

## Centre for Developmental Disability Health

### Privacy Information

#### What does the Centre for Developmental Disabilities Health do?

##### CDDH

- Supports medical practitioners in the community to provide health care to their patients with developmental disabilities
- Provides education to medical practitioners, and medical and allied health students about developmental disabilities
- Conducts research into the health and wellbeing of people with developmental disabilities.

#### What sort of information does CDDH collect about patients seen in their clinics?

Prior to a visit to a CDDH clinician, the patient, or someone supporting them, is asked to complete a Pre-Appointment Questionnaire

This questionnaire asks for information about

- The patient, such as name, date of birth, gender, address, known disabilities
- Key support people and other health and allied health care practitioners
- Services received by the patient
- Current medical concerns, status and history
- Medications
- Information on any behaviour problems

During the clinical appointment, other information required to provide health care to that person will be obtained. Information may also be sought from other people providing health or other services important to the person's health care.

#### What happens to the information collected by CDDH about a patient?

- Patient information is kept in a file, which is stored in a locked filing cabinet.
- Patient information is also kept on a database on the CDDH server, which is protected by a password. Only CDDH staff can access this database.
- Some of the information collected may be shared with the patient's medical practitioners or other professionals involved in managing the patient's health and wellbeing. The purpose of sharing the information is to inform the ongoing care of the patient.
- The patient and person attending a consultation will be informed of those who will receive this information.
- Information will be provided to any other person or organisation with the authorisation of the patient or person who has the authority by law.

#### Can a patient see the information collected about him/her by CDDH?

Yes, according to the Freedom of Information Act

- A patient or someone acting on the patient's behalf can see information in his/her file.

- A patient or someone acting on the patient's behalf can ask for a summary of that information.

If requested, a CDDH clinician will explain the information to the patient or someone acting on the patient's behalf.

If there is a legal reason for not releasing certain information, a CDDH clinician will explain that reason.

If there is information in the file that is incorrect or in disagreement, the patient or person acting on his/her behalf can ask that it is corrected.

### **What does CDDH do with patient information?**

The primary purpose of collecting and sharing relevant information about the person's health issues is to support the person to achieve and maintain optimal health, function and wellbeing.

**De-identified** information may also be used for:

- Quality assurance and improvement activities in relation to the work of the CDDH.
- Reports on CDDH activities for funding and administrative purposes (DHHS, Monash Health)
- Education of medical practitioners, allied health practitioners, medical and allied health students about developmental disability.
- Research into the health and wellbeing of adults with developmental disability.

Research activities may include inviting patients and those who support them to participate in specific research projects. All such research conducted at CDDH will be approved and overseen by Ethics Committee on Research.

### **Will CDDH use or disclose the patient's information for any other reasons?**

- Disclosure of patient information for reasons other than those described above requires the explicit consent of the patient or person who has the authority to act on his/her behalf.

### **Can information about a patient be used or disclosed for reasons other than those outlined here without that person's consent?**

- In an emergency situation, if the patient is unable to give consent, and no one is available to provide consent on his/her behalf then information needed for emergency treatment may be provided without consent.
- When CDDH is required by law to release information about a patient.

### **What happens if the patient doesn't want his/her information to be used for education or research activities?**

- The patient or person who has the authority to act on his/her behalf has the right to refuse permission for information to be used or disclosed for any of the reasons listed above.
- To refuse permission, the patient or person who has the authority to act on his/her behalf completes a Refusal to Use and Disclosure Form.

### **What happens if a person is unable to give or refuse consent for uses and disclosure of his/her information?**

- A person who has the authority to make decisions for the patient, such as a legal guardian or “person responsible” can provide or refuse consent on the patient’s behalf.

**What can a patient or his/her representative do if they have a complaint about the use or disclosure of the patient’s information?**

- Tell a staff member at CDDH about the patient’s concerns.
- Contact the Health Services Commissioner on 1300 582 113
- Contact the Australian Health Practitioner Regulation Agency 1300 419 495

**For further information** please go to "The Health Privacy Principles (esp. Privacy Principle 1.7)" at the Health Services Commission Website: