Lessons from the Labyrinth

Views of Residential Care Officers on
Barriers to Comprehensive Health Care for Adults
with an Intellectual Disability

Associate Professor Nicholas Lennox FRACGP
&
Ms Niki Edwards BA BSocWk MPA

THE UNIVERSITY
OF QUEENSLAND

D·D·U
DEVELOPMENTAL
DISABILITY UNIT

Explanatory Note: The Cover

Choice of a cover for a report dealing with disability issues is fraught with difficulty as language and imagery *DOES* matter. The labyrinth was chosen to honor the client commitment that is so frequently demonstrated by Residential Care Officers employed by DSQ who support adults with an intellectual disability.

This labyrinth utilises a pattern known as the Cretan labyrinth, referring to its ancient and mythological association with the Island of Crete. It is also called the 7-circuit labyrinth, referring to the number of concentric paths, although the pattern exists in 11-circuit and even 15- and 19-circuit versions. According to the book *Labyrinths: Ancient Myths and Modern Uses* by Sig Lonegren, the Cretan pattern depicts the orbit of the planet Mercury as seen from plant Earth.

The labyrinth on the cover symbolically represents the journey of the CHAP project, its passage through time and experience. The many turns of the labyrinth reflect the journey of life, that involves change and transition, rites of passage, cycles of nature. Different from a maze that has dead ends and false passages, the labyrinth has a single path that leads unerringly to the centre. *Of course at the centre are the needs of the clients whom we support and assist*.

Hopefully the labyrinth demonstrates that no time or effort has been wasted during the study; that by working together and allowing the research to be directed by those who really know (the RCOs at the coalface), every step, however circuitous, takes us closer to our goal, improving the health care status of adults with an intellectual disability.

2001

Acknowledgements

Contents

Foreword and Executive Summary

The report, "Lessons from the Labyrinth" provides detailed information regarding the outcomes of implementing a Comprehensive Health Assessment Programme (CHAP) within participating Alternate Living Service houses (ALS) coordinated by Disability Services Queensland (DSQ) in metropolitan Brisbane and its outlying areas. As requested by Disability Services Queensland, barriers to comprehensive health care are identified and considered in some detail. The report should also be considered as a general resource on the health and well-being of adults with an intellectual disability. It is anticipated that the report will provide accessible and relevant information to a range of Disability Services Queensland staff, in particular the Residential Care Officers. The report will be of general interest to medical, health, human and disability services professionals.

The general thrust of the report is that whilst there is much General Practitioners and other health care providers could do and should do to improve their services to adults with an intellectual disability, the same can be held for Disability Services Queensland direct care workers and their managerial staff. The report highlights the importance of attitudes, skills and confidence of direct care workers, who take on the very critical role of health advocates in their efforts to obtain comprehensive health assessment for their clients. These RCOs are central and pivotal individuals in the lives of people with an intellectual disability. RCOs are largely invisible and hidden behind the complex layers of disability services, hence the name of the report, "Lessons from the Labyrinth." Direct care work is as complex and multi-factorial, as is health care. The interface between the disability system and health care system resembles a maze. RCOs have much to contribute and multiple needs to be met if they are to successfully overcome the barriers that impact client health care status. The "care" in the carer may be just as important as the health screening tool or the interaction of the Residential Care Officers with General Practitioners.

The report identifies and explores the many barriers experienced by adults with an intellectual disability as they attempt to access and utilize General Practitioners, primary health care and the wider health care system in Queensland. The implementation of a Comprehensive Health Care Assessment Programme (CHAP), a systemized health screening approach to health care for this vulnerable group highlights the problems that exist when using primary health care services.

The report identifies barriers that have been conceptualized into four categories within the Literature overview:

Part A: Organisational and Systemic Barriers;
Part B: Client Barriers;
Part C: Service Delivery Barriers including General Practitioner Barriers; and
Part D: Direct Care Worker Barriers.

The 21 recommendations contained within the report aim to address the diversity of barriers that impact health care status of adults with an intellectual disability living in community settings. These recommendations relate specifically to the health care needs of adults with an intellectual disability but the complexity of the problems warrant the inclusion of wider and related issues. The recommendations have been presented in summary form within this foreword but can be considered in full detail at the end of the report.

The recommendations should be considered the link or conduit between all chapters contained within the report in that they draw broadly upon the literature overview including current trends in health and human services; and both qualitative and quantitative data collection made possible through the study. Whilst the 2 key recommendations are listed initially, following recommendations are *not* presented in a hierarchical or prioritized order. Each recommendation should be considered important.

The Developmental Disability Unit anticipates and looks forward to ongoing discussion and liaison with Disability Services Queensland (DSQ) in relation to the contents of and recommendations contained with the report. Genuine thanks are extended to Residential Care Officers, Unit Managers and Area Managers who participated in the Comprehensive Health Assessment Programme. Thanks are also extended to senior managers who have supported the research and continue to support the activities of the Developmental Disability Unit.

Summary of Recommendations

Recommendation 1

Disability Services Queensland (DSQ) should implement the CHAP tool across Queensland ALS houses and make the tool available to community clients supported by non-government agencies.

Recommendation 2

Disability Services Queensland (DSQ) needs to allocate funds so that a Health Care Coordinator can be employed by every Area Office. This position would be responsible for the augmentation of health care services and facilitation of liaison with primary health care and specialist services. The Health Care Coordinator would be responsible for the provision of expertise and coordination of a range of support opportunities for staff, specifically to enhance their knowledge, skills and expertise in meeting the health care needs of clients with an intellectual disability.

Recommendation 3

Disability Services Queensland (DSQ) must allocate dedicated funds and resources to workable strategies and solutions that improve the health status of people with an intellectual disability.

Recommendation 4

Disability Services Queensland (DSQ) as lead disability agency needs to ensure that all DSQ direct care staff have access to a range of health related training opportunities that are provided by experts in collaboration with in-house professionals.

Recommendation 5

Disability Services Queensland (DSQ) must support direct care staff to meet both advocacy and duty of care obligations in relation to the health care needs of adults with an intellectual disability. DSQ should adopt an updated Health and Well-being policy and practices to ensure clients access appropriate health care services within community settings.

Recommendation 6

Disability Services Queensland (DSQ) needs to enter into a funded partnership with the Developmental Disability Unit to develop education and training curriculum and resources, implement and evaluate a series of one day training workshops on health and well-being for direct care workers and other disability professionals.

Recommendation 7

In addition to first aid training, all Residential Care Officers should attend a compulsory health education and training workshop "Improving the Health Status of People with an Intellectual Disability". Other Disability Services Queensland (DSQ) staff should be encouraged to attend.

Recommendation 8

Disability Services Queensland (DSQ) should implement a range of inter-professional or multi-professional health education and training initiatives

Recommendation 9

Disability Services Queensland (DSQ) needs to enter into a funded partnership with the Queensland Division of General Practice and the Developmental Disability Unit to develop education and training curriculum and resources, implement and evaluate one-day training workshops for General Practitioners.

Recommendation 10

Disability Services Queensland (DSQ) should fund the Developmental Disability Unit to develop and trial a General Practitioner Protocol (GPP)

Recommendation 11

Disability Services Queensland (DSQ) needs to establish a Health Information Exchange Strategy.

Recommendation 12

Health information exchange could be achieved/enhanced by formal recognition and appropriate resourcing of the Health and Well-Being Group.

Recommendation 13

Disability Services Queensland (DSQ) needs to actively advocate in University settings for increased opportunities in core curriculum for training and education on intellectual disability across the lifespan, e.g. birth to death.

Recommendation 14

Disability Services Queensland (DSQ) should approach Queensland Health and Education Queensland in relation to the establishment and joint University Curriculum, Bursaries and Scholarships in the Health Care of Adults with an Intellectual Disability.

Recommendation 15

Consistent approaches to a definition of intellectual disability and associated terminology should be incorporated into the policies, programmes and all documentation of Disability Services Queensland (DSQ), Queensland Health and other Queensland government agencies.

Recommendation 16

Disability Services Queensland (DSQ) needs to take responsibility for reviewing and modifying DSQ eligibility policy. DSQ, as the lead agency in disability must lobby and collaborate with Queensland Health to similarly review and modify its eligibility criteria for services. Further, both agencies need to ensure their eligibility criteria is flexible enough to adopt a cross-boundary and multi-agency approach that is based upon identification and collaborative response to the individual needs of adults with an intellectual disability.

Recommendation 17

Disability Services Queensland (DSQ) policy and practice needs to reflect multi-system interaction with emphasis upon partnership and collaboration between disability and health services within the community. Joint initiatives should be encouraged and funded.

Recommendation 18

Disability Services Queensland (DSQ) should acknowledge in disability and health policy and practice, the implications of social capital.

Recommendation 19

Disability Services Queensland (DSQ) should involve Queensland Health in the development of Health Protocols that could be utilized by any agency (government or non-government).

Recommendation 20

Disability Services Queensland (DSQ) should establish a Health and Disability Partnership comprising senior representatives from Disability Services Queensland (DSQ) and Queensland Health. Consideration should be given to other government agency representation and involvement but the focus should clearly remain upon health of people with an intellectual disability.

Recommendation 21

The Health and Disability Partnership should develop and operate as a forum which an effectively mediate conflicts and disagreements, e.g. Disability Services Queensland (DSQ) and Queensland Health to ensure the needs of complex clients who do not "fit" the system or eligibility criteria do not fall through the gaps, i.e. fail to receive a service, receive compromised services or receive inappropriate services.

Lessons from the Labyrinth

Chapter One

Understanding CHAP Methodology

1.   Background

There exists limited information regarding the health characteristics and health behaviour of people with an intellectual disability in community living arrangements (Rimmer & Whitfield, 1995). This report aims to qualitatively contribute to improving the health status of people with an intellectual disability by identifying barriers that impede the comprehensive health assessment of a group of adults with an intellectual disability living in the community in metropolitan South East Queensland. The report adopts a biopsychosocial approach to understanding barriers to comprehensive health care for adults with an intellectual disability.

Stakeholders interested in improving health care outcomes for people with an intellectual disability must acknowledge that health is multi-determined by a range of inter-related factors. Health research within the intellectual disability field tends to focus upon the prevalence of and causal factors relating to morbidity and mortality (Fujiuma et al, 1997). Common practice has seen the health needs of people with an intellectual disability discussed at the illness end of the health continuum. Attention has tended to focus upon the specialized medical needs, disease conditions, mortality and problems associated with behaviour management (Fujiuama et al, 1997).

Similarly, research or discussion about health status or health outcomes of people with an intellectual disability has tended to imply passivity with the patient/client/consumer silently receiving something or having something "done" to them. It has not been common practice to evaluate health care status or outcomes from the perspective of the direct care worker, or the person with the intellectual disability for that matter.

Direct care workers play a critical role in community-based service provision to people with an intellectual disability (Rose, 1999). Unfortunately the impact of and contributions direct care staff make to the health care status of this vulnerable population, has not been the subject of extensive research. Human and disability service providers lie outside of the health delivery system and yet because of their support roles, must play an important role in health and well-being. The delivery of primary health care services to this vulnerable population challenges not only health care service providers but also human services and disability service providers.

1.2   Introducing Health and Well-Being

Health and well-being is difficult to define because it combines subjective and objective measurement. Modern discussions of health and well-being emphasize the social context and economic determinants, rather than the prevalence of disease. Although good health is considered by most people to be desirable, maintenance often proves elusive. Four categories of health determinants can be identified (Tarlov, 1996):
  • Genes and biology;
  • Medical care;
  • Health care behaviour, e.g. smoking or obesity; and
  • Social characteristics.

While there exists substantial variation in health and well-being status between populations, there is general consensus that health will also be influenced by
  • Economic security;
  • Access to basic supports such as food, housing, and a range of human services;
  • Nurturing relationships both within and outside families; and
  • Supports and services that are available for children, adolescents and adults
    who have special needs.

Numerous barriers that exist in modern society influence the access and uptake of health care services. These barriers are multi-dimensional and complex in nature. Barriers that impact access to health services shape and influence not only the utilization of health services, but also more importantly health status and outcomes. Barriers are products of, perhaps side effects of the health care context.

The health care system involves a maze of services provided by multiple agencies located in different communities. Eligibility criteria changes between agencies, inter-agency communication is problematic and service delivery is rarely coordinated. The involvement of three tiers of government – commonwealth, state and local adds another dimension of complexity as sharing of responsibility is inconsistent and incoherent (Duckett, 1999). Despite ongoing reforms aimed at improvement, complexity and fragmentation is characteristic of health services in Australia. Rising service costs places pressure upon existing infrastructure and there are concerns that health services will be unable to meet demand (Hancock, 1999).

1.3   The Scope of the Problem

In Australia during 1996-97, capital and recurrent health expenditure comprised $43.2 billion and the amount continues to increase annually (AIHW, 1998). Despite this enormous outlay that comprises more than 8.4 per cent of gross domestic product, not all Australians enjoy reasonable levels of health and well-being.

Here at the beginning of the 21st century, numerous barriers impede and restrict the access of people with an intellectual disability to appropriate health care. Despite limited research evidence, there is growing recognition that this group of people may have greater need when compared to the general population to access primary health care services because of a greater variety of health care problems compared with the general population (Janicki et al, 1999). Central to all problems experienced are communication barriers. Health professionals battle to compensate for this significant impediment to health status.

1.4   The Legacy of Institutions

Adults with an intellectual disability share the same needs and characteristics with other people in modern society. Ideally they enjoy the benefits of relationships with their family and friends and successfully interact with their local communities. Institutionalization of this group of people meant that their health care needs were treated outside of the mainstream health care system. The associated segregation meant that primary health care service providers are not familiar or skilled to deal with the health needs of this population.

Community care policy and current disability legislation promotes the central importance of equality, participation, choice and empowerment for people with disabilities. Health professionals play a vital role in making the key elements of this legislation operational (Keane, 1996). Unfortunately evidence suggests that the gap between the client involvement "ideal" and what "usually" happens is still considerable (Hardy, 1999). The reality of life within the community means that people with an intellectual disability often rely upon careers to live full and meaningful lives. Because people with an intellectual disability experience an increased risk and rate of medical problems, it is often the carer who plays out an important health advocacy role in ensuring the health status of a person with an intellectual disability is optimal. Legislation and policy can influence change, but the translation involves the action of an individual (Keane, 1996). The reliance of people with an intellectual disability upon careers makes this relationship critical to health and well-being.

1.5   Increased Need for Preventive Health Care

Research conducted within Australia demonstrates that people with an intellectual disability experience an increased rate of: (Beange et al, 1999)
- Visual impairment and eye pathology;
- Hearing and communication disorders;
- Cardiovascular disease;
- Spinal abnormalities;
- Skin conditions;
- Weight problems including obesity and under-nutrition;
- Nutrition and digestive disorders;
- Hypertension;
- Epilepsy;
- Dental pathology; and
- Mental disorders.

Primary health care within Australia adopts an opportunistic approach. Health professionals, typically the general practitioner is sought for advice when an individual identifies signs or symptoms or ill-health or disease. People with an intellectual disability experience difficulty with opportunistic health care and often fail to seek or obtain appropriate health care. Many may restrict their health service utilization to acute or emergency care. Health care access can be fragmented and episodic. This group does not take advantage of traditional health promotion (Langan et al, 1993). Preventative care has been virtually ignored despite the reality that people with an intellectual disability have a greater need than most for comprehensive and coordinated care (Lennox et al, 2000).

General Practitioners are the gatekeepers to primary health care services but most are not trained to manage the myriad of health problems experienced by people with an intellectual disability (Stein, 2000). Despite these major shortcomings, General Practitioners provide the portal of opportunity for comprehensive health care to people with an intellectual disability (Lennox et al, 2000). Perhaps it comes as little surprise that medical conditions and health problems experienced by people with an intellectual disability are often unrecognized, misdiagnosed or poorly managed by General Practitioners (Beange, 1996).

Associate Professor Nicholas Lennox FRACGP, Director of the Developmental Disability Unit, School of Population Health, The University of Queensland, continues to research the health care of adults with an intellectual disability. Dr Lennox hypothesizes that comprehensive health assessment, i.e. health checks using a series of prompts for both the carer and General Practitioner, may improve the health outcomes of adults with an intellectual disability.

1.6 Aims of This Report

This report fulfils two related functions. There is detailed information provided on the outcomes of implementing a comprehensive health assessment programme (CHAP) within Alternate Living Service houses (ALS) supported by Disability Services Queensland (DSQ) in metropolitan Brisbane and its outlying areas. As requested by (DSQ), barriers to comprehensive health care are identified and discussed in some detail. Secondly, the report itself can be considered as a general resource on the health and well-being of adults with an intellectual disability. It is anticipated that the report will provide accessible and relevant information to a range of Disability Services Queensland staff, in particular the Residential Care Officers.

The general thrust of the report is that whilst there is much General Practitioners and other primary health care providers could do and should do to improve their services to adults with an intellectual disability, the same can be held for Disability Services Queensland direct care workers and their managerial staff. The report aims to highlight the fact that the key is NOT the CHAP tool that was implemented in the study, but the skills, expertise and knowledge of health care advocates, e.g. Residential Care Officers.

Recommendations for change and improvement are listed at the conclusion of the report. The conclusion clearly states that the researchers do not believe Residential Care Officers have the necessary tool kits to fulfill the health care needs of people with intellectual disability, particularly those with complex medical problems and or health care needs. There are a number of recommendations, but of core and central importance is the **recommendation that Disability Services Queensland must employ as soon as possible, and minimally, one Health Care Coordinator per region**. Implementation of this recommendation would assist in demonstrating that DSQ is sincere in its intentions to meet both duty of care and duty to protect obligations owed to both clients and staff.

Ms Niki Edwards, Developmental Disability Unit Lecturer and Ms Dell Hele, Resource Assistant assisted Dr Nicholas Lennox, the Chief Investigator of the research project. Other staff from the Developmental Disability Unit have also contributed at regular intervals through discussion of findings and consideration of drafts. The body of the research was completed between 1999-2000. Final analysis of the report was completed in late 2000, with the report completed in early 2001. Importantly, the research attempts to objectively reflect the views and opinions of the direct care workers, the Residential Care Officers who are employed to support and assist clients of Disability Services Queensland living in residential accommodation.

The research project, Implementation of a "Comprehensive Health Assessment Programme (CHAP)" was commissioned and funded by the then Department of Families, Youth and Community Care — Disability Services. This government agency is now independent of this department and is known as Disability Services Queensland. Requested outcomes included identification of barriers to implementation within the context of Disability Services Queensland and written recommendations to Disability Services Queensland regarding such.

Disability Services Queensland specifically requested that the Developmental Disability Unit consider:
- The CHAP as a catalyst for a change in health care status of Disability Services Queensland (DSQ) clients;
- The impact of the CHAP upon the Residential Care Officers (and other staff), client(s) and General Practitioner;
- External and internal factors affecting outcomes, particularly positive influences and secondly barriers and impediments to successful implementation.

Options and recommendations regarding barriers and further implementation of a comprehensive health assessment programme across all Area Office within the regions of Disability Services Queensland are contained in Chapter 5 of this report.

1.7   Future Directions

The report is important because it provides an overview of barriers to primary health care services for people with an intellectual disability living in South East Queensland. Information contained in this report can contribute to raising awareness regarding the need for ongoing improvements in improving the health care status of adults with an intellectual disability. The contents of the report should also assist with improving the design and implementation of the comprehensive health care programme. Additionally, general information contained within the report may benefit the wider community and in particular health, human and disability service providers.

However, because there are numerous access barriers, different solutions may need to be developed for different problems. Solutions will be multi-faceted and require injections of not only capital and resources, but personal energy, creativity and commitment. Problems also need to be addressed at many levels – at the coalface, within middle and senior management and at the very top where political and financial decisions are made. Attitudes and values within the wider community constantly need to be challenged and focused upon the rights of people with an intellectual disability to enjoy the benefits of modern society, an important component being health and well-being.

The Developmental Disability Unit thanks Disability Services Queensland for the opportunity to highlight the many unmet health care needs of adults with an intellectual disability. This report provides a vehicle for education, awareness raising and ultimately improved service responses. Government and non-government agencies across Queensland are encouraged to work together, to acknowledge the vulnerability of this group of Australians and to promote their rights to health and well-being.

The Developmental Disability Unit encourages Disability Services Queensland (DSQ) to make the comprehensive health assessment programme, the CHAP tool, available to all Disability Services Queensland (DSQ) clients, regardless of the outcome of this study. Outcomes of this research should also be made available to the wider Queensland community.

2.   The Comprehensive Health Assessment Programme (CHAP)

2.1   Project Aims

- To assess the effectiveness of the CHAP tool in assisting staff and General Practitioners to improve the health and well-being of clients with an intellectual disability living in Disability Services Queensland (DSQ) residential services;
- The identification of factors that impede or promote positive health outcomes for people with an intellectual disability living in Disability Services Queensland (DSQ) residential accommodation;
- The identification of factors which impact the implementation of the CHAP tool in Disability Services Queensland (DSQ) residential accommodation;
- Determination of the impact of the CHAP tool on the health and well being of people with an intellectual disability living in Disability Services Queensland (DSQ) residential services.

2.2   Study Participants

The aims and objectives of the study as originally negotiated between the Developmental Disability Unit and the then Department of Families, Youth and Community Care, involved both Brisbane North and Brisbane South regions of the Disability Services Programme. Clients with an intellectual disability living in residential services, Residential Care Officers, Unit Managers and Area Managers from these regions were accordingly invited to participate.

However, the original project brief was designed and commenced prior to a Departmental restructure. This restructure resulted in the six regions of Disability Services Queensland (DSQ) becoming fully operational during 2000. As a result the Brisbane North and Brisbane South regions no longer exist and Area Offices that participated within the study now belong to newly named regions, e.g. Central region. Accordingly, this report therefore only refers to area office staff for convenience and does not identify the regional status of those area offices or staff within. This approach further assists with both staff and client confidentiality.

Staff who participated in the CHAP project were employed at the time of the study, in the following Disability Services Queensland (DSQ) Area Offices:
- Caboolture;
- Sunshine Coast;
- Wooloowin North;
- Wooloowin Central;
- Mt Gravatt; and
- Gold Coast.

These Area Offices remain operational in 2001. However, it is acknowledged that there has been considerable staff and client movement within these area offices both during and after the completion of the study.

2.2.1 Disability Services Queensland (DSQ) Staff

Area Managers, Unit Managers and Residential Care Officers were invited by the Developmental Disability Unit in a letter to participate in the study. These letters of invitation were attached to the pay slips of these staff in early 1999. The letter of invitation advised staff that the Developmental Disability Unit was undertaking a Comprehensive Health Assessment Programme (CHAP). They were invited participate in the programme.

Residential Care Officer participation in the project involved:
- Completion of a questionnaire which would provide the Developmental Disability Unit researchers with demographic and descriptive information about the Residential Care Officer, their duties and responsibilities, the client(s) they supported and their views towards the General Practitioner that the client utilized;
- Completion of a booklet or "tool" that would gather a detailed health and medical history on behalf of the client that the Residential Care Officers were client coordinator for;
- The Residential Care Officer taking the client to the client's usual General Practitioner for a full medical examination, e.g. a comprehensive health assessment.

Managerial participation in the project involved completion of a similar questionnaire to the one completed by Residential Care Officers. Other staff working with those clients, who did not have a client coordinator role, were encouraged to provide feedback during the project through those staff participating or by contacting the Development Disability Unit.

The CHAP study targeted the Residential Care Officer as the primary participants in the programme because Residential Care Officers are typically the key substitute decision-maker for clients. However, it was acknowledged that Unit Managers and Area Managers play very important roles in assisting Residential Care Officers to carry out their duties, particularly when health care decisions needed to be made. For this reason, these Managers were also recruited into the study. Their views and beliefs about health and well-being were surveyed through a questionnaire.

2.2.2 General Practitioners

The Developmental Disability Unit was involved in negotiations with the Health Insurance Commission (HIC) regarding financial remuneration for General Practitioners undertaking the comprehensive health assessment required for the CHAP project. The HIC formally approved that the "long" consultation required for the CHAP project was covered under the Medicare system. The role of the General Practitioner as explained to the HIC involved:

- Complete a comprehensive health assessment of the adult with an intellectual disability (Disability Services Queensland (DSQ) client), guided by and recording outcomes in the CHAP booklet provided by the Developmental Disability Unit researchers;
- Permit the researchers access to the medical records of the person with an intellectual disability over a 12 month period (originally it had been planned that the Developmental Disability Unit would access the notes/records on one occasion at the end of the project); and
- Participate in one 5 minute telephone call from the research team at the end of the General Practitioner's involvement in the project, to qualitatively assess opinions of the programme.

Unfortunately time and resource constraints made it impossible for the researchers to make contact with General Practitioners at the end of the CHAP study. Dr Lennox is currently involved in a larger study implementing CHAP across a Queensland wide non-government agency supporting adults with an intellectual disability. This study is currently undertaking interviews with General Practitioners. Dr Lennox will ensure that Disability Services Queensland (DSQ) obtains relevant information that will be publicly available regarding the outcomes of this larger CHAP study, particularly interview outcomes with General Practitioners who have undertaken comprehensive health assessments of adults with an intellectual disability.

2.3　Timeframe

The project was initially funded for a two year period. The timeframe as detailed below is sequential but was extended by major difficulties encountered by the Developmental Disability Unit researchers in:

- Obtaining consents from Disability Services Queensland (DSQ) staff, Statutory Health Attorneys and the Adult Guardian (on behalf of clients who were unable to provide consent to participate in the project) and General Practitioners;
- The timely return of completed questionnaires from Residential Care Officers and Managers; and
- The timely return of completed CHAP booklets from Residential Care Officers.

2.3.1 Stage One (Pre-Intervention)

- Ethics proposal developed (including development of information sheets, consent forms and associated paperwork) submitted and approved.
- General information dissemination to families/clients; staff and professional staff; Managers and senior management.
- Establishment of the Project Reference Group – including membership from Health and Well-Being Group within Disability Services Queensland.
- Consent forms for clients, direct care staff and Managers distributed and returned. Contact with the Statutory Health Attorneys and Adult Guardian as necessary.
- Questionnaire survey designed, trialed and implemented.
- Database design and baseline data collection commencement

2.3.2 Stage Two (Tool Dissemination)

- Focused Information Forums at local level for management, professional and direct care staff in Area Offices.
- Assistance offered to individual staff via face to face contact and telephone — after hours message management to address challenges of shift work.
- Distribution of CHAP tool to Residential Care Officer participants via mail direct to houses where employed.

2.3.3 Stage Three (Follow up)

- CHAP tool planned to be completed by end 1999 – CHAP tool (Carer information and General Practitioner information) returned to the Developmental Disability Unit.
- Reminder phone calls at three months provided to Residential Care Officers through mail initially and then phone calls to client's house where employed, as appropriate.
- Contact with Unit Managers or Area Managers through mail and telephone as necessary to encourage CHAP tool return to Developmental Disability Unit within set period.
- Focus groups and informal face to face contact with Disability Services Queensland (DSQ) staff.

2.3.4 Stage Four (Data analysis)

- Data analysis and interpretation incorporating baseline questionnaire survey, data from CHAP tool and focus groups.
- Literature overview and analysis to identify, analyze and consider barriers to health care of people with an intellectual disability.
- Recommendations and conclusions contained in final report.
- Suggestions and recommendations for further research.

2.4 Outcomes

The Developmental Disability Unit proposed that the CHAP tool was an effective method to assist the improvement of health care outcomes for people with an intellectual disability living in residential accommodation coordinated by Disability Services Queensland (DSQ). DDU research suggested that the study outcomes would be suggestive of:

- Improved detection of health care problems by the General Practitioner and careers;
- Increased contact with the General Practitioner;
- Referrals to and increased contact with other medical practitioners/specialists;
- Referrals to and increased contact with other professionals including allied health professionals;
- Improved relationship between the client and the General Practitioner;
- Recognition of the need for an improved relationship between the direct care workers and General Practitioner — possibly the intervention would offer an framework for improved relationship, e.g. clearer communication;
- Enhanced knowledge of direct care workers and their Managers about health care problems for people with an intellectual disability;
- Increased general health care knowledge of direct care workers and their Managers;
- Increased knowledge of General Practitioner about barriers to health care for people with an intellectual disability;
- Increased attention and focus upon health care policy for Disability Services Queensland (DSQ) clients;
- Improved recording of medical information;
- Improved quality of life for clients.

The study is considered to contribute to better understanding of the efficacy of the CHAP tool.

2.5 Implementation

The CHAP project examined the relationship between the person with an intellectual disability (adult client of Disability Services Queensland (DSQ)), their careers (the Residential Care Officer given client coordinator status by Disability Services Queensland (DSQ)) and the client's General Practitioner. Implementation of this project involved:

2.5.1 Education of participants in the CHAP

Information sessions about the health care needs of people with an intellectual disability and the aims of the CHAP project were provided by Dr Lennox and Developmental Disability Unit research staff to potential participants, i.e. Disability Services Queensland (DSQ) employees, specifically Residential Care Officers but also including Area Managers and Unit Managers. The majority of the information and education sessions were provided in Disability Services Queensland (DSQ) premises. At the request of Disability Services Queensland (DSQ) staff, some individual outreaches were made to groups of Residential Care Officers and their Managers in client residences. These information and education sessions were carefully negotiated to ensure the timing suited staff, clients and others.

Following the receipt of consents, Brisbane North staff participating in the project attended an additional health education session. This education session involved a one hour presentation by the Chief Investigator, Associate Professor Nick Lennox on "Health Care Problems Experienced by People with an Intellectual Disability" and a concurrent thirty minute session on "Getting the Most Out of Your Health Care Provider." This education session aimed to focus the interest of the participants on the health care of clients that they supported. The forums also offered the opportunity for staff to raise and answer questions about the CHAP project they had consented to participate in.

Research funds were used to financially compensate Area Offices that released Disability Services Queensland (DSQ) staff to initially attend the information sessions, and then the education sessions. The Developmental Disability Unit reimbursed each Area Office directly.

Issues that featured frequently in questions at information forums, education sessions and telephone calls to the Developmental Disability Unit included:

- Perception that clients were being used in an experiment, i.e. was this appropriate?
- The purpose of research – was this an appropriate exercise in light of normalization and social role valorization? Some staff appeared to hold the belief that a project that involved doctors was ideologically unsound, e.g. that normalization and social role valorization had rejected the medical model.
- Concerns that involvement was associated with support for the medicalisation of disability — would research lead to doctors taking inappropriate control of client's lives again?
- Need for reinforcement that staff information and responses would be treated confidentially — some questions related to rights of access to information collected "confidentially" by the Developmental Disability Unit researchers by Managers or other senior Disability Services Queensland (DSQ) officers;
- Confidentiality of client information – did the Developmental Disability Unit researchers have the ethical right to have access to this information?
- Consent and the capacity of clients to participate in the process – some staff appeared reassured by Developmental Disability Unit offer to visit individually with clients and to tailor an education package to meet the needs of clients to assist them in understanding the project and its aims;
- Contact with General Practitioners – what would happen if they refused to participate in process and what would this mean for the client?
- Many issues regarding the roles and responsibilities of the Statutory Health Attorney — this new role was a large source of tension for Residential Care Officers as the legislation governing this role had only recently been implemented – concerns were often not relevant to the CHAP project but many Residential Care Officers were worried that family members would say no inappropriately or alternatively consent without thought for repercussions for client;
- Rights of clients to refuse to participate, e.g. refusal to cooperate with medical assessment by the General Practitioner, e.g. if the client refused to undergo a blood test would participation in the project automatically result in this right to refuse becoming meaningless (of course the answer was no);
- Problems associated with the inability of some clients to communicate either refusal or agreement to participate in medical procedures of many kinds were discussed in some detail, e.g. passive response being construed as consent;
- Attitude of General Practitioners, e.g. some Residential Care Officers were concerned that General Practitioners would be irritated by the request for full medical assessment — and yet many Residential Care Officers shared their views that the CHAP tool could be positively used to guide medical practitioners and that they would welcome the interest and support;
- Family consultation and liaison – sometimes considered to be a negative necessity other times considered to be a positive process;
- Staff responses to medical assessment outcomes, i.e. what if doctor ordered test and staff or statutory health attorney decided that test or investigation was inappropriate — would involvement in the CHAP programme make it mandatory that the test was carried out.

All issues were constructively addressed. Many concerns had been highlighted and addressed within the study's compulsory (The University of Queensland) Ethics Submission. A full copy of this submission can be found in the Appendices.

2.5.2 Consent

Disability Services Queensland (DSQ) staff, including Unit Managers and Area Managers who consented to participate in the project completed written consent forms. Copies of these consent forms are located within the appendices. These consent forms also formed part of the ethics submission. General information regarding clients and Residential Care Officers participating, the names of General Practitioners etc were obtained by the DDU research team prior to the CHAP tool being distributed amongst regions. This "baseline" information collection occurred via a questionnaire following consents being received from both Disability Services Queensland (DSQ) staff and clients participating in the study.

There were no Disability Services Queensland (DSQ) clients who were able to complete consent forms required for participation. Staff from a number of Area Offices had numerous discussions with Developmental Disability Unit researchers regarding the capacity of Disability Services Queensland (DSQ) clients to consent to the project and a number of innovative educational approaches were discussed. Disability Services

Queensland (DSQ) staff in all cases, made a decision that clients were unable to provide consent. Accordingly, the Developmental Disability Unit sought client consents through either by their Statutory Health Attorney or the Adult Guardian (as appropriate).

The negotiation of consents was a time consuming process involving lengthy phone calls and in some cases personal visits, with not only Disability Services Queensland (DSQ) staff, but on occasion family and relatives who were nominated as Statutory Health Attorneys, interested other people, e.g. advocates of clients and staff from the Adult Guardian. The majority of people contacted outside of Disability Services Queensland (DSQ) were very supportive of focus being placed on the health care needs of people with an intellectual disability. Some family members and relatives shared many personal and often painful experiences recalling past difficulties experienced meeting the health care needs of people with an intellectual disability.

Staff and clients were advised that they didn't have to worry about informing the General Practitioners about the research project. Many staff indicated some concern that they did not believe the General Practitioner, their client(s) were involved with, would participate in the CHAP project, e.g. too busy or perhaps lack of interest were cited as possible reasons for non-participation. The project's Chief Investigator, Dr Lennox made contact with all General Practitioners who could be involved in the study and sought their consent. When a very small number of General Practitioners declined to be involved in the project, contact was made with the relevant Residential Care Officers. The majority of General Practitioners indicated real interest in the project.

2.5.3 Residential Care Officer Questionnaire

As referred above, this questionnaire enabled the Developmental Disability Unit researchers to establish a baseline of fundamental demographic information about the direct care staff, their place of employment and their clients. The questionnaire also obtained the name and contact details of the client's usual General Practitioner who would be asked to carry out the comprehensive health assessment. The Developmental Disability Unit securely stored information obtained. The secure storage of confidential information collected by the Developmental Disability Unit researchers was detailed in the ethics proposal.

2.5.4 The CHAP Tool

The Developmental Disability Unit researchers forwarded the Residential Care Officer a CHAP tool and a letter confirming consent from:
- Either the client's Statutory Health Attorney or the Adult Guardian (as appropriate); and
- The client's General Practitioner.

To assist with preparation and as a prompt for the General Practitioner undertaking the health review, a booklet, often referred to as the CHAP "tool", was prepared by DDU researchers. The CHAP booklet or "tool" consisted of two parts:
- *Part 1* — completed by the Residential Care Officer (nominated as the Client Coordinator) prior to medical assessment by the client's usual General Practitioner. Past and present medical and health history was recorded. The Residential Care Officer was expected to use their personal knowledge, file or historical knowledge and as appropriate. The Residential Care Officer was allowed to make contact with family members or significant others.
- *Part 2* — completed by General Practitioner. This part of the tool guided the doctor through the health assessment, i.e. which health systems to check and was used to record outcomes of comprehensive health assessment that was undertaken. Findings of the health check and recommendations for further investigation or treatment were also recorded. Also included was a concise summary sheet of common health problems experienced by adults with an intellectual disability.

2.5.5 Health review

The CHAP project hinged upon a thorough medical review of each person with an intellectual disability by his or her usual General Practitioner using the CHAP tool. The Residential Care Officer organized the appointment with the usual General Practitioner. Dr Lennox had obtained consent from the General Practitioner about the project. The Residential Care Officer accompanied the client to their doctor for the health review.

At the completion of the health assessment, the Residential Care Officer retained the completed CHAP booklet. Residential Care Officers were encouraged to take photocopies of the health outcomes but the tool was returned to the Developmental Disability Unit. This booklet provided the researchers with data for analysis.

2.5.6 Medical Treatment or Intervention Following from the Health Assessment

Staff were advised that if the General Practitioner identified any medical condition that required treatment, investigations or tests etc, the response to this finding was to be managed by Disability Services Queensland (DSQ) staff in the "normal" way, according to the policies and practices of Disability Services Queensland (DSQ). Fundamentally this meant that participation in the CHAP project did not mean that the client was locked into the outcomes of the comprehensive health assessment, e.g. clients could refuse an intervention or an investigation. Alternatively clients could actively pursue interventions for health care problems that were identified. The researchers stressed that the project did not involve or advocate any experimental research or procedures of an intrusive nature.

2.5.7 Return of the Completed CHAP Tool to the Developmental Disability Unit Researchers

Residential Care Officers were informed that they would be given approximately three months to complete Part 1 of the CHAP tool, organize the appointment for a comprehensive health assessment with the client's usual General Practitioner, and then return the completed CHAP tool to the Developmental Disability Unit. The reality is that staff took far longer to complete the medical assessment and return the tool. This is discussed in detail later in the report.

2.5.8 Post CHAP Interviews and Note Review

The original implementation plan included:
*   Post CHAP interviews of careers and General Practitioners; and
*   Consideration of Departmental/Disability Services Queensland (DSQ) client notes and medical records at the project completion.

Unfortunately despite considerable extension to the two year project timeframe, delays in questionnaire and tool returns and finite resource allocation meant that these activities were not commenced. Major delays in obtaining consents and the return of questionnaires and CHAP tools seriously compromised the project timeframe. Project outcomes were not compromised by the delay but final aspects of the project could not be completed.

2.5.9 Confidentiality

The researchers, Dr Lennox and his team, were careful to point out to staff participating in the research project that client and Disability Services Queensland (DSQ) staff confidentially was to be protected. The Developmental Disability Unit advised that any information collected would not be available to anyone outside the research team. Dr Lennox and his team confirmed that they would not share any identifying information regarding Disability Services Queensland (DSQ) clients or other participants in the study.

Participants knew that any information published or released would generally comment about participants and health issues relevant to the aims of the study but no-one would be identifiable. Anyone reading information published will be unable to tell who participated in the study. There would be no identifying information about clients or staff or families.

2.5.10 Leaving the Project

Client and staff participating in the project were advised that they could indicate at any time during the lifetime of the project that they did not wish to continue in the project. Participants were further advised that a decision to leave the project would not influence their ongoing relationship with the staff, the General Practitioner or family members. Management of their health would continue according to the policies and practices of the Department.

2.6 The Approach to Recruitment

Extraordinary efforts were undertaken by the Developmental Disability Unit researchers to engage both direct care staff and their Managers in the CHAP study. Considerable efforts, including cooperative strategies were also successfully negotiated through both Unit and Area Managers. Support was similarly provided by members of the Health and Well-Being Network that included professional and resource staff.

Prospective participants, i.e. Residential Care Officers, Unit Managers and Area Managers were informed of the CHAP study by a brief invitation to participate that was attached to their pay slips. This invitation to participate was followed up by information and education sessions. Unit Managers were also important

points of contact. They distributed written material about CHAP, communicated the value of the project to staff at appropriate meetings and followed up staff who were tardy in returning consent forms.

Dedicated effort to recruit participants extended far beyond the planned 12 month period recruitment period and included:
- Face to face dialogue in information and education sessions designed to recruit and inform;
- Telephone contact following up enquiries and questions — to individual staff and groups of staff;
- Personal visits to individual staff and groups of staff at times that were convenient to them (for staff unable to attend the information/education sessions);
- Written reminders and personally addressed correspondence to staff at work;
- Telephone calls after hours to staff at their personal residences responding to queries and issues (at their request);
- Repeated telephone calls and face-to-face contact with Managers and other staff.

Concise and easy to read information sheets and fact sheets were distributed at education and information sessions. These information packages were also faxed and mailed to area offices on a number of occasions so that staff who were unable to attend sessions, e.g. were on leave etc, could access important information. Unit Managers were instrumental in distributing information and following up staff. Information sheets were updated and distributed regularly and upon request.

Information and education sessions featured the Chief Investigator, Dr Nicholas Lennox who is both well known and respected by the majority of Disability Services Queensland (DSQ) staff. Dr Lennox provided an overview of health and well-being issues for adults with an intellectual disability whilst also commenting on the CHAP study and encouraging staff to participate. These one and a half hour education sessions were on the whole well attended. Costs accrued by Disability Services Queensland (DSQ), e.g. Residential Care Officer backup, were refunded to Disability Services Queensland (DSQ) by the CHAP study.

2.6.1 Non-participation

There were multiple reasons why some direct care staff failed to consent to participate in the study. One Manager consulted suggested that non-participation related to "attitude problems" and "staff related problems" in Alternate Living Service (ALS) houses. Another manager suggested that non-participation had nothing to do with the CHAP programme itself, and suggested that dissatisfaction with the Department generally could be considered a major factor in non-participation. Further, this Manager suggested that because the Department had supported the CHAP project financially and also philosophically, some direct care staff would never agree to participate.

Managers also explained that some direct care staff had received personal encouragement from Unit Managers to participate in the CHAP programme. Unit Managers had felt that the project held value and credibility therefore had verbally supported participation. Some Residential Care Officers had received a written memorandum from Unit Managers along the lines of "it is voluntary to participate but because the Department is supporting the study, you are encouraged to be involved".

Managers suggested that some staff may have interpreted this written correspondence as a management directive. One Manager suggested that staff used non-participation to relay to management "what they thought of them".

Another alternative reason for non-participation provided to the Developmental Disability Unit researchers related to the stress levels of some staff working in ALS houses. A Manager suggested that some staff had been so stressed that participating in a study of "any sorts" was the last thing on their minds. Sources of stress related to client challenging behaviour and other client related issues. However, other sources of stress cited included investigations into client fund mismanagement, staff transfers and movement, staff sick leave and staff movements and changes generally.

2.7 Mt Gravatt and Gold Coast Area Offices (Brisbane South)

Recruitment and participation activity occurred in both Brisbane North and Brisbane South regions using the same approach and strategies. At the end of the first 12 months of the CHAP study it became apparent that the recruitment strategy targeting Mt Gravatt and Gold Coast Area Offices (at this time the only area offices located within the then Brisbane South region), was providing minimal results. Communication with Managers revealed that staff were grappling with the ramifications of major organisational change. The CHAP project would like to take this opportunity to thank all staff from the

Mt Gravatt and Gold Coast Offices for their interest and assistance during a busy and complex time in the history of DSQ service development.

Late in December 1999 the South Coast Region of Disability Services Queensland (DSQ) became operational and an Area Office was opened at Beenleigh. It was neither appropriate nor realistic to attempt to involve staff from this new area office in the study. Major demands placed upon staff within the then Brisbane South region included the planned relocation of people moving from institutions to the community, a number of capital works projects including a new respite service, and the opening and staffing of new offices. The demands of these changes should not be underestimated.

Only a handful of Brisbane South clients and staff were recruited into the CHAP project despite major efforts by Developmental Disability Unit researchers and Managers in that area. The CHAP study was unable to compete with the demands placed upon staff in regard to the associated organisational change. Discussions with Disability Services Queensland (DSQ) staff suggests that despite clear acknowledgement by a range of staff that although the health and well-being of clients was a clear priority and area of important need, participation in a research project such as CHAP was a very low priority for staff at that time. One Manager suggested that more pressing issues of concern for staff at that time may have related to staff continuity of employment and their location of their employment.

Lessons from the Labyrinth

Chapter Two

Literature Overview: Barriers to Health Care for People with an Intellectual Disability

1.   Introduction

Adults with an intellectual disability represent a growing sector with unmet needs within the Australian population. Their need for primary health care services is increasing as the population ages and more people are assisted to live in community settings (Janicki, 1999). Unfortunately this group tends to experience problems when accessing and utilizing quality health care. There may be limitations in the environment resulting in health care services being physically inaccessible. Often health care professionals don't possess or use the appropriate mix of skills or expertise needed by the adults with an intellectual disability to take full advantage of the health service. General Practitioners and other service providers may forget, omit (with or without insight), or not recommend typical or usual parts of health checks when assessing a person with an intellectual disability. Medical assessment and health checks that are routine within the general population may not be considered for people with an intellectual disability, e.g. breast examination or a prostate check.

Adults with an intellectual disability are often dependent upon paid carers for assistance or alternatively they may experience personal difficulties in asking for advice or assistance. Awkward impasses can occur which cause frustration and anxiety for both the person seeking the service and health professionals. The end result may be that the person with the intellectual disability does not prioritize primary health services and fails to seek preventative health care. They may only pursue medical attention for emergency or acute conditions.

The Literature overview focuses upon barriers to health care access for adults with an intellectual disability. The perspectives and experiences of a number of key stakeholders are addressed within the literature overview, including the General Practitioners and the medical profession, other healthcare providers, consumers, families and human services and disability workers from government/non-government agencies. In attempt to address gaps in knowledge, and despite some overlap, the Literature overview is divided into four parts.

- **Part A** addresses **Systemic and Structural Barriers** influencing services provided to people with a disability. The brief review attempts to identify and comment upon both historical and contemporary influences upon service delivery to people with an intellectual disability. Trends or influences identified have had strategic impact upon the organisation and management of health, human and disability services. Change is both historical and ongoing, influencing overtly and covertly, the health care status of adults with an intellectual disability.
- **Part B** attempts to draw together and analyses the literature that specifically addresses **Client Barriers** which impacts the health care needs of adults with an intellectual disability. Definitions are clarified and significant issues explored.
- **Part C** considers the relationship of the General Practitioner with adults with an intellectual disability but initially looks at related **Service Delivery Provider Barriers**. The management of the health care needs of people with an intellectual disability within the general practice and primary health care settings are discussed.
- Finally, **Part D** identifies a number of **Direct Care Worker Barriers**. The characteristics of direct care workers are explored, including aspects of their relationship with and influences upon the health and well-being of the clients that they support.

2.   Part A: Systemic and Structural Barriers

*Part A of the Literature overview addresses **Systemic and Structural Barriers** influencing services provided to people with a disability. The brief review attempts to identify and comment upon both historical and contemporary influences upon service delivery to people with an intellectual disability. Trends or influences identified have had strategic impact upon the organisation and management of health, human and disability services. Change is both historical and ongoing, influencing overtly and covertly, the health care status of adults with an intellectual disability.*

2.1   Introduction

Adults with an intellectual disability require a range of health services during their lifespan. Despite access to health services being considered by most Australians as a "right", people with an intellectual disability are often excluded. The Australian health care shows little interest in the development of structural opportunities aimed at improving the medical care of people with an intellectual disability. Guidelines and health guidelines for adults with an intellectual disability have been developed and considered by the World Health Organisation during 2001 (Beange, Lennox & Parmenter, 1999). These health guidelines are important in so far that medical and other professionals working within health, human and disability services require additional information about special health risks among this vulnerable group and management protocols for the commonest syndromes (Beange, 1996).

Adequate health care outcomes for people with an intellectual disability, and the general population for that matter, will be dependent upon the health care system being accessible, reliable and consistent over time (Criscione et al, 1993). People with an intellectual disability need to access efficient and effective health services within an integrated human services environment. The service response of both the health sector and the disability sector needs to focus upon the needs of the person with the disability rather than the agenda or best interests of the service provider or agency. Unfortunately the systems do not appear to function unless there is a "crisis" and there is little communication between health, disability and other sectors.

Consideration of both the historical and contemporary barriers to health service delivery and uptake may assist in understanding why services have been slow in developing the capacity and skills to meet the health care needs of people with an intellectual disability. Some professionals may fail to recognize potential benefits associated with preventative health care for people with disabilities. One contemporary impact of the de-medicalisation of disability that can be associated with deinstitutionalization has been the neglect of the health status of people with an intellectual disability.

Australian health care service delivery is theoretically based upon socially just egalitarian principles that guarantee access to health care services for all. However, this is not the experience for many people with an intellectual disability (Elola et al, 1995). People with an intellectual disability find it difficult for a variety of reason to utilize health services available in the general community (Bond et al, 1997). Many people with an intellectual disability experience fear, confusion and anxiety when accessing generic health care services. They may need assistance to become confident in using these services and people with more severe disabilities, may require special assistance. Adults with an intellectual disability may display problem behaviours that make cooperation with examinations and procedures difficult and sometimes impossible. They may require additional time and support, desensitization programmes or perhaps an altered environment.

Access to health care is mediated and influenced by complex social, cultural, psychological and environmental consequences of having an intellectual disability. The identification of barriers — factors that impact the availability, accessibility and acceptability of health services will assist with the development of responsive health care services for people with an intellectual disability. It is important to recognize that barriers are often inter-related or connected and therefore considerable overlap exists.

2.1.2 Conceptualizing Barriers

"The primary experience of a human being with a disability, at least the primary experience in relation to community, is one of thoughtless, unnecessary and hurtful exclusion from nearly every social, political, educational, cultural, commercial or communication transaction. To encounter a barrier to freedom of movement or interaction once in a lifetime seems to send some people into a frenzy of punitive litigation; to encounter such barriers all day every day is the ordinary experience of people who have a disability. Luckily for those who have carelessly erected these barriers, people who have disabilities are much better at accommodating to a hostile environment than those without disabilities are at accommodating energetic, involved, money-spending, talented and responsible citizens with disabilities" (Hastings, 1996).

Barriers influence health service utilization (Sword, 1999). The concept of *barriers* first emerged during the 1960s in literature that considered health behaviour in association with disease detection and prevention (Rosenstock, 1966). The concept of barriers was originally linked to negative aspects or perceived costs of specific health behaviours. Contemporary discussion of barriers that restrict health services access and uptake tend to be considered within the biopsychosocial model of health care. This approach considers the interactive relationship between the individual and their broader social environment as the key determinants of health behaviour (McLeroy et al, 1988). Health behaviour is described as multi-factorial, related to intra-personal factors, interpersonal processes, community factors and having a relationship with public policy (McLeroy et al, 1988; Sword, 1999). Health behaviour, positive or negative, is a dynamic relationship determined by external and internal psychosocial variables (Sword, 1999).

The health care system is theoretically well organized. Imperfections can however become more obvious when people with complex health care problems such as adults with an intellectual disability, require community-based intervention and support. Barriers to effective health care can include: (McGee & Mee-Lee, 1997):
- Excessive boundaries, exclusion and territoriality;
- Inadequate assessment, diagnosis and management;
- Lack of trained staff;
- Inadequate service development leading to reduced consumer choice;
- Rigid funding criteria/streams; and
- Lack of a strong, shared culture of client focus.

Community-based health care lacks coherence for adults with an intellectual disability partly because of its nature, e.g. involves contributions from a range of professionals and caregivers. These professionals and careers may not necessarily work within the formal health care system. The divergence of stakeholders involved in "health care" is a phenomenon of modern society. Commonly these providers of health care fail to communicate and may work parallel to each other. Alternatively they may be unaware of the actions of others involved with the person with an intellectual disability. Although coherent cooperation and client focused action is logical and preferred, it is not a reality (Smeenk et al et al, 1998). Further complexities emerge when inter-relationships with human services and disability services are considered and analyzed.

2.1.3 Access and Availability

The importance of preventive health care and health promotion has been increasingly emphasized in the government policy of most western nations over the last decade (Bowler & Gooding, 1995). Referral to and uptake of primary health care services is variable and dependent upon a range of factors including:
- Availability of the service need identified;
- Physical access including location and operational factors, e.g. hours;
- Willingness and ability of the service to provide and meet that need;
- Cooperation of the client, e.g. consent;
- Awareness of the service provider to intellectual disability; and
- Knowledge and attitude of family member and/or careers.

Health policy goals tend to promote equity and access to health care. Within the ideal health care system geographic, financial, organisational or social barriers are non-existent. Access refers to the match between the health service, the need and the affordable costs with barriers including lack of continuity among fragmented services and complex system, inability of services to respond to particular needs, e.g. patient with disability (Pulcini & Howard, 1997). Access can be construed as an extensive concept that can be quantitatively deficient (does not meet need) or qualitatively deficient (available but not acceptable). Access can also be understood to refer to (Penchansky & Thomas, 1981):
- Availability: volume/type of service relative to client need;
- Accessibility: location of services relative to transport, distance, cost;
- Accommodation: manner in which resources are organized;
- Affordability: price of services relative to ability to pay; and perceived service value; and
- Acceptability: attitude of the client to characteristics of the service provider.

One of the most significant barriers to access is the lack of availability of health care providers and services that are relevant to the needs of people with an intellectual disability. Queensland faces an acute shortage of medical practitioners with experience in the management of health care problems of adults with an intellectual disability.

2.2   Understanding Disability

According to the Australian Bureau of Statistics, approximately 29 per cent of the Australian population (five million people) had one or more impairments or long-term health conditions in 1993 (ABS 1996). Approximately 18 per cent of the Australian population (3.2 million) had one or more disabilities as a result of their condition, and 14 per cent of the population (2.5 million) were categorized as handicapped by their disability. In Queensland in 1998 one in five people in the general population reported a disability and there were an estimated 686, 700 people with disabilities representing 19.9 per cent of the population (FYCCQ, 1999).

Despite the presence of disability, this group is not homogenous and comprises a diversity of people with differing skills and social circumstances. Disability is a broad conceptualization that is inclusive of the following "types" or categories:
- Perceptual (e.g. visual, hearing, cognitive);
- Illness related (e.g. multiple sclerosis, HIV/AIDS);
- Physical (e.g. cerebral palsy)
- Developmental (intellectual disability);
- Psychiatric (e.g. schizophrenia);
- Mobility (e.g. quadriplegia); and
- Environmental (e.g. asthma, allergies) (Rauscher & McClintock, 1997)

The definition of disability adopted by the Disability Discrimination Act 1992 (Commonwealth) is similarly broad and is inclusive of:
- Disabilities resulting from total or partial loss of a person's bodily or mental functions; or
- Total or partial loss of a part of the body; or
- Presence in the body of organisms causing disease or illness; or
- Presence in the body of organisms capable of causing disease or illness; or
- Malfunction, malformation or disfigurement of a part of the person's body; or
- Disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction; or
- Disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgment, or that results in disturbed behaviour.

The World Health Organisation (WHO) definition of disability underpins the service delivery to this population by most western governments. "Disability is a difficulty in seeing, speaking hearing, writing, walking, conceptualizing or any other function within the range considered normal for a human being". These definitions are very important when analyzing barriers and access to health care services for people with an intellectual disability. Boundaries between definitions can be imprecise and they may inappropriately draw from IQ test. Applications of such definitions can result in unreliable and inaccurate clinical assessment of ability or special needs (Martin & Martin, 2000). Until recently the medical model dominated perceptions of people with disabilities and more particularly their societal roles and responsibilities (Munford & Sullivan, 1997). The definitions quoted above reflect a medicalised approach where disability is associated with functional, sensory and cognitive incapacity. Definitions of intellectual disability and problems associated are discussed in more detail later in the Literature overview.

2.2.1 Medicalisation of Disability

The medicalisation of disability is unsurprising given that for most of the 20th century, Australian society reduced disability to a "health" problem. People with disabilities, regardless of whether physical or intellectual, were not considered to have characteristic or significant needs. Medicalisation of disability resulted in the labeling of *all* people with disabilities as "ill" or "sick" and in need of medical care. This approach was influenced and reinforced by religious, moral, legal and medical discourses at the time. People with disabilities also experienced social stigmatization that was associated with their characteristics and "difference". The existence of an intellectual disability or mental illness, regardless of personal capacity or ability was enough for a medical practitioner to make a decision that institutional care was warranted.

The move away from institutions and the focus upon the rights of people with an intellectual disability to live in community care settings responded to policy and service delivery changes that embraced morality, fairness and justice. Rapid de-medicalisation of disability followed but there has been a simultaneous emergence of a well-meant misunderstanding. Medicine continues to be negatively viewed by some because the profession is considered to have historically "failed" people with a disability. Simply living in the community presumably resulted in people with an intellectual disability being "better off" when compared to institutional service provision. This view developed from the belief that community living would solve

all problems experienced by people with an intellectual disability. Certainly there has been considerable change in the provision of health services to people with an intellectual disability following the closure of institutions (Bailey & Cooper, 1997). However, research shows that community care policy is failing to address the health care needs of this group.

Recent research conducted within the United Kingdom (DoH, 2001) suggests that:

- Doctors and health care professionals can fail to recognize the potential health complications of many of the conditions that cause intellectual disability;
- There is inadequate diagnosis and treatment of specific medical conditions experienced by people with an intellectual disability;
- Few people with an intellectual disability access health screening services with uptake rates for breast and cervical screening being particularly poor; and
- Challenging behaviour displayed by people with an intellectual disability often involves the use of psychotropic drugs with poor outcomes as a consequence.

Perhaps there is an increased need to consider the impact of the social system upon health (Lomas, 1998). The way society is organized, the extent to which interaction is encouraged by society's members and the degree to which society's members trust and interact with one another will impact health and well-being. People with an intellectual disability have not fared well within either the social system or the health system. The cohesiveness of the social milieu is likely to be an important determinant upon health of the general population (Lomas, 1998), but the impact may be more significant upon the health of vulnerable people such as those with disabilities. Health needs perhaps should be re-conceptualized into a holistic dimension of care and support that does not necessarily result in the re-medicalisation of disability (McGee & Mee-Lee, 1997).

2.2.2 "Ad hoc" Disability Services Development

Disability services within Australian have a fragmented history. Characteristics included resource constraints, paternalistic attitudes, institutionalization, inequitable access, poor Government leadership and direction, inadequate legislation and policy, non-existent data collection and lack of strategic planning. Programme and service development has continued to be complex and problematic because the target group comprises such a wide diversity of individuals and agencies. The disability services sector is as diverse as the people it purports to support. The lack of homogeneity makes the formulation of either state or commonwealth disability policy a difficult task. Characterized by "difference" and "individuality", people with an intellectual disability may seek or need services from a number of sectors, e.g. employment, housing or health. Layers of government are often involved in different activities.

Diversity relates not only in relation to the type or level of disability, but also in regard to the service or services needed and access to required services (Lindsay, 1996). Needs cross various service systems and sectors. The provision of a "service" to people with an intellectual disability is really an abstraction. "Services" are only limited by imagination and resources. Services and support provided to people with an intellectual disability need to be tailored to meet the individual needs of the person.

A service may be required long term but the components and nature of that service may change and be altered over time. Services and support are constructed, invented and defined. The social construction of care and support for people with an intellectual disability may in itself be a major barrier. The make up and complexity of service needs and the differing profile between individuals has major implications for community-based service delivery. Obviously the lack of homogeneity makes "flexibility" a desired and implicit characteristic of programmes and service initiatives.

The ad hoc history of service system development in both the health and disability arenas has remained a considerable barrier to effective programme development and service delivery. Over the past century health services and disability services have evolved from their charitable and humble origins to emerge as a multi-billion dollar industry. Services provided by both sectors to people with disabilities now operate within a quasi-market where Governments are essentially monopoly purchasers able to dictate policy and funding arrangements (Forster, 1998). Few would refute the fact that health services or disability service provision is now considered big business.

Services to people with an intellectual disability developed from early 19th century religious and charitable philanthropy (Stehlik & Chenoweth, 1996). The origins of these services have benevolent origins. Australian Government responsibility for people with a disability surfaced after the Second World War in response to international debate regarding universal versus selective support of people in need of social welfare assistance (Stehlik & Chenoweth, 1996). Disability services failed to develop as planned or sequenced events. Services for people with disabilities emerged randomly and "accidentally" from health services.

Much has been achieved for people with an intellectual disability through the provision of disability services across Australia. Some suggest that a universal phenomenon exists across the western world where a climate of change is characteristic of the developmental disability field (Stehlik & Chenoweth, 1996). Government policies continue to improve the lives of people with disabilities by changing social, political, and economic structures. Now the 21st century, human services have primary responsibility for providing services to people with disabilities within Australia.

There have been similar advances and improvements within the health of the general population in western societies. Poor sanitation and malnutrition have been historical disease determinants, but in contemporary society these determinants are now primarily economic and social (Rose, 1992). However, towards the end of the 20th century public interest has shifted from focus upon the environment to the individual (Marmot, 1998). Future health advancements benefiting both the general population and people with disabilities may be linked to molecular biology and improved genetic understanding. At the beginning of the 21st century health behaviour is guided by evidence based clinical practice and therapeutic intervention. Evidence based medicine mandates the need to undertake assessment, diagnosis and treatment on an individual basis (Marmot 1998). However, health interventions need to be focused upon the social environment if inequalities in health status are to be effectively addressed (Marmot, 1998).

2.3 Human Services

"Everyone has the right to a standard of living adequate for the health and well-being of himself and his family, including food, clothing, housing and medical care and the necessary social services and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control"

These basic needs were articulated by the United Nations in the 1948 Universal Declaration of Human Rights move towards a definition of "social welfare"(Pinch, 1996). Welfare, replaced more recently with the term "human services" tends to be used synonymously with Government service provision of basic human needs. Human services optimize the welfare of the person and primarily provide health, welfare, social, rehabilitation, medical and educational services which in turn promote individual health and well-being, social development and functional independence (O'Brien, 1997).

Human services is a term which has been widely used in Australia through the 1990s and is inclusive of all the professional and paramedical disciplines that provide services or support people with disabilities in both community and institutional settings (Stehlik & Chenoweth, 1996). In addition to social workers, psychologists, physiotherapists and other therapists, the term also encompasses disability workers, e.g. community care or direct care workers. Despite overlap and shared clientele, the medical profession and health services remain clearly outside the ambit of human services.

Human services, health and social welfare service provision within Australia is fragmented, complex and diverse. The Australian federal and State Governments are directly responsible for more than sixty discrete health and community service programmes established over different time periods, typically on an ad hoc basis. In Australia during 1995/96 $8.9 billion, 1.8 per cent of GDP was spent on welfare services, an increase of 89 per cent since 1989/90 (House of Representatives Standing Committee on Family and Community Services, 1998). In 1994/95 services for the aged and people with a disability accounted for approximately 58 per cent of recurrent expenditure on welfare services by the Commonwealth and State/Territory governments (House of Representatives Standing Committee on Family and Community Services, 1998).

In Australia, human services, including disability services have developed within largely two different, discrete and separate sectors. Human and health services, inclusive of disability services are as a result, defined by overlap, duplication and inequity (Lindsay, 1996). These changes contrast with the meticulously planned National Health Service in Britain. An integrated modern service system for health, social welfare and disability services failed to develop in Australia.

2.4 Conceptualizing Health

Health is conventionally defined in the preamble to the constitution of the World Health Organisation (1946) as: *"…a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity"*.

Health is traditionally considered to be a "desirable" state. Conceptually intangible, health refers to a physical, emotional and mental state. Governments across the world allocate huge budgets for health, social, disability and human services and yet despite such regular and large injections of capital, solutions for the problems are not forthcoming (Wanna et al, 1987). The challenge for government is to establish and maintain infrastructure that produces equitable health and human service system.

Health can also be understood as an everyday life resource, i.e. a means to achievement, fulfillment and ultimately of survival (Baume, 1998). Without health and well-being an individual is unable to functional physically, psychologically and socially within their community. Related is the understanding that in modern society people have the "right" to achieve a reasonable quality of life. Health is not a "merit" good (Hancock, 1999). Society's members are entitled to reasonable access to food, education, housing, and relationships with other human beings in addition to environmental and health determinants.

The blurring of the boundaries between health and human services begins to emerge when considering policy for people with disabilities, e.g. how human service understand and perceive disability. There is some evidence of a paradigm shift where the "problem" of disability has been moved or redefined in a number of policy arenas (Chenoweth, 1997). Despite shifts in the conceptualization of health from illness to well-being, society persists in medicalising disability and considering people with disabilities as being "sick". Although historically health services have taken major responsibility for this group of people, the situation has changed dramatically in Queensland in recent years with the move from Health Department responsibility (Mental Health Services) in the late 1970s to the then Department of Family Services and now Disability Services Queensland.

The provision of health care to people with an intellectual disability obviously involves far more than a biomedical approach that treats the sick. The health and well-being status of people with an intellectual disability can be partially explained as the net result of the interaction of this group with their social and physical environment, i.e. the biopsychosocial approach (Tarlov, 1996). Understanding their social milieu reveals variables that play key roles in influencing the vulnerability of people intellectual disability to an increased prevalence of health care problems.

Services that exist to support "health" don't focus narrowly but are wide-ranging and diverse. The dominance of medical professionals has been challenged by the move out of institutions to community living for people with disabilities. The analysis of health within the biopsychosocial model has also influenced the "health" of people with disabilities being considered within a broader social context including well-being and quality of life concepts (Tarlov, 1996). Ideally the health system seeks synergy through recognizing and integrating all aspects of the health care process.

2.5   Biopsychosocial Model

Health care discussion has traditionally occurred within the medical model that emphasizes the individual biomedical determinants of health. Potential contributions from human services have tended to be overshadowed and diminished by the biomedical and behavioural sciences (Lomas, 1998). Contemporary health service delivery is being increasingly influenced by the emphasis that the social and behavioural sciences places upon "humanness". Health practitioners operate within the human domain so there is increasing recognition that there is a role for human phenomena and the use of subjective experiences (Engel, 1992). This approach can compliment rather than violate the conventional requirement for scientific respectability (Engel, 1997).

Research highlights that there are a broad range of psychosocial factors and socioeconomic conditions that play a role in health determinants (Williamson, 2000). Health and well-being is linked to inter-related biological, behavioural, psychosocial, socioeconomic and environmental determinants. There are multiple variables involved. The description of nature as defined by the "bootstrap" theory promulgated by physicists provides a useful analogy. Nature, like "health", is described as having a central core paradoxically characterized by unity that is dynamic and yet interrelated. Each part of this dynamic web of interrelated events is as important as the other part (Singh, 1995).

In the same way, health outcomes are multi-determined. A combined biological, psychological and social perspective is regarded as necessary to account for the full range of problems that present in primary health care (Mead et al, 2000). The biopsychosocial perspective is a useful conceptual approach that allows illness and disease to be examined and understood within a broader paradigm. Understanding "health" or "illness" involves insight into the meaningful connections between life history and presenting signs or symptoms (Engel, 1997).

Similarly, a socio-ecological view of health argues that health determinants can be located outside of the health care system, e.g. primary determinants of disease are mainly economic and social (Rose, 1992 in Marmot 1998). The interdependent nature of the relationship between people impacts their health and well-being in addition to their physical and social environment. Similar to the biopsychosocial model, health problems are characterized by complexity and inter-relatedness. Methodological pluralism, or the use of a diversity of perspectives is required because the health system is so complex.

Over the past two decades public health policies and programmes have tended to target individual health behaviours and their relationship with "health." Health education and associated media marketing initiatives are good examples where programmes aim to persuade the general population to adopt particular health behaviours, e.g. stopping smoking, benefits associated with immunization, the advantages of exercise and keeping fit, or risks linked to identified sexual behaviours. Evaluations of such initiatives have made public health professionals aware of the need to expand their focus beyond that of individual health behaviours (Williamson, 2000).

There is growing public interest in the relationship of the social environment to health (Lochner et al, 1999). This approach has emerged in response to health problems facing western nations, particularly dissatisfaction with increasing financial and resource costs associated with the traditional biomedical model of health and disease. For example, lower social position increases the chances of ill-health while also decreasing the chances for well-being that constitute quality of life (Marmot et al, 1999). However, despite universal access to health care, inequalities in health have been sustained with possible explanation relating to the multi-factorial nature of health determinants. A combination of psychosocial factors in the environment including social circumstances in which people work or live and their health behaviour can account for overall health status (Marmot et al, 1999).

People with an intellectual disability are not passive players in the dynamics of their health and well-being. A variety of environmental factors play a role in intellectual disability. The needs of adults with an intellectual disability must be ecologically understood within the context of their living environment and communities. Adoption of the biopsychosocial approach to understanding health and well-being provides a sound approach.

2.6   Primary Health Care

Primary health care is at the centre of health and well-being. The model proposes a key role for the primary health sector in community-based health care and health promotion. Community-based health services assume two separate but related functions – primary care and community or continuing care for those people with long-term dependency needs (Legge et al, 1995). Involved in the provision of primary health care are General Practitioners, pharmacists, community health practitioners, primary care hospital services, local government, and volunteers. Emphasis is placed upon continuity of care, collaborative networking between agencies, integration of prevention with acute treatment and concern for population health as well as individual health (Legge et al, 1995).

Primary health care is a model of health delivery that integrates a broad understanding of health, including physical, social, mental and spiritual well-being and not just the absence of disease. Conceptualization of "health" has moved from the historical emphasis on disease treatment to an expanded focus upon optimum health promotion that incorporates modification of lifestyle and the environment (Fukiura et al, 1997). Health is impacted by many factors: biology, environment, lifestyles and the health care system itself (Elola,1995).

Queensland's Primary Health Care Policy was first launched in 1993. This policy reflected the approach adopted in the UK and committed Queensland to re-orientation of the health system. Improvement of the health of all citizens was the objective as opposed to the traditional disease focus. The policy inextricably linked health with social justice principles. Health services were based upon community need with development involving active community and consumer participation.

Interventions should always be based upon a sound understanding of those biological, psychological and social factors that have influenced the health and well-being of the person with an intellectual disability. Ideally, a multi-disciplinary team assessment brings together these different perspectives so that treatment and interventions can improve the person's overall health and well-being (Holland, 1999).

2.6.1 Health Promotion

Health promotion involves levels of collective action that aim to improve living and working conditions conducive to health and well-being. The Ottawa Charter (WHO 1986) stated that health promotion initiates and drives processes of social change aimed at the improvement of living and working conditions conducive to health. Health promotion is guided by three principles: enabling, mediating and advocating. Activities associated with health promotion can be categorised:

*   Supportive environments;
*   Building healthy public policy;
*   Creating Strengthening community action;
*   Developing personal skills; and
*   Reorienting health services .

Population wide health promotion programmes are based upon risk factor conceptualization and disease prevention. The programme or intervention seeks to break or interrupt scientifically proven causal chains as a means of improving health and well-being for individuals. However, a major flaw within this approach is the reality that many groups within a population approach are overlooked or excluded.

Interventions and strategies in health promotion focus upon opportunity to improve health seeking behaviour — windows of opportunity are to promote behaviour conducive to health and improved access to appropriate health and social services. Health seeking behaviour is simply a by-product of day to day activities. Such behaviour blends into patterns of work, family life and recreation. Changing or modification of cultural practice is therefore not an easy ask (Mechanic, 1999). Health promotion focuses upon increasing empowerment of vulnerable individuals and communities, e.g. aims at involving them in cooperative, e.g. groups that share information, provide support and facilitate active coping and effective political advocacy (Mechanic, 1999).

Progress has been made in the reduction of preventable illness and disease within the general population, but the health care needs of people with an intellectual disability have received only scant health promotion attention (Barr et al, 1999). People with an intellectual disability have increased requirements for health care services (Beange et al, 1995) but health problems may only be reported to General Practitioners when disease is obvious, e.g. advanced (Turner & Moss, 1996).

The reactive nature of the health system is a barrier to people with an intellectual disability in so far that it hinges upon ability to identify and then self-report illness or disease. Adults with an intellectual disability are unable to negotiate effective preventive care when they find it difficult to identify and communicate symptoms or signs of being unwell to their families or carer, yet alone to their General Practitioner (Turner & Moss, 1996). Medical assistance can only be obtained when the need for a health service is recognized by the person with the intellectual disability or their carer (Langan et al, 1993). Of concern is the reality that both often lack the necessary capacity and skills to identify health needs and seek appropriate expert assistance.

The high prevalence of health problems relative to the general population has not been recognized by health services and is therefore not adequately addressed. In addition, there is evidence to suggest that people with learning disabilities living in the community consult their General Practitioner less often than other vulnerable groups. Regular, proactive health screening has been proposed as one means of addressing this problem. Screening simply refers to a physical examination of a person who may or may not have symptoms or signs of ill-health

Adults with an intellectual disability therefore appear to have a greater need than most people for continuous, comprehensive and coordinated health care (Lennox et al, 2000). The vast majority of people with an intellectual disability access health services provided in the community but health professionals have failed to prioritize the needs of this group (Aspray et al, 1999). Research has demonstrated that community-based health care is fragmented with less health screening and health promotion among people with an intellectual disability when compared with other patients seen in general practice (Kerr et al, 1996; Whitfield et al, 1996).

Review of Australian and international literature fails to demonstrate good evidence on the effectiveness of proactive screening programmes and health education for adults with an intellectual disability. Despite the need for rigorous and objective evaluations, regular health checks are repeatedly recommended in the literature (Kerr et al, 1996; Lennox & Kerr, 1997).

2.7 Quality of Life

Quality of life is a multi-dimensional construct that has a relationship and causal association with health. Practitioners and researchers use varying definitions, therefore objective measurement is problematic. Quality of life perceptions will vary with regard to time, place, circumstances and individual experience (Peplau, 1994). Because the concept is often considered in light of unmet needs, the views of others about someone's quality of life may also differ from personal perceptions.

The concept developed from the sanctity of life doctrine and has been used in health economics and planning, as well as in clinical and medical decision-making (Koch, 2000). Quality of life is related to the biological, physical, social, cultural and political environment in which people live. There are vast inequalities in health in not just developing nations, but all countries in the world (WHO, 1999). Health inequalities that impact life quality are related to unequal income/wealth distribution and consequent inequalities in education, employment and access to social, political and economic resources (Marmot, 1999).

Quality of life instruments have been inappropriately used to measure not life quality of person with chronic conditions, but the use of tools to advance health planning within the concept of economically scarce resources (Koch, 2000). The stigma of "difference" alone — social exclusion, may limit the person's quality of life, as much as limitations arising from the effects of whatever the disability is. Many instruments measuring quality of life are based upon the medical model and therefore measure the burden of the disease or disability. Typically quality of life measures fail to address the social context within which the person lives on a daily basis (Koch, 2000).

Quality of life is being increasingly recognized as a key issue for people with an intellectual disability (Schalock, 1990). It is a complex and multifaceted concept but generally included subjective and objective dimensions. Quality issues in health care are notably significant for people with an intellectual disability, because the impact of poor quality may have serious repercussions for them when compared to people without disabilities (Walsh & Kastner, 1999).

Outcome measures of health services quality needs to be tailored and adapted (Walsh & Kastner, 1999) to meet the needs of people with an intellectual disability. Research on "quality" has tended to focus upon the residential and social aspects of life (Felce & Perry, 1995). Assessment tools may have included ancillary items on health but none have assessed health related quality of life (Walsh & Kastner, 1999).

Health care quality is a complex conceptualization because it can be interpreted differently. Subjective assessment is a feature. Variables can be clustered together therefore defining domains of quality (Pulcini & Howard, 1997; Williamson, 1991; Walsh & Kastner, 1999). Identification is useful for describing, comparing and analyzing health care operation. Analyses may facilitate and encourage the development of improved or alternate services. For example (Pulcini & Howard, 1997):

- Structure — characteristics of the physical and administrative environment, including staff, their tools and resources, and the interaction of the players;
- Process — how health care is delivered, activities that occur between and within the system players including issues associated with access, coordination, timeframe;
- Outcomes — measurement of the change in the patient's health status, the impact or results of health care, clinical outcomes.
- Satisfaction — consumer or patient satisfaction…"feeling better."

2.8   Trends, Influences and Philosophy of Care

Philosophies of care have developed in response to institutionalization, the era characterized by inhumane treatment of people with disabilities. Community-based services operating within western societies, whether administered as a disability or health service, have typically developed and implemented legislation and that directs programmes and practices to actively support and respect both the human rights and inherent value of each person with an intellectual disability.

2.8.1 Normalization and Social Role Valorization (SRV)

Normalization is concept developed in Scandinavia (Nirje, 1969) that underpinned the deinstitutionalization movement within western societies. The concept developed during the 1960s within a human rights framework. Normalization advocated that people with a disability had the right to enjoy patterns and conditions of everyday living that were as close as possible to the ordinary circumstances and ways of life of general society. The related concept of social role valorization developed in association with normalization during the 1970s. SRV was defined as: *the utilization of means which are as culturally normative as possible: in order to establish and or maintain personal behaviours and characteristics which are as culturally normative as possible* (Wolfensberger,1972).

2.8.2 Deinstitutionalization

Improvement in the daily lives of people with an intellectual disability can be closely associated with the closure of large institutions. Also important has been the impact of changes within the daily living environments of people with disabilities. Across the western world, the dominant policy approach underpinning services to people with disabilities is community-based care, replacing institutional and custodial care. The advent of community care saw government responsibility for people with an intellectual disability shift from the health bureaucracy to human services.

Institutional reform reflected changing beliefs that improved care and support for people with disabilities could be better provided in community settings. Negative characteristics associated with institutional life included block treatment, rigidity of routine, social distance, depersonalization (Felce & Repp, 1992).

Important improvements in accommodation, education, employment, recreational opportunities and human rights have followed deinstitutionalization. Reliance upon a range of social welfare services has emerged as a common element of the daily life of many people with disabilities, as is dependency upon both paid and unpaid carers. Some of these experiences are unique to people with an intellectual disability but many are shared with other vulnerable groups in society.

Deinstitutionalization and community-based care have been actively pursed in western society for more than two decades and the process continues in Australia to date. Legislation and policy documents argue the right of people with an intellectual disability to independence, integration, productivity and satisfaction in their daily lives (Fullerton, 1999). Community care should provide opportunities for people with an intellectual disability to experience increased independence and an enhanced quality of life. Unfortunately community care has not been an outstanding success story for all people with an intellectual disability. Further, little is really known about what are the elements of effective supported accommodation in a community setting (Evans & Moltzen, 2000).

2.8.3 Community Care

"It is no great gain for people with a disability if, instead of being dammed up behind a few thick institutional walls, our lives are poured out into thousands, or millions, of stagnant little puddles, allegedly in the community but in fact isolated by lack of information, by lack of transport, by lack of opportunity, by lack of education, by negative attitudes, from the streams and currents and rapids and ocean waves of its real life" (Hastings, 1996)

The success of community care has been compromised by the lack of capacity and in some cases, willingness of communities to provide a range of services to people with an intellectual disability regardless of severity or complexity of their needs (Bouras & Symanski, 1997). Problems include:
• Community acceptance of people with disabilities;
• Generic services providing a range of appropriate services;
• The training and up skilling of a range of professionals and direct care staff to support people with disabilities relocating in the community; and
• The development of services infrastructure to sustain people in community settings.

There is increasing evidence that smaller, community-based facilities are "better" than larger institutions (Joyce, 1994). Research outcomes such as these could be interpreted as meaning community care rectifies the wrongdoings associated with custodial care. There exists general agreement that an ordinary house in the community is the preferred service model, but far more than a house is needed to achieve and guarantee quality of life outcomes for people with an intellectual disability (Joyce, 1994).

For some people, the standard of support and assistance provided within community settings has been questioned and similarly the quality of life is also of concern. Controversies associated with institutional life, including abuse and neglect appears to have been replicated in some community settings (Zifcak, 1997). Closure of institutions and movement to community settings has not automatically delivered an improved quality of life or resolved the abuse of human rights. Properly funded and delivered support services and real choice of community-based options are necessary for the sustained success of de-institutionalization programmes. Community-based support services should be independently monitored and evaluated to ensure the abuse symptomatic of institutions is not simply transferred to the community (Sidoti, 1998).

Much of the literature addressing the needs of people with an intellectual disability continues to consider the merits and disadvantages of community living. For those who have experienced the reality of institutional life, the benefits associated with living in a community setting are self-evident and there seems little benefit in debating this issue. Energy, research and resources should be expended upon improving access to community-based service provision (Emerson, 1999). Greater benefit could also be achieved if debate focused upon the serious health repercussions experienced by people with an intellectual disability following de-institutionalization.

Health problems experienced by people with an intellectual disability can be related to the failure of policy makers to predict that generic health care services would be unable to meet the health care needs of people with an intellectual disability moving from institutions to community settings (Ziring et al, 1988). Major gaps have been identified in the capacity of generic health care services to respond to the health needs of people with an intellectual disability (Barr et al, 1999). Primary health care services experience major difficulties in providing medical care to this population. Health conditions experienced by people with an intellectual disability can be difficult to detect and diagnose (Bailey & Cooper, 1997).

2.9 Health Status in Community-based Accommodation Settings

In recent times research and public attention has refocused upon the capacity of community-based support services to provide effective and adequate care (Winterhalder, 1997). It is critical that such discussion also includes consideration and monitoring of the health and well-being of people with an intellectual disability. Physical, emotional, psychological and environmental needs must be addressed to defray the risk of replacing institutional care with community chaos (Asprey & Francis,1999).

Debate has tended to take place within the context of economic restraint. Ideally, discussions seeking solutions should take place within an environment that focuses upon the provision of benefit and gain for those most in need. Consumer/Client needs have been denied appropriate expression and clinical imagination has been crushed by systematic under-resourcing (Hart, 1998). Some argue that market based systems impede access to the poorest people who are usually those most unwell and in need. Despite a causal relationship existing between inequality and ill-health, the inverse care law where those most in need are least likely to receive health care services remains firmly in operation (Hart, 1971).

An Australian critic has similarly argued that Australia has an "illness system" rather than a health or "wellness" system (Hancock & Mackey, 1999). Australia health expenditure over the last 10 years reveals that 70 per cent of combined public and private expenditure is allocated to acute medical care including the hospital and pharmaceutical system. Only 5 per cent of total recurrent expenditure has been allocated to community and public health (AIHW, 1996)

Trends in both health and disability policy have shifted from concerns about equality and social justice to cost containment and cost-effectiveness. The measurement and associated improvement in the quality of services has resulted in a "quality revolution". Regardless, there is little rationality in the allocation of resources in residential services in the UK. Resources have a very weak association with indicators of quality of care or quality of life (Emerson, 1999) Dissociation between measures of need and resource allocation (Felce et al, 1998; Emerson, 1999).

There exists broad agreement that community-based living arrangements and support services are a viable preferred option in terms of service quality and lifestyle (Hatton et al, 1995). When compared to institutions, community-based accommodation options have been linked to a number of generally positive outcomes for people with an intellectual disability including:
- Increased consumer satisfaction;
- Increased choice over day to day matters;
- Immediate skill and adaptive behaviour gains;
- Increased participation in community-based activities;
- Increased engagements in domestic and personal activities;
- Increased support from care staff; and
- Decreased amount of time engaged in stereotypic behaviours (Emerson & Hatton, 1994; Hatton & Emerson, 1996).

The consistency of community-based service provision has been identified as a variable of concern and therefore research focus. There is substantial variation in the quality of such services (Emerson, 1999). Community-based living arrangements are not homogenous and include a number of models including group homes, institution based villa arrangements, and "ordinary" homes in the community, larger specialized units. The operation of these models highlights their "difference", both within and between these models of community care accommodation (Hatton et al, 1995). It is important to account for the within model variation to discern variables and determinants of quality service outcomes. Other criticisms include reminders that the "excesses" associated with institutionalization can also occur within the community. Principles of institutionalization can (and do) arise *de novo* within a community placement when brought in by staff that are themselves moving from hospital-based jobs to community-based ones (Winterhalder, 1997).

2.10 Evidence Based Care

"If the absence of research evidence to support many health care interventions does not convince health care professionals of the need for more evidence-based practice, then some examples of ineffective care which at best waste valuable resources, and at worst result in avoidable death and injury to patients should be considered" (Walshe, 1997).

Evidence based medicine (EBM) was first discussed by Cochrane in 1972. Described as the integration of clinical experience and the best external evidence, the approach fundamentally argues that some clinical interventions are therapeutic and others are not (Sackett et al, 1996). There is a wealth of literature

available for consideration. The major advantage associated with an evidence based approach to health care or health related practices, is that there is improved continuity and uniformity of care through the use of common approaches and guidelines developed by researchers and experts. An evidence based approach to care is not only the preference of the medical profession. This approach is being increasingly adopted by other professions.

Evidence based care can enhance clinical practice through the thoughtful identification and compassionate use of individual patient's predicaments, rights and preferences in making clinical decisions about their care (Sackett et al, 1996). Evidence based care integrates theory and practice and is therefore an ideal model of clinical problem solving which involves (Rosenberg & Donald, 1995):

- Formulation of an objective clinical question arising from the patient/consumer's perspective;
- Literature search for relevant clinical articles;
- Evaluation (critical appraisal) of the evidence with particular focus upon validity and usefulness; and
- Implementation of useful findings in clinical practice.

Health care provision to adults with an intellectual disability is complex and effective collaboration between health and human services/disability services professionals is required. Unfortunately in regard to the health care needs of adults with an intellectual disability, relevant evidence based research is scarce — particularly in regard to health care problems or collaboration between professionals and or carers. Anecdotal experience also suggests that there is a serious lack of relevant evidence based information available to disability workers, health workers (including General Practitioners) and other carers who support and care for adults with an intellectual disability.

2.11 Collaborative Care and Consumer/Patient Focused Care

"Doctors and patients will have to learn that diagnoses are not beasts in the jungle to be hunted but human stories within real lives to be understood, with a past and a future, and these agendas have to converge" (Hart, 1998).

The relationship that develops between the medical practitioner and their patient provides a critical basis for personal health care (Baume, 1998). Interaction involves experience and knowledge on both sides. Clinical consultation hinges upon communication where dialogue occurs and symptoms are explored, explained, and analyzed. The relationship involves two-way communication and usually a physical examination. Regardless, doctors give patients on average, 18 seconds before their dialogue is interrupted and they are redirected onto a medical agenda (Beckman & Frankel, 1984).

There are obviously going to be differences between the views of the doctor and the patient regarding illness, health and well-being. However, understanding the belief system for patients is clearly going to be of importance when trying to negotiate changes in health behaviour (Ridsdale, 1995). It has been suggested that doctors should be considered professionally accountable to their patients and that this can only be achieved when patients are viewed as intelligent partners in health decision-making (Hart, 1998). Patients provide at least 85 per cent of the information that the medical practitioner bases the diagnosis and intervention plan (Hart, 1998). More importantly, unless the patient is engaged in the process of managing their health and well-being, optimal outcomes will never be achieved (Kaplan et al, 1996).

Contemporary health care reforms mandate the need to incorporate the patient's/consumer's perspective. Patient focused care (PFC) is a philosophy within which the experience of the patient assumes the most important consideration. PFC aims to address the balance of power between the doctor and patient. Doctors are expected to develop collaborative relationships with their patients, therefore eliciting their needs, expectations and preferences. A number of variables potentially influence the capacity of a medical practitioner to be patient focused. Patient focused care is a style of consultation where the doctor uses the patient's knowledge and experience to guide the interaction. Patients want to be treated as people rather than a medical case or particular health problem. The doctor aims to be congruent with and responsive to the patient as an individual who has unique needs, wants and preferences (Mead et al, 2000).

Emerging evidence reveals benefits associated with patient focused care model (Wedderburn, 1995; Williamson & Henfrey, 1996) including:

- Enhanced quality of care;
- Fewer delays in the course of care;
- Greater continuity in the course of care;
- Greater awareness and ownership of the treatment care plan;
- Planned and agreed care protocols; and
- A focused organisation of the 'service" around which the patient needs are in the centre.

While research has not revealed to date whether there is a causal relationship between communication and health outcomes within the context of the relationship between the General Practitioner and the patient with an intellectual disability, there is little doubt that communication feeds and drives any therapeutic outcomes. Comprehensive health assessment is dependent upon such dialogue.

In a comprehensive review of the literature on physician: patient communication, one study found (Roter, 2000) evidence linking doctor-patient communication to a variety of patient health outcomes including emotional health, symptom resolution, functional status. The consumer movement within health care advocates the need to shift in the balance of power between doctor and patient. Consumers argue that the medical consultation should be a shared process with shared outcomes, e.g. a collaborative and active partnership (Roter, 2000). This task is difficult when the patient with an intellectual disability has communication problems and they are dependent upon carers to identify and interpret signs of illness or being unwell. The role of the medical practitioner in diagnosing and treating in response to this filtered information is therefore made even more difficult.

Medical practitioners tend to rely upon their "expert" status and the provision of health information in their efforts to persuade patients to change their behaviour. A patient-centred approach is being increasingly regarded as crucial to the delivery of quality primary health care. Many health promotion opportunities exist which build upon new clinician-patient partnerships that make patients better informed and effect positive health outcomes (Mechanic, 1999) Health screening provides a window of opportunity to promote behaviour conductive to health and improved access to appropriate and effective health and social services (Mechanic, 1999).

Increasing demands are being placed upon the medical profession for high quality services that are valued by the consumer, the patient. Quality health care will only be achieved through a collaborative approach that extends beyond the traditional doctor: patient boundary. Very few studies have identified the changes that are needed to increase the level of patient satisfaction or have yielded sufficient patient generated data to establish genuine patient oriented standards of effective health care (de la Questa, 1997). There is however, little doubt that health and human services policy will continue to move towards a balance between evidence based health services while at the same time, reflecting sensitivity to the qualitative aspects of patient satisfaction (Fitzpatrick, 1997). An appropriate doctor: patient model involves the selection and delivery of therapeutic interventions which in addition to being desired by the patient, have also been shown to have a positive effect on the clinical outcomes for individual patients.

2.12 Multi-Disciplinary Teams

The provision of high quality care and support to people with an intellectual disability within the contemporary context is a challenging task. The range of physical needs in addition to psychological and physical health needs experienced by people with an intellectual disability necessitate contributions from a range of professional disciplines. Team review provides the ideal framework where the person is considered holistically. Multi-disciplinary health teams have been shown to improve patient outcomes; involve better coordination of care; best use of clinical expertise in areas of professional overlap; demonstrate greater ability to respond to new health challenges. While start up costs may be high the end result is efficiency, patient satisfaction and a culture of comprehensive management, inquiry and progress (Davis et al, 1998).

The development of innovative teamwork is one strategy for meeting the demands of an increasingly complex health care system. The multi-disciplinary team comprises a range of discipline specific professionals who work cooperatively to jointly agreed patient-centred goals whilst simultaneously maintaining professional autonomy. Professionals who work together conjointly and develop collaborative decisions or recommendations may impact the quality of health care. The value and benefits associated with teamwork are usually discussed in relation to: patient care (improved health status and well-being), personnel issues (education, training and job satisfaction) and management concerns (costs, efficiency and effectiveness).

Team members contribute three sets of attributes to the team process: core functions of their profession; specialized post qualification skills (e.g. family therapy); and different life experiences and social background (Meddings & Perkins, 1999). Teamwork encourages the sharing of skills and experience in solving complex clinical problems. Additionally, collaborative teamwork has the potential to encourage greater flexibility and integration. This approach is likely to make the best use of resources .

Multi-disciplinary teamwork provides a humanistic, biopsychosocial approach to decision-making. The team approach safeguards the uniqueness of patients, their individual needs and preferences, and their emotional status. These relevant factors in therapeutic decision-making are often neglected (Bensing, 2000).

An inter-professional perspective has the capacity to ensure evidence based medicine adopts a patient-centred approach, ensuring outcomes are focused upon the patient's needs and perspectives. Team based approaches to decision-making are generally perceived as a necessary criteria for quality health care. Best results are obtained when professionals work collaboratively rather than in isolation. Multi-disciplinary teamwork allows a wide range of important patient care needs to be met, including assessment, treatment management and follow up.

2.13 Economic Rationalism

"There is a lop-sided emphasis on glamour medicine…heroic transplants and in vitro fertilization… [and the] health dollar is distributed more on the basis of media attention and emotional appeal than on equity and efficiency" (Bowman et al & Virtue, 1993)

Health or medical care, and to some degree welfare and social services, was once the clear domain of "doctors' business" (Hart 1998). However, during the 20th century the operation of the health system, human services and disability bureaucracies has increasingly recruited economists and accountants who now attempt to juggle the problem of infinite demand and finite resources. The provision of health care services is expensive therefore western nations pursue cost effectiveness. While doctors may still be considered patient allies and advocates, economists perceive them as unreliable guardians of the public good (Hart, 1998). Haunted by the inflated public expectations and escalating costs, Governments have invested much energy in pursuing the question, "are we spending too much, too little or just right"(Swerissen & Duckett, 1997).

In recent years numerous Australian taskforces, reports and inquiries have attempted to tackle "health inequities", as opposed to the pursuance of fundamental analyses of why gross inequalities persist in modern society. Many of the reviews have called for wide ranging and radical reshaping of economic and social policies. There appears to be growing realization that social policy is increasingly important in contemporary health care. What "works" tends to be framed within a modernist social welfare discourse which stresses market economy principles and economic rationalism.

Government responsibilities have been redefined by international trends, e.g. the development of strategies by the World Health Organisation and the World Bank that respond to the new social, political, economic and environmental challenges. The distribution of resources and wealth has a major impact upon the quality of social and physical environments There is a continuing tendency to link together our understanding of the determinants of health, human development and economic growth when considering public policy. Universal needs in health and social welfare are in a constant state of flux. The impact of the market principles for example, is changing the notion of demand and supply. Consumerism and the exercise of personal choice (individualism) have emerged recently as key policy themes.

There are radical changes in social policy within Australia which also reflect international trends including drastic reductions in welfare spending and privatization of public services to name a few. Economic rationalism drives many of the social policy changes. This ideology prioritizes cost curtailment and profit maximization. The care and protection of society's vulnerable including people with an intellectual disability does not "fit" well within such a philosophy. Society expects the state to protect and nurture people and provide a just community. But is the state capable of doing this?

One author posed the question well, "At what point do the most vulnerable, and resource using citizens become targets for radical cuts" (Anderson, 1996). Yet another accused health care providers of rationing by stealth where decisions were "… wrapped in a mist of clinical judgment and wreathed in tacit complicities that health care should only provide so much, rather than what is best" (Milhill, 1999). Governments and bureaucracies across the world will filter and distort reality to suit political agendas. Health and human services have primarily developed in areas of market failure, typically for vulnerable people who have not succeeded economically. Motivation factors framing the welfare sector include altruism, benevolence, self-help and religious conviction. These motivational factors do not augur well with the language of the economic rationalists.

2.14 Social Capital

"…we ignore what our everyday experience tells us, i.e. the way we organize our society, the extent to which we encourage interaction amongst the citizenry and the degree to which we trust and associate with each other in caring communities is probably the most important determinant of our health" (Lomas, 1998).

There has been increasing interest in social networks, collective action and the concept of "social capital" over the last 15 years. The concept of social capital emerged from sociological analyses concerning the quality of social relations and their impact upon community members (Eren et al, 1999). Central to the concept is the notion that membership of a social group confers obligations and benefits upon individuals, i.e. social capital is an "ingredient" of social relationships (Hawe & Shiell, 2000). The source of social capital includes networks and relationships, with the consequences being power and material benefits.

Over the past two centuries, and until recent times, people with disabilities were segregated from general society. People with disabilities were isolated and excluded from leading culturally inclusive and socially valued roles. Devaluation of people with disabilities have taken many forms:
- Rejection;
- Congregation;
- Discontinuity;
- Loss of autonomy leading to dependency;
- De-individualization;
- Reliance upon others, often artificial paid relationships;
- Systemized poverty;
- Negative imagery and stereotypes; and
- Abuse and brutality (Ramon, 1991)

Crucial to community participation, is leading a socially valued lifestyle that is viewed positively by other members of society. Social capital is created when individuals demonstrate trust and confidence in each other that enables them as a social group to achieve successes in social, cultural and political terms (Eren et al, 1999). Members of social groups are able to make credible commitments that rely upon generalized forms of reciprocity rather than on narrow sequences of specific quid pro quo relationships (Roseland, 2000). Reasons for cooperation; and how trust and reciprocity develop are the variables of interest (Rudd, 2000).

The relevancy to people with an intellectual disability is that social capital can be conceptualized as "sociability" and consequently, the social status of the individual provides the foundations for successful social relations (Eren et al, 1999). Broadly social capital can be perceived as social relationships and networks that enable stakeholder participation. Transactional costs associated with trading are reduced via an increase in levels of trust between the partners and the development of institutions that provide incentives for lasting cooperation (Woolcock, 1998). Logically, people with an intellectual disability hold low stocks of social capital and have been historically provided with little opportunity to "boost" their stakes.

There are numerous definitions of social capital including:
- Social capital enables individuals to fulfill their aspirations through access to goods and services via their social network or through collective action (Castle, 1998);
- The sum of resources , actual or virtual, that accrue to an individual or a group by virtue of possessing of durable network of acquaintance and recognition (Bourdieu & Wacquant, 1992);
- As one's sympathy (antipathy) for others, idealized self, and things (Robinson & Siles, 1997);
- A culture of trust and tolerance, in which extensive networks of voluntary associations emerge (Inglehart, 1997); and
- Obligations and expectations that depend on trustworthiness of the social environment, information-flow capability of the social structure and norms accompanied by sanctions (Coleman, 1988).

Research is also suggestive of causal relationships linking participation in community and civic activities, trust, health and the role that structures within communities. This "social capital" plays a role in developing and promoting health at the community level. Social capital refers to trust, social cohesion, stability, a sense of security and of belonging and it has been used to encourage decision makers to consider the social implications of economic decisions. Putnam (1993), a key author on social capital, defines social capital as the "…features of social organisations such as networks, norms, and social trust that facilitate coordination and cooperation for mutual benefit" (Putnam, 1993). People with an intellectual disability are vulnerable in regard to social capital — their invisibility may also play a lead role in regard to their diminished health and well-being status.

2.14.1   Social Capital and Health Patterns

Health is a powerful ingredient that holds the potential for improving chances in the market of human and social opportunities. Human beings are the subjects of economic, social and health policies that involve opportunities for risk, advantage/gain and disadvantage/loss (Eren et al 1999). The essential idea behind the concept of social capital in the context of public health is the "homo oecomomicus sanitatis". Human being are best understand as those who:

- View themselves primarily as actors aiming at gaining maximum benefits from their investment in themselves;
- Calculate their behaviour according to individual risk assessment where risks are conceptualized in monetary and social costs; and
- Direct their action towards the generation of power, influence and "trust" in order to become accepted partners within desirable relationships.

Mechanisms that link social, economic factors and health are well recognized (Hawe & Shiell, 2000). Socioeconomic status can be measured by income, education, employment and housing tenure. Regardless, people with lower socioeconomic status experience the worst health and well-being. Research suggests a gradient exists whereby position on the social and economic hierarchy also impacts health and well-being in addition to income (Hawe & Shiell, 2000). People with an intellectual disability clearly belong in the poverty stricken group. They experience low socio-economic status and poor health and well-being status, when compared with the general population.

Research has demonstrated the existence of causal relationships between group membership and social trust, and both income inequality and mortality. Research suggests that income equality leads to increased mortality via disinvestments in social capital (Kawachi et al, 1997). The social system in a community relevant to health consists of three elements: (Lomas, 1998)

- Physical structure, e.g. housing development design including direct and indirect effects through the creation or neglect of a health inducing environment;
- Social structure, e.g. in a community including meeting places and opportunities for exchange and interaction; and
- Social cohesion, e.g. cultural and social homogeneity of a community including the physical and social structure which encourages or discourages mutual support and caring, sense of self-esteem and enriched social relationships and so on.

The concept of social capital needs to be anchored to a sense of community and capacity building in order to explain and advance population health (Hawe & Shiell, 2000). The individual is not the target and they are lost within the community structure. Through improved social cohesion, the preservation and advancement of social structures such as meeting places, clubs, associations and all the other elements of a community is considered to be important. These venues allow for the exchange of views and values and engender mutual trust (Lomas, 1998). Individualistic ideology is in operation — individual is currently the unit of social analysis. One consequence is that individualistic interventions are the solutions sought, e.g. health education is therefore considered to be the best way to treat disease (Lomas, 1998).

Power and powerlessness is implicated as variable in the production of health inequalities (Hawe & Shiell, 2000). People need to form alliances and allegiances in order to develop lifestyles conducive to health and well-being. People with an intellectual disability need to gain political strength and the necessary power to advance and support their causes. People with disabilities may live in the same communities as people without disabilities, side by side as neighbours perhaps. However, these "neighbours" don't have the same level of access to the necessary resources relevant to bringing about improvement in their health and well-being. Power, money, expertise, media manipulation are unevenly distributed. They don't have the same capacities when it comes to shaping social, cultural, political, environmental and economic living and working conditions and their impact on health.

3.   Part B: Client Barriers: Health Care Needs of Adults with an Intellectual Disability

Part B draws together and analyses the literature that specifically addresses **Client Barriers** which impacts the health care needs of adults with an intellectual disability. Definitions are clarified and significant issues explored.

3.1 Clarifying Intellectual Disability

Intellectual disability is not a self-explanatory disease or illness. The term embraces a cognitive and adaptive behaviour disability that usually begins during the developmental period, often in childhood (Harris, 1999). Intellectual disability is a dynamic rather than static condition that has the potential for "change" over the lifespan. The meaning of intellectual disability has been shaped by the interplay between language, social interaction and culture, hence confusion and a variety of interpretations. Meanings have evolved over time within specific professional contexts including medicine, social work, psychology and education, although the certainties that were once associated with professional boundaries are blurred and no longer tenable (Nunkoosing, 2000).

Three commonly used clinical definitions of intellectual disability are those of the World Health Organisation ("ICD-10"), the American Association on Mental Retardation ("AAMR") and the American Psychiatric Association ("DSM-IV"). Their definitions of intellectual disability, or "mental retardation" are:

- **ICD-10, 1992**: Mental retardation is a condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills, manifested during the developmental period that contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities.
- **AAMR, 1992**: Mental retardation refers to substantial limitations in present functioning. It is characterized by significantly sub-average intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work. Mental retardation manifests before age 18.
- **DSM-IV, 1994**: The essential feature of Mental Retardation is significantly sub-average general intellectual functioning (Criterion A) that is accompanied by significant limitations in adaptive functioning in at least two of the following skill areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety (Criterion B). The onset must occur before age 18 years (Criterion C).

All definitions describe a person with an intellectual disability as having a significant, lifelong condition with three significant characteristics:

- Reduced ability to understand new or complex information or to learn new skills;
- Reduced ability to cope independently; and
- A condition that began before adulthood (before the age of 18) with a lasting effect on the individual's development.

People with an intellectual disability will require a range of support and assistance that will be dependent upon their individual needs. These needs will vary in accordance to a range of factors such as the age of the person and their lifestyle, preferences and living circumstances. The level of support required will differ. An individual may need the following (see Mental Health Foundation, 1993)

- Occasional and short-term support (intermittent support) where the person may not always need the support or may need only short term support during their life. Support may be high or low intensity, simple or complex. It is used for a specific purpose and to provide general support for a person on an "as-needed" basis. It may also be necessary to support someone in a certain setting.
- Time-limited support that may be high or low intensity and complex. Such support is limited by time or by some other resource and is typically to support the person through a difficult period or when moving from one stage to another in their lives.
- Regular long-term support that usually involves regular help (for example, daily) in at least some environments and is not limited by time.
- Constant and highly-intensive support that is constant and very intensive support provided across different environments. It could involve medical care to keep the person alive. High-intensive support typically involves more staff and resources.

Although the most frequently cited definitions have been explored above, there are many definitions of intellectual disability and equally complex descriptions of levels of support required. Lack of consistency and clarity in the terminology and definitions relating to intellectual disability can be considered a barrier to service development and has contributed to confusion regarding the population. For example, the descriptive term used in the USA is mental retardation or developmental disability whereas the term used commonly in the UK is learning disability. Subtle differences in each descriptive term used can be identified.

Regardless, intellectual disability is formally conceptualized in most definitions with regard to deficits in adaptive behaviours, cognitive ability and the appearance of these problems during the developmental period (Sturmey, 1999). The severity of the disability is linked to need for life-long ongoing support and assistance with basic living or functional activities.

3.2   Prevalence

Although often depicted as a minority group, people with an intellectual disability comprise a significant client group. There exists limited prevalence data and the true number of people with an intellectual disability is really unknown. Minimal demographic and health indicator information is available for forward planning and service development for people with disabilities (Janicki et al, 1999). However, numbers are increasing. As life expectancy in the general population increases in response to advances in the biomedical sciences, people with an intellectual disability are also expected to live longer (Hassan, 2000). For example, many children born and prematurely, with congenital disabilities or chronic health problems would have died often at very young ages if not birth, but now they live and survive longer (Kirk, 1999). Society will have to deal with the resultant macroeconomic costs including increased health care burden. Ethical debates are already occurring in regard to rights of access to health services, priorities in resource limitations and user pays approaches.

Australian Bureau of Statistics (ABS) disability survey provides the only source of prevalence data. In 1993, the ABS Survey of Disability, Ageing and Carers reported that there were 328,000, approximately 1.86 per cent of the general population with an intellectual disability. A more recent 1996 report on disability and disabling conditions estimated that 1.7 per cent of the Australian population responded positively to the 1993 survey screening questions of "slow at learning or understanding" (AIHW, 1997). Prevalence is likely to be underestimated but the figure of 174,000 or 0.99 per cent of the general population is generally considered to be the best figure to use for an overall estimate of the prevalence of intellectual disability in Australia (AIHW, 1997).

Intellectual disability has traditionally been quantified with the terms mild, moderate, severe and profound according to the severity of disability observed, e.g. the ICD-10 adopts this approach. Current preference tends to be shifting towards a descriptive approach of the range of support required as used by the Mental Health Foundation, 1993 (refer above). Regardless, the prevalence of people with moderate, severe or profound intellectual disability is approximately 3-4 per 1000. This is much less than that of mild intellectual disability at over 30 per 1000 (Martin & Martin, 2000).

Over the past fifty years prevalence rates have differed according to the definitions of intellectual disability used in research studies (Borthwick-Duffy & Eyman, 1990). Influences on prevalence rates include improvements in medical/health care, technology, and shifts in society's attitudes towards disability. It is interesting to note that the number of Australian people with an intellectual disability is similar to the indigenous population of Australia who also experience premature death and chronic health problems. While there is general agreement that Aboriginal people and Torres Strait Islanders need access to specialized health programmes and interventions to redress their health needs, the health needs of people with an intellectual disability are not similarly acknowledged (Lennox et al, 2000).

3.3   Vulnerable Health Status

The closure of long stay institutions in recognition that people with an intellectual disability had the right to live a "normalized" life within the community has already been discussed. Despite the implementation of community care policy across Australia, it is disappointing to note that the changes that followed over the last two decades appear to have done little to improve the health status of people with an intellectual disability. Systemic problems are revealed when the health care status adults with an intellectual disability are reviewed. Admirable values and goals are associated with philosophies of care implicit in service provision but the person with the intellectual disability typically takes the blame. Rather thank acknowledging fault with the health and human service system, people with disabilities are attributed with responsibility, e.g. their health needs are complex, service provision stresses the system and so on.

Despite such myths, the need for comprehensive health services to meet both the routine and complex needs of this population has been noted in the literature for some time (Ziring et al, 1988; Criscione et al, 1993). Studies of primary health care services are generally critical of the adequacy of detection and management of secondary conditions, preventative care and prescription practices (Wilson & Haire, 1990),

3.3.1 Morbidity and Mortality

Life expectancy of people with an intellectual disability has increased over the last three decades (Barr et al, 1999) although there is evidence that suggests adults with an intellectual disability continue to experience a shortened lifespan (Janicki & Deb, 1994). Problems can be associated with genetic causes, poor quality of life, austerity of life experiences and opportunities, stress and low expectations on the part of carers, professionals and the client group (Martin & Martin, 2000). It is also anticipated that health problems related to the ageing process including stroke, cardiovascular disease, and malignancy will also be of increasing concern as life expectancy increases (Aspray et al, 1999). For example, old age and disabling conditions, particularly intellectual disability is the greatest single source of healthcare costs (8.1per cent of total) in the Netherlands (Meerding et al, 1998).

Research demonstrates that although the morbidity is treatable, people with an intellectual disability experience numerous unrecognized or poorly managed medical conditions when compared to the general population (Wilson 1990; Beange, 1995). Health problems experienced include a high prevalence of obesity, heart disease (Turner& Moss, 1986), hearing and/or vision impairments, dental pathology (Hinchcliffe et al, 1988), epilepsy, hypertension, musculoskeletal problems (Howells 1986; Beange et al, 1995) and increased psychiatric morbidity (Roy et al, 1997). Polypharmacy, inadequate review of medications and a high prevalence of side effects are also characteristic of people with an intellectual disability (Lennox et al, 2000).

A recent Australian study showed that a group of adults with an intellectual disability living in a affluent area within Sydney, showed on physical examination, an average of five serious medical disorders with only half of these conditions having been detected or treated (Beange, 1995). The mortality rate has been quoted to be at least 10 times that of the general population (Beange, 1995). This group consults a medical practitioner twice as often as the general population, admission rates to hospital have been estimated at twice the Australian average rate, and these vulnerable people are said to undergo many more operations (Beange, 1996). The study demonstrates that more than half of the group took prescription drugs daily, a third were taking multiple drugs, and five per cent were taking more than four drugs.

3.4 Aetiology/Cause

Aetiology refers to the causes of the disorder or intellectual disability. The causation of intellectual disability has an important role in health assessment. Identification of the cause should guide and direct clinical interventions and treatments. There are around 500 genetic disorders associated with intellectual disability with approximately 25 per cent of these genetic conditions showing clinical effects upon the brain and central nervous system (Harris, 1998). Advances in modern diagnostic technology means that in more than 80 per cent of cases, aetiology can be established where people have moderate and more severe levels of intellectual disability (Graves, 1997).

The American Association on Mental Retardation (1992) associates the "cause" of intellectual disability with:
- prenatal causes:
  - chromosomal disorder (e.g. Down syndrome or Fragile X syndrome);
  - syndrome disorders (e.g. tuberous sclerosis or Sturge-Weber syndrome);
  - inborn errors of metabolism (e.g. phenylketonuria (PKU);
  - developmental disorders of brain formation (e.g. spina bifida or hydrocephalus);
  - environmental influences (e.g. placental insufficiency); or
  - thalidomide (drug/toxin);
- perinatal causes
  - intra-uterine disorders (e.g. toxemia/eclampsia or birth trauma); and
  - neonatal disorders (e.g. hemorrhage or meningitis);
- postnatal causes
  - head injuries (e.g. cerebral concussion or intra cranial hemorrhage),
  - infections (e.g. encephalitis or parasitic infection);
  - de-myelinating disorders (e.g. post-infectious disorders);
  - degenerative disorders (e.g. Rett's disorder or Friedreich ataxia);
  - seizure disorders [a]e.g. myoclonic epilepsy or Lennox-Gestalt syndrome);
  - toxic metabolic disorders (e.g. Reye syndrome or lead intoxication);
  - malnutrition; or
  - environmental deprivation (e.g. child abuse and neglect and hypo-connection disorders).

3.4.1 Diagnostic Challenges

Trends suggest that the need for services and support will continue to increase in response to the growing number of people with disabilities who are living longer. Intellectual disability is a chronic condition but the developmental model of intellectual disability emphasizes that learning is a lifelong process and that benefits accrue from early intervention and lifelong opportunities for growth and self-improvement. The existence of an intellectual disability and understanding of its cause or causes should not result in inaction. The search for understanding of aetiology and causation should take the person, their carers and supporting professionals on process of discovery involving thorough assessment (Battaglia et al, 1997).

The search for a diagnosis based on aetiology is important because conditions responsible for the development of an intellectual disability can also result in increased risk of additional morbidity, i.e. health problems (Stein & Ball, 1999). Adults with an intellectual disability experience medical disorders and health problems that can be clearly linked and associated with the aetiology of their disability (phenotypes). For example, some medical and health related problems experienced by adults with an intellectual disability are syndrome specific eg:
- Williams syndrome – cardiac abnormalities, hypertension, visual problems, scoliosis, hypotonia and renal abnormalities; or
- Rett syndrome – refractory errors, epilepsy, vasomotor instability, hyperventilation, apnea, reflux, feeding difficulties and growth failure.

Initial assessment should ideally involve careful observation of physical features, behaviours and family and social history that can assist with specific diagnosis of the cause. A genetic condition can contribute to the person's presentation and complaints (Ryan & Sunada, 1997). The effects of some progressive developmental disorders can also be slowed or prevented through early diagnosis and treatment (Harris, 1998).

Regular surveillance of health status and increased access to primary care are important if prevention of the development or delay that impacts their conditions on adaptive competence and the promotion of healthy ageing (Kapell et al, 1998). Accurate diagnosis can also contribute to treatment and interventions in addition to providing:
- An explanation of, and further information about specific aspects of the particular developmental problems and difficulties;
- Information about possible medical or educational implications, i.e. ongoing management issues;
- Accurate information about genetic risks, e.g. may be useful for the family;
- An opportunity for carers to establish contact with established organisations or support groups organized for those with similar aetiology (Tracey & Graves, 1999).

Adults with an intellectual disability experience increased susceptibility to central nervous system dysfunction and psychosocial vulnerability. This vulnerability can be considered as a risk factor for health status compromise by a range of biomedical and psychosocial factors. Intellectual disability has been described as a "barometer" which sensitively measures the impact of both physical and social insults (Hallahan & Kauffman, 1994). Regardless, an incorrect view exists within the community that diagnosis that is inclusive of the cause of the intellectual disability is unimportant. Some disability service providers have erroneously reduced the benefits of diagnosis and aetiology to unnecessary medicalisation of disability. Some believe that a diagnostic approach has nothing to contribute to the care and support of people with an intellectual disability (Ryan & Sunanda, 1997).

The Census Conference of the American College of Medical Genetics established guidelines regarding the evaluation of patients with intellectual disability (Battaglia et al, 1999) that emphasized the high diagnostic utility of cytogenetic studies and neuro-imaging in combination with comprehensive physical assessment. Such recommendations have implications for ongoing management and treatment of this vulnerable population. The WHO/IASSID health guidelines for adults with an intellectual disability, are also relevant (Beange et al, 1999).

3.5   Misdiagnosis and Mismanagement

There is growing evidence and general agreement that health care problems in this population are unrecognized, misdiagnosed and poorly managed (Beange, 1995). Health care services provided to people with an intellectual disability, particularly by General Practitioners, have been criticized in relation to their failure to:
- Detect and treat health problems and medical conditions; and
- Use preventative health care approaches aimed at reducing health problems (Turner & Moss 1996).

Health professionals often neglect health care problems because they incorrectly perceive that health promotion lies with "treatment" of the individual's disability (Keane, 1996). Diagnostic overshadowing commonly results in adults with an intellectual disability being left without the medical and health services that they require. The term "diagnostic overshadowing" refers to the situation when the intellectual disability is attributed to the presenting problem, e.g. the existence of the intellectual disability is said to explain health problems or perhaps behavioural problems (Turner & Moss, 1996).

Medical problems in adults with an intellectual disability can present atypically and require distinctive clinical skills to detect, diagnose and treat effectively (Kapell et al, 1998). Signs and symptoms of disease and illness can be difficult to identify. Assessment is complicated and compromised by reliance upon carers for assistance, particularly if the person with the intellectual disability cannot communicate and the health professional is reliant upon them for information. Health problems identified may be rarely part of the person's chief complaints at assessment and the major health problem may be missed or undetected until a comprehensive health assessment is undertaken (Ryan & Sunada, 1997). Diagnosis and treatment can be severely limited by:

- Lack of capacity to self-report signs or symptoms of being unwell;
- Atypical presentation of symptoms;
- Necessity to use modified diagnostic methods;
- Doctors' lack of knowledge and experience (Evenhuis, 1999).

Research from the USA, Australia and the United Kingdom demonstrates problems associated with community-based primary health care accessed by people with an intellectual disability. People with complex health care needs may have contact with numerous health care providers including dentists, specialists, chiropodists, General Practitioners and so on. However, the quality of this contact and impact upon the health outcomes of people with an intellectual disability, needs to be considered carefully. Multi-disciplinary involvement is valuable but optimum case management is more desirable (Walsh et al, 1997). Coordination of primary specialist and tertiary care with mental health, rehabilitative, residential and behavioural services are required for the optimum management of medical conditions and for health promotion in this population (Walsh & Criscione, 1997)

The health care needs of this population present obvious challenges to services. However, quality health care is essential for this group of people (Kerr, 1995) because of the increased health care risks when compared to the general population (Beange et al, 1995; Turner & Moss, 1996). Such findings in a minority population commonly result in concern and demand for equity in access to primary health care. Unfortunately the historical consequences of increased health care risks for adults with an intellectual disability include past indifference and contemporary apathy (Beange et al, 1995). The literature encourages a more positive outlook that focuses upon a proactive and preventative approach.

4.   Part C: Service Delivery Barriers including General Practitioner Barriers

*Part C considers the relationship of the General Practitioner with adults with an intellectual disability but initially looks at **related Service Delivery Provider Barriers**. The management of the health care needs of people with an intellectual disability within the general practice and primary health care settings are discussed.*

4.1   Service System Barriers

4.1.1 Attitude and Belief Systems

"The feeble minded are a parasitic, predatory class, never capable of managing their own affairs….They cause unutterable sorrow at home and are a menace and danger to themselves and the community. Feeble minded women are invariably immoral….Every feeble minded person, especially the high-grade imbecile, is a potential criminal, needing only the proper environment and opportunity for the development and expression of his criminal tendencies" (Fernald Walter, US pioneer in disability as quoted in Reiss, 1990)

Professionals and those providing services to people with an intellectual disability would be expected to demonstrate both positive and negative beliefs and attitudes towards the "client" or the "patient". However, health care, disability professionals and carers may make decisions about interventions that are based upon erroneous assumptions regarding people with an intellectual disability (Bond et al, 1997). Common negative

stereotypes include:
- People with disability deviate from the norm and are not normal;
- These people would be better "dead", e.g. eugenics argument;
- People with disabilities are potential carriers of traits that are socially undesirable and clinically avoidable "dead weight existences" therefore they are unworthy of treatment, e.g. they should not have survived (Koch, 2000);
- People with physical disabilities and or cognitive challenges are a social cost, resulting in lifetime financial and resource drain upon society – a burden on a modern economy because they are unable to contribute or repay the cost of their care;
- It is "medically futile" to treat people with an intellectual disability – they do not experience health problems – they are "unaware", i.e. their cognitive capacity precludes awareness of being unwell or being well — they do not experience pain – they do not "feel" – they are invisible;
- People with an intellectual disability are stuck on the evolutionary ladder as compared with non-disabled peers (Nunkoosing, 2000)
- People with disabilities cannot experience a meaningful life as enjoyed by the rest of the community – they need to be protected from themselves and the community needs to be protected from them – treatment should be given to those people who are more "worthy" of care and support;
- Accurate diagnosis is impossible unless the person with an intellectual disability has adequate language/communication skills;
- The medical practitioner is solely responsible for assessment and diagnosis of health care problems.
- Carers have a very limited role on the outside of decision making and on occasion, when invited, can assist the medical practitioner and multi-disciplinary team to demystify information;
- Related is the concept that the medical model is "out" and the social model of disability is "in", i.e. disability is a social construct and people with disabilities constitute an oppressed minority group disability within society (Oliver, 1996);
- Normalization and social role valorization equates with generic community services – specialized services could lead to segregation, separation and new forms of discrimination.

Within disability services, most discussions about medical treatment or health care and service access has taken place within the biomedical illness and disease treatment model. Adoptions of modern philosophies of care such as normalization and social role valorization ideology have resulted in a conundrum. Historically the medical model failed to accord human rights to people with disabilities. Many human services and disability workers approach medical and health services with distrust and suspicion recalling the older approach to treatment that was often reduced to custodial care – warehousing and sedation.

Contemporary research demonstrates that people with an intellectual disability living in the community experience increased health risk factors and greater rates of morbidity and mortality when compared to the general population (Beange et al, 1994; Turner & Moss, 1996). These results have moved researchers within the intellectual disability field on to debate the benefits associated with specialized services versus generic health services. However, the persistence of attitudes and beliefs that may be historically grounded, continue to influence the behaviour of disability and health workers.

Attitudes, beliefs and accepted social norms affect behaviour in health professionals and the wider population (Bowler & Gooding 1995). Attitudes and belief systems may have an instrumental impact upon the health and well-being of adults with an intellectual disability. Attitudes and beliefs have a powerful impact upon service delivery, particularly response to the client or the patient who has an intellectual disability.

4.1.2 Labeling

One of the most powerful and persistent barriers faced by the by people with an intellectual disability and by far the most stigmatizing, is being labeled as "disabled". Historically society has developed policies and strategies that have resulted in inflexibility rather than the adoption of a solution oriented approach. Policies and practices influencing services for people with disabilities have emphasized inability as opposed to capability. Belief systems driving service delivery have been based upon close-minded predictions about what people with disabilities can and cannot do (Reiss, 2000).

Labeling is one aspect but often the most easily identifiable in belief systems. It is also indicative of the pervasive impact of the attitudes. Barriers have and continue to be erected within the minds of virtually all of society's members. However, the approach is particularly constraining and of serious concern when used by those in authority who are able to offer or refuse opportunities. Barriers that exist primarily in people's minds are notoriously difficult to remove, and legislation is rarely effective as a direct means of doing so. While there are differences, either physical or mental, between people, the nature and significance of these differences depend on how we view and interpret them (Bogdan & Taylor,1994).

Rather than seeking to "fix" a developmental disorder, the social model of disability is overseeing a paradigm shift that encourages empowerment and community participation. This model is gaining general acceptance and is informing a range of theories and practices, as it steers responsibility for disability away from the person onto society (Nunkoosing, 2000). Solutions are achieved through modifications to the person, but rather in breaking down the barriers that limit people with disabilities from full participation in their communities and in society in general. Intellectual disability is considered to be a cognitive disability caused through interaction of the person who has limited intellectual functioning with his/her living environments (Luckasson et al, 1992)

Scientific research is continuing to disprove erroneous myths and stereotypes of people with an intellectual disability. However, diagnostic over shadowing, the tendency to explain all negative behaviour and characteristics of intellectual disability remains a major barrier to health and well-being. For example, mental health needs of people with an intellectual disability are under-diagnosed and under-treated (Reiss, 2000).

4.1.3 Self-Efficacy and Lack of Confidence

Closely associated with negative attitudes and professional belief systems is the apparent lack of confidence on the part of health care service providers to provide support and assistance to people with an intellectual disability. Of interest is the concept of self-efficacy, e.g. how the belief and attitudes that the professional holds curtails their capacity to support or provide care.

It is interesting to pursue a possible link between beliefs, attitudes and caring or professional behaviour (Bandura, 1986; Bandura ,1977). Key beliefs and attitudes may play a crucial part in the health intervention. Attitudes or beliefs may impact treatment choices made, the effort or associated energy that empowers or drives a health intervention, and finally how much confidence that the health care provider displays or draws upon in their particular course of action or inaction.

4.1.4 Culture

The simple provision of a comprehensive health care service or programme does not guarantee improved health care outcomes for adults with an intellectual disability. Health care interventions need to "fit" within the organisation. The intervention must recognize and respond to the values of staff and the culture of the organisation. The service must be able to be compatible with the routines, responsibilities and expectations of the organisational culture that staff work within.

Organisations are goal-oriented collectives with highly formalized social structures, within which participants act in both formally and informally structured ways. Organisations are also strongly influenced by environmental and contextual factors. Outcomes may not be the results of organized planned activity or intentional policy. Understanding involves consideration of the full perspective of the system. Fuller analysis will follow if the policy priorities and administrative agenda of the organisation are known and assessed.

Regardless, while the activities and behaviour of direct care workers is theoretically driven by organisational rules, demands and managerial directives, organisational culture and group norms can be very persuasive. Staff act within a closed system that is defined by both explicit rules and implicit practices. The acknowledgement of both sets of rules and procedures is important (Corrigan & McCracken, 1995). Systems can work to establish programmes based on existing beliefs, written policies and guidelines. However if proposed change threatens implicit practices, resistance to change is a common response.

4.1.5 Management

Clearly service delivery staff and their Managers do not operate within a vacuum. Formal and informal hierarchies operate and these in turn exert influences upon staff and client behaviour. Organisational and work culture influences relationships between direct care workers and the clients that they support. A culture that embraces social support can lead to great worker cohesiveness, staff morale and work satisfaction (Schulz, 1995). Managers and their management practices have an equally important influence upon the direct care worker's environment. Managers play significant roles in managing stress and buffering feelings of burnout (Schulz 1995). Organisational requirements of Managers include interventions that aim to:
- Eliminate negative work stressors;
- Strengthen staff resources; and
- Promote staff health and well-being (Petterson & Arnetz, 1998).

Typically management interventions tend to focus upon the actual workload of staff or their productivity. Managers are often required to exercise their discretion when efficiently matching resource and client need. They are challenged by the economic rationalist decree that argues that they do more with less. Conventional practices within health care and human services, involves assigning intensities of both clinical services and treatment settings in a linked manner according to impairment severity (McGee & Mee-Lee, 1997).

Fundamentally this means that resources are allocated to those most in need, typically clients with challenging behaviour and high support needs. One study found that working with clients with high support needs, e.g. highly impaired functioning, severity had no effect or difference on staff burnout (clients with highly impaired functioning) (Schultz et al, 1995) Anecdotal experience of services is very much that improved staffing may have little effect on improved client outcomes.

It is important to note that organisational factors are strongly associated with staff outcomes, rather than factors relating to client characteristics. This pattern is consistently found in community-based accommodation options for people with an intellectual disability (Hatton et al, 1995) Negative attitudes about their auspicing organisation can impact the quality of care delivered to people with an intellectual disability (Blumethal, 1998). While the daily responsibilities of care rests with the direct care worker, these workers require the support of skilled Managers and supervisors. Interactions with management need to adopts a collaborative approach that strengthens effective medical, preventive and health maintenance interventions take place.

Bureaucratic constraints associated with workplaces prevent staff from developing and maintaining many psychosocial interventions, e.g. the need to spend time completing charts or other administrative forms undermines clinical or therapeutic interventions (Corrigan & McCracken, 1995). In some organisations, management may be unwilling to support financially and emotionally, particular programmes or approaches. Systems and organisations can react negatively to change and creativity.

4.1.6 Service Demarcation and Boundaries

Conceptual, operational and organisational schisms exist between health services, mental health services and intellectual disability services. In the USA confusion surrounding the distinction between intellectual disability and mental disorder has been a major obstacle to service delivery (Bouras & Szymanski, 1997). Services have developed separate and individual frameworks for service entry and support that is often based upon subjective or arbitrary criteria. Service delivery in Australia to people with an intellectual disability is characterized by demarcation disputation and jurisdictional challenges using legislation, policy documents and internal eligibility frameworks. Inter-agency communication is at best, rudimentary and access to and between services systems problematic.

Services also demonstrate lack of commitment to people with an intellectual disability (Reiss, 1994). The health care needs of adults with an intellectual disability hold poor credibility and tend to be relegated to the bottom of the policy heap in regard to priorities. The end result is no clear responsibility, fragmentation of services when available and poor quality. The need exists within Australia for an integrated collaborative policy that crosses boundaries and provides a multi-disciplinary approach to the health care needs of people with an intellectual disability. Health interventions need to involve multiple professions and be based upon preventive and pro-active intervention.

4.1.7 Turf Battles: Failure to Collaborate

Under policies driven by economic rationalism and resource constraint, services must be conducted efficiently and effectively. "Grey" areas in skills and expertise can be lost, or shunted around, causing conflict (Rodgers, 1993). Professionals also tend to keep strictly to their position descriptions and to rigid interpretation of eligibility policy. Eligibility policy develops to become a tool to exclude difficult and complex consumers, rather than to meet "need". Opportunities for cross boundary collaboration and networking are not encouraged, but actively discouraged in pursuit of budgetary consideration.

Job identity and a sense of knowing the working role results from identification with the worker's profession and sometimes their employing agency, i.e. the organisation. The organisation is typically self-interested and driven to take care of its members and their roles or responsibilities. Whilst this "role-caring" responsibility has benefits, the detriment is revealed when separatism or territoriality develops in response to real or perceived threats (Jackson & Jong, 2000).

The pressure for collaboration or integration poses threats to the organisation which often results in the so-called "turf battles". Boundary protection is clearly apparent in the interactions between health and disability service professionals. Strategies can involve (Jackson & Jong, 2000):

- Protective communication aims to protect the image of the organisation or the profession and involves the avoidance of taking on additional work, committing to change or admitting not knowing;
- Negative consensus is a strategy that prevents collaboration by use of "lip service", i.e. agreements are made but there is no genuine commitment and no action follows;
- Power plays involve the avoidance of taking on practical issues or difficulties by insisting upon a particular preferred outcome;
- Clinical steamrolling refers to the use of professionals' or Managers' knowledge base or jargon to coercively push others into a particular decision or outcome.

The lack of opportunity for cross disciplinary collaboration can be partially explained by diverse professional or managerial perspectives and ideologies. Each professional lays ownership to a particular body of knowledge and values. Professionals acquire these particular values and moral attitudes over time and tend to assume a distinct and typically oppositional stance to one another (Rodgers, 1993). Despite skill overlap and "sharing" of the client or consumer, professionals seem to develop independent terms of references, using a different language, a separate perspective and models of support. If professionals fear showing lack of knowledge or competence with people with an intellectual disability, collaborative discussions will be impeded.

Services may have also developed separately driven by the priorities and belief systems of the professionals involved. Historical separateness is a common barrier to multi-system service development (Woodward, 1993). The educational programmes of mental health and intellectual disability professionals are so different that even their language becomes a barrier — they speak about people with an intellectual disability using different jargon (Woodward, 1993).

4.1.8 Invisibility of Clients

People with an intellectual disability lack status and visibility within different systems of support. Historically their needs, desires and requests have been placed low on society's political agenda. Blending into the background and restricted by the inability to eloquently argue their case, people with an intellectual disability can be made "invisible". Alternatively their presenting characteristics, particularly challenging behaviour can make them undesirable as clients. This "unwanted" status has historically resulted in clients being moved, shunted and sometimes "dumped" between systems (Woodward, 1993). The modern term suggests that they "fall through the cracks in the system" and disappear.

Despite strategies for collaboration between service systems and service providers, common stereotypes and negative attitudes or beliefs persist. The end result is similar, consideration of their needs can take place within an atmosphere of fear and anxiety. Anecdotal experience suggests that this is clearly the reality for people with an intellectual disability who have dual diagnosis, e.g. a concurrent mental disorder.

Staff and professionals involved with the same client with an intellectual disability can also often work in "parallel" to one another. Sometimes they are unaware of each other's involvement. Whilst they are theoretically not in competition with one another for the client's time, energy and resources, they are definitely *not* operating in cooperation. The lack of communication and coordination of care may have serious negative implications on health and other aspects of quality of life for the person with the intellectual disability (Smeenk et al et al, 1998).

Inter-professional or multi-professional collaboration is often cited as being desirable when working with people with disabilities and yet there is typically little understanding of the concept (Rodgers, 1993). Collaboration refers to working and learning together in the best interests of the person with the disability. Collaboration within this context refers to working jointly to plan the standard of health care to be provided to people with an intellectual disability. The person with the intellectual disability should be the focus with their needs actually driving the service response.

4.1.9 Inverse Care Law

Another important barrier that has already been alluded to within this report relates to the operational characteristics of the Australian health care system and most western health systems for that matter. Health services are provided on a recognition and demand basis. People in need of a health services must initially recognize that they have a health problem and then they must communicate that need for the health service to an appropriate health professional.

The onus to seek help places an additional burden upon people with an intellectual disability and the inverse care law then applies (Hart, 1971) The "inverse care law" decrees that those people most in need of medical care are the least likely to receive it. People with an intellectual disability experience significant difficulties accessing a system where health care is provided only when it is requested (Turner & Moss, 1996).

4.1.10 Resource Dependency Innovation

Despite acknowledgement that barriers or problems exist, innovation and creativity within organisations often appears to be restrained by a resource dependency framework. Typical bureaucratic responses are often guided by government policy or programme initiatives that focus heavily upon increases in resources. Commonly, requests involve requirements for more staff or increased staff" client ratios. There can exist a mind-set that all problems can *only* be solved by solutions that involve "more."

One researcher argued that the diversion of attention away from the problem to resource obtainment was part of the problem. The focus of effort contrasted with the rational understanding that resources within the organisation, personal motivation and capabilities of the "players" or participants were the key factors to success (Zakus, 1998).

While the provision of services to people with an intellectual disability is considered to be an important role within government, commitment is variable. For example, the type and degree of community participation can vary widely but is usually regarded as necessary or even essential because of the lack of government resources (Zakus, 1998). Needed resources are not easily obtainable because the community is not ready to receive them, and is not willing to receive or supply such. Rational use of resources is predicated on the assumption that personal motivation, and the capabilities of participants will be the keys to success (Zakus, 1998). Managers and policy makers therefore have an important role in shaping the environment to make change possible.

4.2   General Practitioners

4.2.1 Introduction

Community-based primary health care is the gateway to health and well-being for people with an intellectual disability (Kerr, 1998). As the backbone of primary care, the General Practitioner will be of key importance for people with an intellectual disability if they are to access quality health care. General Practitioners provide "cradle to grave" care and are likely to be involved with this population through their entire lifespan. Advocates and carers who support people with an intellectual disability will need to develop and maintain strong links with their General Practitioner (Jones & Kerr, 1997).

General Practitioners display mixed attitudes towards the provision of care to people with an intellectual disability (Stein, 2000). Yet, within the community, the General Practitioner is likely to be a major authoritative source of information and advice on health problems for the adult with an intellectual disability. As institutional reform and community care continues it's momentum, adults with an intellectual disability will place increasing demands upon General Practitioners for primary heath care services and referrals to tertiary services.

General Practitioners have had limited contact with this group of people and they have expressed doubts regarding their skills to manage their health needs (Kerr et al, 1995). Research has noted the need for better communication between General Practitioners and specialists including psychiatrists (Beange et al, 1994; Bond et al, 1997; Kerr, 1997). Communication difficulties are cited as a major concern (Lennox et al, 1997). Other concerns relate to lack of skills or expertise and perceptions that taking on a patient with an intellectual disability will result in an increased workload (Bond et al, 1997). General Practitioners appear to lack of confidence in meeting health care needs of this group of people and have acknowledged the need for specialist knowledge and skills/training (Stein, 2000).

4.2.2 Frequency of Contact

The General Practitioner is the health professional most frequently consulted by adults with an intellectual disability who live in the community (Cumella et al, 1992; Evans et al, 1994). However, disagreement exists within the literature in regard to whether people with an intellectual disability consult primary health care more or less frequently than the general population. One researcher concluded that 78 adults with an intellectual disability participating in the study used their General Practitioner very little (if any) more than the control group without disability (Langan et al, 1992). Another study of people with an intellectual disability who were relocated from long term care into the community showed that this group made increased demands upon the primary health care team (Chambers et al, 1998). Other researchers argue that people with an intellectual disability consult primary care teams more frequently than the general population (Stein & Ball, 1999).

A 1998 UK study that suggested that adults with an intellectual disability were less likely to visit their General Practitioner when compared to the general population highlighted the group's failure to regularly access preventative health services (NHS, 1998). Another study cautioned that an increase in consultation rates did not necessarily equate with improved health care status or outcomes, e.g. getting the group to the doctor more frequently would not necessarily result in improved health care outcomes (Stein & Ball, 1999). While it is not clear why some people with an intellectual disability do or don't go to their General Practitioner, it appears likely that the attitude of carers will be an important variable influencing General Practitioner demand (Stein, 2000).

4.2.3 Gatekeeper Role

Through face-to-face clinical consultation the General Practitioner is the gatekeeper to and therefore coordinator of a range of health related services available in community settings, including patient treatment and health screening. The gatekeeper role operates in part to coordinate or reduce referrals to specialists and tertiary health services including hospitalization. As a coordinator, the General Practitioner assists patients to access the full range of specialist health care services. Everyone needs a General Practitioner to serve as the point of access to medical care, including specialist health care. The role also supports a system of health care practice that aims to maintain continuity of care over time. Continuity of care is associated with higher compliance of medication use, fewer hospitalizations, and lower overall costs (Bodenheimer, 1999).

General Practitioners have the potential to provide a wide range of services to their patients, including those with an intellectual disability:

- Hands on assessment, diagnosis and treatment of emerging/acute health care problems;
- Ongoing health care treatment/chronic health care problems and management of associated health conditions;
- General health care management including health promotion and preventative care;
- The provision and interpretation of relevant health and related information;
- Referral to tertiary health care, e.g. consultant medical practitioners; and
- Contributions to multi-disciplinary teamwork by knowledge sharing amongst relevant health and disability professionals.

Within Australia and the United Kingdom, the General Practitioner operates as the major source of preventative health care and health promotion information. Research suggests however, that doctors do not provide preventative care at recommended levels of benchmarks. General Practitioners often describe the information overload experience, while at the same time recognizing the importance of resource and information awareness. Anecdotal experience suggests that General Practitioners are often unaware of appropriate services to refer people with an intellectual disability to.

Other related reasons for failure to provide preventative care include lack of training, low confidence levels, fears, beliefs and lack of health knowledge (Bowman et al, 2000). Other reasons may include forgetting to provide preventive care, negative attitudes towards such care or low confidence in the effectiveness of such care (Bowman et al, 2000). When people with an intellectual disability do access primary health care services, the quality of that service appears to be compromised (Rodgers, 1993). Some General Practitioners in the UK use registers to track patient health status. If the quality of health care is to be improved to adults with an intellectual disability, General Practitioners may need to consider the development of a special needs register to track and monitor health status and outcomes of interventions (Martin & Martin, 2000).

The General Practitioner also has an important role is ensuring that those people who have health needs are aware and can access a range of health services available in the wider community. This role involves more than health assessment and clinical management. General Practitioners facilitate access to a variety of health and related support services including traditional and non-traditional community services. The need for better linkages between primary health care led by the General Practitioner, other health and community services, and consumer and community has been noted within Australia (CHF, 1999). Also well recognized, is the fact that adults with an intellectual disability have complex needs and often require multiple services from a range of community-based health and disability services. The General Practitioner has a central role in providing access to community-based services and agencies.

In recent times Australians have expressed a diversity of views regarding key roles for General Practitioners. Some have argued for increased self-management and participation in decision-making whilst others preferred that the General Practitioner remain within a more traditional role, e.g. the family doctor who faithfully manages all aspects of their health related care. A national consumer driven organisation, the Consumer Health Forum (CHF) conducted Australia wide community consultations during 1992. During these consultations concerns were voiced about the gatekeeper role of General Practitioners. Concerns related to control aspects of the gatekeeper role, e.g. total control of their health and well-being managed was typically handed over to General Practitioners. Total control was perceived as being problematic when General Practitioners had poor knowledge of community services and networks . The logic followed, how could the General Practitioner effectively link patients with appropriate community-based services when they were isolated and often unaware of the most appropriate professionals or alternative health services (CHF, 1999).

The vulnerability of people with a disability was also noted by the CHF. During 1992/93 consumers from Australian disability groups also expressed their strong concern about the gatekeeper role by suggesting that *"General Practitioners are gatekeepers for other social goods" "…they control access through the need for a prescription (at the price of a consultation) to a range of "basic living aids" in relation to bowel and bladder functions… General Practitioners also provide, and therefore control, access to a host of non-health services, as well as health related ones"* (CHF, 1999).

4.2.4 Health Checks and Screening

People with an intellectual disability share with all members of society, the same needs for disease prevention, diagnosis and the management or treatment of illness. Although not all adults with an intellectual disability will have complex health care problems there appears to be practical benefits associated with an annual physical examination for this vulnerable group. Health status can be improved by General Practitioners opportunistically checking health areas of most concern in people with an intellectual disability (Jones & Kerr, 1997).

Comprehensive health care includes access to health education, preventative services, diagnostic and therapeutic services and rehabilitation. It is the General Practitioner who provides a person with an intellectual disability access to all levels of health care, including primary, secondary and tertiary services. The benefits associated with preventive screening through regular health checks, provided by the General Practitioner are of great interest to researchers. Health promotion for people with disabilities is the same as that appropriate for people without disability although needs differ (Keane, 1996). The potential of these tools of health promotion for people with an intellectual disability is under scrutiny although the evidence based value remains inclusive at this stage (Stein & Ball, 1999).

Research has suggested that comprehensive health screening has the ***potential*** to improve health and well-being by showing the high prevalence of undiagnosed medical conditions and disorders in people with an intellectual disability living within the community (Howells, 1986; Wilson & Haire, 1990). Annual physical examination of people with an intellectual disability is a suitable method to enable treatable conditions to be detected. Ideally the end result with be improved health status and therefore an increase in health gain (Stein 2000).

Numerous researchers continue to emphasize the importance of comprehensive health assessment to prevent, delay or minimize disease, risk factors and pre-existing health problems or medical conditions (Lennox et al, 2000). Comprehensive health assessment has the capacity to increase health gain by enhancing both health status and quality of life for people with an intellectual disability.(Towell, 1997).

Research also acknowledges the likely effect of a range of mediating factors with influence on health outcomes. For example, health checks or screening may be viewed as an end in itself and may fail to result in improved health care outcomes eg. the person gets to the doctor but little else happens (Stein, 2000). Carers and professionals may not respond favourably to a referral when the reason for the referral is a group of symptoms that they have become accustomed to, or which is perceived to be refractory to treatment (Roy et al, 1997). Carers may not perceive the problem to be severe enough to warrant attention (Roy et al, 1997).

General Practitioners, other primary health care providers and carers may also benefit from access to evidence based practice standards (Lennox & Kerr, 1997). Evidence based guidelines are currently in demand by health and medical services across the western world. Health guidelines for people with an intellectual disability were recently released by IASSID Special Interest Research group on Health Issues and have been reproduced in the Appendices. These best practice guidelines were developed by IASSID in conjunction with the World Health Organisation (WHO) in recognition of the health care problems experienced by people with an intellectual disability (Lennox et al, 2000). These guidelines may prove to be of some assistance to General Practitioners, primary health care professionals, disability service providers and those who care for and support people with an intellectual disability.

Effective health promotion for people with an intellectual disability requires joint and collaborative relationships between health care practitioners, disability services staff and carers (Barr et al, 1999). The role of carers, direct care staff and other significant people such as key workers also important and research may need to take these variables into account when evaluating health guidelines for this population. For example, carers' attitudes are important determinants of demand for health service (Chambers et al, 1998; Stein, 2000).

General Practitioners acknowledge their gatekeeper responsibilities to people with an intellectual disability but appear to hold negative views regarding the provision to provide annual health screening (Kerr et al, 1996; Stein, 2000). The disparity may have related to lack of knowledge of the importance of health screening for the vulnerable population, rather than lack of interest in regular health checks (Kerr et al 1996). There is also no clear agreement regarding whether annual health checks should be carried out by General Practitioners or opportunistic health screening (Jones & Kerr, 1997).

There also appears to be consensus within research that health screening is most useful when identifying functional disabilities and preventing secondary handicap. Health screening specifically targeted at remediable health problems was considered to be clearly beneficial in people with an intellectual disability (Jones & Kerr, 1997). A survey completed during 2000 by the UK Royal College General Practitioners (RCGP (UK), 2001) found that most General Practitioners (74 per cent) favour a structured health check, and a majority (83 per cent) would wish remuneration for doing them. Such proposed interventions have resource, training and service implications, which people with an intellectual disability rightly deserve to have spent on their behalf for their health and well-being and welfare.

However, given pressures of time and other barriers to service provision in this population, opportunistic health screening in unlikely. Providing that such limitations are acknowledged and ideally remedied, health screening has the potential to improve the health of people with an intellectual disability (Barr et al, 1999).

4.2.5 Obstacles in the General Practice Setting

Studies assessing General Practitioner services provided to people with an intellectual disability in community settings have consistently identified numerous shortcomings (Wilson & Haire 1990; Beange et al, 1995). Research has identified a set of related problems that compromise the management of health care problems of people with an intellectual disability within the general practice setting. Major obstacles experienced by General Practitioners include:

- Inadequate access to medical history and current information on which decisions regarding diagnosis and treatment can be made (Minihan et al, 1993);
- Cognitive/verbal limitations of patients with an intellectual disability therefore making effective communication either problematic, time consuming or impossible (Cumella et al, 1992; Minihan et al, 1993; Beange et al, 1995, Beange, 1996; Plant, 1997);
- Difficulties associated with working with multiple carers, including reliance on paid staff for information and treatment follow up; and
- General isolation resulting in lack of support by other professionals with expertise and knowledge despite the need for advice or referral for additional services (Stein, 2000).

In response, adults with an intellectual disability may receive a lower standard of primary health care when compared to the general community (Plant, 1997). The existence of negative perceptions about the "fit" of adults with an intellectual disability into general practice will have repercussions upon the provision of health services to this population. Many General Practitioners may well be "interested" in seeing people with an intellectual disability within their practices, but they are frustrated by limitations in their medical training, knowledge and resources (Lennox & Chaplin, 1996). As a result of limited expertise, many medical practitioners will be unable to effectively prescribe medication for this group, diagnose appropriately or seek appropriate health and well-being solutions. General Practitioners lack confidence in working with people with an intellectual disability (Plant, 1997) and consider that:

- Their role is limited with this group of people, e.g. prefer a "specialist" with relevant expertise to be involved (Plant, 1997);
- Experience problems with communication between primary care and specialist services (Stein, 2000);
- Lack knowledge about available community services and support (Lennox & Chaplin, 1996);
- Don't communicate amongst themselves about the needs of people with an intellectual disability and don't coordinate services (Cumella et al, 1992; Lennox & Chaplin, 1995; Lennox & Chaplin 1996).
- Poor remuneration leading to inadequate reimbursement for time spent by General Practitioners in clinical consultations with adults with an intellectual disability is another recurrent theme in the literature (Beange & Bauman, 1990; Mininhan et al, 1993; Beange, 1996; Lennox & Chaplin, 1996; Plant, 1997).

The complexity of the health care assessment means that extra time is required to collate and consider appropriate information when compared to the ordinary consultation. This is often the experience when the patient with an intellectual disability requires further consultation time because of communication problems (Stein, 2000). Medicare and health funds do not adequately financially reimburse General Practitioners for the additional time spent with adults with an intellectual disability. Some General Practitioners with relatively large number of people with an intellectual disability on their caseloads suggested that their practice could not financially afford to offer health checks. As a result, some General Practitioners have requested special remuneration to manage the health care of this population (Stein, 2000).

Another related obstacle to effective service delivery is the limitations of short consultation times on history taking and diagnosis (Beange, 1996). Adults with an intellectual disability were considered to have negative workload implications because their consultation routinely involved more time than the "average" patient (Martin et al, 1997). Pressures associated with heavy workload and time constraints associated with seeing patients is a frequently reported stressor in Australian general practice. General Practitioners ascribe stress to (Schattner & Coman, 1998):

- Time constraints associated with seeing complex patients;
- Phone interruptions during consultations;
- Too much work to do within a limited time period; and
- Paperwork.

The extent to which General Practitioners feel stressed by various aspects of their occupation may affect the quality of patient care they provide (Schattner & Coman, 1998). This study argued that General Practitioners were more stressed by their job context rather than job content. There may be lessons here for patients with an intellectual disability. Carers may need to be more careful about appointment times, e.g. choosing quieter periods of the day and avoiding peak rush times or busy waiting rooms. They may need to anticipate the General Practitioner's requirements including written documentation and medical information.

The contemporary General Practitioner is obviously expected to do far more than diagnose and treat disease. To effectively advocate and meet the health care needs of each patient, the General Practitioner, the patient and their carer need to draw upon the shared foundation of knowledge and skills, values and attitudes that will vary from person to person. Tasks that will need to be jointly tackled include diagnosis, investigation, treatment, education and support. Adults with an intellectual disability may need their carer to assume the role of a dedicated health advocate, to assist with successful interaction and communication with the General Practitioner. Research is required to test such an argument.

4.2.6 Communicating Signs and Symptoms

While it may be convenient to attribute blame to the system as to why health problems are not diagnosed or treated appropriately, the very nature of the intellectual disability may contribute. People with an intellectual disability experience difficulty themselves in recognizing and then communicating signs or symptoms of illness or disease (Bond et al, 1997). Despite support from carers, the carers themselves may fail to recognize that the person is unwell or perhaps misunderstand what the person attempts to communicate to them.

Health professionals and medical practitioners also experience clinical skills deficits relevant to assessment, diagnosis and treatment (Criscione, 1993). The problem is further compounded when professionals, direct care staff and carers are unaware of particular medical conditions that are more common in people with an intellectual disability. This lack of awareness can result in under-diagnosis or misdiagnosis (Rodgers, 1993).

Communication difficulties arising from the implications of the person's intellectual disability may challenge a thorough medical assessment and result in inaccuracy. The General Practitioner must take more time, exercise additional skills and display greater sensitivity when initiating, establishing and maintaining effective health communication with the patient, and often the carer (Lennox et al, 1997). Where a person with an intellectual disability cannot communicate, history and associated information of interest to the medical practitioner or health care provider must be derived from the observations or the views and beliefs of carers. The accuracy of the assessment and ultimately the health intervention will often need to be based upon the verbal or written reports of the carers. There is some evidence that the health of people living in community-based accommodation is not optimal because carers are unfamiliar with the people they support (Linaker & Nottestadd, 1998).

4.2.7 Lack of Cooperation

Adults with an intellectual disability may display a range of challenging behaviours which compromise health care or make health care access problematic (Beange et al, 1995). Many adults with an intellectual disability are unable to understand what is required of them during a comprehensive health assessment or a physical examination. Despite carer support and encouragement or even a desensitization programme, the person with the intellectual disability may be unable to fully or even partially cooperate with the health related examination.

Past experiences associated with failure to cooperate and challenging behaviour that is disruptive to others may deter carers from seeking health assessment (Lennox & Kerr, 1997). The person with an intellectual disability may display disruptive behaviour that results in chaos within busy doctors' surgeries. Unable to understand the examination, the person with an intellectual disability may refuse to undergo a physical examination and cooperation may become a problem (Bond et al, 1997). Apprehension regarding invasive treatments and screening procedures may contribute to the person's anxiety and problem behaviour (Martin et al, 1997). Client fears may be linked to traumatic or stressful experiences that have occurred in the past. Other reasons may include inappropriate use of restraint and or perhaps failure to consider modified procedures. Careful consideration may need to be given to the appropriate use of tranquilizers and sedation following exhaustion of less intrusive alternatives.

General practice consultation with people with an intellectual disability can involve emotional and labour intensive interactions. A lengthy appointment or a number of appointments may be required for the history work up and there is increased burden placed upon the carer. General Practitioners often argue that they require more time in the "ordinary" consultation. In the ideal situation, it is suggested that additional time would raise efficiency by improving the quality of decisions in primary care, particularly about prescribed drugs, specialist referrals and hospital admissions (Hart, 1998).

5.   Part D: Direct Care Workers and Barriers

Part D identifies a number of **Direct Care Worker Barriers**. The characteristics of direct care workers are explored, including aspects of their relationship with and influences upon the health and well-being of the clients that they support.

5.1   Introduction

Service delivery to adults with an intellectual disability is labour intensive. Quality services rely upon recruitment and retention of staff who are competent, highly motivated and satisfied with critical aspects of what they are employed to do (Ford & Honnor, 2000). Residential settings for people with an intellectual disability have complex social ecologies (Felce & Repp, 1992). It follows then that many variables within the living environment can potentially influence the quality of health and well-being of adults with an intellectual disability.

The needs and characteristics of the clients are inextricably interrelated with qualities and characteristics of staff (Ford & Honnor, 2000). The characteristics of individual clients, what their home is like, and personal traits and cultures of staff will directly and indirectly influence staff behaviour and interaction with clients (Evans & Moltzen, 2000). The roles, responsibilities and working conditions of direct care workers in residential settings for adults with an intellectual disability have therefore become of increasing interest to researchers (Ford & Honnor, 2000)

A better understanding of who staff are, what they believe and what they think of their clients may well be very important when considering the health care status of people with an intellectual disability. There are many inter-related psychosocial and environmental factors that can influence the relationship between the carer and the client that they support. Direct care workers display a wide variety of caring styles, behaviours and responses to clients. One research project revealed that a client with an intellectual disability likened staff to the "secret service" (Goble, 1999). The quantity and quality of the direct care worker relationship with the client will directly influence and shape client outcomes (Felce & Repp, 1992).

Regardless, there is little literature that explores the existence of a relationship between the health of people with an intellectual disability, and their paid carers. Research also needs to consider how the interactions between staff and clients can be improved, despite the central role played by direct care staff in the lives of people with a disability (Evans & Moltzen, 2000).

5.2   Importance of Direct Care Workers

Direct care workers are central to any discussion on supports and assistance provided to people with an intellectual disability. Staff issues should be an important consideration within the development of services for people with disabilities. Residential services for people with an intellectual disability are staff intensive, with staffing costs accounting for the bulk of total organisational expenditure (Felce et al, 1993). Although staff can be considered an "expensive" and important resource, there is a paucity of information on the support staff behaviours that are most habilitative for the people with a disability that they support (Evans & Moltzen, 2000).

Direct care staff acknowledge they are at the "coalface" and there are many terms to describe their exposed position – in the firing line or on the front line, at the cutting edge, where the action is happening or where the buck stops. Unfortunately organisations often consider the community settings to be unimportant. This view appears to have developed because direct care workers are at the bottom of organisational hierarchies. As a result their role in residential service provision has been under-recognized in the literature (Evans & Moltzen, 2000).

Despite the crucial role played by these staff in almost every aspect of the life of a person with a disability, researchers have largely ignored their experiences (Bromley & Emerson, 1995) Direct care staff are critically important to the health and well-being of people with an intellectual disability. Often working alone, they spend a great deal of time with these consumers and are directly responsible on a day to day basis for a wide range of health related decisions ranging from diet and nutrition through to medication. Often they receive minimal supervision from managers or peers and this report will highlight the reality that many direct cares surveyed have received little education and training in health and well-being.

In Disability Services Queensland, the RCOs (Residential Care Officers) are the group with front line responsibility for clients. RCOs are supported by Managers and multi-disciplinary teams of professionals including social workers and psychologists. Residential Care Officers are responsible for all aspects of daily care and support required by adults with an intellectual disability who live in Alternate Living Service (ALS) houses. These houses are described in some detail later in this report but are typically ordinary homes or flats located within the community. The philosophical underpinnings of service delivery in Disability Services Queensland (DSQ) (normalization, social role valorization, the least restrictive alternative, the developmental model and the dignity of risk) are meaningless unless they are actioned on a daily basis by Residential Care Officers. These carers are pivotal in the lives of the people with an intellectual disability that they support.

Research activity which draws the views of direct care staff can be compromised by data collection difficulties including high staff turnover, shift work, costs associated with shift absences or changes, distrustful attitudes, confidentiality conflicts and so on. As a result, the "views" of direct care staff are often provided second hand, by Managers, professional staff or by policy makers. Considerable "re-interpretation" takes place including reduction or underestimation of key issues. A major strength of this report, is that the opinions of Residential Care Officers and their Managers have been directly surveyed and analyzed.

5.3 Staffing Levels

Some researchers and many direct care staff suggest that the quality of care within community-based accommodation options will depend heavily upon client: staff ratios. Other researchers have rebutted this argument and suggested that the problem may not relate to the low staff to client ratios, but rather to the nature and purpose of the client staff interaction (Felce et al, 2000). Research has failed to demonstrate the existence of a relationship between the client: staff ratios and quality of life of clients (Emerson, 1999). For example, just because staff numbers might be high and programme costs also high, there is no guarantee that client quality of life will be similarly high.

In an "ideal" world one might expect that clients with high support needs that were evident over a 24-hour period would receive this support from a well resourced and reasonably numbered group of trained staff. However such logic does not always determine resource allocation or staffing numbers and profiles. Within the UK and Australia, resources within residential services for people with an intellectual disability do not appear to be allocated on a logical basis, e.g. respond to need. Similarly, the costs of programmes and associated measures of quality can also not be linked and most research has failed to discover any such association (Emerson, 1999).

Gaps between need and provision therefore appear to relate at least in part, to geography and also service characteristics, as well as the needs and characteristics of the clients/consumers. People with more severe and complex disabilities receive:

- Less support from care staff (Felce 1996; Hatton et al, 1996);
- Have less choice (Emerson et al, 1999);
- Less social integration (Emerson et al, 1999); and
- Reduced community participation in community-based activities (Emerson et al, 1999; Felce et al, 1998).

Anecdotal experience suggests that care is not provided uniformly and equitably to all adults with an intellectual disability who live in staff supported community-based accommodation. The provision of "care" will be influenced by specific aspects of what is needed, e.g. if the client is mobile, whether they can communicate and are attentive or responsive to staff and others (Seys et al, 1998). It is only reasonable therefore to note that higher staffing levels tend to be associated with increased levels of support need so that there is increased opportunity for enhanced quality of life.

5.4 Substitute Decision Makers and Advocates

Clients living in Disability Services Queensland (DSQ) supported accommodation will be clearly subordinate to and dependent upon staff. In particular regard to health care needs of people with an intellectual disability, the General Practitioner may be the gatekeeper but given the average time spent with the client, he or she is clearly not the primary decision maker. Direct care worker responsibilities therefore take on holistic parameters. The onus of responsibility for effective communication between the General Practitioner and the patient, shifts to focus upon the paid carer. Inadequate communication between the General Practitioner and the patient with the intellectual disability is clearly a major problem influencing health care outcomes for this population (Lennox et al, 1997). It is therefore logical that the need for improved interaction between direct care workers and the doctor should be of interest to researchers.

Preventative and health promotion activity aims to build on strengths and capabilities of clients, empowering them to minimize risk factor impact associated with their particularistic health conditions (Browne et al, 1995). This holistic focus must therefore be transferred to direct care workers who have assumed important substitute decision-making and advocacy roles on behalf of the clients that they support. Little research has explored the extensive and significant roles play by direct care workers as they exercise these substitute decision-making responsibilities. Many questions arise which are worthy of answers, including the impact of overburdening direct care workers with health care responsibilities given that these workers were not recruited to undertake these responsibilities, they are untrained, unsupported generally in health care intervention and may lack confidence to delivery primary health care.

5.5 Effective Caring and Support

"There would be an atmosphere of acceptance, one that is tolerant, non-critical and in which the patients experiences comfort and security….a congenial, non-authoritarian environment that would strive to minimize triggers to patient distress. Expectations that change is possible would be held by staff and would be reflected in learning opportunities offered to patients….The environment would demonstrate responsiveness to patients' needs and feelings….The climate would encourage normalization….An effective setting would have an educative function, by teaching positive alternatives to inappropriate behaviours, emphasizing patient choice in selection of formal learning programmes and ensuring a wide range of learning opportunities for patients" (Evans & Moltzen, 2000)

While not empirically validated, six principles have been drawn from a broad range of literature to define effective support, i.e. positive caregiver styles for people with a psychiatric disability (Evans & Moltzen, 2000). The following principles that attempt to define an effective therapeutic environment have obvious relevance for staff supporting people with an intellectual disability living in community-based accommodation options.

- Acceptance where an effective relationship exists between staff and the client therefore enabling positive outcomes for the person with the disability;
- Creation of a positive atmosphere in the living environment/context including a range of concepts such as patient autonomy, warmth and friendliness and tolerance for challenging behaviour;
- Expectations of change where incidental learning encourages learning opportunities;
- Responsiveness where the attributions and expectations of support staff about client behaviour determine responses, drawing upon the literature that suggests emotional and behavioural reactions to events are derived from causal beliefs about these events, e.g. people with challenging behaviour are held personally responsible for that behaviour;
- Social/social role valorization where the values based of support staff assist clients to access the typical activities of life within the community, and
- Capacity to benefit from education where support staff teach new skills to clients, including self help and independence skills.

5.6 Teamwork

It has already been stated that research suggests that a multi-disciplinary team approach is the normative approach that is considered necessary to achieve improved health gain and address deficiencies in community provision of health care for people with an intellectual disability. Despite the existence of such teams for many years in both health and disability service provision, the need exists for improved coordination (Kerr et al, 1996). Focus needs to move to collaborative care where the priority and energy is placed upon the needs of the adult with the intellectual disability, beyond the individual worker and with the involvement of the whole team.

It has been argued that multidisciplinary co-operation greatly enhances the care of people with a learning disability (Leifer, 1996). There may be, for example, difficulty with communication that a direct care worker who works with the client on a daily basis and knows the client well, can clarify. There is more chance of health concerns being decoded and understood when all the stakeholder work cooperatively together. Using the general practice consultation as an example, the quality of the individual consultation will be closely related to the quality of the communication achieved within it (Kerr et al, 1996). However, the nature of direct care workers interferes with team participation. The characteristics of shift work and budgetary restraints compromises teamwork, e.g. not all the staff can come together regularly. Multiple carers may not agree upon planned courses of action. Despite the obvious need to foster team development and a collaborative spirit, the isolation of working alone or in small number in community-based accommodation options can exhaust the best of intentions.

5.7 Health Seeking Behaviour

Insight into "how" and "what" direct care workers feel about health care and comprehensive health assessment for people with an intellectual disability may provide assistance in improving health status, service access and uptake. Researchers have recommended further investigation into the attitudes and experiences of professionals involved in primary health care and those affects upon staff behaviour (Bond et, 1997).

There is little research that addresses the interrelationships between staff beliefs and health seeking behaviour. What little exists has focused upon the impact of staff beliefs on challenging behaviour and established that there is a link between staff beliefs and staff behaviour (Hastings, 1997). Research has shown that there is a relationship between individual staff beliefs and beliefs of staff and organisational culture. Staff culture may impact outcomes of staff training (Hastings, 1997).

Despite the pivotal role of the General Practitioner as the gatekeeper to health and other human services, responsibility also lies with support staff and their employing services to ensure health care needs are met (Jones & Kerr, 1997) There is obviously some onus placed upon direct care workers to be competent health advocates. Staff beliefs and personal views about general health care may determine their decisions relating to client health interventions, e.g. passivity or activity. Perhaps the challenge for service providers is to answer the question, "how can direct care workers be meaningfully engaged and involved in maintaining health status for clients with an intellectual disability"?

Past experiences, attitudes and belief systems of staff may be critically important in regard to both indirect and direct effects on clients (Beckwith & Mathews, 1995). Staff attitudes, staff behaviour and client behaviour appear to be connected. Attitudes can have ramifications upon staff behaviour (Beckwith & Mathews, 1995) For example, staff attitudes and opinions may effect client interaction within external networks. The direct care worker role of being a health advocate can affect their ability to negotiate/mediate/access networks for, or on behalf of the client they support.

Research needs to understand what "rules" shape the interaction between direct care workers and the clients that they support when health care needs are being managed. Unfortunately there exists limited information regarding the health characteristics and health behaviour of people with an intellectual disability in community living arrangements (Rimmer & Whitfield, 1995). The attitudes of staff are important because it is belief systems that determine responses to recommended health interventions and treatment. Logically, staff beliefs will therefore influence both the provision and quality of care and support to people with an intellectual disability (Beckwith & Mathews, 1995). Negative attitudes can perpetuate a deviancy cycle where low expectations of people with reduce learning opportunities and negatively affect performance (Beckwith & Mathews, 1995).

5.8   Institution Versus the Community

The relationship between staff and clients appears to have "improved" in response to movement to community-based living options from institutional settings. Certainly accommodation options in community settings are driven by policies and hopefully practices which value a humanized approach to service delivery and support, individualized programmes and a personalized approach. Despite being "improved" from custodial/institutional models, there remains room for improvement. Far more is required than just the provision of an "ordinary" environment (Felce & Perry, 1995). Variables of interest to researchers include: managerial orientation, working methods, staff training as well as nature and size of the setting, level of staff and so on.

Movement to the community aimed to ensure that the negative characteristics of institutional life would be avoided. It is important to point out that a simple transfer to an enriched setting, i.e. a house within the community, does not necessarily result in improved quality of life (Felce & Repp, 1992) or health and well-being status for that matter. Despite living in a house in the community, life can be de-humanized and institutional. Social status and personal power may remain unchanged even though there has been change in the environment (McVilly & Rawlinson, 1998).

5.9   Stress and Burnout

Despite deinstitutionalization, people with an intellectual disability have continued to be dependent upon others. The majority of people living in community-based living options are reliant upon paid carers for many aspects of daily life (Goble, 1999). Institutional reform also resulted in changed working practices, roles and responsibilities for staff employed by community-based services. Stress and burnout associated with working with people with intellectual disability has increased with these changes. The provision of "care" has been described as an implicitly stressful activity resulting in emotional exhaustion, depersonalization and reduced personal accomplishment (Maslach, 1981). Staff in community-based residential settings have been found to be more stressed when compared to their equivalent employee counterparts in hospital settings.

Research in the UK and USA suggests that regardless of the strength of support, staff turnover is a feature of staffed housing services for people with an intellectual disability. Reasons commonly given include poor managerial and peer support, poor communication, slow client progress, violent resident behaviour, shift work, poor remuneration, poor promotion opportunities (Felce, 1993). Factors which influence why staff work in such a demanding area are complex and typically simple relationships between factors cannot been identified (Felce et al, 1993).

Many studies that have identified stress as one of the causes and consequences of staff turnover in health care settings have considered the personal background of staff, the job and organisational attributes (Hiscott & Connop, 1996). One study of staff employed in community settings, showed that need deficiencies and role ambiguity were the predictors of stress and burnout (Chung & Corbett, 1998). However, review of the literature demonstrates are inconsistent findings, e.g. contact with clients can provide relatively high level of job satisfaction whilst others felt it was a prominent source of job dissatisfaction and frustration (Chung & Corbett, 1998). Job satisfaction relates to many dimensions of work undertaken. However, the literature suggests that the personal attributes of staff and the characteristics of the employing organisation are the two most important factors contributing to job satisfaction (Ford & Honnor, 2000). Personal attributes

include age, gender, educational level and tenure whereas organisational factors include employment policies, autonomy, support, recognition and involvement in decision-making (Ford & Honnor, 2000).

Stress is a multifaceted and complex concept that is difficult to define (Parry-Jones et al, 1998). Job satisfaction is a related concept that also poses definitional challenges. There is a tendency for paid carers to appraise potentially stressful situations in terms of whether they feel they have the mental, physical, financial, material etc resources to deal with the situation to their advantage (Hatton et al, 1999). Naturally there will be different responses by staff in the same situation. The literature identifies a number of common elements among social workers, community psychiatric nurses and other community nurses that trigger stressful reactions (Parry-Jones et al, 1998):

- Heavy workloads and caseloads;
- Work relationships;
- Aspects of relationships with service users;
- Insufficient time;
- Lack of resources;
- Staff shortages; and
- Administrative responsibilities.

Research in the intellectual disability suggests that staff perceptions of their work conditions may be more important than objective analysis of factors which trigger stressful reactions (Hatton et al, 1999). Stress has also been linked to challenging behaviour of clients; poor skills; lack of staff support; lack of resources; low status; bureaucracy and work-home conflict (Hatton et al, 1999).

Research has connected the complex nature of large organisations, the work environment, staff and client characteristics, with stress. However, one study of staff working with clients with persistent and serious mental illness showed that client severity was not associated with burnout or work dissatisfaction (Schulz et al, 1995). Similarly, a small study of nursing staff working with clients with challenging behaviour showed that there were significant associations between staff burnout and management issues rather than specifically the clients' behaviour (Chung & Corbett, 1998).

Burnout typically refers to emotional exhaustion and has been attributed to inadequate training, lack of assistance, mismatches between individual knowledge and skills, insufficient feedback on role performance, style of leadership, exercise of power and decision-making processes, sanctions, rewards and status (Carroll & White, 1982 in Chung & Corbett, 1998). This research also detrimentally associated staff burnout with reduced quality of care for clients, including:

- Detached attitudes of concern by staff;
- Shift from humanized to de-humanized roles;
- Quick anger and inflexible stands;
- Cynicism; and
- Inappropriate risk taking.

Staff burnout has been attributed to the emotional demands associated with caring for people with chronic disability, e.g. serious and persistent mental illness. Consistent with this approach, one would expect paid carers of people with an intellectual disability to share similar experiences because of the longer term nature of the dependent relationships (Schulz et al, 1995). Although the evidence base appears to be weak, burnout has been associated with clients who have:

- Long term and severe illness, e.g. chronicity;
- Major social problems;
- A poor prognosis;
- Are unappreciative or unable to give thanks; and
- Are hostile towards staff providing help.

Rather than improvement of work conditions, interventions to address psychosocial stress experienced by staff typically focus upon the provision of support and control, and skills development to enhance coping capacity (Bunce & West, 1996). There exists the possibility for improvement in organisational well-being when interventions are based on needs at the workplace coupled with a positive staff attitude and commitment by management and staff towards such programmes (Petterson & Arnetz, 1998).

5.10 Client Characteristics

Characteristics of clients are of interest to researchers because of the likelihood that these characteristics may influence staff behaviour (Blumental et al, 1998). For example, clients with challenging behaviour receive greatest attention (Emerson et al, 1992). Another study considering employment within a hospital and community services found that "staff interactions with residents" was cited as the best part of the job. This rationale was also given as the main reason for staying employed within that setting (Allen et al, 1990 in Felce et al, 1993)

The quality of service delivery is also likely to be dependent upon a range of staff issues (Hatton et al, 1999). Greater understanding of health outcomes for adults within an intellectual disability may provide insight into the formal and informal rules or patterns that guide staff and client interactions. At this stage, research in this area is virtually non-existent.

5.11 Education and Training

Despite the power of their real and potential influence upon all aspects of the lives of the people with intellectual disabilities within their care, direct care workers are often the lowliest paid of staff employed within a disability service organisation. The direct care worker is also the least likely staff member to possess academic/ professional training (Golden & Reese, 1996). Adults with an intellectual disability have the right to services and support that is provided by competent, trained carers. It is therefore only logical that reciprocal rights are afforded to the carers. Direct care workers need to have access to high standards of training and education that enables them to access and utilize necessary skills and knowledge so they can fulfill their "duty of care" to the clients that they support.

The development and implementation of efficient and effective education and training programmes is important to the quality of life and health and well-being status of clients served. Effective education and training programmes should target both staff and client change, e.g (Jahr, 1998):
- Enhance and improve client outcomes;
- Maintain or improve staff knowledge and skill performance;
- Transfer knowledge and skills across settings and clients;
- Transfer knowledge and skills across and between different client programmes, e.g. disability and mental health services.

Unfortunately participation in a training seminar does not automatically result in appropriate use of acquired knowledge or skills. For example, comprehensive behavioural treatment programmes and procedures have encouraged the development of an array of staff training programmes seeking to increase the competence of staff in the application of behavioural techniques (Jahr, 1998). Despite increased knowledge regarding behavioural management, staff experience difficulty transferring skills learnt in the classroom to situations at the coalface.

There is a lack of congruence between knowledge obtained in research and the competence displayed by professionals (Jahr,1998). Education and training programmes need to target knowledge and skill deficits. Many direct care staff appear to be actively supporting clients without the relevant training. Whilst the onus of responsibility should be on the employing agency to provide needed training and education, the reality is that the onus falls upon the carers to up skill. Training opportunities are typically scarce or often inappropriate. For example, educating staff on "state of the art" theories may be interested but opportunity to access these sort of training opportunities does little for coalface staff who are currently providing care (Corrigan & McCracken, 1995).

Lessons from the Labyrinth

Chapter Three

Data Collection, Analysis and CHAP Outcomes

1.   Introduction

This chapter reports, analyses and comments on data collected from:

- A baseline questionnaire sent to a sample of staff working for Disability Services Queensland — a questionnaire was sent to Residential Care Officers and another similar questionnaire was sent to Unit Managers and Area Managers;
- CHAP outcomes recorded in the CHAP booklet completed by RCOs and the General Practitioner following the comprehensive health assessment of Disability Services Queensland (DSQ) clients participating in the study, by their usual General Practitioners; and
- Focus groups and general discussion with Disability Services Queensland (DSQ) staff.

Data provided is supported by a selected number of graphs. To ensure the report is targeted and brevity is maintained, not all graphs and data collected have been provided.

1.2   Questionnaire

In addition to the CHAP booklet that has already been described in some detail, questionnaires sent to RCOs and Managers comprised the second major data collection component. The final source of data collection was a number of focus groups discussed later in the report.

The three part, 106 item questionnaire sought general demographic information from participating Residential Care Officers in addition to their opinions, perceptions and knowledge regarding the health care needs of adults with an intellectual disability living in Disability Services Queensland (DSQ) community-based accommodation options. Part A sought Client details, Part B on General Practitioner details and Part C staff details. Responses are detailed using these headings.

Questionnaires varied slightly between Residential Care Officers and Managers although core questions were similar. Open ended questions and multiple choice questions were used in the sample. Sample questionnaires for Residential Care Officers, Unit Managers and Area Managers are located in the Appendices.

Residential Care Officers, Unit Managers and Area Managers received the questionnaire during 1999. DSQ Regional Managers at that time were also provided with a questionnaire and prompted to return the questionnaires. Regional Managers did not respond although discussion with Unit and Area Managers during the lifetime of the project, confirmed the ongoing interest and support of Disability Services Queensland (DSQ) senior management.

1.3   Study Participants

1.3.1 DSQ Staff

Disability Services Queensland (DSQ) is the largest disability employer in Queensland with over 900 direct care staff, i.e. Residential Care Officers (RCOs) employed across the state. Within the Area Offices where the CHAP programme was implemented, there were 159 RCOs at the beginning of the programme who were targeted to participate (recruitment was attempted).

Of this 159, *59 RCOs or approximately 37.1 per cent completed all aspects of the programme* (e.g. questionnaire, accompanied client to the doctor for a health check and returned the CHAP booklet to the DDU). These 59 RCOs provided information on 37 clients. Explanation regarding participation rates is provided later in the report.

A total of 19 Managers, including Unit and Area Managers participated in the study. No Regional Directors responded to requests to participate.

1.3.2 DSQ Clients

A total of 68 clients fully participated in the study. The sample represented approximately *52.3 per cent* of the 130 clients who potentially could have participated in the study. Of the total 59 RCOs who participated, 88 per cent (52 RCOs) provided data on one client; 10 per cent (six RCOs) provided data on two clients; and one RCO provided data on four clients. A total of 59 (88 per cent of the sample) provided information on only one client.

Figures 1A and 1B identify the total potential and actual number of RCOs and Managers who participated in the CHAP study. Figure 1A also identifies the number of Alternate Living Service houses that were represented in the study, e.g. the community based client homes where the RCOs worked.

It should be noted that the majority of client homes within each Area Office had at minimum, one RCO participating in the study. Sunshine Coast Area Office had the highest participation rate for RCOs and Mt Gravatt Area Office had the lowest RCO participation rates. Figure 2 identifies RCO respondents according to their Area Offices.

Figure 1A: Number of Participant Consents Received at Study Commencement

Unit	Wooloowin North		Wooloowin Central		Sunshine Coast		Caboolture		Gold Coast		Mt Gravatt		TOTAL	
RCOs	17	47	31	51	11	18	10	17	2	7	8	19	79	159
Clients	19	43	32	37	11	14	10	13	2	6	8	17	82	130
Houses	7	9	12	12	6	6	4	4	1	3	3	7	33	41
A/Managers	1	1	1	1	1	1	0	0	0	1	0	1	4	6
U/Managers	4	4	2	2	2	2	1	1	1	1	3	3	13	13

Figure 1B: Number of Participants Completing CHAP Assessment

	Questionnaires	Chap Booklet
RCO's	59	37
Clients	68	44
A/Managers	6	N/A
U/Managers	13	N/A

client by RCO
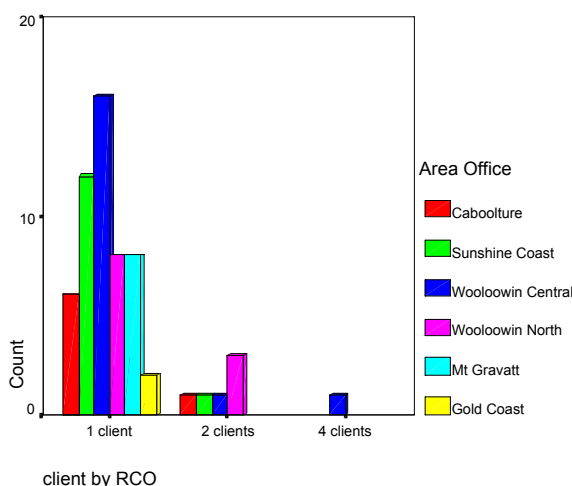
Figure 2 RCO Client Co-ordination by Area Office

AREA OFFICE	RCO - 1 CLIENT	RCO - 2 CLIENTS	RCO - 4 CLIENTS
Caboolture	6	1	
Sunshine Coast	12	1	
Wooloowin Central	16	1	1
Wooloowin North	8	3	
Mt Gravatt	8		
Gold Coast	2		

1.3.3 General Practitioners

Twenty-four General Practitioners fully participated in the CHAP study, e.g. completed a comprehensive health assessment of DSQ clients. At the recruitment phase, 40 GPs had been nominated for possible involvement therefore 60 per cent of the total number of GPs nominated by RCOs participated. The number of clients who had comprehensive health assessments completed by each GP is as follows:

- 12 GPs assessed only one DSQ client;
- 5 GPs assessed two DSQ clients;
- 1 GPs assessed three DSQ clients;
- 1 GPs assessed four DSQ clients; and
- 5 GPs assessed four clients.

1.4   Consent

1.4.1 Client Consent

Data collection began after Residential Care Officers, Managers and DSQ clients they supported had provided consent. Client consent was provided by either their Statutory Health Attorney or the Adult Guardian. No clients independently provided consent. Figure 3 details the source of consent.

Adult Guardian provided 22 consents on behalf of clients without a nominated Statutory Health Attorney

Statutory Health Attorney provided consents on behalf of 60 clients of DSQ

There were no responses to requests for consents from 22 Statutory Health Attorneys, despite written communication.

Initially, there were 105 requests made for client consents. At completion of the study, only 68 clients participated.

Figure 3 Source of Client Consents

Adult Guardian	Statutory Health Attorney	SHA – No/ No Response	TOTAL
22	60	22	104

The Figure shows that despite considerable recruitment effort, including information sheets and a number of letters directed to Statutory Health Attorneys (through the Department to protect confidentiality of SHAs), 22 SHAs either declined consent or failed to respond to requests.

1.4.2 DSQ Staff Consents

Following information sessions 79 consents out of a potential 159 RCOs were received from RCOs indicating willingness to participate in the programme (49.7 per cent). At the completion of the study only 59 RCOs out of these 79 participated fully in the CHAP programme. Reasons for non-participation are discussed in detail later in the report.

Nineteen consent forms were received from Unit and Area Managers at the commencement of the recruitment process.

1.4.3 General Practitioners' Consents

After they had provided consent through either their Statutory Health Attorney or the Adult Guardian, 68 clients provided details of their "usual" General Practitioner. There were ***40 General Practitioners*** nominated by RCOs. The General Practitioners were telephone contacted by A/Prof Lennox and following their verbal consent, the appropriate forms were faxed to them, signed by the General Practitioner and then faxed/returned to the DDU. A total of ***27 General Practitioners provided written consent to the DDU*** during the recruitment phase of the study. At completion of the study, a total of ***24 General Practitioners*** fully participated, e.g. completed 34 comprehensive health assessments.

Fifteen of the 68 clients had been (recently) comprehensively assessed by either Dr Lennox or Dr Wallace from through the DDU Specialist Outpatients Clinic. The rationale for these clients not being re-assessed by their General Practitioner is discussed later in this report. However, the comprehensive health assessment ***findings of 10 DSQ clients assessed by the DDU*** are included in the data analysis.

2. RCO Questionnaire Responses:Client Health Related Perceptions of DSQ RCOs

2.1 Part A: Client Characteristics

2.1.1 Gender

Of the total 68 clients, 45 were male and 23 were female. This representation is not unusual given that the majority of adults with an intellectual disability are male. Most clients had family or relatives involved in their lives (49 clients or 72.1 per cent).

2.1.2 Age

The youngest client was 15 years of age and the oldest was 66 years. Clients were generally "young" although there was a fairly even distribution of age ranges. There were 2 clients older than 60 years, 12 clients aged from 50 –59 years; 16 clients from 40–49; 19 clients from 30–39; and 18 clients from 20–29 years.

2.1.3 Support Needs

RCOs described most of the clients (31 or 45.6 per cent) as having high support needs. Only 10 clients were said to have low support needs (14.7 per cent) and five clients were described as having complex support needs (7.4 per cent). Figure 4 A provides details regarding RCO views of client support needs and Figure 4A describes client mobility.
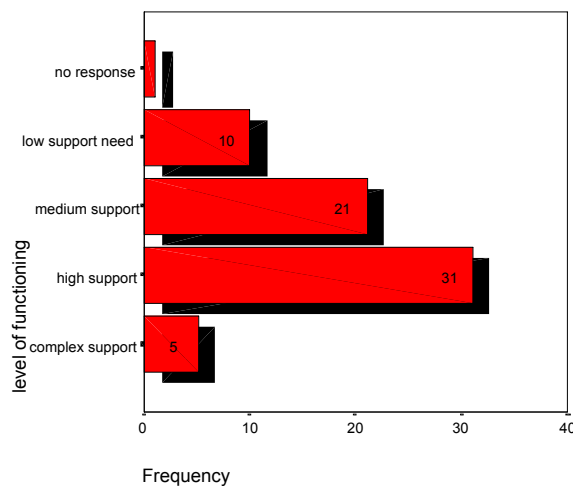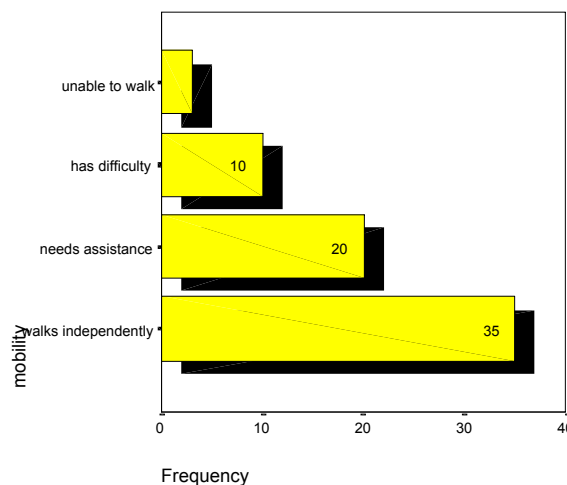
Figure 4A: Client Level of Functioning

Figure 4B: Client Mobility

2.1.4 Accommodation

Figure 5 describes the accommodation type, the number of adults with an intellectual disability sharing and how long the clients had lived there. The community-based accommodation types comprised "ordinary" dwellings situated in and typical of South East Queensland including flats, duplexes and houses with varying bedroom numbers. Some were rented on the private market or through the public state housing programme.

The majority, 43 clients lived in a suburban house that was co-shared with others with an intellectual disability (63.2 per cent). 13 clients (19.1 per cent) lived in a duplex. 9 clients (13.2 per cent) rented a flat or unit and 2 clients (2.9 per cent) lived in a townhouse.
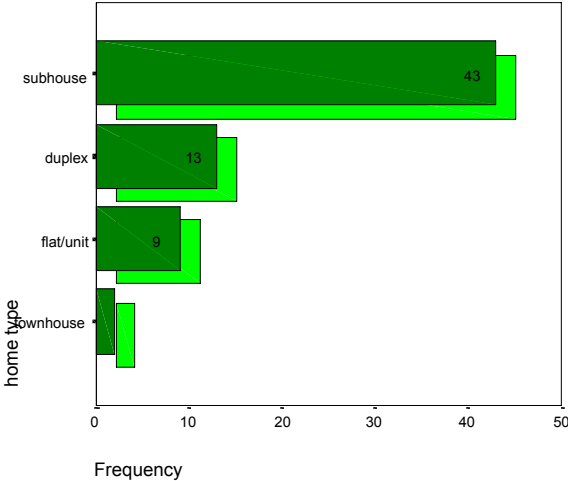
Figure 5: Accommodation Type

Figure 6 identifies how long clients had lived at their current address. Most accommodation options appear to have been long term in nature. The majority of clients had lived at their current address for longer than 12 months with only seven clients living there for less than a year (10.3 per cent). 11 clients (16.2 per cent) had been there fore more than 5 years but 50 per cent (34 clients) had been there from between two to five years.

Figure 6: Length of Time at Address
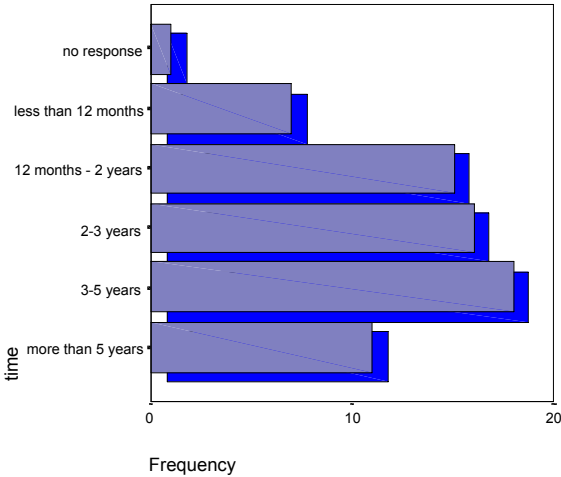
The total number of people sharing their accommodation is explored in Figure 7. The minority lived alone (4 clients or 5.9 per cent). 37 adults with an intellectual disability (54.4 per cent) shared with two or three other people. 27 (39.7 per cent) shared with four or five people.

Figure 7: Number of Clients at Shared Address

Figure 7 bar chart showing number of clients sharing their home with frequency values: lives alone = 4, 2 people = 20, 3 people = 17, 4 people = 12, 5 people = 15.
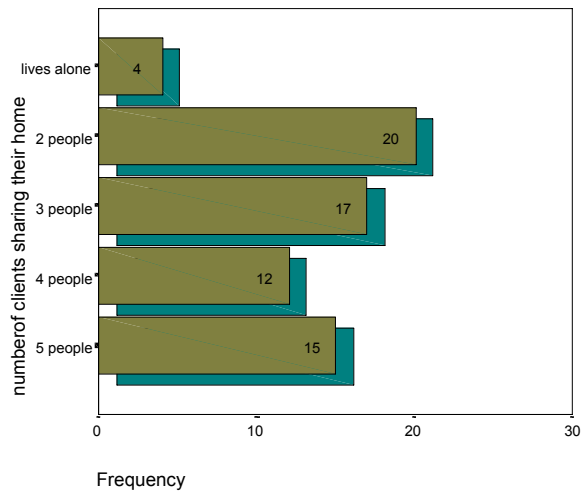
2.1.5 Levels of Support

RCOs provided their views regarding the levels of support required by each accommodation option, e.g. considering the needs of all people who lived there are a group. Figure 8 shows that 27 RCOs (44.1 per cent), reported that the houses they worked within were "totally" dependent. 21(30.9 per cent) suggested that the clients were partially dependent. Only 8 clients were deemed to be mostly independent (11.8 per cent).

Client: direct care worker ratios and support cover arrangements varied. The rationale for shift coverage also varied. RCOs and Managers advise that 24-hour full staff cover versus specific hours per day of support, differs according to the individual needs of the clients.

In this sample, client: staff ratios were typically 1:4 but more than half were 1:5. Residential Care Officers reported that the client characteristics that influenced an increase or decrease of staff above or below the ratio included degrees of independence and in particular, challenging behaviour.

Figure 9 identifies hours of support provided by direct care staff, e.g. the extent of shift coverage. 45 clients (66.2 per cent) received 24-hour cover. All of these clients had overnight RCO coverage. Only two clients (2.9 per cent) were supported for less than eight hours a day. Figure 10 highlights the fact that 17 clients (25 per cent) did not have overnight shift cover and one client was monitored via an intercom.

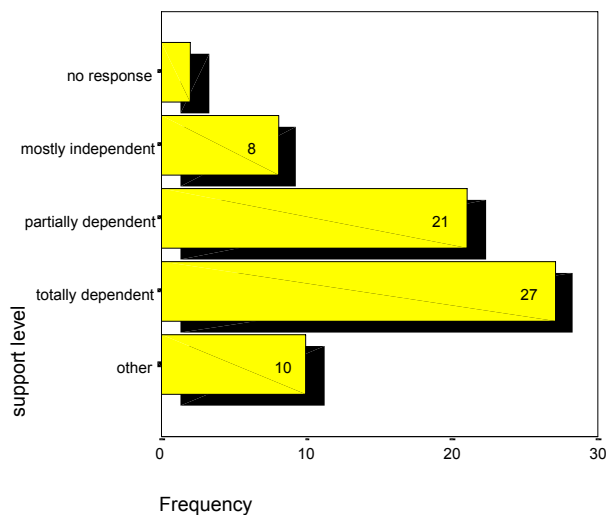**Figure 8 Level of Support at Shared Address**

Figure 8 bar chart showing support level with frequency values: no response (no value shown), mostly independent = 8, partially dependent = 21, totally dependent = 27, other = 10.
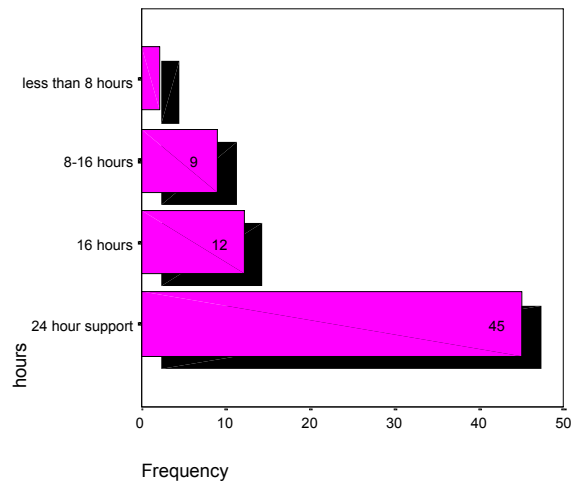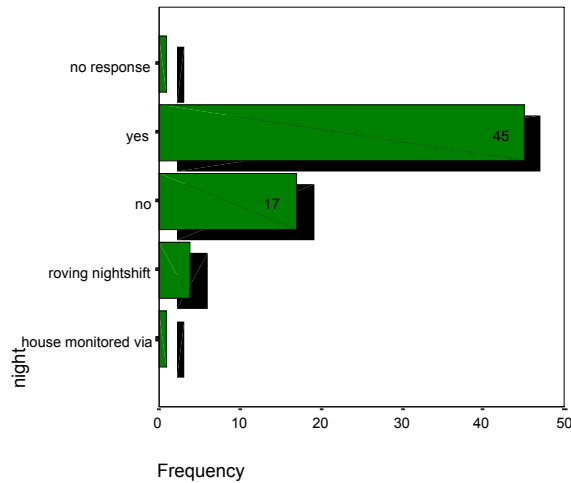
Figure 9 Shift Coverage

Figure 10 Night Cover

2.1.6 Residential Care Officer Perceptions of Client Health and Well-Being

RCOs were asked to indicate their knowledge and perceptions about their client's health history. In general, Residential Care Officers generally perceived clients living in ALS houses to enjoy reasonable standards of health and well-being.

2.1.6.1 Aetiology

RCOs reported that the cause of intellectual disability was ***not*** known for more than half of the clients in the study (36 clients or 52.9 per cent). However, research suggests that advances in technology has meant that aetiology can now be identified in approximately 80 per cent of clients with moderate to severe levels of intellectual disability (Graves, 1997).

Figure 11 shows that the most common cause provided by RCOs was "birth complications" for 12 clients (17.6 per cent). The second most commonly reported cause of the intellectual disability known to the RCOs (11.8 per cent of the sample) was eight people with Down syndrome. Other causes reported included two clients with un-named genetic conditions; one client with PKU; one client with a motor vehicle accident being attributed as the cause and one client with epilepsy as the cause.

Figure 11: Aetiology Known by RCO
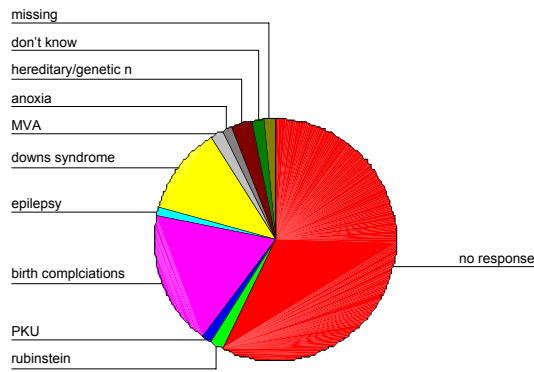
2.1.6.2 Health Status Prior to Comprehensive Health Review

Figures 12 and 13 should be considered together as they provide views of RCO perceptions of the client's health status prior to the health review proposed by the study. Generally RCOs did not identify major health concerns and appear to believe that clients are in fairly good health.

Figure 14 shows that RCO believed that 50% of the clients were considered ***not*** to have a major health problem. This table provides an overview of health concerns identified by RCOs. Figure 15 concludes this snapshot of health status by providing RCO satisfaction levels with client health status. 33 out of the 59 RCOs expressed views that they were pleased and mostly satisfied. 7 RCOs were pleased and even delighted.

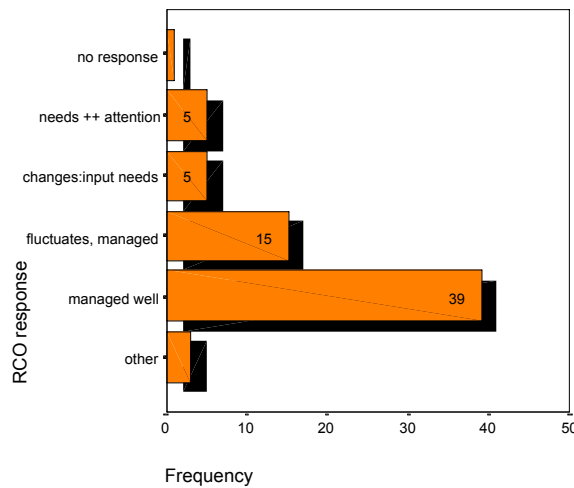**Figure 12: RCO Views of Client Health Status NOW**

Figure 13: RCO Views of PAST Client Health Status
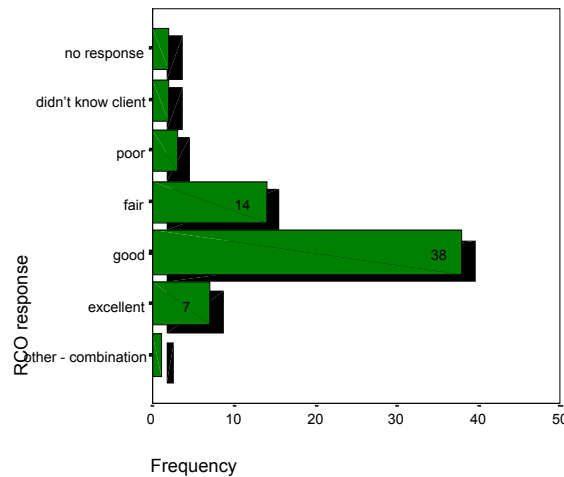
Lessons from the Labyrinth

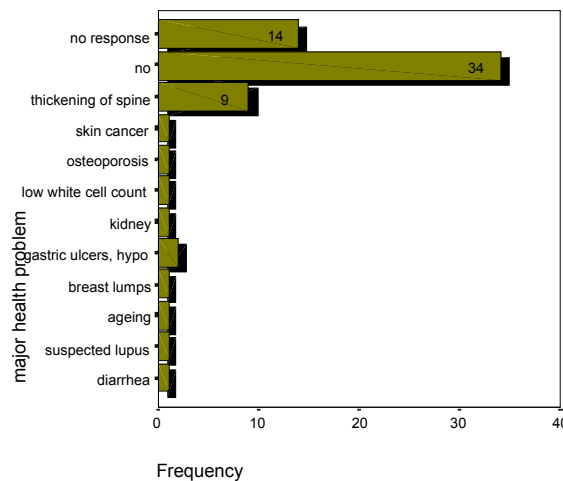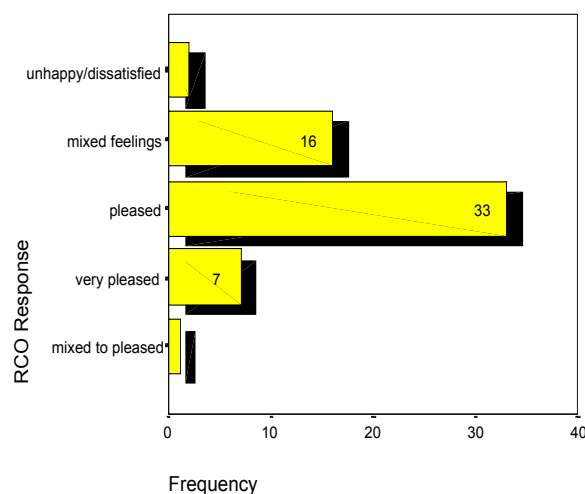## Figure 14: Major Health Concerns of RCOs

Figure 15: RCO Satisfaction with Client Health NOW

2.1.6.3 Challenging Behaviour

RCOs believed that 75% of clients who participated in the study displayed challenging behaviour. Figure 16 shows possible causes of this behaviour provided by RCOs. 18 no responses are included (26.5 per cent). Behaviour that was considerd to be "dangerous" that had occurred within the last 12 months was reported to have been expressed by 33 clients (48.5 per cent).

Figure 17 suggests that the behaviours were enduring with the majority of clients (10 clients) having had such behaviour for more seven years or more (14.7 per cent). 7 clients displayed behaviour for 5-6 years (5.9 per cent) and 3 clients for 2-4 years (4.4 per cent).

RCOs advised that a psychologist was only involved with 19 clients with challenging behaviour. Psychologists were reported to be not involved in 18 clients who had challenging behaviour. The main reason provided for non-involvement included a plan being set in place (15 RCO responses). Other reasons included unavailability of the psychologists (2 responses) and 3 responses that suggested assessment did not warrant a behaviour plan/intervention.

A psychiatrist had assessed 10 clients in the study (14.7 per cent). The majority, i.e. 40 clients, had *not* been seen by a psychiatrist (58.8 per cent). Research suggests that at minimum, 25 per cent of adults with an intellectual disability will experience concurrent mental disorder with their intellectual disability, e.g. a dual diagnosis. Therefore this data suggests that mental disorder had been under-diagnosed or mis-diagnosed.

Medication had been prescribed to manage problem behaviour(s) for 25 clients (36.8 per cent). The General Practitioner was the primary source of medication for problem behaviours (13 clients) although 5 clients had co-involvement of a psychiatrist. A paediatrician was involved with one client.

In 24 clients, RCOs suggested that health morbidity had been ruled out as a cause or trigger for the challenging hehaviour (35.3 per cent). However, this was *not* the case for 21 clients (30.9 per cent) and RCOs were unable to comment for 8 clients (11.8 per cent).

Figure 16 Challenging Behaviour Causes
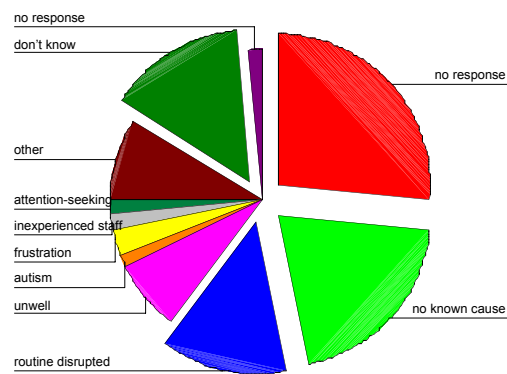
Figure 17 Duration of Challenging Behaviour
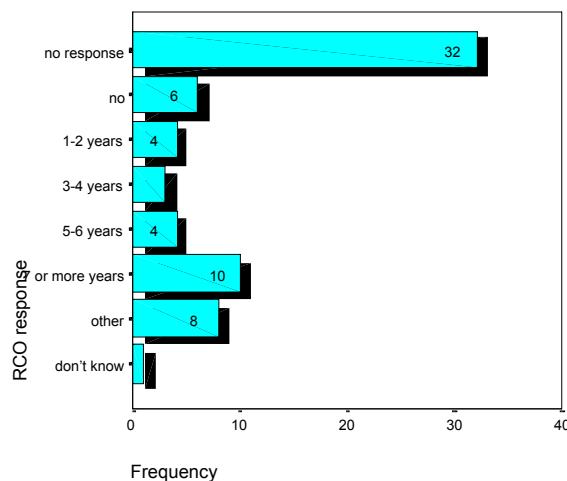
2.1.6.4 Medication

RCOs advised that prior to the comprehensive health assessment, of the 68 clients, 20 clients took NO medication (29.4 per cent) and 48 clients took 1 or more medications (70.6 per cent). Of the 48 clients taking medication there were:

- 10 clients on 1 medication (20.8 per cent)
- 11 clients on 2 medications (22.9 per cent)
- 8 clients on 3 medications (16.6 per cent)
- 9 clients on 4 medications (18.7 per cent)
- 7 clients on 5 medications (14.5 per cent)
- 1 clients on 6 medications (2.08 per cent)
- 2 clients on 7 medications (4.2 per cent)

RCOs reported that 29 of the 48 clients (60.4 per cent) taking 1 or more medications were prescribed anticonvulsants (other medical conditions may also have been treated). Epilepsy was the most common "reason" reason for the prescription of medication. Of the 48 clients taking medication:

- 1 of the 10 clients on 1 medication was treated for epilepsy
- 6 of the 11 clients on 2 medications were treated for epilepsy
  6 of the 8 clients on 3 medications were treated for epilepsy
- 7 of the 9 clients on 4 medications were treated for epilepsy
- 4 of the 7clients on 5 medications were treated for epilepsy
- 1 client on 6 medications was *not* treated for epilepsy
- clients on 7 medications were both treated for epilepsy

RCOs reported that the second most common reason for medication prescription was behaviour management or sedation. Only two clients receiving antipsychotics were prescribed this medication for "psychosis".

Six clients were also prescribed antipsychotic PRN medication in addition to their regular medication. Again the reason for the prescription was behaviour management. The three most common classes of medication prescribed for behaviour management and sedation were anticonvulsants, antipsychotics and

antidepressants. Very few clients received antianxiety medication or sedatives. Reported below are the frequencies of medication type prescribed to the 48 clients (inlcudes 2 clients treated for psychosis).

Anticonvulsants
- 13 sodium valproate (Epilim)
- 12 carbamazepine (Tegretol)
- 10 phenytoin (Dilantin)
- 6 clonazepam (Rivotril)
- 2 lamotragine (Lamictal)
- 1 topiramate (tTopomax)

Antipsychotrics
- 7 thioridazine (Melleril)
- 4 haloperidol (Seranace)
- 4 risperidone
- 3 pericyazine (Neulactil)
- 1 zyprexa (Olanzepine)
- 1 lithicarb (Lithium)

Antidepressants
- 2 paroxetine (Aropax)
- 4 sertraline (Zoloft)
- 1 imipramine (Tofranil)
- 1 fluoxetine (Prozac)

There were three female clients prescribed depo provera for menstrual management and 2 female clients received the oral contraceptive pill for the same purpose. No male clients received any medication to manage sexuality, e.g. androcur. RCOs also reported popular use of over-the-counter purchased vitamins and constipation treatments.

2.2   Part B: General Practitioner Details

2.2.1 Background

RCOs provided details regarding the GP that the client usually attended. The trend for General Practitioner choice tended to be dictated by locality, e.g. clients would move to a location and then direct care staff would network with colleagues and others to identify an appropriate General Practitioner. Focus groups with staff revealed that "good" General Practitioners tended to be "swamped" by Disability Services Queensland (DSQ) clients with an intellectual disability and that staff were aware that too many clients with an intellectual disability could have an adverse effect upon the capacity of the GP to take on more clients with special needs. Some Residential Care Officers said that they were "tight lipped" about their "good" General Practitioner and would not share his or her name with other staff in other houses for fear of that General Practitioner "burning out".

Other Residential Care Officers shared experiences where they traveled considerable distances to access suitable General Practitioner practices. One Residential Care Officer shared the following story. Their usual General Practitioner moved to another practice. They attempted to transfer their clients to the new practice that was fairly close to the old practice location. Their request was refused. This Residential Care Officer had approached 8 General Practitioner practices in and when it was revealed that clients had intellectual disability and challenging behaviour, their request for General Practitioner services were refused.

2.2.2 General Practitioner Details

Forty General Practitioners were nominated by RCOs as the clients' usual doctor. Consent was provided by 27 of these 40 and 24 completed comprehensive health assessments. 27 GPs were the "usual" practitioner for 53 clients, of which:
- 13 GPs had 1 client;
- 7 GPs had 2 clients;
- 4 GPs had 3 clients;
- 2 GPs had 4 clients;
- 1 GP had 6 clients; *and*
- 15 clients were seen by DDU.

Six of the 40 General Practitioners originally nominated by RCOs and clients were unable to participate in the CHAP study. These GPs had already been recruited by the Developmental Disability Unit as participants in a separate comprehensive health assessment project. The Endeavour Foundation project although

substantially larger (Queensland state wide), was similar to the Disability Services Queensland (DSQ) CHAP project. However it was quite a separate project. Involvement of these GPs in the DSQ study would have compromised findings of both studies.

The Developmental Disability Unit wrote to each Residential Care Officer who had nominated such a General Practitioner and thanked them for their ongoing interest in the project. The Disability Services Queensland (DSQ) staff were advised that it was not possible to enroll the nominated General Practitioner in a second CHAP project. It was disappointing but necessary to advise these Residential Care Officers that neither they, nor their nominated General Practitioners were unable to be involved further in the Disability Services Queensland (DSQ) project

One GP did not participate within the study because the DSQ client moved to a nursing home. This move had been sought by staff and was considered to be a good outcome for the client.

A further 6 General Practitioners of the original 40 nominated by DSQ staff who were eligible to participate failed to provide consent following telephone discussion with Dr Lennox and chose not to participate in the study. 3 of these GPs had one DSQ client; 1 GP had two DSQ clients; and 1 GP had three DSQ clients. Some DSQ staff indicated to the DDU that they were concerned about the GP decision not to participate. Reasons provided to the DDU by the GPs for non-participation, e.g. refusal to consent at the initial recruitment stage of the study included:
- GP practice in process of moving to another location;
- GP unwell – poor health;
- GP workload too heavy – had a number of clients with an intellectual disability;
- GP not interested;
- GP failed to return nominated forms despite follow up; and
- GP on leave.

2.2.3 General Practitioners and Completed CHAP Assessments

Forty-four of the 68 clients in the study underwent a comprehensive health assessment. 24 of the 27 GPs who provided consent, completed the CHAP booklet. The number of assessments completed by these 24 GPs is as follows:
- 12 GPs assessed only one DSQ client;
- 5 GPs assessed two DSQ clients;
- 1 GP assessed three DSQ clients;
- 1 GP assessed four DSQ clients; and
- 5 GPs assessed five DSQ clients.

Reasons for the failure of the 3 GPs to complete the comprehensive health assessment included:
- Client state of health, e.g. one client had undergone acute emergency care and direct care staff felt further medical assessment was unnecessary and inappropriate at that point in time for the client;
- Challenging behaviour of one client which has resulted in ongoing medical and health assessments;
- Doctor was too busy and unavailable – kept suggesting that RCOs should make another appointment later when the GP was less busy.

2.2.4 Profile of General Practitioners Used by RCOs

DSQ clients in the study tended to visit GPs who worked in group practices. Only 10 clients visited GPs who worked alone (14.7 per cent). 27 clients saw one preferred GP who worked with others. 30 clients were OK about seeing whoever was available in the GP practice. Figure 1 shows that the majority of adults with an intellectual disability in the study had their health managed by more than one GP.

Figure 2 shows that the majority of clients usually had contact with GPs outside of "usual" GP practice. Focus groups suggested that this type of contact often involved out of hours GP contact through 24 hour emergency clinics or hospital outpatients services. Weekend access to GP was an issue of influence.

Figure 1: Relationship with other GPs

yes, sees other GPs
no response
no, GP works alone
no but >GPs there
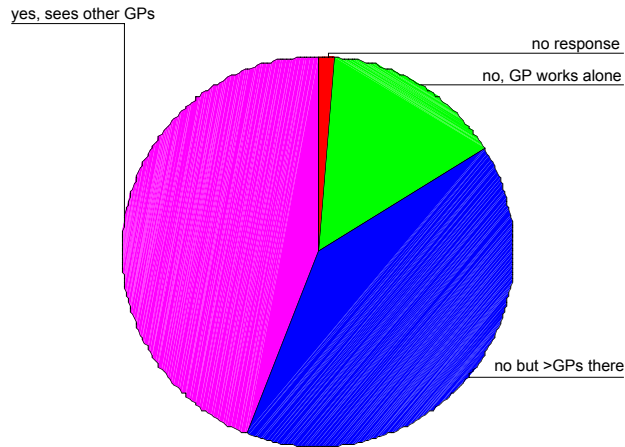
Figure 2: Frequency of Contact with GPs Outside of Practice

no response
yes
no
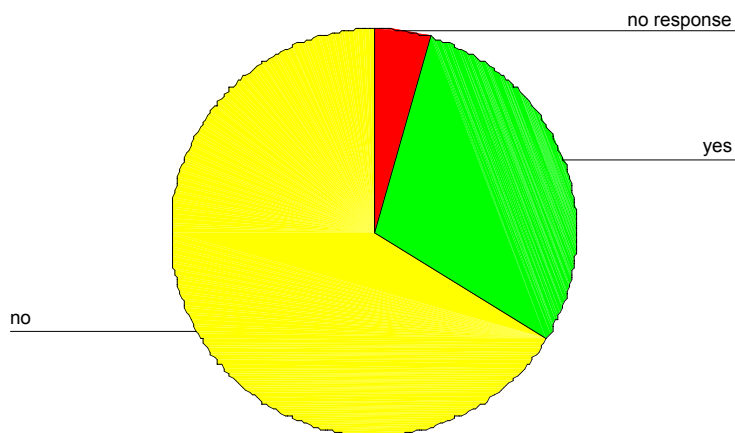
2.2.5 Location for GP Assessment

Figure 3 demonstrates that 53 clients typically saw their General Practitioner at their surgery or clinic (83.8 per cent). Five clients routinely had home visits from their GP as the preferred venue for a consultation (7.4 per cent). A very small number of clients had home visits from the General Practitioner or saw the GP at another venue, e.g. day activity center or similar (5 clients or 7.4 per cent). Reasons for this were discussed in focus groups and included:

- "normal" venue for general population is the doctor's clinic therefore people with disabilities must follow the same rhythms and routines;
- GP preference, e.g. did not "do" home visits;
- Staff felt home visits were inappropriate, e.g. SRV; and
- Staff felt that home visits were not encouraged by management, e.g. considered to be "against policy".

Figure 3: Consultation Location/Venue

Figure 3: Consultation Location/Venue
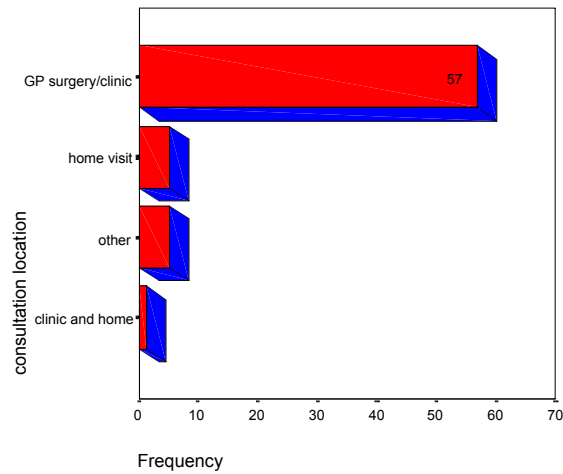
Figure 4 shows a range of reasons why the RCOs believed that the clients saw their GPs at the nominated location, typically the surgery or clinic. 20 RCOs suggested that the major reason was the GPs preference or choice (33.9 per cent of RCOs). Sixteen RCOs considered that the venue was guided by staff preference or suggestion (27.1 per cent of RCOs).

Figure 4: Reasons for the Venue

Figure 4: Reasons for the Venue

Figure 5: Escort Arrangements
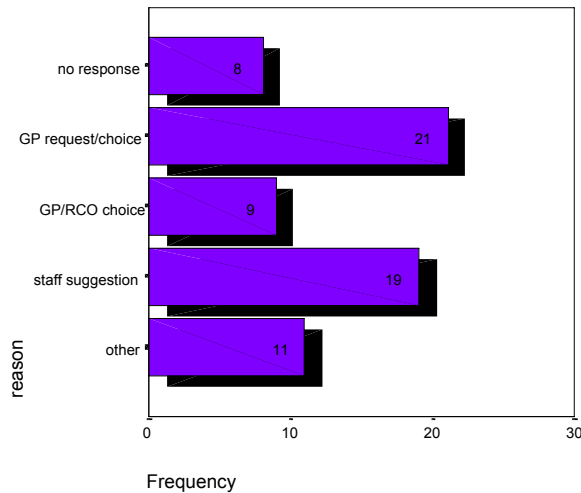
Figure 5: Escort Arrangements
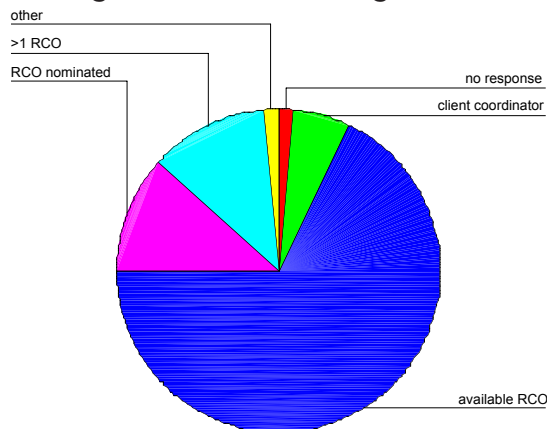
Some staff shared concerns about client refusal to go the doctor's surgery and others stated that they would prefer a home visit to take place. RCOs said in focus groups that challenging behaviour compromised many visits to the doctor, e.g. embarrassing for staff and the client or lack of client cooperation resulted in the visit being a waste of time for all involved. Staffing problems meant that shift coverage was often a barrier.

2.2.6 Escort to General Practitioner

The most frequent response to who was usually the client's accompanying escort when visiting the General Practitioner, was the "RCO who is available." 41 RCOs responded in this way (69.5 per cent). Figure 5 identifies other escorts. RCOs advised in focus groups that low staffing levels and solo shift work arrangements where there is little opportunity to double-up compromises escort arrangements.

2.2.7 Descriptions of the Client: GP and RCO: GP Relationship

Generally RCOs were positive about the relationships between GPs and clients. 54.2 per cent (32 RCOs) suggested that the relationship was "generally OK". 16 RCOs went as far to say that the relationship was "very good". Figure 6 identifies other responses. It is interesting to note that 8 RCOs provided no response or don't know (13.6 per cent of the 59 RCOs).

Figure 6: RCO View of Client: GP Relationship
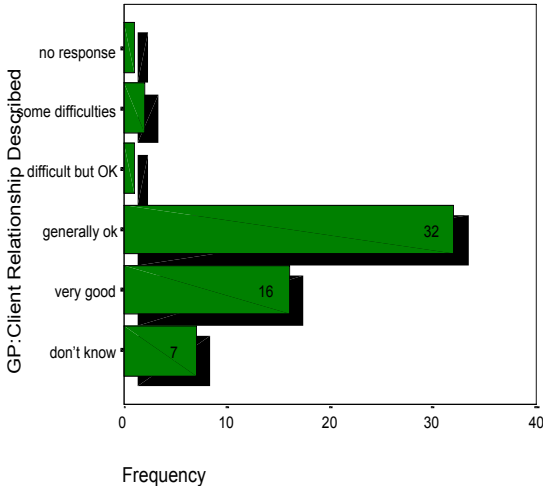
Figure 7: RCO: GP Relationship
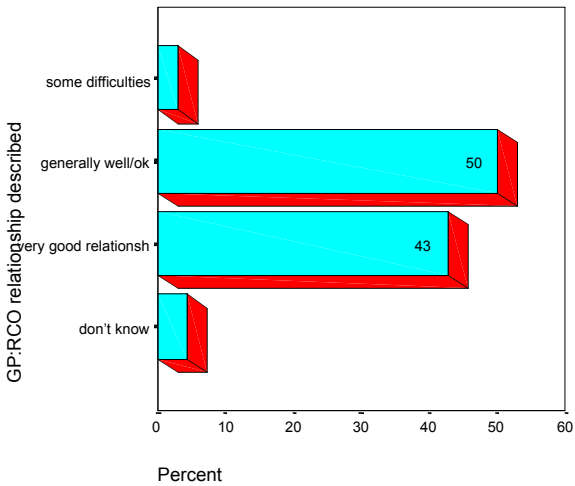
Similarly, Figure 7 demonstrates that the majority of RCOs believed that their relationship with the client's GP was either good/OK (45.8 per cent, 27 RCOs) or very good (45.8 per cent, 27 RCOs). 3 RCOs did not know and only 2 RCOs suggested that there were some difficulties experienced between the RCOs and the doctor (total negative responses comprised 8.5 per cent).

2.2.8 Time GP Spends with Client

There was again a positive response to the question relating to the quality of time that the GP spends with the client during a consultation. 83.1 per cent of RCOs (49) said that the nominated GP did spend enough time with the client. Figure 8 provides more detail.

Figure 8: GP Time Spent with Client

- rarely or never
- sometimes, variable
- needs to improve
- yes, usually
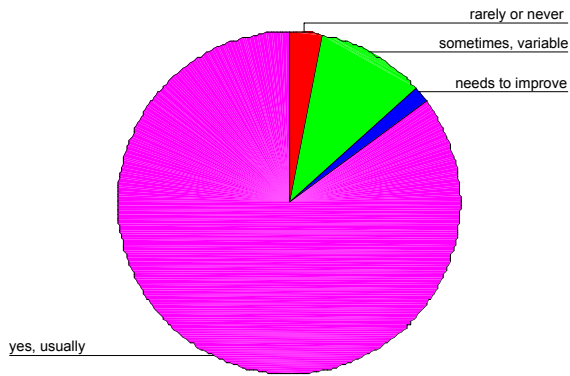
2.2.9 Communication

Figure 9 demonstrates a more variable response when considering communication aspects of the GP consultation. A little more than a third of RCOs (22) felt that the GP spoke directly to the client most of the time (37.3 per cent). 6 RCOs said very little and 16 identified that it varied.

Figure 9: Direct Communication with Client

GP communication style / Frequency

- no response
- not at all — 3
- very little — 6
- half the time varies — 17
- most of the time — 27
- all of the time — 14
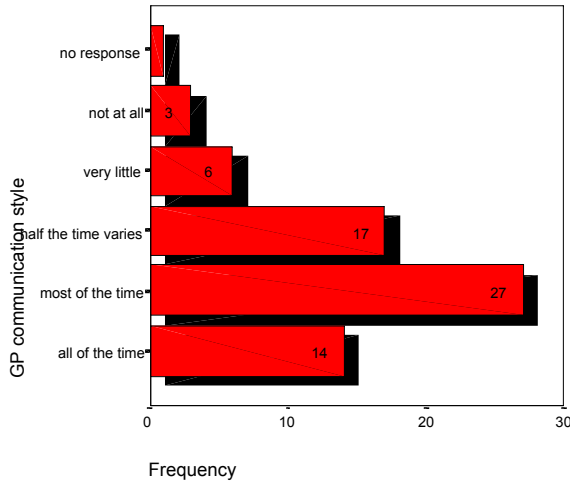
Figure 10: Discussion of Management

- other
- only RCO
- client and RCO
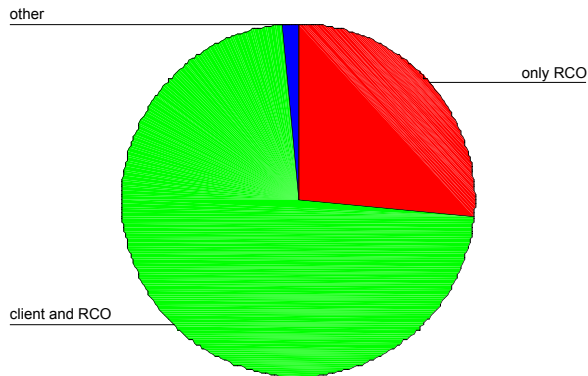
Figure 11:Timing of Consultation
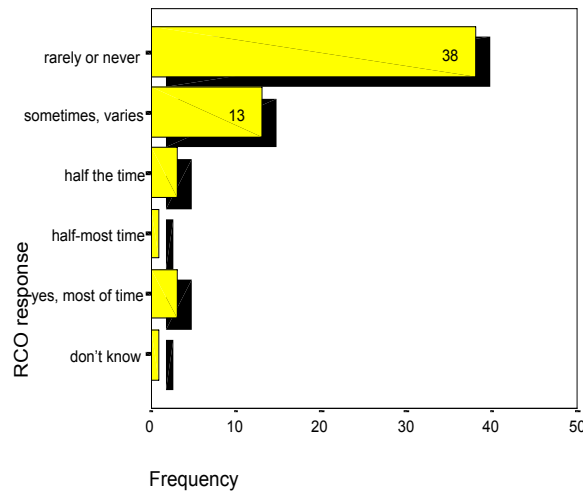
Figure 12: Interruptions during Consultation
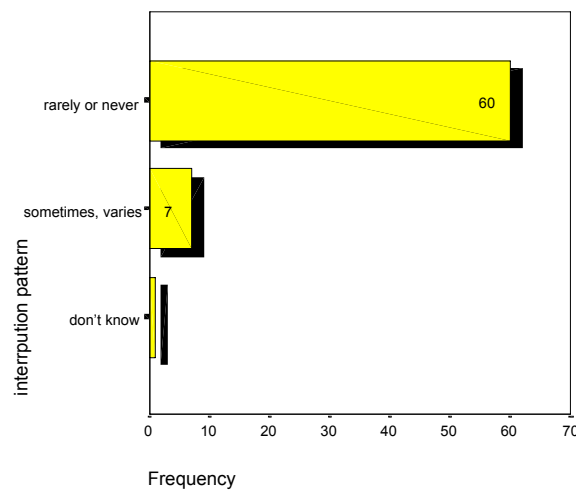
Figure 13: Listening Skills
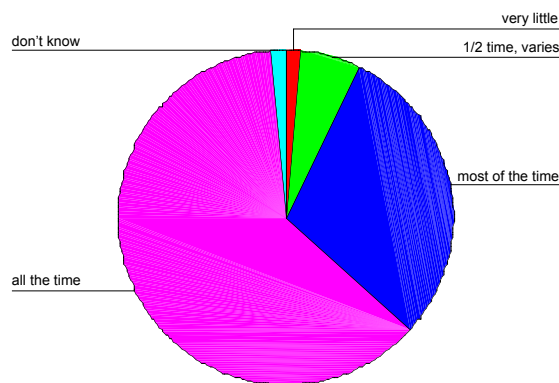
More of interest is Figure 10 that demonstrates the doctor usually discusses the treatment or management plan with the RCO and the client. 40 RCOs made this suggestion (67.8 per cent) whereas only 18 RCOs (30.5 per cent) suggested the doctor communicated only with the RCO escorting the client to the General Practitioner.

Figure 11 shows that 38 RCOs or 64.4 per cent believed that the General Practitioner rarely or never rushed the consultation time. Only 13 RCOs (22 per cent) indicated that sometimes the consultation was rushed.

Figure 12 also is suggestive of the positive regard that RCOs have for their General Practitioners. 86.4 per cent (51 RCOs) stated that interruptions during the consultation occurred rarely or never. A small number, 7 RCOs (11.9 per cent) said that the frequency of interruptions varied.

Figure 13 shows that despite focus groups suggesting that GPs did not pay due attention to RCOs, e.g. consider them to be important actors in client health and well-being status; 35 RCOs in the questionnaire suggested that GPs did listen to RCO concerns "all of the time" (59.3 per cent). Similarly, 18 RCOs (30.5 per cent) said that the GP listened to their concerns most of the time.

2.2.10 Quality of GP Service

When asked if the nominated General Practitioner provided a reasonable or good service, the overwhelming response was yes, most of the time. 51 RCOs took this position (86.4 per cent) with only 7 RCOs (11.9 per cent) suggesting some variability, e.g. "half the time, could be improved".

RCOs were also asked whether they believed that the nominated General Practitioner had a good understanding of the client's health needs. Although there were a range of RCO responses that are detailed in Figure 14, just over half of the RCOs (30 or 50.8 per cent) said the most needs were understood. 20 RCOs (33.9 per cent) said that the GP had a good understanding and 8 (13.6 per cent) said an OK understanding.

Only one RCO suggested that the GP had very little understanding. These responses conflict with the literature that suggests GP are not well trained in this population and do not feel confident in managing their health care problems. Poorly managed and detected morbidity provides further evidence. It may well be that *RCOs perceive that the GPs are doing a good job* although comprehensive health assessment may reveal hidden morbidity, e.g. "occult" health care problems. The CHAP tool may have prompted and guided GPs to be more thorough or vigorous in their health checks.

Figure 14: RCO View about GP Quality of Service
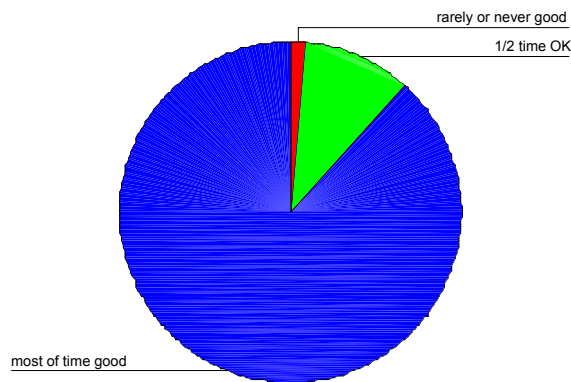
Figure 15: RCO View of GP Knowledge of ID
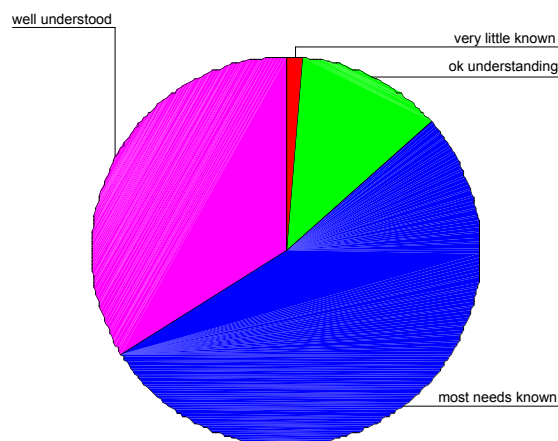
3. Part C: Residential Care Officer Details

3.1 Gender and Age

There were 34 female (57.6 per cent) RCOs and 19 male(32.2 per cent) RCOs who participated in the study. Figure 1 shows that the majority of RCOs were relatively young, with 59.3 per cent being aged between 30–45 years (35 RCOs). 30.6 per cent (18 RCOs) were aged between 45 and 60 years. The youngest RCOs were aged 25–30 (three RCOs) and the oldest RCO was aged over 60.

Figure 1 Age Distribution of Residential Care Officers in Study
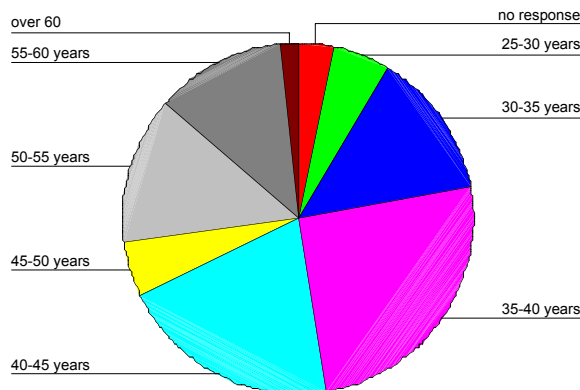
3.2 Qualifications

Forty-three per cent failed to provide qualifications other than RCO qualifications. Six RCOs had a university degree (10.2 per cent). There were three with nursing qualifications and one with a social science degree. Three RCOs possessed various certificates.

3.3 Length of Employment as an RCO

RCOs who participated were experienced with the minimal length of employment being one RCO employed for less than 12 months. 22 RCOs (37.3 per cent) had been employed for more than 10 years.

Their experience extended when asked how long they had worked within disability direct care field.

Figure 2 shows that 35 RCOs, more than half (59.3 per cent of the RCO participants) had been employed as RCOs for more than five years. This level of experience may well account for satisfaction with General Practitioners and health status of clients that is described in the Part B. Only three RCOs had been employed for two or less years.

Experience as a characteristic of the sample is further highlighted when considering length of employment within the disability field or sector, and not just as an RCO. Figure 3 shows that 32 RCOs had worked in the disability field for more than 10 years (54.2 per cent). This percentage increased to 76.2 per cent (another 13 RCOs) when combined with RCOs who had worked in the field for 5-10 years (total of 45 RCOs).

Figure 2: Length of Time as RCO
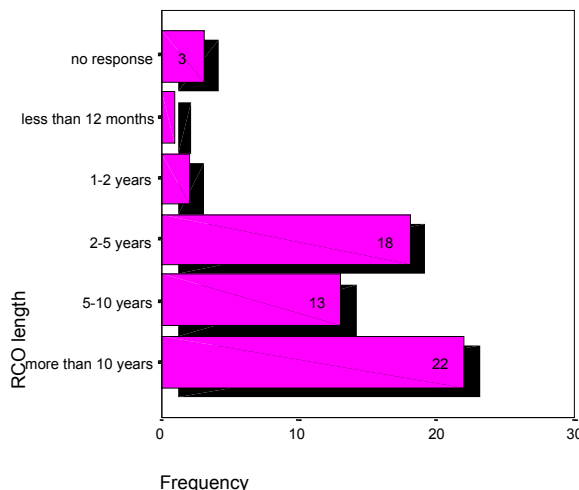
Figure 3: Length of Time within Disability Field
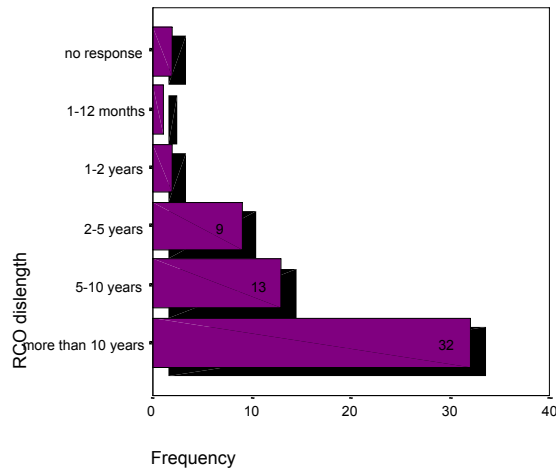
RCOs in the study may stay employed within that profession but do appear to move frequently between houses. The longest time spent in the current house was one RCO who had been there for 12 years. The briefest time was 7 months with two other RCOs reporting 8 months duration (5.1 per cent). In total, 9 RCOs had been in the residence for less than 12 months (15.3 per cent).

The majority of RCOs, i.e. 25 RCOs had spent between 2- 4 years in the houses (42.4 per cent). Two RCOs reported 10 years and one other a few months short of ten years (total of 5.1 per cent). 22 per cent had spent 2 years in the current client residence (13 RCOs).

3.4   Health Priorities

RCOs generally perceived themselves to be very familiar with the clients that they supported. 30.5 per cent (18 RCOs) said that they had a "good working knowledge" of the client that they provided information on. The majority, 62.7 per cent (37 RCOs) said that they had a very good working knowledge.

Figure 4 demonstrates that 55.9 per cent of the RCOs (33 RCOs) believed that the health and well-being of clients ***should be*** a high priority for their region. 22 per cent (13 RCOs) stated that prioritization of health should be considered as a individual consideration, e.g. dependent upon the needs of the client. 7 RCOs felt that health and well-being was no more important than other client needs (11.9 per cent)

Figure 4: Should Health be a Priority?
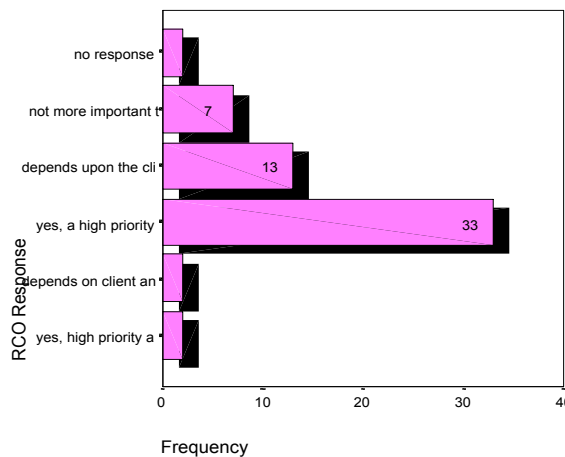
When asked if health was a regional priority 39 RCOs answered yes (66.1 per cent) and only 8 responded with no (13.6 per cent). Interestingly 10 RCOs did not know and 2 did not respond (total approximately 20 per cent).

Figure 5: Is Health a Regional Priority?
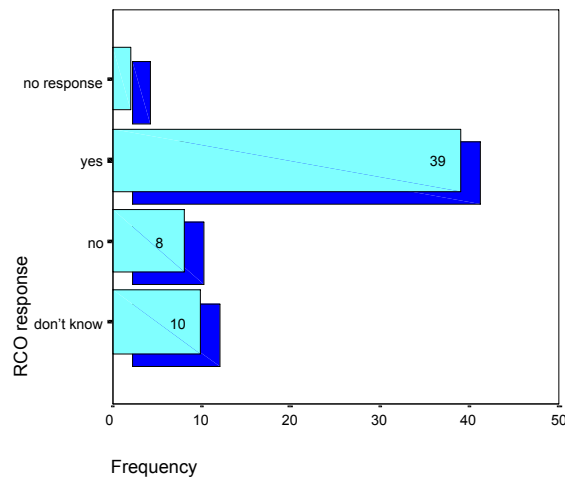
3.5 Time Constraints

Figure 6 shows that 39 RCOs (66.1 per cent) suggested that they had enough time to meet client health needs "most of the time." Only 10 RCOs (16.9 per cent) had enough time always. It is of note that 10 RCOs (16.9 per cent) failed to respond or answered "rarely" or "occasionally".

Figure 6: Time to Meet Health Needs
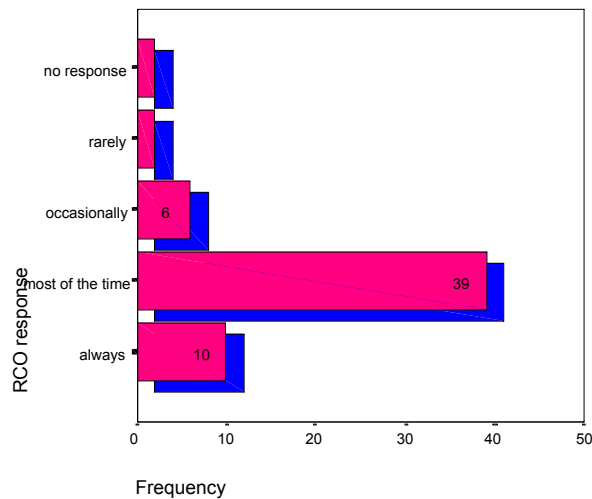
3.6 RCO Disability Related Health Knowledge

These RCOs appear to be quietly confident in regards to their knowledge about health care problems experienced by people with an intellectual disability. Figure 7 shows that 26 RCOs rate their health knowledge capacity as "good" (44.1 per cent). 16 said their knowledge was "OK" and 3 "average" (total 35.6 per cent). Only 2 RCOs (3.4 per cent) considered their knowledge levels to be excellent.

Figure 7: RCO Disability Related Health Knowledge
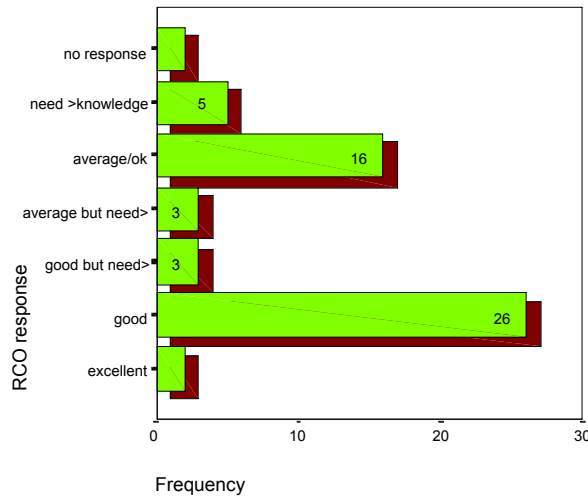
3.7 Personal Health Knowledge

By comparison, RCO were more confident about their personal health knowledge, e.g. general knowledge guiding decisions they made about their own health and well-being. Figure 32 shows that 62.7 per cent (37 RCOs) feeling they possessed good knowledge. 8 RCOs said they had excellent knowledge in this regard.

Figure 8: Personal Health Knowledge
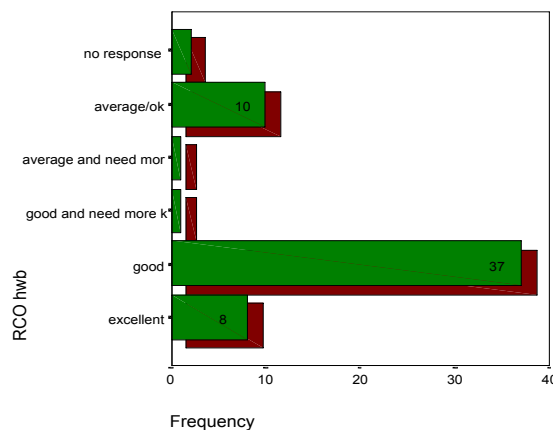
RCOs clearly desire opportunities to increase and or enhance their existing health care knowledge. 54 RCOs, that is 91.5 per cent of the participants desired to increase their knowledge and expertise in health and well-being. Only one RCO said that they had no need to increase health knowledge and 2 RCOs didn't know.

3.8 CHAP Familiarity

The majority of RCOs had a grasp of what the comprehensive health care programme was attempting to achieve. 30 RCOs had a basic understanding (50.8 per cent) and 23 RCOs understood what the programme was trying to achieve (39 per cent). 3 RCOs did not understand and 3 RCOs failed to respond (total 10.2 per cent). These results suggest that training and information disseminated regarding the programme was sufficient.

3.9 RCO Views about Aspects of their Employment

The literature suggests that a relationship may exist between attitudes, values and health behaviour. Similarly RCO attributes about their jobs and the clients they support may have an impact upon client health outcomes and health care status. The following tables do not prove a relationship exists, but they are descriptive and may provide practitioner and clinicians with insight regarding the feelings, thought and actions of direct care workers.

Figure 9: Feelings about being an RCO
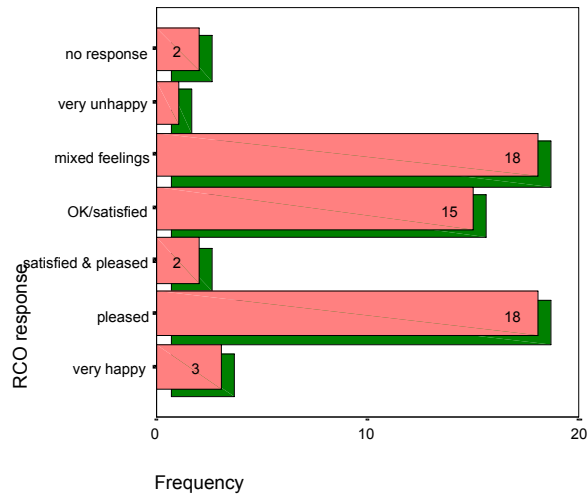
Figure 10: Feelings about Clients
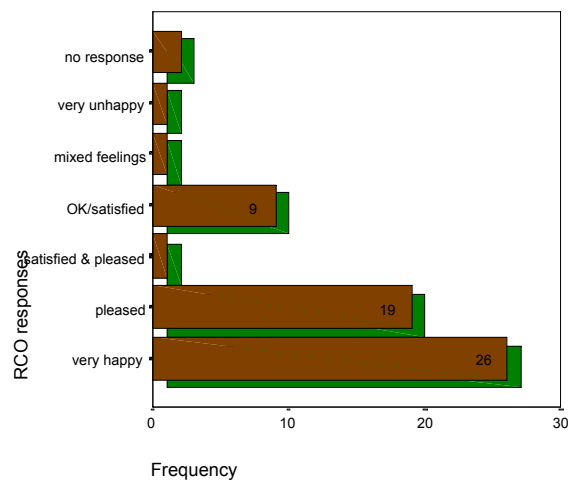
Figure 11: Feelings about Professional Support
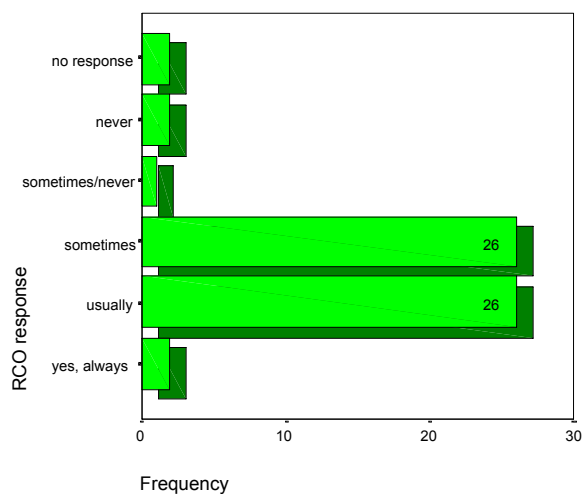
Figure 12: Feelings about Managerial Support
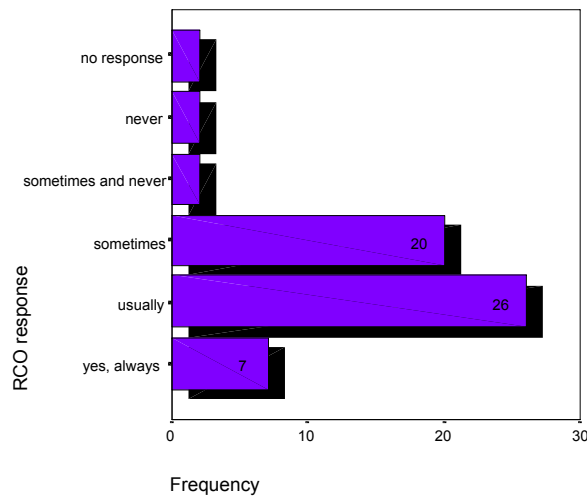
Figure 13: Frequency of Managerial Support
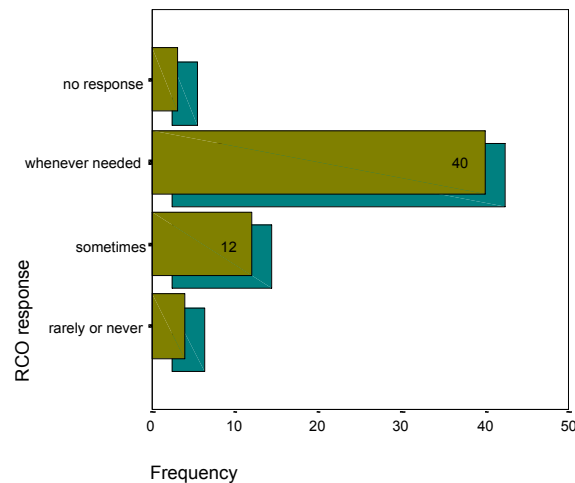
Figure 9 suggests that RCOs experience varying feelings about being a direct care worker. Although only one RCO said they were very unhappy, the majority reflected ambivalent feelings, e.g. 18 RCOs (30.5 per cent) indicated that they had "mixed feelings" and 15 RCOs (25.4 per cent) suggested they were "OK or satisfied". Despite being an experienced group, less than one third of RCOs said they were pleased about all parts of their job as RCOs (18 RCOs or 30.5 per cent). A very small minority, 3 RCOs or 5.1 per cent, said they were very happy.

In focus groups RCOs openly discussed their feelings and commitment to particular clients, driven by their empathy and goodwill or kindness. RCOs also described the physical exhaustion and despair sometimes associated with clients with challenging behaviour or complex support needs. When questioned about what kept them going, some responded with related versions of the following comment "there is no choice, if you gave up or shipped out then most of these people would have no-one there for them".

One plausible conclusion is that it is the "care in the carer" which is the most important, and perhaps the most overlooked and undervalued ingredient in direct care worker. Is it the care in the carer that makes the RCO persevere in getting a blood test done if they know it is important to the health and well-being of the client? Is it the care in the carer that results in the RCO taking the client to the doctor in their own time, unpaid and often unacknowledged because if they did not, the client wouldn't make it to the doctor that week?

Figure 10 considers RCO general feelings about their clients, e.g. all aspects and not just health and well-being. In contrast to views about their job, 76.3 per cent of RCOs said that they very happy (26 RCOs or 44.1 per cent) or pleased to be working with the clients (19 clients or 32.2 per cent).

Feelings about the level of support were more varied. Figure 11 shows that 26 RCOs said that they sometimes got support from professional and resource staff (44.1 per cent). 26 RCO also said they usually got enough

support. Focus group discussions revealed some suggestion that RCO may have lower level expectations of professional support. Some RCOs appear to adopt the attitude, "if they turn up and assistance is useful great but if no-one turns up, life goes on and we cope".

Figure 12 provided a mediocre response by RCOs as to whether they were happy with the support provided by their Managers. 2 RCOs indicated that they never got enough support and another two suggested sometimes to never enough support (total 6.8%). 20 RCOs said they sometimes got enough support (33.9 per cent). The majority response was 26 RCOs (44.1 per cent) who said that they "usually" got enough support. Only 7 RCOs said that they always got the support required. Focus groups made some suggestion that RCOs held low expectations of receiving support therefore some direct care workers said that it was pointless to ask for help when you knew you wouldn't receive any.

Interestingly Figure 13 shows that 67.8 per cent of RCOs (response of 40 RCOs) seek support from their Managers whenever they need advice, assistance or support. 12 RCOs also said they sought support from their Managers only sometimes (20.3 per cent). RCOs do not appear to be frequent seekers of support, e.g. 33 RCOs, more than half of the respondents (54.9 per cent) said that they sought support between once of month or less than once a month. 13 RCOs indicated that they sought support from managers every two weeks (22 per cent). Focus groups suggested that telephone contact might be the most frequent source of support.

Figure 14 reports RCO views about working for the (then) Department of Families Youth and Community Care (DFYCC) and it is likely that perceptions can be transferred across to DSQ although this is a new agency that has undergone significant restructuring and visioning. However, one RCO pointed out that little had changed at the RCO coalface despite ongoing change at the executive levels. 33 RCOs or 55.9 per cent said that they liked working for the department "most of the time." 17 RCOs or 28.8 per cent said "usually" and 5 RCOs (8.5 per cent) reported "sometimes". Only 2 stated "never" and 2 provided no response.

Figure 14: Feelings about Working for Department (DFYCC)
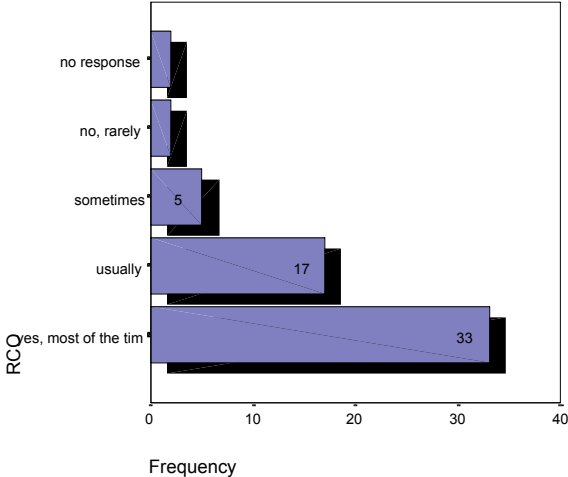
3.10 Information Sources

General Practitioners and other health professionals make strong recommendations to carers that visits to health services should ideally involve experienced carers who know the person well, accompanying the person with the disability. Research and anecdotal evidence suggests GPS like to have access to an extensive health and personal history that is chronologically documented. This history, really a personal health profile, should be readily available to carers, health professionals and other service providers.

Thirty-three RCOs reported in Figure 15 that the client's files, in regard to storage and retrieval of health related information etc was well organized. 19 RCOs similarly suggested that the file was "organized". Combined, these comments represent (88.1 per cent). It is important to note that this is not the experience of the DDU researchers or the literature. It may well be that RCOs are unaware of what information is important, e.g. the significance of aetiology or past history.

Forty-eight RCOs (81.4 per cent) reported that they always file important health related information appropriately (in the client file). Similarly, 28 RCOs (47.5 per cent) reported that other RCOs always filed health related information on the client file. The confidence of RCOs (in the filing behaviour) of other RCOs is *not* as strong. 23 RCOs (39 per cent) said that the filing behaviour of other RCOs varied and 7 (11.9 per cent) indicated that they believed that other RCOs did not file information appropriately.

Figure 16 demonstrates a range of RCO views regarding the importance and relevance of daily communication books as a tool to improve health and well-being record keeping and retrieval. Approximately half of the RCOs, e.g. 30 (50.8 per cent) said that the communication book was the best source of client information regarding health and well-being. 20 RCOs said that "sometimes" this book was the best source (33.9 per cent).

When questioned about the need for an improved system of storing and retrieving information, there was mixed response. Only 32 RCOs concurred, e.g. 54.2 per cent responded with yes. Nineteen clearly said no (32.2 per cent) perhaps considering workload implications for them individually. Focus groups suggested that competing pressures upon RCO time meant that paperwork and activities such as filing were accorded a low priority in the busy schedules of RCO. Further, filing, storage and retrieval of some information was not followed through because some RCOs and Managers for that matter, failed to see the relevance of some information on health and well-being. There are definitive training and education implications here.

Figure 15: File Condition
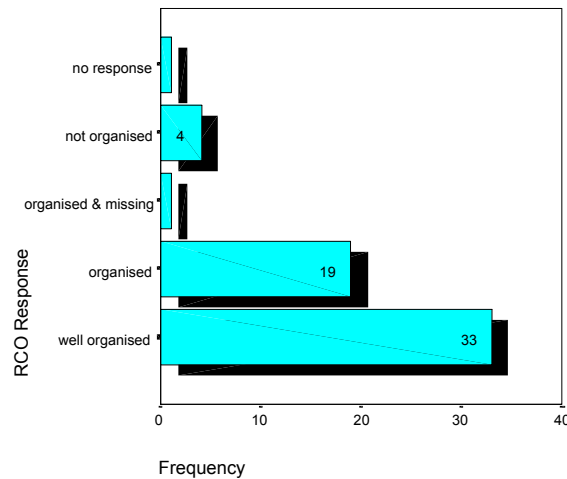
Figure 16: Reliability of Communication Books for Health Information
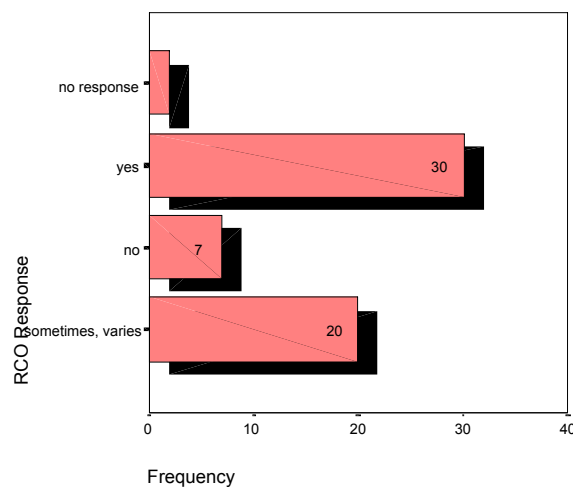
3.11 Concluding Comments (incorporating open-ended RCO comments)

The data shows that generally Residential Care Officers in the study were an experienced group who had worked for many years within the disability field. Most liked working with their clients and held moderately positive attitudes about the health and well-being status of their clients. Many RCOs prioritized the health care needs of clients and suggested that these needs could be met because "where there was a will, there was a way", e.g. RCOs value health status and know it is important for client health and well-being to respond to signs or symptoms of disease or illness:

- "ongoing health needs in house are very high"
- "the time must be found"
- "because we have to"
- "because you can get support to make the time"
- " as a team we are very focused on health care and ensuring that dental, regular serum levels and regular health checks are conducted"

The duty of care that staff owed to clients and a perception that staff were obligated to meet a range of client needs featured repeatedly as an underlying theme in many qualitative responses. Although some staff appeared to understand the importance of a planned, preventative approach to health and well-being, many did not. Some direct care staff voiced concern about the historical approach to health, e.g. an acute/band aid approach was being adopted where if there was a problem that had to be fixed then so be it. In this regard, staff appeared to perceive that resource constraints and time issues became the most significant barriers to health and well-being.

- "Extra staff are provided if we need extra cover for a medical problem"
- "…I feel the work load is shared as each staff (team worker) is responsible for one client"
- "If the need arises, Unit Manager will always meet the (clients' health) needs"

What was evident was the failure of staff activity and health interventions to realise or achieve long-term, planned preventative approach for clients. Some Residential Care Officers did acknowledge this problem but suggested that there were overriding infrastructure problems such as shiftwork. Comments provided by direct care staff reinforce and highlight barriers experienced in meeting the health care needs of clients that they support.

- ….so many different staff in house "pass buck"
- "I work on a part time basis 8 hours per week"
- "shifts are not always convenient for all health issues"
- "All clients require individual and group needs, as well as daily routine to fit into 8 hour shift"
- "Simply not enough time to address properly"
- "Lack of continuity, so may other things requiring attention"
- "Not always possible to find the time to act upon/follow up situations quickly enough".
- "Inertia, hospital waiting lists, always waiting"

Better health may be related to components of the doctor-patient relationship. More effective information gathering and more conversation by patients is related to improved health status (Kaplan, 1989). There is little doubt however, that talking and communication between the patients and the doctor is critical to the consultation. Despite the focus of the relationship being upon communication, most doctors have received inadequate training in regards to communication and counseling.

RCOs appeared to hold reasonable regard for the communication skills of the General Practitioners involved with their clients and did not raise any major concerns regarding the expertise of these medical professionals. It is possible that although the RCOs are generally happy with client health, morbidity may be hidden from both the carer and the General Practitioner. CHAP outcomes discussed later in this report suggest this could be the case.

Focus groups with Residential Care Officers and other staff revealed that whilst they acknowledge that doctors need to have a major education/teaching role within consultations — direct care staff believed the onus was upon them to pursue a workable relationship. Generally staff appeared to be pleased with their General Practitioners although perceptions revealed that there was certainly room for improvement on both sides — the doctor and the Residential Care Officer.

Many direct care workers appear to be satisfied with the General Practitioner although qualitative comments did suggest there remained some room for improvement in regard to the power dynamics in the doctor: client and doctor: relationship.

- "General Practitioner is easy to talk with, listens to your points about…
  and then speak to… examines, and then makes a decision"
- "Very patient, caring and respects clients"
- "Good working/professional relationship with doctor"
- "Finding a good General Practitioner is important, but sometimes you feel like
  an idiot when questioning the doctor, but I feel the Residential Care Officers
  know the clients more than management and should have more input"
- "….already have a good relationship and don't believe that it could be any better"

The majority of Residential Care Officers were happy with their jobs but generally disgruntled regarding working for the wider organisation. Qualitative responses suggested that Residential Care Officers felt isolated. Apart from personal networks and links developed within their own time, the department was viewed as providing few incentives and little concrete assistance that allowed them to have contact with other Residential Care Officers within their own area office, let alone across the organisation. "Residential Care Officers have become all things to all clients and are stretched to maintain and monitor health and well-being of all clients".

Despite evidence of some negativity directed towards "management", responses were generally positive towards RCO work, managers, support and the "department". Findings do however suggest that Residential Care Officers may get greater satisfaction from interaction with clients and co-workers rather than with management and the wider organisation, i.e. Disability Services Queensland.

A major theme within qualitative responses was limitations placed upon direct care work by shift work, client staff ratios and low resources. Challenging behaviour of clients was a frequent health concern as well as stress factor in RCO health and well-being.

- "Health related problems are most times linked to a consumer's behavioural issues"
- "Most clients in the region I work (with) are very healthy – main problems are behavioural"
- "Too easy to overlook or neglect consumers whom are quiet or non-behavioural
  and their health needs".

RCOs recommended a number of strategies and solutions that could improve client health and well-being

- "arrangements for a staff member to be able to take one client to the doctor individually"
- "I hope and wait for something positive to happen with health and well-being, not just
  spending money on projects with no outcomes for the consumers, this agency Disability
  Services Queensland has a very poor history in meeting clients' basic and unmet needs.
  No resources to support clients' choices — no support to Residential Care Officers in the ALS.
  Many promises — many failures in delivery — reducing staff hours — reducing hours of client
  support — and client Residential Care Officer ratio increasing"
- "Client has a 1:1 staffing ratio , this allows adequate time to be spent on health care needs"
- "Finding time and getting extra cover, 1-5 ratio is a big responsibility"
- "….in past lack of consistency in team, not enough time, casual Residential Care Officers
  and more training or incentives to know job properly"

Findings support the need for increased education and training opportunities, for Residential Care Officers to have an increased voice in decision making and to be assisted to be more in touch with what is going in within the larger organisation, e.g. break down the isolation.

## 4.	Part D: Unit Managers and Area Managers Questionnaire

### 4.1	Introduction

Managers were generally very supportive of the study and actively encouraged direct care staff to participate. Some Managers assisted with focus groups and a number actively participated. Without the support of this level of management it is unlikely the study would have been successful. 16 of the 19 Managers who participated in the study said that they had a reasonable understanding of the CHAP programme (84.2 per cent).

Managers responses regarding the support required by clients was generally comparable with responses made by RCOs. Figure 1 shows that 11 Managers said that clients living in houses within their area of responsibility had high support needs (57.9 per cent). 26.3 per cent responded that clients characteristically had complex support needs (5 Managers).

Figure 1: Manager Views of Client Support Needs
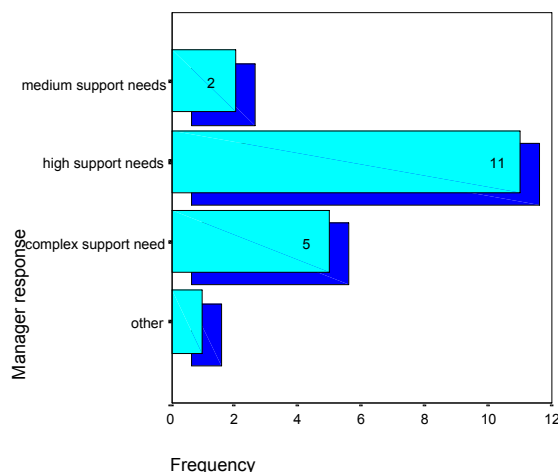
Figure 2 Manager Views about RCO Management
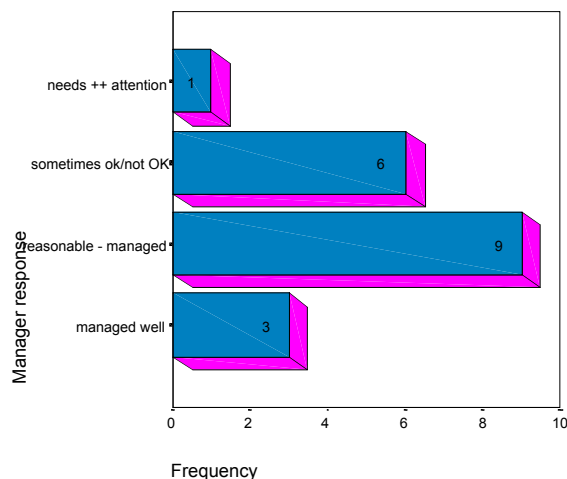
Managers displayed a wide divergence of views regarding the management of health and well-being of clients within their area. Figure 2 shows that less than half of all the Managers (9 Managers or 47.4 per cent) thought that RCO management was "reasonable". The next most popular response was made by 31.6 per cent of Managers (6) who thought that RCOs health and well-being of clients was managed "OK" although increased staff attention was required. 3 Managers (15.8 per cent) suggested that health was "well-managed" by RCOs and only one Managers thought increased attention and intervention by staff was required (5.3 per cent).

Figure 4 shows that 12 Managers (63.2 per cent) appear mostly satisfied with the health status of clients and 6 Managers (31.6 per cent) reported mixed feelings. One Manager did not respond. No Managers reported being very pleased which was an option.

Thirteen Managers indicated in Figure 5 that health and well-being of clients should be a regional priority (68.4 per cent). Only 5 Managers disagreed (26.3 per cent).

Figure 3: Manager Satisfaction with Client Health Status
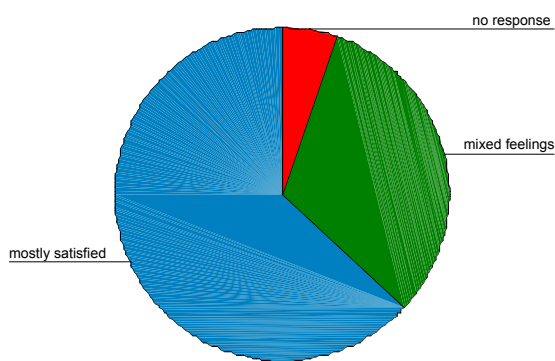
Figure 4: Health as a Regional Priority
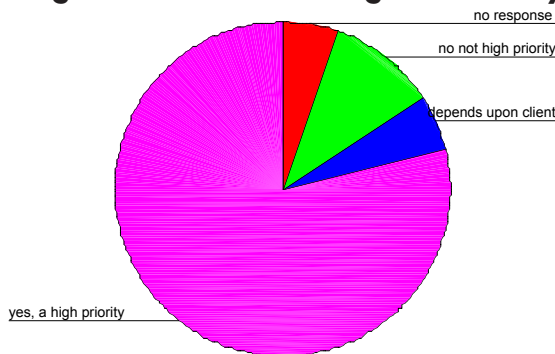
4.2   Gender and Age

A total number of 19 Managers participated in the study including 14 Unit Managers (73.7 per cent) and 5 Area Managers (26.3 per cent including one acting Area Manager). 57.9 per cent of the Managers were female (11) and 42.1 per cent were male (8).

There was a range of ages across the lifespan with more than half of the Managers clustered between 40 and 45 years (10 Managers or 52.6 per cent). The youngest Manager was aged between 25 and 30 years and the oldest Manager was aged between 55 and 60 years. One Manager was aged 30 –35 (15.8 per cent); two were aged 45-50 (10.5 per cent); and four were aged 50-55 years (21.1 per cent).

4.3   Qualifications

47.4 per cent (9) of the Managers had originally been RCOs and therefore had a certificate/equivalent in Residential Care. 7 Managers had a university degree (36.8 per cent). Only one Manager noted "other" training qualification (unknown) and 2 Managers made no response.

4.4   Length of Time in Current Position as Manager

Figure 5 shows that the most experienced Manager had more than 7 years experience and the least experienced had been there for 7 months at the time of completing the questionnaire. Four Managers had been in their position for less than 12 months (21 per cent); four Managers had been there for between 1-2 years; four for more than 2 years and up to 4 years (21per cent); and five Managers had been in their current positions for more than 4 years and up to 5 years (26.3 per cent). One Manager did not respond.

Figure 5: Length of Time as Manager
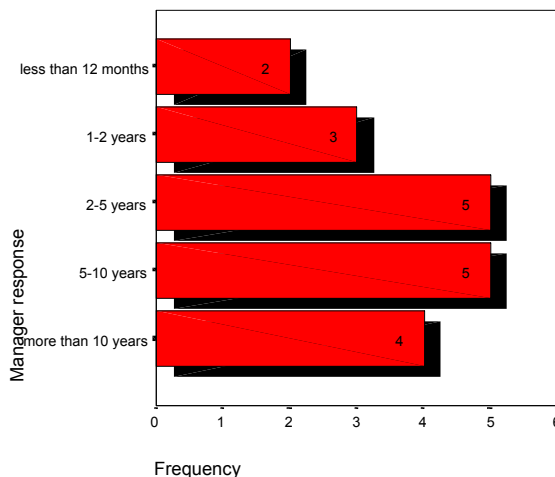
Figure 6: Manager Client Contact
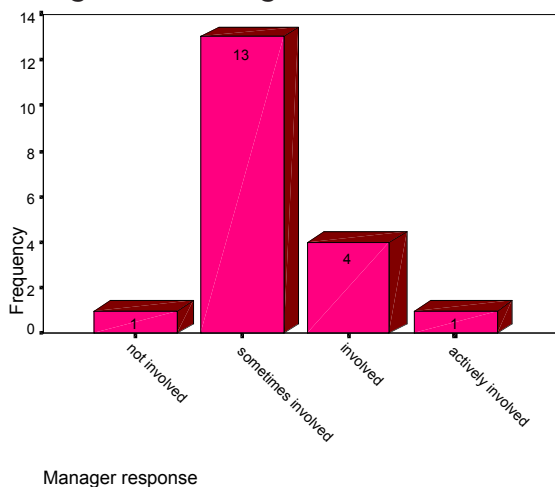
4.5 Client Contact and Involvement

Contact varied considerably and may have had a relationship to the Area Office location and the proximity of Alternate Living Service houses. Focus groups suggested that face–to-face contact with clients and staff depended upon the attitude and personality of the Managers. RCOs advised that some Unit Managers were very "hands-on" and on regular occasions would "cover" houses for RCOs when something urgent came up, e.g. an appointment with the doctor or perhaps another pressing client engagement. Other Managers competently "ruled" by phone according to some RCOs. Some RCOs appreciated lack of contact whereas other RCOs desired increase contact.

Figure 6 shows that 26.3 per cent of Managers (5) had more than 2 face-to-face contacts with clients per week and 15.8 per cent said 2 contacts per week (3 Managers). 5 Managers reported one contact per week (26.3 per cent) and 2 Managers advised one contact with clients per fortnight (10.5 per cent). The majority of Managers, 68.4 per cent (13) described themselves as only sometimes involved with clients. Only one Manager said they were actively involved with clients.

4.6 Managers Views about Contact and Staff Support

Staff contact varied considerably with 42.1 per cent of Managers (8) having 1-2 *contacts* with staff per week. 26.3 per cent of Managers had more than 2 contacts with staff per week (5 Managers). Two managers have one contact with staff per fortnight (10.5 per cent).

11 Managers (57.9 per cent) indicated that they had individual contact with staff and 5 Managers (26.3 per cent) said they did not, e.g. suggesting that group contact occurred. Group meetings were the main source of staff contact for 13 Managers (68.4 per cent) although 2 Managers said this was not the case (10.5 per cent).

Excluding emergencies, 14 Managers had routine telephone contact with staff on more than 2 occasions per week (73.7 per cent). Figure 8 demonstrates frequency of telephone contact — the telephone was the major source of communication with staff for the majority of Managers. 12 Managers or 63.2 per cent advised that this was their primary communication mode. 4 Managers advised that face-to-face contact was their primary mode of communication and 1 Manager advised that writing using the communication book or memos was the "usual" method of communication.

Figure 9 shows that 57.9 per cent of Managers (11) believed that they provided staff with enough support "most of the time". Interestingly one Manager responded that staff "never" get enough support from them and another solo Manager suggested that staff received enough support from them personally only "rarely" (total of 10.6 per cent). Further, 5 Managers comprising 26.3 per cent stated that support was provided occasionally. NO Managers said that staff "always" got enough support from them personally.

Figure 7: Manager Contact with Staff

Figure 8: Telephone Contact Frequency
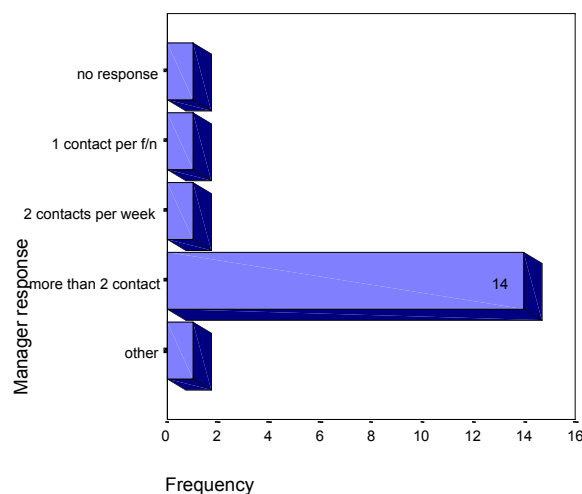
Figure 9: Do RCOs Get Enough Manager Support?
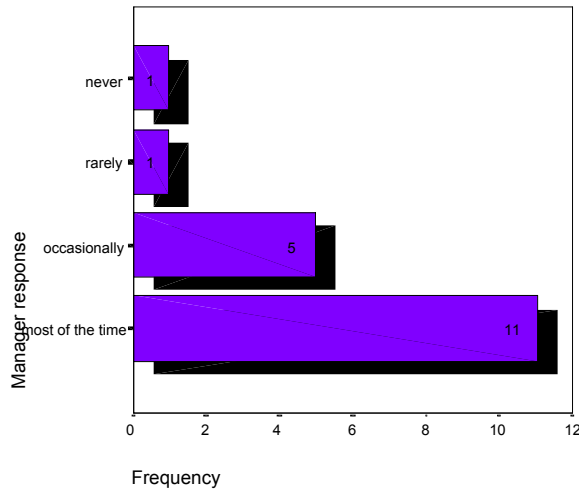
Figure 10: Manager Views: Support Staff in Relation to Health Needs of Clients?
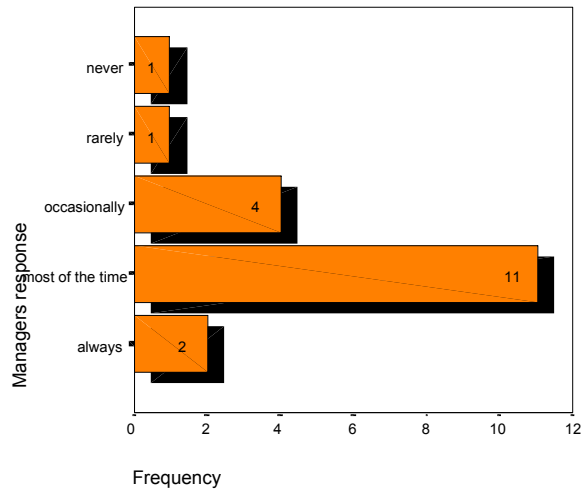
Figure 11: Manager Views Regarding Health Knowledge (Intellectual Disability)
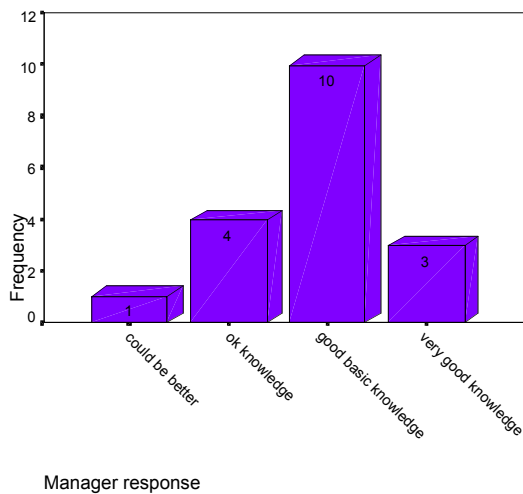
4.7   Managers Views about Health and Well-Being Support

Similar to results above, Managers had mixed views regarding whether they were able to provide "enough time" to needed to meet health and well-being needs of clients in their area. Only 6 Managers had attended health training (31.6 per cent) and 13 had attended no health training (68.4 per cent).

Managers were very positive regarding their general health (in regards to people with an intellectual disability) knowledge. Figure 11 shows that only 5 Managers rated their knowledge as average or OK whereas 13 Managers, more than half of the respondents, considered health knowledge about people with an intellectual disability to be good or excellent (68.5 per cent). Similarly, personal health knowledge was considered by 10 Managers (52.6 per cent) to be good and basic. 3 Managers rated their personal health knowledge as "very good" (15.8 per cent).

Figure 10 indicates that 42.1 per cent of the Managers (8) believed that staff/clients received enough health related support from them "most of the time". 2 Managers did not provide a response to this question. Of note is the fact that 3 Managers responded "rarely" (15.8 per cent) and 6 responded "occasionally" (31.6 per cent).

Some Managers did however voice some concerns regarding the level of health and well-being related support provided to clients in their region, and by default the RCOs that support those clients. Again demographic barriers such as distance or location of ALS houses may influence the provision of support. Focus group discussion and comments made by RCOs suggest that the majority of Managers work very hard but their time and efficiency is compromised by too many competing demands including the management of crises and bureaucratic paperwork. The provision of health related support to clients and RCOs may well suffer as a direct result. Managers may benefit from the provision of targeted health and well-being training tailored to meet their specific needs.

4.8   Managers Views about Support they Receive

Managers were asked whether they received enough support (not just health related) from *their* line managers. The majority, 57.9 per cent (11 Managers) responded with "most of the time" and 2 Managers suggested that they received enough support "always".

There were a number of differences in opinion regarding support from their line managers. These differences in view may reflect job demarcation and responsibilities between Unit Manager and Area Managers. Such differences have not been differentiated in this report in effort to protect the anonymity of participants.

One Manager said that they never received enough support from their line manager and another Manager said that they rarely received enough support. 4 Managers (21.1 per cent) suggested that enough support was "occasionally" provided. These results (total 31.5 per cent of Managers) suggest that DSQ needs to evaluate the support needs of its Managers. Managers will be unable to effectively support *their* subordinate staff unless *they* receive appropriate levels of support. When unsupported, staff can experience stress, anxiety and general dysfunction. Morale can drop and there is often a flow on effect to other staff.

4.9   Frequency of Support

14 Managers (73.7 per cent) advised that they sought advice from their line managers whenever they required advice, assistance or support and the remaining 5 Managers sought such support "sometimes" (26.3 per cent). There were a range of responses to the frequency of support, e.g. how often support described above was requested.

To the question regarding frequency of support there were 18 respondents with 6 Managers making up the majority (31.6 per cent). These Managers requested such support once a week. 5 Managers (26.3 per cent) requested such support every 2 weeks. Other responses included one Manager once a month and three Managers requesting support less than once a month (15.8 per cent).

4.10 Manager Views about Job

Figure 12 shows a range of responses to the questions that sought indication about feelings about all aspects of the Manager job including responsibilities, work environment, conditions and hours of work. Extremes included one Manager stating that they felt "very unhappy" and at the other end of the continuum of views, 6 Managers expressed views that they were "pleased" (31.6 per cent). Those with ambivalent responses were in the majority. 8 Managers expressed "mixed feelings" (42.1 per cent) and 4 Managers were "OK" (21.1 per cent).

Figure 12: Managers Views about Job
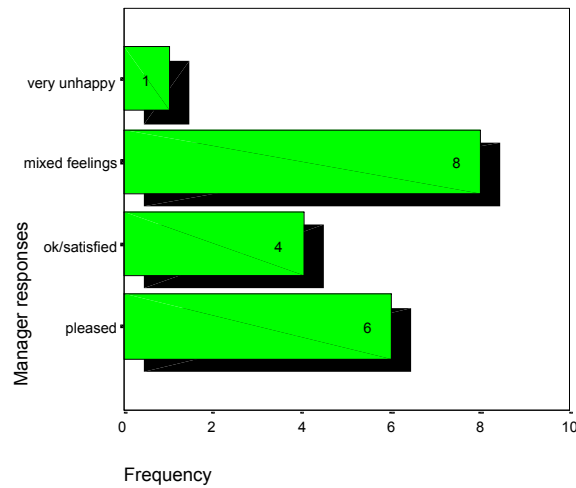
Figure 13: Managers Views about Clients

4.11 Managers Views about Clients

More positive feelings were expressed in Figure 13 where Managers describe feelings about working with clients in their area. Only one Manager had mixed feelings about clients. 4 Managers were OK or satisfied (21.1 per cent) and 8 Managers said they were "pleased" to be working with clients (42.1 per cent). 6 Managers were "very happy" working with clients (31.6 per cent).

4.12 Managers Views about Department

Positive views were generally expressed by Managers regarding working for the then named Disability Operations. Figure 14 shows that a minority of Managers expressed negative views, e.g. 3 Managers said it was "OK" (15.8 per cent) and one Manager said they occasionally liked working for Disability Operations. 11 Managers comprised the majority who liked working for the Department "most of the time" (57.9 per cent). Three Managers said that they always liked working for the Department (15.8 per cent).

4.13 Managers Views about General Practitioners

Managers generally held positive views about GP services. 11 Managers (57.9 per cent) suggested that GPs had a reasonable or "OK" level of understanding about the health care needs of clients with an intellectual disability. Only 4 Managers said that GPs had very little understanding (21.1 per cent).

Managers were generally unable to respond to questions about whether GPs spent enough time with clients. 13 Managers or 68.4 per cent made no response to the question. Views about GPs were clearly the domain of the direct care worker.

4.14 Client Files

Most Managers were not involved in placing information on client files. 13 Managers said they were not (68.4 per cent). 9 Managers thought that RCOs treated health information as important (47.4 per cent) and 8 Managers thought that RCOs did not (42.1 per cent). Similarly, 8 Managers did not view client files as the best source of current client information regarding their health and well-being status. 9 Managers took the opposite view (47.4 per cent). Only 47.4 per cent of Managers (9) supported an improved system for the storage and retrieval of health related client information.

4.15 Concluding Comments about Managers and Barriers to Health and Well-Being (incorporating open ended comments)

Managers in the study considered themselves to have a reasonable level of understanding and experience in managing the health care needs of adults with an intellectual disability. However, they held mixed views regarding their capacity to both provide and receive general support and assistance. They generally had 1 to 2 contacts with staff per week and used the telephone as the preferred and usual method of communication.

Despite reporting that they had little to do with General Practitioners, client health problems or client filing practices relating to health and well-being, they were positive about the health status of clients. Focus groups and RCO feedback strongly suggested the Managers were often involved when crises were occurring or there were problems. Proactive outreach in regard to health and well-being appeared to be limited despite the reasonably high levels of health related expertise self reported by Managers.

A divergence in opinions was often noted in Manager responses. The following views were provided in response to open-ended questions contained in the Manager questionnaire that is contained in full in the Appendices. These issues have been loosely themed below.

Managerial Role conflict
- breadth of responsibility gives them "little time for proactive work"
- " competing priorities".
- "work load of position"
- "not enough time to do it all"
- "I can guide staff but they need to carry through with the task"
- " involvement is due to crisis on highly contentious issues"
- "an overabundance of different agendas"
- "lack of time to follow through issues…workload extreme…when you need to put in 100per cent effort"
- "Issues between staff is very time consuming therefore all staff energy is spent on staff and not on clients"

Resources and Training
- "more money at the coalface is required – not restructures of empires"
- "I believe the work is important and that I can contribute positively and that the Department can do better if we all stick at it. BUT the frustrations of workload, client inequities, poor Residential Care Officer support in training development and the whole issue of devaluing people cause me to question whether there is someone who can do it better" Then it becomes obvious that every Unit Manager is riding the same roller coaster"

Health as a Priority
- "unfortunately usually because of duty of care/legal ramification issues not client welfare priority"
- "health care is important regardless of region/area. Individuals needs the best health care it affects all aspects"
- "most contentious/problematic issues for our clients are health and medication"
Behavioural Overshadowing
- "general belief that changes in people is usually behavioural as opposed to medical"
- "difficulty in getting Residential Care Officers to look beyond the obvious behavioural aspects — until crisis"

Relationship with General Practitioners
- "…I question sometimes whether the doctors are explaining all avenues"
- "staff inability to advocate strongly for clients (as in Dr knows best)
- "(General Practitioner needs to give) more credence given to Residential Care Officer reporting health concerns"
- "depends upon the attitude of staff, willingness to peruse and at times push for future examinations, questions and answers"
- (General Practitioners need) more knowledge on types of disabilities or syndromes that may cause health issues. More time spent with Residential Care Officer and client.
- "…lack of awareness of the problem"
- "…lack of insight, caring from General Practitioners and other medical professionals"
- "Dr's opinions carry a lot of weight"
- "each Residential Care Officer is different, one standard does not represent all"

Residential Care Officer Skills and Responses
- "due to staff changes I often see an overkill of different health issues"
- "range of client needs and deficits in staff skills, e.g. some clients require nursing/aged care in terms of health needs. Cannot expect staff at level of training to interpret all need or be able to foresee severe consequences for client. Nature of role – poor communication"
- "conditions go undetected – lack of routine screening"
- "more input could be given in the area of lifestyle, diet, health care prevention"
- "sometimes staff can overlook issues in communicating the health requirements of clients to other staff – accurate recording would go a long way to addressing this concern"
- "in general, staff are attentive to subtle changes in clients well being and follow this up promptly"
- "staff teams monitor and follow up on detected health issues"
- "problems around escorting staff with adequate knowledge base"

Leadership
- "the odd house needs more push from Managers"
- "see my place as ensuring that visits/follow up and treatment occur in timely way and instructions are carried out. Also that staff pursue most appropriate course, e.g. specialist"
- "there is a missing element in providing quality structures to clients…in house leadership and guidance in the form of a house/team leader, a highly skilled Residential Care Officer".

5. Part E: Outcomes from the Comprehensive Health Assessment

5.1 Introduction

A total of 44 comprehensive health assessments of clients with an intellectual disability were completed, e.g. 53.7 per cent of the 82 clients who had originally consented to participate therefore completed the programme.

Twenty-seven General Practitioners completed 34 health assessments. These GPs were nominated as the clients' "usual" general practitioner and were located within the community. Although there were 15 DSQ clients who consented to participate in the study who had been seen by the Developmental Disability Unit Clinic (Monday clinic at the Mater Hospital Specialist Outpatients), the results of only 10 DSQ clients' comprehensive health assessments completed by either Dr Lennox or Dr Wallace, are reported. These 5 "missing" clients were unable to participate in the study because their "usual" General Practitioner was participating in the Endeavour Foundation project.

Earlier in the project, in response to concerns of RCOs and other staff, it had been decided that where clients had been recently assessed or were booked into the DDU clinic, it would be inappropriate for the client's usual GP to be asked to re-assess the client. RCOs had expressed major concerns regarding the stress this would place upon clients, as well as staff and the GP.

A number of General Practitioners completed multiple health assessments, e.g. comprehensively health checked more than one DSQ client. Details are as follows:
- 12 General Practitioners completed only one health assessment;
- 5 General Practitioners completed two health assessments;
- 1 General Practitioners completed three health assessments;
- 1 General Practitioner completed four health assessments; and
- 5 General Practitioners completed five health assessments.

5.2 General System Review

Analysis of the returned CHAP booklets, used by the general practitioners/DDU to record outcomes of the health assessment reveals at least one new general system review finding in 18 of the 44 clients with an intellectual disability. Of the 18 clients with an intellectual disability, the medical review identified:
- 7 clients with one only finding;
- 4 clients with two new findings;
- 3 clients with 3 new findings;
- 1 client with 4 new findings;
- 2 clients with 5 new findings; and
- 1 client with 6 new findings.

Of 18 clients with new findings, 10 clients had their health assessed by General Practitioners that they usually consulted. Either Dr Lennox or Dr Wallace at the DDU Clinic assessed the remaining 8 clients.

Details are provided in detail below but an overview of the findings reveals that:

Cardiovascular
  43 clients assessed
  New findings N=3
Respiratory
  42 clients assessed
  New findings N=2
Musculo-skeletal
  43 clients assessed
  New findings N= 3
Renal
  40 clients assessed
  New findings N= 5
Gastroenterogical
  42 clients assessed
  New findings N= 6
Central Nervous System
  38 clients assessed
  New findings N=2
Psychiatric/Behavioural
  42 clients assessed
  New findings N= 7
Endocrine
  39 clients assessed
  New findings N= 8

5.3 General Systems Review Findings

Recommended treatment (where it was provided by the medical practitioner) is bracketed following the findings, e.g. heart murmur (EEG)

Cardiovascular
  43 clients assessed
  10 clients by DDU
  33 clients by GP
  New findings N=3
  2 clients with hypertension (1 client ongoing monitoring)
  1 client with heart murmur (ECG)
  Preexisting findings
  1 client with a heart condition (recommended re-referral for ECG)
Respiratory
  42 clients assessed
  10 clients by DDU
  32 clients by GP
  New findings N=2
  1 client with breast lump (biopsy); aspiration (CT chest and swallowing assessment);
      sleep apnoea (observe)
  1 client with wheezing (treatment recorded but not identified)
Musculo-skeletal
  43 clients assessed
  10 clients by DDU
  33 clients by GP
  New findings N= 3
  1 client with postural problems (no recommended treatments recorded)
  2 clients with osteoarthritis (1 with no recommended treatments recorded) (1 suspected for
  investigations including bone mineral density, i.e. DXA — dual energy x-ray absorptiometry)
  Preexisting findings
  1 client with left hemiplegia (exercises for left sided weakness recommended)
  1 client for review of lupus serology

Renal and Urogenital

   40 clients assessed

   10 clients by DDU

   30 clients by GP

   New findings N= 5

   1 client with mild proteinuria; rectal bleeding; anaemic (referred to un-named specialist)

   1 client with incontinence (urine analysis undertaken)

   2 clients with conditions that were not named or described (both for urine analysis)

   1 client with haematuria (investigation and treatment not named but need for repeat investigation noted)

Endocrine

   39 clients assessed

   10 clients by DDU

   29 clients by GP

   New findings N= 8

   5 clients with thyroid/TFT abnormalities (all for re-testing/recheck)

   1 client with osteoporosis (no treatment recorded)

   1 client with low osteriodil levels (ultrasound and hormone tests (menstrual) and ongoing review
       of osterdiodil)

   1 client with polypharmacy (notes recommend reduce medication)

Gastrointestinal

   42 clients assessed

   10 clients DDU

   32 clients by GP

   New findings N= 6

   1 client with abdominal distension (no treatment identified)

   1 client with diarrhoea /Helicobacter pylori (treatment not identified)

   1 client with Helicobacter pylori (treatment recommended but not named)

   1 client with Helicobacter pylori and iron deficiency (cease medication and treatment not identified)

   1 client with eosinophilia/ worms (treatment/medication recommended)

   1 client with Helicobacter pylori and abnormal LFTs (no treatment recommended)

   1 client recommended to undergo a Helicobacter pylori test (no treatment recorded)

Central Nervous System

   38 clients assessed

   10 clients by DDU

   28 clients by GP

   New findings N=2

   1 client with choking/gagging (under review);

   some increased tone R and upper L limb (question whether to decrease Dilantin
       but refer to specialist/noted the need to get history)

   4 other clients all with recommended medication review relating to antiepileptics
       (one recommendation of refer to specialist)

   Pre-existing findings

   4 un-named conditions

Psychiatric/Behavioural

   42 clients assessed

   10 clients by DDU

   32 clients by GP

   New findings N= 7

   1 client with diagnosis of depression ruled out (treatment recommended involvement of
       psychologist)

   1 client with polypharmacy (no treatment recommended)

   1 client with problems relating to worsening masturbation (no treatment recommended
       but notes read "what can be done")

   1 client with new diagnosis of depression/ obsessionality (refer to specialist)

   1 client with dementia/hypersomnia (genetic screening; reduce medication; and refer to specialist)

   1 client with inappropriate drugs (reduce antipsychotic medication)

   1 client with no psychotic behaviour (cease medication)

   2 clients with un-named conditions (review medication)

   Pre-existing findings

   2 un-named conditions

5.4 Preventative Health Care Review

Analysis of the returned CHAP booklets, used by the general practitioners to record outcomes of the health assessment shows that the approach to preventative health care is different to the general system check. Many general practitioners did not carry out recommended preventative health checks. Where reasons were provided as to why the health check was not completed, details are provided. Lack of, or inability of the client to cooperate with the doctor appears to be a major barrier.

Problems with cooperation can be clearly seen when considering vision checks, hearing checks, breast examination and pap smears. Note the vision check where 19 clients failed to cooperate enough for the check to be completed. However, 15 clients were referred for vision follow up with the majority (N=10) referred to an ophthalmologist. Similarly, 4 clients were referred for a hearing assessment.

A snapshot of the preventative health care findings shows that out of 44 clients with an intellectual disability who had comprehensive health assessments completed:
- the vision status of 27 clients was considered by the GPs and more than half, 15 clients were referred for further vision assessment (one additional client possibly following discussion between carer and family);
- 4 clients had pathology detected following otoscopy;
- 4 clients were referred for further hearing assessment (Australian Hearing Service);
- 25 clients were up to date with their tetanus boosters and 24 clients were up to date with their Hepatitis B immunization;
- 6 clients needed tetanus boosters and 7 tetanus boosters were actually given at the time of the health check;
- Hepatitis B serology was indicated in 5 clients with 6 orders for Hepatitis serology requested at the time of the health check by the doctors;
- opportunistic vaccinations occurred – 2 clients were given flu vaccinations and 1 client received a pneumovax vaccination;
- 37 clients had a complete skin check undertaken with 13 abnormalities detected including 3 clients with basal cell carcinomas and 2 kerotoses;
- only 7 female clients underwent breast examination and 2 clients had a pap smear;
- female clients were too distressed to undergo a pap smear and one refused; and
- 20 male clients had their testicles checked with 3 clients having abnormal findings identified including small testes, large testes and a client with one undescended testicle.

5.5 Preventative Health Care Findings

Vision Test
N=17 Assessed
(N=6 DDU, N=11GP)
Test Type
N=3 test type Schnellen using match card
N=2 test type GPs own test
N=11 test type "other"
N=1 test type Unable to Cooperate
Vision Right Eye
N=3 (findings by GP)
N=1 OUT OF 9 rating of 2
N=2 OUT OF 9 rating of 6
Vision Left Eye
N=2 (findings by GP)
Both rating OUT OF 9 given 6
Reason for Vision Test
N=21
(N=1 DDU; N=20 GP)
N=2 poor cooperation
N=16 no cooperation (included the DDU)
N=1 poor/very poor vision
N=1 patient unable to perform test
N=1 blind

Referral for Vision Test
  N=27
  (N=9 DDU; N=18 GP)
  N=10 referred to Ophthalmologist
  N=5 referred to Optometrist
  N=6 referral not required
  N=1 under care of optometrist/ophthalmologist
  N=1 refuses to wear glasses
  N=1 carer to discuss with family
  N=3 other (DDU)

Hearing Test/Otoscopy
Wax Obscuring Tympanic Membrane
  N=11 *yes*
  (N=3 DDU; N=8 GP)
Wax not Obscuring Tympanic Membrane
  N=14 yes (all GP)
Wax Removed
  N=6 *yes* (all GP)
No Abnormality Detected
  N=17 *yes*
  (N=1 DDU; N=16 GP)
Pathology Identified
  N=4 (all GP)
  N=1 scarred drum
  N=1 unknown/refuse to co-operate
  N=1 bilateral perforations discharging
  N=1 left perforated tympana
Hearing Test
  N=24
  N=2 referred for further assessment (includes DDU=1)
  N=4 uncertain
  N=18 no impairment
Referred for Hearing Test
  N=18 responses as follows
  (N=6 DDU; N=12 GP)
  N=4 referred to Australian Hearing Service
  N=9 referral not required
  N=3 referred back to GP (assessed at DDU clinic)
  N=1 has had recent audiology test
  N=1 previously assessed

Immunization Status
Tetanus immunization current/up to date
  N=25 (includes DDU=5)
Tetanus booster indicated
  N=6 (includes 2xDDU)
Tetanus booster given
  N=7 (no DDU)

Hepatitis B immunization current
  N=24 (includes 4xDDU)
Hepatitis B serology indicated
  N=5 (includes 1xDDU)
Hepatitis B serology ordered
  N=7 (includes 2xDDU)

Other immunization information provided
  N=9 (no DDU)
  N=1 Hepatitis B Carrier
  N=1 Hepatitis B due for booster
  N=2 Flu vaccination given (one of these also given Pneumovax)
  N=1 Hepatitis B serology negative, therefore requires vaccination

N=1 Pneumovax (one of these also given Flu vaccination)
N=1 Hepatitis B positive
N=1 arrangements made for 1st Hepatitis B vaccination
N=1 considering Hepatitis A vaccination

Skin status
Was a complete skin examination undertaken?
N=37 *yes*
(N=8 DDU; N=29 GP)
Skin abnormalities found
  N=13
  (N=1 DDU; N=12 GP)
  N=1 has dry skin
  N=2 has sebaceous kerotoses
  N=3 have basal cell carcinoma
  N=1 has acne
  N=1 has dermatitis
  N=1 has benign naive
  N=1 has ulceration
  N=1 has pityriasis vesicular
  N=1 has reduced body hair
  N=1 has scratch marks and thick calluses on feet
Treatment for skin conditions
  N=7 (all GP)
  N=1 treatment mycospor cream
  N=1 treatment review
  N=1 refer to specialist
  N=1 treatment cryotherapy
  N=2 wash in aqueous cream
  N=1 treatment with minomycin

Women's Health
Breast examination undertaken
N=7 *yes*
(N=3 DDU; N=4 GP)
  Reason for NO breast examination
  N=3 (all GP)
  N=1 refused
  N=1 lack of cooperation/for later repeat
  N=1 non co-operation
Pap smear taken/organized
  N=2 yes (both GP)
Reason for no pap smear
  N=15
  (N=1DDU; N=14GP)
  N=1 not indicated (DDU)
  N=5 refused/distressed
  N=1 non cooperation

Men's Health
Checked for undescended testicles
N=20 *yes*
(N=4 DDU; N=16 GP)
Abnormalities found
  N=3
  (N=1 DDU; N=2 GP)
  N=1 has small testes
  N=1 has one undescended testes
  N=1 has large testicles L>R
Investigations ordered
  N=1 (by GP)
Treatment prescribed
  Nil noted

5.6 Concluding Observations

In some general system reviews, whilst there were no new significant findings, opportunistic health promotion took place, e.g. medication was reviewed and adjusted or flu vaccination provided. In other cases, there may have been no new findings recorded but investigatory treatment was recommended.

Although General Practitioners were asked to document their findings and record in detail the recommended treatment or action that would follow, some failed to follow this request. Recordings made in the relevant section of the CHAP booklet were often sketchy and lacking in detail. In fact, some written information was indecipherable and difficult to decipher or comprehend. Notations were often in shorthand and understanding of a third party would have required contextual information. Discussions that occurred between the doctor and the direct care staff accompanying the client may well have provided that contextual clarification and allowed appropriate follow up treatment that was not recorded, to occur.

General Practitioners appeared to experience some problems in recording findings under headings provided in the CHAP booklet, e.g. "systems check." Whilst the headings provided were logical and clear, some GPs appeared to pay little attention to where they recorded or jotted down information and findings. Limited time would account for this approach rather than lack of interest in the study or the area.

Helicobacter pylori (HP) findings identified involved clients who had their comprehensive health assessments undertaken through the DDU clinic, e.g. either by Dr Wallace or Dr Lennox. No GPs in the community recommended HP related investigations.

Benefits associated with comprehensive health assessment have been identified but there would have been value in following up clients in 6 months time and reviewing the GP notes as originally planned. Follow up would have helped to ascertain change and hopefully improvement in client health status, post health review.

Lessons from the Labyrinth

Chapter Four

Discussion, Conclusion and Recommendations

1.   Introduction

A range of potential solutions to improve health care outcomes for adults with an intellectual disability have been identified in the literature including:

- Increase time and remuneration for General Practitioners and other medical consultants (Beange, 1996; Wilson & Haire, 1990);
- Improved liaison and communication with other professionals and agencies involved in the support of people with an intellectual disability (Cumella et al, 1992; Lennox & Chaplin, 1995);
- Establish information systems within primary care, e.g. primary care based registers to monitor health status and interventions (Cumella et al, 1992; Kerr et al, 1996);
- Resource and specialist referral guides (Minihan et al, 1993);
- Improved health promotion, e.g. health checks such as the CHAP trialed in this study (Beange, 1996; Kerr et al, 1996);
- Improve the quantity and quality of education available (Lennox & Diggens, 1999)
- Increase medical education and training at the undergraduate and postgraduate levels (Beange et al, 1995)

It should however be noted, that most of these recommendations are strategies aimed at General Practitioners and other specialist medical officers. There is little research which guides the improvement of health care outcomes from the bottom up, e.g. from the perspective of direct care workers and their roles and responsibilities in both promoting and meeting the health care needs of the clients that they support.

There may well be value in simply raising awareness of health care problems and what best practice prescribes. This approach underpins the Health Guidelines for Adults with an Intellectual Disability that the World Health Organisation is currently considering (Lennox et al, 2000) and in fact is embedded within most education and training initiatives. The production and wide distribution of this report may also increase opportunities for carers to improve the health care of people with an intellectual disability. Implicit within this report is recognition of the need for ongoing education of relevant stakeholders, particularly carers including direct care workers — in addition to General Practitioners and other service providers. Education is required in order to promote the health and well-being of adults with an intellectual disability.

However, the provision of health care to adults with an intellectual disability involves working across the boundaries of health and disability services. Cross boundary service provision is complex and challenging. Tensions experienced include different funding regimes, divergent priorities, boundary overlap, and unfamiliar organisational cultures. Good working relationships require a common commitment to people with an intellectual disability as well as capacity to share information and understand other professional perspectives. It is therefore of little surprise that Residential Care Officers experience the difficulties that they do when attempting to meet the health care needs of the population that they support. Further, they should be commended for displaying the levels of energy and commitment that they do.

Ideally services and supports provided to adults with an intellectual disability should form part of a cohesive and cooperative system that integrates the provision of both disability and preventative health services. Organisational boundaries must not get in the way of care for people with an intellectual disability. Conversely, and of course ideally, each agency or service should be transparently responsible and accountable to the client for their care and support at all times. The provision of services and supports should reflect practical working arrangements rather than complex bureaucratic policies and practices (eligibility criteria) designed to exclude people from services. Flexible roles and responsibilities should emerge. If only government departments and community agencies could relax their polices and guidelines and embrace creativity to enable sharing of professionals, or the pooling of financial and physical resources.

The Developmental Disability Unit argues strongly that Disability Services Queensland (DSQ) must take the initiative as lead agency for people with disabilities and make sustained effort to involve both disability and health workers in the identification and management of health care problems experienced by people with an intellectual disability. Ameliorative strategies and policy based recommendations for change typically discuss the need for radical social re-modeling. This approach is reminiscent and analogous with symptom treatment in medical practice. Put simply, DSQ must strive to set the example. Stop treating only the symptoms, e.g. band-aiding. Treat the cause instead (Tarlov, 1996). To assist and achieve maximum outcomes, this report had made a number of related and integrated recommended changes. Such changes need to be implemented in an integrated and comprehensive manner.

It is impossible to identify one solution or strategy to improve the health status of adults with an intellectual disability. Solutions are multifaceted and involve multiple actors. It is also clear that a multi-element package of remedies are required if superior outcomes are genuinely sought after. For example, simply providing staff training and education will not produce effective change in the health care status of people with an intellectual disability living in Disability Services Queensland (DSQ) supported accommodation options. There are numerous pathways to tackle health inequalities experienced by people with an intellectual disability. However, the recommendations contained within this report draw some inspiration from the social capital literature discussed earlier and reflect four key strategies (Whitehead, 1995):

- Strengthen individuals (people with an intellectual disability, their carers and advocates);
- Strengthen communities;
- Improve access to *essential* services (remembering that people with an intellectual disability have a right to a reasonable standard of health care and associated quality of life); and
- Encourage macroeconomic and microeconomic change.

There is current debate regarding the relevance of social capital and increasing recognition that the social context influences how society's members develop as individuals who have relevance, respect, dignity, independence and the capacity to support or care for themselves and others. DSQ and its staff must be commended for the implementation of a philosophy of service provision which embraces and reinforces the importance of a range of constructs and principles which are critical to quality of life within the community including social/social role valorization, the developmental model and the least restrictive alternative. It is the experience of the research project that direct care staff in general, believe wholeheartedly in this philosophy of service provision and genuinely attempt to serve clients within an appropriate framework of support. However, despite the existence of such powerful rhetoric being replicated in policies, programmes and services, the experience of many people with a disability remains that of social disadvantage, despair and alienation (Hawe, 1998 in Hawe & Shiell, 2000)

The health status of people with an intellectual disability can be enhanced and their health care needs met only when there is genuine recognition that the social environment of the broader community and health status are linked. The power of social capital should not be under-estimated. Disability Services Queensland needs to place focus upon and foster social engagement and human interaction, connection and growth and respect for "all," regardless of disability or health status.

Against this background the following recommendations aim to address the diversity of barriers that impact health care status of adults with an intellectual disability living in community settings. The recommendations also clearly aim to improve health outcomes for adults with an intellectual disability and are relevant to the Queensland setting. The recommendations should be considered the link or conduit between all chapters contained within the report in that they draw broadly upon the literature overview including current trends in health and human services; and both qualitative and quantitative data collection made possible through the study. Whilst the 2 key recommendations are listed initially, following recommendations are *not* presented in a hierarchical or prioritized order. Each recommendation should be considered important. The DDU welcomes continued opportunities to discuss the recommendations in more detail in the future.

2. Summary and Concluding Comments Regarding CHAP and Health Outcomes

The General Practitioner is the gatekeeper to primary health care for people with an intellectual disability. This responsibility is mandated through our health care system, e.g. GPs have exclusive referral rights to specialists and tertiary health care. The access of people with an intellectual disability to a range of health services, including specialist care will be determined by the efficacy of the GP in identifying their health care problems and then their health care related needs.

This report has argued consistently that people with an intellectual disability experience general medical and health related problems that may be difficult for General Practitioners to identify or diagnose. Barriers to high standard implementation of the gatekeeper model in the Australian health care setting includes not

only untrained GPs in regard to the health care needs of adults with an intellectual disability, but loss of faith in the role of GPs by the general public, and in particular RCOs and other disability workers. Focus groups and anecdotal experience strongly suggests that many direct care workers acknowledge that GPs are unable to provide coordinated and comprehensive health care to adults with an intellectual disability.

The CHAP was designed to prompt General Practitioners to look for and assess common health care problems experienced by this vulnerable population. Because these General Practitioners were the "usual" doctors of the clients whose health was assessed, the new findings are suggestive that the General Practitioner had failed to diagnose and treat these conditions in the past. However findings from this study cannot attempt to comment on *why*.

The comprehensive health assessment of 44 clients revealed 18 clients with at least one "new findings". In fact new findings included:
* 7 clients with one only finding;
* 4 clients with two new findings;
* 3 clients with 3 new findings;
* 1 client with 4 new findings;
* 2 clients with 5 new findings; and
* 1 client with 6 new findings.

The general system review revealed:
Cardiovascular
    43 clients assessed
    New findings N=3
Respiratory
    42 clients assessed
    New findings N=2
Musculo-skeletal
    43 clients assessed
    New findings N= 3
Renal
    40 clients assessed
    New findings N= 5
Gastroenterogical
    42 clients assessed
    New findings N= 6
Central Nervous System
    38 clients assessed
    New findings N=2
Psychiatric/Behavioural
    42 clients assessed
    New findings N= 7
Endocrine
    39 clients assessed
    New findings N= 8

Health promotion review identified:
* need for visual and hearing assessments;
* need for immunization boosters including Hepatitis B and Tetanus;
* opportunities for opportunistic health care, e.g. influenza injections;
* skin checks revealing basal cell carcinomas and kerotoses;
* inability for the GP to complete some assessments due to lack of cooperation of the client including breast examinations and pap smears; and
* identification of the need for investigations or tests but no decision/request to undergo the procedure or the test.

3.   The Invisibility of Direct Care Workers

A common view held within some parts of modern society, suggests that services provided to adults with an intellectual disability and many other vulnerable people in society (people who are aged, have mental health problems or physical disabilities) is often poor, and fails to promote independence and a reasonable quality of life. Whilst it is not within the scope of this study to address this perception, it is important to point out that direct care staff who participated within this study demonstrated high levels of interest and

commitment to the clients they supported and in fact, participation in the study may well have been driven by such personal drive. What can be said, is that direct care staff, RCOs in this study know and acknowledge that they are placed within a critical position. Their varied roles and responsibilities are pivotal to all aspects of quality of life of the clients that they support. A DSQ staffer put it so well, "we are expected to be everything to everyone". RCOs know that they have the potential and ability to influence the health and well-being status of their clients. The recognize how crucial health and well-being is but they lack the skills and support to be truly effective.

The Literature overview suggests that the recruitment, training and management of direct care workers, i.e. RCOs, has a significant influence on the quality of care provided to the client they support. Disability Services Queensland (DSQ) Residential Care Officers who participated in the study shared in focus groups that they believe they are badly paid and remunerated for what they do, poorly trained, and unsupported by senior management and wider organisation (many spoke highly of their line managers). RCOs are crucial in the daily lives of people with an intellectual disability yet they like their clients, are potentially vulnerable.

Direct care workers suggest that they there are few or limited opportunities for career improvement. Some suggested that the good RCOs move on to become line managers. Many direct care workers believe that they need to access additional skills and expertise but say that the organisation does not support either their desires or needs. Despite these concerns, the survey results contained within this report show that RCOs prioritize the health care needs of their clients. Perhaps it is the "care" within the "carer" that is responsible for the quality of direct care services provided to clients.

Disability Services Queensland (DSQ) has actively introduced a number of initiatives relating to the education and training of their direct care workforce, and to client service standards. Whilst such change and initiatives are to be commended, additional changes would be required to improve the health care and health status of adults with an intellectual disability. The utilization of the CHAP programme may be valuable in that it influences the behaviour of direct care workers, e.g. these workers may instigate health screening and the provision of relevant information to their General Practitioner. This approach may be an effective way of improving health service delivery and outcomes (Lennox & Kerr, 1997). This report argues for the ongoing implementation of CHAP, as well as making a range of complimentary recommendations.

4.   Barriers to Participation in the Study

4.1   Limitations Associated with the Data Collection

One of the possible limitations of the study relates to the possibility some of the direct care staff that participated (ie questionnaire, completed the CHAP tool, accompanied the client to their usual General Practitioner for a comprehensive health assessment, and returned the completed CHAP tool to the Developmental Disability Unit), shared some common characteristics. One possibility is that RCOs who participated were the motivated and aware RCOs, those who already believed that health and well-being was a priority issue. It is possible that those who participated meant the project was "preaching to the converted".

During the development of the questionnaire, a number of draft versions were trialed with direct care workers, professional/resource staff and Managers from other Disability Services Queensland (DSQ) regions not participating in the research. It is interesting to note that during these trials of the questionnaire, some Managers felt that direct care workers would not answer questions relating to satisfaction. It was also suggested that responses may be dishonest or perhaps provide the researchers with what the RCOs thought they wanted to know, rather than what the true situation was.

It is interesting and pleasing that questions contained in the various survey instruments were (in general) fully completed by respondents. This response may have related to the fact that a lot of explanation occurred regarding confidentiality and approaches to the storage and data entry of identifying information during the recruitment phase of the study. Staff may have felt comforted that they could answer questions openly and honestly. Certainly, preliminary responses shared at focus groups was well received by staff and there remains no indication from direct care workers or Managers for that matter that outcomes from the study do not reflect practice in the field or the true state of the direct care situation. Health and well-being was generally considered to be a priority need area with responses to need curtailed by attitudes, resource constraints and knowledge/skill deficits.

4.2   Views of Managers

Focus groups with Unit and Area Managers revealed their awareness of particular groups of Residential Care Officers who were considered to be "on the ball" and "excellent staff". These Managers spoke informally

amongst themselves about the possible identities and locations of staff (e.g. ALS house or flat address) that had participated in or completed parts of the study. Managers cited the commitment of those staff to their clients, health and well-being and the research ideals as being the reason for participation in the research. The researchers were careful not to identify direct care workers, as per the project commitment that participants would not be identifiable.

The Managers also thought that some staff that either chose not to participate in the study, those who had "dropped out" or failed to accompany clients to their General Practitioner for a health assessment might also share certain characteristics which they discussed informally. A small percentage of direct care staff were considered to be lazy and unreliable, others lacked commitment or interest in their jobs or associated responsibilities. Others were described as "passive aggressive" and managers indicated that they were pursuing concerns through appropriate channels.

It is important to note that Managers also cited a number of legitimate reasons that are discussed below in detail as to why some direct care staff were genuinely unable to participate in the study or failed to return questionnaires and/or the CHAP tool. It is interesting to note that approximately equal numbers of Managers expressed disappointment and concern over the final participation numbers, e.g. questionnaires were completed by 59 RCOs on behalf of 68 clients with 44 completed comprehensive health assessments by General Practitioners being returned to the Developmental Disability Unit.

Other Managers thought the response was very good when considering the contextual issues that are detailed below. These managers made particular reference to apathy and negativity displayed by some direct care workers in regard to various aspects of their employment. Comments were also made about the extremely low status of the Residential Care Officer within the disability services community (and wider community generally) as well as specifically the Disability Services Queensland (DSQ) organisation. There appeared to be general consensus that the majority of Residential Care Officers were hard working professionals who often went beyond their job descriptions, "the call of duty", to meet the needs of clients with an intellectual disability. Examples were cited where Residential Care Officers would accompany clients to medical appointments in their own time or purchase client items when the client was unable to meet the costs. The relationships and friendships that had developed between RCOs and clients were also positively discussed.

Another common scenario that appears to take place across many Area Offices involves staff, again in their own time, attending meetings to advocate for client or address client concerns. The research project actually had personal experience of this type of commitment to clients and the priority accorded by some Residential Care Officers to client health and well-being. One focus group of direct care workers included only one member of staff who was "rostered on duty" and was therefore paid for time contributed. All other members of Alternate Living Service house who attended the focus group, including the line Manger, participated in their own time without payment. The Manager advised that this sort of commitment was "typical of staff from that house who had worked together cohesively and with great stability for some time".

One Manager suggested in a focus group that Residential Care Officers shared some historical similarities with the Queensland Police Service. The suggestion was made that a "few bad eggs remained in employment who gave the majority a bad name". Further discussion suggested that a minority had been involved in scandals in the past. Comments apparently referred to institutional inquiries including the recent Forde Inquiry (not directly relating to Disability Workers but relevant to the then Department of Families, Youth and Community Care); the inquiry into the Townsville non-government Cootharinga Centre and the Brisbane based Carter Inquiry into Basil Stafford. The Carter Inquiry had investigated and responded to allegations of abuse and corruption by staff employed within that institution. It seemed that fallout from these inquiries may have fuelled morale problems. Some Residential Care Officers now appear to believe that the general community views direct care work negatively. Further, some RCO appear to believe that DSQ considers that these workers hold low credibility within the organisation.

4.3   Residential Care Officer Perceptions of Research

Participants who failed to return the questionnaire were carefully and gently followed up by DDU researchers including written prompts to their work address; telephone reminders; and telephone and or email contact with their Managers. The follow up process continued for almost 12 months past the original completion date anticipated and can only be described as a long and tortured process. Other difficulties encountered which delayed making contact with direct care staff and Managers included – resignations, long service leave and other leave entitlements including extended sick leave, acting up arrangements, failure of a range of staff to respond to messages seeking contact or feedback, shift work including contact difficulties relating to contact with staff on evening shifts or rostered days off, entire households moving into new addresses; clients moving to new accommodation options including a nursing home admission or Disability Services

Queensland (DSQ) regions.

A range of reasons were verbally provided by direct care workers to the Developmental Disability Unit as to why they failed to continue their involvement in the project. Some reasons cannot be shared to protect confidentiality but others provided included:

Organisational and Systemic Barriers

- A number of decisions not to continue with the project was based upon perceptions that some Residential Care Officers had been coerced into participating by Managers and this was inappropriate;
- Belief that if management valued the project then there was a hidden agenda — a number of staff were very concerned about confidentiality and whether management would have access to identifying information;
- Some direct care workers felt the researchers had colluded with management in some sort of conspiracy;
- Views that the project was pointless and a waste of money;
- Views that there was little benefit likely for the client or other clients;
- Considered the project to be intrusive and not in the best interests therefore of the client;
- One direct care worker felt management would use the outcome to further scapegoat Residential Care Officers;
- Predominant view that involvement and participation would result in additional work outside of paid hours;
- Another opportunity for the "organisation" to take advantage of staff;
- New staff, untrained and unsure of role.

Client Barriers

- Client was acutely unwell and therefore the project was inappropriate at this point in time (both the General Practitioner and the RCO felt comprehensive health assessment was valuable in this population);
- Believed that the client had recently had a recent and thorough medical assessment and therefore having another health check so soon would be too stressful on the client therefore declined further involvement;
- Challenging behaviour of client made comprehensive health assessment in general practice setting impossible;
- Client refused to cooperate with doctor and declined to participate in physical examination;
- Another client refused to get into the car to see any doctor relating to past trauma regarding an intrusive medical procedure;
- One client physically assaulted staff and medical practitioner therefore staff felt they were unable to return;
- Another client had always refused health checks and this time was no different;
- Family member was seriously ill therefore family declined to consent;
- Unable to contact statutory health attorney/family members for consent.

Direct Care Worker Barriers

- Had not received the questionnaire/tool in the mail (some Residential Care Officers failed to respond to a second mail out and others did respond);
- Had misplaced or lost the questionnaire/tool;
- Could not recall signing the consent form and did not remember much about the project;
- The questionnaire had disappeared from the client's file;
- Did not understand the project and the material provided in the mail therefore had disregarded the project;
- Was too busy to complete the questionnaire/tool or make the necessary medical appointment;
- Simply forgot to complete questionnaire, complete the tool or make the appointment (and despite gentle prompting apparently the majority continued to forget);
- Felt overwhelmed or stressed by work or personal demands therefore were unable to complete required tasks;
- Had only returned from long service or other leave and were unable to complete the questionnaire or make the medical appointment;
- Had accorded a low priority to the task because had not really been uninterested from the beginning;
- Project was different from what had originally thought it was about;
- Too much extra work involved;
- "Irritated" by medicalisation of disability and felt the client was wrongly being labeled as "sick";
- A number of direct care staff felt the project did not sit comfortably with normalization and

social role valorization therefore it was "philosophically" incorrect for them to participate;
- Had only just been allocated client coordinator responsibility therefore felt did not know client well enough to complete documentation or take client to doctor for a health review;
- Unable to locate archival file and therefore unable to complete major components of questionnaire – felt there was no point in continuing with project.

General Practice Barriers
- Had attempted to make an appointment but the doctor was too busy and had suggested they return at a later date (which failed to eventuate despite continued prompting);
- Had been refused the request for a comprehensive health assessment by the General Practitioner on the basis that the General Practitioner knew nothing about the project — records clearly showed that this doctor had discussed the project with Dr Lennox personally and had completed and faxed a consent form to the Developmental Disability Unit;
- Another concerned RCO shared the experience of the General Practitioner moving to another suburb and declining to see the clients in the new surgery despite having consented to participate in the project;
- One General Practitioner refused to participate in the project citing overwhelming practice demands and a high client load of patients with an intellectual disability with acute health needs — said too busy;
- Another General Practitioner went on extended leave leaving the practice in the hands of a locum who openly shared inexperience and lack of confidence to undertake a health assessment of a patient with an intellectual disability;
- RCO described a "tenuous" or problematic relationship with the client's doctor and felt the comprehensive health assessment might compromise the relationship they had spent considerable energy developing;
- One direct care worker suggested that the General Practitioner owned the problem and the CHAP would not change the behaviour of the General Practitioner or their approach to working with clients with an intellectual disability;
- One General Practitioner cited personal ill-health.

Focus groups and staff consultations at the conclusion of the data gathering period revealed that some staff had been generally suspicious of "research" and its relevance to direct care workers. Research of any type with treated with disdain and suspicion. Academics were considered to be too far removed from the "daily grind". Other related concerns included costs associated with the research when benefits were considered to be small or minimal. There were suggestions that the money allocated by DSQ to the project would have been better spent in increasing staff: client ratios or enhancing client health care in more direct ways. A number of direct care staff were also openly antagonistic towards the medical profession, suggesting that social role valorization had rejected medicine and therefore they would not participate in "medical" research.

Some staff felt that the participation of clients in the research project reduced the client to a powerless "guinea pig". Some Residential Care Officers felt that research of any kind used clients and therefore regardless of possible benefit of a comprehensive health assessment, participation was philosophically incorrect.

Other Residential Care Officers were openly disinterested and unmotivated to participate giving no particular reason. Some cited time constraints, competing demands and work pressures. Many felt participation would involve out of hours and additional demands upon their time even though some of these staff eventually did participate because they could see value for themselves, the clients and the General Practitioners.

Other Residential Care Officers felt that they had good relationships with their General Practitioners and could not understand what purpose a comprehensive health assessment would achieve. Some Area Offices had already instigated health reviews and health checklists therefore the project was seen as duplicating existing processes and was therefore an unnecessary time wasting exercise.

Some Residential Care Officers stated clearly that research was totally uncalled for because they knew exactly "what the problem was" and made clear suggestions regarding General Practitioners receiving compulsory education in intellectual disability both at the undergraduate level and postgraduate levels. Others felt that the organisation, i.e. Disability Services Queensland (DSQ) did not value Residential Care Officers therefore the project recommendation and outcomes would achieve little in the long run.

Some Residential Care Officers confidentially shared that they had been pressured by management to participate, e.g. they had been told that because management were funding the research staff had an obligation to participate. Some staff that were disgruntled with management therefore saw non-participation in the research as one method of publicly displaying their dissatisfaction with the wider organisation.

5. Recommendations

Recommendation 1

Disability Services Queensland (DSQ) should immediately begin to **implement the CHAP tool across Queensland** ALS houses and make the tool available to community clients supported by non-government agencies.

The research clearly demonstrates that Residential Care Officers lack expertise and skills in the management of health care problems experienced by their clients. Disability Services Queensland (DSQ) should take care not to underestimate the lack of understanding about the health care management and treatment needs of people with an intellectual disability that exists both within and external to the agency. It is also likely that outcomes from the study have some applicability to other direct care workers supporting people with an intellectual disability under the umbrella of other agencies.

The CHAP tool and programme will continue to undergo modifications and changes in response to the ongoing research and work being carried out by the Developmental Disability Unit. Changes and modifications will be communicated to Disability Services Queensland (DSQ) in an ongoing manner. In the interim period, the Developmental Disability Unit recommends that all Disability Services Queensland (DSQ) clients have the opportunity to benefit from the CHAP. CHAP can easily be coordinated within the individualized planning system used by DSQ to support clients. DSQ should consider the benefits of making the tool and programme available to the wider community. It is also important however, to recognise that education and training are an important component of CHAP.

The CHAP enhances access to primary health care and offers adults with an intellectual disability the opportunity to benefit from a thorough health check with the General Practitioner. The majority of Residential Care Officers who participated in the study found the process useful and analysis of health outcomes following the health checks undertaken as part of the study, clearly demonstrate the potential positive client benefits of health screening.

The DDU recommends that DSQ uses CHAP to:
- ensure that all DSQ community clients enjoy a consistent approach to health care assessment and monitoring (there appears to be significant variation in how health and well-being is managed between Residential Care Officers and from Area Office to Area Office);
- be used as an agreed protocol to guide the health assessment of clients, e.g. framework/timetable to prompt health checks and requests for referral to specialist health services;
- provide clarity and best practice approach to the treatment and monitoring of health care problems commonly experienced by adults with an intellectual disability.

Recommendation 2

Disability Services Queensland (DSQ) needs to allocate funds so that **every Area Office can employ a Health Care Coordinator (HCC)**. This position would be responsible for the augmentation of health care services provided by direct care staff. The incumbent would play a critical role in facilitating liaison with primary health care and specialist services. The HCC should be responsible for the provision of expertise and coordination of a range of support opportunities for direct care staff and other DSQ staff. However, support for Residential Care Officer would be the *priority* for the Health Care Coordinator, specifically to enhance RCO knowledge, skills and expertise in meeting the health care needs of clients with an intellectual disability.

Incumbents of the position should ideally not be located within DSQ area offices. It is in the best interests of the clients, staff and incumbents for the position to be housed "externally". Co-location with an external agency such as the Developmental Disability Unit or a community-based health service is strongly recommended. Such co-location external to DSQ would enhance the independence of the position and commitment to meeting client health needs through RCO and other staff support.

The recent UK White Paper "Valuing People: A new strategy for learning disability for the 21st century" was published in March 2001 and is the first White Paper on learning disability, i.e. intellectual disability, for thirty years. The White Paper proposes an ambitious array of strategies regarding improvement of health care to adults with an intellectual disability. One of the significant recommendations included the appointment of Health Facilitators from each local community learning disability team (CLDT) to support people with learning disabilities and an assurance that all people with learning disabilities are registered with a General Practitioner and have their own Health Action Plan. The HCC role as described in this recommendation share important similarities.

The Health Care Coordinator would contribute to the development of health protocols/plans for clients with an intellectual disability with health care needs. The HCC would be involved in undertaking or

organizing client health assessments including access to oral health and dental care, fitness, mobility, continence, vision, hearing, nutrition and emotional needs as well as medication reviews, side effects and records of any screening tests. The employment of this professional would be expected to increase community access and maintain adults longer in community placements (counteract the impact of ageing). Access to and support from a HCC would contain costs (reduce RCO overtime and shift double ups), increase Residential Care Officer job satisfaction. Improvements between cross agency communication and collaboration would also be anticipated.

RCOs in focus groups asked for a "voice that would carry more weight". They argued that despite the fact that they often knew the client better than anyone, when working with health care workers their voice carried little status. To ensure empowerment in the process of health-related decision making, people with an intellectual disability need to have access to health professionals who possess disability related knowledge and skills (Keane, 1996)

DSQ needs to employ a professional with considerable health care expertise to assist with health triage through community liaison functions. Whilst experienced nursing professionals would be able to argue their capacity to undertake such a role described, other allied professionals should not be excluded from consideration. Health Care Coordinators could be made clearly responsible for negotiating health and disability/human service system barriers that compromise health care status of people with an intellectual disability. This mandate would need to be clearly factored into position descriptions and job recruitment criteria. Key responsibilities (Martin, 1999) would include:

- Collaborative care – when required, assist with or coordinate interaction between staff and medical practitioners, allied health professionals and other professionals involved in health care issues relevant to adults with an intellectual disability.
- Individual health care support – works with and through direct care staff and other members of the multi-disciplinary team in delivering direct care and support to adults with an intellectual disability, e.g. could mentor direct care staff, teach particular health related skills or routines through hands on assistance or facilitate guidance in regard to a particular health issue or concern by another relevant professional or expert.
- Education and information source – provides or facilitate education, training and information opportunities tailored to meet the needs of particular clients, their direct care staff and their team at the coalface.
- Consultation – this professional would be accessible by a range of staff to comment and advise or facilitate access to information/ best practice approaches to health and well-being of adults with an intellectual disability.
- Liaison and Networking – problem solver within and outside the organisation when requested to assist direct care staff or team members in resolving client health problems or health interventions.
- Policy and Practice development and support – promotes high quality health care by contributing within and external to the organisation in the development of policy, practice and protocol development regarding health of adults with an intellectual disability.

Recommendation 3

Disability Services Queensland (DSQ*) must allocate dedicated funds and resources to workable community based strategies and solutions that improve the health status of people with an intellectual disability.*

The Developmental Disability Unit is the only Queensland initiative of its type. The DDU mission, aims and objectives are severely restricted by limited funding and minimal resources. Funding for the Developmental Disability Unit should be substantially increased.

DSQ doesn't need to waste valuable resources proving what is already known, e.g. adults with an intellectual disability *do* have major health care problems. DSQ needs to invest resources and energy on workable strategies and solutions. The DDU attempts to adopt a whole of state focus but resource injection is required if Queensland wide outreach is to be made practicably possible.

Disability Services Queensland (DSQ) should immediately enter into negotiations with the Developmental Disability Unit to considerably enhance funding so that clinical, teaching and research activity can be increased and outreach across Queensland extended significantly. .

Forward budget planning should also consider the allocation of project funding for innovative and creative community-based solutions to address the heath care status of adults with an intellectual disability. Implications of ageing carers and also adults with an intellectual disability who are ageing should be carefully planned and considered in partnership with Queensland Health and the non-government sector.

Recommendation 4

Disability Services Queensland (DSQ) as lead disability agency needs to ensure that ***all direct care staff access to a range of health related training opportunities that are provided by experts*** in collaboration with in-house professionals.

All training and education initiatives undertaken by Disability Services Queensland (DSQ) to all staff needs to adopt a biopsychosocial approach that recognizes the value of contributions from medical and health professionals (biomedical sciences) in addition to the human and social sciences.

Increased training and education opportunities are one simple and effective way in which the health care of people with an intellectual disability can be improved (Lennox & Kerr, 1997). However, education, training and effectiveness need to be linked. What is taught needs to reflect the knowledge and skills needed by practitioners and staff working at the coalface.

Historically disability services rejected the medical model, choosing to adopt a social construct of disability that is to be commended. However, the vulnerability of the population to health care problems means that relevant medical and health care services must be obtained if a person with an intellectual disability is to enjoy a reasonable quality of life. Health should be considered within the biopsychosocial approach with multi-professional educational strategies meeting the education and training needs of staff who come into contact with clients.

Recommendation 5

Disability Services Queensland (DSQ) must support direct care staff to meet both advocacy and duty of care obligations in relation to the health care needs of adults with an intellectual disability. DSQ should ***adopt a policy and practice approach to ensure clients access appropriate health care services within community settings***.

High morbidity and mortality rates clearly dictate the need for Disability Services Queensland (DSQ) staff ensure they are not failing their duty of care to clients by abrogating *total* responsibility for health care needs to the medical or health profession. Similarly, the medical or health profession must not abrogate its duty of care to provide a reasonable standard and range of health services to people with an intellectual disability.

Generic health services, including those located within the community and hospital settings must be available and accessible to people with an intellectual disability. DSQ should adopt a policy and practice approach that where staff can provide evidence of failure to provide appropriate health services should involve immediate discussion and ideally non-adversarial resolution within the hierarchy of the service/provider. Where such collaboration does not quickly resolve the dispute, legal advice should be sought and appropriate action taken.

Where appropriate, the matter should be urgently brought to the attention of appropriate authorities as determined by state and commonwealth legislation, e.g. Health Rights Commission, relevant registration boards and bodies, the Criminal Justice Commission and so on.

Recommendation 6

Disability Services Queensland (DSQ) needs to ***enter into a funded partnership with the Developmental Disability Unit to develop health education and training curriculum and resources relevant to adults with an intellectual disability***, implement and evaluate a series of one day training workshops on health and well-being for direct care workers and other disability professionals.

Consideration should be given to the relevance of such workshops for clients, family members and unpaid carers. Managers and professionals will also need tailored education and training access.

Direct care workers are in the ideal position to encourage and assist the people they support to live healthier lifestyles. They need "hands on" practical training that covers basic skills relating to detection, management and advocacy. These carers will best benefit from an educative approach which involves mentoring, homework, modeling, role plays, *in vivo* practices, use of video taping and feedback. Training is best provided in short, succinct bursts which minimize work disruption and absence from day to day activities, e.g. a one day workshop.

Recommendation 7

In addition to first aid training, all *Residential Care Officers should attend a compulsory health education and training workshop "Improving the Health Status of People with an Intellectual Disability".* Other Disability Services Queensland (DSQ) staff should be encouraged to attend.

The Developmental Disability Unit would be prepared to work collaboratively with health, human and disability services to facilitate the workshops on a regular basis

Residential Care Officers should be given the opportunity to a range of health related education and training opportunities throughout their training, in addition to the education and training workshop described above. Post training opportunities should also be available to experienced RCOs.

Residential Care Officers face a range of problems that may impact the health care status of the adults with an intellectual disability that they support. They need:

- Quality targeted information about relevant aspects of health and intellectual disability;
- Relevant health education and training which is practical and relevant to the clients they are currently supporting and assisting;
- Opportunity to communicate and meet their own education and training needs;
- Enhanced access to external and internal support services including mentors and expert advice — this is likely to be best facilitated through internet access in every ALS house;
- Skills and confidence (health advocacy) that allows them to enter into partnerships with other health and human services professionals, particularly General Practitioners.

Specifically, the education and training workshop would aim to:

- Provide care staff with an understanding of the health services and information on how they can support and assist people with an intellectual ability to work collaboratively with a range of professionals and service providers in health, human and disability services to obtain appropriate health interventions when required;
- Promote equality of access to health care, health promotion and health screening (comprehensive health assessment) services for people with an intellectual disability; Encourage increased awareness, better understanding and confidence to assist in the management and support of the health care needs of people with an intellectual disability.

The workshop could be completed intensively over a three day period or tailored as a seminar series. The following six draft modules are recommended at this stage and detailed in draft dot point form. The Developmental Disability Unit would be prepared to work collaboratively with health, human and disability services to facilitate the workshops on a regular basis.

1. **Overview of Health Care**
- Describes health and intellectual disability;
- Describes signs and symptoms of health problems;
- Explains the operation of the health system including primary health care and health promotion;
- Introduces the IASSID/WHO Health guidelines for Adults with an Intellectual Disability (Beange et al, 1999) and explores the role of the Developmental Disability Unit.

2. **Diagnosis and Assessment**
- Describes signs and symptoms of health care problems commonly experienced by adults with an intellectual disability using case studies, role plays and group activities;
- Explains how to specifically support and assist people with an intellectual disability to identify, recognize, respond and manage common health care problems experienced by this population;
- Demonstrates and explains strategies to support and assist a person with an intellectual disability to access a General Practitioner and other primary health care professionals using practical role plays and problem solving exercises;
- Explains the Comprehensive Health Assessment Programme (health check) in conjunction with IASSID/WHO Health guidelines for Adults with an Intellectual Disability (Beange et al, 1999) and demonstrates how the tool can assist clients and their carers to access appropriate health care.

3. **Client Support and Assistance for Health Interventions**
- Explains the issues around ethics and decision making; consent to treatment; and duties of care and confidentiality using decision making algorithms;
- Identifies support strategies for people with an intellectual disability requiring health interventions using practice dilemmas requested by participants (for example) breast examination; desensitization programmes for pap smears; dental care under general anaesthetic; sleep studies overnight in hospital;

- Explore the needs of a person with an intellectual disability requiring hospitalization including pre-admission issues and post-discharge issues;
- Consider the management of and role of credentialising in chronic health care problems in community-based living situations (for example) diabetes; self-administration of intravenous injections or indwelling catheters;
- Consider strategies to support people with an intellectual disability who have suffered trauma, bereavement, loss, or death.

4. **Health Promotion**
- Describe the relationship between lifestyle and health for people with an intellectual disability;
- Describe and promote lifestyles associated with physical health and well-being;
- Describe and promote lifestyles associated with good emotional and mental health and well-being;
- Explore opportunities and strategies to assist and support people with an intellectual disability to enjoy health and well-being.

5. **Dealing with Inequalities in Health Care**
- Advocate and describe inequalities and social justice in health care;
- Describe sources of social injustice and inequality in health care including exploration of strategies to remediate;
- Apply above issues to people with an intellectual disability and explore how people with an intellectual disability who have complex and chronic health care problems can enjoy an acceptable standard of health and well-being and access quality health care services.

6. **Syndrome Related Health Care Problems**
- Describe the importance of aetiology and cause of the person's intellectual disability upon their health needs;
- Explain the main health care needs and problems experienced by people with Down syndrome, and major other syndromes as negotiated with the participants;
- Explore the health care needs and strategies to meet those needs, experienced by people with a dual diagnosis – includes understanding of the differences between intellectual disability and mental disorder;
- Consider the impact and management of epilepsy upon the health and well-being of people with an intellectual disability;
- Briefly review medication prescription practices and identify community resources for further information and support
- Explain the changing health needs of people with an intellectual disability as they age, including identification and management of dementia.
- DSQ Support and Access to Expertise in Health Care

Recommendation 8

Disability Services Queensland (DSQ) should ***implement a range of inter-professional or multi-professional health education and training initiatives addressing the health care of adults with an intellectual disability, across Queensland.***

A significant element of all health education and training initiatives should be undertaken on an inter-professional or multi-professional basis. Disability Services Queensland (DSQ) needs to investigate and instigate a range of education and training opportunities that foster cross-agency collaboration.

DSQ should consult with the Developmental Disability Unit in regard to the development of such health education and training initiatives. Careful consideration should be given to the implementation of such initiatives in cooperation with Queensland Health and other health agencies, e.g. Health Districts/Hospitals and other non-government health services, e.g. St Vincent's Hospital services.

Recommendation 9

Disability Services Queensland (DSQ) needs to enter into ***a funded partnership with the Queensland Division of General Practice and the Developmental Disability Unit to develop education and training curriculum and resource relevant to the health care needs of adults with an intellectual disability***, implement and evaluate one day training workshops for General Practitioners.

General Practitioners will continue to be the main point of contact, the "gatekeeper" for primary health care. Disability Services Queensland (DSQ) needs to allocate funds to develop a training and education package primarily for General Practitioners, but applicable to other primary care professionals. One day workshops should be multi professional by nature and involve relevant experts from across the professions.

This education strategy should aim to ensure General Practitioners have the skills and expertise that enables them to provide a range of health services to people with an intellectual disability.

The DDU recommends that training programmes for General Practitioners should involve other primary health care team members, service users and carers. Themes for possible inclusion in such a training workshop would focus upon improved coordination and communication. Training in communication and the nature of health care needs of people with an intellectual disability needs to be improved for both the carer and the General Practitioner (Kerr, 1992). Consideration should be given to the need to develop multifaceted packages that "combine" needs into a complete package, e.g. communication skills, advocacy skills, and health knowledge. Such a package could be delivered in a workshop that builds upon the CHAP interventions.

Recommendation 10

Disability Services Queensland (DSQ) should fund the Developmental Disability Unit to develop and trial a General Practitioner Protocol (GPP)

Disability Services Queensland (DSQ) should allocate resources to develop a General Practitioner protocol for the management of the health care of adults with an intellectual disability, e.g. General Practitioner Protocol/checklist.

Direct care staff need to predict and know as far as possible what to expect from a consultation with their General Practitioner (Martin et al 1997) – health advocacy as well as preparation. The General Practitioner protocol could be developed as a project, working in liaison with the Queensland Division of General Practice. Key to such an initiative would be inter-professional collaboration with the aim of achieving dedicated health guidelines.

Possible project strategies could include:
- Tertiary level, expert supervision and support of General Practitioners interested in working with people with an intellectual disability: project could adopt a liaison outreach model approach;
- Identification of General Practitioners who are willing to provide a service to people with an intellectual disability: development of a register;
- Use of consultation prompts — prepared written lists of questions and noticeable changes/symptoms prior to appointments;
- Diagnostic assistance — development of a guide to video recording of signs or symptoms of illness or disease, e.g. seizure activity, behaviour problems and so on.;
- Pool of specially trained health advocates to accompany clients to General Practitioners;
- Disability awareness curricula for General Practitioners.

Recommendation 11

Disability Services Queensland (DSQ) needs to establish a Health Information Exchange Strategy.

Disability Services Queensland (DSQ) direct care and professional staff require health related information relevant to the needs of adults with an intellectual disability. Disability Services Queensland (DSQ) needs to implement a multiple element strategy to ensure an effective health information exchange and support mechanism is established across Queensland. The strategy should link Disability Services Queensland (DSQ) staff across Queensland to evidence based care and best practice.

The strategy should provide opportunities for other stakeholders to participate including Queensland Health staff and other health, human service and disability service providers from both the government and non-government sectors. Members should have face-to-face contact with one another at least annually. In the interim period contact could be sustained through email and phone networking. Other more regular opportunities for face-to-face contact might arise on an as needed basis.

Broad Aims
- To provide a resource group, pooling research findings and evaluating concrete evidence relating to primary health care and initiatives for adults with an intellectual disability;
- To function as an advocacy group, bringing to the attention DSQ the health care needs of the client group and methods of meeting those needs.

Objectives
- To pull together/examine common areas of practice;
- To review current research and thinking;
- To involve clients, family members and other service users;
- To consider multi-professional research;

- To suggest strategies and solutions to problems that can be shared with others;
- To disseminate/communicate issues across the state; and
- To positively develop and influence policy, practice or programme changes.

Examples of Health Information Exchange Initiatives could include:
- **Regular expert forums**. Disability Services Queensland (DSQ) needs to proactively increase the number of forums where respected experts, including researchers can provide relevant presentations relating to the health of adults with an intellectual disability.
- **Bi-montly/regular expert seminars** relating to the health of people with an intellectual disability. Content could include complex case discussions or particular "hot" issues or issues requested by staff, professionals and other service providers. The audience should include Disability Services Queensland (DSQ) staff at all levels as well as actively seeking out professionals and workers from other government and non-government agencies. Primary health care agencies and General Practitioners could be involved as required.
- **Health and Well-Being Stream in annual Direct Care Workers conference**. Current, best practice expertise on health and well-being should be presented to direct care staff by both local, state and national experts. The focus should be placed upon skill and hands on expertise knowledge development workshops.

Recommendation 12

Health information exchange could be achieved/enhanced by *formal recognition and appropriate resourcing of the Health and Well-Being Group.* This loose association of interested and committed DSQ staff, professionals from interested external agencies and some parents has had a long association with DSQ. Known by a number of names, the group was formerly the Women's Health Action Meeting (WHAM) and is probably best known as the Health and Well-Being Group.

Funds should be allocated in each region to ensure direct care staff regularly attend and actively participate in the Health and Well-Being Meeting/Network.

Disability Services Queensland (DSQ) should formally recognize this group as a logical and practical way of networking and linking interested Disability Services Queensland (DSQ) staff. The allocation of appropriate financial and resources should enhance the Health and Well-being Group/Meeting.

Partnership with health, human and disability service providers within government and non-government sectors should be actively encouraged. Resource networks should be used to provide the systematic linkages needed to provide coordinated health care, specialized research and training of carers/professionals in developmental disability (Walsh & Kastner, 1999)

Recommendation 13

Disability Services Queensland (DSQ) needs to actively advocate in University settings for increased opportunities in core curriculum for training and education on intellectual disability across the lifespan, e.g. birth to death.

Curriculum addressing intellectual disability inclusive of health care problems considered within the biopsychosocial model, should be included within:
- Basic undergraduate coursework including nursing, psychology, social work, occupational therapy, speech pathology and so on.;
- MB BS Programme – formerly graduate medical programme;
- Dentistry; and
- Postgraduate coursework – masters and PhD level study.

Recommendation 14

Disability Services Queensland (DSQ) should approach Queensland Health and Education Queensland in relation to *the establishment of and joint University Curriculum, Bursaries and Scholarships in the Health Care of Adults with an Intellectual Disability*.

Disability Services Queensland (DSQ) should give consideration to joint/collaborative bursaries and scholarships being developed and offered between Queensland Health, Queensland Education and Disability Services Queensland (DSQ). The Developmental Disability Unit applauds Disability Services Queensland (DSQ) for recent scholarships offered in this way although it is noted that no students were supported to pursue studies in the disability field.

Recommendation 15

Consistent approaches to a definition of intellectual disability and associated terminology should be incorporated into the policies, programmes and all documentation of Disability Services Queensland (DSQ), Queensland Health and other Queensland government agencies.

Consistent approaches to a definition should be encouraged to enable services and agencies to develop a stronger way of assessing needs and allows for a shared understanding across the different agencies and professional groups.

At present there is considerable confusion in this area, often as a result of the variety of terms used to refer to intellectual disability. People with an intellectual disability are sometimes referred to as "mentally retarded", "mentally handicapped", "sub-normal" or "defective", terms that have pejorative connotations. Intellectual disability has also developed an inaccurate association with mental illness.

Recommendation 16

Disability Services Queensland (DSQ) needs to take responsibility for reviewing and modifying DSQ eligibility policy. DSQ, as the lead agency in disability should lobby and collaborate with Queensland Health to similarly review and modify its eligibility criteria for services. Further, both agencies need to ensure their ***eligibility criteria is flexible enough to adopt a cross-boundary and multi-agency approach that is based upon identification and collaborative response to the individual needs of adults with an intellectual disability.***

Disability Services Queensland (DSQ) must advocate strongly on all levels, e.g. within government across departments, external to state government including local and commonwealth government to ensure the health and well-being of people with an intellectual disability is considered to be a joint responsibility of Disability Services Queensland (DSQ) and Queensland Health. Similarly, to advocate that disability is a joint responsibility of Queensland Health and Disability Services Queensland (DSQ).

Disability Services Queensland (DSQ) policy on eligibility criteria needs to be modified to ensure it reflects: "No service should be withdrawn or refused unless alternative options or alternatives are suggested and implemented".

The isolation between DSQ and Queensland Health needs to be addressed in an environment that focuses upon bridge building. Differences need to be put aside so that contentious issues can be resolved with the clear focus being client. Eligibility criteria need to adopt an approach that seeks to serve clients or consumers, rather than find them ineligible for services.

Historical grievances between government departments, particularly between Disability Services Queensland (DSQ)/Department of Families and Queensland Health need to be set aside to ensure the health status of people with an intellectual disability is not compromised.

Recommendation 17

Disability Services Queensland (DSQ) policy and practice needs to reflect multi-system interaction with emphasis upon partnership and collaboration between disability and health services within the community. Joint initiatives should be encouraged and funded.

There are often numerous services and agencies involved in supporting people with an intellectual disability. The promotion of health and well-being should form an integral component of any service to this vulnerable group. Ideally services should be seamless, e.g. focus upon the person and their individual needs. Services should be co-ordinated and integrated across the health and disability service system, including primary care, tertiary health care and disability support and assistance that are internal or external to the health sector.

The disability culture and health culture need to join together to support multi-system collaboration. The need exists to develop a particular organisational climate and atmosphere that promotes health quality by focusing upon building frameworks and creative solutions rather than focusing on individualized blames approach in a reactive environment. Collaborative dialogue, management and partnerships need to be encouraged, funded, trailed and evaluated.

Recommendation 18

Disability Services Queensland (DSQ) should acknowledge in disability and health policy and practice, the implications of social capital.

There is an powerful but invisible labour force in operation. At the moment the health care status of adults with an intellectual disability is quietly taking advantage of this silent workforce – taking advantage of not only unpaid carers, e.g. family members, relatives and friends but also the caring role of direct care workers.

Direct care workers go far beyond their professional duties and responsibilities, beyond their expertise and knowledge base. The human factor is working solidly to meet the health needs of people with an intellectual disability but this approach lacks community connections. DSQ should allocate resources and manpower into investigating the implications of social capital on disability services staff and clients, with particular emphasis upon the health status of adult clients with an intellectual disability.

Recommendation 19

Disability Services Queensland (DSQ) should develop and implement contemporary health status policy and practice guidelines for adults with an intellectual disability (refer Recommendation 5). DSQ should involve Queensland Health in the development of Health Protocols that could be utilised by any agency (government or non-government).

Inequalities in health status are clearly influenced by a range of causes. Disability Services Queensland (DSQ) is actively working to redress many of these and related issues that will have an impact upon the health and well-being of people with an intellectual disability. However, health policy and practice needs to be developed that reflect evidence based care and best practice. Current practices that impact the health status of clients with an intellectual disability are not being driven by best practice. Policy and practice guidelines are dated and in place inappropriate.

The development of state of the art health policy, practice memorandum and protocols need to be driven by Disability Services Queensland (DSQ) as the lead disability agency, but developed collaboratively with Queensland Health and other stakeholders. It must be openly recognized that the quality of life of people with an intellectual disability – across the lifespan from birth to death, who receive services from Disability Services Queensland (DSQ), are influenced and compromised by their health status. Stakeholders must work closely together to improve the health status of adults with an intellectual disability living in the community.

The review of the Health and Well-Being Policy and Guidelines by the Developmental Disability Unit should be used as a resource and guide in the redevelopment of new policy and practice. The Developmental Disability Unit would welcome involvement in the project.

Recommendation 20

Disability Services Queensland (DSQ) should **establish a Health and Disability Partnership** comprising senior representatives from Disability Services Queensland (DSQ) and Queensland Health. Consideration should be given to other government agency representation and involvement, e.g. Education Queensland, but the focus should clearly remain upon health of people with an intellectual disability.

An innovative and flexible mechanism to begin the development of an effective partnership between Disability Services Queensland (DSQ) and Queensland Health needs to be established. It is recommended that a Health and Disability Partnership be established. Membership of the partnership would include senior officers from each agency, in addition to community and consumer/client membership.

The Partnership could meet three monthly (or more regularly if necessary) to plan, implement and consider education, training and project initiatives. Issues addressed could include:
- Service agreements and objectives;
- Financial arrangements;
- Cross agency initiatives;
- Research and evaluation and so on.

Membership of the Partnership should include academics, policy experts, non-government agency representation, professional staff and consumer representation. The Adult Guardian should be represented. The Partnership could have dual reporting arrangements to the relevant Minister or perhaps the Director-Generals. However, the Partnership should be accorded some levels of independence and authority with appropriate delegations. It should not be considered as an advisory board or meeting. Appropriate resources should be allocated to the Partnership.

Recommendation 21

The *Health and Disability Partnership should develop and operate as a forum which an effectively mediate conflicts and disagreements*, e.g. Disability Services Queensland (DSQ) and Queensland Health to ensure the needs of complex clients who do not "fit" the system or eligibility criteria do not fall through the gaps, i.e. fail to receive a service, receive compromised services or receive inappropriate services.

In addition to details as outlined in Recommendation 10, the Partnership could involve the non-adversarial and innovative resolution of emergent conflicts and disagreements.

Conclusion

This study explored the perceptions of Residential Care Workers about the health care of Disability Services Queensland (DSQ) clients with an intellectual disability whom they supported in community accommodation. Generally, most Residential Care Officers enjoyed a positive relationship with those clients and enjoyed their work and associated responsibilities. On the whole, they were pleased with the health care status of clients that they supported. All had contact with other health care professionals and enjoyed the support of other colleagues. Participants in the study appeared to accept the health care challenges, and in particular challenging behaviour of their clients, their life circumstances and level of support required of carers.

Despite these positive comments, it is clear that there is a pervasive lack of health education and training which is available and or undertaken by direct care workers and their Managers. The majority of the Residential Care Officers who participated in the study reported had not received training in health care apart from obligatory first aid training. Knowledge and skill deficits in health care is a major barrier to appropriate monitoring and meeting of health care problems of Disability Services Queensland (DSQ) clients. Disability Services Queensland (DSQ) should consider duty of care obligations in regard to the capacity and ability of direct care workers to fully complete required aspects of their duties. A systematic training course to educate and up skill Residential Care Officers and their Managers in health care needs of this population should be established as soon as possible.

Residential Care Officers appear to experience low levels of morale and consider themselves as lacking influence in health and medical decision-making related processes, e.g. interactions with General Practitioners. Health education and training opportunities for direct care staff and other professionals needs to incorporate advocacy and communication skills with empower those staff to advocate on behalf of their clients when communication is problematic. However, it is important to note the many talents of Residential Care Officers. Such qualities may compensate for lack of expertise or skills and may have been ignored in past research. Although unable to be measured objectively in this study, RCOs on the whole displayed a high level of enthusiasm, energy and commitment to their clients that went far beyond their position descriptions or job expectations. This "care" in the carer may well be a critical factor in meeting and managing client health care needs.

The study clearly suggests strategies for improvement in the health care of this group of people living in the community. Changing policies and practices of Disability Services Queensland (DSQ) will hopefully positively impact the quality of life of this vulnerable group of people, and have a flow on effect on their health care status. Residential Care Officers need to possess understanding of the health care needs of people with an intellectual disability as they are the support agent most in contact with these clients. It is important for direct care workers and management to work cohesively together to pursue meeting the health care needs of people with an intellectual disability.

Perhaps the most difficult and complex barrier to effective health care for people with an intellectual disability involves demarcation disputation between health care services and disability or human services. This battle is historical and whilst it may impact direct care staff, remedies and solutions may need to be fought at the political level. Whilst artificial barriers do exist in the sense of eligibility criteria or funding guidelines, there is no doubt that multi-agency collaboration and co-operation is an essential component of any strategy aiming to address health care problems in this population.

There are valuable international lessons to learnt and in particular the UK appears to set strong precedents for health care initiatives for adults with an intellectual disability. Recent UK recent government reports have identified and made strategic recommendations regarding the unmet primary health care needs of people with an intellectual disability (Mansell, 1993; Department of Health, 1995; Department of Health, 2001). Barriers to health care faced by people with an intellectual disability have been highlighted within many of these reports. The importance of primary health care and health promotion for quality of life for people with an intellectual disability continues to be emphasized (Martin et al, 1997).

Apart from highlighting the mental health needs of people with an intellectual disability in the Second Mental Health Plan, both the state and commonwealth governments within Australia have been virtually

silent on the health care of this group. Specialist multi-disciplinary health services should be available but economic costs, quality of care, and training of professionals and direct care staff, remain problematic in the UK and the USA (Bouras & Szymanski,1997). These problems appear to be replicated within Australia.

Despite major flaws affecting the efficient operation of the Australian health care system, the search for solutions to improve health care status of people with an intellectual disability must continue. The Developmental Disability Unit congratulates Disability Services Queensland on funding this project to evaluate barriers to implementing a comprehensive health assessment programme for adults with an intellectual disability. There are many changes that need to take place within wider society to appropriately re-shape the approach to people with disabilities. Reforms are also needed within the operation of health care and disability services but until this occurs, CHAP is one step forward to improving the quality of life of people with an intellectual disability who have a vulnerable health status.

Lessons from the Labyrinth

Appendices

1. Selected References

Allen D, 1999, *Mediator Analysis: An Overview of Recent Research on Carers Supporting People with an Intellectual Disability and Challenging Behaviour*, Journal of Intellectual Disability Research, **43** (4), 325-39.

Anderson CA, 1996, *Ethics committees and quality improvement: A Necessary Link*, Journal of Nursing Care Quality, **11**, 1, 22-8.

Australian Institute of Health Welfare, 1996, Australia's Health, AGPS: Canberra.

Australian Institute of Health Welfare, 1998, Health Expenditure Bulletin 14, Canberra: Australian Institute of Health and Welfare

Aspray TJ, Francis RM, Thompson A, Quilliam SJ, 1999, *Patients with Learning Disability in the Community have Special Medical Needs that Should be Planned Fo*r, British Medical Journal, **318,** 476-7.

Bailey NM & Cooper S-A, 1997, *The Current Provision of Specialist Health Services to People with Learning Disabilities in England and Wales*, Journal of Intellectual Disability Research, **41** (1), 52-9.

Bandura A, 1977, *Self-efficacy: Towards A Unifying Theory of Behavioural Change*, Psychological Review, **84**, 191-215.

Bandura A, 1986, Social Foundations of Thought and Action, Englewood Cliffs, NJ, Prentice Hall.

Barr O, Gilgunn J, Kane T & Moore G, 1999, *Health Screening for People with Learning Disabilities by a Community Learning Disability Nursing Service in Northern Ireland*, Journal of Advanced Nursing, **29** (6), 1482-91.

Baum FE, 1998, The New Public Health: An Australian Perspective, Melbourne: Oxford University Press.

Baume P, 1998, *Non-Medical Care*, **in** Baume, P (Ed), The Tasks of Medicine, Sydney: MacLennan & Petty.

Baume, P (Ed), 1998, The Tasks of Medicine, Sydney: MacLennan & Petty.

Beange H & Bauman A, 1990, *Caring for the Developmentally Disabled in the Community*, Australian Family Physician, **19** (10), 1558-63.

Beange H, 1996, *Caring for a Vulnerable Population*, Medical Journal of Australia, **164**, 159-60.

Beange H, Lennox N & Parmenter TR, 1999, *Health Targets for People With an Intellectual Disability*, Journal of Intellectual and Developmental Disability, **24** (4), 283-97.

Beange H, McElduff A & Baker W, 1995, *Medical Disorders of Adults with Mental Retardation: A Population Study*, American Association Mental Retardation, **99** (6): 595-604.

Beange, 1986, *The Medical Model Revisited*, Australia and New Zealand Journal of Developmental Disabilities, **12**, 3-7.

Beckman HB & Frankel RM, 1984, *The Effect of Physician Behaviour on the Collection of Data*, Annals of Internal Medicine, **101**, 692-6.

Beckwith JB & Matthews JM, 1995, JIDR, Measurement of Attitudes of Trainee Professionals to People with Disabilities, 39 (4), 255-62.

Bensing J, 2000, *Bridging the Gap, The Separate Worlds of Evidence Based Medicine and Patient Centred Medicine*, Patient Education and Counseling, **39**, 17-25.

Blumenthal S, Lavender T & Hewson S, 1998, *Role Clarity, Perception of the Organisation and Burnout Amongst Support Workers in Residential Homes for People with Intellectual Disability*, Journal of Intellectual Disability Research, **42** (5), 409-17.

Bodenheimer, 1999, *Primary Care Physicians should be Coordinators, Not Gatekeepers*, Journal of the American Medical Association, **281** (21),1-13.

Bogdan & Taylor, 1994, The Social Meaning of Mental Retardation: Two Life Stores, New York: Teachers College.

Bond L, Kerr M, Dunstan F & Thapar A, 1997, *Attitudes of General Practitioners Towards Health Care for People with Intellectual Disability and the Factors Underlying Those Attitudes*, Journal of Intellectual Disability Research, **41** (5), 391-400.

Borthwick-Duffy SA & Eyman, RK, 1990, *Who are the Dually Diagnosed*, American Journal on Mental Retardation, **94** (6), 17-27.

Bouras N & Symanski L, 1997, *Services for People with Mental Retardation and Psychiatric Disorders: US-UK Comparative Overview*, International Journal of Social Psychiatry, **43** (1), 64-71.

Bowler I & Gooding S, 1995, *Health Promotion in Primary Health Care: The Situation in England*, Patient Education and Counselling, **25**, 293-9.

Bowman MA, Dignan M, Crandall S & Monica MS, 2000, *Changes in Functional Status Related to Health Maintenance Visits to Family Physicians*, The Journal of Family Practice, 49 (5), 428-33.

Bowman D & Virtue M., 1993, *Public Policy Private Lives*, Australian Institute on Intellectual Disability, Canberra.

Bromley J & Emerson E, 1995, *Beliefs and Emotional Reactions of Care Working Staff Working with People with Challenging Behaviour*, Journal of Intellectual Disability Research, **39** (4), 341-52.

Browne G, Roberts J, Gafni A, Weir R, Watt S & Byrne C, 1995, *More Effective and Less Expensive: Lessons form Five Studies Examining Community Approaches to Care*, Health Policy, **34**, 95-112.

Brunner, E and Wilkinson, R (Eds), Health and Social Organisation: Towards a Health Policy for the Twenty-First Century, London: Routledge.

Bunce D & West MA, 1996, *Stress Management and Innovation Interventions at Work*, Human Relations, **49** (2), 209-32.

Chambers R et al, 1998, *The Primary Care Workload and Prescribing Costs Associated with Patients with Learning Disability Discharged from Long Term Care to the Community*, British Journal of Learning Disability, **26**, 9-12.

Chenoweth L, 1997, *Policy Skills for Human Services*, **in**, O'Brien P & Murray R, (Eds), Human Services: Towards Partnership and Support. Sydney: Dunmore Press.

Chung MC & Corbett J, 1998, *The Burnout of Nursing Staff Working with Challenging Behaviour Clients in Hospital Based Bungalows and a Community Unit*, International Journal of Nursing Studies, **35**, 56-64.

Consumers' Health Forum of Australia, 1999, Consumers' Expectations of General Practice in Australia, CHFA: Canberra.

Corrigan PW & McCracken SG, 1995, *Psychiatric Rehabilitation and Staff Development: Educational and Organisational Models*, Clinical Psychology Review, **15** (8), 699-719.

Criscione T, Kastner TA, Walsh KK & Nathanson R, 1993, *Managed Health Care Services for People with Mental Retardation : Impact on Inpatient Utilisation*, Mental Retardation, **31** (5), 297-306.

Cumella S, Corbett JA, Clarke D & Smith B, 1992, *Primary Health Care for People with Learning Disability*, Mental Handicap, **20**, 123-5.

Davis G, Wanna J, Warhurst J and Weller P, 1987, Public Policy in Australia, Sydney: Allen and Unwin, pp. 22-23.

Davis S, Wehmeyer ML, Board JP, Fox S, Maher F & Roberts B, 1998, *Interdisciplinary Teams*, **in** Reiss S & Aman MG (Eds), Psychotropics Medication and Developmental Disabilities: The International Consensus Handbook, Ohio State University: Nisonger Centre.

De la Questa C, 1997, An exploratory investigation into the sources of patient satisfaction in ambulatory care Social Sciences in Health 3, 4, 221-31.

Department of Families, Youth and Community Care, 1997, Disability: A Queensland Profile, Brisbane: Queensland Government.

Department of Health (DoH, UK), 2001, Valuing People: A New Strategy for Learning Disability for the 21st Century, A White Paper, London: HMPO.

Department of Health, 1995, The Health of the Nation; A Strategy for People with Learning Disabilities. London: HMSO.

Duckett S, 1999, Commonwealth/state relations in health, in Hancock, L., Health Policy in the Market State, Sydney: Allen and Unwin

Elola J, Daponte A & Navarro V, 1995, *Health Indicators and the Organisation of Health Care Systems in Western Europe*, American Journal of Public Heath, **85**, 1397-401.

Emerson E, Beasley F, Offord G & Mansell J, 1992, An evaluation of hospital-based specialized staffed housing for people with seriously challenging behaviours.J Intellect Disabil Res. 1992 Aug;36 (Pt 4):291-307.

Emerson E, 1999, *Residential Supports for People with Intellectual Disabilities: Questions and Challenges from the UK*, Journal of Intellectual and Developmental Disability, **24** (4), 309-19.

Emerson E, Hatton C, Robertson J, Henderson D, Cooper J, 1999, *A Descriptive Analysis of the Relationships Between Social Context, Engagement and Stereotypy in Residential Services for People with Severe and Complex Disabilities*, Journal of Applied Research in Intellectual Disabilities, **12**, 11-29.

Engel GL, 1992, *How Much Longer Must Medicine's Science be Bound by a Seventeenth Century World View?*, Psychosomatics, **57**, 3-16.

Engel GL, 1997, *From Biomedical to Biopsychosocial: Being Scientific in the Human Domain*, Psychosomatics, **38** (6), 521-8.

Evans IM & Moltzen NL, 2000, *Defining Effective Community Support for Long-term Psychiatric Patients According to Behavioural Principles*, Australian and New Zealand Journal of Psychiatry, **34** (4),637-44.

Evenhuis H, Henderson CM, Beange H, Lennox N & Chicoine B, 2000, Healthy Aging - Adults with Intellectual Disabilities: Physical Health Issues: A Joint Report of the Health and Aging Special Interest Research Groups of the International Association for the Scientific Study of Intellectual Disabilities, Submitted to the World Health Organization, Geneva, Switzerland.

Felce D & Perry, 1995, *The Extent of Support for Ordinary Living Provided in Staffed Housing: The Relationship between Staffing Levels, Resident Characteristics, Staff: Resident Interactions and Resident Activity Patterns*, Social Science and Medicine, **40** (6), 799-810.

Felce D & Repp A, 1992, *The Behavioural and Social Ecology of Community Houses*, Research in Developmental Disabilities, **13**, 27-42.

Felce D, 1996, *The Quality of Support for Ordinary Living: Staff_Resident Interactions and Resident Activity*, **in** Mansell K & Ericcson (Eds), Deinsitutionalisation and Community Living: Intellectual Disability Services in Britain, Scandanavia and the USA, London" Chapman & Hall.

Felce D, Bowley C, Baxter H, Jones E, Lowe K & Emerson E, 2000, *The Effectiveness of Staff Support: Evaluating Active Support Training Using a Conditional Probability Approach*, Research in Developmental Disabilities, **21**, 243-55.

Felce D, Lowe K & Beswick J, 1993, *Staff Turnover in Ordinary Housing Services for People with Severe or Profound Mental Handicaps*, Journal of Intellectual Disability Research, **37**, 143-52.

Felce D et al, 2000, Exploring the Relationships Between Costs and Quality of Services for Adults With Severe intellectual disabilities and the most severe Challenging Behaviours in Wales: A Multivariate Regression Analysis, Journal Of Intellectual and Developmental Disability, **25** (4), 307-26.

Felce D, Lowe K, Perry J, Baxter H, Jones E, Hallam A & Beecham J, 1998, Service support to people in Wales with severe intellectual disability and the most severe challenging behaviours: processes, outcomes and costs, Journal of Intellectual Disability Research, 42 (5), 390-408.

Fitzpatrick R, 1997, *The Assessment of Patient Satisfaction* **in** Jenkinson C (Ed), Assessment and Evaluation of Health and Medical Care, Buckingham: Open University Press.

Ford J & Honnor J, 2000, *Job Satisfaction of Community Residential Staff Serving Individuals with Severe Intellectual Disabilities*, Journal Of Intellectual and Developmental Disability, **25** (4), 343-62.

Forster, J., 1998, *The Impact of Competition Policy on the Human Services Sector*, Speech to the Consumer Law Centre Conference, July 1998, Melbourne: Brotherhood of St Lawrence.

Freedman AM, 1995, *The Biopsychosocial Paradigm and the Future of Psychiatry*, Comprehensive Psychiatry, **36** (6), 397-406.

Fujiura GT, Fitzsimmons N, Mark B & Chicoine B, 1997, Predictors of BMI among adults with Down syndrome: the social context of health promotion, Research in Developmental Disabilities, 18 (4), 261-74.

Fullerton A, Douglass M & Dodder RA, 1999, *A Reliability Study of Measures Assessing the Impact of Deinstitutionalisation*, Research in Developmental Disabilities, **20** (6), 387-400.

Goble C, 1999, *"Like the Secret Service Isn't It, People with Learning Disabilities" Perceptions of Staff and Services*, Disability and Society, **14** (4), 449-61.

Golden J & Reese M, 1996, *Focus on Communication: Improving Interaction between Staff and Residents Who Have Severe or Profound Mental Retardation*, Research in Developmental Disabilities, **17** (5).

Graves P (Chairman), 1997, Seventh Annual Report of the Medical Committee on Client Mortality (Intellectual Disability), Melbourne: Disability Services Division, Victorian Department of Human Services.

Griffin P, (Eds), Teaching for Diversity and Social Justice, New York: Routledge.

Hancock L & Mackey P, 1999, *Health Care Funding and Rationing Health Care* **in** Hancock L, Health Policy in the Market State, Sydney: Allen and Unwin.

Hancock L, 1999, Health Policy in the Market State, Sydney: Allen and Unwin.

Hardy H, 1999, *Dimensions of Choice in the Assessment and Care Management Process: The Views of Older People, Carers and Care Managers*, Health and Social Care in the Community, **7** (6), 483-491.

Harper DC & Wadsworth JS, 1992, *Improving Health Care Communication for Persons with Mental Retardation*, Public Health Reports, **107** (3), 297-303.

Harris JC, 1998, Developmental Neuropsychiatry, Volume 2: Assessment, Diagnosis and Treatment of Developmental Disorders, New York: Oxford University Press.

Hart JT, 1998, *Expectations of Health Care: Promoted, Managed or Shared*, Health Expectations **1**, 3-13.

Hart JT, 1971, *The Inverse Care Law*, Lancet, **i**, 405-12.

Hassan R, 2000, *Social Consequences of Manufactured Longevity*, Medical Journal of Australia, **173** (11-12), 601-3.

Hastings R, 1997, *Staff Beliefs About The Challenging Behaviours of Children and Adults with Mental Retardation*, Clinical Psychology Review, **17** (7), 775-90.

Hastings RP, 1996, *Staff Strategies and Explanations for Challenging Behaviour*, Journal of Intellectual Disability Research, **40**, 166-75.

Hatton C, Brown R, Caine A & Emerson E, 1995, *Stressors, Coping Strategies and Stress Related Outcomes Among Direct Care Staff in Staffed Houses for People with Learning Difficulties*, Mental Handicap Research, **8**, 252-71.

Hatton C, Emerson E, Robertson J, Henderson D & Cooper J, 1995, *The Quality and Costs of Residential Services for Adults with Multiple Disabilities: A Comparative Evaluation*, Research in Developmental Disabilities, **16** (6):439-60.

Hatton C, Rivers M, Mason H, Mason L, Kiernan C, Emerson E, Alborz A & Reeves D, 1999, *Staff Stressors and Staff Outcomes in Services for Adults with Intellectual Disabilities: The Staff Stressor Questionnaire*, Research in Developmental Disabilities, **4**, 269-85.

Hatton C, Emerson E, Robertson J, Henderson D & Cooper J, 1996, *Factors Associated with Staff Support and Resident Lifestyle in Services for People with Multiple Disabilities,* Journal of Intellectual Disability Research, **40 (5),** 466-77.

Hawe, P., & Shiell, A. (2000). *Social Capital and Health Promotion: A Review*, Social Science & Medicine, **51**, 871-85.

Hiscott RD & Connop PJ, 1996, *Why Hospital Mental Health Staff Terminate Employment,* Perspectives in Psychiatric Care, **32** (1), 7-11.

Holland AJ, 1999, *Psychiatry and Mental Retardation* , International Review of Psychiatry, **11**, 76-82.

House of Representatives Standing Committee on Family and Community Services, 1998, What Price Competition?, A Report on the Competitive Tendering of Welfare Service Provision, June 1998, Parliament of the Commonwealth of Australia.

Howells G, 1986, *Are The Medical Needs of Mentally Handicapped Adults Being Met?* Journal of the Royal College of General Practitioners, **36**, 449-53.

Howells G, 1991, *Mental Heandicap – Care in the Community*, British Journal of General Practice, **41**, 2-4.

Jackson C & de Jong I, 2000, <u>Achieving Effective Health Care Integration: The Essential Guide</u>, Mater University of Queensland Centre for General Practice.

Jahr E, 1998, *Current Issues in Staff Training*, <u>Research in Developmental Disabilities</u>, **19** (1), 73-87.

Janicki M & Dalton A, 1999 (Eds), <u>Dementia, Aging and Intellectual Disabilities: A Handbook</u>, New York: Taylor and Francis.

Janicki M & Deb S, 1994, *Ageing: Our Continuing Challenge*, <u>Journal of Intellectual Disability Research</u>, **38** (3), 229-32.

Janicki MP, Davidson PD, Henderson CM, McCallion P, Force LT & Dalton AJ, 1999, <u>Examining the Health and Disability Status of Adults with Intellectual Disabilities: A Pilot Study</u>, Paper Prepared for IASSID International Roundtable on Aging and Intellectual Disabilities, Geneva, Switzerland, April 20-23, 1999.

Jones RG & Kerr MP, 1997, *A Randomized Control Trial of an Opportunistic Health Screening Tool in Primary Care for People with Intellectual Disability*, <u>Journal of Intellectual Disability Research,</u> **41** (5), 409-15.

Joyce T, 1994, *The Effect of Individual and Environmental Characteristics on Outcomes in Residential Services*, <u>Mental Handicap Research</u>, **7** (2), 134- 46.

Kaplan GA, Pamuk ER, Lynch JW, Cohen RD & Balfour JL, 1996, *Inequality in Income and Mortality in the United States: Analysis of Mortality and Potential Pathways*, <u>British Medical Journal</u>, **312** , 999-1003.

Kaplan RM, 1989, *Health Outcome Models for Policy Analysis*, <u>Health Psychology</u>, **8**, 723-35.

Kaplan RM & Ware JE, 1989, *The Patient's Role in Health Care and Quality Assessment*, **in** Goldfield N & Nash DB (Eds), <u>Providing Quality Care: The Challenge to Physicians</u>, Philadelphia: American College of Physicians.

Kaplan RM, 1991, *Health Related Quality of Life in Patient Decision Making*, <u>Journal of Social Issues,</u> **47**, 69-90.

Kawachi I, Kennedy BP, Lochner K, Prothrow-Stith D, 1997, Social capital income inequality and mortality, American Journal of Public Health, 87, 1491-1498.

Keane S, 1996, *Health, Medication and Consent to Intervention*, **in** Annison J et al (Eds), <u>Disability: A Guide for Health Professionals,</u> Melbourne: Nelson.

Kerr M, 1997, *Primary Health Care for People with Intellectual Disability*, <u>Journal of Intellectual Disability Research</u>, **41** (5), 363-4.

Kerr M, Dunstan F & Thapar A, 1996, *Attitudes of General Practitioners to Caring for People with Learning Disability*, <u>British Journal of General Practice</u>, **46**, 92-4.

Kerr M, Fraser W & Felce D, 1996, *Primary Health Care for People with an Intellectual Disability*, <u>British Journal of Learning Disabilities</u>, **24**, 2-8.

Kerr M, Fraser W, Felce D, 1996, *Primary Health Care for People With a Learning Disability. A Keynote Review*, <u>British Journal of Learning Disabilities</u>, **24**, 2-8.

Kerr MP, Richards RD & Glover G, 1996, *Primary Care for People with a Learning Disability – A Group Practice Survey*, <u>Journal of Applied Research in Intellectual Disability,</u> **9**, 347-52.

Kerr M, Evans S, Nolan M & Fraser W, 1995*, Assessing Clinicians Consultation with People*

with Profound Learning Disability: Producing a Rating Scale, <u>Journal of Intellectual Disability Research</u>, **39** (3), 187-90.

Kirk, 1999, *Caring for children with specialised health care needs in the community: the challenges for primary care,* <u>Health and Social Care in the Community</u> , **5**, 350-57 .

Koch T, 2000, *Life Quality vs the "Quality of Life": Assumptions Underlying Prospective Quality of Life Instruments in Health Planning*, <u>Social Science and Medicine</u>, **51**, 419-27.

Kugel RB & Wolfensberger W. (Eds), 1979, <u>Changing Patterns in Residential Services for the Mentally Retarded,</u> Washington, DC: President's Committee on Mental Retardation US Department of Health and Human Services, Office of Human Development Services.

Langan J, Russell O & Whitfield M, 1993, <u>Community Care and the General Practitioner, Primary Care for People with Learning Disabilities</u>, Bristol: Norah Fry Research Centre.

Langan J, Russell O, Whitfield M, 1992, <u>Community Care and the General Practitioner: Primary Health Care for People with Learning Disabilities</u>, Part 1, Report to the Department of Health, Bristol, Norah Fry Research Centre.

Legge D, Butler P, Wright M, 1995, Report of Best Practice in Primary Health Care Project, Centre for Development and Innovation in Health, Melbourne, July 1995.

Leifer D, 1996, *Take Time To Explain*, Nursing Standard, **11** (2) 14.

Lennox NG & Chaplin R, 1995, *The Psychiatric Care of People with Intellectual Disabilities: The Perceptions of Trainee Psychiatrists and Psychiatric Medical Officers*, Australian and New Zealand Journal of Psychiatry, **29**, 632-7.

Lennox NG & Chaplin R, 1996, *The Psychiatric Care of People with Intellectual Disabilities: The Perceptions of Consultant Psychiatrists in Victoria*, Australia New Zealand Journal of Psychiatry, **30** (6), 774-80.

Lennox N, Beange H & Edwards NS, 2000, *The Health Needs of People with Intellectual Disability*, Medical Journal of Australia, **173**, 328-330.

Lennox N & Diggens J, 1999, *Knowledge, Skills and Attitudes: Medical Schools' Coverage of an Ideal Curriculum on Intellectual Disability*, Journal of Intellectual and Developmental Disability, **24** (4), 341-7.

Lennox N & Diggens J, 1999, *Medical Education and Intellectual Disability : A Survey of Australian Medical Schools*, Journal of Intellectual and Developmental Disability, **24** (4), 333-40.

Lennox N, Diggens J & Ugoni A, 1997, *The General Practice Care of People with Intellectual Disability: Barriers and Solutions*, Journal of Intellectual Disability Research, **41**, 380-90.

Lennox NG & Kerr MP, 1997, Primary health care and people with an intellectual disability: the evidence base, Journal of Intellectual Disability Research, 41, 365-72.

Linaker OM & Nottestadd JA ,1998, *Health and health services for the mentally retarded before and after the reform*, Tidsskr Nor Laegeforening, **188** (3), 351-61.

Lindsay M, 1996, Social Policy Group, Department of the Parliamentary Library Background Paper 2, 1995-96, Commonwealth Disability Policy 1983-1995, Commonwealth Government of Australia.

Lochner K, Kawachi I, Kennedy BP. 1999, *Social Capital: A Guide to Its Measurement*, Health and Place, **5**, 259-270.

Lomas J, 1998, *Social Capital and Health: Implications for Public Health and Epidemiology*, Social Science & Medicine, **47** (9), 1181-8.

Luckasson R, Coulter DL, Polloway EA, Reiss S, Schalock RL, Snell ME, Spitalnick D & Stark JA, 1992, Mental Retardation: Definition, Classification and Systems of Supports, Washington DC: American Association on Mental Retardation.

Marmot MG & Wilkinson RG, (Eds), 1999, Social Determinants of Health, Oxford University Press: Oxford.

Marmot MG. 1998, *Improvement of Social Environment to Improve Health*, Lancet, **351** (9095), 57-60.

Mechanic, David, 1999, *Issues in Promoting Health*, Social Science and Medicine, **48**, 711-8.

Martin GHB & Martin DM, 2000, *A Register for Patients with Learning Disability in General Practice*, Journal of Learning Disabilities, **4** (1), 37-48.

Martin DM, Roy A, Wells MB & Lewis J, 1997, *Health Gain Through Screening – Users and Carers Perspectives on Health Care: Developing Primary Health Care Services for People with an Intellectual Disability*, Journal of Intellectual and Developmental Disability, **22** (4), 241-9.

Maslach C, 1981, *Burnout: A social psychological analysis*, **in** Jones JW, (Ed), The Burnout Syndrome, Park Ridge, Illinois: London House.

McGee MD & Mee-Lee D, 1997, *Rethinking Patient Placement: The Human Service Matrix Model for Matching Services to Needs*, Journal of Substance Abuse Treatment, **14** (2), 141-8.

McLeroy KR, Bibeau D, Steckler A & Glanz K, 1988, *An Ecological Perspective on Health Promotion Programs*, Health Education Quarterly, **15** (4), 351-77.

McVilly KR & Rawlinson RB, 1998, *Quality of Life Issues in the Development and Evaluation of Services for People with Intellectual Disability*, Journal of Intellectual and Developmental Disability, *23*, 199-218.

Mead N & Bower P, 2000, *Patient Centredness: A Conceptual Framework and Review of the Empirical Literature*, Social Science and Medicine, **51**, 1087-110.

Mechanic D, 1999, *Issues in Promoting Health*, Social Science and Medicine, **48**, 711-8.

Mechanic D, 1999, *The State of Behavioural Health in Managed Care*, American Journal of Managed Care, **25**, 17-21.

Meddings S & Perkins R, 1999, *Service User Perspectives on the Treatment of Long-Term Mental Illness*, Psychosocial Rehabilitation Journal, **17**, 37- 54.

Meehan S, Moore E, Barr O, 1995, *Specialist Services for People with Learning Disabilities.* Nursing Times. **91**,13.

Meerding WJ, Bonneux L, Polder JJ, Koopmanschap MA, Van der Maas PJ, 1998, *Demographic and epidemiological determinants of health care costs in the Netherlands: Cost of Illness Study*, British Medical Journal, **7**: 111-5

Mental Health Foundation, 1996, Building Expectations, London: MHF.

Milhill C, 1999, Hard Rations: Getting the right treatment for the NHS, London: Association of the British Pharmaceutical Industry.

Minihan PM, 1986, *Planning for Community Physician Services Prior to Deinstitutionalisation of Mentally Retarded Persons*, American Journal of Public Health, **76,** 1202-6.

Mininhan PM, Dean DH & Lyons CM, 1993, *Managing the Care of Patients with Mental Retardation: A Survey of Physicians*, Mental Retardation, **31** (4), 229-46.

Moss S & Turner S, 1995, The Health of People with Learning Disability, Manchester: Hester Adrian Research Centre.

Munford R. & Sullivan M, 1997, *Social Theories of Disability: The Insurrection of Subjugated Knowledges*, **in** O'Brien P & Murray R, Human Services: Towards Partnership and Support, Sydney: Dunmore Press.

National Health Service, NHS Executive, 1998 Signposts for Success in Commissioning and Providing Health Services for people with Learning Disabilities, London: Department of Health.

NSW Health Department, 1994, Discussion Paper: Future Roles and Direction of Community Health in NSW, Sydney: NSW Health Department.

Nirje B. *The Normalisation Principle and Its Human Management Implications*, **in** Kugel RB & Wolfensberger W. (Eds), 1979, Changing Patterns in Residential Services for the Mentally Retarded, Washington, DC: President's Committee on Mental Retardation US Department of Health and Human Services, Office of Human Development Services.

Nunkoosing K, 2000, *Constructing Learning Disability: Consequences for Men and Women with Learning Disabilities*, Journal of Learning Disabilities, **4** (1), 49-62.

O'Brien P, 1997, *Human Services: Creating or Alleviating Disability*, in O"Brien P and Murray R, 1997, Human Services: Towards Partnership and Support, Sydney: Dunmore Press.

Oliver M, 1993, *Re-defining Disability; A Challenge to Research* **in** Swain J, Finklestein V, French S, Oliver M (Eds), Disability Barriers - Enabling Environments, London: Sage.

Oliver M, 1996, Understanding Disability: From Theory to Practice. Basingstoke: Macmillan.

Palmer GR & Short SD, 1994, Health Care and Public Policy: An Australian Analysis, Macmillan: Melbourne.

Parker JM, 1999, *Patient or Customer*, Collegian, **6** (1), 16-22.

Parry-Jones B, Grant G, McGrath M, Caldock K, Ramcharan P & Robinson CA, 1998, *Stress and Job Satisfaction Among Social Workers, Community Nurses and Community Psychiatric Nurses: Implications for the Care Management Model*, Health and Social Care in the Community, **6** (4), 271-85.

Penchansky R & Thomas JW, 1981, *The Concept of Access: Definition and Relationship to Consumer Satisfaction*, Medical Care, **19** (2), 127-40.

People empoerwment vs social capital. From health promotion to social marketing. paper

Peplau HE, 1994, *Quality of life: An Interpersonal Perspective*, Nursing Science Quarterly, **7**, 10-5.

Petterson I & Arnetz BB, 1998, *Psychosocial Stressors and Well-Being in Health Care Workers: The Impact of An Intervention Program*, Social Science and Medicine, **11**, 1763-72.

Pinch S, 1996, Worlds of Welfare, London: Routledge.

Plant M, 1997, *The Provision of Primary Health Care For Adults who have Learning Disabilities*, British Journal of Developmental Disabilities, 43 (1), 75-8.

Pulcini J & Howard A., 1997, *Framework for Analyzing Health Care Models Serving Adults with Mental Retardation and Other Developmental Disabilities*, <u>Mental Retardation,</u> **35** (3), 209-17.

Putnam,RD, 1993, *The Prosperous Community: Social Capital and Public Life*, <u>The American Prospect</u>, **13**, 35-42.

Ramon S, 1991, <u>Beyond Community Care - Normalization and Integration Work</u>, London: MIND/Macmillan.

Rauscher L & McClintock M, 1997, Ableism Curriculum Design, in Adams M, Bell L & Griffin P, (Eds.), <u>Teaching for Diversity and Social Justice, New York:</u> Routledge.

Reiss S, 2000, *A Mindful Approach to Mental Retardation*, <u>Journal of Social Issues</u>, **56 (**1) 65-80.

Reiss S & Aman MG (Eds), <u>Psychotropics Medication and Developmental Disabilities: The International Consensus Handbook</u>, Ohio State University: Nisonger Centre.

Ridsdale L, 1999, <u>Evidence-based General Practice</u>. London: Harcourt Brace.

Rimmer JH, Braddock D & Marks B, 1995, *Health Characteristics and Behaviours of Adults with Mental Retardation Residing in Three Living Arrangements*, <u>Research in Developmental Disabilities</u>, **16** (6), 489-99.

Rimmer JW & Whitfield M, 1995, <u>Can Primary Health Care Teams and Community Learning Disability Teams Collaborate to Provide Preventive Health Care for Patients with Learning Disabilities?,</u> Bristol: Avon Medical Advisory Group.

Rimmer,JH, Braddock D & Marks B, 1995, *Health Characteristics and Behaviours of Adults with Mental Retardation Residing in Three Living Arrangements*, <u>Research in Developmental Disability</u>, **16,** (6), 489-99.

Rodgers J, 1993, *Primary Health Care Provision for People with Learning Difficulties*, <u>Health and Social Care</u>, **2**, 11-7.

Rose J, 1999, *Stress and Residential Staff Who Work with People Who Have an Intellectual Disability: A Factor Analytic Study*, <u>Journal of Intellectual Disability Research</u>, **43** (4), 268-78.

Rose G. The strategy of preventive medicine. Oxford: Oxford University Press, 1992

Rosenberg W & Donald A, 1995, *Evidence Based Medicine: An Approach to Clinical Problem Solving*, <u>British Medical Journal</u>, **310,** 1122-6.

Rosenstock IM, 1966, *Why People Use Health Services*, <u>Millbank Memorial Fund Quarterly</u>, **44** (33), 94-127.

Roter D, 2000, *The Enduring and Evolving Nature of the Patient-Physician Relationship*, <u>Patient Education and Counseling</u>, **39**, 5-15.

Roy A, Martin DM & Wells MB, 1997, *Health Gain Through Screening- Mental Health: Developing Primary Health Care Services for People with an Intellectual Disability*, <u>Journal of Intellectual and Developmental Disability</u>, **22** (4), 227-39.

Royal College of General Practitioners (RCGP UK), Press Release 29/03/01, <u>Valuing People with Learning Disabilities - The Impact on Primary Care</u>, RCGP response to the UK Government White Paper/Strategic Review.

Sackett D, Rosenberg WMC, Muir Gray JA, Hayes RB, Scott Richardson W, 1996, *Evidence Based Medicine: What It Is and What It Isn't*, <u>British Medical Journal</u>, **312**, 71-72.

Schalock RL, 1990 (Ed), <u>Quality of Life: Perspectives and Issues</u>, Washington DC: American Association on Mental Retardation.

Schattner PL & Coman GJ, 1998, *The Stress of Metropolitan General Practice*, *Medical Journal of Australia*, **169**, 133-7.

Schulz R, Greenley JR & Brown R, 1995, *Organization, Management, and Client Effects on Staff Burnout*, <u>Journal of Health and Social Behaviour</u>, **36**, 333-45.

Seys D, Duker P, Salemink W & Fraken-Wijnhoven J, 1998, *Resident Behaviours and Characteristics as Determinants of Quality of Residential Care: An Observational Study*, <u>Research in Developmental Disabilities</u>, **19** (2), 261-73.

Sidoti C, 1998, The Disability Discrimination Act and the Continuing Battle for equal Rights for People with a Disability, Human Rights Commissioner and Acting Disability Discrimination Commissioner, paper delivered at the ACROD Convention Cairns, 27 November 1998 .

Singh NN, 1995, *Moving Beyond Institutional Care for Individuals with Developmental Disabilities*, <u>Journal of Child and Family Studies</u>, **4** (2), 129-45.

Smeenk F, van Haastregt J, Gubbels E, Witte L & Crebolder H, 1998, *Care Process and Satisfaction Analysis of a Transmural Home Care Program*, <u>International Journal of Nursing Studies</u>, **35**, 146-54.

Stehlik D & Chenoweth L, 1996, <u>Ideologies, Pedagogies and Practice,</u> University Education for the Human Services.

Stein K & Ball D, 1999, *Contact Between People with Learning Disability and General Practitioners: A Cross-Sectional Case Note Survey*, <u>Journal of Public Health Medicine</u>, **21** (2), 192-9.

Stein K, 2000, *Caring for People with Learning Disability: A Survey of General Practitioners' Attitudes in Southampton and South-West Hampshire*, <u>British Journal of Learning Disabilities</u>, **28**. 9-15.

Strassburger K, 1988, *Provision of Health Care for Person with Developmental Disabilities Living in the Community*, <u>Journal of the American Medical Association</u>, **260** (10), 1439-44.

Sturmey P, 1999, Classification: concepts, progress and future, in Bouras N (Ed), <u>Psychiatric and Behavioural Disorders in Developmental Disabilities and Mental Retardation</u>, Cambridge: Cambridge University Press, pp. 6.

Swerissen H & Duckett S, 1995, *Health Policy and Financing* **in** Gardner H (Ed), <u>The Politics of Health: The Australian Experience</u>, London: Churchill Livingstone.

Sword W, 1999, *A Socio-ecological Approach to Understanding Barriers to Prenatal Care for Women of Low Income*, <u>Journal of Advanced Nursing</u>, **29** (5) 1170-1177.

Tarlov AR, 1996, *Social Determinants of Health*: The Sociobiological Translation, in Blane, D,

Towell D, 1997, *Promoting a Better Life for People with Learning Disabilities and their families: A Practical Agenda for the New Government*, <u>British Journal of Learning Disability</u>, **25**, 90-4.

Tracey J & Graves P, 1999, *Assessment of a Child with Developmental Delay*, **in** Lennox N & Diggens J (Eds), <u>Management Guidelines People with Developmental and Intellectual Disabilities</u>, Melbourne: Therapeutic Guidelines.

Turner S & Moss S, 1996, *The Health Needs of Adults with Learning Disabilities and the Health of the Nation Strategy*, <u>Journal of Intellectual Disability Research</u>, **40** (5), 238-50.

Walsh KK & Kastner TA, 1999, *Quality of Health Care for People with Developmental Disabilities: The Challenge of Managed Care*, <u>Mental Retardation</u>, **37**, 1-15.

Walsh KK, Kastner T & Criscione T, 1997, *Characteristics of Hospitalisations for People with Developmental Disabilities: Utilization, Costs and Impact of Care Coordination*, <u>American Journal on Mental Retardation</u>, **101** (5), 505-20.

Walshe K, 1997, *Clinical Effectiveness: The Challenge for Community Nursing* **in** Henessy D (Ed) 1997, <u>Community Health Care Development</u>, Basingstoke:Macmillan..

Wedderburn T, 1995, *What do patients really think?* <u>Health Service Journal</u>, **105** (5435) 18-20.

Wen X, 1997, <u>The Definition and Prevalence of Intellectual Disability in Australia</u>, Canberra: Australian Institute of Health and Welfare.

Whitfield ML, Langan J & Russell O, 1996, *Assessing General Practitioners' Care of Adult Patients with Learning Disability: Case Control Study*, <u>Quality in Health Care</u>, **5**, 31-5.

Williamson DL, 2000, *Health Behaviour and Health: Evidence that the Relationship is not Conditional on Income Adequacy*, <u>Social Science and Medicine</u>, **51**, 1741-54.

Williamson VK & Henfrey D, 1996, *Patient Participation in Medical Audit in Primary Care*, <u>Social Sciences in Health</u>, **2**, 2, 67-76.

Wilson DN & Haire A, 1990, *Health Care Screening for People with Mental Handicap Living in the Community*, <u>British Medical Journal</u>, **301**, 1379-81.

Winterhalder R, 1997, *An Overview of Learning Disabilities*, in Holt, G and Bouras, N (Eds), <u>Mental Health in Learning Disabilities: A Training Pack for Staff Working with People who have a Dual Diagnosis</u>, Brighton: Pavilion, pp. 5.

Wolfensberger W, *Changing Patterns in Residential Services for the Mentally Retarded.* Washington, DC: President's Committee on Mental Retardation, 1969:181-94.

Wolfensberger W, 1972, <u>The Principle of Normalisation in Human Services</u>, Toronto: National Institute on Mental Retardation.

Wolfensberger W, 1983, Social Role Valorisation: *A Proposed New Term for the Principle of Normalisation*, <u>Mental Retardation</u> 21(6): 234-9.

World Health Organisation (WHO), 1986, <u>Ottawa Health Charter</u>, WHO: Geneva.

Zakus D & Lysack C**,** 1998, *Revisiting Community Participation*, <u>Health Policy & Planning</u>, **13**,1-12

Zifcak S, 1997*, Towards 2000: Rights, Responsibilities and Process in the Reform of Mental Health Law*, <u>Australian Journal of Human Rights</u>, **4** (1), pp. 51

Ziring PR, Kastner T, Friedman DL, Pond WS, Barnett ML, Sonnenberg EM, 1988, *Provision of Health Care for Persons with Developmental Disabilities Living in the Community*, <u>Journal of American Medical Association</u>, **269** (10), 1439-44.

Lessons from the Labyrinth

Appendices

2. Ethics

THE UNIVERSITY OF QUEENSLAND

BEHAVIOURAL AND SOCIAL SCIENCES ETHICAL REVIEW COMMITTEE

Please attach a completed questionnaire to each of the 12 copies to be submitted.

QUESTIONNAIRE FOR ETHICAL CLEARANCE

PROJECT TITLE: A Controlled Intervention Trial to Determine the Effectiveness of a Comprehensive Health Assessment Program on the Health of People with an Intellectual Disability

PRINCIPAL INVESTIGAT3OR: A/Prof Nicholas Lennox

CO INVESTIGATORS:

DEPARTMENT: Developmental Disability Unit, Department of Social & Preventive Medicine.

CONTACT DETAILS: *Phone*   *Fax*   *E-mail*
07 3840 2412   07 3840 2445   n.lennox@spmed.uq.edu.au

GRANTING BODY/OR DEGREE ENROLLED:
The Department of Families, Youth and Community Care

PLEASE ANSWER THE FOLLOWING:

1. **Who are the participants?**

2. **Is informed consent obtained from participants?**   Yes
   (If yes, consent form must be attached)

3. **Is an information sheet to be provided?**   Yes
   (This is essential where written consent is not being obtained and a copy should be attached)

4. **Will confidentiality be preserved?**   Yes

5. **Will there be feedback to participants?**   Yes

6. **Have all aspects of risk to participants been addressed?**   Yes
   If the answer to any question is NO please explain why briefly (attach response on a separate sheet)

7. **Does this submission relate to a previous protocol?** Similar or an amendment?   No
   If Yes, please provide clearance no.

8. **Is the source of funding external to the university?**   Yes
   If Yes, please state source: *The Department of Families, Youth and Community Care*

CLEARANCE NO: (office use)

Appendices   **123**

A Controlled Intervention Trial to Determine the Effectiveness of a Comprehensive Health Assessment Program on the Health of People with an Intellectual Disability

The Intervention: A Comprehensive Health Assessment Program

The University of Queensland's Developmental Disability Unit (DDU) is involved in ongoing collaboration with the Department of Families, Youth and Community Care (DFYCC) in the development and implementation of this project. The health care problems of people with an intellectual disability are an ongoing concern for the Queensland government. DFYCC has core agency responsibility for disability within government, notably policy and service delivery responsibilities across Queensland. The outcomes of the project will provide a strong academic and practical foundation upon which to guide future health initiatives for this client group both within and outside government. Strategies can follow which will improve the health and quality of life of adults with intellectual disability. The project has been funded by DFYCC.

The project examines the implementation of a health assessment tool, the Comprehensive Assessment Program (CHAP) that has been designed by the Developmental Disability Unit. The CHAP aims to improve health care outcomes for people with an intellectual disability by providing a structured approach to preparation which precedes a medical consultation, and the actual medical consultation. People with an intellectual disability experience significant health care problems when compared to the general population. Research has shown that there are a number of medical conditions that are commonly misdiagnosed or poorly managed by contemporary primary health care providers. The project examines the relationship between the person with an intellectual disability, their carers and their general practitioner. Outcomes of the research project will assist DFYCC in determining the appropriateness of implementing the CHAP tool across Queensland.

The intention is to establish a baseline as soon as possible with data collection and analysis for this task beginning before the end of 1998. Following the completion of the baseline, the CHAP will be implemented within two regions of the Department of Families, Youth and Community Care where residential services are provided to clients with an intellectual disability. A number of special interventions will take place within one region. The other region will form the control group. Outcomes will be assessed using the control group and baseline. It is anticipated that the project will be completed by June 2000.

Aims

- To assess the effectiveness of the CHAP tool in assisting staff and general practitioners in the identification, treatment and ongoing management of health care problems of clients with an intellectual disability living in DFYCC residential services;

- To evaluate the effectiveness of the CHAP tool in improving health care standards of people with an intellectual disability living in DFYCC residential services;

- The development of strategies to improve health care outcomes for people with an intellectual disability living in DFYCC residential services.

will be involved. It is necessary to involve Unit Managers and Area Managers because Residential Care Officers are not autonomous decision makers regarding clients and depending upon the issue, are obliged to seek guidance and assistance from Unit Managers and/or Area Managers.

Staff from both regions will be surveyed through questionnaire to establish the baseline. Similarly, staff from both regions will receive an education session when the CHAP tool is implemented. An information booklet explaining the tool will accompany each tool. There will be a contact point for inquiries for both regions – telephone and email to ensure the needs of shiftworkers are met afterhours. needs are met. Brisbane South will form the control group and there will be no further interventions after the CHAP implementation.

In Brisbane North, in addition to the education session linked to the CHAP implementation, there will be a specific intervention. This intervention will include the provision of staff relief to Residential Care Officers involved in the study so that they are given appropriate "time out" from their regular responsibilities. This relief will enable then to complete the CHAP tool and organise for the client they are responsible for will be

Objectives

The identification and analysis of:

- major factors which effect the implementation of the CHAP tool;

- key factors which influence successful and unsuccessful interactions of clients and their carers with general practitioners;

- factors which impede or promote positive health outcomes;

- components of the CHAP tool and implementation process, which require modification or change to suit the needs of people with an intellectual disability living in DFYCC residentials.

Background

People with an intellectual disability experience a greater variety of health care problems compared with the general population. Within this group there is an increased prevalence of obesity, heart disease, epilepsy, hypertension, musculoskeletal problems and psychiatric morbidity.[1] Contemporary research suggests there are major inadequacies in the detection and management of medical conditions (eg. hearing and vision impairment, inappropriate use of medication[2], identification of gross pathology[3,4]) and in inadequate health screening. Differences have also been found in hospitalisation and mortality rates, when compared to the general population[2].

This project builds upon this research which suggests that medical practitioners are not following comprehensive health assessment strategies when diagnosing and treating the health care problems of people with an intellectual disability. There is a paucity of research about health outcomes following targeted health interventions or the acceptability of such a process to people with an intellectual disability, carers and General Practitioners.

There are many complex factors which combine to create barriers that prevent the successful provision of effective health care to adults with intellectual disability. Some barriers relate to communication problems typically experienced by people with an intellectual disability who are often unable to speak for themselves. Of importance are the roles that substitute decision makers play in the lives of people with an intellectual disability who are dependent upon others for all or most aspects of their daily care. General practitioners often experience difficulty obtaining a medical history and have been inadequately trained when working with the needs of this group[5]. One potential solution, a comprehensive health assessment program involving individuals, carers, and General Practitioners, addresses these barriers.

In response to the limitations of current research, this project aims to assess the viability of the CHAP tool as a mechanism to assist carers and the general practitioner to improve the health outcomes of people with an intellectual disability. The commitment of the Developmental Disability Unit and the Department of Families, Youth and Community Care to the project is acknowledged and will assist with the aims and objectives being met. Outcomes will have a broader applicability to the disability field and results may assist other disability service providers and health care practitioners, in both government and non-government sectors to improve their services to people with an intellectual disability.

Research Plan

Design: Prospective multiple baseline controlled intervention trial. The study will produce some quantitative data but is primarily qualitative.

Methods: This study will be implemented within two regions of the Department of Families, Youth and Community Care, specifically the Brisbane North and Brisbane South regions. The research will consider clients with an intellectual disability within those regions who are living in residential accommodation. The funding agreement between the Department and the DDU has stipulated the involvement of these two regions. The project will be coordinated by the Developmental Disability Unit, The University of Queensland.

The intervention, a Comprehensive Health Assessment Program (CHAP), involves interaction between the person with an intellectual disability, their primary carer who is a Residential Care Officer, and their General Practitioner. There are approximately x people living residential services in Brisbane North and x people living in residential services in Brisbane South. There are x Residential Care Officers, x Unit Mangers and x Area Managers in Brisbane North. In Brisbane South there are......... Approximately x General Practitioners

will be involved. It is necessary to involve Unit Managers and Area Managers because Residential Care Officers are not autonomous decision makers regarding clients and depending upon the issue, are obliged to seek guidance and assistance from Unit Managers and/or Area Managers.

Staff from both regions will be surveyed through questionnaire to establish the baseline. Similarly, staff from both regions will receive an education session when the CHAP tool is implemented. An information booklet explaining the tool will accompany each tool. There will be a contact point for inquiries for both regions – telephone and email to ensure the needs of shiftworkers are met afterhours. needs are met. Brisbane South will form the control group and there will be no further interventions after the CHAP implementation.

In Brisbane North, in addition to the education session linked to the CHAP implementation, there will be a specific intervention. This intervention will include the provision of staff relief to Residential Care Officers involved in the study so that they are given appropriate "time out" from their regular responsibilities. This relief will enable then to complete the CHAP tool and organise for the client they are responsible for (keyworker role) to visit the medical practitioner. Residential Care Officers will also be assisted by DFYCC professional staff eg social workers, psychologists, occupational therapists etc. to complete these tasks. Finally, they will have access to an additional educational session which will provide advice on health care problems experienced by this population and suggestions on how they can be involved in effective interactions with the general practitioner. There will be hard copies of this information available to staff who cannot attend the additional information session.

There are two parts to the CHAP tool. Residential Care Officers will be expected to complete the first part which is a full medical history, prior to the medical consultation. The tool accompanies the client to the doctor. The General Practitioner completes the second half of the tool which records the outcomes of the client consultation. The completed tool is to be returned to the Developmental Disability Unit following the medical consultation, within four months of the initial distribution.

Cross-validation will be achieved through questionnaire based interviews with the General Practitioners, and consideration of medical records. DFYCC client files will also be scrutinised. Post-intervention interviews after the CHAP completion will include Residential Care Officers, Unit Managers and Area Managers at four months and twelve months. Families, staff, clients, and interested others will be invited to focus sessions at the completion of the interviews to ascertain their views and comments on the CHAP implementation.

Recruitment of Subjects: Each member of the individual/carer/GP triad will be needed for successful participation in the study. DFYCC currently provides all aspects of care to people with an intellectual disability living in residential services. The Department has funded the project and is committed to be actively involved.

An information forum will be organised for each region to explain the project and its aims to staff, DFYCC clients, families, significant others and interested others. If necessary, information forums will be provided within area offices of each region. A detailed information package will be widely distributed to Residential Care Officers through their Area Managers and Unit Managers. This package which will explain the aims and objectives of the project and give appropriate details regarding timeframes, who is involved etc.

Consent is being sought from each member of staff and each client who may participate in the study. The majority of clients in DFYCC have an intellectual disability with high support needs, using older terminology moderate to severe/profound levels of disability. It is therefore expected that clients will not be able to provide informed consent to participation within the study. Family members/significant others who are Statutory Health Attorneys will complete the consents where appropriate. The Adult Guardian will be contacted in regard to those clients who do not have a Statutory Health Attorney. The Chief Investigator and Senior Research Assistant will be contactable via telephone or email for further information following the sessions.

Data Collection: Health outcome variables will be collected from DFYCC client records, telephone calls to Residential Care Officers, Unit Mangers and Area Managers. The notes/medical records of General Practitioners will also be analysed. Variables being considered include the detection of (eg) hearing and vision impairment, hypothyroidism, or other conditions detected as a result of the person undergoing the CHAP, and health screening measures. Qualitative data will be sought from participants through questionnaires and telephone contact. Staff perceptions of the completed CHAP and its outcomes and effects upon the clients will be sought at four months and then again at twelve months. General Practitioners will be similarly assessed at four months and again at twelve months following the initial CHAP distribution. Focus groups will elicit information from adults with intellectual disability, family members, staff and interested others.

Data Analysis: Percentages of detection of hearing and vision impairment, and other health outcomes, will be compared between the intervention and control group. The final report will focus on the size of any effect of the CHAP program, (both relative and absolute) to allow the most direct assessment of its value. The individual will be used as the unit of analysis. Analysis will consider the baseline and correlations or differences between the control and intervention groups. For continuous outcome variables a mixed-effects analysis of variance will be used, with clusters nested within intervention groups[6]. For categorical outcomes, generalised estimating equations will be used with logistic regression to compare the outcomes between groups, after adjusting for potential confounding variables[7]. Qualitative data will be analysed for content and themes.

References

1. Lennox NG, and Kerr MP. 1997, Primary Health Care and intellectual disability: A Review. Primary Care Special Edition of the Journal of Intellectual Disability Research. Special Issue: Primary Health Care, Journal of Intellectual Disability Research 4; (5): 365-372.

2. Beange H, McElduff A, Baker W. 1995, Medical disorders of adults with mental retardation: A population study. American Journal of Mental Retardation, 99; (6): 595-604.

3. Wilson DN, and Haire A. 1990, Health care screening for people with mental handicap living in the community. British Medical Journal, 301: 1379-1381.

4. Beange H. & Bauman A. 1990, Caring for the developmentally disabled in the community. Australian Family Physician 19; 1558-1563.

5. Lennox NG, Diggens J, Ugoni A. 1997, Barriers and Solution to the General Practice Care of People with an Intellectual Disability. Special Issue IASSID Congress: Primary Health Care, Journal of Intellectual Disability Research, 4; (5): 380-390.

6. Koepsell TD, Martin DC, Diehr PH, et al. 1991, Data analysis and sample size issues in evaluations of community-based health promotion and disease prevention programs: a mixed-model analysis of variance approach. Journal of Clinical Epidemiology, 44: 701-3.

7. Zeger SL, Liang K-Y, Albert PS. 1988, Models for longitudinal data: a generalized estimating equation approach. Biometrics, 44: 1049-60.

Expected Outcomes

The expected outcome of the study is to demonstrate that the implementation of the CHAP process will result in improved detection and management of health problems, and appropriate health screening and / or disease prevention activities. The process outcome variables (measured qualitatively) which will be examined are the acceptability, utility and useability of CHAP, and the perceptions of the CHAP as a health promotion/screening tool for both carers and general practitioners.

This study expects to evaluate whether the CHAP is effective in providing adults with intellectual disability with better health outcomes and frequency of health screening than would be experienced without its use. The process also needs to be acceptable to adults with intellectual disability, carers and General Practitioners.

The research will assist DFYCC in determining how appropriate it is to implement the CHAP tool across all regions in Queensland. Because of the leadership role in regard to best practice policy development and program implementation, the Department is also likely to share this resource with other disability service agencies from the non-government sector.

Ethical Statement

The study raises a number of issues which warrant careful ethical consideration. Issues include:

*   the need for informed consent from all participants enrolled in the study including DFYCC clients and staff;

*   acknowledgement that the study is funded by DFYCC and therefore staff may feel some compunction to participate in the study;

*   the study's reliance upon proxy decision makers eg Residential Care Officers and other staff, to reflect the views of people with an intellectual disability who cannot independently speak or care for themselves,

*   implications of access to, use of, storage and publication of sensitive confidential information.

The ability of adults with an intellectual disability to make informed consent varies according to each individual and what their skills and capabilities are. The complexity of the task that consent is being sought for will also need to be considered. Such capabilities will reflect their exposure to education and other psychosocial opportunities for skill development. This is no different for the rest of the population. However, individuals must possess a degree of cognitive capacity or functional competence in order to be able to exercise societal rights such as contracting goods and services, driving a car, marrying or perhaps conducting their own financial affairs. Some people with an intellectual disability can successfully achieve such competency and can exercise informed consent within a variety of scenarios including medical consultations. These people usually have low support needs. They may live quite independently in the community with minimal or occasional support. Older terminology has categorised people with low support needs are being of "borderline" or "mild" levels of intellectual disability.

The majority of people who live within DFYCC residential services are people with an intellectual disability who have moderate to high support needs. These people may be totally dependent upon carers for all aspects of daily life including the provision of food, shelter, hygiene and personal care, and social activities. The older terminology categorised people with high support needs as being of "moderate" or "severe/profound" levels of disability. This client group may not be able to live an independent life and would not be able to guard themselves against serious exploitation or danger. It is suggested that most DFYCC clients in the study will be dependent upon proxy decision makers and will not be able to provide an informed consent to participate in the project.

When informed consent cannot be obtained from people with an intellectual disability, then consent can be sought from the carer or family if they have been appointed a Statutory Health Attorney. This should occur in clinical practice where intrusive examinations are required or medications are prescribed. If clients cannot provide informed consent to the project, consent will be sought from the Statutory Health Attorney. Where a Statutory Health Attorney does not exist, consent will be sought from the Adult Guardian. Discussions with the Adult Guardian suggest that he does not hold any concerns regarding the project and the involvement of DFYCC clients with an intellectual disability. Where consent from the Adult Guardian is required, each will be sought on an individual basis.

It is essential that participants in the project, including DFYCC staff and clients, are not coerced in anyway to participate. This right to exercise choice will be emphasised in the training and information provided to DFYCC staff. It will be made very explicit that whilst the Department has funded the project, there is no organisational directive from DFYCC that staff and clients must be involved. The Department is aware that involvement must be a personal choice and is supportive of this approach to subject recruitment.

On each consent form and again in the information sheets, the right to choose to be involved is highlighted. It is also drawn to the attention of each potential participant that they can choose to leave the project at any stage without any concerns of repercussions. The importance of the process of gaining informed consents and providing relevant information, is indicated by the fact that the Chief Investigator, Associate Professor Lennox, will be actively involved in information sessions to assist DFYCC to understand the tool and its application. At these sessions Dr Lennox will also be reinforcing the importance of voluntary participation in the project.

He will also be available by telephone to carers/people with an intellectual disability and their families, to provide information about the project. In addition, an information brochure for the participants and their carer and families has been produced for the project. This will be reviewed and further re-drafted in consultation with the project reference committee, which will comprise, along with other members, people with an intellectual disability and their families.

DFYCC staff will be specifically instructed not to influence the person with an intellectual disability. Staff will also be instructed to emphasise that the client or carer can terminate their participation at any time. Participation can be terminated by telephone, facsimile or mail.

All data bases related to the study and any other associated information or documentation, will be kept in locked premises. This information will be accessed using computer security codes, or for hard copies, locked in filing cabinets. Participants with an intellectual disability and DFYCC staff will be identified by a number, linked to the person's name but stored separately. Only Associate Professor Lennox and the research staff will have access to the name of the adult with intellectual disability. Participants are assuree in the written information and the information sessions that no identifying information will ever be released. There is also a commitment that published material will also respect this right to privacy and confidentialityand that individual participants will never be able to be identified.

Summary

The CHAP project aims to improve health care outcomes and frequency of screening for people with an intellectual disability living in DFYCC residential services. Clients and staff from two regions, Brisbane North and Brisbane South will participate. The general practitioners who provide services to the clients will also participate.

People with an intellectual disability experience significant health care problems when compared to the general population. It is expected that the research will reinforce the findings of other studies that suggest there are a number of medical conditions that are commonly misdiagnosed or poorly managed by contemporary primary health care providers. The CHAP intervention may provide a successful strategy for improving health benchmarks for people with an intellectual disability. Outcomes of the research project will assist DFYCC in determining the appropriateness of implementing the CHAP across Queensland.

An information sheet will be provided to study participants, and separate consent forms have been constructed for each participant group (adults with intellectual disability, carers, general practitioners). Copies of the information to be provided and the consent forms to be used are included in this application.

INFORMATION SHEET
FOR PARTICIPANTS

Comprehensive Health Assessment Program
(CHAP)

The Department of Families, Youth and Community Care (DFYCC) and the University of Queensland's Developmental Disability Unit are working together in a research project to try to improve the health of adults with intellectual disability living in residential services. Research has shown that people with an intellectual disability experience a greater variety of health care problems compared with the general population. There is an increased prevalence of obesity, heart disease, epilepsy, hypertension, musculoskeletal problems and psychiatric problems. Hearing, visual problems and inappropriate use of medication can also be identified.

One of the reasons why people with an intellectual disability experience health problems may relate to how often they see their general practitioner. Of importance will be how they communicate their health problems and concerns. The detection, diagnosis and management of medical problems is not an easy task for general practitioners. Reasons include communication problems, difficulties in obtaining information eg. poor medical histories, and lack of medical training to work effectively with people with an intellectual disability.

Australian research carried out by the Chief Investigator of this project, suggests that regular health checks using a series of prompts for both the carer and general practitioner may improve health outcomes. International experiences also support the use of a systematic program.

The Comprehensive Health Assessment Program (CHAP) is really a systematic way of collecting and organising health information. Information is stored in a booklet which has two parts. The first part is completed by the person with an intellectual disability, often with the assistance of a carer or family member. Carers assist the general practitioner by providing a medical history which responds to a series of prompts in the CHAP booklet. Dr Lennox has identified key health problem areas that people with an intellectual disability commonly experience. The CHAP booklet accompanies the person with an intellectual disability when they go to their general practitioner. The general practitioner completes part 2 which records the outcomes of the medical assessment. The completed CHAP booklet (part 1 and 2) is returned to the Developmental Disability Unit.

There are many complex factors which influence the health and well-being of people with an intellectual disability. The project will look at the way adults with intellectual disability, their carers, and their local doctors work and interact together. The researchers will carefully consider and analyse what the positive and negative effects of implementing the CHAP are. To do this, carers and general practitioners will participate in interviews where standard questionnaires will be used. These interviews will discuss use of the CHAP by the carers and general practitioners. There will also be some opportunities for focus groups where families, interested others and staff may share their views and comments.

At the end of the project, the outcomes and results will help DFYCC know whether use of the CHAP can improve the health of people with an intellectual disability. If it is an effective strategy for health improvement, the CHAP can be widely used in other areas of residential services, as well as in the wider community.

If you change your mind about being involved in this project, you are able to free to withdraw from the project at any time. You can let the Developmental Disability Unit know by phone, fax, or mail. Contact details are provided at the end of this information sheet.

Clients of Brisbane North and Brisbane South DFYCC

The study involves Brisbane North and Brisbane South regions of the Department of Families, Youth and Community Care. Clients with an intellectual disability living in residential services, and their carers are involved. Both regions will begin the new health check process within the next month. Staff in Brisbane North will receive some additional education. This is to help test the effect of some other factors which might influence health outcomes.

Once the program has started, each adult with intellectual disability will be followed up for a period of one year. Contact will be made with carers at four months and then again at twelve months.

Client involvement in this study requires a visit to the General Practitioner to have a health checkup. This will involve the carer asking the client health related questions and/or perusing relevant files to complete a medical history. This information is recorded in part 1 of the CHAP booklet which is provided to the general practitioner at the beginning of the medical consultation. The General Practitioner then completes a physical examination using the information which the carer has completed. The doctor completes part 2 of the CHAP booklet. After the completion of the examination the General Practitioner returns the completed booklet to the carer who can take copies for the clients residential services records. The booklet is returned by carers to the Developmental Disability Unit as soon as possible.

If the General Practitioner finds any medical condition which needs treatment, investigations or tests, followup treatment, the purchase of medications etc is managed by carers in the "normal" way.

The researchers, Dr Lennox and his team, will use all the information found in the CHAP booklet, but the information won't be available to anyone outside the research team. Dr Lennox and his team will not share any identifying information regarding DFYCC clients or other participants in the study. Information published will talk generally about all the participants in the study. There will be no way that anyone reading information published will be able to tell who participated in the study. There will be no identifying information about clients or staff or families.

General information regarding clients and carers participating, the names of General Practitioners etc. will be obtained by the research team prior to the CHAP being distributed amongst regions. This "baseline" information collection will occur via telephone following consents being received from both staff and clients participating in the study. Where clients cannot provided informed consent, consent can be sought from the Statutory Health Attorney. Where clients do not have a Statutory Health Attorney, the Developmental Disability Unit will seek consent from the Adult Guardian.

Clients can indicate at any time that they do not wish to continue in the project. This decision would not influence their ongoing relationship with the staff, the General Practitioner or family members. Management of their health would continue according to the policies and practices of the Department.

Staff/Carers of Adults with an Intellectual Disability

Area Managers, Unit Managers and Residential Care Officers will participate in the study. Residential Care Officers will complete the CHAP booklet on behalf of the client that they are co-ordinator for. Other carers working with those clients who do not have a client co-ordinator role, can provide feedback through focus groups which will operate towards the end of the study or by contacting the Developmental Disability Unit. The primary participant is the Residential Care Officer because they are usually the key substitute decision maker for clients. However, it is acknowledged that Unit Managers and Area Managers play very important roles in assisting Residential Care Officers to carry out their duties, particularly when health care decisions need to be made.

It has been estimated that it will take each Residential Care Officer about 15-20 minutes to complete the health check on the client that they are co-ordinator for. It will involve completing part 1 of the booklet provided that accompanies the client to the General Practitioner. Staff can ask other carers for advice and information. There is likely to be helpful information in the archival or medical files.

The next step for carers will be making a long appointment with the General Practitioner for the client. It is expected that the client would be accompanied by the Residential Care Officer who is their co-ordinator. Staff are encouraged to take careful notes throughout the study. Contact will be made with staff after the CHAP has been completed. This contact will take place at four months after the CHAP has been given to clients and staff, and then again at twelve months. It is expected that client records will be considered in addition to staff being involved in a short telephone interview.

General Practitioners

The Health Insurance Commission has formally approved that the long consultation required for this project be covered under the Medicare system. The role of the General Practitioner is to:

- complete a comprehensive health assessment of your patient with intellectual disability recording outcomes in the CHAP booklet;
- permit the researchers access to the medical records of the patient with an intellectual disability over a 12 month period (this will be accessed on one occasion at the end of the study period); and
- participate in one 5 minute telephone call from the research team at the end of the General Practitioner's involvement in the project, to qualitatively assess opinions of the program.

Dr Lennox will be contacting general practitioners to obtain their consent for involvement in the study. The doctors will be aware of the study and its aims and objectives prior to carers making appointments for long medical consultations.

This study has been cleared by one of the human ethics committees of the University of Queensland in accordance with the National Health and Medical Research Council's guidelines.

If you would like to speak to an officer of the University of Queensland not involved in the study, you may contact the Ethics Officer on 07 3365 4582 or 07 3365 3924.

You are welcome to discuss your participation in this study with staff from the Developmental Disability Unit, Department of Social and Preventive Medicine, The University of Queensland.

Associate Professor Lennox and other staff members can be contacted on 07 38402412. The fax number is (07) 38402445. Dr Lennox can be emailed at n.lennox@spmed.uq.edu.au.

CLIENT CONSENT FORM

Comprehensive Health Assessment Program
(CHAP)

Signing this consent form means that you understand your part in the study. Most people will begin to participate in the study within the next two months. Your participation is a personal choice. You can choose to be involved or choose not to be involved. Whatever decision you make will not affect your ongoing health management in a negative way. Once you have agreed to be in the study, it will take about 18 months for the project to be completed.

Signing this consent form indicates that you:

1. have had the particulars of the study explained to you, and agree to participate in the project.
2. authorise your doctor to do a physical examination, & make the results available to the researchers.
3. authorise your doctor to let the research team look at your medical records relevant to the study period.
4. authorise your carer to tell the research team about your health problems and outcomes.
5. have had the possible effects of the program explained to you.
6. acknowledge that you are free to participate in the study, and may withdraw from the project at any time.
7. know that the project is for the purpose of research.
8. acknowledge that you are aware that confidentiality of the information provided will be safeguarded.

IT IS IMPORTANT THAT ALL THE DETAILS BELOW ARE COMPLETED – NO BLANK SPACES OR GAPS PLEASE. ALSO PLEASE NOTE THAT SIGNATURES MUST BE WITNESSED BY ANOTHER PERSON.

Signature (client) .... Date ....

Client Name (print please) ....

Client's ALS House Name (print please) ....

Where the client cannot provide an informed consent.

I consent to the participation of (client) .... in the above project.

Signature (Statutory Health Attorney) .... Date ....

Relationship to Client: ....

Signature (Witness to consent) .... Date ....

STAFF/CARER CONSENT FORM

Comprehensive Health Assessment Program
(CHAP)

Signing this consent form means that you understand your part in the study. Most people will begin to particpate in the study within the next two months. Residential Care Officers will perform a health check on a client whom they are co-ordinator for. They will be required to fill out a CHAP booklet and take their client for a medical appointment which they haveorganised. It is expected that the Residential Care Officer will accompany the client to the doctor. Unit Managers and Area Managers will participate in a survey which will discuss their roles in the CHAP.

Researchers will follow up the outcomes of the CHAP for twelve months. This followup will involve consideration of medical records and client notes, telephone contacts at four months and twelve months.

Participation is voluntary. It should be noted that the client cannot participate unless the carers have consented. Once you have agreed to be in the study, it will take about 18 months for everything to be completed.

Signing this consent form indicates that you:

1.   have had the particulars of the study explained to you and consent to participate in the project,.

2.   acknowledge that you have been informed that you are free to participate in the study if you want to, may withdraw from the project at any time, and may withdraw any unprocessed data previously supplied,

3.   acknowledge that the confidentiality of the information you provide will be safeguarded subject to any legal requirements.

IT IS IMPORTANT THAT ALL THE DETAILS BELOW ARE COMPLETED – NO BLANK SPACES OR GAPS PLEASE. ALSO PLEASE NOTE THAT SIGNATURES MUST BE WITNESSED BY ANOTHER PERSON.

Signature (staff participant) .... Date ....

Name and Position of participant (eg. RCO) ....

Client's name (if you are their co-ordinator): ....

Location eg. ALS house name, area office etc. ....

Signature (Witness to consent) .... Date ....

GENERAL PRACTITIONER CONSENT FORM

Comprehensive Health Assessment Program
(CHAP)

Signing this consent form indicates that you understand your role in the study. Your role involves performing a comprehensive health check on the participants in the study who are clients with an intellectual disability living in accommodation services co-ordinated by the Department of Families, Youth and Community Care. The study requires you to record the outcomes of the health check and other relevant information in the CHAP booklet provided. Consent also includes agreement to one follow-up phone call from researchers at the end of your involvement in the study, and permission for the researchers access to your medical records of the study participants on one occasion at the end of the study.

Signing this consent form indicates that you:

1) have had the particulars of the study explained to you and consent to participate in the study,

2) acknowledge that you have been informed that you are free to participate in the study if you want to, and may withdraw from the project at any time,

3) acknowledge that the confidentiality of the information you provide will be safeguarded subject to any legal requirements.

IT IS IMPORTANT THAT ALL THE DETAILS BELOW ARE COMPLETED – NO BLANK SPACES OR GAPS PLEASE. ALSO PLEASE NOTE THAT SIGNATURES MUST BE WITNESSED BY ANOTHER PERSON. PLEASE PRINT.

Signature (General Practitioner .... Date ....

Name of general practitioner ....

Name and address of clinic/medical centre ....

Name and DOB of DFYCC client ....

Signature (Witness to consent):... Date ....

3. Health Guidlines

Lessons from the Labyrinth

Appendices

4.1 Questionnaires
CHAP
COMPREHENSIVE HEALTH ASSESSMENT PROGRAM

INSTRUCTIONS

Please read before YOU begin to complete the questionnaire

It may be helpful for YOU to have quick access to the client's file, including the archival file when YOU are completing this questionnaire. However, many RCOs will be able to answer the questions using their own personal knowledge of the client. This is ok.

The questionnaire has been designed to be completed by the RCO who is the client's nominated keyworker, ie. the client coordinator. **Only complete it if YOU are the client coordinator!**

- Please complete the questionnaire to the best of YOUR own personal knowledge – it has been designed to record YOUR individual views.

- YOU may like to check something with other staff or perhaps a family member of the client, **but YOU don't have to.**

- YOU may like to check the client's archival files or perhaps the personal file, **but YOU don't have to.**

- There are no right and wrong answers. Just "tell it like it really is".

- Don't spend too much time on the questions. Try to complete the questionnaire within 15 – 20 minutes. If YOU want to take a little longer, this is OK.

- YOU don't have to research the questions. If YOU don't know the answer or the information, it is OK to say "don't know".

- Don't forget any information YOU provide is **confidential** and will not be accessed by YOUR managers or the general practitioner used by the client. Identifying information will not be released.

Please ring Niki Edwards, Senior Research Assistant at the Developmental Disability Unit within **seven** days of receiving it. There is a Reply-Paid envelope attached for this purpose.

THANK YOU FOR PARTICIPATING!

Nick Lennox, Chief Investigator and Director, Developmental Disability Unit

---

PART A: GENERAL CLIENT INFORMATION

This information will provide the researchers with a snapshot of your area of responsibility.

1. CHARACTERISTICS

How many clients in your area of responsibility?

How many Alternate Living Service houses are in your area of responsibility?

How many staff in your area of responsibility?

.... RCOs

.... Resource staff (including professionals)

.... Administrative staff

.... other (name)

2.1 Describe the client's home

❑ Suburban house

❑ Duplex

❑ Flat

❑ Part of a townhouse complex

❑ Other: _____

_____
(name)

2.2 How long has the client lived at this address?

❑ More than five years

❑ 3-5 years

❑ 2-3 years

❑ 12 months – 2 years

❑ Less than 12 months

2.3 Do YOU think that the client likes living here **NOW**?

❑ Don't know

❑ Yes, most of the time

❑ Some of the time

❑ No

2.4 Why? _____

_____

_____

_____

_____

2.5 How have YOU answered the above question? (YOU can tick more than one box)

❑ Client behaviour or client's spoken words

❑ Client's behaviour suggests no opinion either way

❑ Personal knowledge of the client over time

❑ Historical/file information

❑ Views of other staff

❑ Views of family/friends

2.6 What is the total number of people usually living at this address?

❑ Lives alone

❑ 2

❑ 3

❑ 4

❑ 5

❑ 6

❑ other: _____

2.7 How many full-time RCOs are rostered to work with YOU at this address over an average seven-day period?

_____

2.8 How many part-time RCOs work with YOU at this address over an average seven-day period?

_____

2.9 How many casual RCOs work with YOU at this address over an average seven-day period?

_____

2.10 Apart from rostered RCOs, are there any other direct care workers employed, eg. lifestyle support workers?

❑ Yes

❑ No

❑ Don't know

2.11 If yes, how many and for what purpose:

_____

_____

_____

2.12 Describe RCO support provided to **all** the people living at this address

❑ 24 hour support

❑ 16 hours

❑ 8-16 hours

❑ less than 8 hours

2.13 Is an RCO on duty all night?

❑ Yes

❑ No

❑ Other arrangement: _____

_____

_____

_____

_____

_____

(describe)

2.13 Can YOU describe the level of support, which is **most typical** of **all** the people living at this address?

❑ Totally dependent

❑ Partially dependent

❑ Mostly independent

❑ Independent

❑ Ranges with some people independent, some more dependent

3. CLIENT CHARACTERISTICS

3.1 What type of disability does the client have (Tick more than one)

❑ Intellectual

❑ Physical

❑ Acquired Brain Injury

❑ Other: _____

3.2 Do YOU know the cause?

❑ Don't know

❑ Cause unknown

❑ Yes _____

_____

_____

_____

_____

(details)

3.3 Do YOU know of any other associated conditions already identified or diagnosed? (Tick more than one)

❑ Hearing problems/Deaf

❑ Visual problems/Blind

❑ Speech/Communication problems

❑ Psychiatric condition

❑ Autism

❑ Cerebral palsy

❑ Epilepsy/seizures

❑ Prader Willi

❑ Fragile X

❑ Dementia

❑ Alzheimers

❑ Other: _____

_____

_____

_____

_____

(details)

3.4 Can YOU describe the client's general level of functioning NOW.

❑ **Low support needs** - mild intellectual disability (manages daily living and community activities with occasional assistance)

❑ **Medium support needs** – moderate intellectual disability (requires regular support with most daily and community activities all of the time)

❏ **High support needs** – Severe intellectual disability (requires continual support with most daily and community activities all of the time)

❏ **Complex support needs** – Profound intellectual disability (requires intense and sustained levels of support with majority of daily and community activities, often multiple physical disabilities and health care problems requiring medical intervention)

❏ Don't know

4. RELATIONSHIP WITH FAMILY OR SIGNIFICANT OTHERS

4.1 Are family members involved in the client's life?

❏ No

❏ Yes, who?_____

_____

4.2 If yes, can YOU indicate how involved they are in the life of the client?

❏ Actively involved

❏ Involved

❏ Sometimes involved

❏ Not involved

❏ Don't know

4.3 If yes, how do YOU feel about their involvement?

❏ Greatly value the involvement

❏ Value the involvement

❏ Mixed feelings about them being involved

❏ Prefer they were not involved

4.4 If family are involved, HOW?

❏ Take client to the doctor

❏ Communicate with the doctor

❏ Discuss health problems with RCOs

❏ Suggest to RCOs solutions to health problems

❏ Discussion with managers and other staff

❏ Other:_____

_____

_____

4.5 Is anyone apart from family, involved in advocating for the client's health and well-being

❏ Don't know

❏ No

❏ Yes

4.6 Why? _____

_____

_____

5. HEARING AND SIGHT

5.1 How is the client's hearing best described by YOU **NOW**?

❏ Normal or manages OK

❏ Mild loss – problems hearing normal speech

❏ Moderate loss – difficult to hear loud speech

❏ Severe/profound loss

❏ Don't know

5.2 How is the client's vision best described by YOU **NOW**?

❏ No vision problems known or identified

❏ Vision problems with/without glasses

❏ Vision impaired even with glasses

❏ Totally blind

❏ Don't know

6. MOBILITY

6.1 How is the client's typical level of mobility best described by YOU NOW?

❏ Walks independently without assistance

❏ Walks independently without assistance but has difficulty (no aids)

❏ Walks independently but requires a physical aid or assistance of another person

❏ Unable to walk – needs assistance of others

7. CHALLENGING BEHAVIOUR

7.1 In the last 12 months, do YOU think that has the client displayed challenging or disruptive behaviour?

❏ Yes

❏ No

❏ Don't know

7.2 If yes, can YOU describe the behaviour:

_____

_____

_____

_____

7.3 Do YOU **know or suspect** of a cause or reason for this behaviour, eg. health related?

❏ No

❏ Don't know

❏ Yes: _____

_____

_____

_____

_____

(details)

7.4 Do YOU know if a doctor has assessed the client for a medical cause or possible health related reason for the behaviour?

❏ Don't know

❏ No

❏ Yes: _____

_____

_____

_____

_____

(details)

7.5 In the last 12 months, do YOU know if the client engaged in behaviour, which is dangerous to themselves or others, eg. self-injured?

❏ Yes

❏ No

❏ Don't know

7.6 If yes, do YOU know if the challenging behaviour existed for longer than 12 months?

❏ No

❏ Don't know

❏ Yes, how long: _____

7.7 If yes, do YOU know if a psychologist is involved in managing the behaviour **NOW**, eg. monitoring or developing a formal behavioural management plan?

❏ Yes

❏ No

❏ Don't know

7.8 If NO (a psychologist is not involved in managing challenging behaviour NOW) why?

❏ Plan set in place some time ago remains current

❏ Psychologist unavailable

❏ Psychologist did not assess behaviour as requiring a plan

❏ Disagreement over existence of challenging behaviour

❏ Other: _____

_____

_____

_____

_____

(details)

7.9 Do YOU know if a psychiatrist is involved managing the behaviour **NOW**?

❏ Yes

❏ Don't know

❏ No

7.10 Do YOU know if the client is taking medication for behaviour problems NOW?

❏ Yes

❏ No

❏ Don't know

7.11 If yes, who prescribes the medication for challenging behaviour?

❏ Psychiatrist

❏ GP

❏ Don't know

❏ Other: _____

_____

(name)

7.12 If yes, who monitors and reviews the medication prescribed, eg. side-effects, need for dosage change etc? _____

_____

_____

_____

_____

7.13 When was the last change to the medication used for managing the behaviour? ___/___/_____

7.14 Why was the medication changed or adjusted? _____

_____

_____

_____

_____

7.15 Do YOU think that the client should be taking this medication, eg. benefits the client overall?

❏ Yes

❏ No

❏ Don't know

8. GENERAL HEALTH

In the last **twelve months** are YOU aware of:

(a) the client having signs or symptoms of the following conditions, **or**

(b) have they had any of the following conditions diagnosed by a doctor or health professionals?(Choose more than one)

8.1 Problems with breathing

❏ Asthma

❏ Bronchitis

❏ Other: _____

8.2 Problems with their heart

❏ Heart disease

❏ High blood pressure

8.3 Problems with their abdomen/stomach/gut

❏ Stomach ulcers

❏ Liver problems

❏ Bowel problems, eg. obstruction

❏ Constipation

❏ Diarrhoea

❏ Reflux

❏ Swallowing problems

8.4 Passing urine

❏ Kidney problems or infections

❏ Bladder problems or infections

❏ Incontinence of urine

8.5 Nervous system

❏ Migraine/headache

❏ Stroke

❏ Epilepsy

8.6 Mental health conditions, eg. depression, schizophrenia etc.

❏ No

❏ Yes: _____
    (diagnosis)

8.7 Other conditions

❏ Diabetes

❏ Cancer: _____
    (name)

❏ Weight problems

❏ Abnormal menstruation – menstrual management problems

❏ Infectious diseases, eg. hepatitis:

_____

    (name)

❏ Other: _____
    (name)

8.8   Does the client need assistance with…?

❏ Gastrostomy

❏ Catheterisation

❏ Colostomy

❏ Regular injections

❏ Nutrition - special diet

❏ Other invasive or special medical procedures: _____

_____

_____

_____

(details)

8.9   Do YOU know if the client has a major health problem which a doctor has diagnosed/identified in the last twelve months?

❏ No

❏ Yes, name: _____

_____

9.   MEDICATION

9.1   Does the client take medication NOW? (Include doctor prescribed, over the counter purchases, eg. from the chemist without a script and alternate health remedies, eg. vitamins etc.)

❏ No

❏ Yes, can YOU please list name of all medication, purpose and how often it is given:

Name of medication & dosage given	Reason (eg. treatment for?)

9.2 Does the client receive any prn (as needed) medication NOW?

❏ No

❏ Don't know

❏ Yes, please list name of medication, its purpose and how often it is given:

Name of medication & dosage given   R e a s o n (eg. treatment for?)

Name of medication & dosage given	Reason (eg. treatment for?)

9.3   Was the medication listed reviewed within the last twelve months?

❏ Don't know

❏ No

❏ Yes, who and when: _____

_____

_____

_____

_____

10.   RECENT MEDICAL EVENTS

10.1   Has the client had any injuries or accidents in the last twelve months?

❏ No

❏ Yes

❏ Don't know

10.2 Has the client been hospitalised in the last twelve months?

❑ No

❑ Yes

❑ Don't know

10.3 If hospitalised, how many times in the last twelve months?

❑ Don't know

❑ Only once

❑ Twice

❑ 3 or more

❑ Other: _____ (total)

10.4 Why?

Reason for admission	Treatment received

10.5 Over the past twelve months, apart from their GPs, can You lists other professionals who saw the client because of their health and well being needs?

Type	Visit per month (approximately)
Social worker	
Psychologist	
Speech therapist	
Occupational therapist	
Domiciliary nurse, eg. Blue Nurses	
Naturopath	

Chiropodist	
Dentist	
Optometrist	
Physiotherapist	
Other: _____	
Reason:	

11. YOUR VIEWS OF THE CLIENT'S HEALTH

11.1 How would YOU describe the client's overall health NOW?

❑ Managed well by those involved

❑ Fluctuates – managed OK NOW

❑ Fluctuates – needs increased attention NOW

❑ Needs increased attention and intervention

11.2 Why?_____

_____

_____

_____

11.3 How would YOU describe the client's health 12 months ago?

❑ Excellent

❑ Good

❑ Fair

❑ Poor

❑ Didn't know client 12 months ago

11.4 How satisfied do YOU feel with the client's health and well-being status NOW?

❑ Delighted/very pleased

❑ Mostly satisfied

❑ Mixed feelings sometimes positive and negative

❑ Unhappy and dissatisfied

PART B: GENERAL PRACTITIONERS

Details about the relationship between RCO's, clients and their GPs

1. INVOLVEMENT WITH GPs

1.1 Do you accompany clients to their GP?

❑ Yes

❑ No

1.2 If yes, when you would be involved in taking clients to their GP?

❑ Request of RCO

❑ Request of other staff………(name)

❑ Request of family member or SHA

❑ Personal decision

❑ Other………………………..(describe)

1.3 Would you like to be more involved in taking clients to their GPs?

❑ No

❑ Yes

❑ Don't know

Why?……………………….(describe)

1.4 How involved are YOU in decisions made about the choice of a GP for each client?

❑ Very involved

❑ Involved

❑ Sometimes involved

❑ Only involved when there are problems

❑ Never involved

1.5 Generally, are YOU involved in management or treatment plans devised by the GP for clients?

❑ Very involved

❑ Involved

❑ Sometimes involved

❑ Only involved when there are problems

❑ Never involved

1.6 Would you like to be more involved in following up treatment or management plans provided by GPs for clients?

❑ Yes

❑ No

❑ Don't know

Why…………………………(describe)

2. GP CHOICE

2.1 Generally, who is involved in choosing a GP/making a decision to see another GP?

❑ RCO who is client coordinator

❑ RCOs working in that house

❑ RCOs and their Unit Manger

❑ Other………………………(name)

❑ Don't know

2.2 Generally why do clients visit a particular GP? (Tick all that apply)

❑ Location/convenience

❑ Family preference/choice

❑ Client likes the doctor

❑ General staff preference/ choice

❑ Often the personal GP of the RCO

❑ Other: _____

2.2 Who usually accompanies clients to their nominated GP?

❑ RCO (client coordinator)

❑ Any RCO who is available

❑ RCO nominated by staff working in house

❑ Unit manager

❑ RCO or staff employed specifically for this task

❑ Other: _____

3. RELATIONSHIP BETWEEN CLIENT and THEIR GP

3.1 Generally, describe the relationship between staff you supervise and GPs in your area:

❑ Don't know

❑ Good relationship – no problems

❑ Mostly OK

❑ Problems

❑ Major difficulties

3.1 Why? _____

_____

_____

_____

3.2 Generally, describe the relationship between clients and GPs in your area:

❑ Don't know

❑ Good relationship – no problems

❑ Mostly OK

❑ Problems

❑ Major difficulties

3.2 Why? _____

_____

_____

_____

What could improve the relationship between clients, staff and GPs in your area?

ONLY ANSWER THE FOLLOWING QUESTIONS IF YOU ACCOMPANY CLIENTS TO THEIR GP

3.4 Generally, do YOU think GPs spend enough time with clients in consultations?

❑ Yes, most of the time

❑ Half the time, could be improved

❑ Sometimes, it varies

❑ Rarely or never

❑ Don't know

3.5 Generally, do YOU think GPs "rush" the consultations with clients?

❑ Yes, most of the time

❑ Half the time, could be improved

❑ Sometimes, it varies

❑ Rarely or never

❑ Don't know

3.6 Do YOU think there are too many interruptions during the consul-tations?

❑ Yes, most of the time

❑ Half the time, could be improved

❑ Sometimes, it varies

❑ Rarely or never

❑ Don't know

3.7 Generally during consultations, who does the nominated GP discuss the treatment or management plan with?

❑ The client

❑ The RCO accompanying the client

❑ The client and the RCO

❑ The client, the RCO and YOU

❑ Does not discuss

❑ Don't know

3.8 Do YOU think the nominated GP listens to YOU about the health problems of the client during the consultation?

❑ No at all

❑ Very little

❑ Half the time, it varies

❑ Most of the time

❑ All the time

❑ Don't know

3.9 Do YOU think the GPs in your area provide a good/reasonable service to their clients?

❑ Yes, most of the time

❑ Half the time, could be improved

❑ Occasionally

❑ Rarely or never

❑ Don't know

3.10 Generally, do YOU think the GPs in your area have a good understanding of the health needs of their clients?

❑ No understanding at all

❑ Very little understanding

❑ OK understanding

❑ Most needs understood

❑ Yes, good understanding

3.11 What do YOU think could improve services provided by GPs in your area to clients?

Discuss: _____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

1. THESE ARE DETAILS ABOUT YOU

1.1   Your age

❏ Over 60

❏ 55-60

❏ 50-55

❏ 45-50

❏   40-45

❏ 35-40

❏ 30-35

❏ 25-30

❏ 20-25

1.2   Gender

❏ Female

❏ Male

1.3   What type of manager are you?

❏ Unit Manager

❏ Area Manager

❏ Regional Manager

1.4   How many staff do you supervise eg report to you as their line manager?

2. TRAINING

2.1   What are YOUR qualifications?

❏ Certificate in residential care

❏ University Degree: _____

_____

_____

_____

_____

(name)

❏ Other: _____

_____

_____

_____

(name)

PART C: DETAILS ABOUT THE MANAGER COMPLETING THIS QUESTIONNAIRE

2.2   Have YOU attended any health-related training **provided by Disability Operations** in the last twelve months, eg. seminars, conferences, etc?

❑ No

❑ Yes, what training and when? _____

_____

_____

_____

_____

_____

2.3   Have YOU attended any health-related education **NOT** organised by DFYCC, eg. seminars, conferences, training, tertiary education etc?

❑ No

❑ Yes, what training and when? _____

_____

_____

_____

_____

_____

2.4   If Yes, why did YOU attend this training?

_____

_____

_____

_____

_____

3.   EMPLOYMENT HISTORY

3.1   Length of employment as a Manager with Disability Operations, DFYCC:

❑ More than 10 years

❑ 5-10 years

❑ 2-5 years

❑ 1-2 years

❑ Less than 12 months

3.2   Length of employment within disability field:

❑ More than 10 years

❑ 5-10 years

❑ 2-5 years

❑ 1-2 years

❑ 1-12 months

3.3   Length of employment in the current position

Years_____

Months_____

4.   CLIENT FAMILIARITY

4.1   Describe YOUR level of awareness of the health care needs of clients in your area.

❑ Very good working knowledge

❑ Good basic knowledge

❑ OK knowledge

❑ "It would be better if I was more familiar with the health care needs of the clients"

5.   YOUR FEELINGS ABOUT BEING A MANAGER

YOU PROVIDE THIS INFORMATION ON A CONFIDENTIAL BASIS TO THE RESEARCHERS.

5.1   In **all aspects of their work** (not just health and well being), do YOU think that RCOs get enough support from professional or resource staff to work effectively as RCOs?

❑ Yes, always

❑ Usually

❑ Sometimes

❑ Never

In all aspects of their work, do you think that staff you supervise get enough support?

❑ Yes, always

❑ Usually

❑ Sometimes

❏ Never

6.4 Are YOU able to give the time needed to meet the needs of staff in your area?

❏ Always

❏ Most of the time

❏ Occasionally

❏ Rarely

❏ Never

6.5 Why?_____

_____

_____

5.2 Do YOU get enough support from YOUR manager/s to work effectively (Not just health-related responsibilities)?

❏ Yes, always

❏ Usually

❏ Sometimes

❏ Never

5.3 Generally, how often do YOU seek support from YOUR manager/s?

❏ Whenever I need advice, assistance or support

❏ Sometimes

❏ Rarely or never

❏ For very specific reasons……………. (describe)

5.4 On average, how often would YOU ask for support described above?

❏ Once a week

❏ Every two weeks

❏ Once a month

❏ Less than once a month

❏ Other………………(describe)

5.5 Generally, how do YOU feel about all pars of YOUR job - responsibilities, work environment, conditions, hours, etc?

❏ Very happy

❏ Pleased

❏ OK/ satisfied

❏ Mixed feelings

❏ Very unhappy

5.6 Generally, how do YOU feel about working with the clients in your area?

❏ Very happy

❏ Pleased

❏ OK/satisfied

❏ Mixed feelings

❏ Unhappy

5.7 Do YOU like working for Disability Operations, DFYCC?

❏ Yes, most of the time

❏ Usually

❏ Sometimes

❏ No, rarely

6. WHAT PRIORITY IS HEALTH?

6.1 Do YOU think the health care needs **of** all clients **should be** a high priority for YOUR region?

❏ Not more important than other client needs

❏ Depends upon the client

❏ Yes, a high priority

❏ Don't know

6.2 Do YOU think the health care needs of **all** clients **are** a high priority for YOUR region?

❏ Yes

❏ No

❏ Don't know

6.3 Why?_____

_____

_____

_____

_____

7. HEALTH KNOWLEDGE AND SKILLS

7.1 How would YOU rate **YOUR** knowledge about health problems experienced by people with an intellectual disability

❏ excellent

❏ good

❏ average/OK

❏ need more knowledge

7.2 How would YOU rate **YOUR** general knowledge about health and well being, eg. decisions YOU make about your own personal health?

❏ excellent

❏ good

❏ average/ok

❏ need more knowledge

7.3 Where has YOUR health knowledge about clients come from? (Tick all that apply)

❏ On the job experience

❏ Training or conferences provided by Disability Operations or DFYCC

❏ Training or conferences I have sought outside of Disability Operations or DFYCC

❏ Books or reference material

❏ Other: _____

7.4 As an RCO, would YOU like to increase YOUR knowledge and expertise in health and well being?

❏ Don't know

❏ No

❏ Yes

7.5 Why?_____
_____
_____
_____
_____

8. MOTIVATION

8.1 Why are YOU participating in this study?

❏ Managers' expectation

❏ Interested

❏ Thought it might help client/s

❏ Didn't know there was a choice

❏ Don't know

8.2 How familiar are YOU with the Comprehensive Health Assess- ment Program (CHAP)

❏ Understand what the program is trying to achieve

❏ Basic understanding

❏ Don't understand

8.3 How would YOU describe client files in regard to storage of health related information, eg. medical details, family history, etc?

❏ Well organised, up to date

❏ Organised and up to date but some information needed is likely to be missing

❏ Not organised and not up to date with major information missing

❏ Other:_____

_____
_____
_____

8.4 Are you involved in placing information on client files?

❏ Yes

❏ No

ANSWER THE FOLLOWING QUESTIONS ONLY IF YOU ARE INVOLVED IN PLACING INFORMATION ON CLIENT FILES

Do YOU **always** get around to putting important client information, notes or comments in client files?

❏ Yes

❏ No

❏ Sometimes, varies

❏ Don't know

Generally, do YOU believe that RCOs in your area **always** get around to putting important information in the client files?

❏ Yes

❏ No

❏ Sometimes, varies

❏ Don't know

Do you think RCOs treat health related information as important eg would have greater chance of being recorded appropriately on client files?

❏ Yes

❏ No

❏ Don't know

Do YOU think client files (including medical or archival files) would be the **best source** of **current** information for YOU regarding the health and well being of clients?

❏ Yes

❏ No

❏ Sometimes, varies

❏ Don't know

Why…………………………..(describe)

Do YOU think communication books in would be the best source of current information for YOU regarding the health and well being of clients?

❏ Yes

❏ No

❏ Sometimes, varies

❏ Don't know

8.5 Do YOU think an improved system of storing and accessing information regarding the health and well being of clients is needed?

❏ Yes

❏ No

❏ Don't know

10. TIME

10.1 How long did this questionnaire take to complete?

❏ Less than ten minutes

❏ 10-20 minutes

❏ 20-30 minutes

❏ Other: _____

10.2 Date questionnaire completed:

_____/_____/20_____

11. OTHER COMENTS ARE WELCOME

Feel free to attach another page.

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

**THANK YOU FOR PARTICIPATING IN
THIS QUESTIONNAIRE.**

**YOUR ASSISTANCE HAS BEEN GREATLY
APPRECIATED.**

Please return this completed questionnaire in the attached self-addressed Reply-Paid envelope.

Please ring Niki Edwards, Senior Research Assistant at the DDU on (07) 3840 2524 if you need assistance.

Lessons from the Labyrinth

Appendices

4.2 Questionnaires

CHAP

Comprehensive Health Assessment Program

INSTRUCTIONS

Please read before YOU begin to complete the questionnaire

It may be helpful for YOU to have quick access to the client's file, including the archival file when YOU are completing this questionnaire. However, many RCOs will be able to answer the questions using their own personal knowledge of the client. This is ok.

The questionnaire has been designed to be completed by the RCO who is the client's nominated keyworker, ie. the client coordinator. **Only complete it if YOU are the client coordinator!**

- Please complete the questionnaire to the best of YOUR own personal knowledge – it has been designed to record YOUR individual views.

- YOU may like to check something with other staff or perhaps a family member of the client, **but YOU don't have to.**

- YOU may like to check the client's archival files or perhaps the personal file, **but YOU don't have to.**

- There are no right and wrong answers. Just "tell it like it really is".

- Don't spend too much time on the questions. Try to complete the questionnaire within 15 – 20 minutes. If YOU want to take a little longer, this is OK.

- YOU don't have to research the questions. If YOU don't know the answer or the information, it is OK to say "don't know".

- Don't forget any information YOU provide is **confidential** and will not be accessed by YOUR managers or the general practitioner used by the client. Identifying information will not be released.

Please ring Niki Edwards, Senior Research Assistant at the Developmental Disability Unit within **seven** days of receiving it. There is a Reply-Paid envelope attached for this purpose.

THANK YOU FOR PARTICIPATING!

Nick Lennox, Chief Investigator and Director, Developmental Disability Unit

---

PART A: DETAILS ABOUT THE CLIENT

RCO who completes details is the client's keyworker eg. client coordinator

IDENTITY

- Full name of client – last name, first name and middle initial _____

_____

- Full address including post code _____

_____

_____

_____

- Telephone Number _____

- Date of birth _____/_____/_____

- Gender
  - ❑ Female
  - ❑ Male

CHARACTERISTICS OF WHERE THE CLIENT LIVES

- Describe the client's home
  - ❑ Suburban house
  - ❑ Duplex
  - ❑ Flat
  - ❑ Part of a townhouse complex
  - ❑ other _____

    (name)

- How long has the client lived at this address
  - ❑ More than five years
  - ❑ 3-5 years
  - ❑ 2-3 years
  - ❑ 12 months – 2 years
  - ❑ Less than 12 months

- Do YOU think that the client likes living here **NOW**?
  - ❑ Don't know
  - ❑ Yes, most of the time

  - ❑ Some of the time
  - ❑ No

  Why _____

_____

_____

_____

- How have YOU answered the above question? (YOU can tick more than one box)
  - ❑ Interpretation of client behaviour or client 's spoken words
  - ❑ Client's behaviour suggests they have no opinion either way
  - ❑ Personal knowledge of the client over time
  - ❑ Historical/file information
  - ❑ Views of other staff
  - ❑ Views of family/friends

- What is the total number of people usually living at this address?
  - ❑ Lives alone
  - ❑ 2
  - ❑ 3
  - ❑ 4
  - ❑ 5
  - ❑ 6
  - ❑ other _____

- How many RCOs are rostered to work with YOU at this address? _____

_____

_____

- Apart from rostered RCOs, are there any other direct care workers employed eg lifestyle support workers?
  - ❑ Yes
  - ❑ No
  - ❑ Don't know

- If yes, how many and for what purpose

  _____

  _____

- Describe RCO support provided to **all** the people living at this address
  - ❑ 24 hour support
  - ❑ 16 hours
  - ❑ 8-16 hours
  - ❑ less than 8 hours

- Is an RCO on duty all night?
  - ❑ Yes
  - ❑ No
  - ❑ Other arrangement_____
    (describe)

- Can YOU describe the level of support which is **most typical** of **all** the people living at this address?
  - ❑ Totally dependent
  - ❑ Partially dependent
  - ❑ Mostly independent
  - ❑ Independent
  - ❑ Ranges with some people independent, some more dependent

CLIENT CHARACTERISTICS

- What type of disability does the client have (tick more than one)
  - ❑ Intellectual
  - ❑ Physical
  - ❑ Acquired Brain Injury
  - ❑ Other _____

- Do YOU know the cause?
  - ❑ Don't know
  - ❑ Cause unknown
  - ❑ Yes_____
    (details)

- Do YOU know of any other associated conditions already identified or diagnosed? (tick more than one)
  - ❑ Hearing problems/Deaf

- ❑ Visual problems/Blind
- ❑ Speech problems
- ❑ Psychiatric condition
- ❑ Autism
- ❑ Cerebral palsy
- ❑ Epilepsy/seizures
- ❑ Prader Willi
- ❑ Fragile X
- ❑ Dementia
- ❑ Alzheimers
- ❑ Other _____
  (details)

- Can YOU describe the client's general level of functioning NOW.
  - ❑ **Low support needs** – mild intellectual disability (manages majority of daily living and community activities with occasional assistance)
  - ❑ **Medium support needs** – moderate intellectual disability (requires regular support with most daily and community activities all of the time)
  - ❑ **High support needs** – Severe intellectual disability (requires continual support with most daily and community activities all of the time)
  - ❑ **Complex support needs** – Profound intellectual disability (requires intense and sustained levels of support with majority of daily and community activities, often multiple physical disabilities and health care problems requiring medical intervention)
  - ❑ Don't know

RELATIONSHIP WITH FAMILY OR SIGNIFICANT OTHERS

- Are family members involved in the client's life?
  - ❑ No
  - ❑ Yes, who _____

- If yes, can YOU indicate how involved they are in the life of the client?
  - ❑ Actively involved
  - ❑ Involved
  - ❑ Sometimes involved
  - ❑ Not involved
  - ❑ Don't know

- If yes, how do YOU feel about their involvement?
  - ❑ Greatly value the involvement
  - ❑ Value the involvement
  - ❑ Mixed feelings about them being involved
  - ❑ Prefer they were not involved

- If family are involved, HOW?
  - ❑ Take client to the doctor
  - ❑ Communicate with the doctor
  - ❑ Discuss health problems with RCOs
  - ❑ Suggest to RCOs solutions to health problems
  - ❑ Discussion with managers and other staff
  - ❑ Other _____

- Is anyone apart from family, involved in advocating for the client's health and well-being
  - ❑ Don't know
  - ❑ No
  - ❑ Yes, why _____
    (details)

HEARING AND SIGHT

- How is the client's hearing best described by YOU **NOW**?
  - ❑ Normal or manages OK
  - ❑ Mild loss – problems hearing normal speech
  - ❑ Moderate loss – difficult to hear loud speech
  - ❑ Severe/profound loss
  - ❑ Don't know

- How is the client's vision best described by YOU NOW?
  - ❑ No vision problems known or identified
  - ❑ Vision problems with/without glasses
  - ❑ Vision impaired even with glasses
  - ❑ Totally blind
  - ❑ Don't know

MOBILITY

- How is the client's typical level of mobility best described by YOU **NOW**?
  - ❑ Walks independently without assistance
  - ❑ Walks independently without assistance but has difficulty (no aids)
  - ❑ Walks independently but requires a physical aid or assistance of another person
  - ❑ Unable to walk – needs assistance of others

CHALLENGING BEHAVIOUR

- In the last 12 months, do YOU think that has the client displayed challenging or disruptive behaviour?
  - ❑ Yes
  - ❑ No
  - ❑ Don't know

- If yes, can YOU describe the behaviour

  _____

- Do YOU **know or suspect** of a cause or reason for this behaviour eg health related?
  - ❑ No
  - ❑ Don't know
  - ❑ Yes _____
    (details)

- Do YOU know if a doctor has assessed the client for a medical cause or possible health related reason for the behaviour?
  - ❑ Don't know
  - ❑ No
  - ❑ Yes _____
    (details)

- In the last 12 months, do YOU know if the client engaged in behaviour which is dangerous to themselves or others eg self-injured?
  - ❑ Yes
  - ❑ No
  - ❑ Don't know

- If yes, do YOU know if the challenging behaviour existed for longer than 12 months?
    - ❑ No
    - ❑ Don't know
    - ❑ Yes, how long _____

- If yes, do YOU know if a psychologist is involved in managing the behaviour **NOW** eg monitoring or developing a formal behavioural management plan?
    - ❑ Yes
    - ❑ No
    - ❑ Don't know

- If NO (a psychologist is not involved in managing challenging behaviour NOW) why?
    - ❑ Plan set in place some time ago remains current
    - ❑ Psychologist unavailable
    - ❑ Psychologist did not assess behaviour as requiring a plan
    - ❑ Disagreement over existence of challenging behaviour
    - ❑ Other_____
    _____
    _____
    (details)

- Do YOU know if a psychiatrist is involved managing the behaviour **NOW**?
    - ❑ Yes
    - ❑ Don't know
    - ❑ No

- Do YOU know if the client is taking medication for behaviour problems NOW?
    - ❑ Yes
    - ❑ No
    - ❑ Don't know

- If yes, who prescribes the medication for challenging behaviour?
    - ❑ Psychiatrist
    - ❑ GP
    - ❑ Don't know

- ❑ Other_____(name)

- If yes, who monitors and reviews the medication prescribed eg side-effects, need for doseage change etc _____

- When was the last change to the medication used for managing the behaviour? ____/____/____

- Why was the medication changed or adjusted _____

- Do YOU think that the client should be taking this medication eg benefits the client overall?
    - ❑ Yes
    - ❑ No
    - ❑ Don't know

GENERAL HEALTH

In the last **twelve months** are YOU aware of:

(a) the client having signs or symptoms of the following conditions, **or**

(b) have they had any of the following conditions diagnosed by a doctor or health professionals?(Choose more than one)

Problems with breathing
- ❑ Asthma
- ❑ Bronchitis
- ❑ Other _____

Problems with their heart
- ❑ Heart disease
- ❑ High blood pressure

Problems with their abdomen/stomach/gut
- ❑ Stomach ulcers
- ❑ Liver problems
- ❑ Bowel problems eg obstruction
- ❑ Constipation
- ❑ Diarrhoea
- ❑ Reflux
- ❑ Swallowing problems

Passing urine

- ❑ Kidney problems or infections
- ❑ Bladder problems or infections
- ❑ Incontinence of urine

Nervous system

- ❑ Migraine/headache
- ❑ Stroke
- ❑ epilepsy

Mental health conditions eg depression, schizophrenia **etc.**

- ❑ No
- ❑ Yes_____(diagnosis)

Other conditions

- ❑ Diabetes
- ❑ Cancer_____(name)
- ❑ Weight problems
- ❑ Abnormal menstruation – menstrual management problems
- ❑ Infectious diseases eg hepatitis _____(name)
- ❑ Other_____(name)

- • Does the client need assistance with….?
  - ❑ Gastrostomy
  - ❑ Catheterisation
  - ❑ Colostomy
  - ❑ Regular injections
  - ❑ Nutrition - special diet
  - ❑ Other invasive or special medical procedures_____(details)

- • Do YOU know if the client has a major health problem which a doctor has diagnosed/identified in the last twelve months?
  - ❑ No
  - ❑ Yes, name_____

MEDICATION

- • Does the client take medication NOW?
  (include doctor prescribed, over the counter purchases eg from the chemist without a script and alternate health remedies eg vitamins etc)

- ❑ No
- ❑ Yes, can YOU please list name of all medication, purpose and how often it is given_____
  _____
  _____
  _____

- • Does the client receive any prn (as needed) medication NOW?
  - ❑ No
  - ❑ Don't know
  - ❑ Yes, please list name of medication, its purpose and how often it is given
  _____
  _____

- • Was the medication listed reviewed within the last twelve months?
  - ❑ Don't know
  - ❑ No
  - ❑ Yes, who and when_____
  _____
  _____

RECENT MEDICAL EVENTS

- • Has the client had any injuries or accidents in the last twelve months?
  - ❑ No
  - ❑ Yes
  - ❑ Don't know

- • Has the client been hospitalised in the last twelve months?
  - ❑ No
  - ❑ Yes
  - ❑ Don't know

- • If hospitalised, how many times in the last twelve months?
  - ❑ Don't know
  - ❑ Only once
  - ❑ Twice
  - ❑ 3 or more
  - ❑ Other_____(total)

Why, name the reason for hospitalisation/s and treatment received eg observation for head injury or surgery to repair fractured wrist etc

_____

- Over the past twelve months, apart from their GP, can YOU list other professionals see the client because of their health and well-being needs?

Type	Visits per month	Reason
Social worker		
Psychologist		
Speech therapist		
Occupational therapist		
Domiciliary nurse eg Blue Nurses		
Naturopath		
Chiropodist		
Dentist		
Optometrist		
Physiotherapist		
Other_____		

YOUR VIEWS OF THE CLIENT'S HEALTH

- How would YOUdescribe the client's overall health NOW?
  - ❏ Managed well by those involved
  - ❏ Fluctuates – managed OK NOW
  - ❏ Fluctuates – needs increased attention NOW
  - ❏ Needs increased attention and intervention

    Why_____

_____

_____

- How would YOU describe the client's health 12 months ago?
  - ❏ Excellent
  - ❏ Good
  - ❏ Fair
  - ❏ Poor
  - ❏ Didn't know client twelve months ago

- How satisfied do YOU feel with the client's health and well-being status NOW?
  - ❏ Delighted/very pleased
  - ❏ Mostly satisfied
  - ❏ Mixed feelings sometimes positive and negative
  - ❏ Unhappy and dissatisfied

PART B: DETAILS ABOUT YOU - THE RCO COMPLEETING THIS QUESTIONNAIRE

- Full name_____

_____

- Your age
  - ❑ Over 60
  - ❑ 55-60
  - ❑ 50-55
  - ❑ 45-50
  - ❑ 40-45
  - ❑ 35-40
  - ❑ 30-35
  - ❑ 25-30
  - ❑ 20-25

- Gender
  - ❑ Female
  - ❑ Male

TRAINING

- What are Your qualifications?
  - ❑ Certificate in residential care
  - ❑ University Degree_____(name)
  - ❑ Other_____(name)

- Have YOU attended any health-related training **provided by Disability Operations** in the last twelve months eg seminars, conferences, etc? (do not include First Aid Training or other sessions included as part of Your RCO certificate)
  - ❑ No
  - ❑ Yes, what training and when_____

_____

- Have YOU attended any health-related education **NOT** organised by DFYCC eg seminars, conferences, training, tertiary education etc?
  - ❑ No
  - ❑ Yes, what training and when_____

_____

- If yes, why did YOU attend this training?

_____

EMPLOYMENT HISTORY

- Length of employment as a RCO with Disability Operations, DFYCC
  - ❑ More than 10 years
  - ❑ 5-10 years
  - ❑ 2-5 years
  - ❑ 1-2 years
  - ❑ Less than 12 months

- Length of employment as RCO/direct care worker in disability field
  - ❑ More than ten years
  - ❑ 5-10 years
  - ❑ 2-5 years
  - ❑ 1-2 years
  - ❑ 1-12 months

- Length of employment in residence where the client lives (add up the total time eg don't include time spent in other houses) _____years_____months

CLIENT FAMILIARITY

- How well do YOU know the client YOU have been nominated as client co-ordinator for?
  - ❑ Very good working knowledge
  - ❑ Good basic knowledge
  - ❑ OK knowledge
  - ❑ "It would be better if I knew the client better"

- How long have YOU **known** the client?
  - ❑ 2-5 years
  - ❑ Between 12 months and 2 years
  - ❑ Less than twelve months
  - ❑ Less than one month
  - ❑ Other_____

- How long have YOU been the client coordinator for the client?
    - ❏ 2-5 years
    - ❏ Between 12 months and 2 years
    - ❏ Less than 12 months
    - ❏ Less than one month
    - ❏ Not the client coordinator – only nominated for the CHAP project
    - ❏ Other_____

YOUR FEELINGS ABOUT BEING AN RCO-

YOU provide this information on a confidential basis to the researchers.

- In **all aspects of Your RCO** work (not just health and well-being), do YOU get enough support from professional or resource staff to work effectively as an RCO?
    - ❏ Yes, always
    - ❏ Usually
    - ❏ Sometimes
    - ❏ Never

- Do YOU get enough support from Your managers to work effectively as an RCO (not just health related responsibilities)?
    - ❏ Yes, always
    - ❏ Usually
    - ❏ Sometimes
    - ❏ Never

- Generally, when do YOU seek support from Your managers or professional staff?
    - ❏ Whenever I need advice, assistance or support
    - ❏ Sometimes
    - ❏ Rarely or never

- On average, how often would YOU ask for support described above?
    - ❏ Once a week
    - ❏ Every two weeks
    - ❏ Once a month
    - ❏ Less than once a month

- Generally, how do YOU feel Your about all part of Your job as an RCO – responsibilities, work environment, conditions, hours etc?
    - ❏ Very happy
    - ❏ Pleased
    - ❏ OK/ satisfied
    - ❏ Mixed feelings
    - ❏ Very unhappy

- Generally, how do YOU feel about working with the clients who YOU provide support to?
    - ❏ Very happy
    - ❏ Pleased
    - ❏ OK/satisfied
    - ❏ Mixed feelings
    - ❏ Unhappy

- Do YOU like working for Disability Operations, DFYCC?
    - ❏ Yes, most of the time
    - ❏ Usually
    - ❏ Sometimes
    - ❏ No, rarely

WHAT PRIORITY IS HEALTH?

- Do YOU think the health care needs of all clients **should be** a high priority for Your region?
    - ❏ Not more important than other client needs
    - ❏ Depends upon the client
    - ❏ Yes, a high priority
    - ❏ Don't know

- Do YOU think the health care needs of all clients are a high priority for Your region?
    - ❏ Yes
    - ❏ No
    - ❏ Don't know
        Please explain_____

- Are YOU able to give the time needed to meet the health care needs of the client?
  - ❑ Always
  - ❑ Most of the time
  - ❑ Occasionally
  - ❑ Rarely
  - ❑ Never

    Please explain _____

_____

HEALTH KNOWLEDGE AND SKILLS

- How would YOU rate Your knowledge about health problems experienced by people with an intellectual disability
  - ❑ excellent
  - ❑ good
  - ❑ average/OK
  - ❑ need more knowledge

- How would YOU rate your general knowledge about health and well-being eg decisions YOU make about Your own personal health?
  - ❑ excellent
  - ❑ good
  - ❑ average/ok
  - ❑ need more knowledge

- Where has your RCO health knowledge about clients come from (tick all that apply)
  - ❑ On the job experience
  - ❑ Training or conferences provided by Disability Operations or DFYCC
  - ❑ Training or conferences I have sought outside of Disability Operations or DFYCC
  - ❑ Books or reference material
  - ❑ Other_____

- As an RCO, would YOU like to increase Your knowledge and expertise in health and well-being?
  - ❑ Don't know
  - ❑ No
  - ❑ Yes

Comments _____

_____

_____

PART C: THE GENERAL PRACTITIONER
Details regarding the general practitioner who the client "usually" visits.

- Full name of General Practitioner nominated for CHAP _____

_____

- Name and address of the GP's practice/ clinic/rooms _____

- Telephone Number of GP _____

- Why does the client usually visit this GP? (tick all that apply)
  - ❏ Location/convenience
  - ❏ Family preference/choice
  - ❏ Client likes this doctor
  - ❏ General staff preference/choice
  - ❏ My choice, is my own personal GP
  - ❏ Other……………………………….

- In the nominated GP's practice, are there other doctors who see the client
  - ❏ No, nominated GP works alone
  - ❏ No, nominated GP works with others but client only sees nominated GP
  - ❏ Yes, sees other GPs in the group practice

- Are there other GPs **outside** of this practice who the client also sees?
  - ❏ No
  - ❏ Yes, why _____

_____

- How often does the client actually get to see the GP nominated for the CHAP research?
  - ❏ Always
  - ❏ Usually, most of the time
  - ❏ Sometimes
  - ❏ Rarely

CHARACTERISTICS OF THE GP NOMINATED FOR THE STUDY

- Where does the client usually see their GP?
  - ❏ At their surgery/in their clinic
  - ❏ Home visit
  - ❏ As part of visit to all clients living at this address
  - ❏ Other_____

- Why does the nominated GP see them here?
  - ❏ GP request/preference
  - ❏ Staff suggestion
  - ❏ Family request
  - ❏ Other_____

- Why was this decision made?
  - ❏ Minimises client distress
  - ❏ GP refuses to see client in clinic/ practice
  - ❏ Other_____

- Who usually accompanies client to the nominated GP?
  - ❏ ME (client coordinator)
  - ❏ RCO who is available
  - ❏ RCO nominated by staff working in house
  - ❏ Unit manager
  - ❏ RCO or staff employed specifically for this task
  - ❏ Other_____

RELATIONSHIP BETWEEN THE CLIENT AND THE GP NOMINATED FOR THE STUDY

- How does the client "get on with" the nominated GP?
  - ❏ Don't know
  - ❏ Generally ok
  - ❏ Some difficulties
  - ❏ Major difficulties

- How do other RCOs "get on with" the nominated GP ?
  - ❑ Don't know
  - ❑ Generally well/ok
  - ❑ Some difficulties
  - ❑ Major difficulties
  - Why_____

- Do YOU think the nominated GP spends enough time with the client?
  - ❑ Yes, most of the time
  - ❑ Half the time, could be improved
  - ❑ Sometimes, it varies
  - ❑ Rarely or never
  - ❑ Don't know

- Does the nominated GP speak directly to the client?
  - ❑ Not at all
  - ❑ Very little
  - ❑ Half the time, it varies
  - ❑ Most of the time
  - ❑ All of the time
  - ❑ Don't know

- Who does the nominated GP discuss the treatment or management plan with?
  - ❑ The client
  - ❑ YOU/the RCO accompanying the client
  - ❑ The client and YOU
  - ❑ Does not discuss

- Do YOU think the nominated GP "rushes" the consultation ?
  - ❑ Yes, most of the time
  - ❑ Half the time, could be improved
  - ❑ Sometimes, it varies
  - ❑ Rarely or never
  - ❑ Don't know

- Do YOU think there are too many interruptions during the consultation?
  - ❑ Yes, most of the time
  - ❑ Half the time, could be improved
  - ❑ Sometimes, it varies
  - ❑ Rarely or never
  - ❑ Don't know

- Do YOU think the nominated GP listens to YOU about the health problems of the client during the consultation?
  - ❑ No at all
  - ❑ Very little
  - ❑ Half the time, it varies
  - ❑ Most of the time
  - ❑ All the time
  - ❑ Don't know

- Do YOU think the nominated GP provides a good/reasonable service to the client?
  - ❑ Yes, most of the time
  - ❑ Half the time, could be improved
  - ❑ Occasionally
  - ❑ Rarely or never
  - ❑ Don't know

- Generally, do YOU think the nominated GP has a good understanding of the health needs of the client?
  - ❑ No understanding at all
  - ❑ Very little understanding
  - ❑ OK understanding
  - ❑ Most needs understood
  - ❑ Yes, good understanding

- What do YOU think could improve the nominated GP's understanding of and relationship with the client? Discuss

  _____
  _____
  _____
  _____

PART D: CONCLUDING COMMENTS

MOTIVATION

- Why are YOU participating in this study
  - ❑ Managers' expectation
  - ❑ Interested
  - ❑ Thought it might help client/s
  - ❑ Didn't know there was a choice
  - ❑ Don't know

- How familiar are YOU with the Comprehensive Health Assessment Program (CHAP)
  - ❑ Understand what the program is trying to achieve
  - ❑ Basic understanding
  - ❑ Don't understand

INFORMATION SOURCES

- What was the **main source** of information for this questionnaire (choose only one)
  - ❑ Mainly, personal knowledge of the client
  - ❑ Personal knowledge and file information
  - ❑ Family member or relative of the client
  - ❑ Other RCOs working in the client's house
  - ❑ Other staff working in my unit or the region
  - ❑ Mainly client files
  - ❑ Other_____

- How would YOU describe the client's file/s in regard to storage of health related information eg medical details, family history etc.
  - ❑ Well organised, up to date with everything I needed
  - ❑ Organised and up to date but some information I needed missing
  - ❑ Not organised and not up to date with major information missing
  - ❑ Other_____

- Do YOU **always** get around to putting important health related client information, notes or comments (eg medical history or perhaps what happened during a visit to the doctor) in client files?
  - ❑ Yes
  - ❑ No
  - ❑ Sometimes, varies
  - ❑ Don't know

- Do other RCOs in YOUR house **always** get around to putting important health related information in the client files?
  - ❑ Yes
  - ❑ No
  - ❑ Sometimes, varies
  - ❑ Don't know

- Are communication books in YOUR house the **best source** of **current** information for YOU regarding the health and well-being of the client?
  - ❑ Yes
  - ❑ No
  - ❑ Sometimes, varies
  - ❑ Don't know

- Do YOU think an improved system of storing and accessing information regarding the health and well-being of clients is needed?
  - ❑ Yes
  - ❑ No
  - ❑ Don't know

- Who provided YOU with extra information YOU needed to complete this questionnaire? (YOU can tick more than one box)
  - ❑ Family member or relative
  - ❑ Other RCOs working in the client's house
  - ❑ Other staff
  - ❑ Other_____

TIME

- How long did this questionnaire take to complete?

  ❑ Less than ten minutes

  ❑ 10-20 minutes

  ❑ 20-30 minutes

  ❑ Other_____

- Date questionnaire completed

  _____/_____/20___

OTHER COMMENTS are welcome: