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The SHAID* CLINIC

**Specialist Health Care for Adults with Intellectual Disability*

19th January 2015

Dear Members of the Joint Select Committee Preventative Health Care,

Thank you for the opportunity to present a submission on issues related to preventive healthcare provision, especially for vulnerable patient groups. My focus is on the healthcare of adults with intellectual disability. Published literature from all over the world shows that there is a health disparity between members of this population compared to their peers in the general population. Their health outcomes are generally worse, reflected in higher morbidity and mortality rates compared to their peers. Importantly, it has been demonstrated in the literature that much of these poorer outcomes are preventable. I believe that this group could benefit substantially from a practical focus on preventive healthcare treatments, where preventive applies for routine health promotion activities as well as for chronic and acute medical issues.

As a preamble, I will first describe my credentials, professional interest and current practice in this area. I am a specialist physician in Internal Medicine and practice at Calvary Health Care Tasmania, Lenah Valley. A large part of my professional career has been involved in the healthcare of adults with intellectual disability in the hospital setting. Since 1998, when working in Brisbane, I commenced outpatient specialised clinics for adults with intellectual disability at Mater and Princess Alexandra hospitals, in addition to my acute general medicine at public hospitals. I have seen many hundreds of patients with intellectual disability over the years. I have also completed a PhD in population health and healthcare of adults with intellectual disability, published many articles in peer reviewed journals, been involved in many disability organisations (including ministerially appointed positions in Queensland), have taught students and registrars, have provided disability health consultation, given many talks locally, nationally and internationally, and received some awards for my work in disability and health. Soon after moving back to Tasmania in 2008 with the support of Calvary Executive, I established a SHAID (*Specialist Healthcare for Adults with Intellectual Disability*) clinic at my rooms in Calvary, Lenah Valley. I have enclosed a brochure about the clinic for your interest (Appendix 3). Its aim is to provide comprehensive medical care of adults with intellectual disability including diagnoses, managements, and reviews with the family doctor, and if necessary other hospital based colleagues and community based allied health services, and the support teams or family. I have undertaken to bulk bill patients and Calvary Executive is committed to continuing to fund the administrative costs of one clinic per week via its Community Funding scheme. The main referrers to the SHAID clinic are General Practitioners and we have excellent collaboration. The disability sector of course is also integral to the health outcomes of their clients, our patients, with intellectual disability. Recently Calvary Health Care Tasmania established a Clinical

Review Committee-SHAID, of which I am Chair, which is responsible for review of care all inpatients with intellectual disability and addressing individual clinician or systemic issues in the care of such vulnerable patients and aims to include the disability sector. The service I provide for adults with intellectual disability clinically and supported by the hospital is a one off in Australia.

The current impact of inequalities in the major determinants of health outcomes, including mental health outcomes in Tasmanians and the capacity for health and community services to meet the needs of populations adversely affected by the social determinants of health

Health disparity in adults with intellectual disability

There is a well documented disparity of health outcomes for adults with intellectual disability. The life expectancy of this population approaches 20-30 years lower than their peers without intellectual disability. The causes of deaths are not usually due to the cause of intellectual disability per se but rather directly and indirectly the social consequences of this. This group of patients more often receives palliative care for potentially treatable and curable conditions, they more often have delay in diagnoses, completely missed diagnoses, more morbidity and mortality which is preventable, have lower rates of preventive dental care, higher rates of surgical complications, missed treatable vision and hearing impairments, more mental health problems, more gastrointestinal and musculoskeletal problems theoretically of preventable nature, and lower rates of immunisations and adherence to daily exercise recommendations, and more under or over nutritional problems, and as well are more often simply not treated for known diagnoses. Infectious disease is also more common in this group. There are much higher rates of emotional, physical, sexual, financial and social abuse of members of this group. Those with mild intellectual disability tend to have higher rates of smoking, but those with more moderate to severe levels lower rates of smoking compared to peers in the general population.

The health profile of this group of patients is different from their peers in the general population both in terms of the type of health problems but also the number of health problems. On average, adults with intellectual disability of all ages have 5-6 medical problems each, half of which would usually require specialist input and half of which would not necessarily be detected unless by specialist review. Compared to their peers in the general population this figure is much higher. Nevertheless, the profile of medical problems as mentioned above is one in which many of the problems, once identified and diagnosed, are fairly easily treatable and manageable, in fact, often curable before they reach untreatable stages. The current generic health system with long waiting lists, short appointment times unhelpful systems, requirements of normal cognition to work out the system for example, general lack of understanding of disability values and principles requires adaptation to cater for a service which would successfully provide preventive healthcare of patients with intellectual disability.

The scope of preventive healthcare in this population group, I propose extends beyond but does include health items such as immunisations, breast checks, for example. A proactive approach to specifically searching for common problems which occur in patients with particular disabilities comprises part of the health promotion and disease prevention in this population. For example, specifically looking for gastro-esophageal reflux in patients with cerebral palsy in whom reflux is known to be more common, may prevent the later onset of gastro-esophageal bleeding, stenosis, vomiting and esophageal cancer. Another example of preventive healthcare is screening and

treatment of *Helicobacter pylori*, a very common infection in this population compared to the general population, and a strategy which would prevent development of peptic ulcer disease and gastric cancer. Such medical risks for these vulnerable groups of patients are not necessarily well known among clinicians, but are would certainly be well known to clinicians with expertise with patients with intellectual disability. In addition to disease knowledge, an understanding that patients with intellectual disability take more time to communicate, may not use words, may rely on their family or support workers to tell their story. This all takes extra time in the appointment. Many clinicians tend to quickly judge the quality of life of their patients with intellectual disability as poor because of their cognitive impairments. They are frequently wrong, failing to assess the wider positive aspects of their lives. But such thinking leads to a nihilistic and minimalist approach for a medical condition or even a failure in attempt to make a diagnosis. which would be regarded as treatable if occurring in a member of the general population.

Addressing this disparity of health outcomes for adults with intellectual disability requires input from both primary care and hospital based clinicians, but with the guiding hand of a specialist dedicated health service for adults with intellectual disability which is available for consultation by colleagues as well as providing direct clinical care to patients. At the moment, Royal Hobart Hospital does not provide any specific service which addresses health prevention needs of the adult population with intellectual disability. Offers of help to provide help to the leadership of Internal Medicine, the department most suited to managing patients with multiple complex medical problems have been ignored.

Reasons for this disparity-social determinants of health, and health and disability elements

Adults with intellectual disability endure a cluster of *negative social determinants* of health. By nature of their cognitive impairment, their education levels achieved are low, their access to employment is reduced so most receive a disability pension as maximum income, many have lower quality social networks, few are married or have children as supports, many have aged parents who themselves are increasingly needing help themselves, access to supported accommodation may be limited, and this group as a whole is unfortunately attributed lower social worth. The rates of significant life events such as change in accommodation, turnover of support workers, various professionals and friends, flatmates, work experiences, assaults are much higher than for the individual without intellectual disability. Life for individuals with intellectual disability tends to be more chaotic because of social issues. It is harder for adults with intellectual disability to express their opinions and choices. Some adults with intellectual disability have trouble speaking but communicate by other means, not always known to the unknown listener. Members of this population might find it impossible on their own to actively participate in their healthcare, or even if they do, it may be harder for them to purchase healthy foods for example, and engage in exercise without help. They may not be able to typically express pain symptoms. Behaviour problems may be more common too, with some behaviours possibly representing a medical problem.

A robust system of dedicated combined support from the health and disability sectors is required to assist them seek routine preventive healthcare for example, or to speak up for them when they are ill, and so prevent deterioration of acute or chronic medical problems. Many patients with intellectual disability are unable to provide a story of their medical symptoms or problems and rely on support workers to tell their story. Many patients with intellectual disability do not express pain

directly. Many would not routinely present for health checks such as mammograms. Many clinicians are not aware of the differing health profiles of this group or may simply attribute their negative health state as being a necessary part of the disability, when in fact it is a treatable condition. These factors create additional risks for missed health benefits and outcomes. Presentation late in a disease, when treatment is much more complex and costly, is not uncommon.

Both the disability and health sectors have vital responsibilities in ensuring that health needs of adults with intellectual disability are met.

As far as the *disability sector* is concerned, ensuring that optimal assistance for medical consultations (either with the GP or in the hospital setting) for adult patients with intellectual disability from their support workers is provided is an important example of the disability sector responsibility. Support workers are often required to present the history of medical problems in the health setting. This is an important responsibility and such necessary support should be taken into account in the funding by service providers. Ensuring that disability support workers incorporate healthy diet and adequate exercise recommendations into daily life of their clients, for example is also important, as well as implementing medical recommendations for illness. Support workers being well organised and well informed as far as health care for acute and chronic medical problems of their clients is also important, and awareness of usual preventive health checks required and organisation of these. The general trend of a high turnover of support workers and a lack of formal liaison between disability and health sectors make this even basic level of care difficult.

In the *health sector* there are many logistic issues that contribute to increased vulnerability of poor health outcomes for this group of patients, which compound the already increased risk from the cluster of negative social determinants of health. Clinicians in day to day work require a history, need to perform examination, do tests, and make diagnoses and management plans then discuss with the patients, and later review. The process of managing adult patients with intellectual disability takes longer, requires assistance of support workers (who may change from visit to visit), GPs and specialists, and more frequent follow up compared to the general population may be required to ensure compliance and understanding. Fitting in such patients into regular generic outpatient clinics or frantic GP clinics just does not work- the time taken to perform a review is much longer, the waiting times must be minimised, time taken to establish some rapport is longer, and particular adaptations such as making appointment reminders to support workers, sending copies of information to patient's homes for support workers, organising tests under sedation if required, contact Person Responsible, having a dedicated phone line all take time, but are important adaptation to the usual service to ensure the clinicians can perform their clinical tasks .

In Tasmania, there is no dedicated system or service other than the SHAID clinic to address the health needs to adults with intellectual disability. The SHAID clinic is fully booked for months and its current capacity for comprehensive healthcare of both acute and chronic health conditions falls short of what is required for the approximately 15,000 patients with intellectual disability in Tasmania. I believe it provides an excellent model of care for those who can access its service, but still falls short in terms of formal liaison with the disability sector in general, and meeting the need for all patients.

As far as documentation of the local figures for health outcomes of this population in preventive, mortality and morbidity, there are no statewide data. In some other Australian states, deaths of

patients with intellectual disability are deemed “reportable” and are examined by a coroner. Two New South Wales Ombudsman reports in the 2000s on deaths of adults with intellectual disability recommend a need for a hospital based dedicated service adapted for the particular social and health vulnerabilities of this patient group. Multiple international studies have concluded that current unhelpful hospital practices require substantial refinement to reduce preventable deaths and suffering in this group of vulnerable patients. An audit I conducted of the local SHAID clinic in 2011 is contained in this submission, Appendix 2. Its findings are consistent with published data elsewhere.

The higher rates of early deaths and preventable illness in this population associated with the multiple negative social determinants of health and lack of collaboration between health and disability sector are costly. International studies suggest that the proportion of the total health care budget for patients with intellectual disability in generic systems is one of the greatest though the service is very inefficient with repeated admissions, long inpatient stays, and without good health outcomes.

Challenges to, and benefits of, the provision of an integrated and collaborative preventive health care model which focuses on prevention and early detection of, an intervention for, chronic disease

In the community, the population with intellectual disability remains devalued. In the health setting, there are logistical difficulties in providing optimal healthcare within usual systems and this, I believe contributes to a reluctance and lack of motivation of current health professionals to become interested in this area of healthcare. In the disability sector, there is no guiding hand to their services as to what is required for their clients entering health systems; in the health system, there is no disability expert body to guide and advise health professionals in disability values and practices. Both sectors necessarily need to work together and talk often.

Provision of healthcare for any patient population with complex biopsychosocial situations and with multiple medical problems would normally require specialist physician input, and so it is the case for this population. Thus establishment of hospital based service delivery comprises a specific focus for the improvement and prevention of chronic and acute medical problems in the population with intellectual disability. This approach, however, does not exclude close working with patients’ general practitioners. Clarification of roles of each health provider in the different sectors is an important part of the overall service delivery. Poor planning in identifying appropriate primary care versus ambulatory or tertiary level care responsibilities could result in unnecessary expense to the public purse let alone poorer health outcomes.

In Tasmania, there is no “watchdog authority” on deaths or adverse medical outcomes of patients with intellectual disability. The presence of a clinical review system to play a role in quality assurance of maintenance of healthcare standards for this population is warranted. Efforts are being made to address these problems within a single private hospital in Hobart via SHAID clinics and the Clinical Review Committee-SHAID, but in its current size is unable to cater for the size of the problems in both public and private, despite the expertise, and its service is dependent on one physician. By bulk billing, the service is unable to provide an income to the clinician as well as paying for extra clinics over and above that already provided by Calvary and discussions with disability sector as required.

The goals of an ideal service are well expressed in the Appendix 1. Such a service is partially already in place at Calvary, though its scale too small. There is ability to share the information obtained in the private setting with the public setting and with GPs but its major limitation is that it is dependent on one clinician and when that clinician leaves work, the service finishes. Funding is required to extend the current clinical service to colleagues and embed a dedicated service within the generic systems of hospitals and general practice. Optimisation of ehealth technology both in seeing patients and storing medical notes is another area of potential development.

One model of funding could comprise a 5 year plan where the lead clinician at Calvary is contracted to implement plans as below:

- to facilitate a clinical hospital based service for adults with intellectual disability (as outlined in appendix 1) in Royal Hobart Hospital, Launceston General, North West Hospital, and Mersey Hospitals within departments of internal medicine, where the service is ultimately performed by existing staff,
- to develop formal liaison mechanisms between local disability and health organisations so as to permit optimisation of logistics and communication of health and disability care practices,
- to set up local clinical review/quality assurance mechanisms for patients with intellectual disability,
- to develop formal liaisons between local general practitioners and the hospital based clinicians and services so that roles of primary and hospital based clinicians are distinguished and clarified,
- to develop and encourage use of community based allied health resources relevant for the needs of adults with intellectual disability, and provide disability specific expertise for these services as required
- to optimise use of ehealth technology in setting up and maintaining the service
- to develop links with disability organisations and support groups within the state.

Ideally at the end of 5 years, the lead clinician at the SHAID clinic at Calvary would revert to only provision of clinical outpatient care though remain a resource for consultation for each public hospital SHAID clinic and the disability sector.

I estimate that the state government would need to fund the lead clinician 2 days per week for 5 years and a contribution to the administrative support of 2 extra weekly clinics at Calvary. Calvary is already committed to the provision of administrative costs of one clinical session per week, and the lead clinician would undertake to continue bulk billing of patients attending the Calvary SHAID clinics.

Support for this 5 year project would be required by the Tasmanian Health Organisation in order to facilitate entry of the lead clinician into the public hospital settings.

Thank you for the opportunity to provide this submission. I am available to present my submission verbally if invited.

Kind Regards

Robyn Wallace

Appendix 1.

Manifesto: BASIC STANDARDS OF HEALTHCARE FOR PEOPLE WITH INTELLECTUAL DISABILITIES, Rotterdam 2003 (Published JIDDR)

The following criteria should be universally recognised and accepted as basic standards of adequate health care for individuals with intellectual disabilities.

- 1. Optimal availability and accessibility to mainstream health services with primary care physicians playing a central role. This means that people with intellectual disabilities will:**
 - a. Use mainstream health services.
 - b. Receive more time for consultations in the clinic or in home visits, when needed.
 - c. Receive adequate support in communication, when needed.
 - d. Receive a proactive approach to their health needs.
 - e. Have no extra financial, physical or legislative barriers to use mainstream services.
 - f. Be able to participate in screening programmes, in the same way as anybody else.
 - g. Be supported in achieving and maintaining a healthy lifestyle that will prevent illness and encourage positive health outcomes.
 - h. Receive understandable information about health and health promotion (also available to family and carers).
 - i. Receive healthcare with good co-operation and co-ordination between different professionals.

- 2. Health professionals (especially physicians, psychiatrists, dentists, nurses and allied professionals) in mainstream health services will have competencies in intellectual disabilities and therefore in some of the more specific health problems in people with intellectual disabilities. This will require that:**
 - a. Health professionals have a responsibility to achieve competencies in the basic standards of health care for people with intellectual disabilities.
 - b. These competencies include the awareness, that not all the health problems of people with intellectual disability are caused by their disability.
 - c. All training programs for health professionals pay attention to intellectual disabilities, including the most common aetiology, some frequent syndromes, aetiology-related health problems, communication, legal and ethical aspects.
 - d. Training in attitude and communicational skills is as important as clinical skills and therefore is part of the training programs.
 - e. Guidelines on specific health issues are available through Internet, CD-ROM or otherwise.
 - f. Health care professionals in mainstream services have easy access to and are able to get advice from specialist colleagues without extra financial, practical or legislative barriers.

- 3. Health professionals (physicians, psychiatrists, dentists, nurses and allied professionals) who are specialised in the specific health needs of individuals with intellectual disabilities are available as a back-up to mainstream health services. These professionals can advise, treat specific medical problems or take over (a part of) the medical care for people with intellectual disabilities. This will require that:**
 - a. Training Programmes are available for health professionals who want to gain competencies in health issues of people with intellectual disabilities.

- b. These specialists create and maintain networks with specialised colleagues in and outside of their own profession, in order to improve their knowledge and skills. This can be achieved by personal contacts or by creating (virtual) centres of expertise.
- c. Research on health issues of people with intellectual disabilities is stimulated in co-operation with academic centres. Academic Chairs in Intellectual Disability Medicine should be created to initiate, stimulate and co-ordinate research projects.

4. Health care for individuals with intellectual disabilities often needs a multidisciplinary approach.

- a. Specific health assessments and/or treatments need co-ordination between different health professionals (eg. visual and hearing impairment, mental health care, care for people with multiple and complex disability, care for the elderly, rehabilitation care).
- b. Specialist training for nurses and other carers is stimulated. This includes learning how to support and care for people with intellectual disabilities who have for instance sensory impairments, autistic spectrum disorders, epilepsy, mental health problems, behavioural / forensic problems, physical and complex disabilities, swallowing and feeding problems and age related problems.

5. Health care for people with intellectual disabilities needs a pro-active approach.

- a. Participation in national screening programmes should be encouraged.
- b. Anticipating health investigations on visual and hearing impairments and other frequent health problems should be evidence based and routinely available.
- c. General and specific health monitoring programmes are developed and implemented. In the development of Health Indicator Systems special attention is paid to people with intellectual disabilities.
- d. Responsibility for the development of anticipating investigation programmes and for their implementation must be clarified (primary care physicians, Public Health Doctors or specialised physicians).
- e. People with intellectual disabilities and their families have a right to aetiological investigations.

Appendix 2.

Audit of the Calvary SHAID (Specialist Healthcare for Adults with Intellectual Disabilities) Clinic from commencement in January 2010 to 21st September 2011

Robyn A Wallace, Physician

Background: It is well known that adult patients with intellectual disabilities are vulnerable in terms of their health. They endure significant preventable morbidity and mortality, in part because of problems in accessing optimal healthcare. In January 2010 at Calvary Health Care Tasmania, a private healthcare facility, a new Tasmanian service providing outpatient specialist physical healthcare to adults with intellectual disabilities commenced. The so-called SHAID (Specialist Healthcare for Adults with Intellectual Disabilities) clinic was supported financially by Calvary in the provision of a single administration professional person who organised appointments, correspondence, and who was available on the end of a dedicated phone line, and physical consulting rooms; clinical work was provided by a specialist Physician in Internal Medicine, and patients were referred by other medical colleagues and bulk billed. The clinics and appointments were organised as described in Wallace and Beange 2008.

Starting in January 2010, the SHAID clinic was held over a four hour session once weekly except for the first week of the month and when the physician was on leave. Each patient had two one-hour appointments for the baseline biopsychosocial review and a third appointment dedicated to methods to optimise access to healthcare within a hospital setting. Correspondence was sent to the referring doctor, the patient and their family and support workers if appropriate.

By the time the clinics had been running for a few months, it became clear that many patients were deemed requiring care from other subspecialists or at-risk for inpatient admission at the local public hospital. Most patients would use public rather than private hospitals for access to other ambulatory and tertiary care because of financial reasons. There were some difficulties in developing collaboration with colleagues from the public hospitals for this patient group. In order to feedback of the value of the service to Calvary Health Care Executive and also Executive staff at the local public hospital, an audit of the patient profile was planned. It was anticipated that such quantitative information would show not only that the service was meeting an unmet healthcare need with potential for morbidity prevention, but would give an idea of the resources and skills needed in the local situation to optimise healthcare for this patient group in the public setting as well.

Aims: To describe the biopsychosocial profile of adult patients with intellectual disabilities who were referred to the new SHAID (Specialist Healthcare for Adults with Intellectual Disabilities) clinic in Hobart from 1st January 2011 to 21st September 2011. It was hypothesised that the local profile would be similar to published data from other specialised hospital based outpatient clinics for adult patients with intellectual disabilities.

Methods: By retrospective chart audit, data from all referred patients' charts were obtained relating to demography, accommodation, ability to perform usual clinical processes, and medical problems. The de-identified data were recorded and percentages calculated. No statistical analysis was required.

All patients who had undergone a full physical health review (taking 2 of the 3 visits) between January 2011 and 21st September were included in the review. Those who had an incomplete review within the dates were excluded.

Demographic data included age, gender, type of accommodation and support; *medical chronic health conditions* (eg cardiac, respiratory, renal, autoimmune, polypharmacy with medications ≥ 5 , mental health concerns, endocrine, musculoskeletal, gastrointestinal, central nervous system, and new diagnostic problems); *health promotion* assessment included hepatitis A and B immunisations, exercise 30 minutes per day, yearly dental appointment, vision and hearing check once as adult, and as required: mammogram, Pap smear, HPV immunisation, annual influenza immunisation; *logistics of care* reviewed ability to perform usual history, examination, testing, diagnoses and management plans was assessed by difficulty compared to a patient from the general population; *need to access sub specialists* in the hospital setting or at-risk of inpatient hospital care were assessed by review of the types of medical problems requiring additional care to that usually provided by a physician in Internal Medicine (eg epilepsy requiring neurologist review), a need for sedation for diagnostic investigations, history of admission in the last 6 months.

Patients or their Persons Responsible had all signed consent before their first appointment for such quality assurance audits to be performed. No one else except the SHAID clinician (RW) reviewed the charts for the purposes of the audit. All collected data were de-identified at the time of annotation.

Results: The weekly SHAID clinic commenced January 2011 and the audit was performed on 21st September 2011. The number of so-far referred patients on 21st September was 63, of whom 39 had undergone 2 of 3 visits required for the baseline physical health assessment, 7 were “half way” through their review, and 17 on the waiting list. The audit was thus only able to be performed on 39 patients’ charts.

The majority of patients were referred by their GP, 5 (13%) by their paediatrician, 1 each by a General Physician, Surgeon and Rehabilitation Physician.

The patient group was middle aged (range 18-69 years) with equal numbers of males and females. Patients had a constellation of negative health determinants. About 60% of patients lived in group homes and the remaining 40% with parents; 38% had previously lived in institutions. All were unmarried. All patients except one who worked full time received a pension. (The one patient who worked had been referred with a diagnosis of “cerebral palsy” which was found to be incorrect).

Nine (23%) patients had Down syndrome, 9 (23%) had other defined causes of intellectual disabilities, 21 (54%) had unknown causes. Of 39 patients, 14 (36%) had substantial motor disabilities (by definition cerebral palsy) of variable causes.

All except one patient, who did not have intellectual disabilities, required substantial help from a proxy to provide a medical history. In about 70% of cases and to varying degrees, behavioural issues impaired the optimal process of history, examination, investigations leading to diagnoses and management plans. In a minority of cases, for some patients, even after a couple of visits, no examination or testing was possible. In most cases, however, some examination was possible, though in a proportion this was quite basic.

On average, patients had 5 medical problems each, 2.2 being already diagnosed and 2.8 either being new or old problems with substantially new management plans. Nearly all patients had unmet health promotion concerns. Interestingly, around 70% of the medical problems were of the type requiring further sub specialist input or the patient would be at high risk of needing hospitalisation at some stage because of this. Gastrointestinal, musculoskeletal, central nervous, and polypharmacy were among the most common systems involved in the medical problems.

Discussion: The audit results are consistent with other more sophisticated published biopsychosocial studies among this population. In the local setting, the study has confirmed that the health norm for middle to ageing adults with intellectual disabilities, is multiple medical problems. Among these is a worryingly high number of newly diagnosed medical problems, now with potential for treatment and reduction of morbidity and premature mortality. Moreover, a majority of the medical problems require input from other hospital-based sub specialists and there is a high potential for many of the patients needing inpatient care. Also primary health care responsibilities such as health promotion are also found to be deficient. It has confirmed that for this group there are inherent difficulties in performing the usual processes of medical evaluation, and that help from family or support workers is nearly always required. It has confirmed that this local population, like others, are over burdened with many negative health determinants. These factors must be taken into account when planning health service delivery for this population.

The audit results support the value of the current structure of the specialised clinic in obtaining decent health care assessments, though, at the same time, highlight some deficiencies in its scope. The practical difficulties of seeing patients with intellectual disabilities in generic outpatient clinics are evident. The times for assessments, for example, are longer than usually needed for patients without intellectual disabilities due to physical, behavioural, cognitive, social issues. Fitting in such patients in a busy generic outpatient clinic creates chaos and minimises any opportunity for a successful outcome. In this sense, a dedicated clinic in terms of its organisation with longer times for appointments is a basic necessity.

Components in the organisation of a successful health care provision for this population include: dedicated clinics with longer times for appointments, a dedicated administration and clinical staff and phone line, acknowledgement of and inclusion of the proxy assistance from family and disability support workers. However, one clinic per week is not enough to address the needs of even the local population, it does not address patients with acute medical problems, nor is it based in an emergency department.

Complete separation of specialised services for adults with intellectual disabilities from generic services is not financially, ethically or medically in the best interests of any health consumer or provider. Rather an ideal is development of a relatively small specialised service providing healthcare for adult patients with intellectual disabilities within the generic setting. That way the usual quality services are available for patients, but the specialised service can aid in facilitation of the care within other departments. Such services would ideally also provide some direct clinical outpatient care, as well as providing a consultation service for colleagues within the hospital setting and other departments such as the emergency department, and be subject to usual quality assurance aspects of the tertiary level care facility. On the one hand there are valuable knowledge issues important for such specialised clinics including those of disability philosophies, common syndromes and their

physical health implications, and where to look these things up, the large social networks of support around one person, consent and legal aspects, health promotion concerns, and the differing health profile, knowledge of the constellation of negative health determinants among this group. On the other hand the same familiar routines of taking history, performing examination, ordering investigations for diagnoses and management planning are required. Placing the specialised service within the generic system also probably reduces costs.

The extra costs of the SHAID service to Calvary and the health provider are conceivably minimised by the hospital enhancing efficiency of already existing generic services, the costs to the patient are minimised by using bulk billing, and the health provider uses Medicare item numbers applicable to a patient group with complex needs. Disability support workers and their service providers also have an obligation to give time and support for the health of its clients.

For a small proportion of adult Tasmanians with intellectual disabilities, the current SHAID clinical service at Calvary Health Care Tasmania is an avenue for the provision of optimal hospital level non acute healthcare to adults with intellectual disabilities. Its limitations include a lack of offering acute medical care, costs of private hospital inpatient care if required, single geographical location, relatively small clinic, so this service cannot meet the needs for all Tasmanians. As well as the private sector, larger public hospital facilities and service providers in the disability sector are required to contribute.

Appendix 3.

About the SHAID (Specialist Healthcare for Adults with Intellectual Disability) Clinic

The SHAID* Clinics

** Specialist Healthcare for Adults with Intellectual Disability Calvary Health Care Tasmania*

*Clinical Associate Professor Robyn A Wallace, BSc(Hons), DipEd, MSc, MBBS, FRACP, PhD, FAFRM
General Physician and Director of SHAID Clinics*

What does the SHAID clinic do?

- Provides outpatient specialist comprehensive medical care for adults (aged 18 years and older) with intellectual or motor disabilities:
 - diagnoses
 - management
 - care of chronic physical health issues
 - health promotion
 - planning for inpatient hospital care
- General clinics for adults with any form of intellectual disability including older people with intellectual disability, those with cerebral palsy, or Down syndrome, or any other type of syndrome, or unknown cause, and young adults previously cared for in children's health services
- Links with local, national and international bodies on intellectual disability healthcare
- Intellectual disability health consultancy service for agencies, governments, individuals
- Teaching and research in the area of intellectual disability healthcare and well being
- Assistance to support team in managing healthcare of their clients, especially in the hospital setting
- Limited assessment of functional skills using
- Private Practice clinics generally bulk billed **

** Need other specialist or general practitioner referral; non-rebatable fee may be charged for late cancellations; extra letters and forms over and above standard letters may incur a charge.

The SHAID clinic does not provide inpatient hospital care, does not provide acute medical care and does not provide any psychiatric services; it provides care for chronic physical health conditions of patients.

What do you need to do to make an appointment?

- GP or Specialist referral letter sent/faxed to Dr Wallace, SHAID Clinic at Calvary including the patient contact details
- Person with intellectual disability to be accompanied by family or regular carer for all appointments
- Bring in all medical files and old tests, medications and a pre-filled questionnaire from the SHAID clinic, Medicare card

Location and contacts

- **Where:** Calvary Cardiac Centre, Calvary Health Care Tasmania, 49 Augusta Road, Lenah Valley, Tasmania, 7008
This is on the lower ground floor of Calvary Hospital
- **When:** The clinic is held on Wednesday afternoon 1230-1530
- **How:** For bookings and information: Ms Bronwyn Zuber (Zube) on Phone 03 6278 5359, Fax 03 6278 9221
- **Who:** Zube's email bronwyn.zuber@calvarycare.org.au
Robyn's email robyn.wallace@calvarycare.org.au