

Building the capacity of

**I**ndividuals,

**families &**

**communities**

**Volume 1**

**Lesley Chenoweth & Daniela Stehlik**

**Evaluation of the Local Area Coordination Program**

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*Hervey Bay Office*

# i. Acknowledgements

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In most projects, there are many players without whom the work simply could not proceed or at best be far less than deserved. This project is no exception. Many people contributed their time, wisdom, advice and support. We take this opportunity to offer our sincere thanks to them all.

First our thanks to the Local Area Coordinators: Bronwyn Butt, Kirsty Chapman, Karen Christmas, Eduardo Flores, Fiona Green, Phil Lavelle, Barbara Leys, Jillian Nicholl, Gay Sargent, and Elaine Thompson. All made us very welcome in their offices and communities and gave generously of their time, insights and local knowledge.

Our sincere appreciation to all the members of the Local Area Coordination Reference Group Anne Cross, Julie Simpson, Roz Cooper and Sue Campbell who have given feedback, helped out with problem solving and provided good advice. We also are indebted to those people with disabilities and family members who acted as our participant advisory group – Dulcie, Gaele, Gypsy, George, Sharon, Sandra, Jodie and Terry.

We also wish to acknowledge the important input of Eddie Bartnik, Disability Services Commission, Western Australia who has been involved in LAC for many years and is perhaps our best national expert. His guidance and advice have been invaluable.

Within Disability Services Queensland (DSQ), first, we wish to acknowledge the support and encouragement of Alan Grimsley, the manager of LAC program. Alan has been the mainstay of our contact with the LAC project. Also at DSQ, our thanks to Lyn Farrell, who held the reins while Alan was on leave and willingly provided advice and support during the report writing phase. Phil Lavelle, the LAC supervisor also provided input and advice throughout the project. Many others in DSQ Central Office assisted with access to databases, information and cups of coffee. Our thanks also to those Regional Directors of DSQ who have supported the pilot program and who have provided thoughtful and critical advice on the evaluation.

Finally our sincere appreciation to the people with disabilities and families and service providers who contributed to the evaluation. They helped by filling in surveys, participating in interviews, answering our endless questions and inviting us into their homes from Cloncurry, to Cooktown to Cooloola. You have taught us much. We hope, in return, that this Report captures your needs, your issues and your hopes for the future.

## ii. The Project Team

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The Principal Investigators for this project were Dr. Lesley Chenoweth, School of Social Work and Social Policy at The University of Queensland (UQ), Brisbane and Associate Professor Daniela Stehlik, at the Centre for Social Science Research at Central Queensland University (CQU), Rockhampton.

Lesley and Dani have worked together for some six years now, focussing on the relationship between people living outside metropolitan settings, their communities and their human service supports. This project provided us with a unique opportunity to work with people with disabilities, their families and their communities, as well as the practitioners involved in the LAC pilot program, to see at first hand the import of that important relationship for all concerned.

We would like to take this opportunity to thank the other members of the team. Our research assistants on the project (at UQ), especially Mandy Nielsen who was there for the whole haul, Chris Brook, Rea Dennis and Heather Douglas who assisted with specific tasks along the way. At CQU, our thanks to Sheree Tait for financial administration and Gayle Burling who provided important desk top publishing assistance

# iii Executive Summary

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A reference group made up of people with disabilities and families who were served by the LAC program was established and consulted for advice on the evaluation.

The team made 18 visits to the 6 pilot areas over an 18-month period and undertook participant observation during these visits. Data were also collected from a range of sources. We conducted two surveys: one of individuals and families who were registered with their LAC and another of agencies in the communities who had contact with the LAC. We also conducted 39 in-depth interviews with individuals and families across the sites and developed social network maps with 28 people within the interview sample. Data extracted from the LAC Program database were also analysed.

Data sources included:

- *Participant observation* (18 visits across 12 different communities in the 6 LAC areas)
- *Participant observations* (LAC Meetings from June 2000 to June 2001)
- *Respondents' Survey* (analysed with SPSS)
- *Agency Survey* (analysed with SPSS)
- *In-depth interviews with people with disabilities and families* (analysed with Ethnograph)
- *Social Network Maps*
- *LAC Database*
- *Community profiles* (including ABS, DSQ and other statistical information)
- *Reflective recordings from individual LACs*

All data are compiled and included in Volume II of this report. The decision by DSQ to conduct a formative evaluation was distinctive and also commendable. This approach allowed for the development of knowledge about LAC, and indeed disability supports, to a deeper level than could have been achieved by an impact evaluation alone.

Research findings indicate that the LAC Program in its pilot phase has made a significant impact on the lives of people with disabilities and families and is beginning to impact on those communities where LAC is operating. It is our informed view that LAC has met its objectives and represents a significant and historic achievement for DSQ. The LAC program is building the capacity of individuals, families and communities across Queensland. DSQ is to be commended to taking the decision to establish LAC as a Statewide strategy for supporting people with disabilities and their families.

The cost benefit analysis has shown that LAC has exceeded all expectations in providing a targeted and effective support to people with disabilities and families living in regional, rural and remote areas of the State. LAC is a low cost strategy with high benefit outcomes and is therefore a remarkably efficient and effective approach to disability support.

**It is therefore our view that LAC should be expanded to other areas of the state covering remote and rural areas initially and moving to regional and finally urban, communities.**

As might be expected with any new program, the LAC pilot program did require a fairly long settling in period and faced considerable challenges as it was being implemented. These included the integration of new forms of technology to overcome the ‘tyranny’ of distance into human service practice; the setting up of LAC offices outside of mainstream government locations; dealing with organisational and structural changes during the pilot period while at the same time providing timely ongoing support to many people with disabilities and families in crisis. Such challenges have been effectively addressed over time, initially by LAC staff and more recently by regional office personnel in collaboration with LAC staff.

**The key positive features of the program are:**

- its commitment to and capacity to operationalise, positive values and principles for people with disabilities and their families;
- its model of training, supervision and support for staff;
- its capacity to deliver early intervention for families across large areas;
- its potential for leadership development; and
- its potential for community capacity building.

**The key challenges facing the LAC program in the future are:**

- safeguarding the integrity of the program in a large bureaucracy;
- expanding LAC to a very large program in terms of area and personnel while maintaining high quality practice;
- maintaining program flexibility; and
- supporting and sustaining its staff.

Our recommendations are presented in full in the following section.

# iv Recommendations

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Many recommendations have arisen from this evaluation. These are outlined in the body of the report as they arise within issues and findings. They have been organised into two broad areas for consideration: first, for DSQ as an organisation and second, more specifically for LAC practice. Included against each recommendation are the Section(s) in the Report it relates to.

<b>A RECOMMENDATIONS FOR DSQ</b>
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## **A.1 Management & Administration**

### A1.1 Whole of Department

A1.1.1 That more work be done at a senior level to ensure the LAC program's full integration into the overall DSQ strategic direction. **(5.1.6; 6.3.2)**

A1.1.2 That regional directors continue to ensure a seamless transition of incorporation of the LAC program into mainstream DSQ. **(5.1.6)**

A1.1.3 That the LAC model of recruitment, training, supervision and support be considered as the model for all DSQ programs. **(5.1.6; 5.1.7; 6.3.2)**

A1.1.4 That the LAC model for recruitment, training, supervision and support be sustained within regional structures and systems. **(5.1.6; 5.1.7)**

A1.1.5 That DSQ commit to the development of leadership in people with disability and families in local areas so they continue to participate in the monitoring of quality. **(5.1.6)**

A1.1.6 That a *principles into practice* monitoring process be developed involving people with disabilities and families. **(5.1.6; 5.1.7)**

A1.1.7 That the DSQ web site more clearly articulate the 'whole of government' potential of the LAC program. **(4.2)**

### A1.2 Safeguarding Practice

A1.2.1 That LAC principles are maintained and supported. **(5.1.1)**

A1.2.2 That the current flexibility within the LAC program is maintained and supported. **(5.1.1)**

A1.2.3 That LAC administrative responsibilities are monitored and maintained at supportable levels. **(5.1.1)**

A1.2.4 That any concerns regarding the financial flexibility of the LAC program be addressed immediately with the relevant State Government authorities **(6.3.2)**.

A1.2.5 That the discretionary monies continue to be available to the LAC program but with some portion available as recurrent funding **(6.3.2)**.

A1.2.6 That LACs be issued with a corporate credit card for discretionary monies to ensure accountability with flexibility and responsiveness to peoples needs **(6.3.2)**.

A1.2.7 That a further, more depthful analysis of the types of supports being provided through these discretionary funds, be undertaken in twelve months time **(6.3.2)**.

A1.2.8 That the central meetings of all LACs be continued for a period of 3 years to ensure consistency of the program across regions as LAC expands. **(5.1.6; 5.1.7)**

A1.2.9 That LAC Program budgets for transport, satellite phones and other means of keeping in touch across vast areas be safeguarded. **(5.1.4)**

### A1.3 Training

A1.3.1 LACs to be offered training and professional development opportunities offered by other departments and centres involved with this work – eg work on social capital, community resiliency etc. **(5.1.4)**

### A1.4 Supervision

A1.4.1 That all LACs continue to report to their regional LAC supervisors who then report to the Regional Director. **(5.1.6)**

A1.4.2 That the workload for LAC supervisors be monitored in view of supervision and travel demands. **(5.1.6)**

## **A.2 Whole of Government**

### A2.1 State networks

A2.1.1 That DSQ, as lead agency, form a 'whole of government' working party on social capital building and community resiliency, building on the LAC model. **(4.2)**

A2.1.2 DSQ to make links across government to other departments concerned with community building – eg Office of Regional communities, Office of Rural communities, DPI, Premiers, - to increase awareness of and share information across similar issues around community. **(4.2; 5.1.4)**

### A2.2 Federal networks

A2.2.1 That DSQ make this report available to relevant Federal Government departments, and invite participation in the recommended Conference (Recommendation 2.3.1). **(4.6)**

### A2.3 Conference

A2.3.1 That a State Conference – *Beyond Social Capital and Resiliency Building – Human Services in the 21<sup>st</sup> Century* – be supported and conducted during 2003, to share findings and insights from LAC program with key agencies and major stakeholders. **(4.2)**

### A2.4 Local Government

A2.4.1 That DSQ develop links with Local Government Association of Queensland (LGAQ) in order to exchange information and develop relationships with key personnel responsible for social policy and programs and establish closer links at the Shire/Council level. **(5.1.4)**

## **A.3 Disability Sector**

A3.1 That DSQ now work to raise the profile of the LAC program in the non-government sector so that learning about new models of support for people with disabilities and families be shared. **(4.5)**

A3.2 That DSQ connects with the identified non-government agencies in the major areas discussed above and identify any barriers to services from their perspectives. **(6.3.3)**

A3.3 That LAC personnel be supported to present papers at conferences outside the disability sector such as, for example, LGAQ, Community Development Conference. **(4.6)**

A3.4 That at a regional level, DSQ facilitate and/or conduct workshops with practitioners across programs and with non-government agencies so that practice knowledge is shared as it is developed. **(5.1.3)**

#### **A.4 Future Research and Evaluation**

##### A4.1 Whole of sector research

A4.1.1 That DSQ take up the challenges of community capacity building and commission ongoing research that enables a more detailed analysis of the economic and social issues through:

- (a) a scoping study of ageing carers
- (b) a scoping study of “non-service users”
- (c) a scoping study of non-government and private services available in rural and remote communities
- (d) the nature and scope of supports for people with disabilities and their families across the state and how they can be further developed. (5.1.2; 5.1.3; 6.2.3)**

##### A4.2 Specific LAC program research and evaluation

A4.2.1 That a further review and evaluation of outcomes of the LAC program be undertaken in 3 years (i.e.. By 2005). **(5.1.3)**

A4.2.1 That a study be undertaken of the efficacy of and processes involved in the integration of informal and formal supports around people and families. **(5.1.3)**

<b>B RECOMMENDATIONS FOR LAC PRACTICE</b>
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#### **B.1 Management and Administration**

##### B1.1 Supervision

B1.1.1 That the issues surrounding dual relationships and ethical concerns are regularly reviewed through supervision of LACs by their supervisors and potential difficulties of dual relationships continue to be acknowledged and support provided. **(5.1.1; 5.1.5)**

## B1.2 Data Collection

B1.2.1 That more sophisticated methods of recording on the database be established to include information on

- (a) DSQ funding applied for (e.g. Family Support).
- (b) DSQ funding received
- (c) Ages of carers/family members (5.1.2)**

B1.2.2 That the database be seen as a tool for use by other service providers, and other DSQ programs. **(5.1.2)**

B1.2.3 That this database knowledge becomes 'common knowledge' through data warehousing within DSQ and thus enables better service provision. **(5.1.2)**

## B1.3 Networking the Sector

B1.3.1 That connections between LACs, people with disabilities and families and non-government sector agencies be made at the 'grass roots level' to facilitate information sharing, networking around common issues and problem solving. **(5.1.5; 6.2.2; 6.2.3)**

B1.3.2 That information thus gleaned be extended to the wider community. **(5.1.5; 6.2.2; 6.2.3)**

## **B.2 Safeguarding Practice**

B2.1 That LACs make links with others undertaking new forms of support locally, regionally, nationally and internationally, to share insights and findings. **(5.1.3)**

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# 1. Background to the Evaluation

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## 1.1 Introducing Local Area Coordination – the Western Australian model

Local Area Coordination offers a uniquely Australian, low-cost, high quality model of service delivery to individuals and families of people with disabilities.

Local Area Coordination originated in rural Western Australia (WA), where it was established in 1989 in the southwest region of that state. Its purpose was to provide support to those individuals, their families and carers, whose access to mainstream services had been disadvantaged by geographic distance from the metropolitan settings, where all such services were then located.

In rural Western Australia, as in Queensland, to have a disability in the 1950s or 1960s usually meant moving to another place to obtain services. As this was usually either Perth or Brisbane, it was also often within an institution. The resultant impact was painful, and in some cases it resulted in family breakdown.

The Local Area Coordinator, as established in Western Australia, became an advocate for people, someone with a 'broad range of skills, experience and local knowledge' (WADSC, 1998:2). The service spread throughout country W.A., and eventually into the metropolitan area of Perth as well. By 1997/98, the Disability Services Commission in Western Australia was responsible for 91 Local Area Coordinators 'covering 70% of the State, with an annual expenditure of approximately \$11.5m.' (1998:2). In 2002 there is now full state coverage of rural regional and metropolitan areas.

## 1.2 LAC in Queensland

While still in opposition, Anna Bligh who became Queensland's first Minister for Disability Services in 1998, visited Western Australia. The introduction of Local Area Coordination, along with other funding enhancements, was proposed as part of a Labor

Party pre-election commitment to address the historic lack of attention and under-funding of disability in Queensland.

Through 1999, a consultative process was undertaken, with visits to 13 regional and rural locations in Queensland, public meetings being held, and discussions with key stakeholders undertaken. The overwhelming responses from community

consultations was positive, with some people already familiar with the WA model, championing its introduction to Queensland.

The pilot project was officially 'launched' later in 1999 to establish Local Area Coordination (LAC) in Queensland. This identified 6 sites and 9 Local Area Coordinators (LACs) including one supervisor, in the following locations – Gympie, Hervey Bay, Murgon, Mundubbera, Mount Isa and Cooktown.

The initial pilot was predicated on a number of criteria – including: that locations should be 'within regional, rural or remote Queensland, [that] at least one LAC should be located within or near an Indigenous community; [that] consideration should be given to population growth areas which have little infrastructure at present; [that] areas should be targeted where there is identified unmet need; [and that] consideration should be given to geographic distance and isolation from existing disability support services' (DSQ internal correspondence, 1999:1).

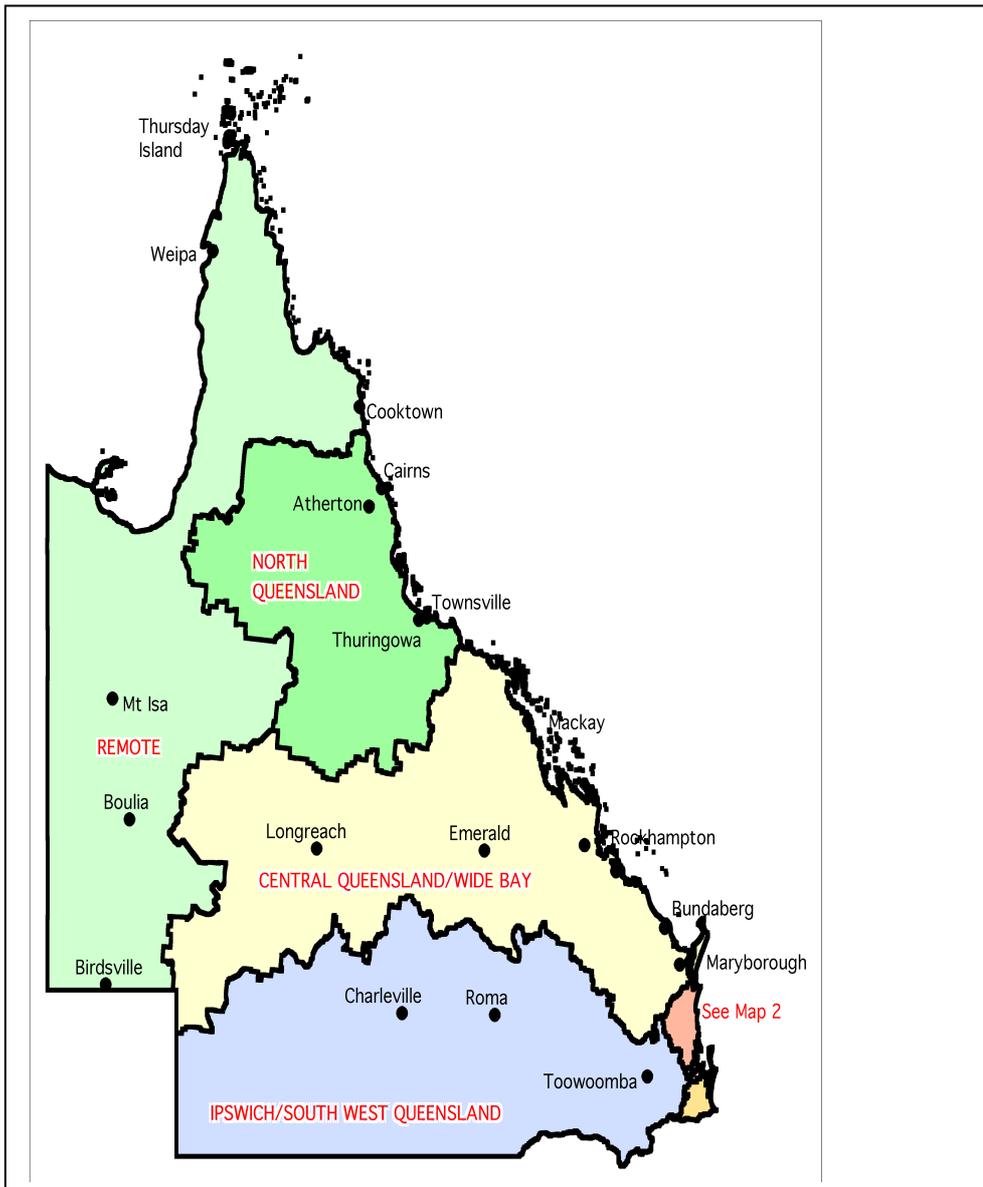
Eligibility for LAC support within the LAC program is different from that of other programs in DSQ. To be eligible for LAC support, individuals and their families need to fit the definition of eligibility within the *Queensland Disability Services Act (1992)*; live in the prescribed LAC areas; and have no priority of access restrictions.

As an important part of the pilot project, LAC was to be managed within DSQ central office (rather than regionalised); and it was to have supervision structured around one supervisor (located in Hervey Bay) for the Wide Bay/Burnett area and the other within DSQ central office. The pilot project also was also to have a Steering Committee; there was to be a component of the budget established for training opportunities and meetings between LACs and for travel to DSQ central office from time to time.

An important, and crucial difference to the original LAC model established in WA<sup>1</sup>, was that, apart from individual and family support; 'community development' would also become core business for each LAC, from the foundation of the program, as well as individual/family support. This community capacity building component of the LAC program has made it a uniquely a Queensland approach. Selection for Local Area Coordinators to fill positions were conducted in late 1999 and first appointments and training was conducted in February/ March 2000.

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<sup>1</sup> It should be noted that while the W.A. model now includes community development, this was not its earlier and foundational purpose.



**Map 1.1 LAC Sites Mt Isa (Remote region) Cooktown (North Queensland)**



**Map 1. 2: South Burnett Region LAC Sites - Gympie, Hervey Bay, Murgon, Mundubbera**

### 1.3 Evaluation Strategy

The evaluation of the LAC Qld. Pilot program was an important component of overall strategy from the beginning. The initial memorandum establishing the LAC Pilot program stated that:

There should be a range of environments and contexts so that evaluation can reveal how [LAC] works best in any particular location (DSQ internal correspondence, 1999:1).

Tenders for the evaluation were subsequently called in early 2000 and the current team appointed in June 2000. The evaluation was to:

1. engage collaboratively with all key stakeholders, especially people with disabilities and their families who are accessing Local Area Coordination;
2. inform project development and operation with the aim of achieving continuous improvement in management and implementation of Local Area Coordination state wide and in each location;
3. identify intended and any unintended outcomes achieved;
4. determine the extent to which outcomes are in accord with project objectives;
5. report on project effectiveness, efficiency and appropriateness; and,
6. provide recommendations relating to the future operation and possible expansion of Local Area Coordination.

There were two components to the evaluation: an Impact Evaluation to determine the impacts and outcomes of LAC against its stated objectives and a

Process or Formative Evaluation using a participatory research approach to gather information about LAC and to feed this information into the LAC pilot as it was being implemented.

The **formative or process** evaluation has adopted a participatory approach and includes a reflective component. All instruments have been developed in partnership with LACs, local advisors and the Reference Group. Learning and knowledge gained in this process has been shared across the LAC community through the period of the evaluation.

The **impact** evaluation involved the collection and analysis of data from families, people with disabilities, LAC coordinators and staff and other relevant stakeholders. Methods included interviews, surveys and reviewing of file notes. Existing records (eg electronic recording) were analysed. Community profiles in each of the six locations were developed. A more detailed description of the methodology is outlined in the following section 2.

# 2 Methodology

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## 2.1 A participatory framework

A participatory approach has been the underpinning to the evaluation methodology. This has two purposes; first, it is a practical goal that aims to improve LAC practice, effectiveness, and stakeholders' understanding as it is happening. Second, this is aligned with emancipatory goals that aim to involve participation and collaboration of stakeholders – especially people with disabilities and their families. This has the secondary gain of developing leadership capacity in the disability sector in regional and rural communities as well as within the LACs themselves, thus building the social capital and resiliency of these communities.

This participatory framework enabled early and informal feedback of findings to those involved in the pilot program. The project was established as 'working alongside' the Local Area Co-ordinators, and extensive site visits were undertaken over the whole period of the evaluation (June 2000 to December 2001).

In addition, Local Area Co-ordinators were in touch, either by phone or email, with the project evaluators, and were involved in assisting to develop the instruments of evaluation – particularly the person and agency survey proformas. A small 'reference' group of people with disabilities and parents also provided advice in the development of the interview instrument and the social network-mapping model. Visits to sites included participant observation techniques that have enabled a more depthful analysis to emerge. Importantly, the DSQ Reference Group has also assisted with drafting this final report

## 2.2 Data collection

Individual families or people with disabilities were invited by Local Area Co-ordinators to participate in the in-depth interviews that commenced in May and were completed in July 2001. All participation was voluntary. All interviews were conducted by the two principal investigators in people's own homes, and occasionally, by telephone. These interviews were analysed using the software package – *Ethnograph*. The total number of interviews overall was 39.

During the interview a Social Networks Map was established with each interviewee. This unique approach to identification of formal and informal support systems has proved an invaluable tool. Some 28 maps were created. Full report of the results of the maps is included in Volume II.

A survey of those individuals and families who were being supported by LACs was undertaken during the period from April to June 2001. This involved sending questionnaires and replied paid envelopes to each Local Area Co-ordinators who then distributed them to families. In this way total confidentiality was maintained. The number of respondents from this survey was 101. The survey questionnaires were completed, returned to the project team and analysed using SPSS software. Full results of the survey are included in Volume II of this Report.

In addition, but importantly, site visits and discussions with LACs in their own environment enabled a picture of the overall pilot, its strengths and challenges, to emerge. There were also informal discussions with people with disabilities and families and with service providers on occasions during such visits. In total 18 visits were made to the 6 sites (See Volume II of this Report for details).



**Burke and Wills  
Monument  
Mt Isa  
Normanton  
Road**

Finally, a detailed community profiling was undertaken (again with the assistance of the LACs) and these are included in Volume II. We also developed an Evaluation Web Site but found this was not useful, as most people involved did not have Internet access. An evaluation newsletter was distributed with the second report and another will be published following the acceptance of this Report and the conclusion of the Evaluation Project.

## **2.3 Confidentiality and Ethics**

In some cases, when conducting the interviews, people told us that they had also completed a questionnaire. However, because of the need for complete confidentiality, there is no cross-referencing between survey data and interview data. In the Report, we provide some narratives of experiences. Where people are called by name in these stories, these are pseudonyms.

We have also not identified individual LACs or communities as they relate to individuals in the report. The report has deliberately not adopted the standpoint of comparing individual LACs but rather discusses the whole program as much as possible. LACs were appointed at different times, offices were established very differently with some having problems finding suitable sites, getting set up and running. As well, LACs were confronted with very different communities, families and needs making comparisons impractical. All the names of LACs have been deleted from these transcripts. In situations where identifying a community would identify the LAC or person, these have been changed.

The study was conducted in accordance with guidelines for ethical research as outlined by The University of Queensland.

# 3. How to Read this Report

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## 3.1 Interim Reporting

This Final Report adds to two previous Interim Reports produced in March 2001 and August 2001. The information provided in those Reports is not necessarily reproduced here, except where necessary.

Briefly, the March Interim Report identified the methodology to be used, the work undertaken to date, and established some emerging themes and issues. It also provided a detailed work schedule for the remainder of the evaluation.

Given the participatory nature of the project, this Report was made available to LACs and discussed with them at a meeting in April, 2001.

Early emergent themes, some of which re-appear in this Report, included: Borders; Supervision and Support; Technology; LAC Practice Issues; one or two person offices, and Indigenous communities.

This Report also included preliminary Community Profiles of each LAC region. These have been reproduced and up dated in Volume II of this Report.

The August Interim Report was structured around three 'contextual' sites for LAC – within the organisation (i.e. DSQ); individual and family and community. Briefly, these are summarised as follows.

Within the DSQ context, LAC requires integration at Senior Management and Regional levels. Since the submission of the Second Interim Report, LAC became integrated within the regional areas of DSQ, and is no longer controlled from Central Office. We also commented here on implications for the future of the program and new placements of LACs in Queensland. Events overtook the evaluation, and new appointments and decisions on sites for the second group of LACs were made at this time. In the LAC in Individual and Family Context, we discussed the nature of the person group, the high level of person crises, the safeguarding and sustaining practices and the intra-Departmental relationships that LACs were finding. Finally, in the community context, we discussed community building from 'ground zero' (also touched on briefly in this Report); and whole of government responses to LAC and issues of community capacity building.

Appendices to the August Report included a preliminary analysis of the respondents' survey; and integrated analysis of social network mapping; a revised perspective of community profiles – this time by shire, by Local Area Coordinator and a table of dates of visits to sites.

Copies of these Interim Reports are available at DSQ.

## 3.2 Language

We have attempted at all times to incorporate the language of those people interviewed or surveyed as part of this project. It is acknowledged within human services, by both consumers and providers, that the language of the sector becomes difficult at times. There has been, for example, much debate about terms such as 'consumer' or 'customer' – rather than 'person' or 'patient' or 'client'. In all situations here, we have attempted to use the term 'people with disabilities', rather than 'users' or 'persons'. However, in relation to the methodology used, on occasion, we also identify and refer to people as 'respondents' when we are speaking specifically about those who answered the survey questionnaire, or as 'interviewees' when speaking collectively, of those we interviewed. No disrespect is meant in either case.

## 3.3 Glossary

Much of the complexity of language in the human services sector resides in the complexity of the acronyms it contains. Many of these appear in this Report. Here, we briefly provide a quick glossary for those reading the Report who may not be fully conversant with all the detailed acronyms.

<b>Acronym</b>	<b>Explanation</b>
DSQ	Disability Services Queensland
LAC program	The overall Local Area Co ordination program in Queensland
LAC	Local Area Co-ordinator
DFYCCQ	Families, Youth and Community Care Queensland (until Feb 2001)
DoF	Dept of Families (after Feb 2001)
LGAQ	Local Government Association Queensland
ALSP	Adult Lifestyle Support Packages
FS	Family Support
MAP	Moving Ahead Program
GROW	Self Help Group for People with mental health issues
SPSS	Software program for statistical analysis

**Table 3.1 Acronyms Used in the Report**

## 3.4 Reading the Recommendations

The Report makes recommendations throughout, usually at the point of discussion. We have identified recommendations in two parts – those made to DSQ overall, and those made to the LAC practitioners. A summary of these recommendations appears at Section iv above.

### **3.5 Report Design and Content**

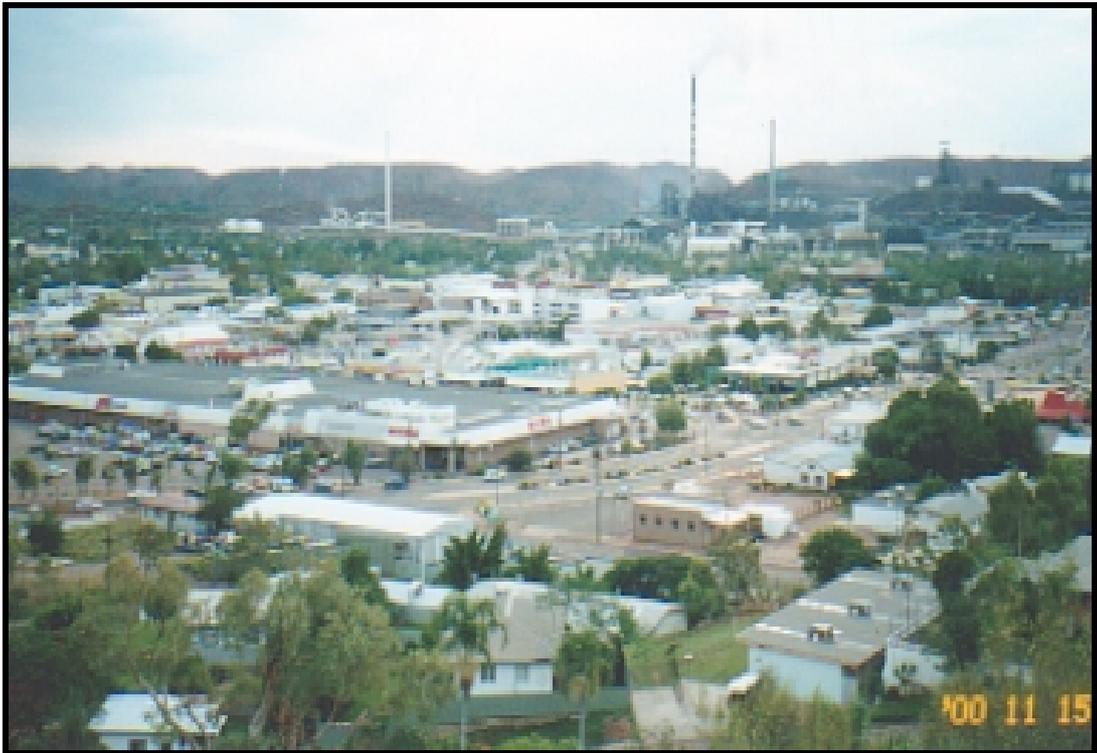
This Report should therefore be read within the context of the two previously discussed Interim Reports.

Section 4 which follows begins with a return to LAC in the broader context – this time from different perspectives. First, we establish the social capital building component of LAC and identify how this ‘fits’ within policy strategic directions established by both State and Federal Governments. We then explore in detail LAC in the context of Queensland government policies on family and community, particularly, non-metropolitan communities. The second section in context is within DSQ and its strategic directions. The research demonstrates that LAC ‘fits’ well within the overall vision of DSQ.

The next section (Section 5) of the report explores LAC in action in detail. This reports on how LACs actually work alongside people with disabilities, families and communities and how the LAC program is managed and supported. In the context of new paradigms of disability support, the research has found that the Queensland LAC pilot model has established a ‘new form’ of disability support, one, which we believe, will create a benchmark in Queensland and in other states. The combination of the individual and community support role is a unique one, and DSQ is to be congratulated in providing the support and encouragement for this previously untried ‘experiment’.

Section 6 reports on the performance and impacts of the LAC pilot program to date. It evaluates how LAC is going in relation to its stated objectives and the impact it has had on people with disabilities, families and communities. A cost-benefit analysis is also presented here.

Finally, we discuss some of the implications of the evaluation for the future.



**Mt Isa Townscape**

# 4. LAC in the Broader Context – Building Social Capital

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While this report focuses on the evaluation of the LAC program within a disability context, the program has potential to inform and impact upon the broader social policy context within the Queensland Government. The work of LAC is particularly pertinent to those policies and initiatives that are relevant to families and communities. Some of these policies were, at the time of writing, at the draft stage (e.g. *Putting Families First*) and are founded on very similar principles. The knowledge obtained through the implementation of LAC is of real relevance to those charged with the implementation of family and community initiatives, across government and with intersectorial links.

This section outlines the policy environment within which the Queensland LAC model currently operates by specifically focusing on its capacity to build community capacity<sup>2</sup> through strengthening social capital<sup>3</sup>. Drawing on current policy documents, as well as recent academic literature, this section is structured within six parts.

1. a brief statement of the issue, focussing on LAC as a builder of social capital and resiliency.
2. a brief outline of the Queensland Government's Strategic plans for families and communities, and establishing the loci within which LAC meshes with these.
3. DSQ's own strategic initiatives, and the place of LAC within these, are discussed.
4. new paradigms of disability – that is, new ways of conceptualising the positive attributes associated with living and working in society and the important role of LAC.
5. establishing the social capital building capacities of local government, and how the Queensland LAC model has the potential to link and strengthen these.
6. an overall snapshot of LAC within the national framework, particularly in regard to recent policies strengthening the relationships between families and the communities in which they live.

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<sup>2</sup> Community capacity building as defined in the Final Report of the Reference Group on Welfare Reform – *Participation Support for a More Equitable Society* (known as the McClure Report) 2000 is: 'the process of accumulation of human, financial and social capital within disadvantaged communities' (2000: 45).

<sup>3</sup> 'Social Capital' can be defined as 'networks of social relations characterised by norms of trust and reciprocity. The essence of social capital is quality social relations' (Stone, 2000:19).

## 4.1 Social Capital in the 21<sup>st</sup> century – LAC in action

If social capital can be understood to be social networks and their strength and quality, these are the networks that operate within families, between families and within communities – and are the networks that the LAC model strengthens and supports through innovative, cost effective action.

Importantly, the health and capacity of the community is seen as crucial in the development of children and in the ‘transmission of parents’ human capital to their children’ (Stone & Hughes, 2001:2), thus the LAC working with parents and children enables the building of such social capital.

Experience over the past decade shows that such social capital does not emerge ‘fully formed’, it requires active support and encouragement. The linkages social capital allows between families, communities and wider society can be supported both formally and informally. Central to the notion of community capacity building are social coalitions between the public/private/volunteer sectors. Local solutions to local problems is the key, good community leadership is the goal, and the aim is to establish strong communities which will support weaker families, and stronger families to support weaker communities (see Stone, 2000:5 for more discussion).

It is now well recognised, for example, that volunteering is a crucial ‘plank’ in the overall social capital framework. However, as volunteering in Australia declines, the importance of dedicated and targeted formal supports becomes crucial. The maintenance of social capital, as the Queensland LAC pilot program has demonstrated, is also the responsibility of formal support systems. Concomitant with the decline in volunteering, has been a growth in policies that support a ‘self help’ model of community care. This self help model can also be seen as a further ‘plank’ in the framework of social capital – however it should not be seen as a reason *not* to provide formal service supports. Indeed, LAC is unique in its capacity to support both the self-help model – through the ongoing empowerment of families – and the building of communities – through its community development focus. In this way, the Queensland LAC model offers what we suggest may be considered as the first *truly 21<sup>st</sup> century human service approach* – an integrated social capital building model which is itself based on trust and reciprocity, while at the same time enabling, empowering and developing families and the communities in which they live.

It is important to see the LAC model as working to build social capital within environments, communities and families that have little or no supports, fewer opportunities for education, employment and socialisation; fewer opportunities to seek financial support; fewer family networks and, often, lack neighbours and friends. As such they are different to those interviewed by the Australian Institute of Family Studies (AIFS) in 2001, and reported on by Stone and Hughes (2001). This random study of over 1,500 Australian households, found that over 99% had at least one friend, and most (94%) knew at least one of their neighbours (p.12). Our research, on the other hand, has found that having a child with a disability, living in remote, rural or regional Queensland, and struggling to enable that child to have a quality of life means that such a family is more likely to be disadvantaged, poor, under educated and lack the important informal networks that research shows builds

social capital. Where 85% of the AIFS study respondents were members of one group or organization, the parents interviewed as part of this current research, were likely *not* to belong to any groups other than those associated with their child's disability.

It is important to point out then, that civic action, which is a vital component of social capital, is often denied these parents, as their energies are focused *internally*, within the family, rather than externally toward the community. There is also the obvious, and distressing fact, that stigmatisation and ostracisation still occur, and in many communities, being different means being shunned. The AIFS study concluded that social cohesion '(a lack of inequalities) within communities also plays [an important role] in facilitating community cooperation and interaction' (p.16) – in other words, it isn't enough if families are working hard to develop their civic responsibilities, if the community in which they live then marginalises them *because* they have a child with a disability. This results in decreasing their reserves of social capital and their individual and collective resiliency.

**Thus, the role of the LAC and the Queensland LAC model is crucial in acting as a conduit between the family and the community.** This means, enabling the social capital linkages to develop, strengthening them if need be through some crucial community development activities, and the LAC being there for the families when needed.

In an address to the AIFS in November 2000, Dorothy Scott from the University of Melbourne argued that not only should 'separate silos such as those of health, mental health, education and welfare ... end, [but] formative evaluations, ... based on process' are needed to ensure that 'creative and innovative programs' are identified and supported (2000:11). In this formative evaluation, we are able to chart the 'therapeutic ingredients' that make up the success of the overall program (Scott, 2000:11).

The next section briefly discusses the policies established in Queensland that have enabled this important initiative to emerge. We also identify the key connections between LAC and specific policies.

## 4.2 Queensland Government Family & Community Policies

The overall priorities for Queensland have been established as including:

- Building Queensland's regions
- Safer and more supportive communities
- Better quality of life
- Skilling Queensland
- Strong Government leadership
- Jobs for Queenslanders

**In all of these areas, the Queensland LAC model playing its part to achieve these goals.** This section briefly addresses each priority area and identifies the strategies that LAC undertakes to meet its established goals.

### (1) **Building Queensland's region.**

While Queensland remains a largely urbanised state, nevertheless, it is also one of the most decentralised in Australia. LAC offices were primarily placed within local government areas that remain less well serviced and with high level needs. These regional areas include the Wide Bay Burnett; North Burnett; Mount Isa; Cooktown; and Gympie. The economic stimulation offered by the employment of additional staff, as well as the ongoing community development work being undertaken by LAC is creating an important economic link that in turn, is helping to build that region. LAC also establishes and promote new alliances and partnerships, between the state government and public and non-government sectors. In addition, and importantly, by providing support to families and people with disabilities, in their own communities and their own homes, means that such individuals do not have to leave their regional area to seek services.

### (2) **Safer and more supportive communities.**

For many communities, the relationship between people with disabilities and the wider society has been a problematic one. One obvious example is access. Many small country towns do not have footpaths, or are built on steep hillsides. Shops in these towns may have many stairs. LAC is 'doing its bit' to ensure a safer environment for people with support needs. Our research shows that involvement of LACs has meant that Gympie and Murgon (to name just two towns) have had access issues addressed. In providing access, LAC enables people with disabilities to mix and mingle with their neighbours and friends. Being part of the community means physically as well as emotionally. In the first 18 months of the program, there is much evidence of an increase in support and of building community capacity to better accept difference.

### (3) **Better Quality of Life.**

As something that all Australians strive for, it is difficult to understand that there are still families and individuals in Queensland whose quality of life is diminished

because of a disability or being a carer for a person with a disability. The LAC program demands and maintains high standards. It demands equal access to services for people, and encourages and supports alternative approaches to meet peoples' needs. Our research has shown that, without a doubt, most of those people with whom LAC has worked over the past 18 months agree that their quality of life has been improved as a result.

**(4) Skilling Queensland.**

In this sense, rather than just 'skilling for work', LAC 'skills for life'. People with disabilities, their families and their communities are often less able to master the complexities of government structures, of non-government sector demands, of criteria for funding and so on. LAC acts as both interpreter and educator. For many of the families LAC has had contact with over this 18-month pilot, the skilling for life has become a crucial opportunity for self-help and empowerment.

**(5) Strong Government Leadership.**

In many communities, the LAC is the only person who takes an interest in the 'whole of life' of families, or individuals. As so much of government service is fragmented into increasingly larger departments; as services often change their names; as criteria for funding changes; the LAC acts as a strong leader within their community, enabling and encouraging people with disabilities and families. This form of leadership is not overt, it does not seek recognition, it works quietly and effectively. It enables, rather than forces; and it supports rather than exhorts. It also builds partnership between the government sector – through Education Queensland and Queensland Health, primarily. As a result, the Queensland Government's own standing is enhanced through this work being undertaken.

**(6) More Jobs for Queenslanders.**

The LAC model enables employment in regional areas for key professional human service practitioners. It demonstrates, by example, how professional staff can work alone, or in a group of two or three, within isolated communities. Such employment opportunities as LAC offers are highly sought after. They provide an incentive for 'locally grown talent' to remain in regional/rural areas, and continue their employment there, without having to leave for the metropolitan centre. In addition, LAC also enables employment opportunities, as they are sought for, for people with disabilities. In many cases, such opportunities are made available through informal networks. In most country towns, 'special' employment options are not available. LAC can broker such 'informal arrangements' and thus successfully build both the social capital of the individual and the community, but also value add to 'jobs for Queenslanders'.

More specifically, the next section identifies those targeted Queensland Government policies which the LAC program supports both directly, and indirectly.

**Families, Youth & Community Care Queensland**

***Putting Families First Draft Policy Statement***

This policy focuses on the importance of families and has three outcomes:

- Giving children the best start

- Valuing and supporting the nurturing role of families
- Creating safe, supportive communities for families

*Putting Families First* also is guided by the following principles:

- Recognition and respect for the diversity of Queensland families
- Promotion of equality of opportunity for all Queensland families
- Development of partnerships between government, community and business
- Promoting a balance between social and economic investment.

## **Department of Families (formerly Dept. Families, Youth & Community Care) Queensland**

### **Coordinated regional social planning framework**

There has been a significant shift from separate portfolio planning processes to broader place based planning. DoF contributes to regional plans that are coordinated through the Communications, Information, Local Government Planning and Sport.

“Families, Youth and Community Care Queensland (FYCCQ) has long recognised the need for an enhanced community capacity in contributing to and influencing decisions that affect people’s lives, rather than Government picking up the pieces once mistakes in the planning and development of communities have been made. This has led to an emphasis on community or “place” planning in the Department” (<http://www.families.qld.gov.au/department/SPFramework.html>).

## **Department of Premier & Cabinet**

### **Community Engagement Division**

The Division is the lead agency for improved government and community engagement. Various other departments/agencies are involved. Five innovations as stated are:

- Learning together by showcasing good practices.
- Reaching out to citizens, reaching out to government.
- Building capacity for local solutions
- Delivering on Diversity
- Putting democracy on line.

### **Social Policy Division**

- Leads and facilitates, in partnership with line agencies and the community sector, social policy innovation and excellence, to optimise social investment for Queenslanders.
- Role is to provide strategic policy advice and direction to the Premier and Cabinet. To coordinate the development and implementation of policy across government, and to provide leadership and advocacy on key social policy issues.
- Has specific portfolio responsibility for providing advice to the Premier in a number of areas, including DSQ.

## **Department of Housing: Community Renewal Programs**

This program's goal is to improve the quality of life, image and confidence of local people. It brings together residents, business, government departments and councils to tackle local issues and find long-term solutions.

Several recommendations arise for DSQ to consider in relation to the ways in which the LAC program is addressing broader government programs and objectives.

### ***Recommendation A2.1.1:***

*That DSQ form a 'whole of government' working party on social capital building and community resiliency, building on the LAC model.*

### ***Recommendation A1.1.7:***

*That the DSQ web site more clearly articulate the 'whole of government' potential of the LAC program*

### ***Recommendation A2.3.1:***

*That a State Conference – Beyond Social Capital and Resiliency Building – Human Services in the 21<sup>st</sup> Century – be supported and conducted during 2003, to share findings, and insights from the LAC program with key agencies and major stakeholders.*

### ***Recommendation A2.1.2:***

*That DSQ make links across government to other departments concerned with community building – e.g. Offices of Regional and Rural Communities, Department of Primary Industries, Premiers to increase awareness of and share information across similar issues around community.*

## **4.3 DSQ and its strategic directions**

This section begins to explore briefly the place of LAC within the DSQ Strategic Plan 2001 - 2005. The DSQ vision is:

### ***Being leaders in innovation and partnership in the disability field***

This is well demonstrated through the support and encouragement DSQ has provided to the LAC pilot, in both its early establishment, and now in its consolidation and expansion across Queensland.

As this report identifies, LAC provides a unique model of innovation and partnership for the rest of Australia. Based on the Western Australian model (see below); the Queensland model has grown to become a hybrid of this early vision of LAC. By incorporating both the individual support and the community development, the Queensland LAC model is uniquely positioned to become the 21<sup>st</sup> century's first innovative form of human service practice. It is a leader also to the non-government sector, to other public sector departments and to the private-for-profit sector. As we

make clear in Sections 5 and 5 in this report – it is extraordinarily cost effective; it is flexible in terms of service delivery and it has the potential to empower those who become involved with it. All of these attributes are part of the DSQ vision.

One particular aspect needs to be highlighted. LAC offers an exemplar of the need to ‘balance ... the use of existing resources and ensuring that programs are user friendly, responsive to individual need and available equitably’ (DSQ Strategic Plan, 2001; 12). Families and individuals, cited in this report, and spoken to extensively throughout the evaluation, would agree. Most do not have high expectations. They are keen to have their children’s or their own needs met, but they do not demand more. LAC offers a modest model of service delivery – no bells, no whistles, just good service.

We present a brief assessment of LAC Program’s Performance against DSQ’s Strategic Directions below.

<b>STRATEGIC DIRECTION</b>	<b>LAC PERFORMANCE</b>
Strengthening individuals, families and communities	✓ All evaluation measures identify strong responses from all people with disabilities and families to service delivery, support and empowerment model. As LAC 'settles in' to communities, increasingly its presence will be acknowledged and valued.
Improving access to services	✓ In most cases, the environments in which LAC are working have little service opportunities. Such services as are available are increasingly being utilised. Capacity building is ensuring that other services are being developed for the future.
Developing and reforming services	✓ LAC has only had 18 months 'on the ground' – however in some communities, its impact is high. There have been a number of successful grants auspiced by LAC, there are examples of new services being established, and of existing services being 'valued added' to by LAC support.
Improving quality of services	✓ In most cases, LAC worked from 'ground zero'. Many families and individuals had no supports, and/or no access to services. Improving quality has therefore meant bringing high quality services (where possible) to people who were otherwise without them.
Increasing service provision	✓ See above. LACs have undertaken some extraordinary successes – however, it is early days, and the strength of the model will continue to develop in its consolidated, regionally based form.
Working collaboratively	✓ LACs are attempting a new form of human service, consequently, their collaboration is with families, with individuals, as well as with the existing service sector, the public sector and private enterprise.
Increasing safeguards and advocacy	✓ For many of the families and individuals now serviced by LAC, the LAC has become their safeguard. They were in danger of either family breakdown, personal health breakdown or lack of carer support. In some cases, the intervention of the LAC meant the difference between continuing to live in the community or being institutionalised. All LACs have demonstrated a high commitment to safeguarding and advocating for their people.
Organisational development	✓ While it is still early, our research suggests that the LAC model may well impact on organisational development within DSQ. The move to the regional environment – which should be closely monitored – may well have this impact.

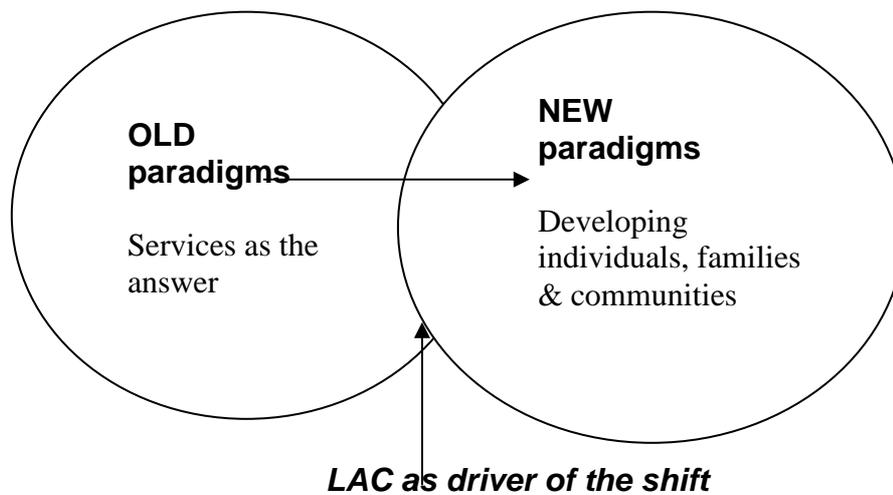
**Table 4.1 LAC Performance against DSQ Strategic Directions**

## 4.4 New paradigms of disability support

In the past decade, the human service sector in Australia and overseas has undergone much upheaval, changes in policies and in selection criteria and needs assessment. Traditional approaches to service delivery – many based on conservative ideals of protection and lack of capacity – are now seen as wanting. The sector is demanding and developing alternative approaches. These include a shift from community living to community membership (Bradley, Ashbaugh & Blaney, 1994) with a focus on participation in community rather than mere presence in it; the work on community building rather than service development (O'Brien & O'Brien, 1998) and a subsequent emergence of the parent and consumer movements led by families and people with disabilities.

Consumers are also demanding equity and access. While voices of many consumers have been heard in urban areas, and services are being provided which meet many needs; in rural/regional and remote Queensland demand remains high. The Unmet Needs Campaign of 1997 demonstrated the passion and commitment of Queensland families, individuals and carers to highlight this need and bring about change. Groups such as Queensland Parents for People with a Disability, Queensland Advocacy Inc and other coalitions of other organisations have lobbied for change. Part of the response to these campaigns was the establishment of LAC.

Drawing on the WA model, the Queensland approach was redesigned to suit our decentralised state. In this context, and as a result of the pilot LAC project, we believe that a new paradigm of disability support and service has now been established. This paradigm works alongside people; it remains flexible; it places no unnecessary demands on individuals; it does not seek to take them away from their homes, or their communities; instead, it supports them, and enables the community to become more welcoming. Figure 4. 1 below illustrates the shift to new paradigms and the potential role of LAC in this. We predict that the Queensland LAC model, if continued and further developed, will be hailed in years to come as a turning point in Queensland's policy on providing support to people with disabilities, and will become a bench mark for other states, and internationally. Its service to families has proved to be the most cost effective response to need, and this kind of investment in families has many outcomes, not just the initial support. As discussed above, it helps to build the social capital needed for a civil society, and the LAC is crucial in this 'mix'.



*Fig. 4.1 The paradigm shift in disability support*

## 4.5 Local government and social capital building

This section briefly outlines the critical role of local government in building social capital and providing an environment in which people with disabilities, their families and their carers are made to feel welcome and involved. In many rural, regional and remote communities, it would be fair to say that local government has come to human services late. Traditional focus has been on roads, rates and rubbish.

The layering of human services onto local government has now spread across Australia. In Queensland, some local governments are still not as fully connected as they could be. This is where the local LAC becomes an important leader. In connecting local government with people with disabilities, their carers and their families, they are truly building social capital for all. In those communities where successful co-operative ventures between local government and the LAC program have eventuated, we have found strong support for the model.

However, we suggest that this is one area where more could be done – and not just by the LAC ‘on the ground’. Within DSQ and DOFQ, contact with the Local Government Association and the Department of Local Government and Planning would enable an education and information campaign which would value add to all sectors. For example, the Western Australian LAC program won a Premiers Award within government and was also promoted as a case study in the Productivity Commission Steering Committee report *Implementing reforms in Government Services*, 1998. This has provided a strong profile for LAC in WA and nationally.

**Recommendation A3.1:**

*That DSQ now work to raise the profile of the LAC program in the non-government sector do that learning about new models of support for people with disabilities and families be shared.*

## **4.6 National frameworks – promoting a ‘can do’ spirit**

In 2000, the Federal Government released its *Stronger Families and Communities Strategy*. As the flagship of welfare reform, the Strategy highlights the determination to provide a ‘social partnership approach’ albeit one which ‘also emphasises family and individual responsibility to be self reliant’. (Stone, 2000:5). The Strategy is underpinned by five principles of welfare reform – all of which are reflected in the Qld LAC pilot model.

- A move to individualised service delivery
- A simple and responsive income support structure
- Changes to incentives and financial assistance
- Mutual obligations
- Social partnerships – building community capacity (Stone, 2000:4).

The Federal Government policy is strongly influenced by identifying the ‘family’ and the ‘community’ as ‘traditional institutions [that] provide the most effective source and form of social support’ (Stone & Hughes, 2000:4).

The Federal strategy aims to build strong communities, by using an integrated partnership between the public and private sectors, while strengthening the volunteer sector. In this way, the Strategy aims to halt the ‘apparent decline in civic life’ while at the same time benefit from ‘governance based on social coalition, a social role and maximisation of profit for business, a community sector bolstered by volunteering and inter-agency co-operation’ (Stone & Hughes, 2000:5).

The role of the LAC within this model can be seen as an exemplar of the ideal approach, and findings from this evaluation (discussed further below) suggest that LAC is an effective strategy for reaching out to people with disability and families in regional and remote areas and building capacity in communities to develop local solutions. LAC serves people and families across age, cultural and linguistic backgrounds, location and living arrangements. It provides a real life example of how such innovation can be achieved by government. While this would appear to be known at the local level and within disability circles, there needs to be a stronger promotion of this “arm” of DSQ to other departments at the Ministerial and senior management levels.

# 5. LAC Program in Action

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This section examines the LAC pilot program in action – that is, the way it is implemented and practiced across the pilot communities and by different LACs.

Generally there is a strong common core of approach and values across all the LACs involved in the pilot study but differences in the ways in which individual LACs operate. The 10 practitioners involved in the pilot study had different educational and professional backgrounds, different experiences and came via different career paths to their LAC position. Some lived in their communities for many years while others came to live in the community when they were appointed as LACs.

The evaluation found that as a result of high quality training and rigorous selection processes as well as supervision and support, all LACs demonstrated awareness of the program's core principles and values and had the ability to operationalise the LAC Program's aims and objectives.

This is a potency to the overall program that demands attention in that the approach is able to respond flexibly to differences in individuals, families and communities as well as to build upon each practitioner's own strengths and capacities.

This feature of LAC practice reflects the “use of self” in social work practice. While not trained as social workers, the LACs in this evaluation demonstrated strong and purposive “use of self” in their practice. This concept refers to the ways in which the practitioner uses herself or himself as:

... a tool or an instrument in the helping process. Just as a physician must be attentive to the condition of medical instruments, the social worker must constantly examine barriers to his or her effectiveness. (Shaefor, Horenjsi & Horenjsi, 1997: 236)

The creative use of self involves the use of aspects of the practitioner's self in the service of others. What practitioners bring to these interactions includes their personality, their individuality, affectivity, valuing, knowing, giftedness, consciousness, imagination, woundedness, capacity for love, self-awareness, a sense of what is other than self, and most importantly their power.

It is not clear from our research whether LACs and LAC Program are conscious of the use of self in their practice explicitly but they demonstrate it intuitively.

## 5.1 The Seven Signposts

One of the discussion papers developed during the pilot period of the LAC program establishment was *The Seven Signposts on the Road Less Travelled* (Grimsley & Lavelle, 2000). This paper has had several drafts and is constantly

being reworked in the context of new learning about LAC practice. These signposts are used here as a framework for presenting findings about the practice of the LAC program. The seven signs cover core principles and processes of the LAC program. Each is now examined using the following structure. Where we draw on respondents' own words, identification of individual LACs has been deleted.



### ***5.1.1. The Relationship as Central***

#### **Statement of the Issue:**

The centrality of relationship is one of the core principles of the LAC program. This involves the establishment of a partnership based on trust and respect, where the LAC actively takes time to develop a strong relationship, and keeps in regular contact. *Doing what it takes* involves listening to needs and acting on them in the context of a strong relationship with people with disabilities and families.

The person centred, facilitative relationship that the LACs develop with people is central to the experience of people with disabilities and families. LACs provide an important ongoing point of contact, an ongoing relationship and ongoing emotional support which is both needed and valued.

#### **The Evidence**

Evidence relating to this signpost is summarised from data analysed from the

- Respondent Survey
- Interviews
- Social network maps
- Participant observation
- Agency survey

The survey identified several aspects of the relationships that LACs have with people with disabilities and families. These aspects refer to the means by which a relationship based on trust and respect can be developed and maintained. For example, qualities of responsiveness, approachability, understanding needs, taking time to explore issues and possibilities, being good listeners and caring in their approach were all rated very positively.

These data were analysed in detail in the Second Interim report.

The interviews with people with disabilities and families also revealed a very strong focus on relationship building and supported the findings of the survey. The ongoing friendship and emotional support of the LAC, which different people access in different ways, is appreciated. The LACs are responsive to the person's individual needs with respect to how much contact to maintain and whether to initiate contact or allow the people to. Some LACs appear to be intuitive on this issue. No people indicated that they felt the LAC intruded into their lives.

For some, the ongoing relationship they have with their LAC has a profound impact on their lives and their sense of feeling able to cope with their situation. This parent's comments reflect how having the LAC has given them hope for "survival".

*"...if [LAC] wasn't about I don't know where I'd be. She has just been absolutely fantastic ... and for me she has been my survival ... my survival because I know that she's there ... she's really been there ... I can say not one bad thing about [them]. Nothing ... it's just been like a dream come true ... when I got involved with [LAC] and the organisation, I just had this wonderful feeling [that if] something does go wrong or I need to know this ... I can always ring and if they're not available ... I don't know what I'd do without [LAC]. She's been absolutely fantastic."*

People expressed their trust and confidence that they could approach their LAC in times of crisis. This parent felt she could contact her LAC immediately in an emergency and compared this experience with other human services.

*"...when my mum died, she had cancer and I put D. in respite care for ... I think the first time was two weeks and then the second time was a week when mum died. ... I didn't think I was entitled to respite care anymore, I had to go and see ... and I went and seen Welfare and they said no I wasn't allowed ... [wasn't]entitled to it because it was only there for abused kids. I said my daughter wasn't abused or nothing, and I thought they'd help me out anyway, but they didn't. So anyhow I went and seen [LAC] late at night ... it was late at night, and I asked [LAC] would she be able to help me out, because I had to catch the train down [to NSW] ... mum would have died ... So, no ... only ever [LAC] helped me out and getting me down there and everything. ... I was with her when she died, yeah, which was good."*

Having ongoing contact is also key to the relationships that LACs have with people and families. LACs, and sometimes people with disabilities and families, seem to put considerable effort into relationship building. Many interviewees spoke of the LAC keeping in touch, phoning them from time to time, to see how they're going, initiating contact. This is greatly appreciated and makes people feel supported and valued. People with a disability and those caring for someone with a disability can find it hard to find the time and energy to maintain relationships so this was even more appreciated.

*"I find [LAC]'s always coming around for something ... And if we don't hear from each other for about, say two, three weeks ... I get a call from them... And they come around to see how I am. And I feel really*

*comfortable with them. I can tell them anything. And I just, they're great, they come over and sit down and ... we have a big chit-chat and we have an espresso. And, um, so it's great and I, I wouldn't be able to do without them because they help me a lot and then just, basically if I don't feel good or I need ... some help care-wise or some moral support I know I can call them ... It's their personality. [LAC] is fantastic."*

As two mothers pointed out, however, it was of concern to them that it may become difficult for the LACs to continue this practice when their workload builds up to the allocated level.

The centrality of the LAC to people and families was also illustrated in their positioning in the social networks maps. As discussed in the Second Interim Report, Only seven people saw the LAC as being part of the service context and the remaining 18 saw them in the family or friend domain. Seven saw their LAC as being like one of the family (4 as close family). Interestingly, eight located their LAC between the friend and service context. These people made comments which suggested they knew that LAC was a "service" but their LAC operated more on a personal and friendly level.

From the Agency Survey, there were several comments by other service providers who had observed the respect that LACs demonstrated for peoples and saw this as good professional practice.

## **Discussion**

All LACs demonstrate a keen understanding of the importance of the relationships with people with disabilities and families and a capacity to develop and maintain positive and valuing relationships with them. Participants expressed awareness of a difference between LAC and other human service workers they may have had contact with and appreciate this difference. The investment in strong and facilitative relationships between LACs and individuals and families is a solid base on which to build inclusive lives and to empower people with disabilities and their families.

Our research shows that formal supports may be reduced and the financial investment is less if relationship building is given higher priority. We have observed how families resist breakdown because there is someone to whom they can turn when they need to, and without fuss. The impact of a small investment that LACs may make out of their discretionary funds is amplified because of the relationship those being supported have in their LAC.

There are several challenges to this key signpost of LAC. First, there is potential concern of the blurring of professional and private boundaries. This is an acknowledged feature for any practitioners working in small communities (Martinez-Brawley, 2001) and workers in such situations need to maintain high consciousness of any potential conflicts of interest. Second, there is also a concern that the relationships remain sustainable. Doing what it takes means not only more effort for workers but being responsive to a range of people and their needs can become demanding.

As the workload increases to the agreed policy of 50 people/families per LAC<sup>4</sup>, DSQ needs to be aware of the amount of time and energy required. There is also a potential that a halo effect may be operating. There is unequivocal support for LAC input as highly valued but this is from a population who have simply had virtually no supports. Anything may be better than nothing. For example, in the social network mapping exercise, many people identified as having a disability service in their life. However, it transpired that they were just on that service's waiting list. People are grateful that their needs may be acknowledged if not met.

In order to sustain such intense work with people, LACs need time for renewal. For example, regular meetings, retreats and opportunities for reflection. To maintain the high consciousness of the principles of LAC, ongoing training, high quality supervision and regional office support must be provided. This keeps these principles in the foreground of LACs' consciousness and provides supports for continuing to implement them.

The flexibility that underpins the LAC program is unique in terms of models in DSQ. While there is already a significant capacity for flexibility in how LACs do their work this needs to be safeguarded, and it not allowed to be diminished.

While it is recognised that LACs need to be able to work without bureaucratic constraints, they are of course working within the constraints of an organisation such as DSQ. Their capacity to reduce their time with people is actively reduced as the demands on their time for administrative matters increases. In other words, time taken up in more formalised bureaucratic tasks reduces the capacity to undertake the core relationship building.

Currently, policy states that all LACs must aim for a maximum of 50 person workload. This level needs to be reviewed and monitored as while many people experience crises, the capacity to support 50 people may be questionable.

Small communities create situations where dual relationships (private and professional) are common. For the practitioner this can be problematic. In the social network maps many LACs were described as family or friends. While this demonstrates the high regard that people with disabilities and families have for their LAC, it is not without some concerns.

As people with disabilities and families become empowered, their expectations will change and possibly demands will increase. This is a positive outcome for LAC program but LACS may need support in how to deal with this.

***Recommendation A1.2.1:***

*That LAC principles are maintained and supported.*

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<sup>4</sup> It is important to note here that it is not expected that all 50 will be in "crisis" at any given time. A full discussion of workload issues is presented in Section 5.2.2

**Recommendation A1.2.2:**

*That the LAC flexibility is maintained and supported.*

**Recommendation A1.2.3:**

*That LAC administrative responsibilities are monitored and maintained at supportable levels.*

**Recommendation B1.1.1:**

*That the issues surrounding dual relationships and ethical concerns are regularly reviewed through supervision of LACs by their supervisors and potential difficulties of dual relationships continue to be acknowledged and support provided*



*Mt Isa Office*

### **5.1.2. Working with Families and Individuals across all ages and life stages and types of disability**

#### **Statement of the Issue**

LACs work with a broad range of people and families. These include extended and blended families, isolated families and families with little or no natural support networks, all of whom are particularly vulnerable when caring for a family member with a disability.

LACs also work with a diverse group of people with disabilities ranging from 0 – 65 years; and with carers who are, on occasion, much older than 65 years – currently estimated at 14.6% over 65 years and expected to increase (*Queensland Government Strategic Framework for Disability 2000:5*). The type of disability is secondary to the level of support required. The LAC principle of believing in individual and family capacity to know their own needs, and make their own decisions is a core value of the LAC program, and our evaluation has found this is strongly supported by all the families interviewed.

## **The Evidence**

- LAC database
- Respondent Survey
- Interviews
- ABS and other statistics

This section addresses the following question - who are the people with disabilities and families currently supported by the LAC Program? Recommendations relating to this issue are made at the end of the overall discussion.

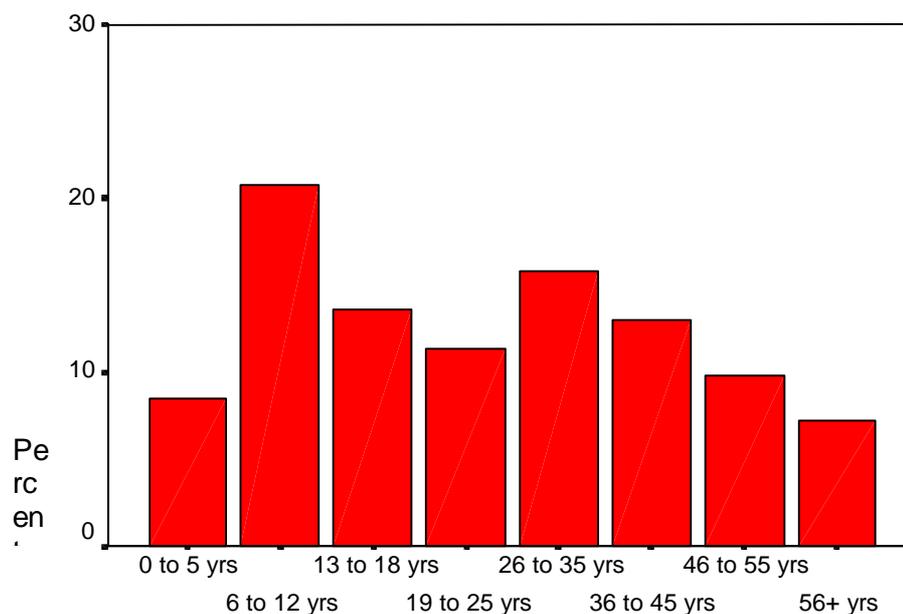
## **Demographics of the LAC pilot program**

Our findings indicate that LACs in the pilot areas are serving people from a diversity of age groups, family arrangements, living situations, communities and types of disability. Since the commencement of LAC in early 2000 to 30/6/2001, LACs in the 6 pilot sites worked with a total of 308 (177 males and 108 females) people with disabilities and their families. This figure includes both active and inactive categories. The total number of active peoples in the pilot sites for the period of evaluation (i.e. 12 months from July 1 00 to June 30 01) was 263 – with 166 males and 97 females – an average of 30 per each LAC<sup>5</sup>.

The following tables, figures and discussions included both the whole number of people served, as well as the specific numbers in each site during the period of the evaluation. The first figure shows the age ranges of the total population (both active and inactive).

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<sup>5</sup> It should be noted that the supervisory position at Hervey Bay has half a workload, and therefore the total number of LACs 'counted' in this discussion is 8.5.



**Fig. 5.1 Age Distribution**

From this picture, it can be seen that the majority of those being supported by the LAC program are families with young or adolescent children or with young adults with disabilities. This reflects the demographics of the LAC pilot sites as well as the general population of regional Queensland. For example in the Northwest, the median age ranges from 28 to 33 years (BRS Social Atlas, 2000).

The table below identifies the same population by type of disability, once again showing the wide range of supports provided.

Type of Disability	Total over period	%
Intellectual disability	120	38
Physical/mobility	93	29
Psychiatric disability	22	7
Acquired brain injury	17	5
Autism	16	5
Hearing Impairment	15	5
Neurological disability	12	4
Visual impairment	10	3
Developmental delay	6	2
Speech disability	4	1
Specific learning disability (excl. ADHD)	1	
Not known	1	
Not categorised	1	
<b>Total:</b>	<b>318</b>	<b>100%</b>

**Table 5.1 Types of disability – total population LAC supported**

From Table 5.1 above, it can be seen that, as expected, given the overall state and national population, the most common form of disability is identified as intellectual disability, closely followed by physical and mobility impairments. This reflects the general pattern of disability within the age range covered by the *Queensland DSA 1992*. While the statistical data from the *ABS Survey of Disability, Ageing and Carers* (1998) identifies physical disabilities as the main disabling condition, it should be pointed out that these figures include all those Queenslanders who are over the age of 64 years, and thus skews the overall population. The same Survey identifies 7.2% of this total population has having an intellectual disability, and the LAC program, with 38% of all those in the pilot, has well targeted this group. It should also be pointed out here that with psychiatric disability at 7.2% of overall state figure (*Disability Services Queensland Strategic Plan, 2000:15*) the LAC pilot program population at 7% is on target. A final comment should be made on the group of people with acquired brain injury. According to the DSQ Strategic Plan the overall population for Queensland is 3.3%. The LAC pilot program has identified and supported some 5%, which is greater than the state average. This would suggest that many people with acquired brain injury are located in rural/remote communities. Later in this section we analyse these figures further by LAC site.

The next section identifies the types of living arrangements for those people involved in the LAC pilot program and are summarised in Table 5.2.

<b>Living arrangements</b>	<b>Total over period</b>	<b>%</b>
Alone	37	11.6
With parents or other family members	222	69.8
With friends	4	1.3
With spouse or partner	31	9.8
Other	21	6.6
Not categorised	3	0.9
Total	318	100

**Table 5.2 Living arrangements**

These figures clearly identify that the majority (nearly 70%) of those people supported by the LAC pilot program are living at home with their parents or another family member. This 'fits' with the identified age range discussed above, but also with the trend, over the past twenty years, for families to remain as principal carers (rather than institutionalised care). It should be noted that the numbers living at home range from 0 to over 50 years. Therefore we should express concern as the potential of unsustainability of these living arrangements as carers themselves age. Ten percent of those who responded to our survey were carers over the age of 65 years. The perceived lack of future strategic planning for this cohort was a concern expressed to us during interviews.

If we consider that close on 90% of the total population supported by the LAC program live in a 'household' with others, what is of concern is the 12% (approximately) who live alone. This concern should be seen in the context of the geographic distances, the lack of services, and the high level support needs, living in

rural and remote communities places on individuals. We interviewed a number of individuals who were living alone, and all of them identified the LAC as a crucial person in their continued independent living. This is also a cohort which requires additional strategic planning for the future.

At a more detailed level, the survey data provided more information about how people live and in what conditions they do so. People live in a rental houses in towns; they live on farms and in small hamlets. Their physical accommodation ranges from sheds to comfortable air-conditioned, three bedroom suburban homes. A significant number of people do not have the phone; many do not have a car and most do not have access to any public transport. Many live long distances from service centres, while some do not drive at all, and are therefore dependent on the assistance of others.

We now provide three narratives of experience to illustrate in more depth the above discussion.

#### **Grandparents caring**

*Rob and Bettie are in their 70s and live in a regional centre. They have cared for Sam their 19 year old grandson, all of his life. Sam is an outgoing, friendly young man and it is obvious from their interactions how much he loves his grandparents and how much they love him. Sam does not speak and his physical needs have increased over the past few years as his mobility has deteriorated. During the 19 years Rob and Bettie have had only one two-week break. Sam's Mum lives in another state and visits Sam and her parents on average about twice a year. Bettie explains the difficulties of even having to support the funded carers who come to help them. "We have to help him do everything. They can't do anything on their own... Rob and I have to be here. Someone has to be here [with Sam] all the time. We can't... we can't both go out , because we [have to] get him up into the chair [and] it takes two of us to get [him] up into the chair." Clearly, the situation for Rob and Bettie is concerning them. They aren't getting any younger. The LAC pilot program has been able to provide some personal care supports to help Rob and Bettie manage so Sam can stay living with them both. Rob and Bettie are now considering longer term plans for Sam with the LAC.*

#### **Caring as a single parent**

*Sheryl is an Indigenous woman who has five children – the eldest Mike has an intellectual disability and the youngest is a baby of a few months. Sheryl has lived in several places in the north west of the state but has now remained in the town she currently lives in for about five years. Her family home is a modest rental with three bedrooms, sparsely furnished and spotless. She has a relationship with Don, the father of the new baby, but they have mutually decided not to live together. Don has an easy relationship with the other kids, including Mike. Mike goes to a special*

*school in the town quite close to where they live. Mike can walk there. Sheryl does not drive, and transport is a real problem for her. Regular outings such as doing the shopping, or going to the hospital, are major logistical exercises. She uses taxis where she can, but that becomes expensive. Sheryl has a strong extended family and is very involved in her community. She speaks of gatherings, parties, sporting events where she and all her children are just 'part of it all'. An issue for Sheryl is the lack of confidentiality around 'private things to do with Mike'. She says that living in a small town means that sometimes she has to seek help from 'people I went to school with, and I don't feel comfortable with that'.*

### ***Living alone***

*Rhonda is in her early 50s and lives alone with her family of goats and beloved cats. She is happiest away from people with her books and 'just relaxing looking at the paddocks'. Rhonda has a depressive illness that can be serious at times, requiring intensive support. When we first meet her, Rhonda lived in an old tin shed on the outskirts of a tiny, rural town. Piles on books and cartons fill the shed, but Rhonda and the cats have their own ways of negotiating through the piles to make the coffee and find that Agatha Christie thriller. Rhonda has few friends locally, but travels to GROW meetings some 45km. Away each week. Rhonda keeps her old Datsun on the road somehow, but finds the petrol costs 'a real shocker'!. She keeps in touch with her GROW friends, and her sisters by phone. She phone bill is 'another shocker, love' she jokes. Rhonda loves living in the bush, having moved from the city many years ago when her illness made coping with her factory job, and urban stress, too much. 'I had only a little bit of money out of my super, but it was enough to buy me these couple of acres. But I love it here. I couldn't stand to live in Brisbane now. Of course people here are a bit 'keep to themselves'. I haven't really made close friends in [this town] but I have other friends in [other towns nearby]. I don't need a lot of people around me really'.*

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## Discussion

People face a range of difficulties in their daily lives. Some of those supported by the LAC pilot program have very complex and extensive impairments and/or support needs. Our research confirmed that people do try to manage and do their best with the situation they have got, and manage as much as possible, without services. Many stories can illustrate the sorts of issues those living with and caring for people with disabilities face.

The combination of disability and geographic and social isolation experienced by many peoples, on top of the usual daily stressors people face, can severely compromise people's coping capacities, and in turn, put extra strain on their relationships, especially family relationships. Many have few people close by whom they can ask for help, so that when relationships with those few people become strained, or the needs of the person with a disability increase, as they do from time to time; or if they (the carer) are growing older and less able to manage, the situation can become overwhelming. In our first Interim Report, we reported on the fact that most of the peoples the LAC pilot program is supporting are those who are close to crisis point. Some of our respondents and interviewees had a number of family members with impairments. For example, one woman who has dyslexia herself, is caring for her daughter who has other disabilities as well as ADHD. In another example, another family has a son with severe disabilities and a father who has had a stem-cell transplant and is undergoing chemotherapy.

People managing their daily lives do not always recognise the specific nature of the support they would find helpful, and, even when they can, they are not always able to seek out the resources they need, for a variety of reasons. LAC supported individuals and families do not have the time at their disposal, simply because of the demands of having a disability or caring for someone who has one. Then geographic distances also limit the services available. Even where services are available, it was reported to us that they are often difficult to access, or even to find out about. Some people spoke of having tried to 'get help' for years, some, even now, did not know that help was available, until they were contacted by their LAC. These 'non service users' were quite a number of those we spoke to and who responded to our survey. We believe that LAC has just identified the 'tip of the iceberg' of this cohort in Queensland.

Living in small communities limited the extent to which, and the ways in which, some peoples felt able to access local services because of privacy concerns, whereas our research found that the LACs were trusted with private information that is sometimes not share with other service providers. This trust and reciprocity are a crucial component of the LAC relationship.

The LAC program enjoys much broader eligibility criteria than other DSQ programs. This means that early intervention can be a reality, and the needs of people can be established early, at the point of crisis. LACs are able to understand the needs of people who do not 'fit' other eligibility criteria (such as those we call the 'non service user') and they can gain a better picture of the overall disability field at the grass roots level across Queensland.

**Recommendation A4.1.1:**

*A4.1.1 That DSQ take up the challenges of community capacity building and commission ongoing research that enables a more detailed analysis of the economic and social issues through:*

- (e) a scoping study of ageing carers*
- (f) a scoping study of “non-service users”*
- (g) a scoping study of non-government and private services available in rural and remote communities*
- (h) the nature and scope of supports for people with disabilities and their families across the state and how they can be further developed.*

**Recommendation B1.2.1:**

*B1.2.1 That more sophisticated methods of recording on the database be established to include information on*

- (a) DSQ funding applied for (e.g. Family Support).*
- (b) DSQ funding received*
- (c) Ages of carers/family members*

**Recommendation B1.2.2:**

*That the database be seen as a tool for use by other service providers, and the rest of DSQ.*

**Recommendation B1.2.3:**

*That this database knowledge becomes ‘common knowledge’ through data warehousing within DSQ and thus enables better service provision.*



*Mundubbera Office*



*Mt Isa Cloncurry Road*

### **5.1.3. Informal Supports, Natural Social Networks and Mainstream Services**

#### **Statement of Issue**

The important distinction between informal and formal networks is an underpinning principle to LAC practice. The emphasis in LAC is primarily on the strengthening and development of people's informal supports and natural social networks. This tends to challenge the disability service paradigm that 'more service supports are the answer'.

Internationally there is a growing espousal of the worth of developing informal supports around people with disabilities as foundation for inclusion. However the practicalities of actually implementing this are not as well documented or as well implemented. Particular concern for this project is the effort to integrate people with disabilities into small communities, which is not without some challenges. There tends to be an assumption that natural social networks are greater or stronger in smaller communities however, this is certainly not universal. Acceptance into small communities can be difficult if one has not lived in the area for many years. Several people spoke of stigma and rejection within their communities which makes the development of informal supports extremely difficult. In addition, such communities rarely have a range of mainstream services and some have none.

It is necessary to gain a deeper understanding here of how support in the context of formal and informal networks might work. While complex and interrelated processes are involved here, a useful heuristic for understanding support is provided in Table 5.3.

Networks	Type of Support	
Formal	Physical	Emotional
<p><b>Professionals</b> physicians, specialists, social workers, therapists, support workers, respite coordinators etc</p> <p><b>Agencies</b> hospitals, early intervention programs, special schools, disability services, mental health services</p> <p><b>Mainstream services</b> bus services, schools, libraries, housing, employment</p>	<p>For example: food, housing, therapy, equipment, aids, personal care, transport, income support or benefits, drugs, support with daily living, surgical procedures, information, respite</p>	<p>For example: Counselling, reassurance, helpful advice, security</p> <p>Grey areas where paid supports become more like family or friends</p> <p>Companionship, affection, love.</p>
Informal	<p>For example: shelter, food, personal care, transport, support with daily living, possessions such as clothes, toys etc</p>	<p>For example: love, encouragement, companionship, fun, physical affection, hugs, security.</p>
<p><b>Individuals</b> relatives, friends, neighbours</p> <p><b>Groups</b> social clubs &amp; churches</p>		

**Table 5.3 Types and sources of support**

It is important to note several key points here about the ways in which such supports operate.

First, it is possible and often very common for both formal and informal networks to provide the same sort of support. For example, a paid worker or a family member can assist a person to get up, have a bath and breakfast every morning. Parents are also very skilled at administering forms of therapy to their child once trained in the procedure. Some specialised forms of support are limited to formal networks.

Second, there is a degree of fluidity and often a blurring of boundaries across these categories. Some forms of physical support also meet emotional needs – a form of therapy may convey reassurance and lower stress. Some emotional supports may decrease the need for physical supports – for example, many parents actually use fewer respite hours when they know it is simply available or they have a supportive family member nearby. Some formal paid workers become closer to their peoples and provide considerable emotional supports. Others may work beyond paid hours and be involved in the person’s life beyond their formal role.

Finally, it is important to distinguish between received and perceived support (Vaux & Harrison, 1985). Received support can be formal or informal and refers to what people get from others – the actions others perform to assist the person or family. Perceived support refers to the perceptions of the person or family assisted about what comes from others and how helpful or unhelpful it is to them.

It is in the complex context of supports, networks and relationships that LACs work with people with disabilities, families and communities.

### **The Evidence**

- interviews
- agency survey
- respondents survey
- social network mapping

The broader picture of the availability of supports around people with disabilities and families can be built from data from the respondents’ survey, the LAC database.

Most people (approximately 88%) live with others – usually their family (approximately 80%). From the interviews however, it emerged that some families are very small – eg one parent and children.

More than half the respondents of the survey (55%) live in a service centre; a further 19% live within a 30-minute drive and 8 % live more than 2 hours drive from a centre. Those living outside service centres live in small hamlets or on farms.

Very few people receive any disability service other than LAC program. The most common form of service support was respite (approximately 37%).

From the interviews a more detailed picture emerged which indicated that many people **perceived** they were in receipt of a service such as respite when in actual fact they had only been placed on a waiting list. As well, many people spoke of being and feeling socially isolated. Some individuals spoke of being more isolated after acquiring their disability.

The social network maps showed that some people had very few friends (0 – 3) and interviews revealed that people also felt they could not ask them for assistance. In several instances where direct support workers were in place the people recorded some of these workers as friends commenting that their workers “were like a friend”.

Others however, had built a few strong friendships and felt they were very supported by them. Some families who had lived in their communities all their lives did have an extensive network of friends who would help out with physical support if needed.

It was very salutary to both investigators to speak to many people and families have demonstrated they are extremely resilient surviving with no services and few informal supports often for many years.

Against this picture, there have been considerable gains in supports through LAC facilitated network building and the use of discretionary funds to provide additional supports. In these cases LACs have provided small amounts of funding for in home supports to be provided by a neighbour or local resident.

LACs are certainly raising awareness of the availability of formal supports and are assisting people and families to apply for funding under other DSQ programs including Adult Lifestyle Support, Family Support and Moving Ahead Programs.

#### ***Dad doing it alone, doing it tough***

*Ron is a single father living with his son Paul 16 who has intellectual disabilities and autism. Just the two of them live in a rundown rented house in a suburban type area in a regional centre. Ron is in receipt of a Disability Support Pension and hasn't worked for many years. He is not able to read and write. Despite living in a major centre with a number of facilities and services, they are extremely isolated. Ron has a small amount of contact with his ex wife who lives in another town but has no other friends or family. Paul attends a special school and recently has started seeing a psychiatrist for "acting funny". It seems that Paul may be developing a psychiatric condition and hearing voices though this is unclear. He is now on psychotropic medication. The future may be grim for Paul and his dad. What will happen after Paul finishes school? Ron is finding Paul's behaviour hard to handle. Ron seems bewildered by these events and unable to think about what to do.*

In this situation, building informal support is very difficult. There are very few existing contacts or relationships on which to build. The LAC is trying to build links between Ron and his neighbours, extended family and other services but Ron does not mix easily with other people and Paul's behaviour may be seen as scary by others who do not know him.

#### ***Marg comes home again***

*Marg is an artist of some note. She regularly exhibits her paintings and hopes she will make some money out of it one day. Marg lives in a country town in a granny flat in her parents' home with her young son who is in primary school. Marg has a*

*physical disability and uses a wheelchair to get around. She needs assistance with some of her personal care and daily chores. Marg is divorced and moved home to her parents because she “needed more help to manage”. She finds living with her parents “a bit claustrophobic” after the freedom of her own home. Marg does not receive any funding for Adult Lifestyle Support but manages with help from her mother, her son and occasional small amounts of funding for some in home support. She regularly goes to her art group and has several friends there who provide mainly friendship and shared interests. She does not receive any physical supports from this network. Another challenge for Marg is transport. She needs to use taxis and finds this expensive even with the vouchers. She also has to send her chair to Brisbane for repairs (which happens quite often) and this confines her to her home for up to 10 days at a time. She explained that “going out on to the streets really knocks the power out of the wheelchair and especially without having a footpath”.*

Marg has few formal supports, some informal family support without which she could not manage but is somewhat restricted in getting out and about to build relationships with others. Her options for extending her social networks rest upon obtaining better physical supports around issues like transport, equipment and perhaps more personal care supports.

### **Old friends help out**

*Bev and John have lived in X.[small community] all their lives. Their own families of origin lived there and they have a large circle of friends. Their comfortable and airy home is in a leafy pleasant street. John owns and runs his small business and is well known in town. Bev and John have one son Damien who is 17 and has multiple disabilities and support needs. Damien attends special school and attends a respite service every few months. Bev and John's friends know Damien really well. Over the years another couple have often taken Damien for the weekend and even for a few weeks while Bev and John have a holiday. In an emergency if anything happened to Bev or John, Bev could ring her friend for help and she would be there. Bev has no qualms about this – she trusts her friend and knows “she loves Damien almost as much as I do”. Bev is currently talking with her LAC about what will happen in terms of supports for Damien when he leaves school.*

This story illustrates an arrangement where formal and informal supports are effectively integrated to meet Damien's needs at the moment. Damien is well known in his community, he is loved and supported by his family and their friends as well as receiving some formal support through the school and respite. It is true that there are some limitations – for example Damien does not have any close friends of his own other than one girl he goes to school with and the future after he leaves school will create more demands for support. However, the family are aware of these and are seeking options with their LAC for Damien.

One illustration where all types of support were successfully integrated concerns a man called Derek, his family, his community and his LAC. Derek, a middle aged man, lived with his mother in a remote part of Queensland far from any neighbours and services. Derek has a psychiatric disability and was becoming very frustrated and agitated to the point where, for many people, the option would be admission to a psychiatric hospital. The LAC here though was able to work with Derek, his mother and his brother to put in place the following supports:

- some emergency respite with the local hospital and then a disability agency,
- mainstream supports from the local real estate agent for a flat, electrical store, other local shops
- informal supports from family and friends

Through all these supports and networks, Derek was able to remain in his community, close to his family and to participate in everyday life in that community.

### **Discussion**

The coordination of formal and informal support is a feature of DSQ programs and represents one important way in which people with disabilities and families can obtain necessary supports and be included more in communities.

The LAC Program has made significant inroads but the amount of time and energy involved cannot be overstated.

There is a challenge in developing informal supports in situations of extreme isolation either through geographical location or social isolation. In such situations there are simply no other people or very few who know the person to the extent they could provide any support at all, particularly in a crisis situation, where trust is required.

Therefore, for many people the extension of support networks into the informal domain will need to be LAC-mediated. This will involve the LAC creating opportunities for the person to meet others, to form relationships and gradually extend the social network. This is already happening in many situations but has translated into real physical support for only a few at this early stage of the programs development.

One reason for this is that many people with disabilities have need for high physical supports – wheelchairs that work, aids and appliances, help to get out of bed, to have a bath, to have a meal, to manage money or go out for a pizza – and they need these every day. At this point in time and for the vast majority of people with disabilities such physical supports are provided only by families or paid services. Very few have friends or neighbours providing these supports on a regular and continuing basis.

There is a dilemma here for LACs in balancing the real needs of individuals and families to be supported with the preservation of self-sufficiency. On one hand, there are people with high needs for formal supports in the LAC pilot sites. Most funded services have long waiting lists and many people and families have no services at all. On the other hand, there are examples of resilient families and individuals who have developed their own support solutions in the absence of formal services. LACs are working alongside all individuals and families to build that resiliency and further the availability of informal supports. There is a strong commitment to seeking informal before formal supports and to engage with mainstream services before specialist disability services.

There is also potential here for more direct funding of people with disabilities and families to engage their own supports in their own homes and by pass the agency. This would allow for a smoother integration of formal and informal supports around the person with a disability.

**Recommendation A4.1.1:**

*That DSQ take up the challenges of community capacity building and commission ongoing research that enables a more detailed analysis of the economic and social issues through:*

- (i) a scoping study of ageing carers*
- (j) a scoping study of “non-service users”*
- (k) a scoping study of non-government and private services available in rural and remote communities*
- (l) the nature and scope of supports for people with disabilities and their families across the state and how they can be further developed.*

**Recommendation A3.4:**

*That, at a regional level, DSQ facilitate and / or conduct workshops with practitioners across programs and with non-government agencies so that practice knowledge is shared as it is developed.*

**Recommendation A4.2.1:**

*That a further review and evaluation of outcomes of the LAC program be undertaken in 3 years (i.e. by 2005).*

**Recommendation B2.1:**

*That LACs to make links with others undertaking new forms of support locally, nationally and internationally to share insights and findings.*

**Recommendation A4.2.1**

*That a study be undertaken of the efficacy of and processes involved in the integration of informal and formal supports around people and families.*



**On the Road - Cooktown**

#### **5.1 4. Community Building**

##### **Statement of the Issue:**

The LAC approach to building community is through working with individuals and families. This aspect of the work aims to develop neighbourhood and local resources as part of the supports around people with disabilities, to raise awareness of disability issues and to develop leadership within the community around disability issues. This approach is strongly based upon the perspectives on community building promoted by John O'Brien and Connie Lyle O'Brien, who in general terms define community building as:

... the intentional creation of relationships and social structures that extend the possibilities for shared identity and common action among people, outside the usual patterns of economic and administrative interaction (1998: ).

Through these strategies LAC aims to achieve full inclusion of people with disabilities in their families in community life. As would be expected at this stage of LAC implementation in Queensland, there is a less developed picture of this aspect of the work. Building community takes time and is perhaps the most developmental feature of LAC work. Comments and observations therefore are preliminary at this stage.

## **The Evidence**

- participant observation
- community profiles
- agency survey

The pilot sites while nominally having 6 LAC offices actually include many different communities. All LACs relate to several communities – some more than 5 as Table 5.4 illustrates.

<b>LAC office</b>	<b>Main Communities included in LAC area</b>
Gympie	Gympie town Tin Can Bay Cooloola
Hervey Bay	Hervey Bay Pialba Urangan Burrum Heads River Heads
Murgon	Murgon Cherbourg* Wondai Kilkivan Goomeri Proston
Mundubbera	Mundubbera Gayndah Eidsvold Monto Perry Biggenden
Mt Isa	Mt Isa Cloncurry Dajarra Camooweal Burketown Doomagee*
Cooktown	Cooktown Weipa Hopevale* Arukun*

**Table 5.4 Main communities included in LAC areas (See Volume II for detailed community profiles of these sites)**

These include a number of Indigenous communities (\* above) who also bring their own ways of operating and specific challenges. Working in these communities is discussed later in this section.

It is important to note here the differences in these communities. For example, Hervey Bay has many services and is a fast growing city with relatively high

consciousness of disability issues. The local council has instigated many projects to improve physical access and is involved in human service provision. Camooweal on the other hand is a small isolated community, which exists as a last stop for travellers leaving Queensland for the Northern Territory. Camooweal had no real awareness of disability issues prior to the arrival of the LAC – for example it has no facilities suitable for people with physical disabilities.

Generally, many communities where LACs have worked have had very few or no formal services for people with disabilities and their families. Where services do exist they are often fully committed to existing peoples and are no longer even offering waiting lists.

There is evidence of LACs working at 3 levels of community building to date. These include

- Developing local resources
- Developing leadership of people with disabilities and families
- Working on specific projects which promote inclusion

First, all LACs have demonstrated a capacity to develop local resources around people with disabilities and their families. The following examples illustrate this work.

#### ***Networking with Service Clubs***

*LAC worked with several service clubs to raise funds for a woman with physical disabilities and living in a small outback town to purchase a scooter. The woman was facing borrowing \$8000 through a credit card or waiting months for a standard aid through Qld Health. Neither of these options were appealing as the woman was in receipt of pension and thus unlikely to be approved for even a credit card loan and she was trapped in her home unable to shop or get out at all. Her isolation was extreme and her situation was far from one of inclusion in her local community. Two service clubs donated funds and the family raised the balance. The woman was able to get her scooter in weeks and was soon out and about her community meeting friends at the shops and being more independent.*

Here the local resources while fiscal, made it possible for relationships to be restored and inclusion a closer reality. In addition, the service clubs' support sends an important message to the community, a message of inclusion and sustainability of living.

## Leadership Development

As well as developing local resources, there have been examples of LACs fostering leadership development for people with disabilities and families around disability issues. These examples illustrate this aspect of community building within the LAC paradigm. These efforts reflect developments after LACs had been in place for several months. This work is highly developmental, from planting an idea, to supporting people to develop new knowledge and skills, and standing alongside them as they take up new leadership roles in their communities.

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### ***Building Leadership***

*Several LACs have encouraged and supported people with disabilities and families to attend workshops and conferences. One LAC sponsored two Indigenous women both of whom have children with disabilities to attend a CRU workshop in major centre. There is a growing awareness of disability issues in their community and efforts are beginning to bring about some positive changes. The two women are viewed as emerging leaders in these efforts. Other LACs have supported people with disabilities to take positions on council committees and another is supporting several parents to work towards developing respite options for all families in their community.*

### ***Putting it all together – a case study***

We present here one case study to illustrate how all levels of community building can come together. We wish to acknowledge here that there is evidence of this happening at all pilot sites. All are community building in their own local and different ways. In some areas, the pressure of working with individuals and families in crisis had to assume priority. For example, in Mt Isa and Mundubbera where there are few service supports, LACs were busy very early working alongside families. Other sites had longer lead times to start community building alongside working with families.

In this case study referrals to the office started out slowly. The LACs there worked quietly in developing personal strengths and local networks and support systems. Networking was a real priority for them in the early months of the office opening.

Some of the efforts that LAC initiated and supported are as follows:

- A two-day workshop run by an outside organisation to help people get a good life. It was attended by about 25 people, whose feedback described it as very positive, relevant and inspiring. One of the LACs, followed this workshop with a program called “Extending the Vision” which was intended to continue and extend the vision. At the time of data collection one meeting had been held so

far which was attended by, again, 25 people. Childcare was arranged for this meeting and another similar meeting was planned.

In addition, the workshops provided an opportunity to provide concrete examples of how improvements can be made in the lives of people with disabilities. For example, we were told a story of an older lady who has a hearing impairment, in addition to other disabilities, who had said, "*I am over all this. I'm too old. I don't want to be bothered*", but ended up attending this workshop. At the event, the LAC talked at length about some of the logistical difficulties of conducting such a workshop and explained that they had provided a microphone to facilitate access because people have the right to support. This lady later attended another meeting held by a local politician, and she requested that he get a microphone because she couldn't hear him. She also told him that "*the meeting [LAC] organised was the first meeting in her life that she had been to where she heard everything that was said*" (and she wanted that to continue happening thank you). This story illustrates the LAC's important skills in leading by example and helping people understand ways to include and have people with disabilities participate in their local community life, including through local government.

Participants spoke positively of the workshops:

*"Oh well, you leave there and you think 'I'm not handicapped at all'."*

- One of the LACs established an Access Advisory Committee to liaise with the local Shire Council on improving access and accessibility of the Council and the town for people with disabilities, and to raise community awareness of the needs of people with disabilities. The Committee has approximately 12 – 18 members, including quite a broad representation of people with disabilities and some families and other interested people, including local councilors. It has achieved concrete outcomes that have been very important to the people involved, some of whom have lobbied unsuccessfully in the past. Councilors have agreed to set aside money for concrete proposals and sought input from people with disabilities, through the Committee, regarding their needs.

One man receiving support from LAC program is on the Committee, having never been involved in committee work before, and described it as a positive experience.

- LACs also organise a number of social activities such as picnics and Christmas parties which were reported positively:

*"... when you go there if you don't have fun ... well the only person you've got to blame is yourself ... it's a diversion ..."*

- In addition a fathers' support group has been set up for dads of children with disabilities. One father reported these activities as useful because they helped families get to know other folk in similar situations.
- Media coverage of these events – TV segments, stories in the local newspaper, and on local radio helped to raise awareness of disability issues

in the community. Several people with disabilities involved are now the media contact people and organise media coverage.

All these strategies and efforts while seemingly separate projects, come together as powerful community building efforts across all 3 levels – (1) developing local resources and raising awareness, (2) promoting leadership by people with disabilities and families, and (3) working on inclusion.

## **Discussion**

Findings about this aspect of the LAC program are somewhat preliminary with insufficient time for longer-term outcomes to be observed and measured. Nevertheless, there is already considerable evidence of community building occurring.

Working in some communities is working from “ground zero”. LACs have the challenge of starting from the basis – raising awareness and making local links. Local governments in rural and remote areas are not used to dealing with people with disabilities and some LACs are making strategic links with local governments.

Some communities are isolated by climatic conditions for many months so that contact with them is difficult. LACs spend hours and days (some even weeks) driving to various small communities. Community building is difficult if one can visit only twice a year. Keeping in touch by phone is an option in some cases and we observed LACs using various means to keep in touch with people in isolated communities – eg making the most of visits to the LAC office centre by key people on other business. Email and Internet are still not readily available to most residents in LAC communities.

As discussed in the previous section, the social isolation of many individuals and families who simply do not have naturally occurring networks to build upon needs to be seen in the context of its impact on community building efforts. The LAC pilot program sites were chosen for their unmet needs, however, our research has found that in many cases, the unmet needs are exacerbated by a lack of consciousness in their communities in which people live.

Transport is a real issue for people living in most centres, as there is often no public transport. This makes attending groups and meetings a real challenge. In some examples, LACs often have to drive people; in others people did resort to taxis but even this becomes difficult in isolated environments.

It is important not to assume all communities are the same and homogenise the community building efforts. Every community will have different strengths, challenges, resiliency and readiness to take on new issues. Most LACs therefore have to develop skills in doing this work across several different communities, a practice which is quite demanding.

There is also an issue of privacy and confidentiality especially in small communities. Not everyone wants to participate in more public efforts.

**Recommendation A2.4.1:**

*That DSQ to develop links with Local Government Association of Queensland in order to exchange information and develop relationships with key personnel responsible for social policy and programs and establish links at the local Shire Council level.*

**Recommendation A2.1.2:**

*That DSQ to make links across government to other departments concerned with community building – eg Office of Regional communities, Office of Rural communities, DPI, Premiers to increase awareness of and share information across similar issues around community.*

**Recommendation A1.2.9:**

*That the LAC Program budgets for transport, satellite phones and other means of keeping in touch across vast areas to be safeguarded*

**Recommendation A1.3.1:**

*That LACs need to be offered training and professional development opportunities offered by other departments and centres involved with this work – eg work on social capital, community resiliency etc*

### **5.1.5. Defined by Place**

#### **Statement of the Issue**

The LAC Program has been designed very strongly on bounded places, with a view that the LACs will gain a really deep knowledge of the strengths, resources and challenges of that place and those communities. By this we mean being part of the community and therefore connected to its members is a feature of LAC practice.

Boundaries need to be carefully maintained as demand for the LAC program support from outside the designated sites will form part of the lobby for extending LAC offices. The disparate nature of the communities within large geographic areas also needs to be grappled with. How can connections be maintained in those communities (for example some the Gulf or Cape), which can only be visited twice a year?

The traditional human service model of being 'distanced' from the community in which a practitioner works is being challenged by approaches for rural and remote communities where practitioners are very much part of their community and have dual relationships across professional and private spheres of life. For example, one may be working as a practitioner with a person who may be the local shopkeeper or on the P. & C. The roles of practitioner and local community citizen can create conflict for practitioners. This is not an uncommon phenomenon and can be understood as a tension between the needs and ways of the local community and the demands and requirements of a centrally based formal organisation. Research indicates that human service workers living in rural and regional communities are more likely to identify and be aligned with their community over their organisation (Chenoweth & Stehlik, 1999, Martinez-Brawley, 2000).

Another way in which an understanding of place can be expressed is through having offices are welcoming and have a community feel rather than being located in a government building. This was an important aspect of the preparation and siting of all the LAC offices. As can be seen in the photographs scattered throughout this report, LAC sites are all located in a variety of settings, not close to government agencies, in ordinary looking shops, buildings or converted houses and with good access for all.

#### **The Evidence**

- Participant observation
- Agency survey
- Interviews

We have observed the development of this aspect of LAC practice over the 18-month period of the evaluation. Initially, there were concerns about the border issue (reported in the First Interim report) as pressure for support came from people living just outside LAC areas. This was especially noted in Gympie, Murgon and to some extent in Hervey Bay (from Maryborough). However, this initial pressure was

managed well by LACs who maintained their boundaries and were very clear about where people needed to live to receive support. In one case, a family moved their son within the LAC area so support could be obtained.

Comments from the agency survey respondents suggest that LACs are largely regarded as knowing their communities well. The issue of whether LACs are from their communities well known as “locals” or whether they have come from outside to take up LAC positions also raised some early concerns.

For example, there were several negative comments made about one LAC (a newcomer) for not working with the key people in the community immediately on arrival in that community. However, this was an isolated example.

The capacity of the LAC to develop good practice relationships has been supported by regional directors and suggests that LACs either have or are quickly developing excellent local knowledge and are accepted as members of these communities. This has been especially critical in working with Indigenous communities. While none of the LACs in the pilot identify as Indigenous, they have earned the respect and trust of Indigenous communities with whom they work. The evaluation has revealed that LACs have an impressive level of knowledge of and sensitivity to Indigenous issues. It remains an important component of reflective practice.

The question of identity and loyalty as a member of the community or a government employee has also emerged in the evaluation. LAC principles are based on them being a member of the community first and as a bureaucrat second. However, some DSQ personnel and some LACs have expressed this as a real dilemma for LAC practice and it is one that the evaluation has identified as needing to be discussed more fully within DSQ management as the LAC program broadens its outreach.

We also observed all LACs offices to be welcoming and accessibly situated in their communities. All the offices were very different – ranging from a 3-bedroom home to shop front offices. In several places the availability of appropriate office spaces was very limited and this took some time to establish in some sites.

Having a presence in the office at all times is impossible. LACs travel many kilometres and need to be away from their offices for long periods of time. Some LACs often have overnight stays in other communities and the LAC in Cooktown is on the road for weeks at a time. This creates an issue then of presence – how can LACs be accessible to all residents across large areas? We observed that LACs have developed a number of strategies to address this. LACs mainly use phones, mobile phones (or satellite in Cooktown) to stay in touch. The use of email or Internet is fairly restricted at this point in time. Also mobile coverage is not sufficiently reliable in Murgon, Mundubbera, Mt Isa or Cooktown. The fax has also been a useful technology and several people now sue them for communicating with their LAC.

## **The Value of Local Knowledge**

A number of the people we interviewed expressed the view that the Lac's knowledge of the local area, services available and people is invaluable. One interviewee put it this way:

*"if you want to find something out they knows who to get on to. And you just get on to them... And all that stuff that no one knows. She kinda knows...She can tell you who to get on to... For years here no one told you nothing. The only ones I was getting around was from P. (service). They'd come around once a year and they'd tell you stuff, but they didn't know much about... round here. It was all Brisbane. You had to get it done in Brisbane"*

### **The LAC linking out**

A number of people with disabilities, families and people working in other agencies commented on the knowledge that their LAC brought into the community. A worker from a disability service explains how the LAC knew about different services and funding:

*The LAC is a vital link for families who have a person with a disability as they assist and coordinate where, when and how services can be accessed. They also can help strengthen the family networks for those who have no funding made available. The [LAC] program is showing just how many people with disabilities exist throughout the state and hopefully forward government planning then may be able to assist so many more people with disabilities.*

### **Discussion**

Our findings and observations in relation to this signpost have raised questions about the relationship of government to place. While boundaries are essential for planning and delivery of government services including the LAC Program, there are two issues that appear to create confusion for some people.

First, different government departments have different regional areas and borders so people may live in different health, disability or education regions. This observation is not new, however it continues to work against a whole of government approach to service delivery.

The evaluation has revealed that for many people living in the pilot site communities the LAC is their only contact with the state government. From the standpoint of a person living remotely, understanding government roles and responsibilities can be somewhat daunting. For example, several LACs have been asked to explain letters received from other government departments bearing the universal Queensland government logo. People assume that LAC represents whatever arm of government has sent the letter.

As well, many people see the LAC simply as the "disability person" and have little knowledge that they represent DSQ or government. This may be seen as a strength of the LAC program.

The second issue is that some people living outside LAC boundaries actually relate to the town or centre within it for shopping, hospital or other services. For example people living in Gunalda relate to Gympie as their centre. People in these locations of communities were initially confused about why they were not included in an LAC area. The expansion of LAC during the period of the evaluation to neighbouring local authorities in a number of cases is therefore strategically sound.

These situations support the view that people relate to the local rather than the central and LACs for the most part are seen as part of the local though in varying degrees. However, LACs are also providing a critical link to outside the community. This takes the form of bringing information about funding, benefits or opportunities to people and is now being extended to supporting local people to attend conferences or training events in other centres. Being of the local community also therefore can assist the goal of leadership development for people with disabilities and families. It is seen as a joint effort between the LAC and others in the community – we are all doing this together to raise awareness and develop more options for people.

The establishment of LAC was not without criticism in a few instances. Some agency survey responses suggested that there was confusion about LACs' roles at least initially. Some also felt that LAC was not needed as much as other professionals such as therapists or that the dollars spent on LAC would be better served in supporting other services already operating.

It is important to recognise that LACs work across disparate communities and hence need to develop senses of places. It should not be assumed that every community within an LAC area is like the one where the office is located.

As the LAC program becomes regionalised, some regions now have several LAC offices. This has the potential to assist management at the regional level by providing sound and detailed local knowledge about different communities within the region and information about people with disabilities and families who may not have had much contact before.

Despite everything, some services are still provided elsewhere primarily in the major regional centres or Brisbane and this means that people will still continue to travel to access them. In addition, as we have previously discussed in earlier in this and our other Reports on the project, the pressure of numbers of peoples in crisis spread across large distances, makes travel times and access a challenge for individual LACs. It is to their credit that they have managed this so well to date.

Communities do remain confused about the variety of government services. Some non-government services still do not have a detailed understanding of the LAC program or its purpose. This needs to be understood however, in the context that LACs were specifically told to network with people and families as a priority NOT disability agencies. It is likely that this approach has yielded the high numbers of non-service users (around 80%) now linked to LAC and thus DSQ.

**Recommendation B1.3.1:**

*That connections between LACs, people with disabilities and families and non-government sector agencies be made at the 'grass roots level' to facilitate information sharing, networking around common issues and problem solving.*

**Recommendation B1.3.2:**

*That information thus gleaned be extended to the wider community.*

**Recommendation B1.1.1:**

*That the issues surrounding dual relationships and ethical concerns are regularly reviewed through supervision of LACs by their supervisors and potential difficulties of dual relationships continue to be acknowledged and support provided.*



*Establishing Mobile contact Kilkivan*

### **5.1.6. Supportive Management Framework**

#### **Statement of the Issue**

LACs work with high levels of autonomy and are required to work creatively and flexibly. As well, LACs are members of a government department requiring high levels of accountability and responsibility. To balance both sets of requirements the LAC program has been developed within a supportive management framework.

This framework includes processes for recruitment, induction and ongoing supervision. The model of support and supervision is the cornerstone of the LAC program. The recruitment and selection process, the quality and intensive training program, and the ongoing support by way of regular meetings, debriefings and opportunities to reflect are crucial to its success.

The model of a supervisor 'clustered' around a number of LACs is critical. This model continually reinforces the centrality of the person with a disability and their family. It allows and encourages values clarification. The model allows for a renewal and sustaining of individual LACs who have high demands placed upon them, and competing priorities to manage. It fosters leadership and offers an alternative to traditional models of human service practice.

## **The evidence**

participant observation in communities and in Brisbane meetings  
discussions with LACs  
LAC practice reflections  
documents - performance appraisal process

## **Recruitment**

The LAC recruitment process included several important strategies. There was extensive consultation with the local community prior to the establishment of LAC and information about the forthcoming LAC positions made known to local residents. Applicants were encouraged to make contact with DSQ and discuss the role with the LAC program manager. In this way applicants could find out more explicit information about the role of a LAC and do some preliminary assessments of their own capacity to take on the job. For example, one LAC consulted their GP to make sure they were fit to take on the position before applying. All interviews were conducted in the local community where the LAC office would be located with a local community member on each selection panel.

## **Induction**

All LACs attended a 2 week long pre-service induction program which was designed to provide all the knowledge needed to commence working as an LAC. The training addressed both programmatic issues (i.e. what happens for the people) and non-programmatic issues (i.e. how the program is administered and managed). It was more strongly oriented the former with emphasis on values and principles, how to work at the three levels of individuals, families and communities and a strong message about the centrality of relationship between an LAC and the people. This was conducted by the Community Resource Unit (CRU).

There was also additional training (as well as the 2 weeks) on departmental procedures, the use of IT and data base, financial management etc. This provided LACs with the practical skills for operating within a government department and how the administration of LAC would work.

All LACs expressed their satisfaction with the training even after working for several months. One LAC suggested that more information about other DSQ programs would have been helpful for them now they were becoming more involved with them.

## **Supervision and support**

All LACs have a supervisor to whom they report. At the commencement of the pilot program, LACs in Gympie, Hervey Bay Murgon and Mundubbera reported to a supervisor based in Hervey Bay. LACs in Mt Isa and Cooktown reported to the Manager of the LAC program based in Brisbane. Since July 2001, LACs in Mt Isa and Cooktown now report to their own supervisor based in Mareeba.

Formal supervision sessions are planned for every 4 to 6 weeks. LACs can contact supervisors at any time for advice, support or guidance on decisions. All LACs indicated that they could usually talk to their supervisor when they needed to and were comfortable ringing either supervisor to “get an answer” quickly if the other was not available.

LAC supervisors have a small workload to keep in touch with practice issues and needs of people. This has been difficult to maintain for the LAC supervisor who has been required to travel a great deal not only to support his LACs but also to assist in the expansion of the program across the state.

### **Performance Appraisal**

Supervision is based on a *LAC performance appraisal* document. This was developed after LAC had been operating for some time which has allowed for hitherto unanticipated issues to be included. The document allows for LACs to set their own goals and address issues for practice and includes provision for feedback from people with disabilities and families. It has 37 measures across different practice tasks and roles. Where it has been used, the process allows for LACs to discuss the breadth of the work, competing demands and address emerging issues.

### **Regular Large Meetings**

During the pilot all LACs attended meetings in Brisbane 4 times per year. Initially this involved only the 9 LACs and the Program Manager but has expanded as new LACs have been appointed. At these meetings, LACs are given up dated information about DSQ programs and operations, have guest presenters offer sessions or workshops on emerging matters or practice issues (eg community building) and dialogue about issues or concerns. The depth of discussion at these regular large meetings is clearly valued by LACs even though it means long travel times away from the office to attend. As one commented:

*We can discuss an issue for 3 or 4 hours which lets you really grapple with it. We nut out what good practice should be and hash out procedural things. It's also good to hear stories of how someone else has done something.*

### **Other support**

The Burnett Wide Bay LACs have cluster meetings with their supervisor. Some LACs have had other professional development opportunities to attend particular workshops. More experienced LACs are also being used to provide guidance and support to newly appointed LACs.

Finally, there is evidence of regions picking up on training and support needs. We are aware that workshops for LACs and other program staff to work through cross-program issues have been conducted in 2 regions. These were reported to be very effective and profitable sessions.

## Discussion

The greatest resource of any organisation but especially a human service, is its people. Investing in people at the front line of any service is always a wise and productive one.

There has been a very strong commitment to supervision and support in this program and this must be seen as a cornerstone of the success of the program. LAC has invested considerable time and money into the supervision and support of LACs and LAC practice. This has been an important safeguard in enabling the program to meet its objectives not just at the outset but to keep meeting those objectives.

There are two significant implications for the work of LAC in this signpost. First, sustaining practitioners in difficult contexts is a serious challenge for all health and human services in rural and remote areas.

Second, the translation of service ideals to the lived experiences of people with disabilities and families has proven to be a complex and difficult task. In most instances and for all kinds of reasons, human services fail to deliver the promise of policy and service objectives. This has been termed variously as the gap between rhetoric and reality (Wolfensberger, 1989) or the “corruption of care” (Wardaugh & Wilding, 1993).

**It is our view that LAC has demonstrated a model for ongoing support and supervision which can begin to address both these challenges.**

However, as LAC grows larger and is regionally managed it will become harder to sustain some of these supports. Funding for supervision and training may become pressured for use for other purposes. Bringing larger numbers of LACs together will be more expensive both financially and in time.

Having supervisors with direct involvement in LAC practice is an important safeguard. While there is a commitment to have a smaller workload for LAC supervisors (i.e.. 25 rather than 50), there is a concern that this may prove to be too many as demands increase. It is acknowledged that we have observed only one supervisor in this situation and this may not reflect an accurate picture of how the model will work in other situations.

**Recommendation A1.1.1:**

*That more work be done at a senior level to ensure the LAC program's full integration into the overall DSQ strategic direction.*

**Recommendation A1.1.2:**

*That regional directors continue to ensure a seamless transition of incorporation of the LAC program into mainstream DSQ.*

**Recommendation A1.1.3:**

*That the LAC model of recruitment, training, supervision and support be considered as the model for all DSQ programs.*

**Recommendation A1.1.4:**

*That the LAC model for recruitment, training, supervision and support be sustained within regional structures and systems.*

**Recommendation A1.2.8:**

*That the central meetings of all LACs be continued for a period of 3 years to ensure consistency of the program across regions as LAC expands.*

**Recommendation A1.4.1:**

*That all LACs continue to report to their regional LAC supervisors who then reports to the Regional Director.*

**Recommendation A1.1.6:**

*That a principles into practice monitoring process be developed involving people with disabilities and families.*

**Recommendation A1.1.5:**

*That DSQ commit to the development of leadership in people with disability and families in local areas so they continue to participate in the monitoring of quality*

**Recommendation A1.4.2:**

*That the workload for LAC supervisors be monitored in view of supervision and travel demands*

## **5.1.7 Principles as the Basis of Decisions and Actions**

### **Statement of the Issue**

While statements of principles and values underpin most human services, it has become increasingly problematic to separate the rhetoric from the reality. It has become difficult to actually practice in a highly principled and ethical manner, when focus is on outputs, rather than process (Eversley, 1999). The challenge facing many human services is how such values and principles can find expression in a climate of managerialism and bureaucratic imperatives. This is not a luxury, it is central to good service delivery and the empowerment of people who are users of human services. It is our view that the LAC pilot program has demonstrated that this can be achieved, however, it requires constant monitoring and safeguarding.

### **The Evidence**

participant observation  
interviews  
respondents' survey  
discussions with LACs

In its documentation, the LAC program explicitly outlines the principles that guide its work. These are listed in Volume II . LACs showed they were acutely aware of these and often referred to them in conversations we had about what they were doing and why. We observed several examples of LACs rejecting an initial strategy because it did not fit with guiding principles and “hold out” for a better one.

For example, one LAC worked for weeks with members of local service clubs to secure extra funding for an expensive piece of equipment for a family rather than using her own discretionary funds.

Another example is where a woman with a disability explained how she had initially refused to see the LAC because too many people had promised to help her but nothing eventuated.

## Guiding Principles

- LAC actions contribute to positive changes and benefits that are able to be sustained
- LAC interventions with individuals and families promote self-sufficiency, not dependence
- it is the needs and aspirations identified by individuals and families themselves which set the direction of LAC actions
- nothing is promised that cannot be delivered
- any support or service provided should as far as possible be controlled by individuals and families who continue to live independently within their own communities
- community building actions arise from the identified needs and aspirations of individuals and families who are themselves connected to this process
- valued and trusting relationships are central to the practice of LAC
- informal support and naturally occurring social and support networks take precedence over formal disability services
- wherever possible mainstream or generic services are utilised in preference to formal disability services
- any funding or service provided should not undermine informal or naturally occurring supports
- any funding is directly controlled by individuals and families
- any financial support aims to build individual, family and community self-sufficiency
- financial support should not displace the resources of other agencies that would reasonably be accessible to individuals and families in the local area
- funding of individuals and families is a strategy of last resort

### Fig 5.2 LAC Guiding Principles

Adhering to such principles also requires sustaining them over time. We have observed that LAC program staff have taken a developmental approach to this and principles are reworked, reviewed and added to as needs and different situations arise. Discussion of principles and examples of how to implement them are also shared at the large LAC meetings. The previous sections illustrate the ways in which principles are embedded in action.

### Discussion

Part of the success of sustaining principles has been through the creation of a culture around LAC. This has been crucial for the establishment of the program in its early stages, especially in creating a strong commitment to people and communities. This was a less critical issue while the program was centrally managed. However, it was reported as creating some sensitivity as the program moved to a regional management structure. Within the larger organisation LAC was seen as “privileged” or “elitist” in some quarters.

All DSQ staff who work with people with disabilities and families have a strong commitment to people with disabilities and DSQ objectives. The challenge in a regionalised structure and the expansion of LAC to new areas, will be to preserve the capacity to sustain the guiding principles.

**Recommendation A1.1.3:**

*That the LAC model of recruitment, training, supervision and support be considered as the model for all DSQ programs.*

**Recommendation A1.1.4:**

*That the LAC model for recruitment, training, supervision and support be sustained within regional structures and systems.*

**Recommendation A1.2.8:**

*That the central meetings of all LACs be continued for a period of 3 years to ensure consistency of the program across regions as LAC expands.*

**Recommendation A1.1.6:**

*That a principles-into-practice monitoring process be developed involving people with disabilities and families.*

## **5.2 Summary of LAC practice**

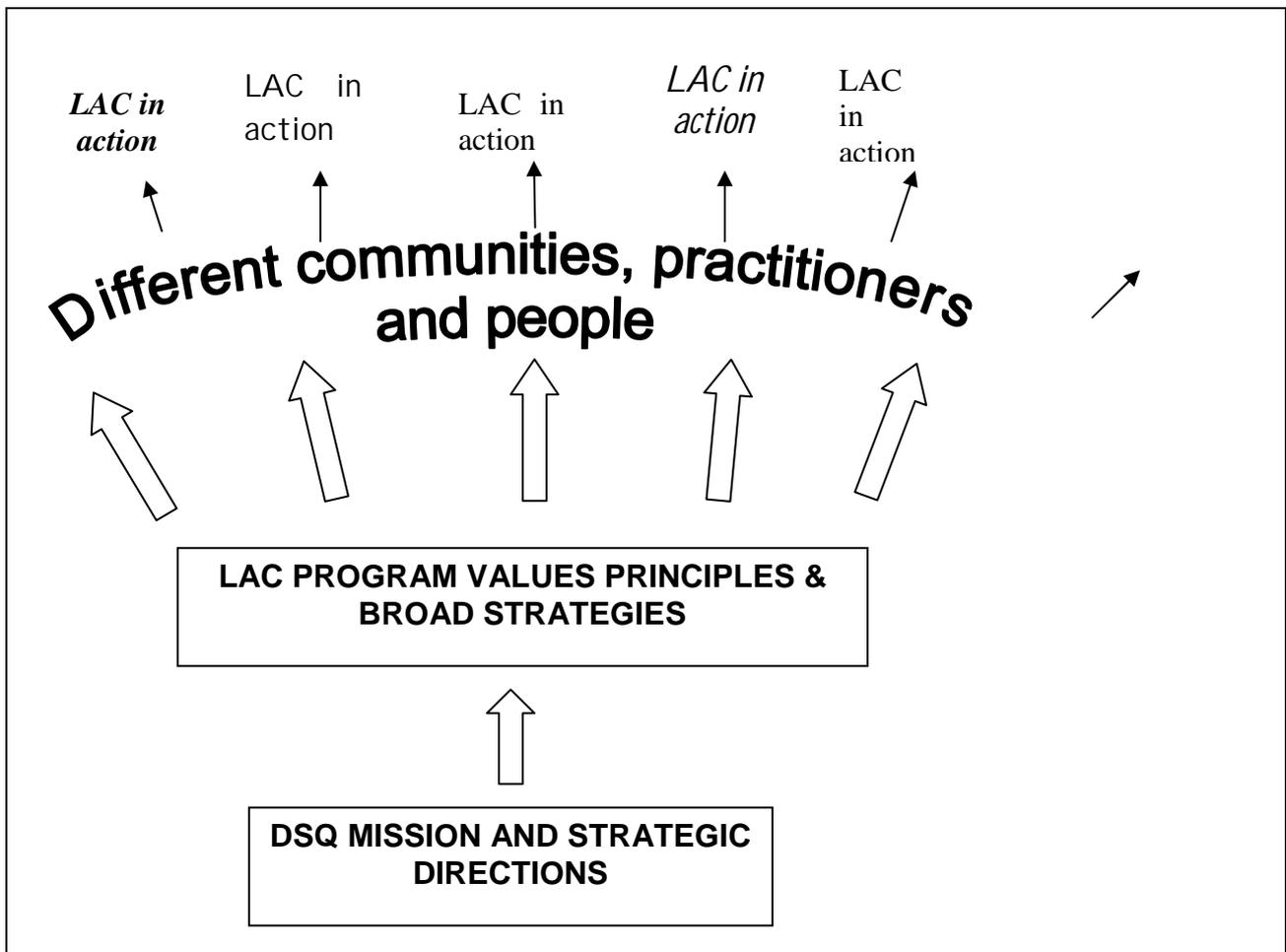
This section draws together insights and analysis of LAC practice. Here we explore the ways in which LAC practice is developing and where it is headed. LAC has developed in different ways across different communities but has held fast to strong common principles. It also illustrates the concept of community embedded practice.

### ***5.2.1 LAC as “Models” of practice***

We have had the opportunity during the evaluation to observe the evolution of LAC practice models. We have seen 10 LACs tentatively embark on the delivery a new program for DSQ. We have observed them grapple with new challenges, reflect deeply, try different strategies and seek advice. We have also seen them working long hours and become stressed and despairing. As the pilot LACs it was not all smooth sailing.

There have been observable changes in their practice over this period of time. LACs now are more confident and articulate about what they do than they were at the beginning of the LAC program. LACs are strongly committed to people with disabilities and families and to the principles of the LAC program.

What has emerged we believe is that LAC allows for different models of practice though all are funded on the same solid core of values, principles and broad strategy. This is illustrated in Figure 5.3 below.



**Fig. 5.3 Process for model development.**

LAC in Action can take various forms depending on

1. the nature of the community
2. the needs of the people with disabilities and families who live there
3. the attributes of the individual LAC practitioner

Having the capacity to allow for different models of practice is essential for a program that requires flexibility and responsiveness.

### **5.2.2 Community embedded practice**

Community-embedded practitioners swim constantly in the sea of community processes, structures and interaction which provide the context, form and tools for their work. (Cheers, 1999:93).

Cheers has proposed the framework of community embedded practice to describe how rural practitioners should go about their work. This framework aptly describes how LAC is operating.

LACs weave themselves into the fabric of everyday community life. They are out in the community being visible, becoming known, learning of people with disabilities and families, working their way into social and political networks and connecting people to each other. They are finding out about current and emerging issues and needs, participating in local projects and committees and, most importantly, supporting people with disabilities and families, to do this as well.

LACs work from a community embedded standpoint to build the capacity and resiliency of individuals, families and their communities in ways that promote the inclusion of people with disabilities in everyday life. Their work is sensible, practical and creative.

Juggling workloads across work with individuals and families and community building work presents a dilemma for LACs and all of them have approached it differently. In the initial few months during the evaluation as the workloads increased quickly for some LACs, anxieties were expressed about workloads. As many early referrals were for people experiencing high needs and crisis, some LACs were concerned about their capacity to manage 50 complex situations at any one time. People with disabilities and family members have picked up on this concern and note that any higher workloads will result in a diminishment of service. Two agency respondents also noted the pressure of extended workloads. However, in the latter stages of the evaluation period these concerns seem to have been resolved. Only one LAC is approaching the 50 quota and different types of support are being provided.

While it is acknowledged that there is great variation in how LACs manage their time, an average breakdown for manageable workloads (N=50) could be as follows in Table 5.5.

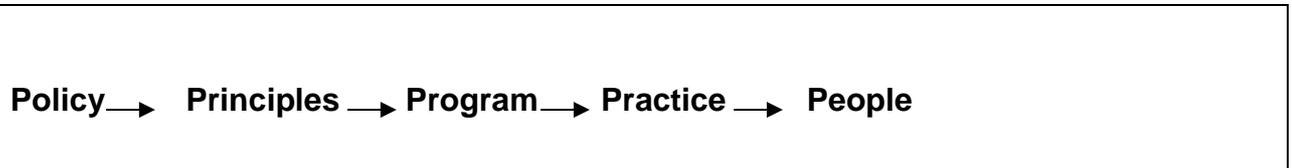
<b>Nature of Work</b>	<b>Proportion of LAC time</b>	<b>No people</b>
Crises	25%	4
Medium to long term planning	20%	10
Building new relationships and responding to immediate need	15%	5
Maintenance and periodic contact	15%	31
One off contacts and response - Level 1	10%	
Other community building work	10%	
Administration	10 %	
Travel	10%	
<b>TOTALS</b>	100%	50

**Table 5.5 Workload time and tasks breakdown**

### **5.2.3 LAC as model disability practice**

In summary our findings and analysis thus far have shown that LAC is emerging as a high quality program which has made the links from policy to the people extremely well. Large human service organisations for people with disabilities are multi-

layered and highly complex environments where commitment and capacity to implement sound service principles is difficult to operationalise. The LAC program has made good progress in sustaining the intent of a policy through to its delivery at the front-line.



**Fig. 5.4 Policy to People Process**

Some of the key features which have made this possible and which therefore should be safeguarded are:

1. LAC was a sound policy initiative for DSQ to adopt. Adopting the Western Australian model and the adapting it to Queensland conditions was an effective strategy.
2. The LAC program developed sound principles which have been incorporated into all components of the program. This has created high program coherency and staff consciousness.
3. Excellent frameworks for training, supervision and support of staff working in rural areas
4. Staff operate with high levels of autonomy allowing for flexibility in response to need
5. High levels of participation by people with disabilities and families in program processes
6. Commitment to monitoring and evaluation of the program

# 6. Impacts of the LAC Pilot Program

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## 6.0 Introduction

This section discusses and reports on the impact of the LAC program. It reports on the performance of LAC against its stated objectives and discusses the outcomes of the pilot LAC program. We discuss the impact of LAC for people with disabilities and families, for DSQ and the disability sector and for communities.

Through an analysis of the LAC database held at DSQ throughout the pilot program, it was possible to outline the numbers of people supported and their characteristics, the types of support provided and discretionary funds used. Drawing from the information also gathered from the Respondent Survey, key outcomes for individuals and their families and the communities in which they live can begin to be identified. Finally, this section summarises the overall impact of the pilot program through a cost/benefit analysis.

### Evidences

DSQ data base

Respondent Survey

Outcomes for families from interviews, participant observation and data base

Cost/benefit analysis

In Section 5.2.2, we discussed the overall active population involved in the LAC pilot program – a total of 263 – 166 men and 97 women. We provided a summary of their ages, and found that the majority were 35 years or younger. We also discussed that these people were being supported by 8.5 co-ordinators in all, an average of 31 per LAC. This next section analyses these general figures in more detail – first, the disbursement of discretionary funding and second, the type and nature of disability by LAC site.

We have assessed the LAC program against its stated objectives and its desired outcomes. On both counts we have concluded that the pilot program has performed well, meeting most of its objectives and delivering positive outcomes for individuals, families and communities.

## 6.1 Performance against Stated Objectives

LAC program has four objectives as listed below in Table 6.1. It is our view that the program has achieved all of its objectives to a degree expected within the timeframe of the pilot. As may be expected, the objectives relating to people and families have been achieved to a greater extent than those for communities. These objectives in relation to the performance of the LAC pilot, are discussed in more detail below.

Objective	Performance
Increase the independence, self-sufficiency and participation in community life of people with disabilities	Already this has increased for many people with disabilities and shows signs of continuing to do so for others.
Increase the capacity of families to continue to provide care and support for their family member with a disability	Many families have received support that has enabled them to continue caring. Some families have been able to remain together and in the area because of LAC intervention and support.
Increase the capacity of people with disabilities to lead valued and quality lives within their local communities	This is steadily being developed as people participate in community activities. There is still considerable need for continued efforts in this area.
Increase the levels of inclusion of people with disabilities and their families within community life	While it is too early to gauge the extent of inclusion at this time, it appears that LACs are building awareness and in time community capacity to include people may be observably increased.

**Table 6.1 LAC Objectives and performance**

### ***6.1.1 Increasing independence, self sufficiency and participation in community life of people with disabilities***

In all pilot LAC sites there is evidence of increases in these qualities for many people and of safeguarding these qualities for people who already experienced them to some degree.

There is evidence that the living situation of people with disabilities influences the impact of the LAC program on their lives. For example, in most sites there were a number of people with disabilities who were living independently. Fourteen percent of people with disabilities who responded to the survey live alone. Most of these people have physical, sensory or psychiatric disabilities. Many of these people have managed or “made do” for many years but nevertheless can be said to be fairly independent and self-sufficient but are usually quite socially isolated. This group requires a safety net to maintain that self- sufficiency in times of crisis or sudden change and further support to become more connected into their communities.

The majority of people with disabilities (usually those with higher support needs) live with their families. These situations also demonstrated individual and family strength and resolve in surviving and making do with little. For many of these families however, the impact of any crisis or change in circumstances jeopardises what independence they may have. The impact of LAC program for this group has been to provide a safeguard against such crises.

People spoke of experiences of isolation and loneliness for people with disabilities either personally or on behalf of their family member. The evaluation found that many people are quite isolated and have little participation in community life other than the basics for survival. The research supports the outcome that the LAC program has increased the opportunities for many of these people to participate. There are many examples of this occurring through the involvement of LAC in people's lives. For example, Rhonda (see Section 5.1.2) is now involved in several local groups and is taking on leadership roles in them. Another example is that of a young woman with psychiatric disability living alone in a country town who now has part time voluntary work and is linked with another young woman with similar disabilities. Two Indigenous boys with intellectual disability are key movers and shakers in the under-18 disco in their community.

While much participation to date has been around disability related activities (e.g. Fathers Group discussed in Section 5.1.5), there is evidence that people are building confidence and making links with other people in their communities. The linking of people into mainstream services (e.g. day care for children with disabilities), and to local shops and services (e.g. Derek's situation discussed in Section 5.1.3) is proving to be an appropriate strategy for increasing participation. This is not a "quick-fix" approach but it is anticipated that it will lead to a sustainable gradual increase in participation for people in the long term.

In summary, the impact of LAC has been to safeguard people's pre-existing capacities for independence and self-sufficiency and to further build supports around people that increases that capacity. In terms of community participation, Lac's strategies of developing people and building community awareness are already yielding positive results.

### ***6.1.2 Increase the capacity of families to continue to provide care and support for their family member with a disability***

This objective is being met for many families living in the pilot site communities. As discussed above, many families have struggled to care for and support their family member despite having little or no formal service support. A feature of many families in the early stages of the LAC implementation was the high levels of crises they faced. The evaluation recorded several instances where families were at the brink of breaking up just as LAC started in their area. There were also instances where the only option for family appeared to be emergency placement of their relative in a residential or hospital (e.g. see Derek's story).

The research has identified a number of ways that the LAC program increases the capacity of families to continue to care in the following ways. These include:

- By early intervention in crisis situations
- By having a relationship with families – listening, responding.
- By advocating on behalf of families to facilitate access to mainstream services

- By creatively using their own and the families' networks to increase informal supports
- By the use of discretionary funds as appropriate, to provide emergency respite or other support
- By supporting families to make their own decisions and choices thus empowering and valuing families
- By linking families with each other *through* community support groups (e.g. fathers group, carers group)
- By assisting families to access other funding, in DSQ (Adult Lifestyle Support, Family Support and Moving Ahead) or other sources (e.g. Commonwealth Carer funds).

### ***6.1.3 Increase the capacity of people with disabilities to lead valued and quality lives within their local communities***

As discussed in detail elsewhere, the purpose of the LAC pilot program was to build capacity in geographic locations where people have been traditionally isolated and segregated from support systems. In many cases, LACs are working hard networking with local agencies to ensure a higher degree of consciousness about the needs of people with disabilities, their families and their carers. In some cases, LACs are working from a low benchmark, and their achievements in the brief period of the pilot program have been remarkable.

There is the potential to continue to build capacity, and for evaluating the impact of future outcomes as the LAC Program rolls out across the state.

#### **6.1.4 Increase the levels of inclusion of people with disabilities and their families within community life**

Again, while it is early days to assess this, there is preliminary evidence that the LAC program has the capacity to increase the levels of inclusion of people with disabilities and their families within community life at the local level.

The pre-requisites for inclusion to happen can be understood as follows:

- *People with disabilities having opportunities to spend time in ordinary community settings and places*
- *People with disabilities having opportunities to engage in activities with ordinary people in those settings*
- *People with disabilities participating in and contributing to community activities*
- *People with disabilities using ordinary services and supports such as housing, transport and child care*
- *Communities welcoming people with disabilities and families to participate and belong*
- *Communities being physically accessible to people with disabilities and families*
- *Communities having the capacity to include people with disabilities*

The LAC program has demonstrated it is able to assist and support people and families to engage in community activities and settings. Through its work in community development, the program has also begun to develop the capacity of communities by raising awareness of disability issues, supporting people to work on access, and at a grass roots level linking people with disabilities, families, mainstream services and other community groups.

The LAC program has great potential not only for doing inclusion-building work but also developing expertise in how to do it. However, it should be pointed out that responsibility for making inclusion happen cannot lie with the LAC Program alone, it is a whole of community, indeed whole of society, objective, and one that requires strategic initiatives at all these levels.

## 6.2 Outcomes of LAC

The LAC program has outlined six desired outcomes which are listed below. Much of the detail of how these outcomes have been achieved is discussed in previous sections. They are summarised here in Table 6.2.

Desired Outcome	Performance
People with disabilities and their families/carers will have greater access to relevant information about available service, supports and funding	✓ Access to information greatly improved via LACs. Survey and interviews indicate this is highly valued by people with disabilities and families.
People with disabilities and their families/carers will have a level of informal support and informal support networks sufficient to meet their needs	✓ This is gradually increasing for most people and families. Certainly people have greater access to such networks. Developing these supports and networks for all will take longer.
People with disabilities and their families/carers will have access to mainstream services which are adequate and appropriate to their needs	✓ Access has improved for many though the adequacy of mainstream supports is still unclear. LACs have high consciousness of issue.
People with disabilities and their families/carers will receive quality supports and services	✓ Certainly the early achievements show how quality supports can become integrated into people's lives. LACs have assisted people to access other funding
People with disabilities and their families/carers will have access to funding for individual and/or family support services	✓ Many people have applied for and some have received these services
People with disabilities and their families/carers will have choice in relation to where, when and how required supports, services and products are purchased and delivered.	✓ LACs have high consciousness and families/carers express respect for choice is evident

**Table 6.2 LAC Desired Outcomes**

The following section discusses in more detail the direct impacts in three areas affected by the pilot program in Queensland – first, for people with disabilities and their families; second, for the disability sector and finally, for communities. These have been identified through all the evidences and data collected. They are identified in bold.

### **6.2.1 Outcomes for people with disabilities and families**

While it is beyond the scope of this evaluation to make a direct statement that 'LAC saves the State government money' – nevertheless there is evidence that the pilot program has worked in an **early intervention, preventative approach** which is keeping families together and keeping people in their local communities. There are many stories that demonstrate how a judicious intervention by the LAC practitioner enabled an individual or a family member to avoid decision-making which would separate or segregate an individual. Despite many families living without much respite and 'making do', people are able to manage with very little, and just having

an LAC 'interested' and able to listen, as well as occasionally provide some financial or resource support, is often enough to enable a maintenance of quality of life, and the capacity to continue.

The LAC model gives people with disabilities the opportunities to determine their own needs and supports and as discussed above, the **flexible discretionary funding support model** enables this to happen with the minimum of fuss, and maximum discretion. This discretionary funding is very new to Queensland, and is not that well understood, either by the sector as a whole, or within DSQ itself. Our research shows that Regional Directors who are supportive of the model, see the potential of this form of support, and encourage LACs to manage their funding in innovative and supportive ways.

There is some exciting, albeit early, evidence of **leadership development** within the group of individuals and their families being supported by the LAC program. It was noteworthy how quickly some families took up the challenge of leadership, and how, with minimal supports from their LAC, took courage and acted in public ways to support their family members, and others. We provide examples throughout this Report. This aspect links to our earlier discussion about social capital and community capacity building (see Section 4).

### **6.2.2 Outcomes for the disability sector**

As discussed elsewhere, the Queensland disability sector has faced a legacy of under-funding and a history of unmet need. In that sense, the LAC pilot program becomes a huge step forward, perhaps taking the sector into new and exciting, but nevertheless challenging areas.

Our research has found that there are over 80% of all those supported by the pilot program for whom contact with any service has been minimal, and some who have never any services or supports. This needs to be seen in the context of the Unmet Needs Campaign. It also proves the point that many have been saying – about the existence of what we term the '**non-service user**'. This throws down the gauntlet to many non government sector agencies, as well as agencies other than DSQ – to begin to develop supports and services for this large cohort.

This LAC pilot program has given Queensland the **most coverage** in terms of disability services ever in its history. Working from a basis of the south-east corner providing most supports, with the eastern seaboard a close second, the pilot program now moves beyond the Great Dividing Range and into parts of Queensland where such services have never been available in real terms. This is a major achievement for DSQ. With the expansion of LAC during the evaluation period from the original 6 offices covering 15 local government areas to a further 11 offices covering 31 local government areas. These offices have been located as a priority in rural, remote and regional areas.

While DSQ has always had a state-wide mandate, actual delivery of supports to people in very remote areas has been problematic. The expanded LAC sites now

represent an unprecedented coverage of the State able to offer support to many more people with disabilities and families.

However, the expansion of LAC into formerly un-serviced or under-serviced areas does create **challenges**. As people become more involved, they also (in terms of leadership) – become will develop increased expectations. Support and services will be sought for from all those who are eligible. This requires DSQ to do much forward planning to meet the inevitable future demands for LAC to be expanded.

In terms of DSQ specifically, the LAC pilot program has already had an impact on ALSP, FS and other similar, programs. LACs have assisted families to make application for these funding packages and several have been successful. This is only to be expected, given the unique nature of the program, its support of people many of whom have not been previously known to DSQ, and its capacity for discretionary funding.

In some discussions, we were told that this **impact has had a positive effect**. For example, the capacity of the LAC to be more familiar with the real needs of individuals has helped other DSQ program staff with their work; in some regional areas, meetings have been arranged where all staff ‘pool’ their knowledge and resources, and work together to achieve positive outcomes for all people. However, the nature of a ‘pilot program’ always creates some anxieties among those involved in existing programs, and the LAC pilot is no exception to this. Some DSQ individuals felt that the attention given to training and staff development for LAC coordinators needed to be extended across all staff. Others felt that the capacity for flexibility and discretionary action put other program staff, with more stringent guidelines, in difficult positions or at a disadvantage. Finally, there was also general concern that the flexible financial arrangements may be pressured to become more ‘mainstream’ by Internal Audit Provisions within the State Government.

Overall, we would state categorically that the pilot LAC program has had a positive effect on DSQ, both short term and long term. We believe that the LAC program will be seen as the bench mark for best practice, and that as it moves into all regional areas, this will become more and more recognised.

***Recommendation A1.1.1:***

*That more work be done at a senior level to ensure its full integration into the overall DSQ strategic direction, to ensure that this historic opportunity is not lost.*

***Recommendation A1.1.2:***

*That regional directors continue to be encouraged to ensure a seamless transition of incorporation of the LAC program into mainstream DSQ.*

***Recommendation A1.1.3***

*That the LAC model of recruitment, training, supervision and support be considered as the model for all DSQ programs.*

### **Recommendation B1.3.1**

*That connections between LACs, people with disabilities and families and non-government sector agencies be made at the 'grass roots level' to facilitate information sharing, networking around common issues and problem solving.*

### **Recommendation B1.3.2**

*That information thus gleaned be extended to the wider community.*

## **6.2.3 Outcomes for communities**

This final section broadly outlines the early impact on communities in which the LAC pilot program has been established. We believe that the short period of the pilot program only enables a preliminary analysis at this time. It is too early to observe any large-scale changes however, there are a number of early markers of change.

In the Second Interim Report, we discussed what we called 'community building from ground zero' – in other words, starting to build community capacity for people with disabilities and their parents in environments where few services, and little supports have been previously available. Thus early signs of success should be celebrated. Expectations should not be unreasonable, given the history of many rural/remote communities. We also identified the use of a 'bottom up' approach, whereby LACs are working with people with disabilities and families in ways which support their participation in community building activities. Examples of this approach are discussed in Section 5. There is also evidence of LACs working within existing, well-established networks in communities.

However, there are some early signs of the potential of the LAC program in its preliminary impacts on communities which we now discuss here. The first of these is the **raising of awareness of disability issues**. In environments where there are not many services, those that are available are usually stretched in terms of needs of people, thus people with disabilities and their families, many of whom are as we discussed above 'non service users', have, through their connection with the LAC program, become part of an important process of community awareness and education. There are many example of this, one suffices here. The LAC negotiating with a wide range of stakeholders to ensure that a young school age child has a stress free school bus trip each day. This issue became of such concern to the family that it threatened to become the reason to split the family. Working alongside bus companies, school teachers, Education Queensland and the family, a resolution was established which proved successful in short term. In this process, the awareness raising and community education conducted impacted in a broad spectrum of the community, and while it was stressful for the family, will hopefully not be an issue for future school children with disabilities.

The second issue concerns the impact of **leadership development** through supporting local workshops and training events. This builds the capacity of the community to become 'self sustaining' in terms of leadership. It works to identify and encourage a 'self help' model, not a dependency one. All LACs have taken up

opportunities such as these for a variety of their consumers. Our research shows that such opportunities build individual and then in turn, community capacity.

Third, **support groups**. LACs have encouraged and supported the coming together of likeminded individuals around particular issues. We discussed this at length in Section 4. Such support groups, fathers, carers and individuals, enable a sustainability of community capacity building. They draw in other individuals beyond the LAC program. They have the capacity to lobby and educate. They become part of the crucial volunteer component of social capital building discussed in Section 4 above.

Fourth, relationships with other **service agencies**. In some cases, early impact of the LAC program was to arouse scepticism and concern that any DSQ funding should be directed to existing community agencies struggling to meet needs of people with disabilities and families in their area. This was reported in the agency survey (See Volume 2) though personal discussions revealed that in most cases these attitudes shifted once relationships with their LAC were developed.

The LAC program enables linkages and networks to be developed across disability agencies and groups, thus strengthening individual agencies' capacity but also building the community capacity. Such support also encourages other agencies to become established. LACs can 'value add' to existing services with that 'extra ingredient' that enables broader communication and information sharing.

Fifth, through the increased numbers of people accessing DSQ and Federal Government programs, an **economic development** can be charted. As we stated above, while it is too preliminary to be able to quantify this, we believe that increased numbers of consumers accessing services enables them to remain in their communities, thus leaving it is not longer an issue. In addition, it also encourages others to consider returning to their communities. In some cases, we interviewed people who had moved back to their communities and kinship networks. In one case, we interviewed a family who had left an LAC supported area, and moved to one where there wasn't an LAC presence. This parent spoke of the difference in her individual capacity, and in the lack of understanding in the community as a whole.

There are other examples of community capacity building we have discussed throughout this Report. LACs are working quietly and steadily in developing their communities. In some cases, this has the full support of local leadership, in others it is still viewed with some suspicion. However, we suggest that this research demonstrates the potential of the program to meet this goal as well as to develop best practice models that can be shared and used as a foundation for the future.

**Recommendation A2.1.1:**

*That DSQ form a 'whole of government' working party on social capital building and community resiliency, building on the LAC model. capacity building in Queensland.*

**Recommendation A4.1.1:**

*That DSQ take up the challenges of community capacity building and commission ongoing research that enables a more detailed analysis of the economic and social issues through:*

*(a) a scoping study of ageing carers*

*(b) a scoping study of “non-service users”*

*(c) a scoping study of non-government and private services available in rural and remote communities*

***Recommendation A3.2***

*That DSQ connects with the identified non-government agencies in the major areas discussed above and identify any barriers to services from their perspectives.*

***Recommendation B1.3.1***

*That connections between LACs, people with disabilities and families and non-government sector agencies be made at the ‘grass roots level’ to facilitate information sharing, networking around common issues and problem solving.*

***Recommendation B1.3.2***

*That information thus gleaned be extended to the wider community.*

## 6.3 Cost benefit analysis

The LAC program represents one of the lowest budget items of DSQ. In comparison with other DSQ programs, LAC offers highly cost effective support. In this section we first examine overall program costings and then analyse the ways in which discretionary funding is used and to what effect.

### 6.3.1 Overall Program costings

The evaluation research has found that the overall costs of establishing the LAC program is as follows:

<b>Cost Item</b>	<b>\$</b>
Salaries/Oncosts/Training/Travel/ & Discretionary funding	990,000
Establishment of each office	150,000
Total:	1,140,000
Average per Site:	190,000
Average per individual LAC:	126,667
<b>Average cost per individual LAC without start up costs</b>	<b>110,000</b>

Table 6. 3 Cost Items for LAC pilot program.

These figures do not include any costs associated with managing the project from Central Office, however they do include the costs associated with the community consultation process undertaken before the establishment of the pilot program.

This should be considered in the context of other DSQ funded programs announced in the 2001 Annual Report. For example, an additional \$6.3m for individualised packages for adults with a disability and their families; the expansion of the Post School Options program; up to \$4.5m. to assist Endeavour Foundation and \$2m. to provide an upgrade of existing services currently under operation. LAC is therefore a very low cost program but one which potentially offers supports to people with disabilities and families across most of the state's area, to those who have never received disability services

Working on the basis of each LAC ultimately working with 50 people, the average on-going cost per individual or family is \$2,200 per annum. This includes any discretionary funding. This figure is an average only and does not represent any actual costs for any one family or person with a disability. Nevertheless, it does provide a basis for comparison.

### 6.3.2 Disbursement of Discretionary Funding

As part of the unique financial structure of the LAC pilot program, all co-ordinators were provided with a \$10,000 discretionary sum, the rules for disbursement of which were clearly defined and agreed to. This amount was to provide support to a total of 50 active people per annum, thus calculated to be around \$200 per person per year. In the first pilot year, the target of 50 was not reached by all LACs, nevertheless the discretionary funds can be seen to help provide high quality, targeted support when needed, *without* a high level cost. In many cases, LACs did not need to use their discretionary funds by resolving issues with recourse to financial solutions, while in other cases, when they did use them, it made the difference in resolving an immediate crisis.

The overall discretionary funds expenditure for the full year of the evaluation (i.e. July 2000 to June 2001) was \$76,892.96. Some LACs reached their annual allowance, others did not, but overall per person it averaged to an expenditure of approx. \$292 per person per year<sup>6</sup>

This expenditure should be seen in the context of a State Government determined increase in financial support for people with disabilities and their families as stated as a goal in the *Queensland Government Strategic Framework for Disability (2000)*. This 'under investment in service' was identified in this document thus:

Queensland has historically under-invested in community infrastructure and social services and continues to have the lowest per capita spending on social and community services in Australia. For example, the combined State and Commonwealth funding contribution to disability support services for Queensland under the *Commonwealth State Disability Agreement* is \$900 per person with a profound or severe disability. The National figure is \$1551 per person (2000:6).

A more detailed analysis of where this support was targeted now follows<sup>7</sup>. The database kept records of expenditure by type of support, and this is analysed below in three ways: first, the total dollar amount, then a percentage of the total overall amount, and finally a estimate of cost per person, per year.

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<sup>6</sup> Calculated at 263 clients.

<sup>7</sup> Accommodation Support; Domestic Support; Education Support; Equipment and other specialised; Family/Caregiver Support;; Personal Support; Professional Support; Recreation Support; Respite Support, not categorized and finally, Other Support .

Type of Support	Dollars Spent	Percentage of total	Amount per person
Accom.	\$3,966.50	5%	\$15 pp
Dom.	\$7,327.70	9.5%	\$28 pp
Educ.	\$1,324.06	2%	\$5 pp
Equip.	\$31,816.44	41%	\$121 pp
Family	\$6,878.62	8.9%	\$26 pp
Personal	\$7,324.44	9.5%	\$28pp
Profess.	\$650	0.8%	\$2.50pp
Recreation	\$3,591.80	4.6%	\$13.60pp
Respite	\$10,696.00	14%	\$41pp
Not Catg.	\$3,003.80	4%	\$11pp
Other	\$312.70	.4%	\$1 pp
<b>Totals</b>	<b>\$76,892.96</b>	<b>100%</b>	<b>\$292</b>

**Table 6.4 Analysis of Discretionary Funds allocated for twelve months during 2000 – 2001.**

It needs to be stated that these funds are extraordinarily cost effective when analysed, particularly as they are annual figures.

As can be seen from the above table – two types of support are highly needed – the first is equipment (average of \$121 per person), and the second is respite (average of \$41 per person). These cost/benefits are supported by the findings of this research and other research into needs of people with disabilities in Australia and internationally. Our interviews with people and their families as well as with LACs, suggest that these two items alone often make the difference between ‘carrying on’ or ‘crisis’. The sort of equipment provided or supported in part includes wheelchairs or scooters, fax machines, beds and other aids.

The issue of lack of respite services in rural and remote Queensland has been well addressed elsewhere, including during the Unmet Needs Campaign. The research found that LACs became very innovative in their capacity to provide respite support. It also found that, for many families interviewed, such respite was the first they had received. In some cases, it was the LAC who first introduced them to the concept of respite. In other words, for a large number of the families being supported by the LAC pilot program, their long-term intensive care was being provided without breaks.

Two important issues emerged from the study. First, there is a need for some capacity to provide very small amounts of funding on a recurrent basis. Some families expressed a concern that the dollars they had been able to access for supports such as childcare were only “one-off” and therefore fragile in the overall context of ongoing supports. LACs also raise this issue as access to other alternative supports in remote areas is often impossible. Small amounts of recurrent funding would alleviate this situation at least in the medium term as generic services and community capacity are developed.

Second, there are concerns expressed about the accountability of LACs in spending discretionary funds. We found no evidence of improper use of these funds; rather, most LACs were extremely frugal and cautious in their use. Nevertheless, some personnel reported a perception that accountability needed to be reviewed. The

flexibility afforded by these funds translates into real outcomes for families and people with disabilities and should be safeguarded.

**Recommendation A1.2.4:**

*That any concerns regarding the financial flexibility of the LAC program be addressed immediately with the relevant State authorities.*

**Recommendation A1.2.5:**

*That the discretionary monies remain available to the LAC program but with some portion available as recurrent funding.*

**Recommendation A1.2.6:**

*That LACs be issued with a corporate credit card for discretionary monies to ensure accountability with flexibility and responsiveness to peoples needs*

**Recommendation A1.2.7:**

*That a further, more depthful analysis of the types of supports being provided through these discretionary funds be undertaken in twelve months time.*



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# 7. Building the Capacity of Individuals, Families & Communities into the future

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This Report has attempted to draw together research conducted over an 18-month period, in a variety of settings, with a large group of individuals. In writing it, we are well aware of the many stories, situations and issues that people raised with us, that we have not been able to deal with in the depth that they deserve.

We summarise the findings here by drawing again on the purpose and goals of the LAC program. As established in Western Australia in 1989, it was designed to 'do what it takes' to enable people with disabilities and their families to continue to live within their communities, whether or not they are geographically isolated from major service centres. As such, this Queensland LAC pilot program is, unequivocally, **meeting its aims.**

The research project enabled us to work alongside the LACs, to meet a variety of stakeholders and discuss the program during its inception. Most individuals could immediately grasp its purpose, and many told us that it was 'about time' that such a program was made available to them.

As we have discussed here, many individuals and family members continue to 'do it tough' in the face of lack of supports, geographic distance, withdrawal of services, or little access to them, no public transport and so on. We found that many LACs were meeting people who had not accessed any formal supports – the so-called 'non service user' – and these particularly were often in crisis, sometimes without even recognising it, and the support offered through the pilot program made a difference to their quality of life, and their long term capacity to cope.

The concept of resiliency can be understood as 'being able to take life's knocks'. How do we continue to bounce back after adversity? Our research over the past six years in Queensland takes this one step further – how does resiliency play it self out within communities? This research builds on previous findings – and has found that community and individual resiliency becomes part of the practice within which human service professionals are engaged. In the LAC pilot program, this has become an overt goal of the program, and as such, it legitimises and strengthens what most practitioners do already – **build community resiliency and build individual resiliency.** The two work alongside each other, dovetail within each other, and enable a sense of future possibilities.

There is strong evidence within this Report that shows that families are caring for their family members, and that those individuals who choose to live alone do so capably and well. The kind of supports required by these people are not large in terms of infrastructure, or in commitment. They come from the quiet, regular contact that LACs provide, the interest taken in people, the time needed and taken to establish trust and reciprocity and the capacity to enable flexible use of resources to meet needs.

This may appear to be a common sense approach to human service delivery. It is. It is not predicated on boundaries and detailed policies, but rather on the desire to enable and empower. These goals are in complete synergy with the vision of DSQ as identified in the current Strategic Plan:

- Strengthening individuals, families and communities
- Improving access to services
- Developing and reforming services
- Improving quality of services
- Increasing service provision
- Working collaboratively
- Increasing safeguards and advocacy

Perhaps the biggest challenge for DSQ's LAC program is sustaining and safeguarding its quality in a climate of expansion and organisational change. There is much to be learned from the LAC program as it unfolds and develops. The disability sector worldwide would benefit from further research and practice development around issues such as the integration of formal and informal supports, how to support practitioners so they remain for the long haul and stay aligned with people with disabilities and their families and how to make good policies "real" in the lived experiences of marginalised people. We believe the program also has something to offer other sectors beyond disability such as those grappling with providing good services to people in remote areas and how to build stronger and resourceful communities in climates of economic constraint. DSQ is to be congratulated for its efforts thus far.



**Murgon Office**

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