

Health Circle Report

Finding Unique Access Solutions



ADVOCACY



POLICY



COMMUNITY

DEVELOPMENTAL DISABILITY *wa*

July 2015

Health Circle Report

Finding Unique Access Solutions

Report on the discussions at the meeting of 31 July 2015

Developmental Disability WA is hosting regular opportunities for members to talk about the health issues that affect them and to be part of designing resources, information, skills and education to help them have a strong voice in the health care of themselves or the people they support. The first Health Circle event focused on supported decision making and difficult decisions. These discussions led to the topic for the second session, seeking examples of tailored, unique ways that people with disabilities may have been assisted to access health services.

Summary comments

It is recognised that people with disabilities may miss out on receiving health care that others take for granted, including screening for preventable illnesses, investigations to reach diagnoses and treatment to improve health and wellbeing. The barriers to accessing health services may rest with the individual's unique circumstances, their disability or capacity to participate, or in the way services are organised, or more likely a combination of both. When people with disabilities do manage to access health services, this can be a difficult or even dangerous experience for them, particularly if it is an emergency situation and if they cannot communicate with health care providers.

Family or support workers will generally attend health care settings with a person with a disability and have useful or critical information that may assist in the care encounter but very often experience being dismissed or pushed aside. The resistance of health care providers to accept the knowledge and authority of carers and family is difficult to understand and hard to challenge when the wellbeing of a vulnerable person is at stake. This is regarded as a cultural issue within health services that can have devastating effects for people with disabilities and their families.

The Disability Liaison Officer (DLO) pilot program represents an effort to encourage greater understanding within health services of the unique needs of people with disabilities when they enter health services. However, DLOs cannot be beside every vulnerable person and so a more extensive, wide-ranging approach is needed.

The context for discussions

The Health settings relevant to the discussions range along a continuum from Home, Pharmacy, General Practice, Dental Clinics, Allied Health services, Specialists Rooms and Hospitals, including wards and Emergency Departments.

The Disability Health Network is a partnership across Disability Services and Health as part of health service reform processes in WA, arising from a Clinical Senate recommendation aimed at improving the responsiveness of health services to the needs of people with

disabilities. Policy development is underway now that is intended lead to system change, service improvements and better health outcomes for people with disabilities. Community activism and engagement with these reform processes is critical to the success and sustainability of changes.

Families and Disability Service Organisations (DSOs) have a mutual interest in challenging the culture within health services of excluding or silencing the people who stand beside or speak up for people with disabilities when they enter health services. All people who support people with disabilities in health care processes have an interest in getting good, accurate information to clinicians, in an economical and helpful way, including in written form, by verbal reporting or from the person themselves through communication systems. Some good clinicians are willing to take the time to listen and see a person as an individual with unique issues. A more common impression of families and support workers is of a systematic resistance within health services to listening to the person or those who accompany them or taking into account particular needs and issues.

Themes from the group discussion

The concept of a Health Passport which provides critical personal and health information about a person with a disability is enthusiastically regarded by family members and support workers who assist people to engage with health services. The *passport* strategy is seen as an efficient way to convey complex information relating to a person who is not able to speak for themselves. If such a system were to be mandated and universal within health and disability service systems, it could prevent errors and improve the outcomes of health care interactions. This is a significant Safety and Quality issue that is a challenge for all people who care about improving health care for people with disabilities. Models of this concept are in use and being explored through the Disability Health Network.

General Practice and GPs are seen as a vital primary health service for people with disabilities and can facilitate access to other services at the Primary, Specialist and hospital levels of care. Limitations in General Practice arise from the small business model of General Practice that constrains the time that can be given to listening to individual issues and dealing with complex needs. The introduction of a new Medicare Schedule item that can be applied to consultations for people with disabilities and complex health needs could enhance care coordination and improve access to health care.

Work of the Side by Side project at DDWA has shown that approaching appointments and meetings differently, in health and other settings, can lead to different outcomes and generally a more effective response. The Side by Side project encourages people to take someone else with them to appointments or meetings, in a role being termed Family Partner, for support, witness and to take notes and intervene if necessary. It is recognised that health funds are limited so new resources may not be available to assist in creating the changes needed in health services. However, the resources in the community (other parents, siblings, friends or paid workers) can be used differently and creatively to challenge the terms of engagement between people with disabilities, their families, and the health system.

Support workers will routinely accompany people with disabilities to health care settings in their support role and therefore represent another means for monitoring and intervening in the way health services are provided.

New ways of thinking about the challenges

For many people with profound disabilities, entering the health system can be a risky and damaging experience. If this can be acknowledged openly, then new ways of dealing with this reality can be developed.

Calls to change the way that the health system operates, and in particular the culture of dismissing the authority of family, may be unrealistic as the health system is a large, diverse and complex arrangement of individuals and services.

The community sector, including families, individuals and disability service organisations, **can** realistically change the way that **they** engage with health services when standing beside a person with a disability. Strategies for assertively supporting people in situations where they are vulnerable and cannot speak for themselves, can be taught/learned and practiced.

The principle of 'never go into an appointment alone' can be adopted by the community sector and strategies to ensure this is effective can be developed. The Side by Side model of peer support can be adapted to apply to a range of settings and different agents, including support workers.

Executive, middle management and front line workers in disability service organisations need to explore these issues from their particular standpoint and address this through policy, training and ongoing support.

Resources already existing that could be better used

The Side by Side model is currently in development and training for Family Partners can be adapted for use by others.

The WA Disability Health Framework: Improving the health care of people with disability 2015-25 (currently in draft, due for release later this year) provides the broad policy context for this work.

Hospital Stay Guideline for Hospitals and Disability Service Organisations (currently in consultation phase) addresses the issues raised at this Health Circle meeting directly. The opportunity to contribute to this document should be taken as soon as possible.

Maxine Drake
July 2015