



Bridging the Gaps Project

Evaluation 2008 – 2009

Parkinson's Victoria

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Introduction

Bridging the Gaps is a project of Parkinson's Victoria, funded by the Lord Mayors Charitable Foundation. The project has successfully developed and published a range of quality information resources about Parkinson's for culturally and linguistically diverse (CALD) communities across Australia. It has also engaged in a range of awareness-raising strategies targeting CALD community members in Victoria, including broad distribution of bi-lingual and multilingual Parkinson's publications, Parkinson's information sessions targeting CALD community members and key messages delivered via ethnic media.

This evaluation report has been produced by Parkinson's Victoria for the purposes of informing this organisation and others - particularly those undertaking similar projects - about the achievements, strengths, challenges and learning from the *Bridging the Gaps* Project.

As this report shows, the Project has indeed begun to 'bridge the gaps'. Access to Parkinson's information for people with low English proficiency has been significantly increased and many CALD community members in Victoria now have greater understanding and awareness of the condition. Project products meet the key standards and expectations for appropriate community language materials: for example, source documents were written in plain language for the purposes of translation; each was checked by community members and all publications are bilingual - with the English version appearing alongside the language other than English (LOTE).

This Project has also contributed to strengthening Parkinson's Victoria as an organisation. It has made and strengthened important links with CALD services and communities and generated improved understandings of the needs of CALD people living with Parkinson's. Parkinson's Victoria is now better able to meet those needs and people from CALD backgrounds now have greater access to our services.

Background

Parkinson's disease is a brain condition that affects the ability to move smoothly and easily. It is more common among people aged over 60 years, but it can affect adults of any age from all cultures and lifestyles. It is one of the most common brain conditions in Australia, with 25 people diagnosed every day. Accessing support, information and specialist treatment can significantly improve quality of life for people living with Parkinson's, including those diagnosed and their families and carers.

Parkinson's Victoria is the peak body representing the needs and interests of people living with Parkinson's in Victoria. Recurrent government funding represents only 21 per cent of our total income and we rely on donations, bequests and other forms of income to

offset the shortfall needed for service provision. We provide a range of support services to assist in managing the condition, to improve quality of life and to reduce the impact of Parkinson's on individuals, families and the wider community. Our service plan recognises CALD communities as a priority target group.

In 1998/99 Parkinson's Victoria engaged the Centre for Culture, Ethnicity and Health (CEH) to conduct exploratory research that would inform a multilingual Parkinson's information campaign. The research showed that people living with Parkinson's from CALD communities face a range of additional challenges due to language and cultural differences. These include misunderstandings and lack of information about the condition, little awareness of others who share the condition and poor knowledge of the allied health services and supports available.

The researchers strongly recommended that Parkinson's Victoria develop a range of print and audio/visual information in community languages and disseminate these in ways that will effectively reach these communities. They also recommended a community education campaign targeting CALD communities and action to promote access and equity for people from CALD backgrounds within Parkinson's Victoria and across health services generally.

Funding was sought and eventually secured with a major grant from the Lord Mayors Charitable Foundation. A Project Worker was employed in February 2008, working 2 days per week on a 12 month contract. Additional State Government (Dept of Human Services) and internal funding have seen the Project extended on reduced Project Worker hours throughout 2009 and continuing into early 2010. Further funding is currently being sought to continue building on the achievements of *Bridging the Gaps* and raising awareness of Parkinson's among CALD communities.

OUTCOMES - Highlights

The *Bridging the Gaps* Project has achieved many successful outcomes. Highlights include:

1. The development and distribution of a suite of bilingual information resources, including print publications and resources in audio and electronic formats.
2. The strengthening of linkages between Parkinson's Victoria and CALD communities and improved awareness among staff, volunteers and management of the issues facing people living with Parkinson's from CALD backgrounds.
3. A community education campaign targeting key groups of CALD community members with Parkinson's information sessions and celebratory launches of the CALD materials.

4. A media campaign targeting members of CALD communities generally, focussing on ethnic media as a means of raising awareness of Parkinson's.

Further information regarding outcomes is contained in the outcomes summary below. This report also includes information about the process used through various elements of the Project.

Summary of Outcomes

1. Development and distribution of a suite of bilingual information resources.

A suite of quality information resources in ten languages were developed and distributed in various formats including print, audio and electronic. All resources meet current best-practice standards with regard to language materials: they are high-quality, professionally developed, bilingual, use plain language and have been community checked.

1.1 Print publications

Print publications produced by the Project are:

- Help Sheets on aspects of living with Parkinson's (A4 format)
- Understanding Parkinson's booklet for community awareness raising (DL format)
- Multilingual poster (A3 format)
- Multilingual booklet (DL format)

Production

All publications are bilingual, in accordance with best practice for language publications, with the English text appearing alongside the other language. The bilingual format is particularly useful for families where, for example, older members may only read their original language but younger members may only read English. Bilingual format is also important for professionals distributing the materials to clients: they can understand and have confidence in the information they are giving and can refer the client to relevant sections if required.

English-only versions of the Understanding Parkinson's booklet and the four Help Sheets were also developed. This helps to provide consistency of information across languages and across the organisation. English versions are distributed as part of the 'Newly Diagnosed Kit' sent to all appropriate help line callers.

All publications were professionally translated and typeset to ensure the quality and accuracy of the material. In accordance with best practice for language materials, the source documents in English were written for the purposes of translation using plain-language and with care to avoid or explain difficult words or concepts. The source documents in English were also checked with Parkinson's professionals and with people with Parkinson's before being finalised for translation.

Translations were checked by community members from each of the language groups. A total of 40 checkers were engaged, with up to six checkers per language. Almost all gave feedback and feedback was given in all languages.

All publications were professionally printed in full-colour, professionally designed using a consistent design and professionally printed. The tulip design was chosen as a recognisable symbol of Parkinson's disease, which assists with recognition and identification of the materials.

Distribution - Victoria

All print publications produced through this Project are available free of charge on request to individuals and organisation in Victoria. Much of the distribution work, such as processing orders received, has been undertaken by Parkinson's Victoria volunteers.

A flyer and order form is available, having the dual role of promoting the resources and encouraging their distribution. Mail-outs containing sample materials, posters, order forms and a covering letter were sent to over 300 individuals and organisations, including ethno-specific and multicultural organisations, Parkinson's practitioners, Neurologists and bi-lingual General Practitioners.

Kits containing the full set of materials in all languages were distributed to key Parkinson's practitioners, including RDNS nurses, movement disorder clinics and Parkinson's specialist nurses.

Across all ten languages, a total of 26 300 pieces of printed information were distributed in Victoria in the 12 month period to December 2009. This constitutes thirty six per cent of the total quantity of bi-lingual materials printed. Languages with the highest number of materials distributed reflect opportunities utilised to distribute materials via services and via information sessions. For example over 6700, or 67 per cent of Greek publications have been distributed, the majority of which were distributed through the networks and services of Australian Greek Welfare Society. Similarly, high distribution rates are evident in the Russian and Turkish materials, reflecting a number of large information sessions having been conducted with these communities. Larger quantities of DL booklets have been distributed than of Help Sheets, which reflects the broader target audience for the booklets.

Orders received show that materials are being distributed by a broad range of service providers, including General Practitioners, Aged Care Assessment Services, Carer organisations, multicultural and ethno-specific agencies and groups: many from rural and regional areas in Victoria as well as from all metropolitan areas.

Distribution - National

Interstate Parkinson's organisations were encouraged by email and at meetings to order and distribute copies of the materials at their own cost. Interstate organisations ordered limited numbers of the materials, with 100 copies being the largest quantity ordered. No information has been provided in relation to interstate distribution of print publications, however it seems likely that distribution outside of Victoria is very limited.

1.2 Audio

Audio reads of Help Sheets 1, 2 and 3 in four languages, Greek, Italian, Vietnamese and Cantonese were developed and made available in December 2009. Audio versions are particularly useful for people who have low literacy or a visual impairment.

The audio reads in four languages were professionally read and produced by SBS. It is hoped that further funding will be secured in the future to extend the number of languages available in this format.

The audio reads in mp3 format can be listened to or downloaded from the website and are available on CD upon request. Website data indicates that audio versions were extremely popular during the first month of availability. In December 09 more hits were recorded on mp3 versions of Help Sheets than on pdf versions and a total of 1139 hits were recorded on the mp3 files in various languages during that month.

English audio reads were produced in-house in January 2010 and are also now available on the website. In-house audio reads in Russian are expected to be available shortly.

1.3 Electronic publications

The publications in 10 languages are available to read or download as pdf documents on the languages section of the Parkinson's Victoria website:
www.parkinsonsvic.org.au/languages.htm.

Care has been taken to maximise access for people with low English proficiency by, for example, providing a bilingual table with headings and icons to make selecting a language and document as easy as possible. A brief introduction to Parkinson's in each language also appears on this section of the website.

Website usage data shows that the languages section is consistently among the top 10 entry pages to the Parkinson's Victoria website. The languages URL received around 2144 hits and 1039 visits during 2009 and is regularly among the top 30 URLs. It is also notable that across the period brochures are hit more often than Help Sheets.

Parkinson's organisations in other states and territories have also made the materials available on their websites in some cases. No data is yet available on usage of this. The materials have not yet been uploaded to the Parkinson's Australia website and this is particularly problematic as all materials promote the Parkinson's Australia website as a source of further information. It is hoped that this situation will be rectified as soon as possible.

The materials have also been made available as links on other organisations' websites, including the Victorian Government's Better Health Channel, the City of Wodonga and the Centre for Cultural Diversity and Ageing. Several contacts have been made in an attempt to make materials available on the Victorian Government's Health Translations Directory, however this has not yet occurred.

2. Strengthening Parkinson's Victoria and its response to CALD communities

The Project has strengthened Parkinson's Victoria and its response to CALD clients on a number of levels.

2.1 Linkages with CALD service providers

Parkinson's Victoria has become a member of the key networks for CALD service providers, for example the North West CALD Partnership and Southern Child and Family CALD Network, and has presented information at meetings of these networks.

The organisation has also been represented at a number of multicultural expos, festivals and workshops, such as the Supporting Access Multicultural workshop for HACC, aged and disability providers in Casey and Cardinia LGAs and a senior citizens' multicultural festival in East Bentleigh.

There are now over 200 contacts on the Parkinson's Victoria CALD mailing list, including ethno-specific and multi-cultural support services. Contacts were kept up to date with the progress of the Project and received copies of the publications and order forms. Many CALD organisations placed orders and many requested and assisted to coordinate Parkinson's information sessions for clients and/or staff. A number also attended the celebrations in Melbourne and Shepparton to launch the resources.

2.2 Identification of Parkinson's health professionals from CALD backgrounds

The Project has identified a number of Parkinson's professionals who are themselves bilingual and/or from a CALD background. A number of bilingual professionals assisted with the development of the materials and with promotion and community education. For example, a Turkish-speaking Neuropsychologist gave a Parkinson's presentation to a large group of Turkish people and promoted the session on a Turkish radio program.

A number of health professionals were also involved in the process of checking translations. It is likely that these relationships will continue to be useful into the future and offers of assistance from bilingual Parkinson's professionals continue to be received.

2.3 Improved awareness of the issues for CALD people living with Parkinson's.

The Project identified a number of people from CALD backgrounds living with Parkinson's. Some of these became involved in the Advisory Group and/or spoke at the launches. Some responded to a questionnaire and some participated in community education sessions. Their input gave a valuable insight to the issues facing people from CALD backgrounds.

Project research, including questionnaire responses and feedback from information sessions, has added to the earlier CEH research. For example, respondents to the Project questionnaire all indicated that Parkinson's is not well understood by people from their culture or community. Further, the challenges of living with Parkinson's for people from CALD communities were described as including: lack of awareness, language/communication difficulties, misinformation, isolation and reluctance to talk about the condition with others.

Comments made by questionnaire respondents include:

“I've found Dad has withdrawn from social situations where he may meet someone new. The friends he does have he sees very infrequently, so he avoids having to explain his condition to people.”

“People with Parkinson's seldom admit or talk about it themselves.”

“Dad originally thought the disease was terminal. He thought it would progress very quickly and that he would end up in a home. I obtained a book [about Parkinson's] in Spain but he is yet to read anything in Spanish published in Australia. It would be great for him to know the role that allied health professionals could play.”

Responses and feedback received through the process of networking informed the development of the information resources and the community education campaign.

2.4 Improved service delivery to people from CALD backgrounds

Improved awareness of the issues facing people from CALD backgrounds among Parkinson's Victoria staff, volunteers and management can be seen as contributing to improved service delivery to CALD clients in Victoria.

There is a range of evidence to indicate improved service delivery, including:

- Ongoing distribution of CALD resources in all formats.
- Requests to the Parkinson's Help Line for various CALD materials, numbering over 100 fulfilled requests in the period March to November 2009. Many other requests have been made for languages which are not yet available.
- Anecdotal evidence from Client Services staff that the number of people from CALD backgrounds contacting the service for advice and assistance has increased, including those using telephone interpreter services. (Unfortunately the current data base does not allow for collation of language or cultural diversity data regarding clients.)
- Training provided to Parkinson's Victoria staff and volunteers in working with interpreters and practical experience in the form of community education sessions with CALD communities.
- Reports to management and the Board of Parkinson's Victoria, raising awareness at this level.
- Increasing requests for community education sessions.

2.5 General benefits for Parkinson's Victoria

This Project has generated numerous benefits for Parkinson's Victoria. The organisation has been promoted widely throughout CALD communities, generating awareness of the organisation and its services, including the challenges it faces such as poor funding. A number of donations have been made in response to the Project's activities and events. Project products included English only versions, which are used as resources for the general community and the template design is used for other English language information sheets. Another important benefit has been the strengthening of the Parkinson's Ambassador Program with the generation of numerous speaking opportunities.

3. Awareness raising through community education

The Project conducted a community education campaign targeting key groups of CALD community members with Parkinson's information sessions and celebratory launches of the CALD resources.

3.1 CALD community education sessions

In the period October 2008 to December 2009 thirteen Parkinson's information sessions targeting CALD community members were conducted, providing Parkinson's information to over six-hundred people from diverse backgrounds. Most sessions were presented to groups of older community members with low English proficiency, but some groups included people of all ages. Groups included: Springvale Indo-Chinese Mutual Assistance Association, Russian-Jewish Senior Citizens Group and Meadow Heights Turkish Women's Group. Several further sessions are scheduled for 2010 and requests for sessions are steadily growing in response to growing awareness.

All sessions used a professional interpreter, mostly funded through the DHS Credit Line, with the exception of a session for German community members which was conducted in English as all participants were bilingual. Most sessions were provided to an existing group at their usual venue and time. A number were more widely promoted to the general community, with approval from the group. For example a session to the Turkish Senior Citizen's group in Dallas was promoted to the general community via flyers and an interview and other promotion on ethnic radio. A number of non-group members were present at the session.

Most CALD Parkinson's sessions were run under the Parkinson's Ambassador Program, which involves volunteers, who are people living with Parkinson's themselves, speaking about their own personal stories and giving key facts and figures. Training on presenting with an interpreter was provided at an Ambassador training session and further training in cross cultural communication is planned.

Ambassador presentations have been shown to be a very powerful way to break down myths and misunderstandings and educate CALD community members about Parkinson's. Ambassadors provide a real-life demonstration of our key message: that with support and information, people with Parkinson's can continue to live a long and productive life. Funding is currently being sought to further resource the Parkinson's Ambassador Program to maximise positive outcomes from CALD sessions.

Some Ambassador sessions included a presentation by a Parkinson's professional and a number included a celebratory launch of the new bilingual publications. One session

included a presentation in Turkish by a bi-lingual Parkinson's professional. Further sessions using bilingual Parkinson's professionals are planned for 2010.

The CALD Parkinson's information sessions have been very successful. In addition to the more than six hundred individuals who have participated, two sessions were recorded and broadcast on SBS radio. A number of people living with Parkinson's attended these sessions and many participants expressed that they knew someone with the condition. For people with personal experience of Parkinson's, the sessions provide a particularly valuable opportunity to learn more about the condition, to ask questions and to meet others who are living with Parkinson's.

The following comments were submitted as evaluation feedback by group-leaders following recent presentations:

“Thank you very much for providing a wonderful and excellent presentation to the elderly Vietnamese community. The ways you are working are really effective. The Ambassador is so fantastic. Our group were so impressed with her presentation.”

“Thank you so much for providing the information session to the Arabic community. The information provided by the two Ambassadors was very powerful and useful because they showed how you can live normally with Parkinson's. Their experience encourages people who suffer with other illnesses to have hope and to make the most of their life.”

“Some of the women never knew about Parkinson's symptoms and confused it with other illnesses. Everyone who attended now has more knowledge to pass on to others in the community.”

3.2 Formal Launches

In addition to the community launches of the CALD publications, two formal launches were held, one in Melbourne and one in Shepparton. The Melbourne launch was conducted by Lord Mayor John So at the Melbourne Town Hall. Fifty people attended, including representatives from ethnic organisations such as Spanish Latin American Welfare Centre (CELAS), Australian Croatian Community Services and the Australian Vietnamese Women's Association; multicultural organisations such as Action on Disability in Ethnic Communities, South Eastern Region Migrant Resource Centre and the Multicultural Centre for Women's Health; health professionals such as Royal District Nursing Service; as well as people with Parkinson's, their families and carers.

The Shepparton launch was conducted by the Manager of the Ethnic Council of Shepparton and District, Mr Chris Hazelman. It was attended by representatives from the Aged Care Assessment Service, Goulburn Valley Community Health, Greater

Shepparton City Council, Villa Maria, the Italian Council, Uniting Care and Family Care, as well as members of the Shepparton Parkinson's Support Group.

Both launches included presentations by the Project Worker about the background and process involved in the development of the CALD resources, as well as speakers giving their own personal perspective as CALD community members living with Parkinson's. The Melbourne launch also included entertainment by accomplished musicians who are themselves living with Parkinson's. Refreshments were available free of charge.

4. Awareness raising through ethnic media

The Project conducted a campaign focussing on ethnic media as a means of raising awareness of Parkinson's disease. Information about Parkinson's and about contacting Parkinson's Victoria for further information and resources, as well as about upcoming community education sessions was promoted as widely as possible through various forms of media. Media information was developed in the form of radio announcements, press releases, flyers and a factsheet called: *Living with Parkinson's in Multicultural Australia*. The following are some of the media opportunities realised:

4.1 Ethnic radio

- Radio announcements in Greek, Italian, Vietnamese and Cantonese, for use as community service announcements. The announcements were professionally produced by SBS and are currently receiving regular national air-play as 'filler' announcements on SBS ethnic radio.
- Parkinson's community presentations in Turkish and Arabic were recorded, edited and presented on ethnic radio by SBS.
- Radio interview with a Turkish-speaking health professional

4.2 Ethnic publications

- Menorah Independent Jewish Magazine in Russian - article based on the *What Is Parkinson's Help Sheet* in Russian
- Golden Years article: *Living Well with Parkinson's Disease*, Sept 2009
- Advertising in El- Telegraph to promote an information session in Arabic

4.3 Mainstream publications

- Postings on Infoxchange website
- Regular articles in Parkinson's Victoria newsletter Signpost including Autumn 2009
- Parkinson's Victoria Support Group Newsletters

PROCESS – highlights

The overall success of the *Bridging the Gaps* Project can be attributed to a series of process-related issues. These include:

1. Project planning
2. Networking and support
3. Advisory Group
4. Community checking

For further details regarding the process used in the *Bridging the Gaps* Project, see the process summary below.

Summary of process

The process used in the development of the Parkinson's CALD resources was a successful one and is therefore outlined here along with challenges encountered, as a guide to other similar projects.

1. Project planning

The Project began with the development of a project plan including timelines and budget estimates. Key elements of the project plan were:

- Developing linkages with key CALD organisations and individuals
- Identifying and seeking support and input from people living with Parkinson's and Parkinson's specialist practitioners from CALD backgrounds
- Establishing an advisory group to guide the Project and its products
- Developing source materials in consultation with key Parkinson's professionals and people living with Parkinson's
- Professional translations
- Community checking of the translations and amending where needed
- Professional design, layout and printing
- Promotion and distribution
- Launches and community awareness raising sessions
- Awareness raising using ethnic media
- Evaluation.

Planning was an essential component in the success of the Project as key elements depended on the completion of other key elements and some aspects were particularly time-consuming, such as community checking.

All elements of the project plan were delivered within timelines and on budget.

1.1 Stages of development

The following is an outline of the stages of development of the publications

1. Source documents in English developed based on existing materials, with advice from Parkinson's Victoria staff
2. Testing of the English source documents via support group members in Melbourne and regional Victoria
3. Professional translation company chosen and briefed
4. Professional designer chosen and briefed
5. Printer chosen and briefed
6. Final source documents forwarded to the translation company
7. Community checking in all 10 languages
8. Where to go Help Sheet – checking details with services listed
9. Draft design approved and forwarded for layout
10. Feedback from checkers communicated to translators and liaison regarding changes
11. Final draft translations received
12. Layout completed by translation company
13. Print
14. Delivery
15. Launch and promotion
16. Storage
17. Distribution – ongoing.

2. Networking and support

Support for the Project was sought from a broad cross-section of individuals, services and staff across the CALD, health, ageing and disability sectors. A flyer explaining the Project and requesting input from CALD people with personal or professional experience of Parkinson's was distributed widely, including by post, email and posting on networking websites. The Project Worker also attended key network meetings to present information about the Project.

Expressions of interest in participating in the Project were received from many CALD organisations and individuals with an interest in Parkinson's including support services, health professionals and people living with the condition. A mailing list was compiled and contact was made during key phases of the Project, including when the materials

were launched. Many respondents were also engaged as community checkers of draft translations and some became members of the Project's advisory group.

Where appropriate, those who expressed an interest in the Project were forwarded a written questionnaire (in English) requesting feedback on their information needs. A small number of completed questionnaires were returned and the responses informed the development of the resources. Unfortunately, funding did not allow for the translation of this questionnaire or responses, which limited its impact.

3. Advisory group

Invitations to be part of the Project Advisory Group were made to key CALD individuals including professionals and people living with Parkinson's. Eight people agreed to join the two Parkinson's Vic representatives in forming the Advisory Group. Group members included representatives from the Centre for Cultural Diversity in Ageing, Alzheimer's Australia, Carers Victoria, the Centre for Culture, Ethnicity and Health and a Neurologist. A further three group members were people living with Parkinson's either as a carer or the person diagnosed.

Terms of reference for the Advisory Group were drafted and agreed by the group. A total of five Advisory Group meetings were held at the offices of Parkinson's Vic. Members also communicated via email and telephone.

The advisory group proved invaluable in guiding the Project on a number of matters, as follows:

3.1 Principles

Based on the input of the advisory group and of Parkinson's Victoria staff, a number of principles were determined for the publications:

- plain language
- easy to translate
- key information only
- positive language
- quality translations, design and printing
- maximise reach by ensuring all information is nationally appropriate
- bi-lingual to provide access where some family members only read English.

3.2 Format

Recommendations from the advisory group determined the format of the materials. The main format originally envisaged was a single booklet in each language, however

individual A4 Help Sheets on specific topics were identified as a preferable format, with a number of benefits:

- Capacity to more readily update or change content, for example adding newly introduced medications or changing service information
- A4 format is easy to download from the internet
- Information can be staged according to the stages of the condition
- Information can be provided in response to specific queries.

Recommendations from the advisory group also contributed to the development of a key-issues 'Understanding Parkinson's' DL booklet in each language and an A3 multilingual poster, as community awareness-raising tools. As the materials began to be utilised feedback was received that while the multilingual poster was a valuable tool, the information it contained would also be valuable in a DL booklet form. Such a booklet was produced in October 2009.

3.3 Choice of languages

Budget constraints necessitated the prioritisation of up to 10 languages. Census data was consulted to gain an indication of need based on numbers of people aged over 45 with low English proficiency. The input of the Advisory Group helped to hone this information into priority languages. For example, the Chinese languages have various written and verbal forms and the group advised that traditional Chinese characters would be the most appropriate written form for the target audience (ie older people living in Australia).

4. Community checking

Checking occurred on the English source document and on each of the translations. The aim of community checking is to ensure that information is accessible and relevant to the general community of people who speak the language.

Source documents were checked by members of Parkinson's Support Groups in metropolitan Melbourne and regional Victoria. This allowed support groups to provide feedback and a suggestion was made that the resources include the capacity to include local contact information. This request was accommodated with a blank box on the back of the DL pamphlet.

Community checking was conducted on draft translations in all 10 languages. Community checkers were volunteers identified through the networking process. They were a mix of professionals within CALD agencies, health professionals and community members, including people living with Parkinson's. A total of 40 checkers were engaged,

with up to six checkers per language. Information about the checking process was sent to all checkers. Almost all gave feedback.

While most checkers made minor suggested changes, feedback was overwhelmingly positive with regard to most languages.

All checkers were formally thanked for their involvement and were forwarded complimentary copies of the final documents and an invitation to attend the major launch at Melbourne Town Hall. Where appropriate, checkers were placed on the CALD contact list for future contact.

Suggested changes from community checkers were forwarded to the translator. In some cases translators responded with criticism of the suggested changes. In these cases, the translator's professional expertise was respected and their version accepted.

Process – What we learnt

A number of points can be made in terms of learning drawn from the Project, or things that could have been more successful if done differently, as follows:

- a) All resources use a generic template, the use of language or culture-specific information could have made the resources more accessible and appropriate (albeit more costly).
- b) The generic template used across all Help Sheets also causes identification problems. Use of a different colour or a different element on each sheet and for each language would be a low-cost way of making them easier to distinguish.
- c) The languages tab on the Parkinson's Vic website is somewhat hidden. A more prominent tab and regular promotion on the home page would improve access.
- d) Parkinson's Australia and some interstate Parkinson's organisations have not included the information on their websites and do not seem to have embraced the Project or its products.
- e) Collection and collation of data to inform ongoing evaluations, for example annual website summaries, feedback from community education sessions and client data such as ethnic background and languages spoken, would offer valuable insights into the success of the Project and future directions.
- f) Current client data collection does not identify numbers of CALD clients or cultural/language background. It is therefore difficult to assess Project outcomes and the need for CALD services and resources.
- g) Available website data has to be compiled manually month by month. Annual comparisons would provide useful data for evaluation. Current information on website hits is also limited to those in the top 10 or top 30.

- h) Feedback in relation to the multi-lingual poster suggests that a useful addition would be the inclusion of the name of the language. This would help professionals in their work with clients as they can ask the client to indicate their language. The production of the multilingual brochure should have alleviated this problem somewhat.
- i) Storage of large numbers of different materials has proven a challenge. Adequate storage is not currently available and this was not fully appreciated prior to delivery. Storage is currently in an outside shed. A suitable storage system would alleviate problems such as resources affected by dust and bugs and at risk of damage from weather.
- j) Feedback suggests that a number of Parkinson's professionals are still not aware of the existence of the CALD Parkinson's resources.

5. Future Planning

Bridging the Gaps has begun to address the needs of people from CALD backgrounds in relation to Parkinson's. There is much work that remains to be done. Planning for 2010 includes costings, prioritisation and funding submissions to philanthropic and government organisations for the following items:

5.1 Priority items:

- Extend the number of languages in which the print publications are available from 10 to at least 14. Priority languages are:
 - Serbian
 - Maltese
 - Polish
 - Khmer (minimal printed quantities only due to poor literacy levels in this language)
- Extend the number of languages in which the radio advertisement is available to firstly include the remaining seven languages: Mandarin, Macedonian, Arabic, Turkish, Croatian, Russian (in-house version underway) and Spanish, followed by the additional four languages above.
- Extend the number of languages in which the audio Help Sheet reads are available, as per radio advertisement above.
- Further strengthen the Parkinson's Ambassador Program's capacity to effectively provide education sessions to CALD groups, including cultural diversity training and the development and translation of key messages in a Power point format.

5.2 Other important items

- Extend the range of Help Sheets to include additional key topics.
- Continue to collect, collate and publish evaluation data relating to Parkinson's Victoria's work with CALD communities.
- Develop policies and training to ensure culturally inclusive service delivery.
- Ongoing position of CALD/Multicultural Worker.

Conclusion

Bridging the Gaps began as a project to address the lack of information and misinformation about Parkinson's disease among people from CALD communities. It has gone a long way towards achieving this, while achieving so much more.

Thousands of people from CALD backgrounds who have attended information sessions, read or listened to information resources or items in the media now have an improved understanding of Parkinson's disease. Many people from CALD backgrounds who are themselves living with Parkinson's now have access to information and support to help manage the condition and achieve the best quality of life. Moreover, the Project has significantly strengthened the networks of Parkinson's Victoria and shown it to be an organisation that strives for best-practice in its work with CALD communities.

An outstanding achievement has been the engagement of the Parkinson's Ambassador Program in CALD community information sessions. The Program has benefited from additional presentation opportunities and training for Ambassadors, while CALD community education sessions conducted by volunteer Ambassadors, who are themselves living with Parkinson's, have been shown to be a very powerful awareness raising tool. This activity is likely to be self-sustaining after the Project's conclusion as CALD networks and services have been made aware of this resource and in practice each presentation generates other opportunities to present.

Perhaps the most significant challenges for the future will be ensuring CALD Parkinson's information is accessible nationally and the expansion of languages.

Unfortunately, funding for this project currently runs out in June 2010. It will be very difficult for this under-resourced organisation to maintain the momentum, build on the project's achievements and manage future challenges. Additional and ongoing funding is required in order to ensure that people from CALD communities have equitable access to information about of this very common condition.