Health Circle Report

Substitute Decision Making

May 2015

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Report on the discussions at the meeting of 25 April 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.

Summary comments

When a person cannot give consent and then participate in diagnostic and treatment processes, their health care needs can go untreated and worsen. Health care needs may not be complex but the treatment may be difficult to provide, leading to avoidable harm and possible escalation of the severity of need. A number of practical and realistic strategies were proposed that could dramatically improve the situation for both health care services and people with profound obstacles to receiving adequate physical, oral and mental health care in WA. The way forward involves *supporting services* to better assist individuals and families to enter health systems and engage positively and safely so that treatment can be provided. It is also critical to *support the decision making and communication capacity of individuals* with disabilities so that they have the best opportunity to have their health needs met. Finally, *families need to be recognised* as currently bearing the burden of providing the best relief that they can in situations where health services cannot respond adequately to their family members' needs.

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 *Decision making continuum* ranges from decisions about simple health care interventions to complex decisions about serious and significant interventions. It was acknowledged that where factors exist such as stress, fear, anxiety, past trauma, noise, light and delays; combined with a person's limited capacity to tolerate these factors, even simple interventions and decisions may become impossible. Historically, a substitute decision maker may have been appointed to make all health care decisions for a person, however progressive thinking encourages processes that inform and support a person to make their own decisions wherever possible.

The *Communication continuum* is the ability of a person to express their wishes and understanding about health care needs, in simple or more complex ways. It was agreed that where a person cannot communicate and be understood in a health care setting, extreme behaviours may be the only way left for them to express their resistance and to actively not

participate in treatment processes. (These avoidance behaviours may not reflect a withdrawal of consent but a withdrawal from participation in treatment)

Finally, the *Systemic change* continuum set the the framework for discussions around reforms or new ways of dealing with the obstacles that many people with disabilities face in dealing with health services and receiving the care that they need. The starting point is the *present* where it is known that people are missing out on the care that they need to live good healthy lives free of pain and disease. *Early work* being done in both Health and Disability jurisdictions provide a mechanism for improvement and constructive collaborations between all parties concerned about people with disabilities receiving good health care. It is reasonable to hope that the *future* will see people with disabilities better able to participate in health care, with services finding flexible and innovative ways to overcome the barriers some people experience in health care settings.

Themes from large and small group discussions

The concept and practice of supported decision making needs to replace the impulse to appoint substitute decision makers, such as Guardians. The inability to speak does not mean that a person cannot express themselves or make decisions.

The state of mind and emotions of any person, including people with disabilities, affects the capacity to make decisions. Feelings of fear, anxiety and stress, as well as time pressures, past traumas and unfamiliar settings can make decision making and communication difficult. Obtaining consent for both treatment and participation in care processes can become difficult or impossible in the presence of strong emotions.

Diagnosis of medical and dental problems is a critical process in health care and if diagnosis cannot occur, further care cannot proceed. Attention needs to be given to making diagnostic processes, such as tests, radiography, and other investigations, accessible for people with communication and decision making difficulties so that people do not miss out on having health problems addressed.

'Challenging behaviour' is the term used to describe behaviours of resistance, aggression and refusal to cooperate. In some situations, it may be the case that such behaviours could be addressed or avoided if a person can be assisted to express themselves in other ways, such as through assistive technology and the development of literacy in languages other than speech.

When health services cannot be provided because a person with a disability cannot participate in care processes, untreated conditions can greatly affect the quality of life of the person concerned and family and carers. Carers can become default care managers, making do as best they can. Simple conditions can persist for long periods and cause great hardship.

People with disabilities may need specialist mental health care but often miss out on this due to the lack of mental health clinicians with expertise in disabilities. Untreated mental health issues, as with physical health issues, can significantly affect quality of life of the person themselves and those around them.

The group was adamant that the training of the health care providers of tomorrow must address the best ways to provide care to people with disabilities, including the involvement of families and ways of engaging with people who may not use speech to communicate.

Anecdotes were provided of some extreme measures used to provide necessary care where the person would not otherwise be able to be treated (such as anaesthetic provided at home and then the patient transported to a health service). There is clear ethical discomfort around these approaches, alongside appreciation of the significant benefit to the person of being able to be treated.

New ways of thinking about the challenges

- Exceptional solutions for rare, complex situations, developed by clinical leaders exercising influence within health services.

Numerous anecdotal reports indicate that exceptional solutions can be found within health service systems, for diagnosis and/or treatment of health conditions for people who have great difficulty participating in health care processes. Sometimes these solutions rely upon 'knowing someone' with influence by association or by chance. These rare situations demonstrate that challenges of access, consent, timeliness and post-treatment recovery can be addressed if the will and resources can be found.

- Familiarise children and young people with health service settings before a crisis or before there is an urgent need to use health services.

Many people who cannot participate in health services have previously experienced trauma that has led to fear and resistance. Safe, managed exposure to health settings while people are well could reduce fear and resistance later.

- Literacy in communication devices and systems can be taught at any age, to enable richer communication and involvement in decisions, including people being taught by peers.

Communication can be achieved by any person, of any age, with the right assistance. Systems and devices are being developed that use images and text, in simple and complex technologies, that enable people without speech to build their capacity to express themselves to people with the capacity to understand their particular language. People without speech, but with fluency in these new technologies, are becoming teachers themselves to their peers. These systems offer great hope and also a means for the humanity of each person to be fully expressed.

- New categories to replace or stand beside Next of Kin in medical records

Next of Kin is acknowledged as being a limited or out-dated category within medical records for identifying the best person in a patient's life who may be able to support them in their encounter with health services. New terms are being used in some settings. 'Nominated support person' or other such generic term could be introduced across all systems to allow for the most helpful person to be stated explicitly in a person's medical record.

- Systems of carer support that ensure that peers can accompany them to clinical appointments with their family member.

The Side By Side program is demonstrating that parents who take a trained peer - Family Partner - with them to appointments and consultations in health and other settings, can experience less stress and better outcomes for their family member. This program was designed to assist families with a child or adult member with disabilities, where participation in health care processes can routinely be difficult and stressful.

- Passports and Emergency Medical Plans

Awareness is growing that planning for medical interactions and treatments, especially for emergency care, is critical for successful outcomes. Hospital passport templates which assist individuals and their supporters to communicate important information about support, as well as medical needs when under pressure, are being developed and trialled around the world. Locally, Youniverse has developed a Medical Emergency Plan template with families which prioritises information needed in medical emergencies and also encourages families to build an informal support network so that they don’t have to be alone in medical settings. Families might need support to develop effective plans - for example many assume that their

loved one's diagnosis is most important (eg Autism), where information about how the person communicates pain, or how to support them in ways which minimise stress, might be more important.

- A symbol/icon or visual code that indicates a communication challenge may be helpful, such as the hearing impairment symbol used in many settings.

- 'Trip Advisor'

The concept of a 'navigational guide' or a system that assists people to navigate unfamiliar services or along a particular patient journey is appealing as a way to avoid the 'trial and error/hit and miss' experience many report when entering the health system.

- Specialisation for Allied Health Professionals interested in complex communication and supported decision making, possibly leading to a new role of Communication Interpreters.

Progress in community settings in the area of supported decision making is encouraging allied health professionals, including advanced practice support workers, to specialise in learning and teaching communication modes that do not involve speech. ECU has introduced a Graduate Certificate in Complex Communication Needs. Communication interpreters, just as with interpreters in languages other than English, assist both health professional and patient to be understood by each other.

Resources already existing that could be better used

- Health professional leaders, across all disciplines in physical, oral and mental health

Senior clinicians and clinical leaders in all health professions are the best placed people to determine how their particular service can be provided in a flexible way that enables a person with complex needs to participate in diagnosis and treatment processes. These leaders can give others on their teams the permission to work differently and change operational processes to ensure that special needs can be met.

- Advocacy services

Advocacy services are funded in Disability and Health sectors to assist the community and should be held accountable for doing so. Such services are also obliged to work flexibly and strenuously to assist people and families with unique challenges in health systems and often have knowledge and contacts not available to other community members.

- Customer Liaison departments in major hospitals

All major hospitals have a department that deals with complaints and advocacy issues for their patients and others. The officers in these departments can be used for advice and access into the health service, particularly for planning in advance or when problems arise during diagnostic and treatment processes.

- Disability Liaison role piloting

The Disability Health Network has been piloting a liaison role in a number of sites in Perth, exploring individual advocacy or system reform to address the barriers to access and care for people with disabilities. The disability community sector can critique the findings of the various models being tested to ensure that the best model or approach is carried forward.

- Examples of existing best practice in supported decision-making, communication support and exceptional solutions for diagnosis and treatment processes

Innovation and creative solutions do exist in WA. If such examples can be gathered and promoted, they may be useful for similar challenges being faced by others.

- Pre-Admission processes

Pre-admission processes enable the organised gathering of information before a clinical episode and can potentially enable planning for unique challenges that may arise. The information gathered does need to be used well during the admission or the effort is wasted. There is scope for these pre-admission processes to be better tested and used to assist with accessing health services.

- Allied health professionals (and perhaps skilled support workers) with foundation skills that can support communication, supported decision making and participation.

The current scope of practice of allied health professionals such as Occupational and Speech Therapists, Physiotherapists, Psychologists and Social Workers can include assisting people to access health services. Some individual practitioners in the disability services area are developing a strong interest and skill base in the area of supporting people to make decisions and in communication strategies when people cannot communicate through speech. Advanced practice support workers may also be a category of worker able to extend their education into the area of being a facilitator of supported decision making.

A call to action

At this time in Western Australia, opportunities exist to bring about positive change in both government and community services to make access to health services for people with disabilities more equitable, flexible and kinder. People with disabilities are citizens with the entitlement to live without pain and disease and without fear of health care diagnostic and treatment processes. New ways of thinking about supported decision making and communication and literacy, in the context of the right will and leadership within the Community, Disability and Health sectors, can improve the lives of individuals and families. All people concerned about improving the way that services operate have the option to become involved in reform activities, including the following:

The Disability Health Network provides a forum and a mechanism for some of the changes that are needed and this can succeed if it is supported to do so. The Network encourages community involvement through subscribing to contact lists for information exchange, participation in consultations and other reform processes.

Developmental Disability WA (DDWA) is taking a community leadership role in many of the current initiatives and is managing some grants that test new approaches, including the Side By Side program.

The Federal government has announced a review of the Medicare system in respect to the payment schedule for services. This may enable the inclusion of Medicare items that provide for extra time needed to assist people with complex needs, including decision making capacity and communication challenges.

Report written by Maxine Drake, May 2015