

Participate in Health Conference 22nd February 2007

"Healthcare Coordination

- developing a community approach linked to a local disability support service."

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'focus' INDIVIDUALISED SUPPORT SERVICES

DROMANA, VICTORIA

Introduction:

This presentation is about a project which aims to support people who have an intellectual disability by:

- improving access to health services
- improving the delivery of health services
- improving consumer satisfaction within health services
- Involving people with a disability and their families to achieve the above

A Service Initiative of:

'**focus**' Individualised Support Services -
which provides :

- Community Support Services
- Accommodation Services
- Outreach Services
- Respite & holiday 'packages'

and has as its Mission that:

every person can say

" I am living the Life I want."

Background to the Project:

☹️ Recognition that significant barriers are preventing people with intellectual disabilities-

- *gaining equality of access to:*
&

- *satisfactory experiences in:*

➤ **Primary Care**

➤ **Acute Care**

➤ **Aged Care**

The project is divided into 3 phases:

- **PHASE 1 (now complete)** – Development of a specific Healthcare function within the disability support service, and progressive extension to community networks.
- **PHASE 2 (in progress) – Research & development leading to implementation of a new community based resource & support model.**
- **PHASE 3** – Project evaluation & possible replication of model.

Phase 2 Involves:

- Joint venture between '*focus*' and '*Peninsula Health*' a major hospital / healthcare network
- **Input from people with disabilities, their families and other disability service organisations**
- Education of health care providers.
- Proposal for improved '*pathways*' to health care.
- Development of a community nursing function from a universally accessible '*shop front*' base.

Objectives

- ▶ Identify co-ordination and care issues for people with an intellectually disability and their carers seeking and/or receiving health care.
- ▶ Develop pathways which integrate care through the range of primary and secondary health and disability services.
- ▶ Provide education to medical and nursing staff of healthcare facilities, so as to promote greater understanding of needs specific to people with an intellectual disability.
- ▶ Identify the elements of a role which can ultimately form the core component of a team to support co-ordination of healthcare for people with an intellectually disability on the Mornington Peninsula
- ▶ Evaluate outcomes from the perspective of people with a disability, carers and services.

Consumer Input

- Separate 'focus groups' for:
 - **People who have a disability** (*in progress*)
 - Family members (*completed*)
 - Paid carers
 - Healthcare providers

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 Participants in groups were recruited through the assistance of local disability support services

 Written consent was obtained

 Discussion was recorded and analysed for content

Group Discussion

AIM:

- To identify common themes relating to experiences in relation to health care services.
- To provide information on what changes would enhance or improve their experience with a healthcare provider.

Discussion Issues

For People with a Disability:

- Have you ever been to a doctor or a hospital? If you have, please tell us what it was like.
- If there were some things about the visit you did not like, what were they, and how could the visit have been made better for you? Were there any good things that you can remember about the visit?....What were they?
- If you have never been to doctor or a hospital, or if you cannot remember what happened when you did go to a doctor or a hospital, what do you think might happen during such a visit ?..... How would you like to be treated?.....How wouldn't you like to be treated?
- Do you think that you need help from someone else when you talk with doctors or staff in hospital?....If you think so, what sort of person might be helpful to you.

Discussion Issues

For Carers & Family Members:

- Please describe your experiences (good or bad) in seeking services from a doctor, a hospital, or any other healthcare provider, in relation to the needs of a person with an intellectual disability.
- If your experiences have not been ideal, what changes might have made them better for you, and also better for the person with a disability.
- If you have not had any direct experience, please discuss what you might consider to be an ideal experience for you.

Family Group Results

Experiences with Healthcare Providers

- No consideration is given to the implications of an impairment in cognitive ability.
- Waiting at hospitals and appointments causes distress for both the carer and person with a disability, and this occurs frequently from waiting in Emergency Department waiting rooms to waiting for GP appointments and outpatient appointments.
- Healthcare Professionals, including medical and nursing staff, do not treat carers with respect and are very patronising towards them often treating them and their sons or daughters like "second class citizens". There is a perceived lack of understanding towards both the carers and the person with an Intellectual Disability. Carers feel they are not listened to by health professionals, particularly in respect to the care needs of their child.
- Family members do not have faith in Health care Professionals and if the person with a disability is in hospital feel they have to stay with them 24 hours a day. Frequently they do and there is no offer of a bed, recliner chair or assistance in caring for the person.
- Hospital environments are often not suitable for patients with an Intellectual Disability.

- **Healthcare Professionals including GPs have very poor knowledge of Intellectual Disabilities and how to manage their care. They require more education and training to deal with patients with an Intellectual disability.**
- **Health Professionals talk to the carers and not the patient. Carers feel there is no balance between communicating with both the carers and the person with an intellectual disability.**
- **Carers will only try to access health services, particularly hospitals and Emergency Departments as a last resort.**
- **Medical staff have poor knowledge of medications and the effect of medications on the person with an Intellectual disability.**
- **Lack of specialist medical staff to treat people with an intellectual disability, particularly when the person becomes an adult.**

Family Group Results

Suggested Improvements:

- Liaison nurse to assist with the care of people with an intellectual disability.
- Providing a specialised area within a hospital to care for patients with an intellectual disability (Dental Hospital has a special needs unit which is well trained and well staffed to manage patients with special needs).
- Increased training and education for health professionals, including medical staff, nursing and allied health. Training would need to include clinical issues as well as improving attitudes and compassion towards the person with an intellectual disability and their carer.
- Hospitals should ensure all carers are able to stay with the person with a disability if they wish and accommodation or recliner chair should be made available.

- A specialised hospital- for people with a intellectual disability.
- General Practitioners need to understand that the carers often knows what is 'best'.
- Specialised accommodation for persons with an intellectual disability i.e. Nursing Home for disabled people when they require aged care
- Directory of services and GPs who are' ID friendly.
- Workers from a disability service should accompany people with an intellectual disability into hospital.
- Medical staff and nursing staff need to listen to the parent and be aware they know their son or daughter and their care needs- they need to listen to the carer and not assume that a lack of medical training means that they do not have anything to contribute.

- People with an Intellectual Disability need either a carer or an advocate with them speaking on their behalf.
- Medical and nursing staff need to treat patients with respect and dignity.
- Improved knowledge of medications and the effect on the person with an Intellectual Disability.
- Increased services for respite options for patients with high or special needs.
- The option of being able to take a break and not stay with the person 24 hours a day whilst in hospital and ensuring adequate care & supervision is provided.
- All intellectually disabled people should be registered so their information comes up on a screen when they present to hospital. , including diagnosis, care plan and treatment plan. A travelling history is another option.

In summary.....

The project aims to provide a consistent, accessible and integrated system to more equitably meet the health needs of people with intellectual disability, thus -

**enabling people with ID to exercise their
"Right to the right health Care"**

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