues and her involvement in the Muslim community and appointed on a part-time basis. The steering committee involved representatives from the several agencies involved as well as a family carer. The Committee consisted of Anne Atkinson (EDAC), Thuan Geh (EDAC), Amar Versani (Carers WA), Maranda Ali (Consumer Representative and family carer) and Wajma Padshah (MWSC). Anne Atkinson chaired the steering committee, which met on a monthly basis, whilst Wajma Padshah was responsible for providing immediate assistance and supervision to the project officer. The project was accommodated at the MWSC.

To ensure that the needs of Muslim family carers were met in both workshops, a focus group of family carers was initiated. Over the course of several meetings of family carers, relevant issues were identified which then formed the basis for the two workshops.

The first workshop was designed to meet the immediate needs of family carers and focused on their own personal care needs. The second workshop was directed towards service providers, in particular, paid respite carers, to give them the skills and understanding required to work with people with a disability and their families from Muslim communities.

The third objective of the project was to provide information to people within the Muslim community who were interested in training to become paid carers. Not only would this objective provide people with employment, but also provide a pool of paid carers in the disability area with the understanding of Islamic practices and the skills required for professional caring.

The final objective of the project was to create the foundation for the development of a Muslim carers support group. It was envisaged that members of the focus group would provide the initial membership of the support group. Several activities were suggested with a picnic to celebrate the conclusion of the project as the first step in encouraging family carers to meet each other in an informal setting.

2. THE FOCUS GROUP

The focus group was initiated to identify the needs of Muslim family carers. This information was used as the basis for the two workshops. The Project Officer worked closely with members of the focus group throughout the course of the project.

2.1 Recruitment of Family Carers

Initially ten carers were contacted with the help of MWSC. These carers were clients of MWSC who had previously used their services. The MWSC staff had initially contacted the carers to seek their permission to pass on their contact details to the Project Officer. The Project Officer then contacted all the carers by phone and explained the aims and objectives of the project as well as what their role would be in the project. All ten carers agreed to be the part of the project.

2.2 Focus Group meetings and Individual Consultations

It was found that family carers were more open when discussing issues of concern individually, rather than a group setting. It was perhaps for this reason that, although six carers confirmed their interest in attending the first meeting, only two carers were present.

The setting of the meeting was informal with morning tea provided. The carers were informed of the purpose of the project and the focus group, which was to seek their views and allow them to share their concerns so that training workshops to address these issues could be planned. The carers were asked open questions about who they were caring for and their particular disability, and what some of their concerns were in regards to their roles as carers.

It was clarified that the focus group was not a support group but rather an opportunity for carers to discuss and raise issues affecting them. The Project Officer took note of these issues and, apart from incorporating them into the contents of the workshops, took the time to provide relevant information and referrals to appropriate services so that carer's immediate concerns were addressed.

Carers who were not able to attend the focus group meeting were contacted individually. Overall nine family carers, caring for family members with various disabilities, were consulted.

A total of three focus group meetings were held. Only three carers attended the first focus group meeting on the day that was scheduled. Another six individual interviews were held following the first focus group. The second and third focus groups had

various numbers of attendees and there were no individual interviews done due to the unavailability of the carers. Home visits were organised for two carers and only one was at home at the time of the visit. A total of three telephone consultations were also done. All participants were given a \$25 honorarium to reimburse any travel costs they might have incurred.

2.3 Issues Raised

Carers Workshop

From the two focus group meetings held and six individual consultations undertaken, several common concerns were identified. These included:

- financial difficulties
- lack of social support
- poor physical and emotional health, and
- the general lack of knowledge of services available to assist.

Service Providers workshop

The issues raised in this round of consultations focused on the need of service providers to have an understanding of Muslim practices when it came to dealing with family members with a disability. These included:

- Basics of Islam
- Issues of Gender
- Prayers
- Muslim rituals (washing)
- Clothing
- Halal food
- Whom to contact in case of emergency

2.4 From Focus Group to Support Group

Although the numbers of family carers attending focus group meetings and workshops was not as high as wished, the participants who did attend were highly motivated and very enthusiastic. It is envisaged that these carers would form the basis of a Muslim Carers Support Group through which issues of concern could be raised and addressed, information and training sessions given and opportunities provided for social activities with and without the family members they were caring for.

In an attempt to introduce the idea of a support group to members of the focus group, the steering committee saw a function to celebrate the completion of the project as an excellent opportunity to encourage the focus group members to continue their contact

and form a support group. To facilitate this, a family picnic was organized. All family carers were invited via mail. Unfortunately only one carer came along with her family. Nonetheless the picnic provided an opportunity for members of the steering committee to also celebrate the end of the project.

It is recognized that the formation of a support group will be a slow and painstaking process requiring the guidance and support of Carers WA as well as the MWSC and EDAC.

3. WORKSHOP FOR FAMILY CARERS

3.1 The Workshop

The workshop for the carers was held on 16th of August at the MWSC office and was organized in collaboration with Carers WA. The workshop was three hours long divided into two sessions. A break for lunch and prayer was given mid-way. The workshop was facilitated by two presenters from Carers WA who used a power-point presentation and provided handouts for all participants.

Two presenters from Carers WA facilitated the workshop with the aid of PowerPoint presentations and handouts for all participants.

Although seven carers had confirmed their attendance only five carers attended. Two of the carers needed an interpreter. The interpreter had also been a past carer herself and participated in the discussion.

3.2 Workshop Content

The main purpose of the workshop was to provide information to carers on physical and emotional aspects of self-care.

It was aimed that at the conclusion of this workshop, the carers would be able to:

- Identify the impacts that caring has had on them as individuals
- Identify key times when they feel run down
- Identify their needs as individuals
- List different ways they can take timeout for themselves

- List ways of making time out a regular reality

Due to time constraints and the fact that participants wished to have open discussion about their issues of concern, not all the above outcomes were fully covered.

3.3 Workshop Evaluation

Participants' responses

The general response of the participant carers was very positive and indicated that they appreciated the opportunity to discuss their issues of concern. The items they raised included complaints about medical representatives, the frustration of having to cope with certain family members who want to spoil the care recipient, and the difficulties they faced if they wanted to express their fears about the care recipient or if they wanted any changes in their treatment. It was difficult to stop the open discussion to continue the presentation.

Open discussions also assisted the carers to see the commonalities with other carers and realize that they were not alone in experiencing difficulties.

From the discussion it was also evident that few carers were willing or wished to utilise respite care and spend time separated from the person they cared for. Some of the comments included,

- *we don't want to have a break from our caring role*
- *I don't want to go anywhere without my son, I want the government to do something where we can go together and enjoy time together.*
- *In many cases the care receiver is not happy without the carer and vice versa.*

There may be several reasons for this, including the unfamiliarity with respite services and the distrust of paid carers who might be insensitive to Muslim practices.

Although most concerns remain unaddressed participants were given information on how to deal with some concerns. Their comments also indicated that they felt better after being advised that they have done the best for the family member who needed their care:

Presenter's responses

The presenters commented that the carers were very open about the problems they were experiencing and indicated their concern about the issues that carers raised. However, the presenters felt limited in offering solutions as some matters were beyond their work area.

4. THE WORKSHOP FOR RESPITE CARERS/SERVICE PROVIDERS

4.1 Workshop Organisation

Taking guidance from the family carer consultation a workshop/information session was arranged for the service providers. The workshop was held on 8 November 2006 at Technology Park (Bentley). Run over two hours, the workshop was presented by the Project Officer and the MWSC Welfare Worker.

Although 15 service providers enrolled for the workshop, only 13 attended. Of these, only one was a paid carer. The majority of participants were LACs with the remainder representing Centrelink, a carer's agency, and an occupational therapist.

A handout to accompany the workshop providing general information about Islamic practices was given to all participants.

4.2 Contents

The workshop was a specifically designed workshop that addressed the needs of service providers working with people with disabilities from Muslim communities. This two-hour workshop aimed to introduce participants to a range of issues which are of particular concern to Muslim people with a disability and their families. These include:

- Muslim families, cultural diversity and disability
- Daily Muslim practices
- Times of religious significance (Ramadan)
- Halal food
- Clothing
- Adopting a care plan for a Muslim client

4.3 Workshop Evaluations

Two evaluations of the workshop were held to test the effectiveness of the content and presentation of the workshop. The first was conducted immediately after the workshop and the second some two weeks later.

Post-workshop evaluation by Service Providers (13 returns)

The feedback straight after the presentation was generally positive. Feedback forms were handed out for further comments which were later collected and analysed

Participants found that the workshop provided a background to the beliefs, practices and rituals of Islam. The participants were impressed with the open and relaxed atmosphere of the workshop. Questions were asked freely and all of them were answered satisfactorily, often with doses of humour.

Analysis of the workshop based on participant feedback.

1. *What did you find was the **most useful** section of the workshop?*

Participants found that the workshop provided a background to the beliefs, rituals, etc of Islam that formed the basis from which to ask more questions. There was still some confusion over the meanings of *Islam* and *Muslim*. Participants were also mindful of cultural diversity within the Muslim community in Western Australia which they found interesting and useful. They were also impressed with the open and relaxed atmosphere of the workshop that they felt allowed them to ask questions and to have them answered honestly with humour.

2. *What was the **least useful** section of the workshop?*

The only comment came from a non-carer who complained that the last section was not relevant to her area. Apart from that – all responses were very positive.

3. *How much do you think you learnt about the needs of Muslim clients and their families/carers?*

On a scale of 1 (not much) to 5 (a lot), 5 participants responded that they had learnt a lot, 5 participants answered with 4/5 and 3 participants with 3/5. All participants then responded that they were happy with the amount of information they had learnt.

4. *What do you think was the **most important** thing you learnt today?*

Understanding Islam; cultural diversity within the Muslim community; asking Muslim clients what they need instead of making assumptions; family relationships and the wider community.

5. *Can you think of **any gaps** that were not covered in this workshop or were insufficiently covered?*

More on specific needs of Muslim families with people with disabilities, more on what services are available for Muslim clients, specific information on washing and other rituals, the needs of Muslim carers and strategies for providing services to Muslim clients in the long term.

6. *Do you think the hours for this workshop were sufficient (2 hours)?*

Approximately half the participants thought 2 hours was enough, the other half thought that an additional half hour or hour would cover the information they required and allow more

time for discussion. One participant thought the 2 hours gave good background coverage but would like another workshop to go into issues in more depth.

7. *Any other comments?*

Most comments were appreciative of the workshop and found it worthwhile. Several comments praised the presentation and found the presenters excellent. One participant asked for a workshop specifically for her work area. In general though, participants were very complimentary of the workshop, its structure, presentation and content.

Long term follow-up evaluation of the workshop

A follow-up evaluation was conducted two weeks after the workshop. This consisted of 10 to 30 minute phone interviews with 10 participants. The participant's general impression of the workshop after this time period was that it was perhaps too general in its coverage of the issues and did not contain enough specific material relating to caring for people with disability and their families.

1. *Name three things you remember from the workshop*

Most participants mentioned that the workshop presented general information rather than giving specific examples or raising specific issues of how to deal with clients with a disability from a Muslim background. Although the generalised information was interesting, they found that further specific information would have been more useful. Two participants found that issues relating to care were common to all clients and not just Muslim clients.

Some of the issues remembered were related to Muslim rituals and values, especially those to do with dress, food, ablutions, gender and prayer. Several participants were struck by the similarities between the philosophy underlying Islam and that of other religions.

2. *Name three things that you thought of after the workshop that you wished had been covered.*

Almost without exception, participants would have liked more examples of practical matters and ways of dealing with Muslim clients and their families. One common example was related to approaching families and what to do in a Muslim home. One participant expressed disappointment that the workshop did not really mention disability at all with the examples of Muslim needs relating to aged care in a non-Muslim nursing home.

Another said that she would have liked personal stories that illustrated Muslim needs so she could develop an understanding of what was required.

Without a doubt, the general consensus from the answers to the first two questions was that there should be less generalised material and more on disability and specific care matters and how carers or service providers might assist clients in practical ways. Specific examples included how to help clients with ablutions, and other daily rituals and practices.

3. *Was there anything that you might have liked to have asked during the workshop but didn't have the opportunity?*

Several participants had a few questions but most thought that the informality of the workshop allowed for open discussion and they had asked what they liked. Two participants felt uncomfortable asking questions; one was a male and one felt that her question might have led to a heated discussion.

4. *Presentation*

Most participants found the presentation of the material excellent. In particular they appreciated the informality of the sessions that allowed them to feel free to ask questions and discuss issues. Two participants would have liked more small group discussions and one suggested small groups led by Muslim discussion leaders.

5. *Handouts*

Most participants had read the handouts after the workshop and found them to have a good coverage although, again, they would have liked detailed instructions on how to help clients carry out daily practices. Most participants had shared the information and handouts with other colleagues. Only two participants admitted to not having read the handouts.

6. *Length of workshop*

The majority of participants found 2 hours to be too short for discussion, and to gain more detailed information. Most found that two and half to three hours would have been better. Some found that 2 hours was suitable for a general background session but that could be followed by another workshop that focused on more concrete issues that dealt with their specific service and work duties.

7. *What ways would you use the information you gained from the workshop in your daily job duties?*

Most participants mentioned passing on the information gained in the workshop and sharing the handouts. Two participants mentioned that they had found it easier to approach and talk with their Muslim clients and had a far greater understanding of families and their daily practices.

8. *Any other comments*

All participants commented that they found the workshop very worthwhile, had enjoyed it and felt it was very useful to their work. Two participants expressed a wish to have the workshop held in their workplaces, while one thought it would be excellent as a module in several TAFE and other training courses for service providers.

4.4 Information Booklet for Service Providers

A comprehensive handout to assist caregivers was prepared to re-emphasise the material delivered in the workshop as well as give a background to the religious practices. This booklet is further edited to take into consideration the participants' feedback and is attached as an appendix. It is anticipated that this booklet will be given to participants in future workshops for service providers.

5. MUSLIM CARERS' (PAID) INFORMATION SESSION

5.1 Aims and Background

EDAC and MWSC had identified the need to have ethno/faith specific carers for Muslims with disabilities. It had been noted that the majority of Muslims, especially those of a migrant background, would not wish to have respite when the carer was not someone they fully trusted. Through the recruitment of Muslim carers it was hoped to provide an alternative for such family carers.

5.2 Recruitment Drive and Outcome

A flyer was designed inviting interested individuals to attend an information session training to become a professional carer. These flyers were distributed widely within the Muslim community. Ramadan (the fasting month for Muslims) was chosen as an ideal time to promote the flyer at the mosques as large numbers of Muslims frequent the mosque during this time. As well as the mosques, the flyers were posted at various Muslim Schools, halal outlets, mailing lists and websites. Announcements were also made through the Pakistani radio program on Radio 6EBA. .

A number of individuals contacted MWSC to get more information about the session. Four people showed interest and confirmed their attendance at the session, but only two were present on the day. The Project Officer gave relevant information including information booklets from TAFE on Community Services training, Centrelink

information on financial assistance while studying and referral to other training agencies through the Job Network members. The Project Officer also shared her own experience on the training and the requirements of a carer.

6. RECOMMENDATIONS

1. It was apparent from the various carers' group meetings and consultations that Muslim family carers' experienced a number of problems, however there was generally a limited knowledge of the resources and services available which could assist in addressing these problems.

Recommendation One: **Initiate a regular forum that provided opportunities for carers to express their concerns and to organise sessions to provide information to address these concerns.**

2. One significant problem that emerged from group meetings and consultations was the need to learn skills for caring for family members with physical disabilities.

Recommendation Two: **Provide practical physical care training and other skills training for family carers, especially those caring for people with physical disabilities.**

3. It was evident from the participant's comments from the workshop for service providers, that there is a low level of knowledge and understanding of Muslim practices and belief. Evaluations indicated that participants were very keen to gain knowledge and skills not only to improve care for Muslim clients but also for their own general knowledge. However, they indicated that workshops should be skill based and focused on caring for people with disabilities.

Recommendation Three: **To provide skills based workshops on Muslim practices in relation to caring for people with disabilities. These workshops should be offered on a regular basis to service providers in the disability sector.**

4. Even though the response from family carer's to accept paid carers for periods of respite was generally received negatively, there does need to be a pool of trained carers with a full understanding of Muslim practices in times of emergency.

Recommendation Four: **That the program to encourage people from Muslim communities to undergo carer training in a recognized training institution be encouraged. The promotion of such courses should come not only from within the Muslim community but also through training institutions.**

5. It was recognized throughout this project that, although there were limited numbers attending focus group meetings and the workshop, when family carers did meet together they gained enormously from the experience in sharing their concerns and being aware that they were not alone in handling the many problems they were confronted with. It was evident then that a Muslim Support Group be established based on the membership of the focus group and others who had participated in the project.

Recommendation Five: **That with the guidance and assistance of Carers WA, the MWSC and EDAC, a Muslim Carers Support Group is established and efforts made to recruit members through-out the coming years.**

7. APPENDICES

Muslim Carer Recruitment Flyer

Service Provider Workshop Flyer

Information Booklet for Service Providers (separate booklet)



Do you have what it takes to CARE?

Want to start a new career...?

If you...

Are a compassionate person

Have spare time

Want to boost your income and

Want to be part of a team that contributes to the community...

...then there's a great opportunity for you!

An information session to learn more about becoming a paid carer is scheduled for early November, to register your interest and further information please, contact 9451 5696 or 0433 131 543



This initiative is part of a joint project by the Ethnic Disability Advocacy Centre and the Muslim Women's Support Centre (Inc). Supported by Carers WA

*The Muslim Women's Support Centre
and
Ethnic Disability Advocacy Centre*

Invite

Service Providers (particularly Respite Carers)

To a pilot workshop on

The Needs of Muslim Clients with a Disability and their Families

This two-hour workshop will introduce participants to a range of issues which are of particular concern to Muslim people with a disability and their families. These include:

- Muslim families, cultural diversity and disability
- Daily Muslim practices
- Times of religious significance (Ramadan, etc)
- Halal food
- Clothing
- Adopting a care plan for a Muslim client

Comprehensive handouts to assist caregivers will accompany the workshop and re-emphasise the material delivered in the workshop. The handouts will also include a range of simple Halal recipes from several countries.

Date: Wednesday 8 November 2006

Time: 9.30 - 11.30 am

Venue: Seminar Room 3
Technology Park Function Centre
2 Brodie Drive
Bentley

RSVP: 1st November to Anne Atkinson or Veronica Fitzgerald at EDAC.
Phone: 9388 7455 or email admin@edac.org.au

Please note: there are only 15 places in this workshop so please put your names down early and avoid disappointment.

Supported by CarersWA