

## **Centre for Developmental Disability Health Victoria Privacy Information**

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

The CDDHV is engaged in

- Supporting medical practitioners in the community to provide health care to people with developmental disabilities
- Providing education to medical practitioners, and medical and allied health students about developmental disabilities
- Conducting research into the health and wellbeing of people with developmental disabilities.

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

Prior to a visit to a CDDHV clinician, someone who has responsibility for the daily care of the patient may be asked to complete a Pre-Appointment Questionnaire (depending on whether the referral is for a GP, Psychiatrist, or Human Relations Counsellor). 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 a clinical appointment, other information that will be needed to provide health care or counselling to a person will be obtained. In addition, information may be obtained from other people providing health or other services important to the patient's care.

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

- Patient information is kept in a file, which is stored in a locked filing cabinet.
- Some of the information is also kept on a database on the CDDHV server, which is protected by a password. Only CDDHV staff can access this database.
- Some of the information collected may be given to medical practitioners or other professionals involved in managing the patient's health and wellbeing. The patient and person attending a consultation will be informed of all people 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 CDDHV?**

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 CDDHV 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 CDDHV clinician will explain the 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 CDDHV do with patient information?**

As well as using the information for the purpose of managing the health and wellbeing of patients, information stored in the database is used in a way that cannot identify the patient or others involved with the patient (i.e., in a deidentified form) for the following purposes:

- Evaluation of CDDHV services and products within quality assurance activities, which are reported to the Victorian Department of Human Services (funding body).
- 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 include use of group information to research particular conditions in people with developmental disabilities, and using contact details (i.e., disclosure of information to researchers at CDDHV) to invite patients to participate in specific research projects. All research conducted at CDDHV will have received approval from the Monash University Standing Committee on Research involving Humans.

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

- If CDDHV wishes to use or disclose patient information for reasons other than those described above, the consent of the patient or person who has the authority to act on his/her behalf will be sought.

### **When 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, when no one else is available who can provide consent on behalf of the person, and the information is needed for emergency treatment.

- When CDDHV 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 next-of-kin 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 CDDHV about the patient's concerns.
- Contact the Health Services Commissioner on 03-8601-5200 or 1-800-131-066.
- Contact the Medical Practitioners Board of Victoria on 03-9655-0500 or 1-800-016-151.

For further information please go to "The Health Privacy Principles (esp. Privacy Principle 1.7)" at the Health Services Commission Website:  
[www.health.vic.gov.au/hsc/downloads/hppextract.pdf](http://www.health.vic.gov.au/hsc/downloads/hppextract.pdf)