



# Food Court Friends

*Building relationships through research*

**scope**

FOR PEOPLE WITH A DISABILITY

---

## Acknowledgements

The authors would like to thank the ANZ Trustees Philanthropy Partners under the 'Community Inclusion for the Disabled in Victoria – Percy & Ruby Haddy Foundation' for their funding of the project and support throughout.

We would like to thank the following for their time and support in contributing to the research.

Management and Staff at Sunshine Marketplace, Sunshine Plaza and Brimbank Shopping Centre

Staff and Students of Caroline Chisholm Catholic College

Members of Scope Young Ambassadors program

Peter Reis, Co-ordinator of the St Albans Day and Lifestyle Centre

Yousef Jabbour, Co-ordinator of the Scope Community Group, Braybrook

A special thanks to the members of the Scope Community Group, Braybrook who were committed throughout the project in their role as co-researchers. Their enthusiasm and spirit was appreciated by all those who worked with them.

**Citation:** Campain, R. and Wilson, E. (2010), *Food Court Friends: Building Relationships through Research*, Melbourne, Scope (Vic).

**Authors:** Campain, Robert and Wilson, Erin

**Distribution:** Further copies of Campain, R. and Wilson, E. (2010), *Food Court Friends: Building Relationships through Research* can be obtained from the Scope website, <http://www.scopevic.org.au> or by contacting:

Dr Robert Campain  
Research Fellow, Scope  
[rcampain@scopevic.org.au](mailto:rcampain@scopevic.org.au)

Dr Erin Wilson  
Senior Lecturer, School of Health and Social Development, Deakin University and  
Senior Research Fellow, Scope  
[erin.wilson@deakin.edu.au](mailto:erin.wilson@deakin.edu.au)

ISBN 978-0-9757076-9-2

**Copyright:** Scope (Vic) Ltd., Melbourne, 2010

**Published by:** Scope (Vic) Ltd, 830 Whitehorse Road, Box Hill, Victoria, 3128  
Ph: (03) 9843 3000

---

## **Contents**

<b>Summary</b>	<b>1</b>
<b>Setting the Scene</b>	<b>2</b>
The Policy Context: Scope’s Mission and the Victorian Government’s Vision	2
The Main Participants	3
The Need for Research	5
Project Aims	6
Method	9
<b>Scanning the Literature</b>	<b>18</b>
Community Inclusion	18
Individual Lifestyles – Planning and Action	19
Attitude Change	20
Australian Empirical Studies	21
<b>The Project</b>	<b>24</b>
Identifying the Issues of People with Disabilities	24
Training of Co-Researchers and Research Partners	24
Identifying the Issues at Sunshine Marketplace, Sunshine Plaza and Brimbank Shopping Centre	25
Commencing the Responses: Designing Communicating Aids	27
Implementing the Responses: Surveying and Distribution of the Communication Tools at Sunshine Marketplace	28
Evaluating the Communication Guide: Follow-Up Surveying and Evaluation at Sunshine Marketplace	32
Concluding the Project	33
<b>Outcomes and Reflections</b>	<b>34</b>
Assisting Communication	34
The Collaborative Research Model	36
Attitude Change	39
Limitations	40
<b>Recommendations</b>	<b>42</b>
The Collaborative Research Model	42
Shopkeepers and Community Inclusion	45
<b>Conclusion</b>	<b>48</b>
<b>References</b>	<b>50</b>
<b>Appendices</b>	<b>53</b>



---

## Summary

The Food Court Friends research project was initiated in 2006 and conducted over a period of three years. It began at a time when people with a disability (Scope clients) were increasing their community involvement, including frequent visits to indoor shopping centres – including Sunshine Marketplace, Sunshine Plaza and Brimbank Shopping Centre. Time there was often spent in the Food Courts. The aim of the research was to identify and address key issues pertaining to the experience of shopping centres for people with disabilities who were Scope clients from the St Albans Day and Lifestyle Centre and the Scope Community Group (Braybrook),<sup>1</sup> along with the experiences of the shopkeepers<sup>2</sup> and other shopping centre personnel when engaging with people with disabilities. The first task was to identify the key issues before implementing strategies to address these, followed by the evaluation of these strategies. The key issue identified focused on concerns with communication, with a communication guide sheet subsequently designed and distributed to shopkeepers to assist them in communicating with people with disabilities. Constraints such as time limitations restricted the communication guide sheet strategy to Sunshine Marketplace. Central to the project was the role of people with disabilities from the Scope Community Group working as co-researchers, in collaboration with students from Caroline Chisholm Catholic College who worked as research partners. Conference presentations by members of the Scope Community Group highlighted the involvement of people with disabilities. Findings stressed the need for, and benefits of, people with disabilities having a central role in research, while community inclusion work in shopping centres requires ongoing work in partnership with centre management of these venues.

Funding was sought and gained from the ANZ Trustees Philanthropy Partners under the ‘Community Inclusion for the Disabled in Victoria – Percy & Ruby Haddy Foundation’ with the project matching the philosophy and aims of the trustees and the foundation.

---

<sup>1</sup> See pages 3 & 4 for description of these two groups.

<sup>2</sup> Shopkeepers in this project include owners of stores, managers and staff working in them, and are synonymous with retailers.

---

## Section One: Setting the Scene

### The Policy Context: Scope's Mission and the Victorian Government's Vision

Scope is a disability service provider in Victoria offering a full range of services including residential, therapy, day placement, employment, and community inclusion services and supports. The organisation was established in 1948 and has continually expanded to work with people of all ages who experience a wide range of disabilities. Scope is committed to overcoming the personal, structural and attitudinal barriers that people with disabilities often encounter in seeking to participate in the community. Scope's mission is to 'support people with disabilities to achieve their potential in welcoming and inclusive communities' (2009: 1). This is reflected in the organisation's strategic plan 2009–2012 which drives Scope's achievements:

- People choose Scope,
- Communities include people with a disability,
- We perform to a high standard,
- Scope's voice inspires action,
- We are sustainable (Scope, 2010).

These values and strategies reflect the Victorian Government's vision of inclusive community as outlined in the *Victorian State Disability Plan 2002-2012*, with the aim:

*...to strengthen the Victorian community so that it is more welcoming and accessible, so that people with disability can fully and equally participate in the life of the Victorian community (2002: 11).*

The Food Court Friends project aims to reflect Scope's key priorities while working towards achieving the Victorian Government's vision for inclusive communities. In doing so, the aim is to provide positive outcomes for individuals, the disability sector, and the broader community. Given the limited research conducted around shopping centres and community inclusion for people with disabilities, the Food Court Friends project seeks to be a part of this journey of positive community change. As with any journey, there are setbacks, detours and unexpected encounters. This journey is no exception; therefore in recounting the story, the journey is as significant for its insights as for its final outcomes.

---

## **The Main Participants**

### The St Albans Day and Lifestyle Centre and the Scope Community Group

The St Albans Day and Lifestyle Centre is a Scope day service that dates back to the late 1970s. In recent years the co-ordinator and their team have sought to transform the practices of the centre away from a more traditional group approach in which all activities take place in the centre between regular daytime hours. Increasingly, staff have adopted a person centred approach with a greater focus on providing a life of choice for individuals, while supporting people in pursuing their leisure interests both in the day centre and in community venues. These venues include shopping centres, cinemas, neighbourhood houses, parks and museums. Often these activities are conducted in conjunction with other community groups. People are also supported in independent living skills, with some people supported in the transition to their own accommodation when they have identified this as something they wish to achieve. Within the centre various activities are conducted to supplement the community work. Such activities include painting and other craft activities, singing and dancing, and the opportunity to develop daily living skills such as cooking and money management. At present approximately twenty eight people are supported by the St Albans Day and Lifestyle Centre.

The Scope Community Group, whose members acted as co-researchers on the project, have strong ties with the St Albans Day and Lifestyle Centre. The centre serves as one of their bases in which they engage in a range of educational and social activities. The Scope Community Group was an early group in Scope to step out of a traditional day service model. The group comprises approximately twelve adults, ranging in age from early twenties to late forties. All of them have a person centred plan and are supported in a person centred manner. The group has been in existence since 2003 when the Victorian Department of Human Services funded Scope to work with a group of young adults, several of whom displayed behaviours of concern. With the move to a person centred approach – supported and encouraged by the co-ordinators involved – the group now spends more of its time engaged in a variety of community activities. This includes circus skills training, gym membership, the Club Wild disco, training courses, movies and shared holidays. Individuals have been supported in finding and maintaining suitable accommodation, in building relationships with people outside the group, while some have been aided in establishing casual or part-time employment. Initially the group was located at a renovated shop front, but now Scope provides a space in a community centre as a ‘base’ for the group’s community activities, with some people also joining in a few of the activities conducted at the St Albans Day and

---

Lifestyle Centre. Some members of the original group remain and have indicated that the number of activities has increased, while many have expressed that the level of purpose and meaning in the group involvement has also significantly evolved.

The Scope Community Group is currently comprised of individuals with a range of levels of intellectual disability. Most require relatively low levels of support, with some more independent than others. A few need more intensive support on a daily basis. The person centred approach, adopted by the co-ordinator and support staff, places emphasis on providing choice for people in meeting their needs and goals while fostering independence through the supporting process. All of the group members have the capacity to intentionally communicate. Where there are physical disabilities these are relatively 'minor' and do not appear to impede any members of the group to any significant extent as they go about their daily lives.

#### Caroline Chisholm Catholic College

From its inception, the project has involved students from Caroline Chisholm Catholic College as research partners. The college's involvement began with the Scope Young Ambassadors program. The work of Scope Young Ambassadors' staff was instrumental in creating a relationship with the college that has continued throughout the course of the project. The Scope Young Ambassadors program conducts formal disability awareness programs for secondary school students, comprising a number of sessions over a brief period of time. The program is based on a social model of disability, with a focus on a variety of disability issues, personal experiences of living with disability, and what people with disabilities can achieve. Reflecting on the Scope Young Ambassadors program, Kleeman and Wilson in their work on disability awareness programs note:

*The program aims for positive behaviour change towards people with disabilities among the participating students. Scope Young Ambassadors aims to achieve this through raising awareness and understanding of the lives of people with disabilities...The program intentionally focuses on enacting behaviours through various learning activities that require specific student actions in real life contexts (such as working collaboratively with people with disability in a service, work, or project setting) (2007: 30).*



---

The students at the college undergoing the Victorian Certificate of Applied Learning (VCAL) stream are required to do a certain amount of community work. Having undergone the Scope Young Ambassadors program, a link was established with the Scope Community Group which led to student involvement in the Food Court Friends project – an involvement that remained across three years, with different groups of students, until the project’s completion.

### **The Need for Research**

In recent years, people with disabilities from the St Albans Day and Lifestyle Centre and the Scope Community Group have increasingly been accessing local indoor shopping centres. There was a recognised need, as articulated by people from these groups, to collate and understand some of the key issues faced by people with disabilities when using shopping centres. Initial thoughts on the project focused on people’s experiences at the Food Court as much of their time in the shopping centre was spent there, hence the project name. However, the focus shifted to embracing the wider shopping centre in line with people’s broader shopping experiences as they sought to access a variety of shops and services. Scope clients reported experiences varying from re-affirming and positive, to upsetting and negative.

The desire therefore to meet the needs and choices of Scope clients meant that the issues raised by people with a disability with regard to shopping centres had to be addressed. Whilst staff may accompany individuals to shopping centres, the long term goal is for individuals to become significantly independent in their activities. Even in the short term, staff/client ratios require that staff move between a number of individuals undertaking a range of self-determined activities in a range of venues. To resource this, staff support clients to increase their skills so that they are able to function effectively when they undertake unaccompanied activities for periods of time. Staffing levels do not enable staff to support/accompany every individual at all times, nor is this desirable in many cases. While clients are actively supported by staff in their activities, Scope has sought to encourage and support people in becoming more independent. This independence needs to be supported by a more inclusive community. Therefore, central to supporting the independence of people with disabilities, is the task of facilitating broader social change. Scope’s practice is driven by the social model of disability which regards disability as a social barrier to be overcome rather than an individual affliction.

---

Social barriers are evident in shopping centres. Shopping centres operate not only as venues of consumption, but provide a variety of services and social activities where people gather and associate with one another, and are therefore a central component of communities. In order therefore to achieve community inclusion for people with disabilities, shopping centres need to be recognised as central institutions in creating a more welcoming and inclusive community. In recent years, there have been attempts made throughout shopping centres in Victoria to enable greater access for a wide range of people including those who use wheelchairs and require ramps to make access possible. Though important, these changes are merely a starting point, with much more work to be done to make shopping centres more accessible to all and therefore to add to the important work of community inclusion. As well as physical access, inclusion must also involve positive interactions between people, as well as the building of meaningful relationships in which people have a sense of belonging and a valid social role.

As Scope's community inclusion work progressed, Yoland Wadsworth's work, and her advocacy of participatory action research, was shaping Scope researchers' thoughts around ways of researching significant disability issues. Participatory action research can be defined as involving a cycle of questioning, planning, action, reflection, in a continuous cycle that seeks to bring about change while conscious of the role of various participants in the entire process (Wadsworth, 1998). Both the co-ordinator of St Albans Day and Lifestyle Centre and Scope's research co-ordinator were exploring the importance of this research methodology and its significance to the disability sector. This research methodology complemented the community activities and the stated needs of the two groups of Scope clients, along with Scope's priorities as outlined in the strategic plan 2009-2012, and the Victorian Government vision as outlined in the *Victorian State Disability Plan 2002-2012*. Together, these factors led to the Food Court Friends project – in essence an aim to document and understand key issues and concerns within shopping centres from the perspective of Scope clients, management, shopkeepers and their staff, and then to attempt to develop solutions at the various City of Brimbank shopping centres.

### **Project Aims**

The project is based on the rationale that understanding the experiences of all parties (Scope clients, shopkeepers and associated personnel), and then responding to the issues identified, will increase positive interactions and assist in the building of meaningful relationships between all those involved.

---

The research questions arose from ongoing discussion amongst a formally trained researcher and service co-ordinators, and included:

- What are the issues and experiences of people with disabilities (Scope clients from the Scope Community Group in Braybrook and the St Albans Day and Lifestyle Centre) at Sunshine Marketplace, the Brimbank Shopping Centre and the Sunshine Plaza?
- What are the issues and experiences of shopkeepers and associated personnel of the Sunshine Marketplace, the Brimbank Shopping Centre and the Sunshine Plaza, in engaging with people with disabilities?
- How might the experiences of all parties be improved?
- What are the outcomes of strategies enacted to improve interactions between these various groups?

These questions sought to address the need to listen to what people had to say and to give a platform for people's experiences and understandings, while then seeking to act upon the information and so change things for the better of all those concerned.

In addressing these key questions the aims of the project were to:

- Work with members of the Scope Community Group as co-researchers. This process sought to empower people with disabilities through building the skills and confidence of those who undertook participant/researcher roles in the project;
- Increase the awareness of shopkeepers and associated personnel of the needs of people with disabilities using these facilities;
- Work with shopkeepers and associated personnel to identify their concerns when providing services to people with disabilities;
- Develop simple strategies and resources with the input of shopkeepers and associated personnel, and people with disabilities, to facilitate the provision of services to people with disabilities and assist in the building of relationships.

The project planned to identify the perceptions of shopkeepers and associated personnel regarding people with disabilities, then move to implementing and

---

evaluating the effectiveness of strategies employed to address negative perceptions and behaviours. Throughout, researchers planned to document the experience of people with disabilities as they increasingly accessed these shopping centres and built relationships with personnel. The project's aims were initially ambitious, and deliberately so, for the issues faced by people with disabilities in shopping centres and the people they engage with could be viewed as representative of issues faced by many in the wider community. Concerns with communication and accessibility for example can be felt by a variety of people in their own unique way. While needing to acknowledge the specific concerns of people with disabilities and the need to address them, recognising the more universal human concerns may help to avoid stigmatising specific groups. The concerns of one group are often felt by others and impact everyone – such an understanding can hopefully lead to a unified approach to solutions rather than a divisive 'us' and 'them' approach.

Ultimately, the project was more modest in its achievements, yet the findings, developments, successes and failures, all serve to inform future practice and ways in which change can make a positive difference, both for people with disabilities and others in the broader community.

#### Attitude change

While not initially stated as a key objective, attitude change emerged as a significant theme throughout the course of the project. As with most projects, and in line with participatory action research that encourages ongoing reflection and input of the participants, the course of events throughout the project led to observations that were worth pursuing. It was noticeable to both the formally trained lead researchers and support staff, that when the students and members of Scope Community Group worked together, the processes of time, proximity and interaction, led to greater mutual understanding and a relaxing of social awkwardness. Members of the Scope Community Group remarked how they had gradually warmed to the students and had come to feel more relaxed in their company. This was evident in the manner in which both groups worked together during the time they were engaged at the shopping centre. As a result, the lead researchers decided to facilitate a small discussion with students around attitude change. This involved a short informal discussion with some students new to the project in its final stages. This was undertaken at the Caroline Chisholm Catholic College one afternoon when one of the lead researchers met the students to outline the project and discuss the requirements in the weeks ahead, with part of the conversation focusing on attitudes towards people with disability. This was

---

followed by further discussion at the end of the students' time with the Scope Community Group. While this aspect of attitude change was not central to the project, it was deemed to be worth exploring as the insights gained are significant when considering future possibilities. While there is a large amount of literature on attitude change, by comparison there is minimal work in relation to disability (Kleeman and Wilson, 2007: 11).

Overall, the aims of the project can be regarded as a quest for change that seeks to reform shopping centres, and positively impact people's attitudes. In doing so, the work contributes to further social change that makes social inclusion a more meaningful experience for all concerned.

## **Method**

Scope's approach is based on the value of placing people with disabilities at the forefront of the work Scope does, and to ensure that change is driven by the needs and desires of people with disabilities. Therefore, it is crucial that any research should always be guided by the experiences and understandings of people with disabilities. This project highlights a *collaborative* model of research that affirms people with disabilities as co-researchers helping to plan and implement research, along with the actions that flow from it. It is hoped that the model might be useful in other research contexts to increase the involvement of people with disabilities in research about their own issues.

The research project utilised a range of data collection methods over three years, including:

- Discussion groups with people with disabilities who elected to participate;
- Interviews and surveys with shopkeepers and associated personnel who elected to participate;
- Interviews and surveys to assess the use/impact of the strategies used to address key issues.

---

The questions<sup>3</sup> used in discussion groups and interviews (refer to Appendices One and Two for the questions) evolved from discussions among the lead researchers<sup>4</sup> and service co-ordinators. Discussion groups were used for several purposes:

- To identify the issues relating to inclusion at shopping centres, and the barriers to inclusion;
- To gain feedback from people with disabilities throughout the project following the implementation of strategies;
- To interpret and reflect on data/comments from shopkeepers by checking against the experiences of people with disabilities.

The following table outlines the timeframe and methods employed throughout the duration of the research:

---

<sup>3</sup> It should be noted that the questions were not developed in collaboration with people with disabilities. Future research would do well to address this omission and would be in line with the principles of participatory action research.

<sup>4</sup> In the first year of the project, a project officer worked with one of the lead researchers. The project officer resigned towards the end of 2006 and was replaced by a lead researcher.

**Table 1: Project timeframe and methods**

<b>Research stage / timeframe</b>	<b>Research methods</b>
Phase 1: (2006) Identifying the issues of people with a disability	<ul style="list-style-type: none"> <li>• Discussion groups with people with disabilities about their experiences of shopping at Brimbank Shopping Centre, Sunshine Marketplace and Sunshine Plaza.</li> </ul>
Phase 2: (2006) Establishing the research group	<ul style="list-style-type: none"> <li>• Training of co-researchers and research partners (series of three two-hour workshops).</li> </ul>
Phase 3: (2006) Identifying the issues of shopkeepers	<ul style="list-style-type: none"> <li>• Surveying of shopkeepers and shopping centre personnel at the three shopping centres (by co-researchers and research partners)</li> <li>• Data analysis (by lead researchers).</li> </ul>
Phase 4: (2007) Commencing the responses	<ul style="list-style-type: none"> <li>• Meetings with shopping centre management to discuss the findings (research team).</li> <li>• Development of the communication boards and the communication guide (speech therapist).</li> </ul>
Phase 5: (2007) Implementing the responses	<ul style="list-style-type: none"> <li>• Implementing the communication boards (speech therapist).</li> <li>• Training of co-researchers and research partners (series of two two-hour workshops).</li> <li>• Surveying of shopkeepers at Sunshine Marketplace accompanied by distribution of communication guide (by co-researchers and research partners).</li> <li>• Discussion groups with people with disabilities (conducted by a lead researcher).</li> <li>• Data analysis (by lead researchers).</li> </ul>
Phase 6: (2008) Evaluating the communication guide	<ul style="list-style-type: none"> <li>• Training of co-researchers and research partners (series of two two-hour workshops).</li> <li>• Discussion groups with people with disabilities (conducted by a lead researcher).</li> <li>• Surveying of shopkeepers at one shopping centre (by co-researchers and research partners).</li> <li>• Data analysis (by lead researchers).</li> </ul>
Phase 7: (2009) Concluding the project	<ul style="list-style-type: none"> <li>• Discussion groups with people with disabilities (run by the lead researcher) to discuss and seek final input on the project, including the experiences of people with disabilities, the overall findings, limitations and recommendations.</li> </ul>

---

### A collaborative model

From the inception of the project it was envisioned that an *inclusive* research process would be adopted. In their work on inclusive research, Walmsley and Johnson note that ‘inclusive research as a term covers two major disability research traditions, participatory and emancipatory research’ (2003: 62) and seeks to include people with intellectual disabilities ‘as more than just research subjects or respondents’ (Walmsley, 2001: 188). Walmsley and Johnson (2003) propose a range of roles for people with intellectual disability in inclusive research including ‘instigators of ideas, research designers, interviewers, data analysts, authors, disseminators and users’ (p.10).

This project was informed by the stated benefits and purposes of the *participatory* and *emancipatory* paradigms, including those that evolved prior to the formal development of ‘inclusive’ research. For example, participatory research involves a stated commitment to move responsibility for knowledge creation away from the researcher to a shared responsibility with the participant group, and enables those affected by an issue to be engaged in finding out more about it. Participatory researchers offer a wide range of rationales for the participation process – from the development of new understandings (Pinar, 1981: 181), to the increased capacity of participants via active engagement in the planning, executing and dissemination of the research (Lather, 1986). Participatory research proposes

*a genuinely democratic or non-coercive process whereby those to be helped, determine the purposes and outcomes of their own inquiry* (Wadsworth: 1998: not paginated).

Emancipatory research shares these goals with an explicit focus on social change. As argued by Friere, a founding thinker in emancipatory theory, emancipatory research explicitly seeks to change the consciousness of participants in order to achieve new understandings about their world (Friere, 1972) and, by doing so, change social and power relations (Friere, 1972; Smith, 1990a and 1990b). Disability researchers Ward and Flynn (1994), argue that emancipatory research ‘places people with disabilities and their concerns centre stage at every point in a research process aimed at facilitating their empowerment’ which fundamentally changes the social relations of knowledge production (1994: 31). Likewise Felske (1994: 188), in her work on disability research, identifies that such an approach not only seeks to document the conditions of lived experience but to ‘change the conditions ... to radically restructure



---

society'. As Walmsley (2001: 195) argues, 'emancipatory research is as much a form of political action as it is research'. A related feature of emancipatory research is the level of control over the research process and product by those who are traditionally considered the 'objects' of research. In discussing emancipatory research within the disability field, Walmsley (2001: 196 citing Finkelstein, 1999) suggests that it 'is not emancipatory if it follows the agenda set by others' and control by people with disability includes determining topic, methods and dissemination.

These ideas are powerful drivers for the design of inclusive research, including this project. However, whilst the project intentions aligned with these ideals, from the commencement of the project it was recognised that the research design was unlikely to fully realise them. In light of the everyday reality of the project, not all elements of these paradigms seemed relevant or desired by researchers and people with disabilities alike. As a result, the research design that evolved aimed to affirm people with a disability as co-researchers, helping to plan and implement research along with the actions that flow from it, while recognising that they also valued other aspects of working collaboratively (such as sharing social time together), and that the project was just one aspect of their busy lives. In this context, the various researcher roles created within the project carried many intentions and values.

This project offered three researcher roles. People with a disability worked as *co-researchers* (to varying degrees at different stages of the research), secondary school students acted as *research partners* to support the activity of data collection, and both groups worked together with formally trained *lead researchers*. The following outlines the model that was adopted, but as subsequently discovered, the reality was both more and less than this. Each of the research roles within the model is described below.

#### Lead researcher role

The Food Court Friends project identified an explicit role for the two Scope lead researchers (both without disabilities) who had previous research training and experience. The feminist researcher, Patty Lather, describes this role as a catalyst (Lather, 1986), while within the emancipatory methodology, it has been described as a 'challenger' (Freire, 1972) or critical friend (Carr and Kemmis, 1986) to the participating group. Within inclusive research approaches, the role of the formally trained, usually non-disabled researcher, has also been labelled a 'research supporter'

---

acting as facilitator, advisor and sometimes trainer (Williams and Simons, 2005: 10). Stone and Priestly (1996) argue that the formally trained ‘non-disabled’ researcher must not be detached, but work closely with people with disabilities and be guided by an ethic of improving the lives of the people the researcher works with. In this sense, the researcher’s skills should be at the disposal of people with disabilities (1996: 703). In the Food Court Friends project, lead researchers sometimes adopted these roles, but were also largely responsible for the design of the overall project and research elements, working collaboratively with service co-ordinators of the Scope Community Group in this regard. Lead researchers managed the training of co-researchers and research partners, and designed data collection methods, analysed data, and authored documents.

While the lead researcher role was dominated by the management of traditional research tasks and responsibilities, it also aimed to involve significant contact and relationships with co-researchers. Lead researchers participated in many events, both related to the research and of a more social nature, in keeping with a natural process of building relationships between colleagues. This process of relationship building and engagement in the social world of co-researchers is a feature of participatory research discussed in what are known as post colonial research methodologies.<sup>5</sup> Bishop, like Freire (1972), argues that relationship building enables an understanding of the social context of participants’ views. The emphasis on relationships is part of recognising that working together as a group is always more than a technical activity but involves a myriad of roles and responsibilities to members and the group as a whole (Bishop, 1996). Social time together and the building of relationships was a central motivation for co-researcher involvement, and all members of the research team probably enjoyed this element the most.

### *Co-researcher role*

In keeping with aspects of a participatory research methodology, the project aimed to engage people with disabilities (up to twelve Scope Community Group members) as co-researchers in the planning of the project, the collection of data, and implementation of the project over its three year life span. Consistent with the approach of inclusive research, co-researchers engaged in a range of socially valued roles (Walmsley, 2001: 191) including:

---

<sup>5</sup> In short, one interest of post colonial research methodologies is how to manage relations between researchers and research participants/subjects where the social relations have been defined by a dominant group that has marginalised the ‘other’.

- 
- Training (along with research partners, discussed below) over several weeks each year, related to: the aims and methods of the project; the skills of interviewing; surveying; data documentation; dealing with negative feedback or difficult situations during interviews; and the associated issues of ethics and confidentiality. Training involved role-playing interviews, as well as significant time spent building relationships between co-researchers and other members of the research team;
  - Collection of data via interviews and surveys with shopkeepers and associated shopping centre personnel to identify the main issues affecting these people in dealing with people with disabilities. Co-researchers worked with teams of research partners to do interviews and surveys with shopping centre personnel inside the nominated shopping centres;
  - Meetings with shopping centre management to discuss findings and propose suitable interventions to address issues raised by shopping centre personnel;
  - Implementing a planned intervention in shopping centres which involved delivering a communication guide to shopkeepers;
  - Discussions about project activities, progress, and future actions;
  - Group discussions at the completion of the project about the findings, recommendations, and limitations of the project. In addition, co-researchers reflected on their experiences, motivations and feelings about involvement in the project as co-researchers; and
  - Concluding events such as social time with all members of the research team.

It should also be noted that part of the co-researcher role involved dissemination of the findings.<sup>6</sup>

While these roles were both planned and encouraged, the actual reality reflected these stated roles to varying degrees.

### Research partner role

One of the project's strengths was its collaboration with Caroline Chisholm Catholic College and their Victorian Certificate of Applied Learning (VCAL) students between 2006-2008. In each of the three years of the project, successive groups of students (around fifteen each year) worked as research partners to support co-researchers in the

---

<sup>6</sup> To date, two conference presentations have been given by members of the Scope Community Group and the lead researchers (Australasian Society for the Study of Intellectual Disability, 2008 and Victorian Advocacy League for Individuals with Intellectual Disability, 2009). These were seen by presenters as valuable opportunities for co-researchers to share their experiences and understandings.

---

collection of data in shopping centres. Successive teams of research partners worked on the project once a fortnight across eight to ten weeks each year. This involved participating in training, as discussed above, and working collaboratively to collect data where research partners formed groups with co-researchers to interview and survey shopkeepers and shopping centre personnel. These teams of co-researchers and research partners adopted the roles of interviewer and note-taker according to preference. They were assisted by Scope support workers who were present if needed to address any issues arising. While this approach is a valuable expansion of a participatory and inclusive method, its most significant value was seen to be its potential to foster relationships and to change attitudes as research team members interacted both during research activities and social events.

### *Speech Therapist - implementation resource role*

Given the action orientation of the project, a speech therapist was an important part of the implementation stage. A Scope speech therapist worked primarily with one of the lead researchers to develop appropriate responses to the issues of communication identified through interviewing shopkeepers and associated personnel. The speech therapist worked to develop both communication boards and the communication guide, and provided basic instruction to retailers who volunteered to use the communication boards.

### *The need for reflection*

The need to empower people with disabilities in research has been strongly stated by many researchers (Stone & Priestly, 1996, Ward & Flynn, 1994, Ramcharan & Grant, 1994) and it cannot be definitively claimed that this has been achieved in this project. Both lead researchers are mindful that in attempting to work in accordance to the ideals of inclusive research there are times when they have not been as successful as they would have hoped. Yet, in attempting to work in a reflective manner, the lead researchers have throughout the project sought to empower people with disabilities as co-researchers and been mindful of the way in which the project, its processes and outcomes, should reflect the needs of people with disabilities as articulated by them rather than the lead researchers. *Empathetic awareness* requires trying to look at the world through an individual's eyes and is important for all researchers in working with people with disabilities.

---

*The use of the reflexive stance becomes important when using inclusive research methods because it examines what our motivations are and why and how we are using a particular tool. It allows the audience to make an informed interpretation of a situation. It also addresses the problem of objectivity because it makes the research process more transparent (Owens, 2007: 311).*

The reflexive stance is an ongoing process that should be practiced from the inception of a research project through to its conclusion – including the writing up and dissemination of the results. The lead researchers have endeavoured to adopt a reflective process throughout the research project by continuing to review all aspects of the work, particularly the ways in which the lead researchers have collaborated with the co-researchers and research partners, and to question the benefit of the project for people with disabilities.

To what extent this has been achieved is subject to debate and to the evaluations of those whom the research seeks to serve. What can be stated is that the model used here is a useful starting point when considering the ways to develop people with disabilities as co-researchers, while mindful that it is just one step on the path to empowerment for people with disabilities which includes empowerment in future research projects.

## **Section Two: Scanning the Literature**

A vast array of literature can inform a project and it is not always possible, nor necessary, to outline in detail all the literature examined throughout the course of the project. Nor is it possible to review all the relevant literature given the inexhaustible quantity of material available. There are however core texts and empirical research projects that are central to this project and worth outlining here in some detail.

### **Community Inclusion**

As previously mentioned, the Victorian Government has outlined a vision in the *State Disability Plan 2002-2012* based on fundamental principles of human rights and social justice. The Victorian Government's vision for the future is that:

*By 2012, Victoria will be a stronger and more inclusive community – a place where diversity is embraced and celebrated, and where everyone has the same opportunities to participate in the life of the community, and the same responsibilities towards society as all other citizens of Victoria (2002: 7).*

The Victorian Government states that the meaning of community may be different for different people and that people can belong to a multitude of communities (2002: 35). While acknowledging contestation over the definition of community, the Victorian Government claims that 'inclusive communities benefit all members of the community, by reducing the inequalities and disadvantages that unfairly undermine some people's opportunities to take part in community life' (2002: 36). This vision underlines the work of the Food Court Friends project, and is reflected by the efforts of Scope who endeavour to work in partnership with others to create welcoming and inclusive communities.

It is equally important to consider the various institutions that comprise a community. In a consumer oriented society, shopping centres are central to community existence. While there are many critiques of Western consumerist culture, the sociologist Rob Shields, who has written extensively on social spaces and shopping malls, argues that shopping centres now go beyond convenience shopping and instead are sites of community events (1992: 105). Thus 'Shopping is not just a functional activity. Consumption has become a communal activity, even a form of solidarity' (1992: 110). While accessing shopping centres, Scope clients were frequently frustrated by

many of the barriers which they confronted – physical, attitudinal or people’s lack of disability awareness. It is important therefore that any attempts to build more inclusive communities should include shopping centres.

While recognising that shopping centres are potentially venues of community, it is also important to consider what community inclusion is, and how we might recognise it and measure it. Schleien, Green and Stone (1999: 2) offer three distinct characteristics of inclusion: 1) *physical inclusion*, being the right to and actuality of physical accessibility, 2) *functional inclusion*, as the ‘ability to function successfully’ in given environments; and 3) *social inclusion* as social acceptance and participation in ‘positive interactions’ with others. These distinct characteristics emphasise distinctions between physical presence and a wider range of social and participative outcomes which encompass a wide variety of possibilities for individuals. In working with social institutions such as shopping centres to aid inclusion for people with disabilities, all three characteristics mentioned here are central to such work with the emphasis on going beyond just a physical presence.

### **Individual Lifestyles – Planning and Action**

In order to achieve its vision of building inclusive communities, the Victorian Government has outlined a number of goals, one of which is pursuing individual lifestyles. As stated in the *Victorian State Disability Plan 2002-2012*:

*Enabling people with disability to pursue their own individual lifestyle means ensuring that people have maximum control over their own lives. To achieve this, the Government will reorient disability supports so that they are more responsive and more focused on people’s individual needs and choices, and to the needs of their families and carers (2002: 11).*

This vision aligns with the tenets of Scope’s *Strategic Plan 2009-2012*, with the priority of empowering individuals to make their own choices. To achieve this, Scope has embarked on person centred practice employing person centred planners, while ensuring that support staff and co-ordinators are trained in this method. The importance of person centred practice has been outlined in a vast array of literature arguing for its benefits to people with disabilities. Helen Sanderson, based in the United Kingdom, is a contemporary advocate of the person centred approach and person centred planning. She defines the combined method of the person centred approach and person centred planning as ‘a process of continual listening, and

learning; focused on what is important to someone now, and for the future; and acting upon this in alliance with their family and friends' (Sanderson, 2000: 2). Flexibility, with the ability to constantly adapt, becomes fundamental to this individualised approach that is guided by the rights of the individual to lead a life of choice, aided and supported, rather than controlled, by service providers.

*Person centred planning, requires that staff have a flexible and responsive approach to meet peoples' changing circumstances, guided by the principles of good planning rather than a standard procedure. Staff need to be constantly problem solving in partnership with the person and their family and friends (Sanderson, 2000: 2-3).*

More important though than planning is the necessity for person centred thinking:

*For people being supported by services, it is not person centred planning that matters as much as the pervasive presence of person centred thinking...Only a small percentage of people need to know how to write good person centred plans, but everyone involved needs to have good skills in person centred thinking, in the value based skills that underlie the planning (Sanderson and Smull, n.d.).*

However, thinking in itself is not enough unless it is followed by action. Eric Emerson and Roger Stancliffe, in their research into person centred planning, state a need for planning *and* action if person centred planning is not to become just another fad: 'effective PCP [person centred planning] must lead to person-centred *action*' (Emerson and Stancliffe, 2004: 24).

The Food Court Friends project has been guided by such principles and ideas in supporting people with disabilities in living their life of choice through planning and action, while working to overcome the barriers that prevent individual achievement and community inclusion.

### **Attitude Change**

One such barrier to community inclusion is the negative attitudes that continue to exist towards people with disabilities. In a study of attitudes towards people with disabilities in Australia, Yazbeck, McVilly and Parmenter (2004) concur that despite



the introduction of inclusive legislation and significant shifts in social policy, disability phobia still exists in Australia (Yazbeck et al, 2004: 109). Disability researchers, Kleeman and Wilson, note in their study on disability awareness programs that 'whilst a sizeable body of research has been undertaken around changing attitudes towards marginalised groups or overcoming stereotypes, less work has been undertaken specific to disability' (2007 :11). Their review of the literature notes the need for community education to raise general awareness regarding disability, but as Lippa observes, attitude change occurs mainly through personal contact with a person with a disability (Lippa in Kleeman and Wilson, 2007: 6). Of most importance, according to Murfitt in his work on changing attitudes to disability, is that attitude change is most likely to occur through different groups working together with equal status towards mutual goals (Murfitt, 2006: 158).

The Food Court Friends project, through the collaborative work between people with disabilities and secondary school students, enables an opportunity to enhance attitude change and to gain some insight into attitude awareness and foster change through people's experiences.

### **Australian Empirical Studies**

To date, there is very little research that engages with shopkeepers, shopping centres and community inclusion that is specific to people with disabilities. The lead researchers have however identified three key Australian studies to draw on. The most recent work on shopkeeper perceptions of people with disabilities is the work undertaken at Box Hill Centro by the Communication Resource Centre of Scope: 'Communicating in the Community' (Williams, Bryce, Smith, Iacono: 2005). This research identified a need for community development work with a focus largely on communication difficulties between shopping centre personnel and people with disabilities.

As outlined in the work of Williams et al (2005), surveying amongst shop and service staff at the Centro Box Hill complex led to project workers identifying a need for disability awareness training as well as the development of customised resources. Random sampling of all types of shops and services, including support staff such as a cleaner, police officers and a public transport staff member, identified that many workers were ill-equipped for working and communicating with people with disabilities, especially those with complex communication needs or uncommon behavioural modes. Communication was a major issue, with 88% indicating that they

experienced problems understanding customers/members of the public – this includes those with a disability and those whose first language is not English. Such problems resulted in feelings of frustration along with feeling helpless, worried or ‘bad’ (Williams et al, 2005: 1). Communication aids and a communication strategies guide for shopkeepers were used to address communication issues; all of which were deemed to assist in positive and successful communication for all those involved (Communication Resource Centre, Scope, 2008: 27-29).

The Food Court Friends project also drew on previous work by Parsons, Elkins, and Sigafos (2000) who interviewed small business owners, in four urban and four country regions in Queensland, about their concerns relating to interactions with people with disabilities. The study noted that ‘exposure to persons with intellectual disabilities as customers may lead to accepting attitudes on the part of the business community’ (2000: 245) and that ‘acceptance by the community is crucial if people with intellectual disabilities are to fully become part of the community’ (2000: 249). The authors concluded that while some concerns were indicated, overall ‘the vast majority of business people across the neighbourhoods, regions and types of businesses appeared to have few special concerns about having persons with intellectual disabilities as customers’ (2000: 250). Significantly, the study excluded large shopping centres as it was felt that the shop owners and employees would have less knowledge of the individual customers. Also the study does not examine the interactive concerns from the perspective of people with disabilities.

Finally, researchers Bramston et al (2002) sought to determine the degree to which feelings of belonging of adolescents with intellectual disability are associated with quality of life. In their study on community inclusion for adolescents with intellectual disabilities in Queensland, the researchers noted that adolescents with intellectual disabilities use public facilities less than their peers without intellectual disabilities, and that they engage in more solitary activities. Given this, they conclude that ‘it is not surprising that they identify less with the neighbourhood and feel a poorer sense of belonging than their peers’ (2002: 394). As the authors note, the word ‘community’ has many different meanings. These range from relationships based on common interests and ideas – which may transcend geographical location – to ones based on a specific geographical residential site with recognised boundaries (2002: 386).

A common theme is a feeling of belonging, and the authors draw on McMillan and Chavis (1986) who define community as a ‘sense of shared emotional connection, membership and sense of belonging, that one can have some influence over other community members, and that one’s needs are recognised and fulfilled because one

belongs' (2002: 386). The findings illustrate the importance of community inclusion for all community members and that experiencing a 'sense of belonging' is associated with a positive quality of life.

Together these three studies indicate the importance of considering community inclusion for people with disabilities and the significance of shopping centres as central to community inclusion activities. The Food Court Friends project continues this work of measuring and aiding inclusion, while also significantly involving people with disabilities in the research.

## **Section Three: The Project**

### **Identifying the Issues of People with Disabilities**

Two discussion groups were held in 2006 with members of the Scope Community Group and St Albans Day and Lifestyle Centre to identify whether people accessed indoor shopping centres and which shops they visited. They were then asked about any problems and what they thought might help to rectify the issues identified. Support staff witnessed, and people with disabilities reported, a range of difficulties in the interactions between shopkeepers, security personnel and people with disabilities. These experiences involved difficulties in communication, with shopping centre staff often ignoring the person with a disability while addressing the carer, and problems of accessibility within the shopping centres. While self-operating doors and wide malls are positive steps towards addressing this problem, there remained concerns with high counters and shop inaccessibility due to crowding of aisles with products. Some instances of non disabled people using specially designated car parking spaces for people with disability were also reported. The overall lack of disability awareness encountered in the shopping centres hindered the efforts to encourage greater independence for people with disabilities.

### **Training of Co-Researchers and Research Partners**

Prior to undertaking surveys among shopkeepers and associated personnel at three shopping centres, a number of training sessions were conducted to prepare both the members of the Scope Community Group and the college students for the task of gathering the data. Initial sessions focused on building relationships between the Scope clients and the students. Various social activities were undertaken, including afternoon tea and 'speed dating' games to enable participants to get to know one another. Some of the students sought to document part of the process by filming activities and making a short documentary. This was later shown to all participants at a certificate presentation ceremony at the conclusion of the shopping centre survey work.

The training took place over a number of weeks, as outlined in Section One ('A Collaborative Model', p.12). This was conducted by the lead researchers and a Scope psychologist. This training can be deemed to have developed skills for people beyond the task at hand – raising disability awareness amongst students, increasing the confidence and self-esteem amongst participants, and fostering attitude change. While these were not specifically measured (apart from an informal discussion on attitudes

with the last group of students in 2008) and were not deemed to be specific outcomes from the project, discussion and feedback from all participants indicated that these outcomes were evident and somewhat significant. The relationship with Caroline Chisholm Catholic College continued throughout the project, with students working with members of the Scope Community Group in 2006, 2007 and 2008.

### **Identifying the Issues at Sunshine Marketplace, Sunshine Plaza and Brimbank Shopping Centre**

The initial surveying work at the three shopping centres was undertaken in 2006 across two days. It involved members of the Scope Community Group working in groups with the students, with assistance from Scope support workers who were nearby should any concerns arise. Shopping centre personnel were interviewed and asked to identify their experiences in interacting with people with disabilities, issues arising, and strategies adopted to deal with these (see Appendix Two). The surveying of personnel at each centre took approximately one hour. Table 2 shows the number of interviews and surveys that took place across the three shopping centres, while Table 3 shows the total number of participants across the three shopping centres according to personnel.

**Table 2: Composition of interviews and surveys with shopping centre personnel**

<b>Sunshine Plaza</b>	<b>Sunshine Marketplace</b>	<b>Brimbank Central</b>	<b>Total no. of Interviews/surveys</b>
10	11	10 Total includes 1 group interview	31

**Table 3: Composition of participant sample within the three shopping centres**

<b>Shopkeepers</b>	<b>Other Shopping Centre Personnel</b>	<b>Total Participants</b>
29	6	35

Responses from shopping centre personnel indicate that the most common encounters with people with disabilities who shop at these venues are with people who use wheelchairs. However, when shopping centre personnel were asked to describe the problems they have experienced with people with disabilities, the most common difficulties related to communication problems and trying to understand what the

person is saying. It was also found that many surveyed relied on an accompanying person, who is with the person with a disability, to facilitate communication.

On the whole, shopping centre personnel identified a positive interest in increasing their skills and knowledge about disability. Specifically of benefit, as identified by respondents, would be skills development about the different communication aids that people with disabilities use as well as Disability Awareness Training to learn about the needs of people with disabilities when they use shopping centre facilities. In addition, retailers appeared willing to adopt resources such as picture board menus and charts that facilitate communication, where these are available.

It was also found that the security personnel often play a role when shopkeepers encounter problems. Security personnel appeared to have a role as communicators who can assist with difficulties in understanding a person with a disability, or as gatekeepers of equipment such as wheelchairs that are loaned out to patrons. Security personnel are therefore a resource that ideally could be used in bringing about greater inclusion of people with disabilities in shopping centres.

Other problems that were identified by shopkeepers include some mention of problems with high shop counters or lack of visibility, and narrow walkways or “squashy” spaces in shops which make it difficult for people with disabilities to access, particularly those who use wheelchairs. A small number of shopkeepers also mentioned that it can be time-consuming to serve a person with a disability, with specific mention of problems during busy peak-hour times of the day and having to take the time to be patient with a customer who is difficult to understand.

Some of the more positive findings of the project relate to the ways that shopkeepers do respond to the needs of people with disabilities who come into these shopping centres, such as taking food to the table for them, handling drinks or money, moving objects to clear a pathway, pointing to food, giving the person a pen and paper to facilitate communication, and speaking clearly. It was also positive to learn that many shopkeepers who participated in the interviews suggested that they consider people with disabilities to be the same as every other customer, and that all customers should be treated equally.

Table 4 outlines the problems identified by shopping centre personnel and the number that identified a particular problem. Notably, approximately one-third of respondents identified no problems when dealing with people with disabilities though the extent or frequency of their encounters is not known.

**Table 4: Problems identified by shopping centre personnel in providing services to people with disabilities**

<b>Problems Identified by Shopping Centre Personnel</b>	<b>Number of Respondents</b>
Communication	16
No problem/Not encountered a problem	9
Relying on accompanying person to facilitate communication/support	8
Access & mobility	8
Visibility (high counters)	2

Note: Sample size = 31 (total number of interviews/surveys conducted including one group interview).

Reports were subsequently written up by the project officer and distributed to management of the three shopping centres. Discussions with management occurred in 2007 to follow-up on the issues raised in the reports.

### **Commencing the Responses – Designing Communication Aids**

The project officer resigned at the end of 2006 and was replaced by a lead researcher at the beginning of 2007, who then began work on the project with a speech therapist from the Scope Communication Resource Centre. After discussions between the researcher, the speech therapist, the St Albans Day and Lifestyle Service co-ordinator, the Scope Community Group co-ordinator, and representative members from Scope’s clientele, meetings were held with senior management at the three shopping centres in February 2007. Management from these centres met with two members from the Scope Community Group and a lead researcher, discussing the survey results and how to begin to address the key issues identified. Management were sympathetic to the matters raised and identified in the reports, and outlined steps already commenced to address these issues.

Management noted that the problem of physical accessibility in individual shops for people with disabilities had been previously raised with shopkeepers by shopping centre management. The difficulty is that shopkeepers are free, within certain legal limits, to establish their counters, position their merchandise, and to use their space as they see fit. The use of space in particular ways often leads to the crowding of aisles with merchandise. The challenge here is to raise awareness and promote the consideration of access for people with disabilities, while recognizing the retailer’s right to use their space according to their requirements. According to group discussions with clients from St Albans Day and Lifestyle Centre, this issue appears

to relate to certain stores only – mainly budget stores that sell a range of products cheaply and seek to maximise their available space. Management were reluctant to push the issue with shopkeepers too strongly, recognizing that as long as legal requirements are being met, then shopkeepers have the freedom to use their space as they see fit.

Overall, during discussion groups, Scope clients indicated that access around the centres in general was satisfactory – it was only in certain stores that it became difficult at times.

With regard to disability parking (as identified by people with disabilities), management at Sunshine Marketplace and Brimbank Shopping Centre indicated that the issue had been raised with the local council. The council had indicated that it had increased its monitoring of parking and the issuing of fines where there is transgression in the car parks of the three shopping centres. It is likely that the stringent monitoring of parking and the sanctions involved will have some impact on the unauthorised use of disability parking spaces. Subsequent feedback from support staff indicated that unauthorised use of disability parking spaces was no longer an issue.

### **Implementing the Responses: Surveying and Distribution of the Communication Tools at Sunshine Marketplace**

Given shopping centre managements' recognition that guidelines exist for individual shops with regard to accessibility and their reluctance to strongly push the issue with individual shopkeepers, and given the ongoing action with regard to disability parking, it was agreed at these meetings with shopping centre management to focus on the issue of communication between people with disabilities and shopkeepers. It was decided, after consultation with members of the St Albans Day and Lifestyle Centre and Scope Community Group, that Scope could offer shopkeepers communication boards which had previously been implemented at Box Hill Centro – a project that a Scope speech therapist had a significant role in. Initially a lead researcher and speech therapist approached a number of individual stores offering them the use of these communication boards to be designed in consultation with them. Unfortunately, none of them accepted the offer.

It was then decided – with agreement and support from centre management at Sunshine Marketplace and Brimbank Shopping Centre – to contact all shopkeepers by



email outlining the project and offering them Scope's services to design communication boards for their store. Management from these centres subsequently sent out an email to all shopping centre personnel to advise them that staff and clients from Scope were available to work with them individually to aid in assisting with communication. It was agreed with centre management at Sunshine Plaza that while they were keen to work with Scope, it was best to put on hold any projects given that the centre was in a period of major transition and building works. Any project work would have minimal impact given that there was a large degree of uncertainty as to which shopkeepers would be staying on. This redevelopment continued throughout 2009.

Following the email that was sent out to shopping centre personnel at Sunshine Marketplace, two shopkeepers at the centre expressed interest. Unfortunately, there was no interest expressed at this time from any of Brimbank's shopkeepers. While the response rate was disappointing, this was also an advantage as it meant that resources could be focused solely on these two stores as a trial. The speech therapist and a lead researcher met with the managers of the two stores to discuss the communication boards. Their requirements were ascertained in terms of the products they deal with and the main enquiries they get from customers. The speech therapist also took photos of some of the main products to aid in designing the communication boards. She began the task of designing the boards, while working with a lead researcher to design a communication guide sheet for distribution to shopkeepers. This is an instructional tool with ten guidelines on communicating with a person with a disability (see Appendix Three). This was later shown to the members of the Scope Community Group who were invited to comment on the draft and to express any changes or other recommendations. The final version was approved by the group.

Initial drafts of the communication boards were shown to the shopkeepers for their approval before completing final versions. Copies were given to the two retailers (2007) to commence their trial of them. The speech therapist gave some basic training in using them, with the intention of following up occasionally to see how retailers were using the communication boards and how effective the boards were in aiding them in communication. This follow up work occurred early in 2008 over a period of four months. The indications were that the boards had rarely been used. Shopkeepers indicated that they were awkward to use, with staff reverting to addressing support workers (rather than the person with the disability) when there was uncertainty, or relying on techniques such as pointing or holding items up. One retailer had in fact dispensed with the boards, while the other no longer had them within easy access for staff.

This reluctance to use the boards indicates that possibly more training, ongoing support and encouragement is required for people to use them. Both the lead researcher and the speech therapist felt that despite an indication of their willingness to cooperate, the enthusiasm of the shopkeepers was limited as both stores were always busy. Time constraints meant their other commitments did not allow more time for training and ongoing support. It is also possible that individually tailored communication boards for the person with a disability are more effective and more empowering. A generic communication tool located at individual shops may not suit an individual's needs and in fact may hinder communication given that generic boards structure communication in a way that is not specific to the personal preferences of those involved.

Along with the communication boards, the other key task involved the distribution of the communication guide sheet (discussed above) amongst shopkeepers which took place in October 2007. The distribution of this guide was also an opportunity for the Scope Community Group and students from Caroline Chisholm Catholic College to collaborate together. Given the success of the project in 2006 with the two groups working together, this was a chance to further the relationship between the community group and the college. Students from the college were available from September on a fortnightly basis. This allowed five sessions with the students – a time constraint that necessitated that the shopping centre work be restricted to Sunshine Marketplace. Two sessions of training were conducted, this time focused on skills related to disseminating the communication guide. Of significant value were the role plays that enabled everyone to participate in acting out a variety of scenarios to prepare them for meeting shopkeepers.

On October 8 2007, the participants divided into groups of five and made their way around Sunshine Marketplace armed with lists of shopkeepers, maps, the communication guide, a Scope fact file sheet which provided information on the organisation and its services, and assorted Scope stationery such as pens and highlighters. Most shopkeepers were willing to give a few minutes of their time to listen to what the project members had to say and to accept the material offered to them. Fifty-eight shops were visited, with communication guides left with 88% of these stores. Shopkeepers were also asked whether they had ever had a difficult experience in communication with a person with a disability, with 55% saying they had.

**Table 5: Summary of visits to shopkeepers at Sunshine Marketplace, October 2007**

<b>No. of stores visited</b>	<b>Have they (shopkeepers) had a difficult experience in communication?</b>	<b>No. of communication guides left with shopkeepers.</b>
Spoke to: 42	Yes: 23	51
Too busy: 16	No: 19	
Total: 58	Total: 42	Total: 51

It was hoped that the communication guides would aid people in communication while also helping to promote disability awareness. Like the communication boards issued to the two participating shopkeepers, it was recognised that many shopkeepers may put the material aside and not refer to it. However, it was felt that if a small number use the guides then this is a significant step in aiding communication. Also the activity involving the students and people with disabilities helped to raise disability awareness in general, while the time students and Scope clients spent together was valuable in building social skills and aiding disability awareness. The activities in working together in partnership also worked towards building self-esteem and confidence for participants in a way that is a small step towards greater community inclusion. While there is no rigorous data around these issues, informal conversations with members of the Scope Community Group, following the time spent with students, have indicated the personal benefits of working closely with others while being involved in a shared task with responsibilities and obligations. At the completion of the work in the shopping centres, all participants took part in playing computer games at the *Intencity* interactive games venue, followed by the awarding of certificates to all those involved.

## **Evaluating the Communication Guide: Follow-Up Surveying and Evaluation at Sunshine Marketplace**

Caroline Chisholm Catholic College had expressed their desire to continue working on the Food Court Friends project in the second half of 2008. This involved a similar approach and method to that used in 2007 but was again governed by a limited amount of time to build rapport and engage in training for the participants.

Training was conducted over the course of two sessions throughout September. An initial session enabled people to introduce themselves, play a few games and join in discussion over food and drink. This appeared to work well and paved the way for the following two sessions which were devoted mainly to training, with social time at the end of each session. This prepared both the students and the members of the Scope Community Group for the work in the shopping centre. Time limitations meant that the work would again be restricted to Sunshine Marketplace. This activity was a combination of following up some of the initial work of 2007. It involved questioning shopkeepers over any difficulties they may have had with communication, as well as their use of the communication guide handed out the previous year. The groups again provided shopkeepers with the communication guide sheet and some Scope stationery.

In October 2008, students were matched with a member of the Scope Community Group, with each group visiting shops on the list they were provided with. They were assisted by a support worker, a lead researcher, or the school teacher. As in 2007, the majority of the shops in the centre were visited. Members of the Scope Community Group and the students were encouraged to do the work, with the assistance of the support person only when required. This method was seen as important in encouraging the co-researchers to do much of the work to enable skill development and to provide a sense of ownership of the task at hand. No problems were encountered and the task was completed by all those involved. Finally, one last session was devoted to a luncheon, along with the awarding of certificates to all participants, with a movie ticket given to each student. The Scope Community Group members were each paid \$20 for their work at the shopping centre which totalled one and a half hours.

**Table 6: Summary of visits to shopkeepers at Sunshine Marketplace, October 2008**

No. of stores visited	Have they had a difficult experience in communication?	If you used the guide we gave out last year, did you find it useful?	Was a communication guide left this time?
Spoke to: 52	Yes: 18	Yes: 9	Yes: 47
Too busy: 5	No: 30	No: 20	
Total: 57	Total: 48	Total: 29	Total: 47

Virtually the same number of stores were visited as in 2007, but whereas 16 stores out of 58 (28%) were too busy to speak with us in 2007, in 2008 only 5 out of 57 (9%) were too busy. This could be due to any number of factors, but overall the greater willingness to give up a small amount of time to speak with the Scope representatives was encouraging.

The issue of communication difficulties between customers with a disability and shopping centre personnel that was identified in the first round of interviews in 2006, continued to be identified in both 2007 and 2008 surveying, as discussed above. In 2007, approximately fifty five percent (55%) of shopkeepers surveyed confirmed that they had experienced difficulty in communicating with people with a disability. In 2008, this percentage had decreased slightly to around thirty seven percent (37%) of those surveyed. Around half of the respondents (56%) in 2008 identified that they had used the communication guide given out in 2007, though only thirty one percent (31%) of these had found it to be useful. While it is difficult to interpret these results given the wide array of reasons that could be attributed to them, a tentative conclusion could be drawn that communication guides had made a positive difference for almost one third of the shopkeepers who used them, and that overall, the prevalence of communication difficulties between shopkeepers and people with a disability had decreased.

### **Concluding the Project**

A final discussion group was held to gain feedback from the co-researchers once the project work in the shopping centres was complete. Various conversations took place to allow the participants to reflect on their experiences, offer comment on what they thought was significant and to discuss the findings. Overall the discussion presented in the next section reflects the conclusions of the lead researchers who have drawn on the data, their own insights and understandings, and the ideas of the co-researchers reflecting on the project as a whole.

## **Section Four: Outcomes and Reflections**

As discussed in Section One, the Food Court Friends project had a variety of aims. In short, these focused on:

- Identifying and responding to the concerns of shopping centre personnel and people with disability about issues affecting their interactions;
- Involving people with disabilities as researchers in a collaborative research model;
- Building relationships between stakeholders which evolved over time into a more specific focus on collaboration between people with disabilities and students which involved attitude change.

The following discussion presents the conclusions of the lead researchers, informed by the co-researchers, as to the success in achieving these and the limitations associated with each aspect of the project work. Janine Owens argues that the involvement of different groups of people, and individuals within those groups, creates a range of perspectives and motives. Such wide-ranging collaborative and interactive research can never be an exact science. Such research challenges notions of objectivity, and calls on all involved to employ a level of reflexivity, assessing the role of the researcher as an active ‘part of the world being studied’ (Owens, 2007: 302). The following conclusions represent observations and reflections of the lead researchers, blended with the available data generated by the project, and the views of other members of the research team, most importantly, the co-researchers.

### **Assisting Communication**

As discussed in Section Three, the strategies employed to address communication problems included both the specific development of communication boards for two retailers, and a more wide-spread and repeated dissemination of a communication guide. Given the limited use of the communication boards, and subsequent withdrawal of both retailers from the project, discussion here focuses on evaluating the impact of the communication guide.

While the communication guide was distributed amongst the majority of shopkeepers at Sunshine Marketplace, it is difficult to evaluate and make definitive claims as to the effectiveness of the guide. There is difficulty in firmly establishing cause and effect with regard to the impact of the communication guide, especially in relying on people’s reported perceptions. This means that the conclusions presented here are

somewhat tentative. Nevertheless, they provide some insights into the effectiveness of the processes involved and considerations regarding future work in such relevant matters.

In 2008, shopkeepers were briefly questioned as to whether they used the guide and found it valuable. At best, the follow-up surveying provides a snapshot of shopkeepers' use of the guide and its effectiveness. The surveying revealed that twenty-nine stores (or a little more than half surveyed) had indicated that they had used the guide. Of these, nine (or one third) had found it useful. Three of them elaborated further, indicating they had discussed it with their staff, and that it had helped them in how to communicate with people with disabilities and those for whom English is limited. Another indicated they had it up on the staffroom wall and used it for all new staff in assisting them with any communication issues they may face. Another indicated they used it as an ongoing tool of reference. Though small in number, this reported use and evident valuing of the communication guide is an encouraging result. This is consistent with results from the Box Hill Centro 'Good Communication is Good Business' project (Communication Resource Centre, 2008) which suggests that provision of both targeted and generic communication resources to shopping centre personnel yields an increase in successful communication between personnel and people with disabilities.

Throughout the period of the research, people with disabilities continued visiting the shopping centres. Two group discussions with Scope clients – averaging five people – were conducted at six monthly intervals over a twelve month period (2007-2008) to determine if people's experiences were changing and why (see Appendix Four for the discussion questions). The overall consensus was that at Sunshine Marketplace people's experiences were slightly improved (staff friendlier and more willing to engage and take time to communicate), though it is impossible to truly determine why this is the case. It is difficult to state that the communication guide alone has made a positive difference in people's experiences – participants did not reveal any indications that the guide had been used in their presence. However, the feedback from a small group of shopkeepers, and the experience of the Scope clients, would indicate that the willingness for the project participants to meet with shopkeepers and engage them in some small way with the communication guide is a positive step.

One Scope client remarked that it was good for people in the community to see that people with disabilities can speak and act for themselves (while acknowledging various levels of support may be required), and that it wasn't a case of just relying on others to speak on behalf of people with disabilities. While people overall found

shopkeepers friendly and helpful, there was still concern that some were not. One person remarked that while some shopkeepers were ‘nice and helpful’, some were ‘nasty and unfriendly’ with an unwillingness to talk or offer assistance. One member of the Scope Community Group still experienced times when staff spoke directly to the support worker rather than to them. This was also reflected in the research process itself, with two co-researchers commenting that shopkeepers related more to the student than the person with the disability, often answering to the student even when it was the person with the disability who had asked the question.

One person indicated that she was finding shopping easier and was gaining confidence in going shopping on her own – both in asking for what she wants and in handling money. Others had some difficulty in communicating but were happy to point to what they wanted. Two participants noted that while they still required support, they were more confident in buying something as they were encouraged by support workers to be more independent.

Overall, there was a sense that people were finding shopping easier as their confidence developed through ongoing support and because many retail staff (though not all) were more friendly and helpful. This highlights the need for ongoing shopping centre disability inclusion and awareness work. While in this instance the evidence as to the effectiveness of the communication guide is not conclusive, there is anecdotal evidence to suggest that the project work has had a positive impact and that more focused and continuing work could have a more positive and sustained impact.

### **The Collaborative Research Model**

From the commencement of the project it was important that people with disabilities be involved as co-researchers while respecting their right to determine whether to participate or not. This also included the understanding that they were free to opt out of the project at any time. As a result, levels of involvement fluctuated with some individuals involved from start to finish, while some chose to be involved at certain times and not at others. The involvement of people with disabilities as co-researchers was a strength of the project. It made the formally trained lead researchers mindful of the significance of their work in that they could not be detached clinical observers, but that every action they undertook was of significance to the people whom the research aimed to benefit. It also meant that the co-researchers could have a voice and could help shape the research in a manner that was significant to them. However, it would be misleading to say that there was an unproblematic equal relationship. The two lead researchers were mindful that as the main authors of the project, it was they that were



leading discussions, assisting the co-researchers, initiating contacts with others, arranging timetables, drawing on their research skills and experiences, and guiding the process overall. In this sense they were undertaking the role of mentors to the co-researchers – those with disabilities. While in this mentoring role, attempts were made to empower the co-researchers and assist them in exercising their choice and expressing their viewpoints as much as possible.

Various levels of intellectual disability meant that some of the co-researchers were more understanding of the process and aims than others. While attempts were made to inform everyone throughout the project of key developments and aims, cognitive differences meant that some of the co-researchers were more empowered and informed than others. These observations reflect the difficult issues to be considered when utilising the collaborative model. Overall, the use of co-researchers is a progressive step toward empowerment and serves as a check on the role of formally trained academic researchers. It helps to hold such researchers accountable and is an ongoing reminder of the true nature of the task at hand – that all disability research must be guided by an ethic of ultimately assisting people with disabilities in a manner that serves as a positive empowering tool. This is not always easy to achieve, but sensitivity to the needs and concerns of people with disabilities, the use of a collaborative research model, and ongoing reflection on the process, can all serve as significant means to ensure the research is founded on benefitting people with disabilities.

It is important also to consider that people with disabilities may be involved in the research for multiple reasons. This is true for all researchers who may benefit from research involvement in multiple ways. The social nature of the work involved meant that people with disabilities were engaged in activities that not only fitted the paradigm of research, but also incorporated other socially valued roles. While people with disabilities were defined as co-researchers, it became obvious that people's involvement (including lead researchers) was informed by a variety of motives, with the social features of being actively together a major aspect of the collaborative process of everyone involved. This is significant in considering the multiple benefits that can be gained from research and which may go beyond its stated aims.

Co-researchers often remarked how much they enjoyed being with the students (i.e., research partners) and being involved in the key tasks of the Food Court Friends project. Throughout the training process there was time for various social activities, while the shopping centre project work was also somewhat social in that people worked together in surveying the shopkeepers. Concluding events at the completion

of the surveying involved people with disabilities and the school students, and involved playing computer games at the *Intencity* interactive games venue, followed by the awarding of certificates to all involved. In one year, students (research partners) also screened a short video made by students to capture their experience on the project. The co-researchers enjoyed working with the students and engaging in activities with them, with one person stating that it had helped them in making it easier to talk and be with people. They found the students friendly and respectful, with one person commenting that 'They didn't judge us because we have disabilities – some people are very judgmental'.

In evaluating the project it is important to recognise that the research criteria is but one element. Equally as significant, perhaps even more so, is the positive value of social interaction for all those involved.

It should also be noted that part of the project involves dissemination of the results. As previously mentioned, to date two conference presentations have been given by members of the Scope Community Group and the lead researchers. They include the 'Australasian Society for the Study of Intellectual Disability' (ASSID) conference in Melbourne (November 2008) and the Victorian Advocacy League for Individuals with Intellectual Disability (VALID) conference in Geelong (February 2009). This was a valuable opportunity for people from the Scope Community Group to share their experiences and understandings, underlining the importance of the co-researcher method. The presenters were thoughtful and insightful in sharing their experiences. They were warmly acknowledged by the audiences for their achievement. The Scope Community Group members were very excited after their presentations and proud of their success. It could be seen also as an exercise in building confidence for participants – they later told the lead researchers how much they had enjoyed these occasions and how pleased they were at having taken part in these events.

In a discussion group at the end of the project, most of the co-researchers indicated that it was good to have people with disabilities involved in the project – that it was important to try and build relationships and break down barriers. Even on a small scale, there was a chance for interaction and for people to learn something about people with disabilities. However, one Scope Community Group member remarked that while they did not mind doing research, it sometimes was a bit too much and that they would rather do other things. This is a significant point to consider. While it is important that people with disabilities be given the opportunity to conduct research and be central figures in research projects and agendas, it is also important that people not feel obliged or pressured to be involved in such activities. Encouraging choice,

and giving people the chance to speak for themselves, means ensuring people who have little or no interest in research can comfortably choose not to be involved, or to be involved in a limited capacity.

### **Attitude Change**

In working with the Caroline Chisholm Catholic College students in 2008, an informal discussion was conducted by a lead researcher with students as part of the introduction to the project prior to them meeting the Scope Community Group (see Appendix Five for the questions that arose during the informal discussion). The students discussed how they felt about people with disabilities. Initial responses focused on awkwardness in how to behave and feeling sorry for people with disabilities. During discussions eight weeks later, after four two hour sessions with the Scope Community Group members, there was an indication of a shift in outlook. There was an appreciation of the personalities of the Scope Community Group members, recognising they were good people. The students no longer ‘felt sorry’ for them but appreciated that people with disabilities have a variety of skills and abilities.

This appreciation was also reflected in the question as to whether they felt people with disabilities are different. From an overwhelming response of ‘yes’ during the first meeting, later reflections noted that people with disabilities are not as different as many of the students first thought once they got to know them.

In both discussions conducted with the students there was encouraging feedback in terms of positive experiences of interaction with people with disabilities. In discussing how people with disabilities should be treated, both discussion periods yielded affirmative responses in terms of being treated equally and not being excluded. This was best summed up by the reflection of one student:

*‘I realise we have more in common than not in common’.*

Again, while we must be cautious in our findings from a simple and limited discussion, the indications here are that, firstly, the students appeared to be sensitive to people with disabilities even if they felt somewhat awkward and uncertain how to act around them. Secondly, the time spent interacting with people with disabilities served to remove some of this awkwardness while making the students even more appreciative of people with disabilities. Students intuited a sense of common humanity and purpose that removed some of the hesitations and doubts they initially

expressed. How this translates to longer terms attitudes and behaviours cannot be considered here but it does suggest a positive starting point for more significant actions in the future. It also points to the benefits of coordinated activity between people without disabilities and people with disabilities in enhancing understanding and attitude change, and/or reinforcing positive attitudes. There are also the benefits for people with disabilities who, on numerous occasions, told the lead researchers of their enjoyment in working with the students and how they looked forward to their time together.

### **Limitations**

There are limitations to the study worth considering. First to consider is attitude change and the value of the responses from the students. It is possible the students were influenced by the lead researcher and told the researcher what they – the students – thought the researcher wanted to hear. Also time limitations meant there was no real opportunity to tease out the students' responses in greater detail. Consideration must also be given to the possible influence of the presence and responses of their friends. Overall, there was no method of validating their responses. However, while acknowledging these limitations, the responses are worth considering and evaluating in terms of future consideration when addressing similar issues. The lack of rigour suggests caution in reaching any definitive conclusions here. However, the indications are that spending time with people with disabilities – even in a minor capacity – can lead to positive attitude change.

There were also problems to do with availability and being able to get everyone together at a specific time and place. Time constraints meant that the training had to be limited. It also meant that fitting in with the students' timetable meant that some members of the Scope Community Group could not be available at that time for the project – either for the training or for the shopping centre work. These constraints impacted on the depth of work that the groups involved could do and the rigour of data collection.

The question of rigour is also reflected in the issue of involving a group of people with disability partnered with secondary students who had various levels of skills and engagement with the project. While the students were enthusiastic and involved, and impressed everyone with the manner in which they conducted themselves and committed themselves to the project, the data collected by co-researchers in partnership with students was generally lacking in the detail that the lead researchers hoped to gather. This is not a criticism of the students, nor of the co-researchers, but

an observation that utilising others to do the research means professional researchers have to relinquish control – and even expectations – and accept the limitations this may involve.

There are also limitations with regard to the involvement and commitment of shopping centre management and shopkeepers. Three shopping centres were initially contacted and involved in the initial surveying, however follow up contact with centre management only yielded one shopping centre that was willing to continue the involvement. At subsequent meetings with the other two shopping centres there was a degree of enthusiasm and support for the project and the proposed work. However, one centre was undergoing major building changes which meant future uncertainty, and the centre management felt the time was not right to commit to the project. The other centre contacted shopkeepers by email but responses indicated that it was not a good time for people to commit to the project on an ongoing basis. It was therefore decided by the lead and co-researchers that it was better to focus on the one shopping centre that was willing to support the project. It is necessary to acknowledge the various demands faced by management and shopkeepers and the time constraints they are subject to. Declining to be involved does not indicate disregard for such projects and their aims, but reflects demands placed on people's time and the range of commitments they already have.

With regard to the project methodology, the lead researchers aimed to work collaboratively with the co-researchers and sought to apply the ideals of an inclusive approach to research throughout the project. To what extent the lead researchers continually upheld such ideals are open to debate. A variety of barriers contributed to times when the reality did not fully live up to the ideals of inclusive research: availability of people with disabilities along with their changes in involvement, funding limitations, and the need for a formally trained researcher to oversee the complexity of the project – particularly in relation to initiating contact and co-ordinating people, data analysis, and report writing. However, despite this, the lead researchers sought to be mindful of these issues of 'expertise' and the implicit power arrangements, and to address them through ongoing reflection on the research process, while continually seeking to work with, and to seek input from people with disabilities.

All of these various limitations and constraints impacted the depth and rigour of the research so that the findings are more reflective and exploratory, while opening up future research possibilities.

## **Section Five: Recommendations**

Based on the outcomes and reflections from the previous section, the following outlines key recommendations to consider for future research utilising a collaborative research model, along with ways in which community inclusion work in shopping centres can be further advanced. Behind all this is the need for ongoing reflexivity on the part of the formally trained researchers to question the work they are doing and whether it is being conducted in the right spirit and ethic.

### **The Collaborative Research Model**

#### 1) Time and talk to foster the involvement of people with disability

A key issue for future research is the need to consider the level of involvement of people with disabilities and giving people the choice to determine this level. This means having to consider people's cognitive capacity to grasp the significance of the project and what is involved. Time needs to be spent with people, either as a group or individually, discussing the project and the degree of involvement in a manner that is understood by those involved. Of most importance is to be sensitive to the needs and desires of people, to always recognize the crucial purpose of the research (to serve the interests of people with disabilities in creating better lives), and to be guided by the requirements of those the research serves as opposed to the formally trained researchers' self-interest. All of this involves continually checking with people and informing them as to the progress of the research, while continually encouraging people to make informed choices as to the direction of the project and regarding their involvement – or non-involvement – over time.

#### 2) Appropriate ways to share information

In discussions with people with disabilities it is important to consider the methods by which information is conveyed. It means an understanding of how people best communicate and digest information. It involves a degree of empathy on the part of the formally trained researcher who needs to be able to work effectively with people with disabilities, recognise and be mindful of power relationships, and to work in a manner that empowers people and appreciates the unique talents of individuals and what they contribute to the project. While the formally trained researchers have research skills and knowledge, and may be the leaders and driving force of the project, there is a need to share this knowledge and to support people in their

involvement to the degree to which they wish to be involved. This last point is significant, for in wishing to empower and share knowledge/findings with people, the lead researchers here were often aware that not all people with disabilities wished to be swamped with lots of information, and were happier to help out practically while leaving organising and idea generating to others.

### 3) Recognise multiple reasons to be involved

While it is important to involve people with disabilities in research it pays to be mindful that people may have a variety of motivations. It is important to appreciate that, in some cases, the research elements or agenda may be of little interest to the people involved. This becomes problematic if researchers hold to a fixed paradigm and research agenda and are unable to accommodate alternate ways of seeing the activity. While it is important that people with disabilities be given the opportunity to conduct research and be central figures in research projects and agendas, it is also important to recognise and accept that people with disabilities may not always wish to be at the forefront or even be involved in the research – and that when they are, important motivations other than research may be the driving factor of their involvement. Throughout the Food Court Friends project, the social interaction was a prime motivator for co-researchers' involvement (and was important also for the lead researchers and the students) and was a positive feature throughout the project.

### 4) Time to build relationships as central to the method

The involvement of students was of significant value and extremely important to the project. Not only were their practical efforts for the project vital, but the time spent with the Scope Community Group was positive for both groups. As discussed earlier, there is an argument to be made for a degree of attitude change through the close proximity of people who are given the chance to get to know one another, and therefore enable stereotypes and even prejudices to be challenged. It would therefore be useful for significant amounts of time to be allocated for groups to work together where possible. This could involve other projects/activities that could be useful for all concerned – particularly community based ones which would require mutual support in working together. Of course there are time constraints around these possibilities as was discovered on this project. It may therefore require significant discussion, planning and thought in fitting into students' schedules and their educational requirements, along with the schedules and requirements of people with disabilities.

Any opportunities to build relationships are significant and are a small step in the process of community inclusion.

5) The provision of training

More time together also allows more time for research training for both people with disabilities and students. This would allow greater discussion and practice around the collection of data which – as mentioned earlier – would preferably capture more detail, particularly with qualitative information in understanding peoples’ experiences. Such training needs to cover the project and its aims, and the tasks to be done, as well as provide opportunities to role play scenarios where people can play out a whole range of possible developments and discuss issues that arise. Other important considerations include ethical requirements for participants, the outlining of support should people require it, and who to speak to about the project if people have concerns (this should be a trusted person or organization outside of the project – perhaps a psychologist or disability advocacy group).

6) Broaden ideas about what is ‘valid’ data

A collaborative research model involving people with intellectual disability as researchers also calls for the ‘non-disabled’ academically trained researchers to confront their positivist training and the paradigms they have been trained in that determine what is and is not valid data. As Ward and Flynn note in their chapter on emancipatory research:

*They [social science researchers] learn to believe that their published research accurately describes the existence of a neat and sequential pattern of research procedures, each step presupposing the completion of the preceding one. They learn not to question this model of reporting which creates an oversimplified and dishonest picture of research activities (Ward and Flynn, 1994: 35).*

What is therefore required is time working together in a manner that empowers people with disabilities as co-researchers so that they increasingly determine the manner in which data is collected, and what information will yield meaningful results that reflects the needs of people with disabilities. This also means challenging research



paradigms that may meet the needs of academia but may not necessarily be in the best interests of people with disabilities.

#### 7) Paying people with disability as researchers

Part of the process of empowering people with disabilities as co-researchers raises the issue of paying people as researchers. For this project, co-researchers were paid \$20 for the time spent at the shopping centre conducting the project work (approximately one and a half to two hours). They were not paid during training sessions which were deemed to be part of a skill development/mentoring process. Students were given a movie voucher for their work at the shopping centre. In considering issues of equality and the valuing of people with disabilities as co-researchers, disability research must address the issue of payment given that the formally trained researchers are paid for their work. The members of the Scope Community Group stated that the issue of payment for their involvement was important. As well as a financial incentive, it is likely that financial payment legitimized their efforts and was significant to the way in which they regarded themselves as important contributors to the project.

### **Shopkeepers and Community Inclusion**

#### 1) Increasing time and resources for community development work

One of the biggest problems encountered in the project was obtaining shopkeepers' commitment to the project. This is not a reflection on the shopkeepers' goodwill or lack of, but is reflective of their commitments and time constraints, and perhaps scepticism on their part as to what their involvement will entail with concern over future demands they feel may be made on them. It is therefore important that thought and time be allocated at the start of any project involving shopkeepers as to how to get them involved in the project. This may involve initial meetings with centre management devising the best strategy to liaise with shopkeepers. In this case the method involved both the lead researcher and speech therapist visiting stores followed by a later strategy of emailing them. The face to face approach yielded no success. Both the lead researcher and speech therapist felt that shopkeepers are busy people and often have to make decisions as to what they can or cannot support, or be involved with, at any given time. It may be that the project was not presented in a manner that sought to address shopkeepers' needs as well as those of people with

disabilities. This could be addressed by the use of a community worker on future projects.

A community worker could strategise and work with shopkeepers in designing an approach that suits their needs, while demonstrating how disability awareness training and support around issues such as communication would be of mutual benefit to the shopkeepers and their clientele. It might be possible that the community worker could address shopkeepers as a group in meetings with centre management. Such an approach would create a positive impression of centre management support for the project. It would also provide a forum for the outlining of project methods and aims, while allowing time and space for questions. Such a forum could create an environment of obtaining ongoing management/shopkeeper involvement and commitment from the beginning of the project.

2) Increasing resources for building the communication capacity of shopping centre personnel

The communication tools need to be considered in light of the knowledge gained from the project. Generic communication boards tailored to a store's needs were not successful in this case. It may be that more support and encouragement to staff to use them is required. This would mean that a speech therapist would need to be available to work with shopkeepers. Each person with a disability has their own means of communication and it may be that shopkeepers and staff require training, focusing on communication and understanding various methods of communication. In this manner the communication guide offers useful tips and does appear to be a useful support. Again some basic training could be offered to explain the guide and the points it makes, while ongoing follow-up work may make shopkeepers and their staff more mindful of using it or reacquainting themselves with its information on a regular basis.

3) Provide disability awareness education by people with disability

Finally, discussions with co-researchers at the end of the project led to reflections about educating people about disability both in the retail and service sectors, and within other sectors of the community. The co-researchers felt that people did not have enough understanding about people with disabilities, their concerns and the social barriers they encounter. They suggested that there needed to be greater disability awareness created through educating people at every opportunity. When

conducting research, it is certainly worth considering whether people with disabilities are interested in working as trainers/educators on community inclusion projects. Their knowledge and understanding of key disability issues would be instrumental in educating people firsthand and sharing (if willing) some of their personal experiences (while mindful of the ethical considerations involved).

## **Conclusion: ‘We have more in common than not in common’.**

The work of community inclusion and building relationships can take many forms and should be an integral element of much contemporary work – including research – in partnership with people with disabilities. The study conducted in Queensland of one hundred and thirty two students – which helped to inform the Food Court Friends project – concluded that among adolescents with an intellectual disability, feelings of life satisfaction were significantly related to a sense of community – this includes having activities, friends and support (Bramston et al, 2002: 394). Community can take many shapes and forms and may refer to a localised area incorporating a wide array of people and organisations including shopping centres, or it may refer to a small group of people such as that represented by the Scope Community Group. This group, supported by Scope and its staff, helps to provide activities, friendship and support for those involved. It also serves as a foundation upon which to build wider community inclusion. In doing so, the activities involved – such as the Food Court Friends project – help to reinforce the solidarity of the Scope Community Group while reaching out to the wider community to build stronger bonds. Such an attempt to build community reflects the thoughts of the sociologist Zygmunt Bauman who, in his work on community, states:

*If there is to be a community in the world of individuals, it can only be (and it needs to be) a community woven together from sharing and mutual care; a community of concern and responsibility for the equal right to be human and the equal ability to act on that right (2001: 149-150).*

In attempting to build such a caring, inclusive community, all disability research and projects should be driven by the needs of people with disabilities. Therefore researchers/project officers need to continually reflect on their practice and consider whether or not they are working in a manner that benefits the needs of people that the research is meant to serve. In this sense the collaboration with people with disabilities as co-researchers is a significant step to achieving this aim. The Food Court Friends project offers a collaborative model with insights into ways of working with people as co-researchers. In working together, formally trained researchers, people with disabilities, and students, have sought to engage with shopping centre personnel. In doing so, they have worked to address some of the key issues shopkeepers and people with disabilities have identified as a barrier to a pleasant and meaningful shopping experience. And while people – both individually and in groups – have different

needs, it is important to realise that there is always a common humanity on which to recognise shared needs, and to build inclusive communities on this basis.

The Food Court Friends project has sought to implement the goals of the Victorian Government and Scope in working towards creating more inclusive communities. It is hoped that the knowledge gained from this experience has led to creating change, while it may also inform and benefit others who may undertake such important work. In doing so, research can not only lead to greater understanding of important issues and contribute to social change, but of itself may lead to the building of relationships for all those involved.

## References

- Bauman, Z. (2001), *Community: Seeking Safety in an Insecure World*, Polity Press, Cambridge.
- Bishop, R. (1996), *Collaborative Research Stories. Whakawhanaungatnaga*, Dunmore Press, New Zealand.
- Bramston, P. Bruggerman K. & Pretty, G. (2002), 'Community Perspectives and Subjective Quality of Life' in *International Journal of Disability, Development and Education*, pp. 385-397.
- Carr, W. and Kemmis, S. (1986), *Becoming Critical: Education, Knowledge and Action Research*, Deakin University Press, Victoria.
- Communication Resource Centre, Scope, (2008), *Communicating with the Community at Centro Box Hill*, Scope (Vic) Ltd, Melbourne.
- Disability Services Division, Victorian Government Department of Human Services, (2002), *Victorian State Disability Plan 2002-2012*, Melbourne.
- Emerson, E. and Stancliffe, R. J. (2004), 'Planning and Action: Comments on Mansell & Beadle-Brown' in *Journal of Applied Research in Intellectual Disabilities*, Vol. 17, pp. 23-26.
- Felske, A.W. (1994), 'Knowing about Knowing: Margin Notes on Disability Research' in *Disability is Not Measles: New Research Paradigms in Disability*, M. H. Rioux & M. Bach, M., L'Institut Roehar Institute, Ontario.
- Freire, P. (1972), *Pedagogy of the oppressed*, Penguin, London.
- Kleeman, J. and Wilson, E. (2007), *Seeing is Believing: Changing Attitudes to Disability. A review of disability awareness programs in Victoria and ways to progress outcome measurement for attitude change*, Scope (Vic), Melbourne.
- Lather, P. (1986), 'Issues of Validity in Openly Ideological Research: Between a rock and a soft place' in *Interchange*, Vol. 17 (4), pp. 63-84.
- Murfitt, K. F. (2006), *Attitude Change in Employment of People Who Have a Disability*, Deakin University, School of Psychology, Melbourne, Australia.
- Owens, J. (2007), 'Liberating Voices through Narrative Methods: the case for an interpretive research approach' in *Disability & Society*, Vol. 22, No. 3, pp. 299-313.
- Parsons, G. Elkins, J. and Sigafoos, J. (2000), 'Are People with Intellectual Disabilities Just Another Customer? Interviews with Business Owners and Staff' in *Mental Retardation*, Vol. 38, No. 3, pp. 244-252.
- Pinar, W. (1981), 'Whole, Bright, Deep with Understanding: Issues in qualitative research and autobiographical method' in *Journal of curriculum studies*, Vol. 13, (3), pp. 173-188.
- Ramcharan, P. and Grant, G. (1994), 'Setting One Agenda for Empowering Persons with a Disadvantage within the Research Process' in *Disability is Not Measles: New Research Paradigms in Disability*, M. H. Rioux, & M. Bach (eds), L'Institut Roehar Institute, Ontario.

Sanderson, H. (2000), *Person Centred Planning: Key Features and Approaches*, <http://www.paradigm-uk.org/pdf/Articles/helensandersonpaper.pdf> (retrieved February 18 2007).

Sanderson, H. and Smull, M. (n.d.), *Person Centred Thinking and Planning*, <http://www.helensandersonassociates.co.uk/PDFs/Person%20Centred%20Thinking%20and%20Planning%20Handout%20for%20website.pdf>, (retrieved April 7 2007).

Schleien, S. Green, F. & Stone, C. (1999), 'Making Friends Within Inclusive Recreation Programs' in *Journal of Leisureability*, Vol. 26 (3), <http://www.lin.ca/resource/html/Vol26/V26N3A4.htm>, (retrieved October 31, 2005).

Scope, (2009), *For People with a Disability: Scope Annual Report 2008-2009*, Scope (Vic) Ltd, Victoria.

Scope, (2010), *The Scope Strategic Plan 2009-2012*, <http://www.scopevic.org.au/index.php/site/howare/reportsaccountability/strategicplan> (retrieved October 2010).

Shields, R. (1992), 'The Individual, Consumption Cultures and the Fate of Community' in R. Shields, (ed), *Lifestyle Shopping: the Subject of Consumption*, Routledge, London.

Smith, D. (1990a), *Texts, Facts and Femininity: Exploring the relations of ruling*, Routledge, London.

Smith, D. (1990b), *The Conceptual Practices of Power: A feminist sociology of knowledge*, Northeastern University Press, Boston.

Stone, E. & Priestly, M. (1996), 'Parasites, Pawns and Partners: Disability Research and the Role of Non-Disabled Researchers' in *The British Journal of Sociology*, Vol. 47, No. 4, pp. 699-716.

Wadsworth, Y. (1998), 'What is Participatory Action Research?' in *Action research international*, <http://www.scu.edu.au/schools/gcm/ar/ari/p-ywadsworth98.html>, (retrieved November 9, 2009).

Walmsley, J. (2001), 'Normalisation: Emancipatory Research and Inclusive Research in Learning Disability' in *Disability and Society*, Vol 16 (2), pp.187-205.

Walmsley, J. and Johnson, K. (2003), *Inclusive Research with People with Learning Disabilities: Past, Present and Future*, Jessica Kingsley Publishers, London.

Ward, L. and Flynn, M. (1994), 'What Matters Most: Disability, Research and Empowerment' in *Disability is Not Measles: New Research Paradigms in Disability*, M. H. Rioux, and M. Bach, (eds), L'Institut Roehrer Institute, Ontario.

White, G. W. (2002), 'Consumer Participation in Disability Research: The Golden Rule as a Guide for Ethical Practice' in *Rehabilitation Psychology*, Vol. 47, No. 4 pp. 438-446.

Williams, M. Bryce, R. Smith, M. and Iacono, T. (2005), *Communicating in the Community*, Internal publication, Scope (Vic) Ltd, Victoria.

Williams, V. and Simons, K. (2005), 'More researching together: the role of nondisabled researchers in working with People First members' in *British Journal of Learning Disabilities*, Vol. 33, Issue 1, pp. 6-14.

Yazbeck, M. McVilly, K. and Parmenter, T. R. (2004), 'Attitudes Towards People With Intellectual Disabilities: An Australian Perspective' in *Journal of Disability Policy Studies*, Vol. 15, No. 2, pp. 97-111.



## **Appendices**

### **Appendix One: Discussion Group Questions for People with a Disability**

Question 1: Do you shop at Sunshine Plaza, Sunshine Marketplace or Brimbank Shopping Centre?

Question 2: What are the main shops you like to go to?

Question 3: Have you had any problems with people at the shops (shopkeepers, security, shoppers)?

Question 4: What would make it better for you? (what would help solve these problems?).

Question 5: How do people treat you there? (are there some people you see a lot and get on with?).

### **Appendix Two: Questions for Shopkeepers and Personnel**

Question 1: What have your experiences been in interacting with people with disabilities who come into the shopping centre?

Question 2: Can you describe any problems you may have had in talking to a person with a disability?

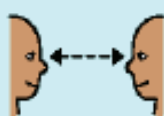
Question 3: Have you resolved or addressed these issues to date?

Question 4: What would help you with these problems?

Question 5: Are there things you are unsure about how to handle or what to do?

Question 6: What have been some of your positive interactions with people with disabilities who come into the shopping centre?

## Appendix Three: Communication Guide Sheet



Don't ignore the person. Speak directly to them rather than to the person with them.



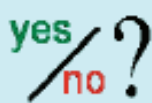
Use clear simple language and don't shout!



Use other ways of communicating e.g. show objects, point to pictures, write things down



Give the person time to communicate and answer your question.



Use yes/no questions to clarify information e.g. Would you like some help?, Would you like some sugar?



Don't pretend to understand. Ask the person to repeat it or say it in another way.



Treat the person as an adult, not as a child. e.g. don't patronise.

# Don't panic! Relax and have fun!

For further information please contact Scope St Albans on 9366 7433

#### **Appendix Four: Discussion Group Questions for People with Disabilities**

Question 1: Have you been shopping at Sunshine Marketplace over the past few months?

Question 2: Have you noticed people there using any of the strategies we planned (list these)?

Question 3: Has that made things better for you?

Question 4: Are there still problems – what kind?

Question 5: Have you noticed any improvements in how people treat you?

#### **Appendix Five: Attitude Change Discussion Topics with Research Partners**

What do we mean by disability?

How do you feel about people with disabilities?

How are people with disabilities similar to people without disabilities?

What have your experiences been in interacting with people with disabilities?

Can you describe any problems or discomforts you may have had in communicating or interacting with people with disabilities?

What have been some of your positive experiences of interacting with people with disabilities?

How should people with disabilities be treated?

**scope**

FOR PEOPLE WITH A DISABILITY

830 Whitehorse Road Box Hill, Victoria 3128

Ph 03) 9843 3000

Fax 03) 9843 2030

[www.scopevic.org.au](http://www.scopevic.org.au)